National Institute for Health and Clinical Excellence

Patient experience in generic terms
Guidance and Quality Standard Consultation Comments Table
21 June – 19 July 2011

No	Stakeholder	Document	Section No	Page No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
486	Age UK	NICE		5	Re: 'If patients do not have the capacity to make decisions…'. The Guidance should make clear that capacity is time and decision-specific. We suggest rephrasing to: 'If there are decisions that need to be taken and the patient does not have the capacity to do so at the time, healthcare professionals…'	Thank you for your suggestion, this has been amended.
954	Age UK	QS	QS2	7	Suggest adding '…and memory problems' to the Quality Statement in view of the number of health service users who are older people with dementia or other cognitive impairment. Suggest adding: 'Information is also gathered from informal and formal carers'.	Thank you for your comment. This quality standard has been expanded where reworded.
1029	Age UK	QS	QS5	11	Suggest that 'toileting' or 'continence' is added to the list of physical needs as this is often quoted as an aspect of care where the need for dignity was not met. Suggest adding: '…and a clear plan put in place to meet those needs'.	Thank you for your comment. Personal hygiene covers these aspects.
1	Alzheimer's Society	All	general	general	Dementia poses a large challenge to the NHS. People with dementia are some of the highest users of health services, occupying up to a quarter of hospital beds at any one time, and yet 77% of carers expressed that they were dissatisfied with the dementia care provided. It is therefore essential that any standards apply to people with	Thank you for your comment. The guideline is directed to generic patient experience in all settings.

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					dementia	
2	Alzheimer's Society	All	general	general	In a separate survey of people with dementia and carers who were still in their own home, 50% also felt they received insufficient care and support which led to unnecessary hospital admissions and early admission to long term care. Yet where care was available, satisfaction with services were high. In addition, up to 40% of people with dementia do not have a diagnosis and are therefore not referred to any treatment. This illustrates that while the standard to which care is delivered may be high, unless it is available to the patient their experience will necessarily be poor. The standards for patient experience in generic terms assume that a diagnosis already exists and make no mention of patient experience before they are referred to services or where services are not available in a particular area. We would like to see reference to timely assessment, diagnosis and referral and acknowledgement that part of patient experience of services depends on if services are available to the person.	Thank you for your comment. The recommendations do not assume that a diagnosis already exists and are intended to cover experiences in all parts of the NHS. Patients without a diagnosis, for whatever reason, are entitled to the same care and consideration as those with a diagnosis. We have included recommendation that patients should be informed of usual treatment options even if these are not available in their local area.
159	Alzheimer's Society	Full	4.1.2	23	Among the factors mentioned which may affect the patient's ability to participate in consultations and care, capacity is not mentioned. Decreasing capacity is one of the primary factors which influence a person with dementia's ability to participate in their care and this will change over time, so it is important that it is fully considered by the health professionals treating them as part of their holistic care.	Thank you for your comment, recommendations about consent and capacity have been added to the guideline.
160	Alzheimer's Society	Full	4.1.8	23	We fully support 'Treat all patients with respect, kindness, dignity, compassion, understanding and honesty' as an essential requirement of care. Many of the unacceptable failings of care in recent	Thank you for your comment.

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					times have involved healthcare staff failing to treat people with dementia with dignity.	
182	Alzheimer's Society	Full	4.1.15	24	We would suggest adding communicating with a patient about food, particularly if it has not been eaten. We hear reports of people with dementia who are not assisted to eat and then have their meals removed by hospital staff after an allotted period of time, which contributes to malnourishment.	Thank you for your comment. Recommendation 13 addresses providing healthcare professionals with training in regards to nutrition.
183	Alzheimer's Society	Full	4.1.16	24	We would support the instruction to health professionals not to assume that pain relief is adequate. However, asking the patient regularly would not necessarily address this issue for people with severe dementia who may not be able to communicate the level of their pain. We would suggest that health professionals should be encouraged to use the full range of their clinical skill to assess levels of pain. In particular there are specific tools which can be used to assess pain relief in people with dementia. We would suggest the guidance makes reference to these.	Thank you for your comment. Recommendation 13 has been reworded to include assessment of pain relief.
184	Alzheimer's Society	Full	4.1.24	24	We fully support the involvement of carers within the patient's care as carers are often an integral part of the care of people with dementia. We feel that this could be more fully reflected within the Quality standard, with similar levels of respect and information sharing shown to carers as to patients.	Thank you for your comment. We agree that the needs of carers are important and that attention to carers can be a significant influence on patient experience. We had however to limit the areas we were able to consider. Recommendations 28 and 29 refer to how information can be shared with carers.
786	Alzheimer's Society	QS	general	general	Many of the suggested methods of data collection will not capture the experience of people with dementia. For example, the NHS inpatient survey relies on patients completing a complex questionnaire, which many people with severe dementia may not respond to. We suggest that	Thank you for your comment. We expect that further advice from the National Quality Board and when it is established from the NHS Commissioning Board on how data will be captured to reflect your concerns.

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					ways of capturing the experience of people with dementia are more fully considered.	
955	Alzheimer's Society	QS	2	7	In addition to the comment made in point 3 about including capacity in the factors which may limit patient's ability to participate in their care, we feel that 'asking' the patient about their difficulties engaging in care may not be the best way of revealing those difficulties. This is particularly pertinent for people with dearly stages of dementia where cognition may be impaired, but if efforts are made to engage in an appropriate way the person can still be fully involved in their own care. We would suggest that the quality statement returns to the recommendation in the full guideline which would encourage staff to 'consider the extent' which would suggest they use the full range of their skills to assess a patient's difficulties in participating in care. This would also reinforce the responsibility of staff to use the Mental Capacity Act appropriately. We would also suggest that this should be reassessed over time, to meet the patient's changing needs.	Thank you for your comment. It is intended that through asking engagement is achieved.
984	Alzheimer's Society	QS	3	9	We would suggest that it is important that patients are able to have their beliefs, concerns and preferences taken into account beyond being given the opportunity to express them.	Thank you for your comment. This quality standard has been changed to reflect this.
1030	Alzheimer's Society	QS	5	11	We would suggest that it is important for patients to have their physical needs and psychological concerns met beyond having them assessed. As mentioned previously, many of the unacceptable failings of care in recent times have involved basic needs of people with dementia not being met.	Thank you for your comment. As stated in the description, they are assessed and addressed. This has been added to the quality statement.
1105	Alzheimer's Society	QS	8	15	We feel that this standard should specifically include respect and support for decisions about treatment made in advance. Diminishing capacity	Thank you for your comment. The final version of the quality standard contains a statement on respect and support on

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					in dementia means that it is important that decisions made about care in advance are respected and implemented.	decisions about treatment.
787	Amgen Ltd	QS	General	General	We are fully supportive of all quality statements outlined in this document as evidence states that if patients have involvement in their care, outcomes are improved due to a variety of reasons including better adherence.1 Implementation of these quality standards will contribute towards achieving this vision and ensure that the five overarching domains set out in the NHS Outcomes Framework2 are realised.	Thank you for your comment.
985	Amgen Ltd	QS	3 8 9 15	9 15 16 22	We are of the view that QS 3, 8, 9 and 15 which broadly focus on patient centred care should be regarded with particular importance. The vision of patient centred care is considered a critical aspect of health care quality3. The NHS is focusing on placing patients and their experience at the centre of quality improvement with the aim of the Department of Health being that "shared decision-making will become the norm: no decision about me without me".1	Thank you for your comment.
1176	Amgen Ltd	QS	12	19	We fully support quality statement 12 concerning patients' continuity of care being considered. The appropriate management of patients, especially	Thank you for your comment.

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[1] Department of Health: Equity and Excellence: Liberating the NHS. 2011
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf

[2] Department of Health: The NHS Outcomes Framework 2011/2012.2010.
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_123138.pdf

[3] Patient-centred Care, The King's Fund; http://www.kingsfund.org.uk/topics/patientcentred_care/

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					those patients with long-term conditions, is likely to have a substantial impact in relation to the £20 billion efficiency saving requirement. Patients with long-term conditions like osteoporosis should have the option to have their condition managed in the community setting and should also have access to innovative, NICE-recommended, patient centred medicines which are likely to reduce emergency admissions, increase patient compliance to their medication and reduce medicines wastage.	
1250	Amgen Ltd	QS	16	23	We would like to request that this quality statement be broadened to include details around treatment options and safe prescribing. Broadening the statement in this way would support the achievement of high quality of care as defined in NHS Outcomes Framework2, primarily in the following domains: 1) Preventing people from dying prematurely 2) Enhancing quality of life for people with long-term conditions 5) Treating and caring for people in a safe environment and protecting them from avoidable harm	Thank you for your comment. See new wording in previous response above.
1273	Amgen Ltd	QS	17	24	We would like to request that quality statement 17 be broadened, particularly where it is states that patients should have access to high quality decision tools. It is important that these tools have information regarding safe prescribing of medicines as well as available treatment options in order for patients to be treated in a safe environment and protected from avoidable harm as outlined in domain 5 of the	Thank you for your comment. In the final version of the quality standard, decision support tools are being used as one method of assessing shared decision making.

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					NHS Outcomes Framework2 .	
423	Arthritis Care	NICE	general	general	Arthritis and Arthritis Care 1. Arthritis is the biggest cause of physical disability in the UK, affecting up to 10 million people, including 12,000 children, and accounting for 1 in 3 GP visits. Arthritis in particular is the single biggest cause of physical disability in the UK, and carries a huge economic as well as human and social cost, estimated at £7 billion annually in terms of lost labour in 20074. Arthritis can be severely debilitating, preventing people from being able to work or remain independent, and in many cases preventing them from doing simple everyday tasks. Musculoskeletal conditions in general are now the 4th largest area of spending in the NHS, up from 5th last year5. 2. Arthritis Care is the UK's leading organisation working with and for people with all forms of arthritis. People with arthritis are at the heart of our work: they form our membership, are involved in all of our activities and direct what we do. We believe that people with arthritis are entitled to receive the best possible treatment and support, and to have their voice heard in decisions affecting their health and well-being. 3. Because there are over 200 different types of arthritis and they affect people in many	Thank you for your comments. The ordering of documents has been reviewed following consultation. Themes that emerged from the evidence reviewed are utilised for organising the Quality Standard, further illustrating the interdependency of the Quality Standard with the original source guidance. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board. The Guidance emphasise the importance of recognising the individual and being responsive to their own needs. Recommendations on continuity of care emphasise the person or situation specific elements and guides service delivery commissioning.

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[4] *Fit to Work?*, The Work Foundation, September 2007

[5] National Programme Budgeting Data, Department of Health, October 2010

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					different ways, personalised care, shared decision-making and support to self-manage are particularly important for people with arthritis, and should underpin all healthcare services. General observations 4. Arthritis Care strongly believes that this particular Quality Standard is exceptionally important, as patient experience is a fundamental aspect and a key measure of providing high-quality care for all. 5. Having clear, robust and comprehensive guidelines for improving the experience of care for NHS patients is crucial, and it should be made clear that this particular Quality Standard must underpin the delivery of all health and social care throughout the NHS and at all levels. 6. The draft guidance is on the whole very good and mostly comprehensive. 7. The guidance must ensure that the focus rests on measuring patient outcomes (e.g. improved quality of life), not just output (e.g. provision of information). All output should refer to a clearly-defined outcome. Key to measuring outcomes is patient feedback and patient-reported improvements. 8. A common problem which often leads to many	

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					people with arthritis not getting the services they need, or having a negative experience of care, is that there are still persistent misperceptions about arthritis as just an older persons' condition, a few aches and pains, or something which you can't do much about. These misperceptions are still very common both among the public and among health professionals, not least GPs, whose training on musculoskeletal conditions is currently inadequate6. A positive patient experience for people with arthritis therefore rests to a large degree on successfully challenging these myths, both through better awareness-raising and formal training. The NHS must regard this as a priority. 9. There is also a need to measure patient experience across service boundaries, so that they encompass whole patient pathways. 10. Responsiveness of service is a recurrent them in patient experience. There must be prompt delivery of care or referral for specialist treatment, where appropriate. No service should be subject to unreasonable waiting times, especially when this may lead to complications or an increase in the severity of symptoms or disease. Early intervention is particularly important for people with rheumatoid arthritis, for whom the first 3 months since the onset of symptoms are	

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[6] *Managing people with long – term conditions*, King's Fund, 2010

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					crucial for controlling the progress of the disease.[7] 11. The Quality Standard must also ensure that it draws on the recommendations of key reports which look at the issue of patient experience, in particular: How to deliver high-quality, patient-centred, cost-effective care: consensus solutions from the voluntary sector [8], Improving the Quality of Care in General Practice[9] and the King's Fund report on Managing people with long – term conditions.[10] 12. There must be clear and robust monitoring mechanisms to ensure that this Quality Standard is duly implemented in practice. Draft Quality Statements 13. These are particularly important, as they are most likely to be used and referred to in an ongoing way as part of regular care provision. It is important, therefore, that they accurately reflect and clearly express the key provisions of the full guidance. 14. The draft quality statements are for the most part useful and comprehensive. Statements which are particularly well-	

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[7] *Services for people with rheumatoid arthritis*, National Audit Office, July 2009

[8] http://www.kingsfund.org.uk/publications/articles/how_to_deliver.html

[9] *Improving the Quality of Care in General Practice*, King's Fund, 2011

[10] *Managing people with long – term conditions*, King's Fund, 2010

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					framed and which are especially important for people with arthritis include statements 9 (personalised care), 12 (continuity of care), 15 (shared decision-making), 16 (information-provision) and 17 (decision aids). We would therefore like to see these statements in particular moved much closer to the top of the list, as numbered statements tend to be viewed as a hierarchy in practice, even where this is not the intention. Other NICE Clinical Guidelines pick out Key Recommendations, but these seem to be lacking in this document. 15. There are, however, several important omissions. In particular, neither the statements nor the guidance itself touch on personalised care plans or care planning. This is an important part of delivering continuous, personalised care as well as embedding shared decision-making across the board, and ensuring that patients follow the care pathway that's right for them and with their own active involvement in the planning process. 87% of 16. respondents to an Arthritis Care survey of what people with arthritis want from their GP (Sep 2010) said that they would like to discuss and agree an overall care and treatment package with their GP. 17. Care plans are also vital to ensure that the	

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					discussion between patient and healthcare professional is documented and that other information such as a medicines management and contingency planning for exacerbation is captured. Care plans should be as detailed as necessary, and may be shared with carers or family members (subject to consent). They also provide a very measurable way of ensuring that many of the recommendations in this guidance are in fact applied in practice. It is important, therefore that both the guidance and the statements include a clear requirement for inclusive, personalised care planning for patients with long-term conditions	
556	Arthritis Care	NICE	1.1.3	8	The Patient as an Individual: 18. One of the most common things that people with arthritis regularly tell us is that they want to be seen and treated as a whole person by health professionals, as opposed to a condition. A culture shift is required for this to become the norm across the NHS, particularly in Primary Care, where many cases of arthritis are dealt with. 19. Together with better communication and listening skills, health professionals must also be more aware of the real impact of arthritis on people's lives, beyond the purely medical impact or clinical aspects of the condition. This must include an awareness of co-morbidities which are common to arthritis, such as depression, and a preparedness to treat each	Thank you, we agree with your comment. Thank you, we agree with your comment, depression as a comorbidity is considered in recommendation 12, Essential requirements of care Thank you for your comment. The recommendations do not explicitly mention the impact of the condition on the ability to

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					individual holistically in light of this. 20. Additionally, as clearly identified in Dame Carol Black's report, Working for a Healthier Tomorrow[11], and subsequent work in this area, arthritis can have a severe impact on many people's ability to remain in or return to work, which can further reduce their independence and self-confidence and cause or aggravate co-morbidities such as depression. Draft QS should contain an explicit requirement on health professionals to ask patients, as a matter of course, about the impact of their condition on their ability to work, as suggested by the draft guidance document, para 1.1.3. Health professionals should also use the Fit Note and existing resources such as www.yourworkhealth.com to directly assist patients in being able to remain or return to work.	work, however, recommendation 1 mentions "Understanding of how the condition affects the person, and the person's circumstances", which can include the patient ability to work.
573	Arthritis Care	NICE	1.2 -	9 -	Essential requirements of Care: 21. Care for people with arthritis must be genuinely integrated and multidisciplinary, including GPs, nurses, specialists and allied health professionals. Health professionals should also be aware of other sources of information and support and direct patients to these as a matter of course, including organisations such as Arthritis Care. We provide a range of services for people with arthritis, including accredited information booklets, free and confidential Helplines, self-	Thank you for your comment. Whilst we recognise the particular needs of those with arthritis, the remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline.

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[11] *Working for a Healthier Tomorrow*, Dame Carol Black, March 2008

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					management courses and peer support groups (physical and online), all of which demonstrably provide highly valued additional support to many people with arthritis. It is important that health professionals are aware of these services and refer patients with symptoms of arthritis to us. 22. There is a strong and proven link between arthritis and lifestyle factors (e.g. osteoarthritis and obesity and rheumatoid arthritis and smoking, respectively). It is also important, therefore, that people with suspected arthritis are provided with information regarding lifestyle issues, e.g. exercise, both as prevention and as a means to better manage the condition, thereby helping to control it. 23. Pain is the main symptom of arthritis, and health professionals must be equipped to spot and deal with chronic pain effectively.	
622	Arthritis Care	NICE	1.3 -	11 -	Tailoring Healthcare Services to the Individual 24. Because arthritis can take many forms and affect different people in different ways, personalised care is essential in the effective treatment and management of arthritis. Early intervention, prompt referral and support to self-manage must be key elements of this, with the overall aim of keeping people healthier and independent for longer. 25. As arthritis often severely impacts on a person's mobility, bringing care closer to home is also particularly important for people with	Thank you for your comment and information. Thank you for your comment. We recognise the particular needs of those with arthritis. The remit for the guidance is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline.

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					arthritis. 26. It is important to understand, however, that people with arthritis will have different needs, and will respond differently, depending on their personal circumstances at the time. If patients are experiencing an acute episode such as a flare-up, for example, they are most likely to need - and want - prompt, high-quality treatment. If the visit is more concerned with managing an ongoing condition and its overall impact on a person's life, which will often be the case, what the patient will find most beneficial is likely to focus more on lifestyle choices and self-management.	
656	Arthritis Care	NICE	1.3.9 -1.3.11	12 -13	27. Another omission is in relation to the fact that before statement 8 (right to choose) can be applied meaningfully, patients must be provided with a choice of treatment in the first place. While this may be obvious, it is not presently made clear in the current statements, and may therefore compromise, or skew, the implementation of statement 8 in practice.	Thank you for your comment. The ordering of this has been altered.
671	Arthritis Care	NICE	1.4 -	13 -	Continuity of care and relationships 28. Continuous, person-centred care is very important for people with arthritis, whose condition is long-term but can vary significantly from time to time. Having a personalised care plan, as mentioned above, is particularly important in this respect.	Thank you for your comment. It is important to remember that continuity of care will differ between individuals and disease areas. The guidance intended to outline the general principles.
690	Arthritis Care	NICE	1.5 -	14 -	Enabling Patients to actively participate in their care	Thank you for your comment. Refinement of recommendations post consultation have

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					29. This is a very important dimension to the overall guidance, and sits at the heart of patient-centred care. The very notion of "no decision about me, without me" rests on the full and active participation of patients in designing their own care, and their empowerment to make the choice of treatment that's right for them. 30. This is perhaps particularly important for all long-term conditions, insofar as their successful management relies to a large extent on the patient being informed and being able to take an active role in self-managing. Patients who are able to successfully self-manage feel more in control, will be less reliant on the health system, are less likely to need invasive or expensive interventions, and are less likely to develop co-morbidities such as depression. 31. It is important that this Quality Standard therefore fully incorporates and cross-references existing data and work that has been and is currently being conducted around, for example, shared decision-making, treat-to-target and enhanced recovery.	strengthened the importance of active participation, and clarified terminology in particular relation to shared decision making.
728	Arthritis Care	NICE	1.5.14 1.5.26 1.5.29	16 18 19	32. Statement 16 (information-provision) should be refined via explicit mention of existing quality assurance mechanisms, in particular the DH Information Standard. 33. We also encourage NICE to look to a wider	Thank you for your suggestion. This guidance by nature is generic, with a non population and non setting specific focus. We understand that the department of health is commissioning a single measure for patient experience which will be used at a

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					range of additional sources of data to inform the application of the quality statements, in addition to NHS sources. None of the statements have any identified "other possible national data sources" beyond existing indicators, although a good amount of relevant and robust data does exist to underpin the various statements. Arthritis Care in particular can provide substantial qualitative and quantitative data about the needs of people with arthritis to inform the development of patient experience measures and the implementation of the various quality statements.	commissioning level.
783	Arthritis Care	NICE	3	20	Implementation The guidance has very little to say on the subject of the training implications for health professionals that are inherent in these aspirations for improved patient care, other than to say it should take place and be looked for as part of the compliance process. The Quality Standard should explicitly recognise that voluntary and user-led organisations such as Arthritis Care can play a substantial role in this area. There is a list of 66 recommendations, but no specific Quality Standards that are measurable, practical, or achievable, to demonstrate that this work can be translated into improving clinical practice.	Thank you for your comment. We agree that training is important in the implementation of the Guidance. The NICE implementation team will consider these issues.
424	Birmingham and Solihull NHS Cluster	NICE	General	General	Our comments are as follows: the relationship between the numbering in the NICE document and the Quality Standard is unclear. At times there is no correlating number to establish how the proposed standard is to be measured.	Thank you for your comment. Guidance recommendations are distilled to form quality statements, and the source recommendations are listed for these. They are meant to be separate documents and therefore numbering systems are inevitably different.

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557	Birmingham and Solihull NHS Cluster	NICE	1.1.2	8	Our comments are as follows: specifically difficulties with reading, understanding or speaking English. This could be expanded to establish what the patients' first language is and then go on to ask if there are any difficulties in communication.	Thank you for your comment, this is too much detail for inclusion in this guideline.
574	Birmingham and Solihull NHS Cluster	NICE	1.1.6	9	Our comments are as follows: Staff need to be appropriately trained on patients religious and belief requirements and assumptions should not be based on appearance.	Thank you for your comment. Staff training needs are outside the remit of this guideline.
603	Birmingham and Solihull NHS Cluster	NICE	1.2.7	10	Our comments are as follows: this should include education and training on patients Religious Beliefs with respect to food.	Thank you for your comment. We agree that religious belief and food is important, we had however to limit the areas we were able to consider.
623	Birmingham and Solihull NHS Cluster	NICE	1.3.4	11	Our comments are as follows: that patients are introduced to the team in the reception area, for example via photo board, advised if a student or observer will be present at their consultation and offered the opportunity to decline their presence prior to the consultation.	Thank you for your comment and suggestion. It Recommendations 37 and 38 address the introduction of the healthcare team.
657	Birmingham and Solihull NHS Cluster	NICE	1.3.11	12	Our comments are as follows: Will the patient have the opportunity to revisit their treatment options should their circumstances change.	Thank you for your comment. This is addressed in recommendation 19.
691	Birmingham and Solihull NHS Cluster	NICE	1.4.4	14	Our comments are as follows: to include – patients are aware of what is happening next, for example who they will see next and why they need to be seen by this service provider.	Thank you for your comment. We have included recommendations that patients should be informed about the roles and responsibilities of healthcare team and consider this adequate to cover your point.
692	Birmingham and Solihull NHS Cluster	NICE	1.5.1	14	Our comments are as follows: where possible a treatment room/consultation room is made available to aid discussion of patients' condition and ensure privacy is respected.	Thank you for your comment. The guideline has not made recommendations on the physical environment, but does recommend that a patient's right to confidentiality is maintained.
719	Birmingham	NIC	1.5.6	15	Our comments are as follows: we are pleased that	Thank you for your comment.

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	and Solihull NHS Cluster	E			the patients understanding of words has been taken into consideration and included in these guidelines.	
720	Birmingham and Solihull NHS Cluster	NICE	1.5.10	15	Our comments are as follows: we are pleased that this has been included in these guidelines.	Thank you for your comment.
729	Birmingham and Solihull NHS Cluster	NICE	1.5.17	16	Our comments are as follows: we are pleased that this has been included in the guidelines	Thank you for your comment.
788	Birmingham and Solihull NHS Cluster	QS	General	General	Our comments are as follows: the relationship between the numbering in the NICE document and the Quality Standard is unclear. At times there is no correlating number to establish how the proposed standard is to be measured.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
789	Birmingham and Solihull NHS Cluster	QS	General	General	Our comments are as follows: If patient experience, both negative and positive, is to be accurately documented, with a view of improvement, then provisions need to be made to actively collate that information. This means collating information from groups that are seldom heard, in particular BME patients (taking into account socio-economic and language issues), patients with a learning disability and disability in the broader sense including patients from the protected characteristics under the Equality Act 2010. It is important that the information collected be used as evidence and to ensure improvement.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
915	Birmingham and Solihull NHS Cluster	QS	1	5	Our comments are as follows: staff who interact directly with patients need to have ongoing continual professional development, not a once a year tick box exercise as part of the annual assessment. We are pleased that delivering high	Thank you for your comment.

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					quality patient experience is seen as a part of the day to day role and not an 'add on'. It's important that this becomes part of the culture of the organisation.	
916	Birmingham and Solihull NHS Cluster	QS	1	5	Draft Quality measure, Structure: Our comments are as follows: We are pleased that these are included in the Quality Standard as their interactions with patients are important and form part of the patients overall experience.	Thank you for your comment.
957	Birmingham and Solihull NHS Cluster	QS	2	7	Our comments are as follows: the Quality Statement does not indicate how this information will be shared with different Health Professionals involved in a patients care. Patients will not want to have to repeat that they have particular needs each time they attend a consultation or see someone different for example a deaf patient who communicates by Sign Language, this information should be referenced on the referral from one provider to another.	Thank you for your comment. This is too much information to include in the quality statement. The main guideline includes a recommendation on the exchange of information.
986	Birmingham and Solihull NHS Cluster	QS	3	9	Our comments are as follows: it is not clear what is meant by the term Health Beliefs.	Thank you for your comment. 'Health beliefs' refers to a patient's health behaviours in relation to their perceived susceptibility and severity of their illness, the barriers and benefits of adopting a behaviour.
1010	Birmingham and Solihull NHS Cluster	QS	4	10	Our comments are as follows: incorporating this standard into the appraisal process is a positive way to ensure that these values are embedded into Providers services and individuals take personal responsibility and ownership for delivering a positive patient experience.	Thank you for your supportive comment.
1084	Birmingham and Solihull NHS Cluster	QS	7	13	Our comments are as follows: it is not clear what is meant by the term, first point of contact. For example some patients may think this refers to first contact with GP, others may think this refers to first contact with hospital consultant. This makes this	This is an important point to raise. At the first consultation, regardless of care setting the patient's preferences should be noted and form part of ongoing communication between all those who are involved in their care.

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					standard difficult to measure.	
1085	Birmingham and Solihull NHS Cluster	QS	7	13	Our comments are as follows: will this be revisited at points in the patients care as circumstances may change from first contact.	Thank you for your comment. This is an important point to raise. At the first consultation, regardless of care setting the patient's preferences should be noted and form part of ongoing communication between all those who are involved in their care.
1126	Birmingham and Solihull NHS Cluster	QS	9	16	Our comments are as follows: there are concerns with respect to how this standard will meet patient expectation. However this is an aspirational standard and should be included.	Thank you
1218	Birmingham and Solihull NHS Cluster	QS	14	21	Our comments are as follows: we are pleased that the Quality Standard includes confirmation of the patients understanding. This is important as just giving information is not the same as the information being understood by the patient.	Thank you for your comment. We agree.
3	Breakthrough Breast Cancer	All	General	General	Breakthrough Breast Cancer is a pioneering charity dedicated to the prevention, treatment and ultimate eradication of breast cancer. We fight on three fronts: research, campaigning and education. Our aim is to bring together the best minds and rally the support of all those whose lives have been, or may one day be, affected by the disease. The result will save lives and change futures – by removing the fear of breast cancer for good. This submission reflects the views of Breakthrough, based on our experience of working with people with personal experience of, or who are concerned about, breast cancer. We regularly consult with members of our Campaigns and Advocacy Network (Breakthrough CAN) for their views on a range of breast cancer issues. Originally founded by women with personal experience of breast cancer,	Thank you for your comments. We have responded to these in the separate sections to which they apply.

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					Breakthrough CAN brings together over 1,600 individuals, regional groups and national organisations to campaign for improvements in breast cancer research, treatments and services. Breakthrough CAN were surveyed to find out their opinions of the Quality Standards for Patient Experience, with 22 members responding. Some of the results of this survey are included below. In addition, this submission reflects the findings of large patient surveys conducted this year as a part of Breakthrough's Service Pledge. The Service Pledge is an innovative tool developed by Breakthrough Breast Cancer to enable patients and health professionals to work in partnership towards world class breast cancer services. By working together individual breast units, patients and healthcare professionals can collaboratively identify how services at the unit can be improved. Patient involvement is achieved through the use of surveys, patient interviews and patient representatives. These allow patients to feed back about the services they have received and comment on the aspects of the service they feel can be improved. The 1,506 patients responding to the surveys were from 25 separate breast units and had finished treatment 6-12 months prior to being involved. Finally, this response draws on the findings of the 2010 National Cancer Patient Experience (NCPE) Survey. This survey examined the experiences of 67,713 cancer patients treated as day cases or inpatients at 158 different NHS Trusts during the first three months of 2010.1	

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					1 Department of Health. (Dec 2010) National Cancer Patient Experience Survey Programme – 2010 National Survey Report.	
558	Breakthrough Breast Cancer	NICE	1.1.3	8	The patient's domestic, social and work situation should also be considered in relation to determining their ability to self-care.	Thank you for your comment. We have added self care to recommendation 3.
624	Breakthrough Breast Cancer	NICE	1.3.2	11	Patients should have the opportunity to discuss their treatment options thoroughly, as well as being given information about their options. This should be specifically stated in the guideline.	Thank you for your comment. This is addressed in recommendations 20 to 27
672	Breakthrough Breast Cancer	NICE	1.4.1	13	This should be amended as suggested above for quality statement 12. (line 25)	Thank you for your comment.
693	Breakthrough Breast Cancer	NICE	1.5	14	We would suggest that the wording of the first sentence be amended to read "Many patients wish to be considered as active participants in their own health care, and to be involved in the creation and management of their health strategy and use of services." There are likely to be some patients who will not wish to be involved in decision-making and may prefer some decisions to be made for them. Although in most cases patients should be thoroughly involved in their care, if their preference is that they do not wish to be involved this should be respected (in line with quality standard 3).	Thank you for your comment. The developers agree and this has been changed in line with your suggestion.
746	Breakthrough Breast Cancer	NICE	1.5.19	17	Charities can be a source of reliable high quality information and support and should be included in the list of sources.	Thank you for your comment. This recommendation did not intend to set out the types of services available, and therefore the GDG believe the current wording is sufficient.
790	Breakthrough Breast Cancer	QS	General	General	Breakthrough CAN members responding to Breakthrough's survey had generally positive opinions of the quality standards. In total, 17 of 22 respondents believed that all essential aspects of	Thank you for your comment.

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					patient experience were addressed by the quality statements. Among the 5 who disagreed, no gaps in the quality statements were consistently identified.	
791	Breakthrough Breast Cancer	QS	2,14	General	The principle of understanding barriers to communication is very important and should be included in the quality standards. However, if there is a need to cut down on the number of quality statements, statement 2 could be incorporated into statement 14 as both relate to establishing the most effective way of communicating with a patient.	Thank you for your comment.
792	Breakthrough Breast Cancer	QS	13, 14	General	When given a list of the draft quality statements and asked to identify the three statements that they considered to be the most important for people affected by breast cancer, no respondents identified this statement in their top 3. It is possible that this may because healthcare professionals having a "demonstrated competency" is more of a measure of communication skills rather than an outcome in and of itself. Statement 13 could be incorporated into 14 as a process measure as statement 14 reflects the competencies that should be demonstrated in communication skills. This could be worded "Proportion of patients cared for by healthcare professionals who have a demonstrated competency in communication skills". Additional process measures for statement 14 could be: a) Proportion of patients who were asked if they understood the information given to them and were given the opportunity to	Thank you for your comment. The quality standard has been changed to reflect this.

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					ask questions for clarification. b) Proportion of patients who had their communication with their healthcare professional tailored to a style most suitable for them.	
917	Breakthrough Breast Cancer	QS	1	5	It is very important that healthcare professionals strive to comply with the NICE guidance on patient experience. However, the most important goal is that they should strive to ensure that the patient experience is the best it can be; the NICE guidance is a tool to achieve this outcome. Therefore, we suggest amending the quality statement to read, "Healthcare professionals and all other staff who interact directly with patients are, as part of their annual performance assessment, evaluated and mentored for compliance with the NICE guidance on patient experience in adult NHS services. Healthcare professionals and staff strive at all times to ensure that patients have the best possible experience of care."	Thank you for your comment and we agree with your point. That is why the GDG wanted this statement to form the basis of informing culture change.
918	Breakthrough Breast Cancer	QS	1	5	There is no outcome measure included under "Draft quality measure". This outcome should reflect the overall goal of the NICE guidance on patient experience in adult NHS services. The outcome wording could be "Healthcare services are acceptable and appropriate, and all people using the NHS have the best possible experience of care".	Thank you for your comment. The outcome measure has been adjusted.
919	Breakthrough Breast Cancer	QS	1	5	The description of what the quality statement will mean for patients relates to internal NHS processes rather than to its actual impact on patients. We suggest changing the wording to "Patients can be assured that they will have contact with NHS staff who are familiar with, and	Thank you for your comment. Post consultation wording of recommendations and quality statements have been further refined.

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					take account of, NICE guidance on patient experience and strive at all times to ensure that patients have the best possible experience of care."	
920	Breakthrough Breast Cancer	QS	1	5	This quality statement may be difficult to monitor in practice as few healthcare professionals will be routinely observed when interacting directly with patients. If this quality statement is to have impact, annual performance assessments must include mechanisms to incorporate patient views and feedback on healthcare professionals' contributions to ensuring a positive patient experience.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
958	Breakthrough Breast Cancer	QS	2	7	Throughout this quality statement, it is stated that patients should be asked about their disabilities. However, it is never directly stated that these needs must be addressed and practical solutions sought to ensure that patients can participate in their consultations and care. We would suggest that this is stated throughout, for example by changing the wording of the quality statement to "Patients are asked about any physical or learning disabilities, sight or hearing problems, and difficulties with reading, understanding or speaking English. If barriers to communication are identified, practical solutions are sought to help maximise their participation in consultations and care." The structure and process measures, and description of what the quality statement means for each audience would also need to be amended to include the need to address communication difficulties.	Thank you for your comment. Post consultation wording has been further refined to reflect individualising care.
987	Breakthrough Breast Cancer	QS	3	9	Throughout this quality statement, it is stated that patients are "given the opportunity to discuss" their beliefs, concerns and preferences. However, it is	Thank you for your comment. The quality statement has been changed to reflect this.

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					never specified that these beliefs, concerns and preferences should be recognised and taken into account throughout their care. Therefore, we suggest changing the wording of the quality statement to "Patients are given the opportunity to discuss their health beliefs, concerns and preferences and these are taken into account in order to individualise their care." The quality measures and description of what the quality statement means for each audience should be similarly amended.	
1011	Breakthrough Breast Cancer	QS	4	10	When given a list of the draft quality statements and asked to identify the three statements that they considered to be the most important for people affected by breast cancer, half of the 22 respondents placed this statement in their top 3. Therefore this statement should definitely be retained in the final quality standard.	Thank you for your comment. This quality statement has been retained.
1012	Breakthrough Breast Cancer	QS	4	10	This quality statement has no associated process measure. Process measures are important to ensure that the quality standards are incorporated into routine practice. We suggest two possible process measures: a) Proportion of healthcare professionals who receive training on how to effectively treat patients with kindness, compassion, courtesy, respect, understanding and honesty. b) Proportion of healthcare professionals who were assessed based on these values in their annual appraisal.	Thank you for your comments. Process measures on the training of staff are contained within statement 2 of the final version. Statement 1 focuses much more on the patient's experience of care.
1013	Breakthrough Breast Cancer	QS	4	10	We suggest a slight change to the wording of the description of what the quality statement means for patients. Rather than "Patients are treated with dignity, kindness, compassion, courtesy, respect,	Thank you for your suggestion.

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					understanding and honesty" we suggest "Patients feel they are consistently treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty." This wording better reflects that patients will be the best judges of how they are treated and this cannot be truly judged by anyone other than the patient themselves.	
1014	Breakthrough Breast Cancer	QS	4	10	For cancer patients, the NCPE survey is another relevant existing indicator for this quality statement, as it contains the question "Were you treated with respect and dignity by the doctors and nurses and other hospital staff?" In the 2010 NCPE survey, overall 82% of cancer patients said they were always treated with respect and dignity but there were significant variations between individual Trusts with 65% as the lowest Trust score. Other indicators relevant to this quality standard from the NCPE survey include the proportion of cancer patients who said they felt they were treated as a "whole person" rather than a set of symptoms (78% in the 2010 survey) and the proportion of cancer patients who said that doctors did not talk in front of them as if they weren't there (88% in the 2010 survey). The responses to both of these questions can give an indication of whether patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty. There were significant variations in scores between individual Trusts on both of these questions.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1031	Breakthrough Breast Cancer	QS	5	11	Throughout this quality statement, it is stated that patients should have their needs and concerned assessed. However, it is never specified that any	Thank you for your comment. As stated in the description, they are assessed and addressed. This has been added to the

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					problems identified during this assessment should be addressed. Therefore, we suggest changing the wording of the quality statement to "Patients regularly have their physical needs (such as nutrition, hydration and personal hygiene) and psychological concerns (such as fear and anxiety) assessed and any problems addressed in an environment that maintains their dignity and confidentiality". The quality measures and description of what the quality statement means for each audience should be similarly amended.	quality statement.
1032	Breakthrough Breast Cancer	QS	5	11	This quality statement has no associated process measure. We suggest the following process measure: "Proportion of patients who have had their physical and psychological needs assessed and any problems addressed in a suitable environment that maintains their dignity and confidentiality."	Thank you for your suggestion.
1060	Breakthrough Breast Cancer	QS	6	12	Patient survey results from Breakthrough's Service Pledge sites suggest that staff in breast units perform better in this area than staff on hospital wards. 82% of patients said that all staff in the breast unit had introduced themselves, whereas only 57% of patients said that all ward staff had introduced themselves. It is very important that patients are introduced to each member of their care team so that they can feel comfortable interacting with them. We hope that this quality standard will help to drive up performance in this area.	Thank you for your supportive comment
1086	Breakthrough Breast Cancer	QS	7	13	This is a particularly important quality statement for breast cancer patients as results from the NCPE survey show that scores are relatively low for the indicators most relevant to this statement: • Only 68% of breast cancer patients	Thank you for your supportive comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is

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					responding to the NCPE survey said that if members of their family wanted to speak to a doctor there were definitely enough opportunities for them to do so. - Only 57% of breast cancer patients responding to the NCPE survey said that the staff gave their family all the information they needed. - 78% of breast cancer patients responding to the NCPE survey said that they were told that they could bring a friend or family member to their diagnosis appointment. It is very important that family, friends and carers are involved in care according to patient preferences so they can give appropriate support. Therefore, we hope that this quality statement will drive up performance in this area for breast cancer patients.	established from the NHS Commissioning Board.
1106	Breakthrough Breast Cancer	QS	8	15	This quality statement has no associated process measure. We suggest two possible process measures: a) Proportion of patients who are asked about their preference for treatment b) Proportion of healthcare professionals who are evaluated on their respect for and support of patients treatment preferences as part of their annual assessment. In line with this process measure, the description of what the quality statement means for healthcare professionals should have a second sentence: "This is monitored and incorporated into their annual assessment."	Thank you for your comment. The focus of this quality statement is whether patients felt they had their rights respected and supported. Not whether the notes say they were.

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1128	Breakthrough Breast Cancer	QS	9	16	When given a list of the draft quality statements and asked to identify the three statements that they considered to be the most important for people affected by breast cancer, 10 (almost half) of the 22 respondents placed this statement in their top 3. Therefore this statement should definitely be retained in the final quality standard.	Thank you for your comment. It remains.
1129	Breakthrough Breast Cancer	QS	9	16	This quality statement has no associated process measure. We suggest the following process measure: "Proportion of patients who regularly have their needs and circumstances assessed in order to individualise their care."	Thank you for your comment. See previous comment on NQB guidance.
1146	Breakthrough Breast Cancer	QS	10	17	Although it is very important that information is exchanged between relevant healthcare professionals to ensure seamless patient care, it is vital that patients are informed of this and appropriate consent is sought before any information is shared. This should be reflected throughout the quality statement. For example: a) The quality statement should be amended to read "Information about patient care is exchanged in a timely, appropriate, clear and accurate manner between relevant healthcare professionals with appropriate consent from the patient to ensure effective coordination and prioritisation of care." b) The structure measure and descriptions of what the quality statement means for each audience should be similarly updated. c) A process measure should be added: "The proportion of patients who were asked consent for their information to be exchanged between healthcare	Thank you for your comment. This has been amended to: Information about the patient and their care is exchanged in a clear and accurate manner between relevant health and social care professionals to ensure effective co-ordination and organisation of care.

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					professionals.	
1147	Breakthrough Breast Cancer	QS	10	17	An additional outcome for this quality statement could be included to reflect the importance of care coordination: "Evidence from experience surveys and feedback that patients felt they had timely and appropriate coordination of care."	Thank you for your observation. We did use NHS survey data in informing guidance recommendations.
1148	Breakthrough Breast Cancer	QS	10	17	A relevant existing indicator for this quality statement can be found in the NCPE survey where patients are asked whether they were ever given conflicting information by healthcare professionals while they were in hospital. This is an important measure of effective coordination of care between healthcare professionals which can directly assess the impact on the patient.	Thank you for your comment.
1166	Breakthrough Breast Cancer	QS	11	18	It is important that not only do patients have information about who to contact about their needs, but that they are actually able to get in contact with this person and have their needs addressed. Results from the 2010 NCPE survey show that 75% of cancer patients found that it was easy to contact their clinical nurse specialist (who is often the first point of contact for patients). Therefore we suggest including an additional outcome measure: "Evidence from patient experience surveys and feedback that patients have been able to reach this contact in a timely manner and have had their needs dealt with effectively." Similarly, the description of what the quality statement means for patients should include a second sentence "They are able to reach this contact in a timely manner and have their needs dealt with effectively."	Thank you for your comment. Wording of recommendations has been further refined post consultation.

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1177	Breakthrough Breast Cancer	QS	12	19	Continuity of care is very important to build trust between patients and healthcare professionals and ensure that care is consistent. However, this quality statement is not worded strongly enough to ensure that this continuity of care is provided. We suggest stronger wording: "Patients have continuity of care – this could involve seeing the same healthcare professional or healthcare team to promote and maintain continuity of care." Amongst patients at Breakthrough's Service Pledge sites, only 30% said that they had always seen the same member of staff whenever they had an appointment at the breast unit. Interestingly, 28% said that they had not seen the same staff member but would have liked to, whereas 40% said they had not seen the same member of staff but they did not mind this. This suggests that for some patients continuity of staff contact is not vital. However, it is vital that continuity of care and good information flow between healthcare professionals is maintained if the staff contact is changed.	Thank you, we agree with your comment.
1178	Breakthrough Breast Cancer	QS	12	19	This quality statement has no associated process measure. We suggest the following: "Proportion of patients who saw the same healthcare professional or healthcare team throughout their care."	Thank you for your suggestion. Given the difficulties in identifying the correct denominator the focus had been placed on patient experience feedback. If a local organisation can identify a specific cohort then they are free to measure this.
1179	Breakthrough Breast Cancer	QS	12	19	The description of what the quality statement means for patients should reflect the importance of care continuity, reading "Patients see the same healthcare professionals or healthcare team throughout their care where appropriate, giving them continuity of care."	Thank you for your observation. Wording of recommendations and quality statements has been further refined to reflect stakeholder comments.

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1193	Breakthrough Breast Cancer	QS	13	20	If statement 13 is retained as an independent quality statement rather than incorporated into statement 14, it should have an associated outcome measure added. We suggest "Patients report having effective communication with their healthcare professionals including open, clear and honest discussion about their treatment"	Thank you for your comment.
1219	Breakthrough Breast Cancer	QS	14	21	The description of what the quality statement means for patients could be expanded to better reflect the impact of this statement on them: "Patients are communicated with in a manner that is most suitable for them, and are asked if they understand the information given to them, allowing them to better understand their options and be involved in their care if they wish."	Thank you for your comment.
1227	Breakthrough Breast Cancer	QS	15	22	When given a list of the draft quality statements and asked to identify the three statements that they considered to be the most important for people affected by breast cancer, 10 (almost half) of the 22 respondents placed this statement in their top 3. Therefore this statement should definitely be retained in the final quality standard.	Thank you for your comment. A statement on shared decision making has been retained in the final quality standard.
1228	Breakthrough Breast Cancer	QS	15	22	There are several relevant existing indicators within the NCPE survey: • The proportion of patients responding to the NCPE survey who said that they were definitely involved as much as they wanted to be in decisions about their treatment. • The proportion of patients who said that, when having tests for cancer, staff explained the purpose of the tests completely • The proportion of patients who said that, when having tests for cancer, staff	Thank you for your comment. Noted

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					explained what would be done during the tests completely.	
1229	Breakthrough Breast Cancer	QS	15	22	This quality statement has no associated process measure. We suggest three possible process measures: a) Proportion of healthcare professionals who have received training on facilitating shared decision making b) Proportion of patients who were given verbal and written information about the options available to them and were involved in the decision-making process c) See suggestion below (line 36)	Thank you for your comment.
1252	Breakthrough Breast Cancer	QS	16	23	It is important that information is provided both verbally and in written format so that patients have every opportunity to understand their options and be involved in their care. Therefore we suggest amending the quality statement to read "Patients are provided with evidence-based verbal and written information that is understandable, personalised and clearly communicated."	Thank you for your comment. The statement is based on detailed recommendations that establish that it should be available in both forms.
1253	Breakthrough Breast Cancer	QS	16	23	There are several relevant existing indicators for cancer patients relating to this quality statement within the NCPE survey: • The proportion of patients who said that, when having tests for cancer, they were given written information about their tests that was easy to understand. • The proportion of patients who said that they were given written information about the type of cancer they had that was easy to understand. • The proportion of patients who said that they were given written information about	Thank you for your helpful comment. We have kept to the generic patient surveys. If local organisations can use surveys for particular patient groups that they may wish to do so.

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					- the side effects of their treatment - The proportion of patients who said they were given written information about their operation.	
1275	Breakthrough Breast Cancer	QS	15,17	24	When given a list of the draft quality statements and asked to identify the three statements that they considered to be the most important for people affected by breast cancer, no respondents to Breakthrough's CAN survey placed statement 17 in their top 3. In addition, three respondents commented that they did not understand the wording used in statement 17 ("support tools" and "decision aids" were specifically mentioned as jargon). As this wording may render this statement unintelligible to patients and the aim of these tools is to enable shared decision-making, we suggest that statement 17 be incorporated into statement 15 as a process measure: "Proportion of patients provided with decision support tools such as patient decision aids"	Thank you for your comment, we have addressed this post consultation
1276	Breakthrough Breast Cancer	QS	17	24	If quality statement 17 is retained as a separate quality statement rather than incorporated into statement 15, jargon should be avoided in the main quality statement to enable patients to understand it. In addition, the importance of decision aids being not only accessible, but also useful, should be reflected. Therefore we suggest that the outcome measure be amended to read "Evidence from experience surveys and feedback that patients felt able to access decision support tools such as patient decision aids and that they felt confident in	Thank you for your comment. The GDG reduced the number of statements in the final quality standard and incorporated decision support tools into the measurement of the statement on shared decision making.

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					using them."	
425	Breast Cancer Care	NICE	General	General	Comment 1 is also applicable to the clinical guideline.	Thank you for your comment. Consultation comments have been fully considered in redrafting both the guidance and the quality standard.
559	Breast Cancer Care	NICE	1.1.2	8	See comment 4.	Thank you for your comment.
575	Breast Cancer Care	NICE	1.1.6	9	This should include avoiding assumptions based on sexual orientation especially as sexual orientation as a category was included in the National Cancer Patient Experience Survey and it has been agreed that this will be carried over into the larger NHS Inpatient Experience Survey.	Thank you for your comment. We have added a specific recommendation about the Equalities Act to ensure we have not omitted any individuals or groups.
576	Breast Cancer Care	NICE	1.2.1	9	See comment 6.	
604	Breast Cancer Care	NICE	1.2.4	10	We would reiterate the importance of broaching sensitive subjects but would acknowledge the fact that some healthcare professionals may not have the knowledge/expertise or information to deal with these issues themselves and subsequently should be aware of how best to 'signpost' appropriately (e.g. such as referrals for sexual counselling).	Thank you for your comment.
625	Breast Cancer Care	NICE	1.3.3	11	Knowledge about, and referral to, specialist support services for certain groups (e.g. lesbian, gay and bisexual patients) is often lacking. Healthcare professionals should be able to inform patients about local and national specialist support services (often voluntary sector organisations) should the patient require them.	Thank you for your comment and suggestion. It has been incorporated into the recommendation.
673	Breast Cancer Care	NICE	1.3.12	13	This point should include access to formal complaint procedures that are easily accessible and advertised to patients.	Thank you for your comment. A recommendation (33) has been added addressing this.
730	Breast Cancer Care	NICE	1.5.12	16	We would like to see "evidence based" information here.	Thank you, this has been highlighted in related recommendations and in the quality

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						standard.
747	Breast Cancer Care	NICE	1.5.19	17	This point should include specialist support groups for different equalities groups.	Thank you for your comment. This recommendation did not intend to set out the types of services available, and therefore the GDG believe the current wording is sufficient.
793	Breast Cancer Care	QS	General	General	We would like to suggest another Quality Standard that reads: "Every patient shall be treated without discrimination or prejudice and in line with the legal protections that are afforded them in the Equality Act 2010." Inequalities in outcomes and patient experience are well documented and we feel that a Quality Standard that makes direct reference to a patient's legal rights in terms of their level of treatment and care would ensure that equalities remains at the heart of improving practice.	Thank you for your suggestion. All recommendations and statements are developed in line with current legislation and the equalities act specifically referred to.
794	Breast Cancer Care	QS	General	General	We would like to suggest another Quality Standard that reads: "Where available patients should have easy and timely access to leave feedback, make complaints and judge the quality of the service they received with the expectation that their views will aid service improvements". This is in recognition of the fact that patients' input is crucial to service improvements. Patients are being asked to become more involved in their healthcare and with the use of Patient Reported Outcome Measures (PROMs) and the like, this investment by patients should be matched with a commitment from service providers to make best use of the data that is collected from them. Robust, confidential and timely complaints procedures should be widely advertised, not only to empower patients but also to ensure accountability.	Thank you for your suggestion. Unfortunately we are limited in the number of quality statements we can have.
795	Breast Cancer Care	QS	General	General	We would like to suggest another Quality Standard that reads: "Patients have the right to expect adequate staffing levels and expertise to meet	Thank you for your suggestion. Unfortunately we are limited in the number of quality statements we can have.

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					their healthcare needs. Many of the draft Quality Standards listed are dependent on this crucial area. Cuts to frontline services that are currently in operation are threatening to undermine all of these Quality Standards pertaining to improving patient experience. We therefore believe that the expectation of having enough healthcare professionals such as nurses on the staff who are able to deliver on these Standards is vital.	
959	Breast Cancer Care	QS	2	7 -8	We do not believe it is just enough to "ask" patients about their physical and communication needs. We would prefer wording that spells out that the information received from patients as to their individual needs will be acted upon and these needs met to maximise their participation in consultations and care.	Thank you for your comment. Post consultation wording has been further refined to reflect individualising care.
988	Breast Cancer Care	QS	3	9	We would like to see this Quality Standard include the following wording: "at various stages along the care pathway". Preferences and concerns can change over time depending on the stage of disease or changing circumstances. The opportunity for patients to discuss their health beliefs, concerns and preferences should not be perceived as a 'one-off' exercise and opportunities for discussion should be factored in at various points along the care pathway.	Thank you for your comment. As the quality standard applies to all of the NHS, reviewing it along the care pathway is not always appropriate.
1015	Breast Cancer Care	QS	4	10	This is a fundamental Standard for all NHS patients, which is why it was extremely worrying when the National Cancer Patient Experience Survey 2010 found significantly worse results for those in different equalities groups, including older people, those from BME backgrounds and lesbian, gay and bisexual patients. The fact that certain groups are reporting significantly worse outcomes indicates that focus should be targeted here. To	Thank you for your comment. Whilst we agree with you, the principles in the quality statement should apply regardless of the areas you have listed. Equalities Act now embedded and referenced.

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					highlight this we would suggest an addition to the end of this Quality Standard along the lines of: "regardless of gender, age, race, sexual orientation, disability and other protected characteristics".	
1130	Breast Cancer Care	QS	9	16	We wondered if reference should be made to a care plan here, as the tried, tested and tangible means by which this Quality Standard can be made a reality. We know that care plan provision is still patchy and having reference to them here would be another lever by which they can be rolled out so all patients benefit from them, as well as have a written record of their needs and how they will be met.	Thank you for your comment. Post consultation wording in guidance recommendations has been refined. We agree with the importance of care planning.
1149	Breast Cancer Care	QS	10	17	In light of the drive towards integrating care, particularly between health and social care, it may be worth specifying information exchange between professionals from both of these sectors, as well as just within the NHS.	Thank you for your comment.
1254	Breast Cancer Care	QS	16	23	We are pleased to see that "evidence based" information is stipulated here. It may be helpful to be explicit that this includes non-clinical as well as clinical information – something we found lacking in the National Cancer Patient Experience Survey. Only 53% of breast cancer patients said that they had been given information about financial help or benefits by hospital staff. Only 61% of breast cancer patients were told that they were entitled to free prescriptions. This kind of information is invaluable for patients, particularly if it saves them money at a time when incomes have to drop suddenly, especially for those diagnosed who are still of working age. The impact of financial worries at this time exacerbates an already emotionally exhausting and stressful situation. Therefore timely	Thank you for your comment, this has been considered.

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					information for non-medical as well as clinical information should be specified in this particular Quality Standard.	
1255	Breast Cancer Care	QS	16	23	Delivering evidence- based information will also be dependent on healthcare professionals being offered 'up to date' training opportunities. These opportunities are often limited in a stretched health care service and so mentioning it here would provide a lever to encourage continuing investment in NHS staff at a precarious time.	We agree, please see previous comments relating to this.
48E	British Association of Critical Care Nurses (BACCN)	Full	General	General	The full clinical guideline is 120 pages long. It is concerning as many health care professionals will not have the time to read this and ensure it is implemented	Thank you for your comment. The implementation of the guidance does not require healthcare professionals to read the full guideline.
48B	British Association of Critical Care Nurses (BACCN)	Full	General	General	Educational programmes for staff are not apparent	Thank you for your comment. NICE recommendations do not cover detail of staff training or how services should be delivered. The Quality Standard provides guidance to commissioners on essential elements of care provision, and training is locally agreed as part of the commissioning framework.
48C	British Association of Critical Care Nurses (BACCN)	Full	General	General	It should be made clearer that education programmes should ensure we have communication training embedded within them and those staff not meeting the benchmark will receive training / mentoring	Thank you for your comment. NICE recommendations do not generally cover the mechanisms of how staff achieve competency. This is the remit of professional and employing organisations.
48D	British Association of Critical Care Nurses (BACCN)	Full	General	General	The Draft quality statements are clear	Thank you for your comment

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221B	British Association of Critical Care Nurses (BACCN)	Full		25 -26	Recommendations 37 – 47:The majority of people who are critically ill have significant communication issues and it is unclear whether these are addressed fully	Thank you for your comment. The GDG recognise that the examples we provide may not cover the needs of all groups but that communication needs still need to be considered.
221C	British Association of Critical Care Nurses (BACCN)	Full		25	Recommendation 41: Not everyone will know what "idiom" means	Thank you for your comment. The GDG wished to leave idiom in the recommendation and we have added this to the glossary
276B	British Association of Critical Care Nurses (BACCN)	Full		27 -28	Recommendation 65: Good that patient education programme are addressed	Thank you for your comment.
425B	British Association of Critical Care Nurses (BACCN)	NICE	General	General	The short version is significantly easier to read	Thank you for your comment
425C	British Association of Critical Care Nurses (BACCN)	NICE	General	General	It is not exactly clear whether the long and short versions are the same as numbering is rather different	Thank you for your comment. The NICE version only contains the recommendations from the FULL version.
489	British Medical Association	NICE	QS10	6	Further clarification is needed on what is meant by 'timely manner'.	Thank you for your comment. This has been reworded.
490	British Medical Association	NICE	QS10	6	With regard to confidentiality on a ward round, where possible patients who have particularly sensitive issues are brought to a private room. When this is not possible, a patient's consultation may be overheard by up to three patients located in the same bay due to the	Thank you for your comment. Recommendations refined post consultation has reflected the importance of this issue.

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					extremely poor soundproofing qualities of the curtains surrounding patient beds. This needs to be acknowledged in the guidance.	
491	British Medical Association	NICE	QS2	6	The BMA's 2007 report Disability equality within healthcare: The role of healthcare professionals called for increased disability competence among doctors and other healthcare professionals. Disability competence is not just about understanding practical access issues, it is also about treating all patients with respect, not making assumptions about how someone wants to be treated, and being able and willing to ask questions when necessary. This type of skill can also be learned through broader equality and diversity training rather than that specifically focused on disability. Increased understanding by healthcare professionals about the diverse needs of the population is vital in order to maintain high standards of care and health outcomes of patients.	Thank you for your comment. These issues are addressed in the final quality standard. They are further covered in the main guideline document.
492	British Medical Association	NICE	QS13	6	As highlighted in the BMA's 2007 report The right to health: A toolkit for health professionals, for the majority of healthcare professionals, the most significant immediate impact they can have on their patients' enjoyment of the right to health is to provide them with the highest available standards of care. An essential component of this is good communication. Ensuring effective communication occurs is imperative. Under the new arrangements outlined by the Government patients will need to understand the basis for decisions if some types of care are not affordable within the NHS.	Thank you for your comment

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					Good communication engenders meaningful and trusting relationships between healthcare professionals and their patients. The BMA's 2004 report Communication skills education for doctors: an update, outlines the benefits of good communication skills and the barriers to effective communication. The BMA's Equality and Diversity Committee 2006 report Guide to effective communication – non-discriminatory language, promotes good practice in using language in an inclusive way, which shows respect for, and sensitivity towards, all members of the community.	
796	British Medical Association	QS	General	General	The standards would benefit from a statement calling on all healthcare staff to introduce themselves and explain their role to the patient.	Thank you for your comment. This is reflected in the final version of the quality standard.
797	British Medical Association		General	General	There needs to be an acknowledgement that the implementation of these guidelines will require additional training, as well as consideration for the time taken for staff to comply with the standards, as this will have cost implications.	Thank you for your comment. We believe that recommendations draw on existing under graduate and mandatory training. We anticipate that training issues will be reflected in local commissioning agreements.
879	British Medical Association	QS		1	The introductory section of the draft quality standard states that it will not cover people using NHS services for mental health or the experiences of carers of people using NHS services. It would be useful to state where this information can be found.	Thank you for your comment. A separate guideline entitled; service user experience in adult mental health, is being developed and will be available at the same time.
888	British Medical Association	QS		3	Points 2-6 cover physical, social, cultural and psychological needs and how they should be assessed. There is, however, no reference to recording, assessing, respecting or accommodating religious or spiritual beliefs of patients. The spiritual, cultural and religious needs of	Thank you for your comment. These aspects are covered in the full guideline recommendations from which the quality standards have been developed.

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					patients are integral parts of holistic care, and should be taken into consideration when planning and delivering care. In times of illness, personal faith and beliefs can play an important part in the well-being of many patients. Being aware of the individual's spiritual needs, beliefs, culture and customs may enhance and enrich the patient experience.	
905	British Medical Association	QS	17	4	We suggest rephrasing 'high quality' to 'proven effective' as something that is high quality is not always effective.	Thank you for your comment. As we were restricted in the number of quality statements this has been removed.
906	British Medical Association	QS	17	4	Further clarification is needed on what is meant by 'patient decision aids'.	Thank you for your comment. As we were restricted in the number of quality statements this has been removed.
907	British Medical Association	QS	13	4	It would be useful to explain what is meant by 'competency' in communication skills.	Thank you for your comment. This is a current focus in healthcare undergraduate training, and therefore this guidance is related to systems already in place.
1150	British Medical Association	QS	10	17	For information, the BMA 's 2009 Consent Toolkit supports doctors when they are seeking consent by providing answers to common questions raised by this process. The toolkit consists of a series of cards relating to specific areas of consent such as providing treatment to children; consent and research; and obtaining consent for teaching purposes.	Thank you for your comment.
49	British Society of Gastroenterology	Full	General	General	This is a guideline of 120 pages pointing out that patient experience of care is far from ideal in the NHS. This is not a new concept (as demonstrated by the references to William Osler) but it may be helpful to categorise what patients regard as a poor experience in healthcare. The categories are reasonable and cover most of the problems relating to poor experience in the NHS. It should	Thank you for your comment. The aspects of care the Guidance covers were partly drawn from a scoping study undertaken by the University of Warwick, which included studies that included poor experiences of care.

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					be realised that many of these issues are interdependent, and therefore measuring one will inevitably mean measuring part of another. The issues I have with this are:	
50	British Society of Gastroenterology	FULL	General	General	1. It reads like a manual of medicine and nursing care .These are things that doctors and nurses (and many other professionals) strive to achieve every day of their lives. The implication that this is a revelation in care is not justified but providing standards in these areas may be so.	Thank you for your comment. We agree that many people working with patients strive to achieve these aspects of care. Our remit was to develop quality standards to ensure that patient experience is assessed along with other aspects of quality i.e. safety and effectiveness.
51	British Society of Gastroenterology	Full	General	General	4. References risks and benefits of procedures, the risk is often explained in great detail, and is easy to comprehend. The risk of not having a procedure is easy to understand. However the true benefits of procedures is much harder to convey. In particular, changes in QoL are hard to convey to patients, (even if we have data showing how they change after a procedure). The change in QoL may be what the patient wants to know but much more work needs to be done in how this can be explained to patients in a meaningful way. Many health care professionals will not understand QoL changes and therefore they cannot explain it to patients.	Thank you for your comment. The GDG considered that patients should have the medical aims of a procedure discussed with them and patient understanding and expectations explored. The GDG disagree that many health care professionals will not understand QoL.
52	British Society of Gastroenterology	Full	General	General	5. There is no advice on difficult areas such as "end of life care/the withdrawal of care" or how we should collect evidence that we are compliant with these NICE guidelines	Thank you for your comment. In November 2011 NICE published a quality standard on End of Life care.
53	British Society of Gastroenter	Full	General	General	6. We are not clear that the costs vs benefits to patients or the service have been fully considered in the guidance as it is presented. Who is going to	Thank you for your comment. NICE implementation team provide detailed costing to support this guidance. We expect that

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	ology				collect the metrics of all these outcomes and at what cost?	further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
124	British Society of Gastroenterology	Full	1	10	It is stated (section 1 line31) that tools for measuring patient experience have not been well developed. The sentence below does not seem to read that well: Historically, measures of experience have not been robustly developed or tested, the consequence being potential skewing of data and what should be a cautious approach in responding to this data. The authors may not be aware of the extensive work on cancer patients "satisfaction with care" research, published via the EORTC quality of life group (Bredart et al), The tool produced there (QLQ SAT32) is a validated questionnaire to assess quality of care in cancer patients, The validation of this tool has taken years and many hundreds of patients. For all patient disease groups it should be stated which validated questionnaires are to be used .If there are no validated questionnaires, how are we to use comparisons between different health care providers and how can we be sure there are changes over time?	Thank you for your comment. We did not specifically include a review of instruments and agree that the use of validated instruments is important and greater emphasis must be placed on this. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
185	British Society of Gastroenterology	Full	4.1.15	24	2.From the BSG aspect, nutrition is clearly relevant. (section 4.1.15). This advice should be expanded to include relevant discussions with patients and or relatives about whether enteral or parenteral feeding are appropriate. Measures of nutrition should be undertaken and explained to	Thank you for your comment. Guideline 32; Nutrition support in adults, addresses these issues.

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					the patient. Number of times patients are starved for investigations that are delayed or cancelled should be recorded and audited. The nutritional section seems thin on details. How about protected meal times, colour-coded trays depending or risk of malnutrition? Someone with a nutritional interest may have further comments on this section.	
1127	British Society of Paediatric Gastroenterology, Hepatology & Nutrition	QS	Statements 9 and 10	16 & 17	Statements 9 and 10 tailoring health care services to the individual and Continuity of care and relationships-exchange of information. Our comments are that we request a Quality Statement for Service providers, professionals and Commissioners on Transition into the adult health care sector. Transition from paediatric to adult services is a process that does not end at the exit from the paediatric clinic, but continues into the adult sector, which needs to provide developmentally-appropriate clinical care. It is a Quality Standard that adult services provide well managed active transition process that proceeds in a planned and purposeful way. While the young person with a chronic medical condition may have outgrown the paediatric healthcare environment, they may have delayed psychosocial milestones, reduced independence, social isolation and increased educational and vocational difficulties (Stam H, Hartman E, Deurloo J et al. (2006) Young adult patients with a history of paediatric disease: impact	Thank you for your observation. We recognise the importance of the points made, but this was outside the remit of this work.

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					on course of life and transition in adulthood. J Adolescent Health 39, 4–13). Adult health services assume that patients have an extent of autonomy and have the capacity to negotiate the healthcare system. However, management tasks may present greater obstacles and be more problematic in young people who may be overwhelmed by the burden of healthcare issues and inappropriate expectations of clinicians. There have been several reports of increased unemployment in young adults that is not always related to their disability or educational achievement and may be increased risk of non-adherence or lack of follow-up, which carries dangers of morbidity and mortality as well as poor social and educational outcomes. (McDonagh JE (2007) Transition of care from paediatric to 304adult rheumatology Arch Dis Child 92, 802–807.). Sir Ian Kennedy's recent review of Children's Health Services in the UK (Kennedy I . Getting It Right for Children and Young People—Overcoming Cultural Barriers in the NHS so as to Meet Their Needs. London: Department of Health, 2010), reports that transition, 'long the cause of complaint and unhappiness',is a 'critical area' for service improvement, as existing abrupt transfers are failing to meet young people's needs. He called for discrete funding for this area, and a shift in focus towards the needs of the young person and away from 'bureaucratic barriers' between paediatric and adult care. This document is one that could do what Sir Ian Kennedy suggests.	

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4	British Thoracic Society	All	General	General	The NICE draft guidance and derived quality standard are thorough pieces of work, cover important areas, and in many ways are to be commended. However, they are focussed on the patient as someone to whom things are done: the patient's beliefs are respected, the patient's circumstances are examined, information is given, the patient is supported in shared decision-making, information about the patient is exchanged, and so on. All this is good, but omits the idea of partnership between the patient and healthcare professionals: patients come with information, with expert knowledge of their own physical and mental state, and with respect for professional views. They do not need to be 'involved in their own healthcare' - they are already involved. The current guidance and quality standard are based on reviews of patient experience and expectations in a paternalistic (and maternalistic!) service, before the age of Google. Guidance and quality standards therefore match the past, but not the future.	Thank you for your comment. It is not our intention to suggest that the patient is someone to whom something is done. We recognise that the language in the draft version was more paternalistic than we intend and have reviewed this with NICE editors and the Guideline Group to ensure a more appropriate tone.
54	British Thoracic Society	Full	General	General	A short executive summary (three-minute read) would be helpful.	Thank you for your comment. The main output from this work is the recommendations and quality standards.
798	British Thoracic Society	QS	General	General	I think there is some very useful stuff in it and the repetition is helpful, although some of it still needs close reading. In general I would like to see more acknowledgement about what is required for patients with special needs. Maybe a general bit nearer the beginning could cover it, but in particular I think No 14 on communication needs something specific. For example, paragraph 5	Thank you for your comment. We recognise the particular needs of those with special needs. The remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline.

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					could add something like ' have an understanding of how to communicate with patients with special needs such as those with learning difficulties or severe hearing impairment.	
426	Care Quality Commission	NICE	general	general	Suggest the reference to the related mental health service user experience guidance document and the nature of the relationship between the two is made explicit early on in the document.	Thank you for your comment, This will be addressed.
427	Care Quality Commission	NICE	general	general	There seem to be some gaps in this guideline including: • Quality statements/standards in the mental health document that would be relevant to non-mental health settings • Clearer statements on meeting the diverse needs of people that use health services • A greater focus on care pathways, ensuring communication between different professionals/ agencies involved – e.g. at the point of admission or discharge from hospital.	Thank you for your comment. Individuality and diversity have been considered in the Guidance.
487	Care Quality Commission	NICE	general	5	Suggest rephrasing the first sentence – to improving the experience of people who use adult NHS funded services	Thank you for your suggestion
493	Care Quality Commission	NICE	QS 1	6	Should this standard also make reference to assessment at the point of recruitment of staff's approach to people who use services (perhaps particularly evidence of their potential for meeting the requirements of standard 4)? Does the requirement to comply with the quality standards effectively mandate NICE guidance? Whilst supportive of the idea of evaluating professionals' performance in relation to patient experience, is including 'compliance' problematic in that it this is guidance and within this context	Thank you for your comment. The GDG decided that this quality statement should focus on the ongoing performance assessments. The quality standards do not effectively mandate NCIE guidance. It is not mandatory that an organisation assesses itself against any standard. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality

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					professionals should be able to assess if they are following NICE or any other guidance - as long as they are using recognised published evidence on which to base their practice.	Board and, when it is established from the NHS Commissioning Board.
494	Care Quality Commission	NICE	QS2	6	Patients should also be asked about any psychological, emotional or mental health issues	Thank you for your comment. The statement has been amended to better reflect the recommendation. It now reads "physical and psychological needs regularly assessed and addressed including, nutrition, hydration, pain relief, personal hygiene and anxiety"".
495	Care Quality Commission	NICE	QS5	6	Should this be '..assessed and treated in an environment …'	Thank you for your comment. The corresponding quality statement has now been amended to reflect addressing needs.
496	Care Quality Commission	NICE	QS8	6	This is an important principle but implementation is likely to be mediated by the realities of and variations in terms of availability, resource constraints etc. It would be helpful if the guidance could acknowledge this in some way – otherwise there is a risk that if the standards are not seen as realistic, that they will be ignored.	Thank you for your comment. The statements are intended to be aspirational and challenge services to provide high quality patient experience. To aid implementation please refer to 'Nice support for commissioners and other using guidance and quality standard on patient experience in adult NHS service'
497	Care Quality Commission	NICE	QS8	6	This statement may need to be qualified for people whose rights are restricted under mental health legislation.	Thank you for your comment. People detained under mental health legislation should still have their preferences respected and supported. An applicable statement can be found in the service user experience quality standard.
498	Care Quality Commission	NICE	QS12	6	We would suggest that this statement needs to be strengthened considering the importance that most people attach to continuity of care and to reflect the detailed guidance on p13.	Thank you for your comment.
499	Care Quality Commission	NICE	QS13	6	Should this statement be expanded rather than just focusing on competency in communication?	Thank you for your comment. The GDG have decided this statement should focus on the competency of staff.
560	Care Quality	NIC	1.1.2	8	It is also important to respond to any factors	Thank you for your comment, this is too much

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	Commission	E			identified as well as considering them – including making any reasonable adjustments to enable involvement in one's care and treatment.	detail for inclusion in this guideline.
658	Care Quality Commission	NICE	QS8/ 1.3.10/ 1.3.11	12	Although quality standard 8 and sections 1.3.10/ 1.3.11 acknowledges a patient's right to decline treatment, in general the guidance is predicated on the assumption that people will want treatment. We are cognisant of the current debates about end-of-life care - sometimes people want to be enabled to refuse treatment and to be confident that palliative care only will be provided when the time comes. As indicated in both the full guidance document this can be discussed/ recorded in advance through Advance Decisions. It may therefore be important to acknowledge this within the guidance, if only to raise its profile and give clinicians and patients permission to talk about it openly. It may also be helpful to cross reference the end-of-life draft quality standards.	Thank you for your comment. We recognise the importance of end-of-life care however we had to limit the areas that we could consider. In addition, an End of Life Care Quality Standard will be published in November of this year.
731	Care Quality Commission	NICE	1.5.18	16	A key finding of our national surveys of patient experience is the significant proportion of people who do not have the side-effects of medication explained to them. Could a reference to this be added?	Thank you for your comment. A separate Medicines Adherence quality standard is planned which will cover medicine taking in more detail.
56	Central South Coast Cancer Network	Full	General	General	The documents starts out very well with using clear English, setting the background and explaining who and how the document was produced. As the document progresses though it gets repetitive and for me confusing. Much is made of "evidence" based decision making, but for me the document contains very little that I would consider evidence.	Thank you for your comment. We acknowledge the repetitive nature of the document but we are required to provide support for our recommendations. The recommendations primarily draw on secondary sources rather than primary evidence.
57	Central South Coast Cancer	Full	General	General	The document does not state it's intended target audience or objective. I fear that due to it's size very few clinicians or patients will read it. A good	Thank you for your comment. The intended audience and objective of the guidance is detailed in chapter 2. The recommendations

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	Network				edit and moving area specific information into supporting documents would do a lot to increase the value of the document.	will be published as part of a clinical pathway and a patient version will also be published with the final version.
58	Central South Coast Cancer Network	Full	General	General	The document promises "A focused thematic qualitative overview", which sounds interesting. I found the first such table confusing, I could not relate it to specifics, and indeed I found it cryptic. I put this down to the fact that it was not a way of imparting information I was familiar with. As I progressed through the document I found the tables even more confusing.	Thank you for your comment and regret that you found it difficult to follow some of the tables. .The intention of the tables is to summarise key themes or aspects of patient experience and represents a qualitative approach to data synthesis. A more detailed account of the qualitative overview is found in Appendix B.
128	Central South Coast Cancer Network	Full	21	12	A specific area that I felt could do with explanation and what proposals are being considered to drive change is: NHS cultural shift - what culture are we moving from to ? an over used idiom.	Thank you for your comment. We envisage a culture where patients are enabled to have a good experience, feel supported, well informed and communicated with in a way that meets their needs. They should feel equals with health care professionals. The description of the Warwick Patient Experiences Framework describes this culture from the patient perspective.
145	Central South Coast Cancer Network	Full	17.3	17	A specific area that I felt could do with explanation and what proposals are being considered to drive change is: Reference to saving through patients early presentation through better communication of warning symptoms. A concept that has great potential to benefit patients and clinicians alike.	Thank you for your comment. The recommendation made in this guidance are intended to focus on the patient/clinician interaction. Topics were prioritised for inclusion by the guideline development group. Recommendations have been made about maximising patient participation (recommendation 40 and 45) which should encourage the discussion of warning symptoms.
148	Central South Coast Cancer Network	Full	3.6.	18	Systematic literature revues - this is an area where some common method of publication / reference would be of considerable value.	Thank you for your comment. But we are unclear what you refer to.

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149	Central South Coast Cancer Network	Full	3.6.2.1	18	18-23 Systematic literature search - surprised that New Scientist was not included as it's been voted top medical journal on several occasions. What mechanisms are in place to maintain currency?	Thank you for your comment. We searched for literature indexed on the major databases listed in section 3.6.2.1. New Scientist is a non-peer reviewed magazine.
222	Central South Coast Cancer Network	Full	22	25	Enabling patients to actively participate in their care - item 45 offer patients copies of correspondence - there should be an opt-in choice for communication, preferably just cc on emails. What additional cost are associated with copies - editorial, legal etc	Thank you for your comment. Copying letters to patients was part of the NHS plan and the department of health already have guidelines in place for good practice in this area.
288	Central South Coast Cancer Network	Full	31	31	Information communication and education - an area that would deliver great benefits.	Thank you for your comment.
348	Central South Coast Cancer Network	Full		58 -	Chapter 9 looks at the benefits and cost of midwife pre and post natal support and it's effect on the patient. It's not clear how valid a proxy this is for other conditions, the concept of continuity over the course of treatment is the key point and it gets lost rather than re-enforced.	Thank you for your comment. We initially aimed to identify evidence for any intervention that might be applied to operationalise continuity of care (for example: key workers, hand-held records, etc). However due to complexities with the evidence identified and the time constraints of development, midwife-led care was selected for full review as there was a clear mechanism for operationalising continuity of care in that clinical area that was well defined in the literature. The aim of the review was to see if components of care could be identified that specifically improve continuity and could be generalised across disease areas. As the concept of continuity of care is multi-faceted, there are many things that might impact continuity over the course of treatment – for example, continuity of healthcare professional, transfer of medical notes, appropriate booking systems, etc. – and it

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						was discussed how what is important for one person might be different for another. While we recognise pregnancy is not an illness requiring "treatment", the GDG believe the principles are transferable and this is reflected in the recommendations.
352	Central South Coast Cancer Network	Full	17	63	A specific area that I felt could do with explanation and what proposals are being considered to drive change is: Contains information on specific treatments which seems out of place in a general document. This is just one occurrence of condition specific information that has questionable value as it dilutes the document.	Thank you for your comment. We initially aimed to identify evidence for any intervention that might be applied to operationalise continuity of care (for example: key workers, hand-held records, etc). However due to complexities with the evidence identified and the time constraints of development, midwife-led care was selected for full review as there was a clear mechanism for operationalising continuity of care in that clinical area that was well defined in the literature. The aim of this review was to see if components of care could be identified that specifically improve continuity and could be generalised across disease areas.
799	Chelsea and Westminster Hospital NHS Foundation Trust	QS	General	General	We appreciate the work that has been taken forward in developing these standards and appreciate the challenge in defining the contributing factors to a multifaceted concept.	Thank you for your comment.
800	Chelsea and Westminster Hospital NHS Foundation Trust	QS	General	General	We view that the draft quality statements link to the existing Care Quality Commission Essential Standards of Quality and Safety, and that there is a risk of replicating approaches to measuring and monitoring these standards which exist through CQC compliance assessment, our quality account and CQUIN measures. We are concerned about the potential demotivation of staff as a result of the	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.

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					duplication of data collection and reporting and question what added value will result from this.	
801	Chelsea and Westminster Hospital NHS Foundation Trust	QS	General	General	We have concerns about standards for the patient experience being externally derived and measured, as we feel that the focus should be on organisational / staff ownership.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
802	Chelsea and Westminster Hospital NHS Foundation Trust	QS	General	General	We consider that 17 statements could be reduced to a smaller number – for example, a single quality statement relating to communication with patients.	Thank you for your comment. The quality statements have been reduced to 14.
803	Chelsea and Westminster Hospital NHS Foundation Trust	QS	General	General	We view that there would be real value in robust evidence around approaches and methodology to enable the accessing and understanding of the patient experience	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board. This will inevitably help us better understand how to adapt service provision in relation to improving the quality of patient experience.
921	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 1	5	Some inconsistent terms. Uses 'healthcare professionals and all other staff' in the quality statement but health and social care professionals in the audience section	Thank you for your comment. This has been addressed.
922	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 1	5	All 17 statements may not be appropriate to all staff groups who interact with patients	Thank you for your comment.

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960	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 2	7	There is not a clear relationship between the draft quality statement and the suggested outcome ‘patients felt involved in consultation and their care’. There are many other factors which could influence the feeling of involvement.	Thank you for your comment. This quality statement is intended to make people feel involved in their care.
989	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 3	9	Should the quality statement read Patients or those acting on their behalf	Thank you for comment. The style of quality standards is to generally refer to the patient.
990	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 3	9	Would patients and the public understand what ‘health beliefs’ are?	Thank you for your comment. This term relates to individual belief about their personal health. We have been advised by NICE editors to utilise this phrase.
991	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 3	9	Should the quality statement also include ‘usual activities of living’	Thank you for your comment.
1016	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 4	10	Could quality statement 4 be an overarching quality statement? Are the other quality statements antecedents to this?	Thank you for your comment.
1033	Chelsea and Westminster Hospital NHS Foundation	QS	QS 5	11	Should the quality statement incorporate social and spiritual needs?	Thank you for your comment. The quality statement is limited to physical and psychological needs.

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	Trust					
1034	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 5	11	How can 'regularly' be defined within the quality statement?	Thank you for your comment. This is an important issue that needs local application. The use of the word 'regularly' enables those caring for the individual to integrate this assessment of needs on a day to day base or more frequently.
1131	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 9	16	How can 'regularly' be defined within the quality statement? Should this be as needs and circumstances change?	Thank you for your comment. This has been amended to emphasise that current care is tailored to current needs.
1151	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 10	17	There is not a clear link between quality statement 10 and the suggested outcome. The QS refers to the process of information sharing between care professionals. The outcome relates to the patients permission for information sharing	Thank you for your comment.
1180	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 12	19	The QS focuses on continuity of care. We view that the focus should be on the continuity of information and communication between healthcare professionals and teams.	Thank you for your comment. This is addressed in the final version of the quality standard.
1194	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 13	20	The quality statement refers to healthcare professionals. We view that this should relate to healthcare professionals and all other staff	Thank you for your comment.
1195	Chelsea and Westminster Hospital	QS	QS 13	20	There is a need to define what 'competency' is.	Thank you for your comment. We believe this exists within the professional literature and is widely used in health care delivery.

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	NHS Foundation Trust					
1220	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 14	21	The quality statement refers to healthcare professionals. We view that this should relate to healthcare professionals and all other staff	Thank you for your comment.
1256	Chelsea and Westminster Hospital NHS Foundation Trust	QS	QS 16	23	The outcome for QS 16 states that patients felt provided with evidence based information that is free of clinical bias. Lack of bias may be difficult for patients to define or interpret as an outcome	Thank you for your comment. See new wording in previous response above.
626	Chronic pain policy coalition	NICE	1.2.10	11	Our comments are as follows: this section reads as if assessment of the impact of pain medication should only be considered if the patient is already taking them. There is nothing in the section about how to assess pain We would suggest that the section reads 'Pain assessment should be the 5th vital sign and should be undertaken routinely. If patients are on pain medication or other pain management approaches they should be routinely monitored for side effects and complications and patient outcomes should be regularly reviewed.' The provision of pain relief medication alone is frequently inadequate to manage someone's pain and this can lead to inappropriately rapid escalation of dose. This should be considered in the guidance.	Thank you for your comment. This recommendation is generic and for all who are in pain. In regards to your second point, this has now been included in recommendation 15.

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694	Chronic pain policy coalition	NICE	1.5	14	Our comments are as follows: it is important that unhelpful labels and metaphors are avoided when talking to patients. When a patient is seeing a variety of health professionals is it important to establish what was been said to the patient and their understanding of what has been said to them and not to complicate this by mixed messages eg back pain could be explained as 'disc degeneration', 'arthritis', 'osteoarthritis' and 'wear and tear' which all amount to the same condition but a patient may perceive this as four separate diagnoses.	Thank you for your comment. Recommendations post consultation has reflected feedback, but we do acknowledge the limitations of the guidance in changing clinician behaviours. We have encouraged the use of consistent language and have emphasised the importance of pain relief.
1035	Chronic pain policy coalition	QS	5	11	Our comments are as follows: pain and comfort should be added into the examples of physical needs assessment and distress into the psychological needs assessment. The Guideline Development Group (GDG) considered it important that consideration is given to whether patients can self medicate whilst in hospital to ensure continuity in the management of their health. GDG members recognised that this is a potentially difficult area but they were aware of services that had protocols and arrangements in place that allowed this to happen. This should be considered for all medications and may be particularly useful for pain relief. The GDG regarded pain management as being an area of poor practice and considered it was essential for healthcare professionals to have a non-judgemental attitude towards pain management and treat every patient as an individual. If pain management is recognised as being poor then much more work needs to be	Thank you for your suggestion. Pain has been included.

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					done to understand why it is poor rather than a bold statement such as the above. People with rheumatoid arthritis have access to a named member of the multidisciplinary team (for example a specialist nurse) who is responsible for coordinating their care (From NICE Guidelines on rheumatoid arthritis pg 17). Could something similar be implemented for people with long term pain?	
577	College of Occupational Therapists	NICE	1.2	9	The first sentence refers to 'physical symptoms'. Patients receive treatment for their mental health / psychological symptoms as well. The last sentence refers to inpatient settings. The fundamental needs referred to in this paragraph should be applied equally across all patient settings, not just healthcare settings. This is particularly important as increasing amounts of healthcare treatments are provided in patients' own homes.	Thank you for your comment. The first sentence states that there are needs other than physical needs, which are then further addressed. The paragraph you refer to has been corrected to illustrate that care is provided in residential settings.
605	College of Occupational Therapists	NICE	1.2.7	10	Nutrition needs to be appropriate as well as adequate – this is to address special dietary needs, cultural needs or bariatric patients.	Thank you for your comment. 'Adequate' has been added to the recommendation.
606	College of Occupational Therapists	NICE	1.2.8	10	We would suggest adding 'at all times' to read 'Ensure that the patient's nutrition and hydration are adequate at all times and when the patient .....' The last bullet point refers to 'providing appropriate support, such as modified eating aids' – it is important to also provide drinking as well as eating equipment. People cannot eat or drink if they are not correctly	Thank you for your comment. 'At all times' and 'drinking aids' has been added to recommendation 14. It is felt that the latter point is addressed in this recommendation.

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					positioned – we would therefore suggest including a point about ensuring the patient is correctly positioned in their bed or chair to enable them to eat and drink independently. (For more information please contact the College of Occupational Therapists.)	
627	College of Occupational Therapists	NICE	1.3.3	11	We suggest that patients should also be told about other help available to them e.g. from the voluntary sector.	Thank you for your comment. Information about other services has been included in the recommendation.
659	College of Occupational Therapists	NICE	1.3.8	12	Whilst the College agrees with the need to offer patients with long term conditions regular reviews, this is not always practical. Many staff have found that they rely on patients to self refer back to services as they are insufficiently resourced to monitor them regularly. This is often the case for those patients with neurological or arthritic problems.	Thank you for your comment and observations.
674	College of Occupational Therapists	NICE	1.4.2	13	The first bullet point implies that the patient takes no responsibility for themselves. It is also not reasonable to expect one healthcare professional to be 'responsible' for the care and treatment of a patient with a long term condition.	Thank you for your comment. We do not mean to imply that one healthcare professional should be taking responsibility for all aspects of a patients care and treatment. Explaining who is responsible can mean explaining how team structures work in delivering clinical care.
961	College of Occupational Therapists	QS	QS2	7	Patients should also routinely be asked about other special needs like diet, religion or culture.	Thank you for your comment. This is quality standard is focused towards barriers which may prevent involving the patient in their care.
992	College of Occupational Therapists	QS	QS3	9	'Health beliefs' is an unusual term to use and we would suggest it is clarified in the guidance.	Thank you for your comment. This term relates to individual belief about their personal health. We have been advised by NICE editors to utilise this phrase.

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1036	College of Occupational Therapists	QS	QS5	11	Having needs assessed is only as good as any intervention or actions that follow. This statement makes no recommendations for further actions. Interventions or treatment should also be carried out in an environment that maintains dignity and confidentiality.	Thank you for your comment. The statement has been altered to reflect this.
1107	College of Occupational Therapists	QS	QS8	15	Patients' rights should be respected without prejudice – we would recommend this is added so patients continue to be fairly treated. This can be a particular problem if patients refuse treatment.	Thank you for your comment
1152	College of Occupational Therapists	QS	QS10	17	Whilst it is appreciated this is healthcare guidance, it is important to remember that patients are discharged e.g. from hospital back home or into care homes. In order to achieve this, information also needs to be exchanged in a timely, appropriate, clear and accurate manner with community services, some of which will be social services. We would therefore suggest making reference to social care and healthcare professionals.	Thank you for your comment. This has been reworded to include social care professionals.
474	County Durham & Darlington NHS Foundation Trust	NICE	General	3	Staff who reviewed the draft guidance felt that the style and format of the guidance meant that it was easy to read which made it accessible to staff. Unfortunately, however it was felt that the guidance was very much focussed around adult acute care, therefore missing the opportunity to emphasise that patient experience work should also be carried out within the community setting.	Thank you for your comment. The Guidance is generic and aims to be applicable to all patient groups.
475	County Durham & Darlington NHS	NICE	Introduction	3	• We would like to see the guidance be more explicit in how to turn quality statements in to tangible measures that	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National

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	Foundation Trust				are easily assessed across all NHS adult services including community.	Quality Board and when it is established from the NHS Commissioning Board.
476	County Durham & Darlington NHS Foundation Trust	NICE	Introduction	3	- It was felt that some fundamental key aspects of care were missing regarding pressure ulcer prevention, end of life care and falls and that these initiatives required formal National evaluation	Thank you for your comment. End of life care is covered in a related quality of standard, pressure ulcer prevention guidance is currently being updated and falls prevention is being considered for update and quality standards development.
477	County Durham & Darlington NHS Foundation Trust	NICE	Introduction	3	- Clarification is needed regarding what 'generic patient experience' is as opposed to specialist patient experienc3e	Thank you for your comment. Generic patient experience relates to aspects or dimensions of experience that are relevant for all patients, as opposed to aspects or dimensions that are relevant only for specific groups.
483	County Durham & Darlington NHS Foundation Trust	NICE	Introduction	4	- The aim of the guidance 'to provide clear guidance on the components of a good patient experience. ..provide(s) the evidence and the direction for creating sustainable change that will result in an 'NHS cultural shift' is very ambition but can this rhetoric be turned in to reality. The introduction includes some very ambitious aspirational statements however these need to be balanced with a realistic approach.	Thank you for your comment. It was the intention of the GDG that the Guidance should be aspirational and provide a vision for the NHS which demonstrates a good patient experience. The GDG felt that recent cases of poor care emphasised the importance of an aspirational approach.
484	County Durham &	NICE		4	- It is important to emphasise that the best possible patient experience should be	Thank you for your comment. We agree that patient experiences can vary among

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	Darlington NHS Foundation Trust				defined by the individual patient and therefore will vary from patient to patient.	individuals. The intention of this Guidance is to consider generic aspects or dimensions of care that have relevance for everyone, and are underpinned by strong links to the evidence. Recommendations that focus on good communication and enabling active patient participation should lead to the elicitation of aspects of experience that have particular importance for individuals.
500	County Durham & Darlington NHS Foundation Trust	NICE	Draft Statements	6	On the whole the draft quality statements are good, however there were a number that it was felt needed some alteration to ensure that they encompassed the whole health economy.	Thank you for your comment.
501	County Durham & Darlington NHS Foundation Trust	NICE	QS6	6	Appears to focus on the acute care model, but seems to forget that within a community setting, especially where home care occurs, that introduction to all members of the healthcare team is neither practicable nor necessary.	Thank you for your comment. The GDG felt that the patient should be introduced to members of the healthcare team in all settings.
502	County Durham & Darlington NHS Foundation Trust	NICE	QS7	6	• There is not only a need to respect patient's decisions regarding sharing of information, there is also a need to review their wishes. As a patient's condition changes the amount of information this wish to have shared may well change.	Thank you for your comment. The Quality Standard has been changed to reflect this.
503	County Durham & Darlington NHS Foundation	NICE	QS10	6	• Should include not only relevant healthcare professionals but also where applicable, Local Authorities, police and	Thank you for your comment. This is outside the scope of the quality standard .

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	Trust				other agencies.	
504	County Durham & Darlington NHS Foundation Trust	NICE	QS11	6	• Clear Simple advice about who to contact, avoiding multiple telephone numbers. Single point of access.	Thank you for your comment.
505	County Durham & Darlington NHS Foundation Trust	NICE	QS12	6	• This is crucial for older people and needs more commitment in the statement.	Thank you for your comment. The quality standard is applicable to all users of adult NHS services.
506	County Durham & Darlington NHS Foundation Trust	NICE	QS13	6	• Strongly agree that staff should have to demonstrate competency in communication.	Thank you for your comment.
549	County Durham & Darlington NHS Foundation Trust	NICE	QS15	7	• Strongly agree with this statement, particularly that patients are informed of and understand all relevant options, outcomes and implications consistent with what is important to them.	Thank you for your comment.
550	County Durham & Darlington NHS Foundation Trust	NICE	QS17	7	• If there is an assessed need for high quality decision support tools, organisations should be encouraged and supported to develop these. Perhaps NICE itself could be involved in developing	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.

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					these?	
562	County Durham & Darlington NHS Foundation Trust	NICE	1.1.1	8	See and Treat patient as an individual	Thank you for your comment, the recommendation has been amended accordingly.
578	County Durham & Darlington NHS Foundation Trust	NICE	1.1.4	9	Patients' values and beliefs should be considered.	Thank you, we agree with your observation.
579	County Durham & Darlington NHS Foundation Trust	NICE	1.1.5	9	Patients' beliefs etc. should be listened to and also importantly documented.	This was debated by the GDG. The groups disagree with your suggestion, but would like to thank you for raising it.
580	County Durham & Darlington NHS Foundation Trust	NICE	1.1.6	9	Although gender is addressed, sexual orientation is missing.	Thank you for your comment. We have replaced this recommendation with reference to the Equalities Act to ensure we have not omitted any individuals or groups.
581	County Durham & Darlington NHS Foundation Trust	NICE	1.1.7	9	Would it be applicable to still do this for a young, fit, adult having a minor procedure? A holistic approach should always be used, but within context rather than always for everyone.	Thank you, we acknowledge your comment, the guideline is non-setting, non-population specific.
582	County	NIC	1.2	9	As care moves closer to home, addressing	Thank you for your comment. The paragraph

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	Durham & Darlington NHS Foundation Trust	E			fundamental needs is equally important in a community setting as it is in an acute care setting and it is disappointing to see this neglected in NICE guidance. Additionally, a fundamental need goes beyond nutrition, safety and pain management and all should be mentioned with equal gravity.	you refer to has been corrected to illustrate that care is provided in other settings i.e. residential settings.
607	County Durham & Darlington NHS Foundation Trust	NICE	1.2.4	10	'Broach' has quite negative connotations and suggests that the subject should only be discussed if they really have to. Perhaps 'Be prepared to discuss…' or a different more positive phrase should be used.	Thank you for your comment. 'Broach' has been replaced by 'be prepared to raise…' (see recommendation 10).
608	County Durham & Darlington NHS Foundation Trust	NICE	1.2.6	10	Clarity is needed about whether the patient is depressed or anxious as a result of being in the care system, or whether it is a result of an anxiety disorder. Also, who would assess this?	Thank you for your comment. This is outside of the scope of this guideline. A separate mental health guideline has been written for those using adult mental health services.
609	County Durham & Darlington NHS Foundation Trust	NICE	1.2.7	10	Is it sufficient assurance to say that the patient's nutrition and hydration is 'adequate'?	Thank you for your comment. This has been addressed in refinement of recommendations post consultation.
610	County Durham & Darlington NHS Foundation Trust	NICE	1.2.8	10	Feeding patients who are unable to feed themselves is missing from the final bullet point.	Thank you for your comment. Recommendation 14 reflects this.
628	County Durham & Darlington	NICE	1.2.10	11	1.2.10 Planning for good pain management in end of life care is also important here, as well as providing appropriate pain relief	Thank you for comment. End of life care is not in the remit of this guideline. An End of Life Care quality standard has been

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	NHS Foundation Trust					published.
629	County Durham & Darlington NHS Foundation Trust	NICE	1.2.11	11	Must also address skin care and prevention of pressure ulcers in patients with bladder and bowel incontinence as well as dressing patients in their own clothes. Essence of Care benchmark.	Thank you for your comment. We agree that the need to prevent pressure ulcers is important, as is dressing patients in their own clothing, however we had to limit the areas we were able to consider. For pressure ulcer management please refer to guidelines CG7 and CG29. These are also in the process of being updated.
630	County Durham & Darlington NHS Foundation Trust	NICE	1.3.1	11	Sounds too much like lots of buzz words with little meaning. Needs to be made more meaningful.	Thank you for your comment. The GDG felt that the recommendation clearly highlighted the need for an individualised approach to patient care.
631	County Durham & Darlington NHS Foundation Trust	NICE	1.3.3	11	Inform rather than tell patients?	Thank you for your comment. This has been changed to 'inform'.
632	County Durham & Darlington NHS Foundation Trust	NICE	1.3.4	11	Consider this in a community care setting where this may not be possible. Perhaps via a leaflet	Thank you for your comment. NICE are currently considering tools for implementation of this guidance.
660	County Durham & Darlington NHS Foundation Trust	NICE	1.3.6	12	Needs meet consent criteria should be highlighted here.	Thank you for your comment. Recommendation 30 addresses the issue of consent based on Department of Health policy.

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661	County Durham & Darlington NHS Foundation Trust	NICE	1.3.7	12	Example of a style would be helpful here.	Thank you for your comment. This recommendation has now been changed to say' way', which would be at the discretion of the healthcare professional and patient.
662	County Durham & Darlington NHS Foundation Trust	NICE	1.3.9-1.3.10	12	Emphasis on documenting these differences	Thank you for your comment.
675	County Durham & Darlington NHS Foundation Trust	NICE	1.3.12	13	Real time feedback?	Thank you for your comment. The GDG felt that this was not feasible.
676	County Durham & Darlington NHS Foundation Trust	NICE	Continuity of care	13	Introduction sounds a little jargon heavy. There is emerging evidence that many patient safety incidents occur at the junction where care is being handed over, transferred and where patients are being discharged.	Thank you for your comment.
677	County Durham & Darlington NHS Foundation Trust	NICE	Continuity of care	13	Continuity of care is essential to older people but in the community setting is becoming more difficult to deliver because we are only able to offer a service rather than an individual.	Thank you for your comment.
678	County Durham & Darlington NHS Foundation	NICE	1.4.2	13	Inform the patient that the caseload holder is responsible.	Thank you for your comment. As the recommendations are designed to span all settings and disease areas, this may not hold true in all cases.

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	Trust					
695	County Durham & Darlington NHS Foundation Trust	NICE	1.4.5	14	Exchange of information between healthcare professionals and other agencies where appropriate.	Thank you for your comment. This has been amended for clarity.
696	County Durham & Darlington NHS Foundation Trust	NICE	1.5	14	Introduction is a good guiding principle, however should also take in to consideration that some older, sicker more vulnerable patients may want others to participate for them.	Thank you for your comment. In these situations staff should introduce themselves to carers and families.
697	County Durham & Darlington NHS Foundation Trust	NICE	1.5.10	14	Clarify that this should include all clinicians including doctors.	Thank you for your comment. This does include clinicians including doctors.
721	County Durham & Darlington NHS Foundation Trust	NICE	1.5.11	15	Clarity required for this point as unclear what it is really trying to say.	Thank you for your comment, this recommendation has been removed.
748	County Durham & Darlington NHS Foundation Trust	NICE	1.5.21	17	Treatment/ care as not all treatment is perceived as care.	Thank you for your comment. The GDG believe the current wording is sufficient.
749	County Durham & Darlington	NICE	1.5.23	17	This sounds like a one off process but in fact should be continuous as patients only take in about 20% of information given at any one time.	Thank you for your comment. Please see the recommendations on communication and information.

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	NHS Foundation Trust				Build in time for refreshing and revisiting information with the patient.	
768	County Durham & Darlington NHS Foundation Trust	NICE	1.5.26	18	How will NICE get assurance of this across the NHS? Also numerical data still requires a good explanation for those people who are not comfortable with numbers. Diagrammatic formats will definitely aid this.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
778	County Durham & Darlington NHS Foundation Trust	NICE	1.5.29	19	Examples of education programmes would be useful	Thank you for your comment, but the actual content of education programmes is disease specific and this is addressed in individual guidelines.
59	Department for work and pensions	Full	General	General	Is there a reason why employment is mentioned in NICE's guidance on care plans, etc, for adult mental health users but not for adult service users in generic terms?	Thank you for your comment. This guidance was required to be generic to all adult patients and we do not usually embed employment issues in this type of guidance.
663	Department for work and pensions	NICE	1.3.5 and 1.3.6	12	If the management of the patient's condition extends to employment then the patient should be offered the opportunity to include their employer in these discussions.	Thank you for your comment. This is not in the remit of this guideline.
698	Department for work and pensions	NICE	1.4.3	14	If the patient agrees, then this information should also be shared with their employer. This doesn't have to be face to face; written information can work just as well.	Thank you for your comment. This will come down to patient preference.
889	Department for work and pensions	QS	Draft Quality statement No. 3	3	The discussion of health beliefs should include how these beliefs interact with a successful return to work (where applicable) since we know that work can have therapeutic effects on health. This ties in well with patient self-efficacy: high self-efficacy in health and work beliefs can indicate greater independence in the self-management of	Thank you for your comment. We recognise the particular needs of those returning to work, however, the remit for the guideline is generic patient experience in the NHS

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					health conditions. Others with lower self-efficacy may require greater levels of support to develop independence in self-management.	
6	Department of Health	All	General	General	Impact for commissioners - It would be helpful to have more information in either the guidance or quality standard to support commissioners in how they use the quality standard in commissioning of services. There is a place marker in the NICE guidance which states that tools will be available to help implement the guidance so this may cover this point. Given this is one of the key objectives of quality standards this would really benefit from some strengthening.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board. Please see: http://www.nice.org.uk/usingguidance/commissioningguides/aboutcommissioningguides.jsp
7	Department of Health	All	General	General	Coverage both acute and non-acute settings needs to be reflected in the standards. The Indicators seem to reference the acute sector. There are also indicators and survey instruments in primary care which would benefit from referencing. For example the GP Patient Survey and the LT6 indicator used for the QIPP programme.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board. The quality standard is for all settings and therefore should apply across all settings.
8	Department of Health	All	General	General	Major omissions - Aspects which we know are extremely important to patients, and therefore it would be helpful to include this as part of the quality statements: Access – the Picker Framework describes this as 'Access to care', with attention to time spent waiting for admission or time between admission and placement in a room in the inpatient setting, and waiting time for an appointment or visit in the outpatient setting'. Confidence in the surrounding environment (Patient Environment) – aspects of the physical environment which relate to it being seen as a comfortable safe place to be such as noise and	Thank you for your comment. We agree that the environment and access have significant impacts on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address environment or access. We have included recommendations and associated quality statements on some elements of continuity of care across transitions. Proposed topics for future quality

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					cleanliness. Transitions of Care – we know this is an area important to patients and that it is also an area which the NHS does not manage well.	standards include long term conditions and patients with co-morbidities and it is expected that other aspects of transitions will be included in these.
9	Department of Health	All	General	General	In the scope of the document it would be helpful to make it clear on who this is applicable for such as those with Long Term Conditions, Primary Care etc	Thank you for your comment. The guidance is applicable to all patients and is generic and not specific to groups or conditions. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues.
9	Department of Health	All	General	General	In the scope of the document it would be helpful to make it clear on who this is applicable for such as those with Long Term Conditions, Primary Care etc	Thank you for your comment. The guidance is generic guidance for all patients in all settings. The scope excludes people under 18 years and people accessing mental health services for whom separate guidance has been developed in parallel with this work.
10	Department of Health	All	General	General	The key focus is on the individual and the QUALITY STANDARD is quite patient/person centred, which is helpful	Thank you for your comment
11	Department of Health	All	General	General	Are all the statements based on evidence or are some based on a consensus approach - if the latter then helpful for the guidance to make it clear why included.	Thank you for your comment. The quality statements are derived from the recommendations of the guideline. These are interpreted from evidence when available, with absence of evidence the GDG make recommendations based on consensus.
12	Department of Health	All	General	General	It would be helpful to reference one of the existing patient experience architectures for the each of the quality statements. This then helps commissioners and surpra trust organisations (eg NHS Commissioning Board) in the application of the quality standards to existing data sets and data collections for reporting and action	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.

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13	Department of Health	All	General	General	We need to keep in mind that there are likely to be links with the Commissioning Outcomes Framework.	Thank you for your comment
14	Department of Health	All	General	General	Ideally for each of the quality statements it should be clear how organisations audit whether or not these have been achieved, and therefore further guidance on the auditing aspects would be helpful - ie in the absence of an indicator what are the outcomes you would expect an organisation to achieve ? Are there a number of structural or process indicators which need specifying?	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
15	Department of Health	All	General	General	It would be worth spelling out what these standards mean at an organisational level.	Thank you for your comment. Please refer to the service provider section.
16	Department of Health	All	General	General	One practical suggestion is for these quality statements to be turned into a service promises for patients of what to expect. NICE saying this could be very valuable when new organisations such as Healthwatch England examine Public accountability and consider what could be tracked/monitored.	Thank you for your suggestion. This is perhaps something that the Department of Health could facilitate.
18	Department of Health	All	General	General	It would be helpful, if possible, to clarify what aspects are the most important - or more likely to highlight an approach for how the more important aspects might be determined according to local priorities. Some aspects of patient experience we know generally the NHS needs to improve such as transitions of care. Also linked to this, it would be worth highlighting what aspects of patient experience have been omitted and why.	Thank you for your comment. The GDG consider that all aspects are important. NICE are currently considering what implementation support to provide for this guidance It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained. Some of this is outline in chapter 2 and we have added information to the chapter on Frameworks and Themes (chapter 5) to outline these decisions more clearly.
19	Department of Health	All	General	General	It would be helpful to reference the NHS Constitution - eg patient involvement is a right	Thank you, this comment has been actioned.

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					under the NHS Constitution. Providers have a legal duty to have regard to the NHS Constitution rights and pledges, commissioners are to have regard to and also to act with a view to securing services which uphold the Constitution.	
20	Department of Health	All	General	General	With the indicators applying to most episodes of care, it would be helpful if the burden of collection of data was also considered, and also how they may be facilitated through existing mechanisms such as PROMS, and Patient Surveys. With 16.8 million 'finished consultant episodes' + GP consultations the burden is not insignificant. Also the coordination of data collection is important if the patient is not to be requested several times for similar but different pieces of information.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
21	Department of Health	All	General	General	It would be helpful to have some advice on the frequency which the same patient is contacted about their patient experience - we are at risk of requesting feedback on such a regular basis that the patient gets 'over - surveyed'	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
46	Department of Health	Appendix A	A4.1 a)	5	[5 line 31, 6 lines 1-5] Welcome the acknowledgement that the guidance needs to draw on Lord Darzi's report, particularly "..within a clean, safe and well-managed environment", and, the NHS Constitution which describes what patients can expect from the service – the Constitution includes "Quality of care and environment". The forthcoming Healthcare Bill will strengthen the NHS Constitution to make NHS commissioners actively promote the requirements of the Constitution. A good reference source would be the Governments response to the NHS Future Forum's Listening Exercise.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would not address the physical environment.

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					However, the physical environment is not then covered in the full report or in the recommendations.	
47	Department of Health	Appendix A	A4.1 b)	6	Would also recommend that the Kings Funds charitable foundations work on 'Enhancing the healing environment' be referenced at this point.	Thank you for your comment. This appendix is the scope which cannot be amended at this stage
48	Department of Health	Appendix A	A.5.4 (e)	7	Physical environments has not been addressed as described within the methodology. The literature review should have identified appropriate studies that demonstrate the importance of physical environments for care with regard to the patient's experience, such as for example: BMA science and education report ""The psychological and social needs of patients" (January 2011) – "There is a developing evidence base … on the positive effects of changing the way in which we care, and the environment in which we offer care." ASPECT – A Staff and Patient Environment Calibration Tool – based on a database of over 600 pieces of research. That research deals with the way the healthcare environment can impact on the levels of satisfaction shown by staff and patients and on the health outcomes of patients and the performance of staff; NHS PAM – Premises Assurance Model – the aim of the model is to improve the performance of premises utilised in the delivery of clinical services and delivering on premises aspects of the quality and productivity challenge. Which is designed to enable the measurement of quality using the Darzi definition, and, with specific reference to the environment there is a patient experience domain	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline would not address physical environment.

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					to this model.	
125	Department of Health	Full	1	10 12	Lines 11-12 In highlighting the concepts of 'high quality care for all' – the NHS Constitution also addresses "Quality of care and environment" – "to ensure that services are provided in a clean and safe environment that is fit for purpose, based on national best practice (pledge)" - this is a holistic concept across the physical environments for care and not limited to certain facets such as the environment in relation to nutrition or privacy as seems to be reflected throughout the document. Lines 15-16: Recommend that the GDG further explore key concepts surrounding patient experience of physical environments in order to ensure that this guidance is fully consistent with the NHS Constitution as described on page 12 lines 15 and 16.	Thank you for your comment. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.
129	Department of Health	Full	1	12	The NHS Constitution identifies "Quality of Care and the Environment" as a NHS Constitution right "You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality." (Section 2a of the NHS Constitution) The draft guidance states that it meets all key aspects of the Constitution, but it does not properly cover the above constitutional right. Recommend that the GDG further develop the clinical guidelines to include the physical environment aspects of patient experience and	Thank you for your comment. We have amended the introduction to clarify that not all areas of the constitution are covered. Effectiveness and safety are separate aspects of quality defined by Lord Darzi in the next Stage review. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would not address physical environment.

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					how it enables the NHS Constitution pledge, as described above, to be delivered.	
130	Department of Health	Full	1	12	Line 16: The consultation draft affirms, "This guidance meets all key aspects outlined in the NHS constitution, with particular emphasis on creating a baseline (national standards) from which improvement in the quality of patient experience can be routinely measured." To achieve the affirmation made in the draft, the guidance will have to consider the above mentioned Constitution's rights and pledges and, in addition, develop methodologies to enable the system to measure patients experience of the physical environment.	Thank you for your comment. Once the recommendations and standards are finalised the quality standard team will aim to identify existing measurement and/or indicate where further work is required to develop instruments.
131	Department of Health	Full	2.1	13	line 5-6: The claim is made that NICE guidelines are based on the best available research evidence, yet it becomes apparent that a large body of evidence with regard to the physical environment has been ignored. (see AEDET comment and reference to 600 pieces of research etc)	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address environment.
134	Department of Health	Full	2.3	14	Line 3: The phrase "professional group" might more accurately be described as "clinical professional group". We consider there is a shortfall in the knowledge with regard to physical environment and its affects on clinical outcomes and patient experience which should be addressed. Recommend the focus of	Thank you for your comment. Professionals included academics as well as clinical professionals so the wider term is more appropriate. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on

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					the Group be augmented with support from independent academic institutions and stakeholders who are specialists in this field.	clinician/patient interaction and organisational issues and not address physical environment.
138	Department of Health	Full	3.1	15	(see also page 7, A5.4 e) The literature review should have identified appropriate studies that demonstrate the importance of physical environments for care with regard to the patient's experience. Recommend the GDG include within their "multiple sources of evidence", other robust, well researched evidence sources. This will then provide appropriate links to the scope at Appendix A (see comments above at page 7, A5.4(e))	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environments.
143	Department of Health	Full	3.1.1	16	The built environment absorbs a large proportion of the NHS budget (third after staff and drugs costs) yet is not taken into account. Recommend that the economic considerations include ways in which a good environment might contribute to better, more efficient care in an efficient manner.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address environment.
146	Department of Health	Full	3.5	17	(see also page 5, A4.1 a) The reliance on existing guidelines has constrained the opportunity for a more thorough review of patient experience. Recommend the GDG redress this situation and look beyond NICE guidance to take into account	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on

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					the physical environments for care and how this benefits the patient experience (as acknowledged in the scope and the background to the guidelines – reference Darzi and the Constitution – comments to Appendix 1 refer)	clinician/patient interaction and organisational issues and not address physical environment.
150	Department of Health	Full	3.6.1	18	The review questions reinforce the problems of adopting narrow review parameters (identified above). Recommend that the research strategy be widened to search for new areas as opposed to being confined to areas already assumed to be important	Thank you for your comment. We agree that the timescale for the development of this work was short and this limited the areas we were able to cover. NICE was asked to produce initial guidance on generic patient experience within a short timeframe.
153	Department of Health	Full	3.6.2.2	19	Recommend the search should have identified and taken into account research around the impact of cleaning and the proportion of single rooms	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the issue of cleaning and accommodation.
161	Department of Health	Full	4.1	23	Line 3: "The patient as an individual" - Recommend include a requirement to evaluate and understand the extent to which the physical environment impacts on, or affects, the patient's experience of care.	Thank you for your comment. We agree that the physical environment is important but it was agreed with NICE that we would not include the physical environment in this guideline.
162	Department of Health	Full	4.1	23	Line 24: "Essential requirements of care" - this is a holistic concept across the physical environments for care and not limited to certain facets such as the environment in relation to nutrition or privacy as seems to be reflected throughout the document. Recommend include a requirement about the care environment – this is especially relevant where	Thank you for your comment. We agree that the care environment has an important impact on patient experience. It was not however included in the scope as we had to limit areas we were able to consider.

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					care takes place in a patient's own home.	
186	Department of Health	Full	4.1	24	Line 18: "Tailoring healthcare services to the individual" – Recommend include the need to tailor the physical environment to the needs of the individual e.g. use of single rooms, management of ventilation, heating and lighting etc.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
223	Department of Health	Full	4.1	25	Line 22- "Enabling patients to actively participate in their care" – Recommend include aspects of the physical environment that make participation easier i.e. room relationships, acoustics, control of the physical environment etc.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
284	Department of Health	Full	5.2.1	29 & 30	Table 3: "Patient Experience Frameworks" and Table 3 refer to the Dimensions of Patient Care in Gerteis et al. Table 3 - dimension 4. 'Physical comfort' acknowledges 'surroundings and hospital environment' as areas requiring attention with regard to helping with the activities of daily living and pain management. There are extensive academic studies that support this requirement e.g. Lawson and Phiri University of Sheffield 'The Architectural Environment and its Effect on Patient Health Outcomes', which, amongst other significant findings, demonstrates a link between the management of pain and the quality of the physical environment. Recommend the draft guidance reflects the importance of the physical environment to patient	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.

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					experience.	
289	Department of Health	Full	5.2.2	31	Table 4 'Dimensions in IOM framework for patient centred care' dimension (6) 'Involvement of family and friends' stresses the importance of 'Focuses on accommodating family and friends on whom patients may rely' and '…making them welcome and comfortable in the care delivery setting, and recognising their needs and contributions.' There are extensive academic studies which support this requirement such as Maggie Redshaw University of the West of England study 'The impact of a new hospital environment on children, families and staff'. This research sought to explore some of the ways in which the hospital environment impacts on sick children and their families and on staff caring for them, and to closely examine the effects of changes in the built environment and interior design on the attitudes, experiences and perceptions of these groups. Recommend the draft guidance includes a quality standard recommendation to account for this.	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.
292	Department of Health	Full	5.3	35	The preceding section evaluates a number of frameworks for patient experience, most of which include specific mention of the care environment, i.e. • 5.2.3 re access and location • table 5 re infrastructure and physical comfort Yet, despite this, the physical environment for care is not included. Recommend that this omission be rectified and that the requirement to address physical environments for care within the frameworks be included.	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.

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297	Department of Health	Full	5.4.1	37	Line 22: Whilst reference is made to the Picker Institute reports and the 'physical and environmental needs' (note that this is about the way that services and systems work) is addressed amongst the 8 aspects of care, this is not developed within the key domains at table 7. The need is demonstrated by other evidence: a paper by Picker and the King's Fund "Patient Choice" (2010) in referring to surveys on patients preferences stated "There are a core set of factors that are important to patients when making decisions about which hospital to be referred to: cleanliness, quality of care and the standard of facilities." Recommend that include this aspect of care in the key domains (i.e. 'physical and environmental needs').	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.
299	Department of Health	Full	Questions contributing to domains	39 & 40	Recommend a key question should have been in respect of 'physical and environmental needs' as per the Picker et al aspects of care (page 37, line 22) this would include cleanliness, but not be exclusive to cleanliness.	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.
302	Department of Health	Full	General	43	(see also page 23, line 24 above) Table 8 does not address all the elements described in figure 2 i.e. patient comfort, or as described in the 8 aspects of care (Picker et al). To address this omission, the theme for 'Essential requirements of care' be amended see page 23	Thank you for your comment. We have added 'comfort' to the Essential requirements of care to ensure that comfort is explicitly included.

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					line 24 above).	
307	Department of Health	Full	6.1	44	(see also page 23 line 3 above) The introduction acknowledges that the "patient as an individual" is affected by a range of different influences. Recommend that the physical environment be included in the Recommendations to reflect the powerful impact and influence on the patient.	Thank you for your comment. We agree that the physical environment is important but it was agreed with NICE that we would not include the physical environment in this guideline.
317	Department of Health	Full	7.1	48	(see also page 23, line 24 above) "Essential requirements of care" – see comments above Recommend that the physical environment be included as an essential component .	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
340	Department of Health	Full	8	56	(see also page 24, line 18 etc above) "Tailoring healthcare services to the individual" Recommend there is sufficient evidence to propose an additional recommendation to: Acknowledge the importance of the physical environment being tailored to the patients needs, i.e. light, heat, noise, social interaction, location of essential equipment – nurse call bell etc.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
349	Department of Health	Full	9	58	Recommend inclusion of physical environments for care within the recommendations in recognition of how the physical environment can enhance and support the continuity of care and developing relationships.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on

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						clinician/patient interaction and organisational issues and not address physical environment.
358	Department of Health	Full	10	71	(see also page 25, line 22 etc) Enabling patients to actively participate in their care Recommend inclusion of physical environments for care in the recommendations – see comments chap 2, page 25, line 22 etc.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
412	Department of Health	Full & NICE	General	General	The guidance goes on to present a framework approach and within each dimension of the framework there are a series of actions, some of which, but not all, are recognised as linking directly to the statements. This provides a welcome amount of detail, but does raise the question of whether there is a hierarchy to the guidance and that measurement of the statements and/or guidance could be very complex.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
428	Department of Health	NICE	Evidence Base	General	Although this is clear in the detailed document, the detailed work underpinning the guidance is not as clear in the summary document. A statement would help engage different professional groups quickly.	Thank you for your comment. The NICE version does not usually include information about the work leading to the recommendations.
429	Department of Health	NICE	Transactional and relational aspects of patient experience	General	Make clear the importance of both transactional and relational aspects of good patient experience. Whilst transactional aspects of experience could be measured and standardised from the statements it is inappropriate to attempt to standardise relational aspects of experience as the emotional and human dynamic elements are personal to the individual and will change throughout the course of their care.	Thank you for your comment. The nature of the guidance is generic and is by design applied to all care settings and all populations. That said, recommendations relating to 'knowing the individual' we would expect address your central point.

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430	Department of Health	NICE	Measurement and Reporting	General	Describe how the standards and/or guidance will be measured and reported. This should include stressing the importance of different methodologies to measure transactional and relational aspects of experience. Relational aspects of experience is most difficult to measure but could be assessed by whether the organisation has a range of patient reported feedback mechanisms and can demonstrate that as a result of feedback they took action. Measurements of the statements will require a variety of feedback mechanisms. For some the data source is clear for others new data sources will need to be developed. Feedback from patients on whether the statements were met in order to deliver the guidance will require the collection of real time insight data.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
431	Department of Health	NICE	Alignment to PEPP review of national survey architecture	General	It is crucial that the DH PEPP and NICE guidance are aligned in order ensure an appropriate data source for national and local collection in the new survey architecture. For example PEPP will provide recommendations on the future of the national patient experience architecture that could be used to demonstrate a baseline and delivery against the guidance.	We agree with your comment. We are aware that the Department of Health have commissioned the development of a tool for measuring patient experience. The NCGC have participated in national meetings to look at the complementariness of guidance and system alignment. In sharing our work in confidence, we believe that this is possible but will need to be facilitated by the Department of Health.
432	Department of Health	NICE	Guidance for Commissioners	General	There is an opportunity for the guidance to provide support for commissioners to use the statements in their contracting discussions.	Thank you for this comment
433	Department of Health	NICE	General	General	Strong on the relationship and interpersonal issues, which is fine of itself, but says little on other issues that evidence shows are important to	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with

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					patients e.g. environment and cultural sensitivity of services.	NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address building (environment/access…...)
434	Department of Health	NICE	General	General	It would be helpul to cover continuity of care more fully.	Thank you for this comment. Continuity of care remains a key section.
435	Department of Health	NICE	General	General	The MH ones are strong on discharge planning, range of needs being assessed, families being informed, notice being given etc. Which is just as important for the general guideline.	Thank you for this comment. Particular issues relating to discharge in specific populations such as mental health are important. The generic guidance has emphasised the importance of this through continuity of care and communication of information recommendations.
436	Department of Health	NICE	General	General	This whole section is titled too narrowly - it would be helpful to have more about seamless/joined-up care rather than relationships alone.	Thank you for your comment. It would be useful to know which section this comment is referring to. Chapter titles have been revised after consultation,
437	Department of Health	NICE	General	General	This section would benefit from addressing the main risks around service interfaces that can disrupt the patient experience (and indeed safety).	Thank you for your comment. It would be useful to know which section this comment is referring to. Recommendations about continuity of care have been revised.
438	Department of Health	NICE	General	General	Patients being clear how to self manage after discharge is important and the current wording feels little more than simple contact telephone numbers.	Thank you for your comment. It would be useful to know which section this comment is referring to. The GDG recognise the importance of self-management for many patients, especially those with long term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could not do justice to the topic of self management in

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						its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.
439	Department of Health	NICE	General	General	Some of this strongly relates in to self care, which would benefit from being included in the information section.	Thank you for your comment. It would be useful to know which section this comment is referring to. The GDG recognise the importance of self-management for many patients, especially those with long term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could not do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board. Recommendations have been revised and sub-headers added.
440	Department of Health	NICE	General	General	It would be good to be clear which recommendations go above and beyond basic nursing standards, law etc and refer to these rather than including them fully.	Thank you for your comment. We will talk to NICE editors/Implementation Team to seek their advice if this is possible. We have referred to appropriate legislation within the guidance.
804	Department of Health	QS	General	General	These need checking since some of the references are inappropriate. Eg quality statement 3 references q44 of the Inpatient survey and Quality Statement 5 doesn't reference q44. Quality Statement 5, Quality statement 7 could ref q43 of the Inpatient survey.	Thank you for your comment. This has been referred to the technical analyst at NICE.
805	Department of Health	QS	General	General	Not clear why many of the quality statements do not have process measures defined.	Thank you for your comment. Process measures have been included where it was

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						felt it would be of use to do so.
806	Department of Health	QS	General	General	Some of the statements require organisational focus, some professional but some can only be demonstrated through patient reported feedback. It would be good to be explicit .	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
807	Department of Health	QS	General	General	The statements for commissioners would benefit from reflecting the legal duties to be placed upon CCGs around promoting individual patient involvement.	Thank you for your comment. This work is linked to statutory guidance and is implicit in recommendations and quality standards. Please see: http://www.nice.org.uk/usingguidance/commissioningguides/aboutcommissioningguides.jsp
808	Department of Health	QS	Leadership and culture	General	There are no statements that address the leadership and organisational culture which set the tone and expectation of the organisation and therefore it would be good to include this requirement.	Thank you for your comment. This was outside the scope of the guidance.
809	Department of Health	QS	General	General	The Quality Standard and the Quality Statements do not adequately address the physical environments for care – this is a major omission. To fill this gap, we recommend a separate quality statement, along with a full review of how the care environment can be integrated into the remaining statements.	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
810	Department of Health	QS	General	General	Of the 17 statements included in the standard we believe each should reference the physical environment eg access to services means locating them in a convenient place to get to. We welcome the inclusion of the environment in statement 5, privacy and dignity, but feel this should be reflected in all other statements. However, not withstanding this we think a stand	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical

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					alone statement covering all aspects of the physical environment is also needed.	environment.
880	Department of Health	QS	General	1	The healthcare estate is the third largest cost and biggest area of capital investment in the NHS and as such is fundamental to establishing the base line for quality of service that people should expect to receive. Surveys show us that the quality of the physical environment – cleanliness, noise, litter, maintenance etc can affect patient choice and quality of experience. The physical environment is key to supporting delivery of care, nursing practices and so influences patient outcomes i.e. wellbeing, comfort, security etc. The physical environment supports clinical care, plus patient treatment pathways, for example £100M to improve single sex accommodation, car parking, access, toilet and bathing facilities etc.	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
881	Department of Health	QS	Scope & Evidence Sources	1	The scope appears to us to include the physical environment. The evidence sources do not include any attention to the well established body of evidence demonstrating the importance of good environment on positive health outcomes.	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
882	Department of Health	QS	Overview of Statements	1	The 66 recommendations and 17 quality statements do not include any substantial reference to the physical environment and therefore do not adequately reflect the importance of the physical environment in determining a good patient experience.	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical

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						environment.
883	Department of Health	QS	Quality Measures	1	The document does not refer to quality measures relating to the environment although they do exist, e.g. good environments can reduce the need for analgesics (Lawson and Phiri 2000).	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
885	Department of Health	QS	Diversity, equality and language	2	This section ignores the important contribution in promoting equality ie the needs of different ethnic groups to have specific facilities, and the need for adequate signage eg BMA report on the psychological and social needs of patients (Jan 2011). The needs of disabled patients are also materially affected by the environment eg access, accessible WCs, and the ability to cope with normal daily living activities as acknowledged by the Picker Institute. We note there is no equality impact assessment included in the document.	Thank you for your comment. We recognise the particular needs of ethnic groups and the disabled; however the remit for the guideline and quality standards is generic patient experience in the NHS. Following consultation, the equalities act is now referenced.
886	Department of Health	QS	Consultation and feedback	2	We note the intention of the guidance development group to "further refine" the statements and measures. However, we believe a much more fundamental review is required due to the omission of the physical environment.	Thank you for your comment. We agree that the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the physical environment.
962	Department of Health	QS	Statement 2	7	We would challenge the assumption that to "ask about" is always and necessarily sufficient to establish any communication difficulties. We would	Thank you for your comment. Post consultation wording has been further refined.

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					prefer "to assess" or "evaluate".	
963	Department of Health	QS	Statement 2	7	In QS2, providers should go further than establishing factors that might affect involvement, but should assess and address factors... Commissioners need to go further than ensuring providers train their staff, but should actively monitor performance of those staff and require that any training be regularly refreshed (this last point would apply throughout the document wherever there is mention of training).	Thank you for your comment. This quality statement has been altered in response to your comment and others.
964	Department of Health	QS	Statement 2	7	A better indicator might be Q21 'did they explain your care and treatment in a way you could understand' i.e. were any barriers of language, hearing problem etc overcome?	Thank you for your comment. Post consultation wording has been further refined.
993	Department of Health	QS	Statement 3	9	This indicator is only a partial measure. It asks about worry and fears but nothing about their health beliefs and preferences. Perhaps a better question would be one like Q41 in the In-patients survey that asks whether they were involved as much as they wanted to be in decisions about their care - making a presumption that their decision would take into account their preferences and health beliefs. Or even use both indicators.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1017	Department of Health	QS	Statement 4	10	In QS4, it would be helpful to show how commissioners could contract for the desired behaviours, and not just expect providers to embed them in practice.	Thank you for your comment. This is outside the remit of this guideline.
1037	Department of Health	QS	Statement 5	11	Aspects of care are included which would be expected to be referenced in other clinical standards such as nutrition and hydration. Is it appropriate to include these and are they better referenced to other standards?	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance.

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1061	Department of Health	QS	Statement 6	12	Relevant existing indicators' box - replace 'involvement in decision-making' with 'whether staff introduce themselves' - the question highlighted does not reflect the quality standard.	Thank you for your comment - corrected
1087	Department of Health	QS	Statement 7	13	There are no suggested indicators, but possibly Q43 of the In-patient survey would be helpful?	Thank you for your supportive comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1108	Department of Health	QS	Statement 8	15	These are very poor indicators - they say nothing about 'choice' which I think the QS is really getting at.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1153	Department of Health	QS	Statement 10	17	A very poor indicator since it measures family involvement not healthcare professionals.	Thank you for your comment. These references have been removed.
1167	Department of Health	QS	Statement 11	18	Worth including transition of care into other NHS services, not just the NHS service they are currently receiving care from.	Thank you for your comment.
1230	Department of Health	QS	Statement 15	22	In the decision making section it would be helpful to add a requirement to ascertain how much involvement patients want, and not make assumptions; clinicians typically underestimate this. The section presenting risk information which was detailed and helpful for that.	See above
1257	Department of Health	QS	Statement 16	23	"Patients are provided with evidence-based information that is understandable, personalised and clearly communicated" - it would be helpful if this also made clear the need for healthcare professionals to signpost information more widely and tailor this to individuals needs. This is picked	Thank you for your comment. We agree

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					up in 1.5.19 of the guidance.	
1258	Department of Health	QS	Statement 16	23	Worth including signposting to other information services to pick up broader patient requirements such as financial support and support groups. The policy for this on Information Prescriptions was in the white paper 'Our health our care our say'. Evidence for this is available on http://www.informationprescription.info/ including the research and evaluation report.	Thank you for your comment. Noted.
1277	Department of Health	QS	Statement 17	24	There needs to be consistently in the use of 'decision support tools' and 'patient decision aids' - ie 'Quality Standard Programme' document, page 24 but there may be other references in other documents.	Thank you for your comment. The GDG have reduced the number of statements in the final quality standard and incorporated decision support tools into the measurement of the statement on shared decision making.
1278	Department of Health	QS	Statement 17	24	Under 'draft quality measure' it mentions 'NHS accredited decision support tools' - it would be helpful to explain what is meant by 'NHS accredited'?	**NHS accredited tools are available via the NHS Direct website: http://www.nhsdirect.nhs.uk/DecisionAids**
1279	Department of Health	QS	Statement 17	24	Under 'definitions' in page 24 - the second sentence seems to suggest PDAs are all about clinical evidence when in fact they are about other 'evidence' that will help a patient reach a decision e.g. their values or priorities. This aspect of PDAs needs to be reflected. One way of doing this is to use the following: 'Decision aids help patients to participate with their practitioners in making deliberative, personalised choices among healthcare options.' (Annette O'Connor in Evidence Based Medicine 2001; 6; 100 - 102 doi: 10.1136.6.4 100).	Thank you for your comment
1280	Department of Health	QS	Statement 17	24	It would be helpful to position shared decision-making as the preferred norm not something associated only with decision aides as rec 64 comes across.	Thank you for your comment. The GDG reduced the number of statements in the final quality standard and incorporated decision support tools into the measurement of the statement on shared decision making.

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1293	Department of Health	QS	Appendix 1 Policy context	25	The evidence sources are incomplete. It is particularly important to reference the NHS Constitution and the 2009 Health Care Bill. It should also reference the Hygiene Code of Practice and current registration requirements.	Thank you for your comment. Noted and corrected
1294	Department of Health	QS	Appendix 1 Key development sources	25	We note that the sole development source is the draft NICE guidance, which we believe is seriously flawed – please see our comments on the clinical guidelines.	We do not agree with this comment. The rigour attached to the development of recommendations is clearly established in the evidence to recommendations sections. We have addressed individual concerns raised, and these are clarified in relation to the scope agreed with NICE. The guidance has benefitted from multiple sources of evidence as outlined in the methods section and are consistent with NICE methodology.
1295	Department of Health	QS	Appendix 1 National data sources	25	The CQC survey used as a data source makes extensive reference to the physical environment.	Thank you for your comment. Physical environment is not within scope.
811	Dudley PCT	QS	General	General	The PCT's Urgent Care Lead Commissioner states that there is nothing you would argue against in this but raised the question of how the standards would be monitored and who would do the follow up actions	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board. Please see: http://www.nice.org.uk/usingguidance/commissioningguides/aboutcommissioningguides.jsp
812	Dudley PCT	QS	General	General	GP lead has "no real problems" with this document	Thank you for your comment.
813	Dudley PCT	QS	General	General	Commissioning Lead general comment is how would we monitor some of the outcomes/measures?	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National

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						Quality Board and when it is established from the NHS Commissioning Board.
814	Dudley PCT	QS	General	General	Commissioning Lead – what about quality standards for carers and/or input from carers?	Thank you for your comment. We agree that carers are important; however, we had to limit the areas we were able to consider.
815	Dudley PCT	QS	General	General	Commissioning Lead feels that the quality statements are clear and measurable and that the information should be fairly easy to collect	Thank you for your comment.
386	Expert Reviewer	FULL	10.4.1.5	100	In the Cochrane Review of Patient Decision Aids, selective outcome reporting is one of the elements contained within the assessment for Risk of Bias. Was there a specific reason why this was separated out and the other items were not identified? I have concerns about saying "there was selective reporting" because mostly the trials did not report that there was a published protocol and therefore it was not possible to determine if there was selective reporting.	Thank you for your comment. This has been removed and people are referred to the paper for further details about the risk of bias.
388	Expert Reviewer	FULL		102	In Table 33, do you need to indicate that the comparator was usual care for most if not all of these studies?	Thank you for your comment. This has been included for clarity.
390	Expert Reviewer	FULL		104	Evidence Statement Clinical: these results are compared to usual care – does this need to be made more explicit?	Thank you for your comment. This has been added for clarity.
391	Expert Reviewer	FULL		104	Stacey 2001 – should be Stacey 2011	Thank you. This has been corrected.
392	Expert Reviewer	FULL		104	Item 58 – Seem comment 4 above re this item not indicating a discussion of options despite it being in the decision making section	Unclear what the comment is asking for.
401	Expert Reviewer	FULL		106	Quality of Evidence - Did you see the systematic review on communicating probabilities that was published by Lyndal Trevena? Trevena L, Davey HM, Barratt A, Butow P, Caldwell P. A systematic review on communicating with patients about	Thank you for your comment. This paper has been added to the review. It was not identified by the search strategy due to its indexing terms.

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					evidence. Journal of Evaluation in Clinical Practice. 2006.	
402	Expert Reviewer	FULL		106	See comment 5 above re the Ottawa Personal Decision Guide	Thank you for your comment, but we are unsure what this refers to.
404	Expert Reviewer	FULL		107	Does this need to indicate that results of patient decision aids are when they are compared to usual care?	Thank you. This has been included for clarity.
405	Expert Reviewer	FULL		107	"…international standards, or availability from recognized providers, can help…" I find this sentence very awkward and think it is trying to say 2 different things. Can it be split in 2 sentences or made more clear.	Thank you for your comment. This has been amended for clarity.
406	Expert Reviewer	FULL		107	In regards to statement about "significant heterogeneity in the results", I agree that there is significant heterogeneity but despite heterogeneity there is consistency in the forest plots for the main outcomes – should this be reflected in this appraisal of the quality of the evidence?	Thank you for your comment. This is addressed in the evidence to recommendations sections.
413	Expert Reviewer	Full & NICE	general	General	I reviewed the NICE document and parts of the FULL document referring to patient decision aids. I was somewhat frustrated that I couldn't make the items between documents. They are labelled differently. Was this done for a reason?	Thank you for your comment. The NICE version only contains the recommendations from the FULL version of the Guidance.
478	Expert Reviewer	NICE		3	"The aim of the guidance is to provide the NHS with clear guidance on what components…" This seems awkward with guidance in the sentence twice.	Thank you for your comment. This has been amended post consultation.
551	Expert Reviewer	NICE		7	Item 16 – sounds like oral only – not sure if it should be more explicit about using various ways to provide patients with evidence-based information.	Thank you for your comment. The statement has been changed to reflect this.
586	Expert Reviewer	NICE	1.1.6	9	Missing 'on' for 'based-on'	Thank you, the typo has been corrected
679	Expert	NIC		13	There is lost of extra space on the bottom half of	This has been corrected.

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754	Expert Reviewer	NICE	1.5.22	17	This item is missing any discussion of options. Sounds like it is about getting patient to agree to a screening, investigation or treatment. Given, this is in the decision making section, should it be more explicit about discussion more than one option and/or the alternate options from the one being presented.	Thank you for your comment. The wording of this recommendation has been amended.
769	Expert Reviewer	NICE	1.5.28	18	On our website at the Ottawa Hospital Research Institute, in addition to having the Cochrane Inventory of available decision aids, we have the Ottawa Personal Decision Guide that is a generic decision aid for any health or social decision (www.ohri.ca/decisionaid). We provide permission for anyone to use it in French, English or Spanish. Many organizations in the US have requested permission to use it	Thank you for your comment.
779	Expert Reviewer	NICE	1.5.28	19	In the last bullet, can you change decision to choice? The decision is usually what they face but once an option is selected we usually call it their choice.	Thank you for your comment. This has been amended.
60	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	Full	General	General	We note that no members of the guideline development group have a role or background in dentistry or oral healthcare. We would also highlight that nowhere with the guidelines is there mention of dentistry, the dental profession or oral healthcare.	Thank you for your comment. The guideline is generic for all patients who use NHS services. This includes dental services. As the guideline is generic we have not made mention of individual services and were unable have members from all healthcare groups on the GDG.
61	Faculty of General Dental Practice (UK), The	Full	General	General	The guidelines contain many references to training. It is to be assumed that patients should be assured that the individual treating them has completed this training. It may be helpful for patients to be able to verify that this is the case	Thank you for your comment and suggestion. The implementation team will consider how the guidance is implemented.

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	Royal College of Surgeons of England				should they wish to so, e.g. by having access to an audited record of the training their practitioner has undertaken.	
62	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	Full	General	General	From a patient's perspective, it is worth noting that one of the most important factors that determine a positive patient experience is the notion that there is equivalence in the system, i.e. that regardless of age, where they live or any other factor, patients are able to access equivalent NHS services. Patient experience can also be closely linked with evidence of more than adequate knowledge and practical skill by their healthcare professional, although it is difficult to be assured of these factors.	Thank you for your comment.
135	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	Full	2.4	14	It may be helpful to detail what is included in NHS adult services is this document, ensuring that dental care is also listed here.	Thank you for your comment. We have added some examples to the section on what is included.
441	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	General	General	These NICE guidelines are to be applauded. They articulate what should be happening in any healthcare setting, and most of the quality standards are applicable to the primary care dental services. It is also worth noting that many of the outcomes may be measured by validated patient questionnaires. Primary care dentistry is a business as well as a service and, as such, most practices will recognise that the patient experience is paramount so as to ensure patient attendance and viability of the business.	Thank you for your comment. The Guidance is relevant for primary care dentistry. The GDG would view the Guidance as necessary in enabling health care professionals understand patient concerns, developing effective communication and enhancing care by providing an appropriate 'architecture' for this activity.

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					However, we may also foresee some potential issues specific to NHS primary care dentistry in demonstrating compliance with these guidelines. Following the publication of theses guidelines and quality standards, all NHS commissioners and providers will be required to provide evidence of compliance. Providers (practice owners) could be individuals or body corporates and it is their role to ensure compliance with NICE guidance and the quality improvement processes employed by PCTs. This can be problematic as most healthcare workers in primary dental care (i.e. dentists, hygienists, therapists, etc) are self-employed and work to contracts between themselves and providers which focus on delivery of activity in the form of units of dental activity rather than quality of care and patient experience. The onus for ensuring that the quality standards in this document are met and providing evidence to support this will therefore rest with the providers as NHS contract holders. Given the current concerns within NHS dentistry around the burdens on the profession, it may be that some see the provision of evidence of compliance with these guidelines as becoming a 'tick-box exercise', diverting resources away from understanding patient concerns, effective communication between professionals and providing hands-on patient care.	
442	Faculty of General Dental Practice (UK), The	NICE	General	General	These guidelines appear to be as much about caring, general politeness and emotional intelligence as they are about asking specific questions of patients. In all of these aspects, it may be said that general dental practice is ahead	Thank you for your comment

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	Royal College of Surgeons of England				of the rest of the NHS as patients have long had the option of choosing which dental practice and/or dentist they visit – in this sense, primary care dentistry has learnt lessons from commercial businesses operating in a competitive market in that patients (customers) will return if the practice has a patient (customer)-centred approach. There has also long been the recognition that patients want different things from their dentist, i.e. some want regular checks and monitoring whereas others just want problems dealt with effectively on an occasional basis.	
443	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	General	General	With regard to primary care dentistry, the guidelines do not set out expectations on how an individual's past and present health is captured beyond asking the patient. This should be considered as part of the guidance to primary dental care practitioners.	Thank you for your comment. The Guidance by nature is generic and reaches across all patient groups. We anticipate that this is something that primary care dental health practices can embed into their care process when implementing this guidance.
444	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	General	General	The guidelines are well presented, clear and comprehensive. They appear to cover all of the points that patients might expect to see in such a document.	Thank you for your comment
445	Faculty of General Dental Practice (UK), The	NICE	General	General	The guidelines should be fully endorsed so far as they relate to primary care dentistry, with particularly support for the section on communication.	Thank you for your comment

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	Royal College of Surgeons of England					
446	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	General	General	While the ideals of the guidelines are laudable, we have concerns that they only apply to dentistry in a very general sense. Also, the guidelines make no mention of how the subject of co-payments might be handled (e.g. for drugs that are not approved by NICE but can be paid for by the patient and administered by health service staff) or other financial arrangements that general dental practitioners deal with on a daily basis.	Thank you for your comment. The subject of co-payments is a specific issue and not appropriate for a generic guideline.
447	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	General	General	We note that there is no mention in this document of the responsibilities that might apply to the patients; if healthcare is to be a partnership then some responsibilities must lie with the patient. We would refer NICE to guidance developed by the FGDP(UK)'s Lay Advisory Group 'Patient's Rights and Responsibilities' which includes patients' responsibilities in a primary dental care setting.	Thank you for your comment. We are very supportive of related guidance that is complimentary. We will talk to the PPIP and Implementation Teams to seek their advice.
485	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	Intro	4	We applaud the basis on which the recommendations were developed, set out in the sentence beginning 'The recommendations in this guidance have been informed by research evidence,…'.	Thank you for your comment
507	Faculty of General Dental Practice	NICE	Draft quality statements	6 -7	This section gives a clear indication to patients of the sort of quality standards they might expect.	Thank you for your comment.

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	(UK), The Royal College of Surgeons of England					
587	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.1.7	9	While there should be support for the theory of the vision set out in this point, one might question how this may be achieved realistically given the time constraints placed on practitioners in the NHS. In practice, this standard may only be appropriate in a limited number of more serious situations within a primary care setting.	Thank you for your comment. We acknowledge your comment, the guideline is non-setting, non-population specific.
588	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.2.3	9	There is particular support for the inclusion of this statement. It may also be relevant to include encouragement for the healthcare profession to relate back to the patient any conclusions reached in discussions about their care while they were not present.	Thank you for your comment. This has been included in recommendation 38.
637	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.3.1	11	This statement is to be supported, particularly the need to take into account the patient's locality, access and personal preferences.	Thank you for your comment
638	Faculty of General Dental	NICE	1.3.3	11	Primary dental care practitioners have a key role to play in providing support for patients that smoke in the form of oral health advice and encouragement	Thank you for your comment.

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	Practice (UK), The Royal College of Surgeons of England				to access smoking cessation services.	
666	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.3.10	12	It may be appropriate to include within this statement a reference to encouraging the patient to seek a second opinion where the practitioner has real concerns about a treatment being declined.	Thank you for your comment. This has been added as a separate recommendation.
680	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.3.12	13	It might be useful here to give examples of the types of formats that patients might use to provide feedback.	Thank you for your comment. The GDG felt that this would come under individual feedback mechanisms of healthcare providers. NICE implementation team are currently considering tools to support implementation of this guidance.
681	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.4.2	13	This is an important to include in the guidance as many complaints by patients concern shortcomings in communication.	Thank you for your comment. The recommendations are for good practice, whereas complaints are often a result of failures of good practice. There is a discussion about complaints in the introduction to the guideline.
704	Faculty of General	NICE	1.5.1 – 1.5.11	14 -15	The statements concerning communication are key in primary care dentistry since it is failings in	Thank you for your comment.

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	Dental Practice (UK), The Royal College of Surgeons of England				this area that most often lead to disciplinary hearings.	
734	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.5.13	16	In the context of primary care dentistry, reference should be made to a dental treatment plan being an example of appropriate patient information.	Thank you for your suggestion. This guidance by nature is generic, with a non population and non setting specific focus.
735	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	NICE	1.5.17	16	It may be appropriate to examine more closely the issues around the recording of consultations. Further discussion around potential consequences and where the recording of consultations may or may not be appropriate is necessary for the FGDP(UK) to support I am also concerned that patients may record consultations in that this may open the door for all consultations to be recorded(might not be a bad thing)	Thank you for your suggestion. Commissioners implementing this guidance we anticipate may request the approach you are suggesting.
816	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	General	General	It is difficult to assess the extent to which NHS primary care practitioners could reasonably be expected to meet each of the quality statements. From a lay perspective, it may be fair to assume that clinicians would make a judgement in this regard based on evidence and what could be achieved within current parameters or available resources.	Thank you for your observation. The guidance is aimed at 'improving patient experience' and service providers will need to respond to the individual and corporate challenges of achieving this. We believe this guidance provides the structure for system alignment and improvements.

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817	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	General	General	While the sentiments in the quality standards are to be applauded, it is clear that healthcare providers will require appropriate support in order to implement any changes necessary. In addition, the 'evidence of local arrangements' referred to throughout the document will need to be sufficiently robust to ensure best patient experience while being proportionate so as not to overburden the healthcare provider.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
818	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	General	General	From a primary dental care perspective, the quality standards appear laudable, though we may point to potential shortcomings concerning the effectiveness of some of the monitoring measures; these may be too simple and in many cases the denominators may be insufficiently defined. The quality standards would benefit from statements regarding the appropriate handling of conflict or complaints, as well suitable training to enable staff to comply with the standards.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
819	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	General	General	The issue of access to services is not covered in this document, though is certainly part of the patient experience.	Thank you for your comment. We agree that access has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address access.
820	Faculty of General Dental Practice (UK), The Royal	QS	General	General	One might expect these quality standards to have included issues related to patient safety since this is central to patient experience. It may also be relevant to include a standard around disease prevention advice and preventative care.	Thank you for your comment. We agree that safety is important and can be a significant influence on patient experience. We had however to limit the areas we were able to consider.

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	College of Surgeons of England					
923	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	1	5	In NHS primary care dentistry, compliance with NICE guidance is assessed by commissioners (PCTs) in their annual review and by the NHS Business Services Authority to a limited extent. The PCT annual review will need to be developed to encompass patient experience.	Thank you for your comment.
994	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	3	9	The development of a specific feedback tool will be required by commissioners and providers to facilitate the meeting of this quality standard in an NHS primary dental care setting.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
995	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	3	9	It may be better to replace 'given the opportunity' with 'encouraged'.	Thank you for your comment. The Quality statement has been altered.
996	Faculty of General Dental Practice (UK), The	QS	3 & 4	9 -10	While the detail appears to address these quality standards adequately, their language and format do not translate very well for patients and are arranged in a rather technical layout designed for internal use.	Thank you for your comment. The language of the statements has been simplified in the final version of the quality standard

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	Royal College of Surgeons of England					
1039	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	5	11	We agree with the need for this standard, but we would stress that service providers should only assess patients needs and concerns in areas where the provider has appropriate competency.	Thank you for your comment.
1062	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	6	12	We would point out that it is impossible to introduce all members of the care team formally where a patient's dental care involves teams in both the primary and secondary care environment. Furthermore, it may be worth qualifying this statement to indicate that patients should be introduced to/have roles explained for those professionals with whom they will interact.	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1088	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	7	13	It should be noted that, within primary care dentistry, patients preferences for the sharing of their information is not determined on a routine basis. With the maintenance of patient confidentiality being of the utmost importance, this quality standard may only be applicable where patients are accompanied by carers.	Thank you for your comment. The guidance is designed to shape service delivery that will improve patient experience. We encourage service outlined to align with the Quality Standard.
1132	Faculty of General Dental Practice	QS	9	16	There are good points here made in relation to tailored care, though for this guidance to apply to primary care dentistry (and some other areas of NHS care), reference must also be made to	Thank you for your comment.

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	(UK), The Royal College of Surgeons of England				affordability of a service.	
1155	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	10	17	With regard to exchange of information between healthcare professionals, we must note that the current NHS dental contract does not promote continuity of care and relationships. The patient only remains a patient for the course of treatment provided.	Thank you for your observation
1181	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	12	19	Might improve by adding 'and wherever possible met' after 'Patients have their requirements for continuity of care considered'.	Thank you for your suggestion. This is not measurable.
1196	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	13	20	Demonstration of 'competency in communications skills' suggests that the professional has been subject to an assessment of those skills, therefore an example of an outcome measure would be useful, e.g. a patient questionnaire.	Thank you for your comment. This can only be determined at a local level in agreement with commissioners of services.
1259	Faculty of General Dental	QS	16	23	It is unclear to what extent the provision of evidence-based information to patients currently takes place in primary care dentistry. Furthermore,	Thank you for your comment. The guidance is designed to help inform improvement in quality of information provision.

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	Practice (UK), The Royal College of Surgeons of England				an evidence base in dentistry is still evolving and often decisions are based on consensus view from experts in a given area.	
1282	Faculty of General Dental Practice (UK), The Royal College of Surgeons of England	QS	17	24	In primary care dentistry, we are not aware of the use or development of recognised evidence-based decision support tools for patients.	Thank you for your comment. These are available via the NHS Direct website: http://www.nhsdirect.nhs.uk/DecisionAids
22	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	All	General	General	EQ5D needs to be revised. Patients within each major disease group need to be asked what is important to them by trained marketing professionals experienced in running focus groups. It must be ensured that all aspects of the disease and treatment are covered e.g. incontinence, sleeplessness which isn't included at the moment. This can be used to revise QALYs	Thank you for your comment. Such work would need to be undertaken as part of a formal research project and is outside of the scope of guideline development.
23	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent	All	General	General	Non-compliance with medicine is 60%, so NICE needs to make sure that side effects of medicines and treatments are taken into account properly. They are not given sufficient weight at present. These side effects need to be properly explained to the patients and alternatives available if the side effects are not acceptable to the patients.	Thank you for your comment. NICE has produced a guideline on Medicines Adherence which covers this area.

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	, voluntary patient group					
24	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	All	General	General	It would have been useful to have specific questions to answer.	Thank you for your comment. NICE Consultation does not adopt this approach.
25	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	All	General	General	Measuring patient satisfaction/experience: This should be done on a continuous basis not on way day per year. Measuring patient experience while being treated will not be accurate. Patients will feel vulnerable and will not want to complain in case the member of staff finds out. It should be measured after their treatment within 1 month and should be anonymous. The results should be taken seriously and acted upon. Patients should be encouraged to suggest improvements and be given plenty of room to do so.	Thank you for your comment. The GDG consider that there are multiple mechanisms for both collecting and receiving feedback and the use of these will vary according to NHS setting. We agree patients should be encouraged to provide feedback and suggest improvements, please see recommendations (NICE) 1.3.14 and 1.3.15
63	FEmISA – Fibroid Embolisation: Information, Support & Advice an	Full	General	General	Patient Organisation should have been asked to contribute to the formulation of these guidelines e.g. The Patients Association, Cancer Research UK, Age UK etc	Thank you for your comment. The guideline development group was recruited using an open process and the consultation process is the usual way for stakeholders to comment on proposed guidance.

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	independent, voluntary patient group					
64	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	Full	General	General	NICE has never asked patients what they want and how they want to be treated. This is a fundamental pre-requisite for developing these guidelines. There should have been a very large survey with the public and patients with acute, terminal and chronic diseases to ask for their input before these guidelines were written.	Thank you for your comment. NICE does not carry out primary research but develops guidance from research that is already in the public domain. The Warwick scoping study, which informed the guidance, utilised a wide range of peer-reviewed studies that had examined patient experiences. There were six patient representatives on the GDG who has a important role in ensuring the guidance focused on areas of importance to patients.
139	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	Full	3.1 -3.4	15 16 17	NICE being economics based has very little understanding of the needs and desires of patients, their families and carers and doesn't ask them. Reviewing existing literature will not help as NHS patient surveys leave very little room for patients to make comments and does not ask about patients' needs or how they value medical treatments or what should be improved. The NHS patient questions consist mainly of pre-coded questions and gives very little room for common or ideas to improve the NHS. It does not ask what families or carers think.	Thank you for your comment. NICE is not an economic-based organisation. It produces clinical guideline for the NHS taking into account clinical effectiveness and cost effectiveness. Guideline development groups are multidisciplinary and always include patients and/or carer members. In this guideline in particular patients and carers had a strong representation on the group. NHS patient surveys were only one of a number of evidence sources that was used to inform this guideline.
155	FEmISA – Fibroid Embolisation: Information, Support & Advice an	Full	4.1	21	Point 3: This point is well made and need greater emphasis. Patients are people not walking diseases. They still have a life outside their illness, still need to work, look after children, go shopping etc. The NHS both primary care and hospitals expects patients to drop everything to go to clinics during	Thank you for your comment, we agree with your observations. The guideline cannot go into details about appointment timing and working hours for hospitals and surgeries, however, coordination and prioritisation of care is mentioned in the Continuity of care and relationship section.

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	independent, voluntary patient group				working hours, go backwards and forwards for blood tests, prescription renewals, GP appointments all on different days at different times instead of integrating these and having them at one visit and outside normal working hours. This is particularly difficult for people with chronic diseases who need continuing care.	
156	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	Full	4.1	21 & 22	Essentials of care: A very important point that is not covered – patients need to be fully and objectively informed of all the possible treatment options and given unbiased information about them. In FEmISA we still find women only being given the option of hysterectomy for heavy menstrual bleeding, not being told about other less invasive options. Often if the woman asks she is told that the other options are no good, or not OK for her when they are.	Thank you for your comments. This is addressed in recommendations 21, 53, 59 and 61 in the full guideline.
157	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	Full	4.1	21 & 22	Essentials of care: Patients are often not told about the side effects of their treatments, this is especially true in primary care. It is unsurprising that 60% are not fully compliant with their medicines when they are not told what to expect and the medicine or treatment adversely affects their life. It is very important that side effects are discussed and what to do about them.	Thank you for your comment. For areas related to medicine adherence, please refer to guideline CG76; Medicine Adherence.
682	FEmISA – Fibroid Embolisation:	NICE	1.4	13	Continuity of Care: Where a team is involved as with care of the terminally ill/dying each team member needs to ensure the patient understands where they are	Thank you for your comment. The developers agree and refer you to the recommendations on communication.

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	Information, Support & Advice an independent, voluntary patient group				from and what they are for. It can be very confusing, who is a nurse, who is a carer, especially as they don't see the same one each time.	
755	FEmISA – Fibroid Embolisation: Information, Support & Advice an independent, voluntary patient group	NICE	1.5.22	17	Explain the possible alternatives, risks and side effects of any diagnostic tests e.g. perforation of the GI tract and death with colonoscopy	Thank you for your comment. The GDG believe this is covered by the recommendation as it states you should provide information about and discuss "risks, benefits and possible consequences".
770	Frimley Park Hospital	NICE	1.5.26	18	Stipulating the required wording as set out in the bullet points might prevent an individualised communication with the patient so maybe it can be considered as suggested best practice examples of communicating messages.	Thank you for your comment. At the beginning of the recommendation it sets out that you should personalise the risks and benefits as far as possible, and the section on communication sets this out also.
821	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	Do some quality statements have a higher priority than others? If so, is this reflected in the sequence?	Thank you for your comment. The quality standards were not in priority order, but reflect the order of the guideline document.
822	Gloucestershire Hospitals NHS Foundation	QS	general	general	If some of the quality statements do not have a higher priority than others, can they be given an indication of priority to support implementation?	Thank you for your comment. Quality statements have been distilled into 14 final statements, and there is no hierarchy of importance.

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	Trust					
823	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	It is a shame that these guidelines need to include things that should be a given such as 'seeing the patient as an individual'. Although the evidence points to this is what is needed it is sad when we need to write guidelines telling people in the caring professions how to care.	Thank you for your comment.
824	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	This document raises points which are valid and obviously needed for patient experience, but if we are going to achieve what the guideline sets out to achieve, it needs to be shorter and more workable for staff in order for them to achieve it. Even the short version at 26 pages long is long, and quite simply, for nursing staff on the front line to change their practice in line with this and enhance patient experience, however when we communicate this to them (albeit that this is the underpinning policy) it needs to be much shorter and snappier with the key points highlighted.	Thank you for your comments. The documents follow a standard format
825	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	There are too many standards, and as a result there is repetition within them.	Thank you for your comment. The final version has been limited to 14 quality statements.
826	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	It refers to standards across Adult NHS but this is a very broad brush and there might have to be some accommodation for the differences between community and acute provision and the different dynamics of service provision.	Thank you for your comment. The remit for the guideline is generic patient experience in the NHS.
827	Gloucestershire Hospitals NHS	QS	general	general	Regarding the style and format – there is no definition as to who / what service providers are and there was confusion within the standards – with whom does the responsibility lie. Are service	Thank you for your comment. A Service provider relates to the organisation and health and social care professionals relates to the individual.

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	Foundation Trust				providers and health and social care professionals one and the same?	
828	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	There is some detail within the NICE guidance which would have been informative within the quality standards programme- just the headers from each section would be helpful.	Thank you for your comment. The chapter headers are included.
829	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	When will the Commissioners responsibilities come into place? What if they are not in place now and Trusts / services are already commissioned? Will there be a time frame for implementation?	Thank you for your comment. We anticipate that guidance will be provided by the National Quality Board and the NHS commissioning Board.
830	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	There are references within many of the standards to 'training staff' – how, when, with what resources, which staff groups – does training result in transformation / compliance?	This is a current focus in healthcare undergraduate training, and therefore this guidance is related to systems already in place.
831	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	Other Standards include the requirement that patients receive information about their care that is clear, accurate, understandable and relevant an explicit standard would be difficult to measure and is not required.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
832	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	The standards are clear and cover many of the issues relating to improving the patient experience that have been identified nationally and locally.	Thank you for your comment.
833	Gloucestershire	QS	general	general	We are not sure how the standards relate to or link with the Care Quality Commission Standards,	Thank you for your comment. We agree that the recommendations and standards overlap

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	Hospitals NHS Foundation Trust				Information Governance Toolkit Standards or any NHSLA standards relating to the patient experience and think that Nationally there needs to be more connections made between all of these Nationally to avoid duplication of effort and or confusion	both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance
834	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	Is there any intention to develop a national competency assessment for communication skills or whether this would be the KSF Dimension relating to communication (We would hope this would be the case but that would require 'joined up' thinking Nationally)	Thank you for your comment. This is a current focus in healthcare undergraduate training, and therefore this guidance is related to systems already in place.
835	Gloucestershire Hospitals NHS Foundation Trust	QS	general	general	There is a need for all of the National and externally imposed standards such as NICE, CQC, NHSLA, HSE, NMC and GMC codes / standards of conduct, NHS KSF etc to cross reference each other to avoid confusion and avoid duplication of effort.	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance
924	Gloucestershire Hospitals NHS Foundation Trust	QS	1	5	Reference to 'all' staff – how does this fit with those staff who receives different appraisals? For example, medical and dental staff. Non-medical staff and 'other' categories receive very similar appraisals. What about Locums, bank staff, agency staff, doctors in training and student nurses and other nurses?	Thank you for your comment. The statement has been amended to "annual appraisal or performance assessment". This is irrespective of type of staff and should be agreed locally.
925	Gloucestershire Hospitals NHS Foundation Trust	QS	1	5	The guidance requires evidence that the quality standards are discussed at appraisal. Appraisal for doctors is structured according to the GMC guidance for doctors which covers much of what is included in the draft NICE guidance. It is obviously not possible to cover every aspect in the time available for appraisal, but appraisal is increasingly being strengthened to make sure that appropriate	Thank you for your comment. The statement has been amended to "annual appraisal or performance assessment". This is irrespective of type of staff and should be agreed locally.

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					evidence is brought to the appraisal and the key areas assessed.	
926	Gloucestershire Hospitals NHS Foundation Trust	QS	1	5	This quality standard should be located towards the end of the list of quality standards so that the reference made to 'NICE' standards on the patient experience would then be in context for all staff undertaking appraisals	Thank you for your comment.
927	Gloucestershire Hospitals NHS Foundation Trust	QS	1	5	This statement is introducing what appears to be another 1:1 / appraisal process	Thank you for your comment.
928	Gloucestershire Hospitals NHS Foundation Trust	QS	1	5	Within a) There is reference within this document to 'annual performance assessments', care needs to be taken when implementing a system of 'performance review' the appraisal system is the appraisal and development review; at this meeting achievements, job description and competencies may be checked but it has moved away from the perceived negativity of 'performance review'. Line Managers and Appraisers currently have difficulty implementing an annual appraisal – would this 'performance assessment' be part of the appraisal or different? Would there be a requirement to record that this performance assessment had taken place – for which staff groups. How could this be managed?	Thank you for your comment. The statement has been amended to "annual appraisal or performance assessment". This is irrespective of type of staff and should be agreed locally.
929	Gloucestershire Hospitals NHS Foundation	QS	1	5	Within b) 'evaluation and mentoring' evaluation against what? – a local standard, who will determine this? how will it be cascaded (Trust values and Leadership Behaviours have taken years to disseminate)?	Thank you for your comment. The evaluation and mentoring is against the NICE guidance on patient experience.

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	Trust					
930	Gloucestershire Hospitals NHS Foundation Trust	QS	1	5	Mentoring – what is the definition of this in this context? Who is mentoring who What do you need to be a mentor? Is this in fact line management / supervision?	Thank you for your comment. The use of the term is widely accepted in healthcare as a person who can advise and support development.
965	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	This standard is essential when linked to safeguarding or the process for obtaining consent to treatment. Some of the assessments referred to in this quality standard will be difficult to record for the purpose of audit due to the different routes into the Acute Trust (there are approximately 8).	Thank you for your comment.
966	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	Inpatients will be very easy to audit against the 'Gloucestershire patient profile' which is an assessment of inpatient post 24 hours.	Thank you for your comment.
967	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	The 'Patients First' system used in the emergency department will record part of the information.	Thank you for your comment.
968	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	We do not routinely check sight and hearing problems or difficulties with reading English in the outpatient departments.	Thank you for your comment. The quality standards are designed to span all settings.
969	Gloucestershire	QS	2	7	How can we be sure to endorse or check compliance when patients are referred through a	Thank you for your comment. The quality standards are designed to span all settings

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	Hospitals NHS Foundation Trust				telephone help line, emergency hospital referral or telephone pre-assessments?	
970	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	The quality measure will be partially reliant upon the GP referral letter and other information forwarded from primary care.	Thank you for your comment. The quality standards are designed to span all settings
971	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	Asking patients about physical or learning difficulties, sight or hearing problems is relatively easier than ascertaining whether an individual has dyslexia difficulty reading, or with literacy – the individual may not admit or may not know.	Thank you for your comment.
972	Gloucestershire Hospitals NHS Foundation Trust	QS	2	7	It would make more sense to combine this standard with standard 14 (Healthcare professionals establish and use the most suitable way of communicating with each patient and confirm the patient's understanding) because for everyone regardless of needs healthcare professionals would establish the best way of communicating with patients.	Thank you for your comment. The quality standards have been altered.
997	Gloucestershire Hospitals NHS Foundation Trust	QS	3	9	Patients may or may not have realistic health preferences. Sometimes a preference made by a patient could be a luxury and it might not be possible for staff to deliver the preference within the resources available.	Thank you for your comment. This is therefore an opportunity to discuss these.
998	Gloucestershire Hospitals NHS Foundation	QS	3	9	The healthcare system currently being delivered is driven mainly by the Western medical model, are we prepared to change this medical model to accommodate a variety of health beliefs?	Thank you for your comment. The quality standard is aimed at understanding the patient and incorporating their beliefs into their care where possible.

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	Trust					
999	Gloucestershire Hospitals NHS Foundation Trust	QS	3	9	There is a difference that needs to be clear within this measure, firstly in allowing patients to express their views and for staff to respect the expression of views and secondly in acknowledging the staff and their ability to respond to all of the health beliefs, concerns or preferences in order to individualise care. Staff can become confused when responding to the 'Choice' agenda.	Thank you for your comment. As the descriptor states, staff should be guided in how to do this.
1000	Gloucestershire Hospitals NHS Foundation Trust	QS	3	9	This standard needs to acknowledge that the patient might choose for the staff to become the decision maker; as the health professional.	Thank you for your comment. This is a valid preference; however it is not possible to give examples of all patient preferences.
1001	Gloucestershire Hospitals NHS Foundation Trust	QS	3	9	There are times in a healthcare pathway when it is not possible nor feasible to give patients an opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care – particularly in acute / emergency care and critical care services – this should be taken into account within the standard.	Thank you for your comment. Where this is not possible, it would not take place.
1002	Gloucestershire Hospitals NHS Foundation Trust	QS	3	9	There should be reference to the whole patient pathway – this may happen at the primary care stage but be less accommodated once a referral has been made; time for discussion may be limited.	Thank you for your comment. As the quality standard is for all of the NHS, reviewing it along the care pathway is not always appropriate.
1003	Gloucestershire Hospitals NHS Foundation Trust	QS	3	9	There is reference to commissioners ensuring providers follow guidance that enables staff to identify the patient's health beliefs, concerns and preferences – what is this guidance? Would this result in documentation change, or how would guidance be disseminated?	Thank you for your comment. The implementation team will consider how the guidance is implemented.

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					Is this across the whole of the health sector so that there is consistency?	
1019	Gloucestershire Hospitals NHS Foundation Trust	QS	4	10	This is a very good standard. Is the language used in this quality standard going to be used consistently and translated to all staff groups? For example, the 'duties of a doctor' issued by the General Medical Council (GMC) entitled 'good medical practice'.	Thank you for your comment. The standards relate to all staff groups.
1020	Gloucestershire Hospitals NHS Foundation Trust	QS	4	10	If so Statement 13 (Patients are cared for by healthcare professionals who have a demonstrated competency in communication skills) could be woven within the statement.	Thank you for your comment.
1021	Gloucestershire Hospitals NHS Foundation Trust	QS	4	10	Health and social care professionals, reference made to annual appraisal – this could be challenged. This should be part of ongoing assessment by appraisers / line managers / supervisors and not part of an annual 'performance assessment'	Thank you for your comment. This has been changed to ongoing assessment.
1040	Gloucestershire Hospitals NHS Foundation Trust	QS	5	11	'Fear' and 'anxiety' is not always assessed. There will be a requirement to identify and capture the training needs of all staff according to their role. We question whether all staff always understand their role with regard to psychological fear?	Thank you for your comment. This would be a local issue regarding training.
1041	Gloucestershire Hospitals NHS Foundation Trust	QS	5	11	This is a good statement but will require a lot of background work to ensure compliance.	Thank you for your comment. This will be a local responsibility.
1042	Gloucestershire	QS	5	11	This statement appears to confuse the patient experience – improving the experience of care for	Thank you for your comment.

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	Hospitals NHS Foundation Trust				people with other standards including essence of care. It need not be included within these standards.	
1043	Gloucestershire Hospitals NHS Foundation Trust	QS	5	11	Service Providers – how are service providers going to ensure professionals are appropriately trained in assessment of physiological and psychological need? Who are the professionals? What is an appropriate trained level? Is there a different level depending on role?	Thank you for your comment. This will be a local responsibility.
1044	Gloucestershire Hospitals NHS Foundation Trust	QS	5	11	Hospital environments cannot guarantee an environment that maintains their dignity and confidentiality – it is done so far as is reasonably practicable.	Thank you for your comment. The GDG has identified this as one of the basic underpinnings of good care.
1045	Gloucestershire Hospitals NHS Foundation Trust	QS	5	11	On acute wards patients have to be assessed in bays / behind curtains every effort is made to maintain dignity and confidentiality – which is the key and this is covered in Statement 4 (or the NHS constitution etc).	Thank you for your comment. The quality standard aims to ensure that health care professionals treat patients with dignity and confidentiality.
1063	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	The introduction to all members of their care team and the expectation to be given a clear explanation of role should be reasonable. What does 'all' mean? Could the term 'all' be replaced with the term 'immediate' or 'core' healthcare team?	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1064	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	Explain the term 'introduced', could this mean a physical introduction or could the patient be made aware of a name and role of a member of staff, for example, having information on the ward or on the website with explanations of uniforms and roles?	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".

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1065	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	This standard could be changed to 'Patients are introduced to all healthcare professional delivering care, as appropriate, tailoring to the patient's individual communication needs.	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1066	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	Patients are introduced to all members of the healthcare team and given a clear explanation of each member's roles and responsibilities.	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1067	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	If out at a social function and you were introduced to a crowd of people – is it likely you will remember them or what their role and responsibilities are? Unlikely and that is without the stress of an unfamiliar environment, treatment or health pathway, stress, terminology etc	Thank you for your observation. This does not detract from the importance of clear understanding of role and responsibility.
1068	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	It is more appropriate for the healthcare team to introduce themselves and give a clear explanation of their role and responsibilities, and for this to be done at an appropriate time in the care / treatment pathway.	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1069	Gloucestershire Hospitals NHS Foundation Trust	QS	6	12	The statement should be reworded 'All members of the healthcare team have a responsibility to give a clear explanation of their roles and responsibilities to the patient'.	Please see amended wording above
1070	Gloucestershire Hospitals NHS Foundation	QS	6	12	This then takes into account that it is the healthcare team members that that particular patient has contact with – rather than the wider (which can be very wide) healthcare team who may not be involved in the patients care at all	Please see amended wording above

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1090	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	The draft quality measure and process on preferences for involving and sharing information should not just be at the 'first point of contact', but the process should state this is continually reviewed and assessed alongside the patient's pathway.	Thank you for your comment
1091	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	Define 'first point of contact'. Does this include the patient letter?	Thank you for your comment. This is an important point to raise. At the first consultation, regardless of care setting the patient's preferences should be noted and form part of ongoing communication between all those who are involved in their care.
1092	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	Will this be at the first point of contact when a patient is diagnosed with a chronic condition and referred to the team? What about patients who have a diagnosis of cancer within their pathway and referred to the oncology service?	See above comment.
1093	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	Staff sometimes fail to share information with carers when it is appropriate to do so	Thank you for your comment. We appreciate this.
1094	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	The patients will need to take some responsibility for proactively informing staff of their preferences.	Thank you for your comment. We agree, this should be facilitated.
1095	Gloucestershire Hospitals	QS	7	13	How do we know or capture if there are other people who have a legal right to have access to information? What if the patient has an advocate	Thank you for your comment. These are important issues and can only be resolved by applying the statement to the case specific

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	NHS Foundation Trust				and the patient does not accept responsibility for their own healthcare decisions? What about if the patient has a 'Lasting Power of Attorney for health and welfare decisions? What if there are legal guardian issues to do with health?	context.
1096	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	Should the indicators come from within the nursing teams or be evaluated through the patient experience?	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1097	Gloucestershire Hospitals NHS Foundation Trust	QS	7	13	Statement clear and can be evidenced – may be worth taking into account that at the first point of contact patients may not know what their preferences are because at that point they may not have a diagnosis or treatment plan so preferences should not just be continuously respected throughout but re established through the pathway.	Thank you for your comment.
1109	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	A patient may have capacity to consent but may choose to make an unwise informed healthcare choice. Staff can only offer support in context to the constraints of the situation.	Thank you for your comment
1110	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	Staff can respect a patient's choice but cannot always and will not always be in a position to support healthcare choices. For example, what if there are safeguarding issues as a result of a patient's choice to decline treatment? What about the impact this might have on other family members and managing the fallout? In practice, there are grey areas and this is particular to oncology.	Thank you for your comment. We agree.

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1111	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	Staff can only offer opportunities for further discussion and where appropriate refer the patient to the GP for access to help and support if the patient changes their mind about declining treatment post-discharge.	Thank you for your comment
1112	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	The recommendations for treatment options and choice must be presented in the patients best interest	Thank you for your comment. We agree.
1113	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	Consideration should be given as to whether this statement is a part of statement 15 (Patients, when making decisions about screening, investigation, treatment and care, are supported to be involved in shared decision-making to ensure that they are informed of and understand all relevant options, outcomes and implications consistent with what is important to them).	Thank you for your comment. The statements had been simplified to ensure they are understandable.
1114	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	Service providers – are requested to ensure health service providers are appropriately trained to respect and support a patient's right to choose, accept or decline treatment What is 'appropriately trained'? Who are the health service providers?	Thank you for your comment. These are important questions that need to be answered by commissioners of service delivery.
1115	Gloucestershire Hospitals NHS Foundation Trust	QS	8	15	Are their measures in place to determine if patients have chosen / accepted or declined treatment? Does there need to be processes in place for demonstrating this?	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1133	Gloucestershire Hospitals	QS	9	16	Personal preferences can sometime be unrealistic and unachievable, they cannot always be taken into account in practice; personal preferences	Thank you for your observation

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	NHS Foundation Trust				therefore cannot always be met.	
1134	Gloucestershire Hospitals NHS Foundation Trust	QS	9	16	It is not always possible to tailor care to an individual's needs that takes into account their locality, access and personal preferences	Thank you for your observation
1135	Gloucestershire Hospitals NHS Foundation Trust	QS	9	16	Sometimes it is about where the treatment can be accessed, where the best provision is, where care and services have been centralised to ensure best practice and patient safety. This is setting an expectation that cannot always be realised. The statement should take that into account because where services are provided often is about quality / consistency.	Thank you for your comment. The guidance is designed to shape commissioning of service delivery models.
1136	Gloucestershire Hospitals NHS Foundation Trust	QS	9	16	Commissioners- to ensure that service providers have arrangements for training staff in the tailoring of services to meet the patient's needs. What training? To whom?	Thank you for your comment. This has to be agreed with commissioners of service delivery at a local level.
1182	Gloucestershire Hospitals NHS Foundation Trust	QS	12	19	It is not always possible to see the same healthcare professional or team. The patient can be assured that they will see a competent and knowledgeable member of staff.	Thank you for your comment. The statements are aspirational and we appreciate the point you are making.
1183	Gloucestershire Hospitals NHS Foundation	QS	12	19	This statement could be changed to 'patients have their requirements for continuity of care considered. Within the description of what the quality statement means for each audience, the patients section -	Thank you for your comment. We disagree with your suggested amendment.

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	Trust				'see the same healthcare professionals or healthcare team throughout their care' - should be removed as it will more likely be shared care from a team.	
1197	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	The difficulty with this standard is how to demonstrate competency.	Thank you for your comment. This will be determined at a local level in agreement with commissioners of services.
1198	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	Is this more about linguistic ability?	Thank you for your comment. No, we do not believe it is as restricted as this.
1199	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	Attitudes and skills learnt are not always demonstrated. This forms part of the Trust's Knowledge and Skills Framework (KSF) but this is not always assessed.	Thank you for your comment. We agree
1200	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	The quality statement is correct but we are concerned about how we will demonstrate competencies from senior consultants to porters.	Thank you for your comment. This will be determined at a local level in agreement with commissioners of services.
1201	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	Give consideration as to whether this should be a separate standard as to achieve the other quality standards healthcare professionals have to be competent communicators.	Thank you for your comment. It remains separate

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1202	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	This standard does not define what it means by communication skills – what areas of communication?	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1203	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	It is not specific enough whereas if it were detailed within the other statements there would be more specificity.	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1204	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	What is meant by 'evidence to ensure that healthcare professionals are trained and competent in communication skills'; what level of training? To who? About what?	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1205	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	How is competence going to be demonstrated? Training doesn't necessarily result in competence.	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1206	Gloucestershire Hospitals NHS Foundation Trust	QS	13	20	What is going to be recorded to demonstrate that a 'proportion of professionals' have been trained? What is a proportion? Is this for local interpretation? Would the standard be the same at one Trust to another?	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1207	Gloucestershire Hospitals NHS Foundation	QS	13	20	Commissioners ensure service providers have arrangements for competency based training in communication skills – what is competency based training, who decides content?	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.

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1232	Gloucestershire Hospitals NHS Foundation Trust	QS	15	22	We feel that this statement is rather aspirational. Within the description of what the quality statement means for each audience / service providers: - We wonder how screening can offer shared decision making as a letter is often just sent out to the patients. - The training offered to staff on helping people to make decisions has a very solid foundation but the reality would be in its delivery	Thank you for your comment. By nature QS are aspirational that establish a benchmark for improving quality. Reworded, please see above comments
1233	Gloucestershire Hospitals NHS Foundation Trust	QS	15	22	Please define shared decision making.	Please see the definition here: http://www.institute.nhs.uk/nhs_alert/guest_editorials/may_2011_guest_editorial.html
1234	Gloucestershire Hospitals NHS Foundation Trust	QS	15	22	Staff do not always have the information relating to risks and benefits readily available.	Thank you for your comment. See new wording in previous response above.
1235	Gloucestershire Hospitals NHS Foundation Trust	QS	15	22	As detailed earlier this seems as though it should incorporate Statement 8	Thank you for your comment. The wording has been amended.
1236	Gloucestershire Hospitals NHS Foundation Trust	QS	15	22	It would also be more valuable to have included Statement 16 (Patients are provided with evidence-based information that is understandable, personalised and clearly communicated.) within this statement because the patient should be informed of and understand all relevant options, outcomes and implications	Thank you for your comment. The wording has been amended.

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					supported by evidence-based information. These shouldn't be two separate quality standards.	
1237	Gloucestershire Hospitals NHS Foundation Trust	QS	15	22	Again within the standard there is reference to ensuring 'staff are appropriately trained in facilitating shared decision-making' Who is referred to as staff? What is appropriate training? Who decides these?	Thank you for your comment. Previous comments have addressed these points.
1260	Gloucestershire Hospitals NHS Foundation Trust	QS	16	23	We feel that this statement relates to quality standard 2	Thank you for your comment. The GDG reduced the number of statements in the final quality standard.
1261	Gloucestershire Hospitals NHS Foundation Trust	QS	16	23	Offering personalised information is going to be a challenge as we offer generic patient information leaflets	Thank you for your comment. This can be achieved through verbal reinforcement.
1262	Gloucestershire Hospitals NHS Foundation Trust	QS	16	23	Within statement 16 service providers are described as requiring to ensure that information about patient care that is evidence-based, and understandable is available to staff – if the healthcare staff are the service providers then the responsibility lies with everyone?	Thank you for your comment. We agree.
1284	Gloucestershire Hospitals NHS Foundation Trust	QS	17	24	What are patient decision aids?	Thank you for your comment. These are available via the NHS Direct website: http://www.nhsdirect.nhs.uk/DecisionAids
1285	Gloucestershire	QS	17	24	This standard links to training issues and has resource implications	Thank you for your comment. Noted

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	Hospitals NHS Foundation Trust					
1286	Gloucestershire Hospitals NHS Foundation Trust	QS	17	24	Incorporate within Statement 15 so that decision aids are not seen as an add on but as an inherent part of the discussion with patients and their choice	Thank you for your comment. The GDG reduced the number of statements in the final quality standard and incorporated decision support tools into the measurement of the statement on shared decision making.
191	Grünenthal	Full	4.1.17	24	Grünenthal welcomes the emphasis given to pain relief in the full guidance document Patient experience in adult NHS services: improving the experience of care for people using NHS services as one of the basic human rights and requirements of patient care to have pain managed effectively. Often pain is seen as a psycho social problem and not as a disease in its own right. We agree it is important for healthcare professionals to regularly assess patients' levels of pain and provide pain relief in a timely and appropriate manner to effectively manage their pain and give the patient the best quality of life possible by balancing minimal medication side effects with effective pain control.	Thank you for your comment.
508	Grünenthal	NICE	QS5	6	Grünenthal believes draft quality statement five should make explicit reference to the importance of pain relief and reflect the wording of the full guidance document (Section 4.1.17, page 24) which states that patients' pain levels should be assessed and addressed regularly by healthcare professionals. It is not enough for healthcare professionals to	Thank you for your comment. This quality statement has been changed to reflect the need for pain assessment.

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					assess patients' needs and psychological concerns without providing tailored services to meet their needs. The balance between side effect and effective pain control requires to be met. While the full guidance document acknowledges this point, we believe the current wording of the draft quality statement fails to reflect that. As a result, we would like to see the wording for the draft quality statement amended as follows: "Patients regularly have their needs (such as nutrition, hydration, levels of pain and personal hygiene) and psychological concerns (such as fear and anxiety) assessed and treated appropriately in an environment that maintains their dignity and confidentiality. The patient should have a personalised Pain management plan which strikes the balance between medication side effects and optimal pain relief so that the patient can maintain a good quality of life".	
639	Grünenthal	NICE	1.2.10	11	Grünenthal welcomes the emphasis given to pain relief in the draft NICE guidance as one of the essential requirements of patient care. We agree it is important for healthcare professionals to regularly assess patients' level of pain and provide pain relief in a timely manner.	Thank you for your comment
890	Grünenthal	QS	QS5	3	Grünenthal thinks it is important that quality statement five makes explicit reference to the importance of pain relief and reflects the wording of the full guidance document (Section 4.1.17, page 24) that pain relief should be one of the essential requirements of care. As a result, we would like to see draft quality statement five amended as follows:	Thank you for your comment. The quality standard has been changed to reflect this.

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					"Patients regularly have their needs (such as nutrition, hydration, levels of pain and personal hygiene) and psychological concerns (such as fear and anxiety) assessed and treated appropriately in an environment that maintains their dignity and confidentiality The patient should have a personalised Pain management plan which strikes the balance between medication side effects and optimal pain relief so that the patient can maintain a good quality of life".	
1046	Grünenthal	QS	QS5	11	Grünenthal welcomes the reference to pain relief in the description on what this quality statement means for patients. However, as set out above, we would like draft quality statement five to read as follows: "Patients regularly have their needs (such as nutrition, hydration, levels of pain and personal hygiene) and psychological concerns (such as fear and anxiety) assessed and treated appropriately in an environment that maintains their dignity and confidentiality. The patient should have a personalised Pain management plan which strikes the balance between medication side effects and optimal pain relief so that the patient can maintain a good quality of life". .	Thank you for your comment. This has been corrected to include this.
1047	Grünenthal	QS		11	Grünenthal thinks the section on existing indicators needs to be amended to ensure all relevant questions from the NHS inpatient survey to this particular quality statement are referenced in the document. Questions 47 and 48 from the section 'Your care	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance.

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					and treatment' of the NHS inpatient survey are of relevance to the indicators already listed on page 11 of the document. These questions ask whether the patient was in pain when entering a hospital and if the hospital staff did everything they could to help control their pain. As a result, we would like to see these two questions referenced in addition to the questions already mentioned as indicators for quality statement five.	
68	Hertfordshire Community NHS Trust	FULL	General	General	Recommendations assist in providing prompts for the areas to consider in the QS, when setting qualitative measures.	Thank you for your comment
351	Hertfordshire Community NHS Trust	FULL	9.2.3	60	Offer people with RA an annual review to: RA is not covered in the abbreviations – not shown anywhere that this means rheumatoid arthritis – not clear for a non-medic	Thank you for your comment. This refers to people with Rheumatoid Arthritis and has now be spelled out in full.
448	Hertfordshire Community NHS Trust	NICE	General	General	Style and format is fine. Overall document is easy to follow and read. Laid out well, detailing QS against individual statements is useful in enabling the referencing.	Thank you for your comment
449	Hertfordshire Community NHS Trust	NICE	General	General	Not sure safety is addressed in detail – what about efficacy and what about effectiveness?	Thank you for your comment. The definition of Quality used by the National Quality Board includes three domains: effectiveness, safety and patient experience. This guidance is covering patient experience in generic terms only. Areas specific to patient experience of individual conditions will be included in topic specific guidance as will safety and effectiveness.
450	Hertfordshire Community	NICE	General	General	Patient experience – what about mobility issues and what about menu choice at mealtimes?	Thank you for your comment, the developers believe this is too great detail for inclusion in this guidance.

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	NHS Trust					
509	Hertfordshire Community NHS Trust	NICE		6	Quality statement 1 – is this appropriate? Too vague – what is the specific guideline – is it part of the annual assessment audit programme?	Thank you for your comment. The full name of the guidance has been included and GDG members recognised the importance of implementation of this guidance into annual processes at an individual and organisational performance level..
510	Hertfordshire Community NHS Trust	NICE		6	Quality statement 3 – what is 'health beliefs' – is this a universally recognised statement/wording? What does it mean? Should it be 'health understanding'? Add in what has been written in paragraph 1.1.4 instead.	Thank you for your comment. This is a commonly used phrase in NICE guidance relating to the individuals personal beliefs about their own health.
511	Hertfordshire Community NHS Trust	NICE		6	Quality statement 4 – reword 'culture'	Thank you for your suggestion, this has been amended.
512	Hertfordshire Community NHS Trust	NICE		6	Quality statement 6 – change to healthcare team for their healthcare pathway and episode of care – do we need to define healthcare team?	Thank you for your suggestion. This statement has been changed to say all healthcare professionals involved in their care.
513	Hertfordshire Community NHS Trust	NICE		6	Quality statement 8 – what about the safety of treatment, medicines, drugs, medicines management etc to include 'SAFETY' domain……change to patients' INFORMED right to choose …….supported following inclusion of all information e.g. Side-effects, risks etc	Thank you for your comment. We agree that safety is important. We had however to limit the areas we were able to consider.
514	Hertfordshire Community NHS Trust	NICE		6	Quality statement 9 – what about access? Define what access is? Add in relation to services commissioned to actually deliver it.	Thank you for your comment. The quality standard has been changed to reflect this.
515	Hertfordshire Community NHS Trust	NICE		6	Quality statement 10 – how do you measure this and how easy is it to get this information? Provide further clarity re agreed nationally agreed metrics	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National

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						Quality Board and when it is established from the NHS Commissioning Board.
516	Hertfordshire Community NHS Trust	NICE		6	Quality statement 11 – add in 'at each point of care delivery'	Thank you for your suggestion.
517	Hertfordshire Community NHS Trust	NICE		6	Quality statement 13 – how do you measure/ensure this? Who is defining competency? Is this left to individual authorities or health professional bodies/council? Change to demonstrating an awareness of their impact or efficacy of communication skills	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
518	Hertfordshire Community NHS Trust	NICE		6	Quality statement 14 – very similar to statement 13 – get rid of statement 13	Thank you for your comment. The GDG reduced the number of statements in the final quality standard.
552	Hertfordshire Community NHS Trust	NICE		7	Quality statement 15 – combine with Quality statement 8. Quality statement 8, 15, 16 are very similar. Quality statement 15 – add in metrics of understanding and right to decline information. Define 'shared decision-making' - what is meant by this term?	Thank you for your comments. An explanation of shared decision making can be found in the glossary of the guideline.
553	Hertfordshire Community NHS Trust	NICE		7	Quality statement 17 – is it expected that the national or locally adapted patient decision support tools are applied? Define 'high-quality'	Thank you for your comment. This statement has been removed.
589	Hertfordshire Community NHS Trust	NICE	1.2.3	9	What about a patients' capacity to make a decision – check patients' mental capacity and ability to understand. Need a statement about this earlier in the document re mental capacity etc as we see this appear in 1.3.8/1.3.10	Thank you for your comment. This is addressed in recommendation 31.
611	Hertfordshire Community	NICE	1.2.7	10	Should it be Health Care 'TEAM'	Thank you for your comment. This recommendation has been left as healthcare professionals as it was felt it is these people

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	NHS Trust					that need such training.
705	Hertfordshire Community NHS Trust	NICE	1.5.2	14	Maintaining eye contact in certain groups/cultures can be construed as hostile behaviour. Maybe use the phrase maintain 'APPROPRIATE' eye contact. Also what is meant by appropriately covered – use 'ensure patients' dignity is maintained.'	Thank you for your comment. We have amended the recommendation as you suggest.
723	Hertfordshire Community NHS Trust	NICE	1.5.10	15	Need to align awareness/competency in national agreement and competence training and who determines this?	Thank you. Competency training in communication is already present in undergraduate curricula. Operationalising this recommendation can only happen at a local commissioning level.
756	Hertfordshire Community NHS Trust	NICE	1.5.22	17	Should treatment specify medication, and should risks mention any safety efficacy issues?	Thank you for your comment. The GDG believe this is covered by the existing recommendation under discussions of the "treatment".
771	Hertfordshire Community NHS Trust	NICE	1.5.26	18	If all the different information is to be conveyed – is there an agreement as to the level of understanding that all patients have regarding numerical presentation of data?	Thank you for your comment. It is not intended that the information is conveyed in all of those formats, but rather it should be conveyed in accordance with those principles.
772	Hertfordshire Community NHS Trust	NICE	1.5.28	18	Change to the principle of shared decision-making BELOW. Decision-making is down to the patient or the patients' advocate to make the decision on behalf of the patient.	Thank you for your comment. Refinement to recommendations addresses this.
1071	Hertfordshire Community NHS Trust	QS	6	12	Add in 'involved in their care' in the quality statement.	Please see amended wording above
1098	Hertfordshire Community NHS Trust	QS	7	13	No mention of the patient's 'capacity' to make this decision.	Thank you for your comment. The GDG has re-focused this statement to emphasise shared decision making which by implication accounts for capacity.
1208	Hertfordshire Community	QS	13	20	'Demonstrated competency' is open to wide ranging interpretation. Is there a national agreed measurement for determining competency in	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.

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	NHS Trust				communication?	
1222	Hertfordshire Community NHS Trust	QS	14	21	Statement similar to 13,could elements from both not be combined to form 1 standard.	Thank you for your comment. The GDG included one statement on training of staff in the final version.
69	HTA – Referee 1	Full	general	general	The group used existing economic evaluations to consider the economic aspects of two areas, midwife-led care and decision aids. A cost impact analysis for patient education programmes would have been very useful, but was not provided.	Thank you for your comment. This guideline did not seek to make recommendations about whether or not patient education programmes should be provided because effectiveness and cost effectiveness will vary by intervention and condition (for example, people with more severe conditions may be more willing to make behavioural changes) and so this consideration is best retained within condition-specific guidelines. In this review we therefore aimed to undertake a focused search to explore whether there was evidence about generic components of patient education programmes that improve patient-related outcomes and are transferable across disease populations. An economic search was not be undertaken for this review question as useful cost effectiveness analysis would not be able to be performed for generic components and disease specific analyses would not be generalisable. This approach has been clarified in section 3.6 (Methods) and section 10.5 (Education programmes). The recommendation made is to ensure that patient's are informed about existing programmes and as such was considered to have minimal economic implications.
70	HTA – Referee 1	Full	general	general	A list of key areas for further research at the end of the guideline would be useful.	Thank you for your comment. The guidance was developed using high level systematic reviews in prioritised areas only and not

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						detailed search strategies. In this context it did not seem appropriate to develop detailed research recommendations.
71	HTA – Referee 1	Full	general	general	I found the summary evidence tables difficult to follow. For example, in which direction were the effect sizes identified in Table 13? In what units are the incremental costs in Table 14 (e.g. cost per what?). It would be helpful to highlight the outcomes that were statistically significant, particularly as OR, RR and MD are used interchangeably where for OR and RR the 'line of no effect' is at RR=1, while for MD this is at 0.	Thank you for your comment. More detail about the direction of effect has been added to the full guideline. In Table 14 the cost per what has been clarified.
72	HTA – Referee 1	Full	general	general	Please give p-values if not significant, rather than NS	Thank you for your comment. It is NICE convention to report information about the size of effect with confidence interval (which indicates whether it was statistically significant or not). P values are commonly misinterpreted as evidence of effect, whereas it actually addresses the question of whether the intervention effect is precisely nil.
73	HTA – Referee 1	Full	general	general	3.1 How far are the recommendations based on the findings? Are they a) justified i.e. not overstated or understated given the evidence? b) Complete? i.e. are all the important aspects of the evidence reflected? No comments	Thank you for your comment
74	HTA – Referee 1	Full	general	general	3.2 Are any important limitations of the evidence clearly described and discussed? No comments	Thank you for your comment. The limitations of the Warwick scoping study are included in the report in appendix B.
75	HTA – Referee 1	Full	general	general	There are a few typos in the report (including p>0.05 instead of p<0.05).	Thank you for your comment. We will endeavour to correct any typos or errors identified.
76	HTA – Referee 1	Full	general	general	Please see my comments above regarding individual Figures and the evidence tables.	Thank you for your comment
77	HTA –	Full	general	general	4.2 Please comment on whether the research	Thank you for your comment. The guidance

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	Referee 1				recommendations, if included, are clear and justified. As noted above, a separate section on research recommendations would be very helpful.	was developed using high level systematic reviews in prioritised areas only and not detailed search strategies. In this context it did not seem appropriate to develop detailed research recommendations.
78	HTA – Referee 1	Full	general	general	I have been asked to focus on the methodology of this report, which appears to be thorough given the timeframe in which the group was working. My only real niggle is that cost-effectiveness does not seem to have been given much consideration (e.g. improving patient nutrition would not be cost free, but may well be cost-effective). I also believe the structure of the report could be improved, which would make it much easier to see how all the individual components of the study fit together.	Thank you for your comment. The approach taken to considering cost effectiveness and rationale are outlined in Section 3.1.1. Where a review of the clinical literature for alternative interventions was undertaken a parallel review of the economic literature was also undertaken. Given the broad and generic nature of the guideline useful original cost-effectiveness analysis was not considered feasible. For all recommendations economic considerations have been noted in terms of whether there is likely to be additional costs and whether there may be cost or health offsets. In many places it was considered that the recommendation was clearly a minimum expectation of what type of patient experience is acceptable, which is not necessarily to do with improving 'health' and where this was the case this has been noted. To take the example you have given about nutrition, it was considered that ensuring adequate nutrition and hydration was clearly a fundamental aspect of care and not one that needed justifying on health improvement grounds.
79	HTA – Referee 1	Full	general	general	Many of the recommendations overlap with existing professional guidelines, such as Tomorrow's Doctors and it would be helpful to note these links.	Thank you for your comment. We are aware that many of the recommendations overlap with existing professionals codes. NICE are currently considering what implementation support to provide for this guidance

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136	HTA – Referee 1	Full	2.5	14	While reading the introduction on page 48 I was reminded why aspects of care such as patient safety/hand washing were not included. It would be useful to include this in the section on what the guideline does not cover.	Thank you for your comment. We have added further detail to the section on what the guideline does not cover.
144	HTA – Referee 1	Full	3.1	16	I found Figure 1 very hard to understand. Undoubtedly a significant amount of work has been undertaken to produce this guideline, but I was unclear of the hierarchy of the process (e.g. what fed into what). I wondered if existing NICE recommendations would have been helpful in the development of the framework.	Thank you for your comment. Section 3.1 has been amended for clarity. The GDG drew on each of the key evidence sources to develop recommendations. These recommendations were then used as the basis of the quality standards. The framework was based on the narrative review, and cross checked against the themes identified in the existing NICE recommendations.
147	HTA – Referee 1	Full	3.5	17	The group did not include Public Health guidance in its review of existing NICE recommendations. While I doubt that any patient experience themes were missed as a result, it would have been useful to know the group's rationale for this.	Thank you for your comment. It was anticipated that the recommendations in the public health guidance would be too general and that we would reach saturation when identifying key themes in the clinical guidance without needing to review those in the public health guidance.
151	HTA – Referee 1	Full	3.6.1	18	It would be helpful to know why these, and not other, review questions were chosen. I understand why the reviews aimed at identifying only systematic reviews, but this needs to be made clear. Why was cost-effectiveness only included in one review question (although it was considered in two)? The review question on continuity of care is not matched by the review that took place, which only considered midwife-led care. I am uncertain as to whether the continuity of midwife-led care can be generalized to other models of care (this is acknowledged on page 69).	Thank you for your comment. Reviews were prioritised by the GDG. They were selected taking into consideration the areas that were important to the group but also where evidence was expected to be identified that could inform GDG decision making. We have additional added text to this effect to section 3.6. The continuity of care review question has been amended to include cost-effectiveness – this was an accidental omission. The rationale for not including cost effectiveness in the other review questions has been clarified in the review protocols/methods

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						section. The continuity of care review protocol and methods section has been amended to reflect the protocol amendment to focus on midwife led care.
154	HTA – Referee 1	Full	3.6.3 3.6.4	19	Only one researcher was responsible for key decisions within each review. This is understandable given the time constraints.	Thank you for your comment.
285	HTA – Referee 1	Full	5.2	29	How did the group decide that an existing framework had been "influential"?	Thank you for your comment. The description of frameworks as influential is a subjective judgement but is based on the widespread use of these frameworks in health systems worldwide.
293	HTA – Referee 1	Full	5.3	35	Why was the IoM framework chosen as the focus?	Thank you for your comment. The IOM Framework was chosen as it is commonly used by a range of organisations including the Kings Fund. A comparison of frameworks undertaken as part of the development of NICE Guidance demonstrated the similarity in content between many of the existing frameworks. The aim of using the IoM framework was to structure the thematic abstraction and analysis of data by enabling a critique of the IOM dimensions. Other frameworks are likely to have worked in a similar way in terms of aiding the analysis.
300	HTA – Referee 1	Full	5.5	42 -43	It would be helpful to have a diagrammatic mapping of the seven outcomes shown in Figure 2 to the five themes shown in Table 8.	Thank you for your comment. We have added a table to indicate the relationship.
389	HTA – Referee 1	Full	10.4.1.5	102	Table 33 – does it matter what the comparator was?	Thank you for your comment. The comparator was usual care. This has been added to the table heading.
410	HTA – Referee 1	Full	10.5.1.3	111	It is a shame that no economic review was undertaken for patient education programmes since these potentially have a large impact on	Thank you for your comment. This guideline did not seek to make recommendations about whether or not patient education programmes

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					costs.	should be provided because effectiveness and cost effectiveness will vary by intervention and condition (for example, people with more severe conditions may be more willing to make behavioural changes) and so this consideration is best retained within condition-specific guidelines. In this review we therefore aimed to undertake a focused search to explore whether there was evidence about generic components of patient education programmes that improve patient-related outcomes and are transferable across disease populations. An economic search was not undertaken for this review question as useful cost effectiveness analysis would not be able to be performed for generic components and disease specific analyses would not be generalisable. This approach has been clarified in section 3.6 (Methods) and section 10.5 (Education programmes). The recommendation made is to ensure that patient's are informed about existing programmes and as such was considered to have minimal economic implications.
80	HTA – Referee 2	Full	general	general	Focussing on individualisation of care risks ignoring the critical aspect of patients' embeddedness in social networks. It is laudable that the report recognises the importance of families and friends in relation to 'lived experiences', but little is discussed as to how this might be incorporated into the guidelines.	Thank you for your comment. The remit of the guidance is for generic patient experience of care in NHS settings but we have recognised the broader aspects of networks through the section on a patient as individual. There are elements within some of the recommendations that consider the patient's family and friends. However, the focus of the guideline is still on the individual patient.

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123	HTA – Referee 2	Full	5.1.2.b	4	Very limited attention given to the role of carers in relation to patients' experiences	Thank you for your comment. We agree that the needs of carers are important and that attention to carers can be a significant influence on patient experience. We had however to limit the areas we were able to consider.
126	HTA – Referee 2	Full	1	10	The concept of patient satisfaction has been researched over a period of 50 years in the NHS (McGhee, 1961). While some commentators, such as Paul Clearly, maintain that it is a defective indicator of quality, the evidence is unsubstantiated. Part of the problem is the way in which satisfaction is understood and also the methods used to measure it. For most scholars using the concept, the term is a shorthand for patient evaluation of quality, as expressed in an affective way. Measures that simply ask patients to 'report' exclude the key aspect of patients doing the evaluation.	Thank you for your comment. There is evidence of satisfaction as a flawed concept which is more likely to pick up on patient's feelings of gratefulness. We would not advocate use of this concept. There are difficulties with the methods used to evaluate care but these are linked to the poor concept of satisfaction and not being nuanced enough to capture the complexities of evaluation. Evaluation should include both cognitive and affective aspects, whereas the Cleary approach primarily focused on cognitive. We agree more focus is needed on developing our understanding of patient evaluation and robust instruments to measure it.
140	HTA – Referee 2	Full	3.1	15	While there inevitably needs to be some way of making the review manageable within the time and resource constraints, it is not clear why, in the qualitative scoping study, the 'disease areas' were all chronic conditions, rather than having a spread of acute/chronic conditions and maybe one that is not a disease; e.g. maternity care. The (weak) claim for generalisability is made in Section 5.3 (p35).	Thank you for your comment. They were selected as three key areas of significant disease burden which include chronic and acute patients likely to have had a range of experiences of the NHS. For example diabetes includes patients with chronic conditions. However, many of the cardiac studies included patients with acute conditions. We aimed to get a spread of experiences across the three areas but do acknowledge some limitations in that the study could not be extended to a wider range of conditions. The aim was to draw from

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						across the three areas to identify the dimensions or aspects of experience that apply to all three patient groups and to extrapolate to all patients. This extrapolation was tested in two main ways – through comparison with other frameworks of patient experience to provide a form of validity check (many aspects were similar) and through the consensus process where the GDG tested the robustness of the Warwick framework through their discussion.
163	HTA – Referee 2	Full	4.1.6	23	Avoiding assumptions about aggregations of patients is important, but, at the same time, socio-demographic factors should sensitise staff to a number of related issues; i.e. don’t assume, but don’t ignore either.	Thank you for your comment. We have included recommendations to ensure that NHS staff are aware of patients as individuals and take other factors such as work/domestic and social circumstances into account.
226	HTA – Referee 2	Full	4.1.30	25	Respect should also be given to patients who do not wish to choose (e.g. Thompson, 2007. Soc Sci & Med 64 (6), 1297–1310).	Thank you for your comment.
227	HTA – Referee 2	Full	4.1.42	25	Jargon is fine if it is mutually understood, as it is an efficient way to communicate. The need is to check if it is mutually understood.	Thank you for your comment. We have altered this recommendation to clarify this.
252	HTA – Referee 2	Full	4.1.52 & 10.3.2	26 & 78	Sorry to be pedantic, but while ‘verbal’ is colloquially used for speech, it actually means ‘with words’. Perhaps better to use ‘oral’ to distinguish it from written.	Thank you for your comment. We have changed verbal to oral.
277	HTA – Referee 2	Full	4.1.62	27	While adjectives can be interpreted quite differently by different people, so can numerical data (if not more so).	Thank you for your comment.
286	HTA – Referee 2	Full	5.2	29	While the chosen frameworks are very helpful, there is a risk in using a criterion that includes them for the reason that they are influential. The important criteria should be whether they are valid and useful. As recognised later, most of the	Thank you for your comment. We agree, which is why an additional scoping study was commissioned and the GDG used their experience to consider the frameworks.

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					development emanated from inpatient hospital care, which needs to be balanced with other types of care. There is some attention to outpatients, but primary care and community care are less evident (see Bikker and Thompson, 2006. Social Science & Medicine, 63 (6), 1671-1683.).	
291	HTA – Referee 2	Full	5.2.4	34	Shared decision-making is not always desired or appropriate, despite the normative pressure in policy documents (see Thompson (2007) above).	Thank you for your comment. We recognise the complexity of the term shared decision making and the theoretical and practical issues about the concept and its implementation. We are using the term to describe a process of patient involvement rather than an outcome.
295	HTA – Referee 2	Full	5.3	36	More and better information, while often demanded, appears to be rarely used for decision-making, but rather for 'making sense' and feeling in control (see Martin Marshall and others).	Thank you for your comment. We recognise that information is used in a number of ways by patients and not just for decision-making.
303	HTA – Referee 2	Full	5.5	43	Patients do not always wish to be active participants in their health care/strategy. This is recognised later on in Section 10.1 (p71).	Thank you for your comment. The intention is not to impose participation but to enable participation to the extent that the patient wishes.
304	HTA – Referee 2	Full	5.5	43	The first and third themes seem to be so interrelated that it is not clear why they are discussed separately.	Thank you for your comment. The GDG have reviewed the themes and disagree about the overlap between these themes. We acknowledge that the headings are potentially misleading and the GDG have therefore changed the headings to 'Knowing the patient as an individual' and 'Tailoring services for each patient' to more clearly differentiate the themes.
308	HTA – Referee 2	Full	6.2.1	44	It is not clear whether the term 'main theme' is the key underpinning theme of the condition, or whether it is simply the one used to exemplify the issues.	Thank you for your comment. It is used to exemplify the issues.

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310	HTA – Referee 2	Full	6.2.1	45	There appears to be an error here, insofar as 'lived experience' is not as described. The theme is presumably supposed to be 'Responsiveness of services'.	Thank you, the guideline has been amended accordingly.
313	HTA – Referee 2	Full	6.3	46	In the trade off between clinical benefits and harms, there is a need to be mindful of the possibility of undue pressure being placed on patients to be active when they might be unwilling on unready to do so.	Thank you for your comment, the guideline has been amended accordingly.
314	HTA – Referee 2	Full	6.3	46	Under 'other considerations', "…service need to recognise patient individuality" AND their social embeddedness; i.e. family, friends and communities are also important to understand how patients understand and 'experience' care.	Thank you for your comment, the guideline has been amended accordingly.
339	HTA – Referee 2	Full	8.3	55	While services should be tailored to individuals, the key dimension of equity should not be overlooked.	Thank you for your comment
341	HTA – Referee 2	Full	8.3	56	Rec.30: add " or if they decline to choose".	Thank you for your comment. Recommendation 25 addresses this.
409	HTA – Referee 2	Full	10.5.1.3	110	It is not clear what the note to Table 35 means here; i.e. significant at p>0.05. I presume this is a typo.	Thank you. This was a typing error and has been corrected.
26	James Paget University Hospitals NHS Foundation Trust	All	General	General	Our comments are as follows: Further work needs to be undertaken in general to tease out the specific criteria within the broad statements that are made.	Thank you for your observations. Further refining has taken place following consultation.
931	James Paget University Hospitals NHS	QS	1	5	Our comments are as follows: Further clarity is required on how to evaluate compliance with NICE guidance.	Thank you for your comment. Local organisations are free to use local methods to measure compliance if they feel they are suitable. The measures suggested are high level indicators to form the basis of audit

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	Foundation Trust					criteria. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board
932	James Paget University Hospitals NHS Foundation Trust	QS	1	5	Our comments are as follows: Further clarity is required on how to evaluate staff for compliance.	Thank you for your comment. Local organisations are free to use local methods to measure compliance if they feel they are suitable. The measures suggested are high level indicators to form the basis of audit criteria. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and , when it is established from the NHS Commissioning Board
933	James Paget University Hospitals NHS Foundation Trust	QS	1	5	Our comments are as follows: Further clarity is required on how to show evidence of mentoring staff for compliance with the guidance.	Thank you. This will be subject to local service level agreement.
934	James Paget University Hospitals NHS Foundation Trust	QS	1	5	Our comments are as follows: What is meant by 'interacting directly with patients' – further clarity is required.	Thank you for your comment. This refers to those in the NHS who have direct patient contact.
973	James Paget University Hospitals	QS	2	7	Our comments are as follows: What about patients with 'mental health' problems – they may need support to be involved in consultations about their own care (for non mental	Thank you for your comment. This quality statement has been adjusted to reflect this.

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	NHS Foundation Trust				health issues)	
1004	James Paget University Hospitals NHS Foundation Trust	QS	3	9	Our comments are as follows: Regarding numerator and denominator – patients who use NHS services but come in as an emergency and are unable to respond require carers to inform staff of health beliefs etc in order to individualise care so perhaps the statement needs to include patients or carer. The other suggestion is 'where able' could be added.	Thank you for your comment. This change has been made.
1005	James Paget University Hospitals NHS Foundation Trust	QS	3	9	Our comments are as follows: Relevant existing indicators – local surveys performed in-house also need to be included as a valid indicator particularly as the NHS National surveys are small sample sizes.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1022	James Paget University Hospitals NHS Foundation Trust	QS	4	10	Our comments are as follows: Further clarity needs to be given on how to measure these behaviours in staff appraisal.	Thank you for your comment. We expect that this will be agreed with commissioners at a local level.
1048	James Paget University Hospitals NHS Foundation Trust	QS	5	11	Our comments are as follows: Guidance needs to be given on which tools can be used to measure psychological concerns (fear & anxiety) in patients.	Thank you for your comment. Whilst NICE will provide guidance on how quality standards and the associated measures should be used, individual tools such as these can be decided locally.
1072	James Paget University	QS	6	12	Our comments are as follows: Measuring compliance by obtaining patient responses to questions is unreliable as it is based	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used

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	Hospitals NHS Foundation Trust				on memory and during stressful hospital situations research has proved that information is not retained.	by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1073	James Paget University Hospitals NHS Foundation Trust	QS	6	12	Our comments are as follows: How can you measure the proportion of patients introduced to all members of the care team? All members of the 'care team' could include the back room staff e.g. secretary but the patient may not need to be in contact with the secretary so 'all members' is not practical as a measure.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1074	James Paget University Hospitals NHS Foundation Trust	QS	6	12	Our comments are as follows: All members of the care team introduce themselves to patients however it would not be possible to give explanation of role, responsibilities and contribution to care. Generally the introductions would be around " Hello, I'm Ann Another and I'm your nurse and I'll be taking care of you today" .	Thank you for your comment. This has been amended to: All staff involved in providing NHS services should ensure that their name, role and responsibilities are known by the patient before any discussions or consultation take place. Where possible the patient should see the same healthcare professional or healthcare team
1099	James Paget University Hospitals NHS Foundation Trust	QS	7	13	Our comments are as follows: Please clarify what 'First point of contact' means. Is this 'new referrals' or is it the first person to clerk the patient in? Also what about patients being unconscious or unable to speak?	Thank you for your comment. This is an important point to raise. At the first consultation, regardless of care setting the patient's preferences should be noted and form part of ongoing communication between all those who are involved in their care.
1100	James Paget University Hospitals NHS Foundation Trust	QS	7	13	Our comments are as follows: Further clarity is required on how to measure this.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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1116	James Paget University Hospitals NHS Foundation Trust	QS	8	15	Our comments are as follows: Measuring compliance by obtaining patient responses to questions is unreliable as it is based on memory and during stressful hospital situations research has proved that information is not retained.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1137	James Paget University Hospitals NHS Foundation Trust	QS	9	16	Our comments are as follows: Further clarity is required on what training can be given to staff in the tailoring of services to meet patient needs. The statement is unclear.	Thank you for your comment. This has to be agreed with commissioners of service delivery at a local level.
1156	James Paget University Hospitals NHS Foundation Trust	QS	10	17	Our comments are as follows: Using question Q43 & Q68 from the national survey does not reflect views of patients without family / friends and using survey responses to measure achievement is difficult because the response is based on an individual own expectation which may or may not be an appropriate expectation.	Thank you for your comment. These references have been removed.
1169	James Paget University Hospitals NHS Foundation Trust	QS	11	18	Our comments are as follows: Add 'Patients and or carers' are given clear advice – as patients maybe in care homes and it would be the 'carer / care home' who made contact regarding ongoing healthcare needs.	Thank you for your comment. We believe the statement covers this.
1170	James Paget University Hospitals NHS Foundation	QS	11	18	Our comments are as follows: Additional evidence within NHS processors e.g. electronic discharge summary need to be included and not rely only on patient survey responses based on memory.	Thank you for your comment. This does not rely on patient memory. The process measure would be sourced from patient records.

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	Trust					
1209	James Paget University Hospitals NHS Foundation Trust	QS	13	20	Our comments are as follows: Pre-registration training for health professionals includes communication skills training. Please clarify what is required.	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1223	James Paget University Hospitals NHS Foundation Trust	QS	14	21	Our comments are as follows: Additional indicators need to be decided upon that can be used as evidence and not just NHS surveys.	Thank you for your comment.
1263	James Paget University Hospitals NHS Foundation Trust	QS	16	23	Our comments are as follows: Clarity is required around whether this is referring to verbal or written or both. Evidence from surveys would be difficult for emergency patients, we suggest another approach would need to be used, please give guidance or suggestions how this works for 'emergency' care.	Thank you for your comment. This relates to detailed recommendations that says that information should be presented both verbally and in written form.
1287	James Paget University Hospitals NHS Foundation Trust	QS	17	24	Our comments are as follows: Information about and the availability of patient decision aids needs to be centralised and equitable for all ensuring usage is maximised.	Thank you for your comment. Please see reworded statement above.
452	Kent Community Health NHS Trust	NICE	general	general	The QS seem to be more focussed on care delivered in Acute setting particularly in-patient care. The QS will be harder to monitor where a car pathway involves patients moving between acute and community settings.	Thank you for your comment. The Guidance is intended to be generic and would apply to patients moving between care settings.

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519	Kent Community Health NHS Trust	NICE	QS2	6	The QS needs to be clear about whether patients are asked for this information at the assessment stage or at the referral stage, and if at referral whether the duty should be on the person referring (eg the GP) or on the organisation accepting the referral	Thank you for your comment. It is intended that patients will be asked for this information at the starting pint of care. If documented well, this will not have to be repeated.
520	Kent Community Health NHS Trust	NICE	QS5	6	The QS will be much harder to apply in a setting in the patient's own home or when receiving a community service that is not in-patient care. The QS either needs to state that where the assessment takes place in the patient's own home it is not applicable or provide further clarification.	Thank you for your comment. It is felt that such assessment can be taken in a community setting.
521	Kent Community Health NHS Trust	NICE	QS6	6	It will not be practical in a community service to introduce patients to all of the healthcare team. The QS needs either to be reworded to state 'all members of the healthcare team present' or 'the member of the healthcare team who will be the main point of contact during their care or treatment'	Thank you for your comment. The statement has been changed to reflect this 'all healthcare professionals involved in their care'
522	Kent Community Health NHS Trust	NICE	QS12	6	The QS needs to be clearer about what patients can expect. We believe the priority is that the care or treatment plan has continuity and that it is not always possible in for example community nursing for the same nurse to attend every time. The QS should therefore say 'seeing the same healthcare team unless there is a clinical need for the patient to be transferred to another team'	Thank you for your comment. The statement states that the same healthcare professional or team is seen whenever possible, as it is realised that this may not always be possible.
523	Kent Community Health NHS Trust	NICE	QS13	6	The QS will be difficult to monitor as staff may have received training but how they apply this in practice will vary.	Thank you for your comment. It is anticipated that organisations can ask patients whether they were communicated with clearly.
453	Kettering General hospital	NICE	QS 17	General	QS 17 identifies 'decision aids' in the table of Quality Standards but fails to expand on what these are. There is one cross reference for using 'decision aids' but still no example of the tools that	Thank you for your comment. The Quality Standards do not provide further detail in the statements themselves.

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					may be considered	
554	Kettering General Hospital NHS Foundation Trust	NICE	QS 17	7	QS 17 identifies 'decision aids' in the table of Quality Standards but fails to expand on what these are. There is one cross reference for using 'decision aids' but still no example of the tools that may be considered	Thank you for your comment. This statement has been removed.
81	Leeds Community Healthcare NHS Trust	Full	General	General	The statements are clear & relevant. They are also somewhat repetitive however the difficulty will come in how to capture consistent qualitative & quantitative data in order to measure against the standards & who will actually decide what are the appropriate outcome measures on which to check that staff are complying with the standards. The variance in services could be huge!	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
82	Leeds Community Healthcare NHS Trust	Full	General	General	We are concerned there is no mention of joint involvement in the planning of care and setting patient goals for e.g. I want to walk in my garden or I want to be able to go shopping.	Thank you for your comment. We have tried to convey the importance of partnership between clinicians and patients, as we agree this is a key aspect of the Guidance.
83	Leeds Community Healthcare NHS Trust	Full	General	General	We are concerned that there is no mention that 'real time 'feedback should be collected on a regular basis for e.g. via monthly survey.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
946	Leeds Community Healthcare NHS Trust	QS	1	6	Our comments are we recommend there is a definition of what is an adult service i.e. an age group.	Thank you for your comment. Adult service is defined as services used by those over the age of 16 years old.
1210	Leeds Community Healthcare NHS Trust	QS	13	20	Our comments are that we are concerned about what will be the communication competency and how this will be measured	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.

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1288	Leeds Community Healthcare NHS Trust	QS	17	24	Need to define what is a high quality decision support tool	Thank you for your comment. Please see reworded statement above.
27	Liverpool PCT	All	General	General	No mention of basic Human Rights or relevant Legislation	Thank you for your comment. The GDG recognised the importance of human rights in relation to healthcare and were content to ensure that care interventions are shaped by the healthcare professional's codes of professional conduct. The recommendations are developed in line with Equality and Diversity legislation.
28	Liverpool PCT	All	General	General	Whilst it may not have been within the remit of the guidance, the importance of disaggregating data by Equality Target groups does not appear to feature in evaluation of surveys. Whilst the documents notes that equality issues maybe barriers, it is important to understand the patient experience may have a significant differential impact due to belonging to a particular group/community. Patient experience surveys have shown that BME groups, in general, report a worse experience of treatment and care, choice, information, access and waiting.	Thank you for your comment. We recognise that who you are and how you are perceived has a significant impact on experience. For this reason one of our main themes concerns recognising who the patient is. NICE are currently considering what implementation support to provide for this guidance
29	Liverpool PCT	All	General	General	The guidance doesn't mention the newer protected groups (LGBT, religion, carers, etc…) and it doesn't really give any functional guidance or pointers as to what is expected in terms of minimal good practice. Given that who you are, how you are perceived, and a patient's cultural experiences and expectations are central to expectations of what constitutes a good contact with clinicians and health workers, this would seem to be a major	Thank you for your comment. Guidance and quality standards are intended to be aspirational and not minimal good practice. The guidance does not prescribe how a service should be delivered but what patients should expect.

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					systemic omission. It would be good to see the main document illustrated with some examples from across all groups. Given that there is ample evidence of poor experience among so many protected groups this is a major weakness and undermines the supposed goal of the guidance.	
44	Liverpool PCT	All.	General	General	Has an equality impact assessment been conducted and published to accompany NICE clinical guidelines and quality standards.	Thank you for your comment. An equality impact assessment form is published with all NICE guidance.
837	Liverpool PCT	QS	General	General	The reference to structure in the draft quality measures should be strengthened to provide evidence of implementation of local arrangements.	Thank you for your comment.
838	Liverpool PCT	QS	General	General	We are unclear as to how GP's and other independents would be measured on this? How does the development of this NICE guideline link into the new primary care Direct Enhanced Service Specification for Patient Participation?	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board.
839	Liverpool PCT	QS	3	General	This standard is already in the CQC Essential Standards of Quality and Safety (Outcome 1) What benefit do we get from asking this again? Asking providers to repeat work can be counter productive.	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance
840	Liverpool PCT	QS	8	General	This standard is covered by Outcome 2 of the CQC Essential Standards of Quality and Safety. What benefit do we get from asking this again?	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance
841	Liverpool PCT	QS	General	General	The Patient Experience Quality Standards set out here generally have clear and understandable	Thank you for your comments.

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					concepts and definitions. The Quality Statements could be strengthened by being as specific as possible for example QS 1 states "Healthcare professionals and all other staff who interact directly with patients" this could read all staff or all public facing staff. To make Quality Standards more accessible you may wish to group standards together in the three domains of quality or by type e.g. communication, workforce, clinical quality, etc. If we were to implement the standards within the NHS Contract we would aim for a 1-2 year implementation plan with improvement trajectories. Some of the standards would take time to setup. For example changes to trust IT systems and training. Trusts would not accept a 100% achievement measure and we would not want to set Trusts unachievable targets. Some of the Quality Standards require input from patients which will not always be possible, e.g. trauma patients. For these standards we would need to establish exclusion criteria and agreed achievable targets. The majority of the Quality Standards outlined rely on the National Inpatient, Outpatient or Emergency Department survey results for monitoring and outcomes. In some cases, the specific questions from the surveys are a loose fit to the Quality Standards and do not give a suitable answer to the question and requirement set by the Quality	We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance Furthermore, we expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					Standard. For example QS 8. The descriptions of what the quality standards mean for each audience give clear instruction to each party. However, as commissioners we would look for a monitoring process to ensure delivery over the contract year. We would want to see how a provider aims to achieve set miles stones with action plans Improvement trajectories and innovative methodologies.	
884	Liverpool PCT	QS	Scope	1	Scope – We are not clear why this does not cover people who use mental health services, or carers. Consultation and Involvement from Mental Health Charities i.e. MIND, is needed for a view. Rational for decision needs to be clear, could be seen as a breach under Disability Equality. User involvement is noted within the specific duties with regard to Disability. Using mental health service users and carer experience has been found to be an effective way is expelling myths and fears of mental health services and improving experience and satisfaction.	Thank you for your comment. A separate guideline (Service User Experience in Adult Mental Health), is being developed and will be available at the same time.
887	Liverpool PCT	QS	Diversity Equality and Language	2	This section could be strengthened with the Equality duties, and make specific reference to other "protected characteristics" as described within the Act. I.e. Lesbian Gay Transgender Community.	Thank you for your comment. The section has been updated to reflect this.
1264	Liverpool PCT	QS	16	23	Mentions understandable, but fails to mention information being accessible, responsive or appropriate.	Thank you for your comment.
1289	Liverpool PCT	QS	17	24	[Also NICE 1.5.27, page 18] If NICE are recommending the use of decision support tools then they should specify some tools and aids that they have reviewed as part of this process and	Thank you for your comment. Please see reworded statement above. Those accredited are available for use on the NHS Direct website:

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					deem fit for use.	http://www.nhsdirect.nhs.uk/DecisionAids
30	Lundbeck	All	General	General	Recommendation 22 in 'Tailoring healthcare services to the individual' in the patient experience in generic terms NICE guideline: 'Tell the patient about health and social services that are available (for example, smoking cessation services), and encourage them to access these according to their individual needs' would benefit from inclusion of alcohol services as an example alongside smoking cessation. There is a substantial body of evidence in NICE guidelines (PH24, CG100 & CG115) supporting screening, brief interventions and specialist treatment services for people drinking above recommended limits or with alcohol dependency. The revised recommendation would be 'Tell the patient about health and social services that are available (for example, smoking cessation and treatment of alcohol-related harm services), and encourage them to access these according to their individual needs'. Lundbeck would also support inclusion of this specific recommendation within quality statement 9 or 15 of the patient experience in generic terms QUALITY STANDARD.	Thank you for your comment. This recommendation has been rewritten and all examples removed to ensure applicability. Thank you for your request to include it in the quality standards. Unfortunately we have not been able to include it as we were limited in the number or quality standards that we could have.
842	Lundbeck	QS	General	General	Lundbeck suggest that recommendation 13 in 'Essential requirements of care' in the patient experience in generic terms NICE guideline: 'If anxiety disorder or depression is suspected, follow the appropriate stepped-care model	Thank you for your comment. We agree that this is important; however we are limited in the number of quality statements we are able to produce.

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					recommended in: • 'Generalised anxiety disorder and panic disorder (with or without agoraphobia) in adults' (NICE clinical guideline 113) or • 'Depression' (NICE clinical guideline 90) or • 'Depression in adults with a chronic physical health problem' (NICE clinical guideline 91)' is an additional quality statement in the patient experience in generic terms QS or included in the description of quality statement 9. This will help ensure depression and anxiety, which are commonly coexisting conditions, are routinely managed in all healthcare settings according to the NICE guidelines.	
891	Lundbeck	QS	General	3	Lundbeck fully support the requirement that 'services are commissioned from and coordinated across all relevant agencies encompassing the whole spectrum of patient care. An integrated approach to provision of services is fundamental to the delivery of high quality care to patients'. The importance of an integrated approach was highlighted in the recent 'listening exercise' for the NHS reforms and will help ensure secondary prevention services for public health priorities such as screening and brief interventions for alcohol misuse are commissioned and funded in primary care settings.	Thank you for your comment.
1117	Lundbeck	QS	Statement 8	15	Lundbeck support the inclusion of this quality statement – 'Patients' rights to choose, accept or decline treatment are respected and supported'. We believe it would be usefully supported by	Thank you for your comment

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					including recommendation 21 from the generic terms NICE guideline 'Give the patient information about relevant and available treatment options, even if these are not provided locally' as an additional quality statement or incorporated into statement 8.	
1265	Lundbeck	QS	Statement 16	23	Lundbeck support the inclusion of this quality statement - 'Patients are provided with evidence-based information that is understandable, personalised and clearly communicated'.	Thank you for your comment.
414	MacMillan Cancer Support	Full & NICE	General	General	Macmillan welcomes this NICE guidance and believes that overall it rings true with the comments and concerns raised to us by people affected by cancer. However, we were extremely disappointed by the short timescale given to respond to this consultation, particularly as it limited our ability to engage with people affected by cancer who are the true experts on patient experience. We would like to highlight work that Macmillan Cancer Support is undertaking to improve patient experience that complements these recommendations and quality standards. By identifying 'moments that matter' to both patients and professionals, Macmillan has developed a set of behaviours or 'quick win' actions that staff can easily apply to their every day work. The outcome of applying these behaviours will significantly improve both patient experience and the vocational satisfaction of staff. These behaviours form part of a national Standard that improves patient experience through the practical application of human rights principles, such as dignity and	Thank you for your comment and information. We agree that the timescale for the development of this work was short. NICE was requested by Department of Health and National Quality Board to produce initial guidance on generic patient experience within a short timeframe.

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					respect. The importance of achieving these basic, but essential, entitlements has been highlighted in a recent report by the Parliamentary and Health Services Ombudsman. (Care and Compassion? February 2011). We have attached a short briefing with this submission that gives more details about the standard and our work.	
415	MacMillan Cancer Support	Full & NICE	General	General	We are also very disappointed that a recommendation has not been included that states explicitly the need to provide patients with information that covers all their holistic needs, and not just clinical. Patients also require information on practical, emotional, social, spiritual and financial matters. These needs are acknowledged in recommendation 1.1.7 but there is no reference to providing information on these issues later in the guidance. We suggest including a recommendation: Patients are provided with information at key points before, during and after treatment, which covers a range of relevant issues including clinical, practical, financial and emotional.	Thank you for your comment. The GDG did not think that all professionals should be able to provide information on practical, emotional, spiritual and financial matters but that they should be aware of how people might access this information and support. We have added to the recommendation to include this.
416	MacMillan Cancer Support	Full & NICE	General	General	There appears to be strong bias within these recommendations (and hence quality standards) towards inpatient care. Obviously the patient experience of primary and community care is of equal importance, particularly as the majority of patients will have more frequent interactions with these services. As such, the recommendations and standards tend towards treatment or interventions more commonly the focus of secondary care; as opposed to the management of a condition or the maintenance of quality of life. We suggest that more emphasis be given to	Thank you for your comment. The guidance is not intended to be geared towards inpatient care and we agree about the importance of patient experience of primary and community care. To be able to develop generic guidance we have concentrated on staff- patient interactions particularly. We recognise the importance of communication and support to help patients to manage their conditions and sustain quality of life. We have indicated to NICE the importance of self management as a topic and have been assured that this will

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					communication and support helping patients to manage their conditions and sustain quality of life.	be raised with the National Quality Board.
563	MacMillan Cancer Support	NICE	1.1	8	While we strongly agree with the recommendations 1.1.1 to 1.1.4, we believe these recommendations are too passive. We believe that health professionals should not only 'consider' or 'be aware' but should also be required to act accordingly. For example recommendation 1.1.2 should read: Ensure that factors such as physical or learning disabilities…are addressed so that the patient is able to participate as fully as possible in consultations and care.	Thank you for your comment. Some of the recommendations have been amended to make them more active, adding for example 'and treat' 'and take into account'.
564	MacMillan Cancer Support	NICE	1.1.3	8	We were pleased to see 'work situation' included in the factors that should be considered in recommendation 1.1.3. However, we would recommend that healthcare professionals also consider how the patient's health condition will impact upon their domestic, social and work situation.	Thank you for your comment, this is too much detail for inclusion in this guideline., however, recommendation 1 mentions "Understanding of how the condition affects the person, and the person's circumstances", which can include all the factors you mentioned.
590	MacMillan Cancer Support	NICE	1.1.6	9	We suggest that recommendation 1.1.6 should include sexual preference and should therefore read: Avoid making assumptions about the patient based on their • Culture, ethnic origin or religious beliefs • Age, gender, sexual preference, educational level or socioeconomic status • Disability or health status	Thank you for your comment. . We have replaced this recommendation with reference to the Equalities Act to ensure we have not omitted any individuals or groups.
591	MacMillan	NIC	1.1.7	9	We strongly support the inclusion of	Thank you, the guidance is generic and so

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	Cancer Support	E			recommendation 1.1.7. We are particularly pleased to see financial circumstances included. This is especially important since the 2010 National Cancer Patient Experience Survey showed only 50% of those who wanted financial information were given any.12 However, we believe some crucial amendments need to be made to this recommendation to ensure that it guides commissioners and providers to provide high-quality care and support for patients. We believe that assessment and care planning should be done throughout a patient's journey. The idea of ongoing assessment, with written care plans detailing interventions to be made, is supported by the NICE Supportive and Palliative Care Guidance (#1.16 – #1.21).13 We would also like to see employment circumstances included in the list of key points that should be assessed and discussed regularly in recommendation 1.1.7. Over half of people with cancer surveyed (52%) who were in work at the point of diagnosis stated that they were not informed by a health professional about the impact their cancer diagnosis might have on their working lives.14 Many people with cancer would like to continue to work or return to work after their treatment has ended but require support and advice to do so.	needs to cover patients who are not receiving ongoing care. We have concentrated the guidance on generic issues. Recommendation 1 recommends that an understanding of the patient as an individual is required and this includes how the condition affects the person. This includes all aspects of patient's life including employment. We include need for psychological, social and financial support and regular review of these in recommendation 7. .

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[12] Department of Health (2010). *National Cancer Patient Experience Survey.*
[13] NICE Supportive and Palliative Care Guidance 2004.
[14] YouGov online survey of 1,740 UK adults living with cancer, (2010)).

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					We therefore suggest recommendation 1.1.7 should read: Assess and discuss the patient's physical, psychological, domestic, social, spiritual, employment and financial circumstances on a regular basis and at key points in their care. Patients should be offered structured and holistic assessments at key points, which result in a mutually-agreed written care plan and support offered where appropriate.	
592	MacMillan Cancer Support	NICE	1.2	9	We strongly support the inclusion of the recommendations under the essential requirements of care. We do not believe the statement that attention to these fundamental needs apply particularly to inpatient settings. We believe they are vital for all care, regardless of the setting or circumstances to which they are being delivered. Therefore no distinction should be made as all care should be delivered to the highest standard and the patient experience should always be a vital consideration.	Thank you for your comment. This paragraph has been changed to reflect the provision of these elements of care in all settings.
593	MacMillan Cancer Support	NICE	1.2.3	9	Patients tell us that they become particularly annoyed or upset if health professionals address them incorrectly or mispronounce their name. Healthcare professionals should take the time to ask a patient how they wish to be addressed and should pay attention to ensuring they pronounce names correctly. We suggest this could be included in recommendation 1.2.3 which would then read: Do not discuss the patient in their presence without addressing them directly in the manner which they have indicated is their preference.	Thank you for your comment. This is addressed in recommendation 42.

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612	MacMillan Cancer Support	NICE	1.2.4	10	We also suggest that recommendation 1.2.4 should be strengthened to read: Be prepared to broach sensitive issues with all patients, such as sexual activity, as these are unlikely to be raised by some patients. Health professionals are more likely to make assumptions about a patient when it comes to more sensitive issues that they may feel uncomfortable raising. For example they may dismiss an older patient as having no desire to discuss issues such as sexual activity when this may not be the case. These recommendations may also provide the opportunity to highlight the need for healthcare professionals to discuss preferences at the end of life and would support the quality standards for end of life care currently out for consultation. Clinicians are often reluctant to discuss end of life issues with patients while they are still delivering active treatment. This consequently militates against effective end-of-life care planning. Talking with people about their preferences at the end of life increases patient choice and may help families feel better prepared.	Thank you for your comment. The GDG felt that it was not appropriate to discuss such issues with all patients. Recommendation 10 states that ‘ these are unlikely to be raised by some patients’. The End of Life Care Quality Standard will be published in November 2011.
640	MacMillan Cancer Support	NICE	1.3.2	11	We believe recommendation 1.3.2 is too passive. Not only should patients be given information but this information must be tailored to their needs and they must be offered appropriate support to understand it, for example use of pictures, interpreters or advocates (as outlined in recommendation 1.5.4).	Thank you for your comment. It is felt that as the information is about treatment options it will be tailored to the treatment that they need.

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641	MacMillan Cancer Support	NICE	1.3.4	11	Recommendation 1.3.4 should highlight to healthcare professionals the need to consider how they introduce themselves in relation to addressing the patient. For example it can be disempowering to introduce themselves and colleagues using full titles while referring to the patient by their first name.	Thank you for your comment. This is addressed post consultation in several recommendations.
667	MacMillan Cancer Support	NICE	1.3.7, 1.3.8	12	We strongly agree with recommendations 1.3.7 and 1.3.8, which set out how discussions with patients should be conducted. However, we believe this should include: • allowing adequate time so that discussions do not feel rushed, • allowing and inviting questions, • and ensuring questions or opinions are not dismissed but are addressed and answered with respect.	Thank you for your comment. Allowing adequate time has been included in the recommendation. The focus is on discussing treatments at which patients would be able to ask any questions.
683	MacMillan Cancer Support	NICE	1.3.12	13	We very strongly support recommendation 1.3.12. Patients should be encouraged to give feedback about the suitability and quality of their care. Health services cannot and will not improve if patients are unable to offer such feedback. However, many do not feel able to give this due to the bureaucratic manner of such feedback processes or because they feel making a complaint will result in hostility from their care providers.	Thank you for your comment. Recommendation 32 and 33 have been written to address this.
684	MacMillan Cancer Support	NICE	1.4	13	We propose that a recommendation be added that explicitly highlights good communication directed at the patient for the purpose of aiding continuity. For example about appointment times, directions and practical matters. Communication with the patient should be coordinated and joined up. Poor administration and communication is often a key	Thank you for your comment. Recommendation 36 has been amended to highlight this.

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			1.4.5	14	frustration for patients and is most likely to fail when a patient moves between different care settings or services. In addition, to support this, recommendation 1.4.5 should read: Ensure clear and timely exchange of patient information between healthcare professionals and the patient.	
706	MacMillan Cancer Support	NICE	1.5	14	It is important that all the recommendations under the banner of communication, but in particular 1.5.2 and 1.5.3, be applied by all staff working directly with patients in the NHS and not just healthcare professionals. Patients tell us that the interactions they have with non-healthcare professionals such as administration, reception and porter staff can also impact greatly upon their experience of care. We suggest that this point be made explicit within the recommendations.	Thank you for your comment. The wording has been amended to reflect this.
707	MacMillan Cancer Support	NICE	1.5.1	14	In keeping with our point 12, recommendation 1.5.1 should be amended to read: Ensure that the environment is conducive to discussion and questions and that the patient's privacy is respected, particularly when discussing sensitive, personal issues. Efficient time should be allocated for such discussions and the patient's comments and questions acknowledged and addressed.	Thank you for your comment, this has been considered and reflected in refinement to recommendations/quality statements.
708	MacMillan Cancer Support	NICE	1.5.3	14	We strongly support 1.5.3 but would add the need to pay attention to ensuring the patient's name is pronounced correctly.	Thank you for your comment.
709	MacMillan Cancer	NICE	1.5.4	14 /15	We also strongly support recommendation 1.5.4. However, it is disappointing that the use of	Thank you for your comment. We recognise the importance of advocacy and that it may

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	Support				advocates is not given more prominence in the recommendations. One of the biggest barriers to enabling voice and choice is based on the power dynamics that exist between professionals and patients. Obviously with the power more balanced in favour of professionals. This is further exacerbated based on who you are, the type of cancer you have and where you live. User engagement and participation can only be realised for those that the system routinely fails if there are appropriate support services in place. The use of peer advocates/community based advocacy for 'seldom heard communities' is an effective intervention that enables more people to navigate the system, understand their rights, and facilitate informed decision making – all key to participation and choice.	be more important for some groups than others.
724	MacMillan Cancer Support	NICE	1.5.11	15	We are unclear to what recommendation 1.5.11 refers and believe it requires more detail.	Thank you for your comment. We have removed this recommendation following stakeholder comment.
737	MacMillan Cancer Support	NICE	1.5.13	16	We suggest that recommendation 1.5.13 ought to come before 1.5.12 to ensure health professionals recognise the need for accessible information. It is important that patients receive information and support throughout their cancer journey, and that the information and support they receive is relevant for them at that time in the journey. We believe the recommendation also needs to make reference to the need to offer this at key points in the patient's journey. Cancer Information Prescriptions, which are currently being rolled out across England, provide a solution for providers in offering this continual support.	Thank you for your suggestion. The recommendations have been reordered and amended.
738	MacMillan Cancer	NICE	1.5.16	16	We agree that it is essential for patients to receive both verbal and written information.	Thank you for your comment.

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757	MacMillan Cancer Support	NICE	1.5.23	17	We also agree that it is essential for healthcare professionals to clarify the patient's hope for treatment. This is particularly crucial when patients are reaching the end of their lives and may not appreciate that treatment is palliative as opposed to curative. It is important that healthcare professionals have an active discussion about options when patients are nearing the end of their life.	Thank you for your comment. We agree and this is stated in recommendation 23.
758	MacMillan Cancer Support	NICE	1.5.24	17	We support the need to give patients and their families adequate time to decide whether to undergo investigations and/or treatment.	Thank you.
843	MacMillan Cancer Support	QS	General	General	Macmillan welcomes the publication of these quality standards and is heartened to see the value that the government and the NHS are placing on the need to improve patient experience.	Thank you for your comment.
844	MacMillan Cancer Support	QS	General	General	We would like to see the following NICE recommendations added to the quality standards as we believe they are crucial to delivering a high quality patient experience: • Recommendation 1.3.12 • Recommendations 1.5.1, 1.5.2, and 1.5.3	Thank you for your comment. Whilst we recognise the importance of these areas, we are limited in the number of quality statements we can produce.
845	MacMillan Cancer Support	QS	General	General	However, we are disappointed that the measures and existing indicators available to determine whether these standards are being and will be met are weak, tenuous or not identified. Patient experience has always proved hard to judge and without the ability to record whether these quality statements are being implemented, we fear the incentives will not be in place to make these statements a reality.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board. NICE are currently considering what implementation support to provide for this guidance

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					Disappointingly, other relevant existing indicators and national data sources have been missed. This includes data on patient complaints. NHS services record the subject matter of complaints and this is published nationally and annually. This information might prove highly useful in determining whether quality standards are being met. For example a high number of complaints relating to communication or dignity and respect would signal a problem in these areas. Likewise a small number of complaints overall can indicate a problem, as good NHS organisations often encourage patients to complain. Commissioners can also judge an organisation's commitment to improving patient experience by requesting to see how they are actioning complaints. The National Cancer Patient Experience Survey provides much data directly related to the quality standards. The most recent survey took place in 2010 and will be repeated shortly. The General Practice Patient Survey would also prove a useful source of data on the quality of patient experience in primary care, which is under-represented in the data sets/existing indicators highlighted for the quality standards. Patient experience surveys have proven a crucial method in determining the quality of care but it is vital that they are repeated regularly so that health professionals and patients can determine whether interventions are leading to improvements. The national commissioning board should strongly consider the revision of national patient experience surveys to ensure that the included questions are	

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					a reflection of the quality standards. It is also imperative that the government and commissioners encourage providers to seek other methods for recording patient experience such as complaints audits and real-time feedback.	
846	MacMillan Cancer Support	QS	General	General	These quality standards should link with the other quality standards being produced and all other quality standards should make reference to them in order to highlight the importance of patient experience.	Thank you for your comment. We understand that this will be linked guidance across NICE pathways.
935	MacMillan Cancer Support	QS	1	5	Patients tell us that their interactions with non-healthcare professionals working in the NHS such as administration, reception and porter staff can also impact greatly upon their experience of care. It is right, therefore, that these quality standards be applied to all staff who interact with patients.	Thank you for your comment. These quality standards are directed at all staff who interact with patients.
974	MacMillan Cancer Support	QS	2 14	7 21	We believe that the outcome warranted from these standards is very similar and so these standards should be combined. Health care professionals should act accordingly to ensure that patients can participate as fully as possible in consultations and care despite physical or learning disabilities etc. This requires more than simply asking about any factors that may limit a patient's participation but requires the health care professional to act accordingly. This should be reflected in the draft quality measure. It is simply not sufficient to record whether a patient was asked about these factors as this gives no ability to determine whether this lead to a satisfactory outcome for the patient. We suggest that the combined draft quality standard should read: Healthcare professionals ensure that patients are	Thank you for your comment. These two recommendations have been amalgamated.

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					able to participate in consultations and care regardless of any physical or learning disabilities, sight or hearing problems, difficulties with reading, understanding or speaking English, by establishing and using the most suitable way of communicating and confirming the patient's understanding. We suggest the draft quality measure should be amended to: Structure: Evidence of local arrangements to ensure that patients are able to participate in consultations and care regardless of any physical or learning disabilities, sight or hearing problems, difficulties with reading, understanding or speaking English. Process: Proportion of patients who were helped to participate in consultations and care regardless of any physical or learning disabilities, sight or hearing problems, difficulties with reading, understanding or speaking English during their consultation. Numerator – the number of patients in the denominator who were able to participate in consultations and care regardless of any physical or learning disabilities, sight or hearing problems, difficulties with reading, understanding or speaking English. Denominator – the number of patients accessing NHS services Outcome: Evidence from patient experience	

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					surveys and feedback that patients felt involved in consultations and their care.	
1006	MacMillan Cancer Support	QS	3	9	Likewise quality statement 3 is not strong enough. Health care professionals should discuss and assess a patient's health beliefs, concerns and preferences and provide personalised treatment and care. We suggest that preferences should be defined. The standard could read: Health care professionals should discuss and assess a patient's health beliefs, concerns and preferences, such as treatment and locality, and provide personalised treatment and care accordingly. This should also be reflected in the draft quality measure: Structure: Evidence of local arrangements to ensure that health professionals are assessing a patient's health beliefs, concerns and preferences and are providing personalised treatment and care. Process: Proportion of patients whose health beliefs, concerns and preferences were assessed and who were given personalised treatment and care. Numerator – the number of patients in the denominator whose health beliefs, concerns and preferences were assessed and who were given personalised treatment and care. Denominator – the number of patients accessing NHS services	Thank you for your comment and suggestions. NICE technical advisers have the responsibility for identifying appropriate measures.

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					Outcome: Evidence from experience surveys and feedback that patients felt they were given the opportunity to discuss their health beliefs, concerns and preferences, in order to individualise their care. Existence of a care plan is also strong evidence that a patient is receiving personalised care.	
1049	MacMillan Cancer Support	QS	5	11	We believe this quality standard is poorly written and does not adequately summarise NICE recommendations 1.2.2, 1.2.5, 1.2.8, 1.2.10 and 1.2.11. It does not make clear that these physical needs and psychological concerns should be met and not just assessed. Nor does it make clear that the patient's confidentiality should be respected at all times and not just when these needs and concerns are being addressed. This quality standard also implies that these are the only factors which ought to be assessed when the NICE recommendations make clear that a much fuller range of factors ought to be addressed such as financial and emotional. The strength of the associated NICE recommendations has been greatly weakened in this standard. We suggest this be split in two to read: • Patients regularly have their physical, psychological, domestic, social, spiritual, employment and financial circumstances assessed at key points in their care. This should include nutrition, hydration and personal hygiene as well as their fears and	Thank you for your comment. The quality standard has been changed to reflect this. These are not the only factors to be assessed, but it was decided by the GDG for the quality standard that physical and psychological areas should be focused on. Other concerns are included in the applicable quality statement. Furthermore, we expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					anxiety. - Patients' rights to confidentiality are respected at all times. In addition, the relevant existing indicators highlighted are ones that determine whether privacy was retained and do not assess whether important factors such as nutrition and pain relief are being met. This could be assessed from data collected in the national inpatient survey which includes questions on food, eating and pain. Clinical audit data may also provide evidence related to these factors.	
1075	MacMillan Cancer Support	QS	6	12	See our comments in point 12 related to NICE recommendation 1.3.4. It is likely that this particular quality standard is a useful marker for the patient's overall experience of care, as a failure of the health care team to introduce themselves and explain their role would demonstrate a failure in the most basic duties of care. This quality standard could be easily assessed if relevant questions were included in the national patient experience surveys and we would suggest that this is considered.	Agree with your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1138	MacMillan Cancer Support	QS	9	16	We suggest that this standard on tailored care make reference to the use of holistic assessment and care planning. These are useful tools in ensuring that care is tailored to the individual's needs. We believe that assessment and care planning should be done throughout a patient's journey. The idea of ongoing assessment, with written care plans detailing interventions to be	Thank you for your comments which are welcomed. We reviewed the literature focussed on patients experience, not on tools to facilitate planning of care. We believe your suggestions are consistent with guidance recommendations on continuity of care and on communication.

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					made, is supported by the NICE Supportive and Palliative Care Guidance (#1.16 – #1.21).15 We are particularly keen to see that patients receive individualised care plans based on a holistic assessment of their needs (i.e. not just clinical needs, but also psychosocial, practical and financial needs, etc) at the point at which they finish treatment. Such individualised treatment and care should be offered to patients in follow up and not just during treatment.	
1157	MacMillan Cancer Support	QS	10	17	See our comments in point 15 related to NICE recommendation 1.4.5.	Thank you for your comment.
1171	MacMillan Cancer Support	QS	11	18	We think the statement should not only say that patients have 'advice about who to contact, how to contact them and when….', but should also explicitly say that this should include what to do outside of normal working hours. This is especially important in palliative care, and indeed the NICE Supportive and Palliative Care Guidance notes that a reduction in out-of-hours support is probably to blame for people not dying in their place of choice.16 Most people would prefer to die at home and not in a hospital – between 56% and 74% according to different sources.17 However, recent statistics show that only 25% of people diagnosed with cancer die at home.18 We believe that the provision of out-of-hours support could help people to die in their place of choice.	Thank you for your comment. Wording of recommendations has been further refined post consultation.

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[15] NICE Supportive and Palliative Care Guidance 2004.
[16] NICE Supportive and Palliative Care Guidance 2004.
[17] National Audit Office 2008. *End of Life Care.*
[18] Taken from Macmillan Cancer Support online survey of 1,019 UK adults living with cancer, February 2010.

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1238	MacMillan Cancer Support	QS	15	22	We believe quality statement 15 is poorly written and by combining NICE recommendations 1.5.21, 1.5.22, 1.5.23, 1.5.24 and 1.5.28 they have been greatly weakened. We suggest this statement should be separated out to read: • Healthcare professionals and patients fully discuss diagnosis, prognosis and treatment, and clarify what the patient hopes treatment will achieve. • Patients and healthcare professionals partake in shared-decision making and patients are given time to decide whether to undergo investigations and/or treatment.	Thank you for your comment. The wording has been amended.
1266	MacMillan Cancer Support	QS	16	23	We believe this statement needs to make reference to the need to offer information at key points in the patient journey and should specify the range of information the patient is likely to require. This is important because healthcare professionals often fail to realise the need to give information on non-clinical issues such as information on financial and work issues. Cancer Information Prescriptions, which are currently being rolled out across England, provide a solution for providers in offering this continual support. We suggest the statement be re-drafted to read: Patients are provided with evidence-based information at key points before, during and after treatment, which is understandable, personalised and clearly communicated, and that covers a range of relevant issues including clinical, practical, financial and emotional.	Thank you for your comment. This is clear throughout the guideline recommendations and the quality statements.

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84	Medtronic Ltd	Full	General	General	While Medtronic have no specific comment to make at this time we thank NICE for the opportunity to review the document.	Thank you.
85	Mencap	FULL	General	General	Mencap broadly support NICE's proposals but believes it needs certain additions in order to address the significant ongoing challenges faced by this group. People with a learning disability continue to experience worse health outcomes than the general population and are still dying prematurely.Mencap have campaigned for many years for the health needs of people with a learning disability to be better served by the NHS.	Thank you for your comment. This is an important issue and we have highlighted the importance of equality issues.
164	Mencap	FULL	4	23	Point 2) – As well as healthcare professionals being aware as to whether someone has a learning disability, it is also vital they are aware of whether a patient has other underlying health conditions – as people with a learning disability are at disproportionate risk of many other health conditions, such as epilepsy. Unfortunately Mencap are still hearing too many cases where healthcare professionals are seeing the learning disability and not successfully treating the underlying illness – so called diagnostic overshadowing. Mencap would like to see a line about healthcare professionals needing to be aware of "avoiding diagnostic overshadowing" . This point is also linked in with point 16) and 17) (page 24). Mencap know that medication for an underlying health condition is often not given when people with a learning disability are admitted to	Thank you for your comment. These guidelines are applicable to all patients who access adult NHS services. Recommendation 19 makes reference to coexisting conditions. Recommendation 13 addresses pain and recommendation 17 addresses continuation of medications whilst in hospital.

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					hospital for another problem. People with a learning disability should continue to receive the medication they need, irrespective of where they are at any time. If in hospital, the hospital must ensure these are given. Finally this point is tied in with this is the question of pain relief. People with a learning disability experience pain and should have the same access to pain relief as everyone else.	
165	Mencap	FULL	4	23	Point 6) Mencap are currently supporting many families whose loved one with a learning disability have died while in the care of the NHS. An oft-cited problem is that some healthcare professionals still make perjorative statements and assumptions about patients with a learning disability. Mencap believe it is vital that the NICE guidance is explicit that such discriminatory and illegal assumptions must not be made. Avoiding discrimination is particularly vital around the issue of Do Not Resuscitate decisions. The law is clear that people with a learning disability should be afforded an equal right to life, under the Human Rights Act – and it is vital that this is respected and emphasised in this document.	Thank you for this comment. We have now added a recommendation about assessing capacity according to the Mental Capacity Act (2005) and involvement with family of people who may lack capacity. We agree with your point relating to do not resuscitate decisions, this particular point is outside the scope of this guidance.
192	Mencap	FULL	4	24	Point 15) In the nutrition section, it would also be worth flagging up the specific risk of dysphagia (swallowing problems) particularly for those people with Profound and Multiple Learning Disabilities. This is particularly important, as some people with PMLD, may also be non-verbal – and so unable to	Thank you for your comment. This is addressed in the more nutrition focused guideline CG32; Nutrition support in adults.

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					flag up if food has got lodged and they are unable to breathe.	
193	Mencap	FULL	4	24	While Point 20) is helpful, Mencap would like it to be bolstered to emphasise that healthcare professionals are under legal duties, particularly the Equality Act, to make reasonable adjustments to the way in which they deliver care. While many Trusts are making some of the easier reasonable adjustments (easy read literature, longer appointment time) there remains an issue that healthcare professionals are still not making reasonable adjustments to the actual way in which they deliver healthcare and as a result, people with a learning disability continue to experience worse outcomes.	Thank you for your comment. We recognise the particular needs of disabled people. The remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline. All recommendations are written in line with the Equality Act and we have added a specific recommendation about the Equality Act.
194	Mencap	FULL	4	24	Point 26). Across the UK there are a range of communication aids that allow people with a learning disability and their families/carers to record their personal preferences (food, communication) and basic health information. One such is the Health Passport – often carried by people with a learning disability. While there are a range of "versions" – the NICE guidance could usefully flag up that communication aids such as Health Passport exist and that they should be taken seriously This point about communication also ties in with points 31)& 40). For patients who may be non-verbal or who display behaviour that challenges services, reasonable adjustments should also be made that allow their views are sought.	Thank you for your comment. We recognise the particular needs of disabled people. The remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline.

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					Sometimes this will need to be through a parent or carer – but can also be about making reasonable adjustments in the way communication is handled. Mencap has guidance on communicating successfully with people with pmld.	
278	Mencap	FULL	4	27	Point 64). It would be worth flagging the role that Mental Health Advocates (IMHAs) and Independent Mental Capacity Advocates (IMCAs) and that these should be sought if there is a question around the capacity to consent of individuals receiving treatment.	Thank you for your comment. A recommendation has been added (recommendation 30) pertaining to consent.
936	Mersey Internal Audit Agency (MIAA)	QS	1	5	In the draft quality statement, it states that healthcare professionals as part of their performance assessment will be evaluated & mentored for compliance with NICE guidance etc. How will this compliance at individual level be measured and what is the consequence of non-compliance for that individual?	Thank you for your comment. Quality Standards are not mandatory. It is for local decision what should be done if a staff member is not compliant with patient experience requirements.
975	Mersey Internal Audit Agency (MIAA)	QS	2	7	Suggest that question around patient perception of their involvement in consultations and their care is included in patient experience surveys in all areas not just ambulance service users.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1007	Mersey Internal Audit Agency (MIAA)	QS	3	9	Similar to comment above – questions relating to beliefs, concerns and preferences included in all patient experience questionnaires.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1050	Mersey Internal	QS	5	11	Draft quality measure – what level of evidence of 'local arrangements' would be required?	Thank you for your comment. We expect that further advice about how quality standards

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	Audit Agency (MIAA)					and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1076	Mersey Internal Audit Agency (MIAA)	QS	6	12	As for comments 2 & 3 above – question/s understanding of roles & responsibilities should be standard in all patient experience surveys.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1118	Mersey Internal Audit Agency (MIAA)	QS	8	15	As for comments 2,3 & 5 above. In fact, if the' outcome' of the quality measure is dependent on evidence from experience surveys and feedback then it might be useful to provide a core list of questions to be included in surveys to ensure that the relevant information is captured.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1139	Mersey Internal Audit Agency (MIAA)	QS	9	16	Draft quality measure – what level of evidence of 'local arrangements' would be required?	Thank you for your comment. This has been reworded
1158	Mersey Internal Audit Agency (MIAA)	QS	10	17	This statement is confusing – is it about systems to enable exchange of information or it is about patients giving their consent for this to happen? The quality statement is about exchange of information between healthcare professionals with no mention of consent. Then the quality measure 'outcome' is around evidence that patients were asked if they wanted their information shared. Might need to be separated into 2 sections to make it clearer.	Thank you for your comment. This has been reworded. See above.
1184	Mersey Internal Audit	QS	12	19	Is this quality statement realistic, practical and achievable? Surely this should be about managing expectations and aligning them with reality not	See previous related comments

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	Agency (MIAA)				making carte blanche promises which, with the best will in the world, may not be achievable 100% of the time.	
1211	Mersey Internal Audit Agency (MIAA)	QS	13	20	There is slight discrepancy between quality statement and quality measure. Having evidence of staff being trained in communication skills is not the same as demonstrating competency in communication skills.	Thank you for your comment. Amended
1267	Mersey Internal Audit Agency (MIAA)	QS	16	23	QS is relying on evidence from patients that information was provided. This may be the case but unfortunately accuracy of patient recall is not always reliable so evidence for this might be better gathered from provider/giver of the information.	Thank you for your comment. Noted but this is always likely to be a reality.
31	MHRA	All	General	General	No comment	No response needed
524	Muscular Dystrophy Campaign	NICE	2	6	Health professionals must seek out specialist information regarding rare conditions such as muscular dystrophy in order to treat the patient appropriately or refer the patient to an appropriate specialist. Managed clinical networks, like the Neuromuscular network in the South West enable general health professionals to consult with Neuromuscular Specialists who can advise best courses of treatment for rare conditions.	Thank you for your comment.
525	Muscular Dystrophy Campaign	NICE	QS6	6	Patients should be given a named lead who has responsibility for their health care and can be contacted during their inpatient stay to ensure high quality specialist care.	Thank you for your comment. This would make the quality standard too inpatient specific and not applicable to all who access adult NHS services.
526	Muscular Dystrophy Campaign	NICE	General	6 -7	There should be a specific guidance statement regarding transition into adult services. Many people with a neuromuscular condition and other rare conditions note transition from paediatric services to adult services as an area of difficulty.	Thank you for your comment. We recognise the important issue of transition from paediatric to adult care. Whilst paediatric care is outside the scope of the guidance, we do believe the valuable points raised are

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					There is often very poor communication between the two services and no named lead to ensure that the patient has the care and support they require to protect their health.	addressed in recommendations targeted at continuity of care and the importance of communication between service providers at points of care transition.
594	Muscular Dystrophy Campaign	NICE	1.2.7	9	All healthcare professionals who are directly involved in a neuromuscular patient's care must be trained to deal with their specific and complex health requirements. This is relevant to nutrition and all areas of care.	Thank you for your comment.
710	Muscular Dystrophy Campaign	NICE	1.4.4	14	Care co-ordination is essential for a neuromuscular patient due to the number of different specialists required to treat their condition and the level of physical disablement associated with a progressive muscle wasting condition. There must be effective communication between health professionals and social services to ensure that the patients have the support to protect their health and independence.	Thank you for your comment. The developers agree and believe this is addressed in the recommendations on communication.
725	Muscular Dystrophy Campaign	NICE	1.5.8	15	Most neuromuscular patients are very well informed in regards to their complex needs as they are used to conveying their needs to generic health professionals. However we often hear of patients not being listened to. It should be emphasised that patients should be given the opportunity to express and input their opinions regarding courses of treatment.	Thank you. We believe this point is addressed in other related recommendations.
32	Napp Pharmaceuticals Ltd	All	General	General	(examples from 30, 31, 38, 43, 48 and 51) The guideline refers frequently to pain as an issue. For example: p 30, 5.2.1. Table 3 point 4 Physical comfort: Pain management...... p 31, 5.2.2. Table 4 Physical comfort: expert	Thank you for your comment. The statement has been changed to reflect this.

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					management of symptoms such as pain...... p 38, 5.4.3. line 29 and 30 Pain Control p 43 In 5.5. Table 8 under Essential requirements of care: ....such as nutrition, safety and pain management. p 48 7.1 Introduction In the description of a good patient experience a number of requirements are mentioned including prevention and management of pain. And on p 51 7.3: The GDG regarded the area of pain management as being an area of poor practice. However although pain is frequently mentioned this has not been translated to the wording of any of the draft quality statements. Please see comment on Draft quality statement 5.	
33	Napp Pharmaceuticals Ltd	All	General	General	Equity issue: In March 2007 The Patients Association published a report carried out by the Picker Institute on Pain in Older People. The report looked at pain in older patients, in particular, those in nursing homes. In terms of the generic patient experience this report might suggest that there are potential inequities for those older patients who rely on care from nursing homes and other providers.	Thank you for your comment. NICE guidance covers all patients receiving care from the NHS, irrespective of the local contractual arrangements to provide this care. Pain is included within this general guidance and covered in this quality statement.
195	Napp Pharmaceuti	Full	7.3	24 & 51	Recommendations We would suggest that recommendation 17 is also	Thank you for your comment. This recommendation has been altered to include

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	cals Ltd				re-worded to be the same as the above; Do not assume that pain relief is adequate. Ask the patient about his or her levels of pain with the aid of an appropriate pain scale if necessary. Record the scores, act on them so as to provide timely pain relief and adjust as necessary.	this.
324	Napp Pharmaceuticals Ltd	Full	7.3	51	In other considerations in relation to pain the following statement appears "The GDG regarded the area of pain management as being an area of poor practice". This perception may be true but it is not universally correct as there are a number of centres of excellence across the UK. However improvements can be made and achieved through sharing of good practice and the development of better pain management education plans from undergraduate level upwards.	Thank you for your comment. This statement has been changed.
354	Napp Pharmaceuticals Ltd	Full	9.3	68	Recommendations 33 Inform the patient about: & 36 Ensure clear and timely exchange of........... Continuity of care is important for patients but this relies on the transfer of well documented information between members of the healthcare team. We would encourage the inclusion within this recommendation of a statement concerning the sharing of well documented evidence collected using appropriate and recognised tools. (e.g. pain scores, etc.) i.e. reassure the patient that assessment details (including pain scores, etc.) have been recorded in the notes for access by any healthcare team	Thank you for your comment. The developers did not believe this level of detail necessary in the continuity of care recommendations.

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					member. Simple pain scales may be found by following the links: http://www.npc.nhs.uk/therapeutics/pain/overview/resources/pda_pain_overview.pdf http://www.npcrc.org/resources/resources_show.htm?doc_id=376168	
371	Napp Pharmaceuticals Ltd	Full	10.3.2	77 & 78	Recommendations 48 to 52 and 54. No mention is made of alternative methods of supplying information such as the internet.	Thank you for your comment. The recommendations are not specifying where the professionals sources information and we recognise that this is often via the internet.
393	Napp Pharmaceuticals Ltd	Full	10.4.2	104	Recommendation 58 We would suggest that a further bullet point could be added before the bullet starting "set aside........." e.g. • Explain how any assessment tools will be or should be used, such as patient self-reporting charts (e.g. peak flow), pain assessment tools (e.g. VAS, pain scales etc.) and how the patient should keep records to aid the healthcare team in diagnosis and treatment. This also helps to empower the patient to take a responsible active part in the management of his or her condition.	Thank you for your comment. The GDG did not believe this level of detail was necessary.

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642	Napp Pharmaceuticals Ltd	NICE	1.2.10	11	We would suggest that this section should mention the use of pain measurement tools and recoding the pain scores. For example: Do not assume that pain relief is adequate. Ask the patient about his or her levels of pain with the aid of an appropriate pain scale if necessary. Record the scores, act on them so as to provide timely pain relief and adjust as necessary.	Thank you for your comment. Pain measurement tools has been added to this recommendation
1051	Napp Pharmaceuticals Ltd	QS	QS5	11	Description of the what the quality statement means for each audience In the section starting Patients are assessed....pain relief is mentioned alongside eating, drinking, continence, fear and anxiety. Patients rate pain relief as being one of the most important issues. We suggest that pain should be included in the wording of the draft quality statement: Patients regularly have their physical needs (such as nutrition, hydration, pain relief and personal hygiene and psychological concerns (fear and anxiety) assessed in an environment that maintains their dignity and confidentiality.	Thank you for your comment.
1185	Napp Pharmaceuticals Ltd	QS	QS 12	19	(also would apply to NICE 1.4.1: page 13) We agree that continuity of care should lead to better outcomes for patients. This does require better communication of issues between health care professionals caring for the patient.	Thank you for your comment

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					For example: for good pain management it is important to document the patients pain scores and type of pain (a number tools are available for this) so that there is a point of reference for the healthcare professional or wider healthcare team. Simple pain scales may be found by following the links: http://www.npc.nhs.uk/therapeutics/pain/overview/resources/pda_pain_overview.pdf http://www.npcrc.org/resources/resources_show.htm?doc_id=376168 We believe that it is important, therefore, to include a short statement within the Description of what the quality statement means for each audience which encourages good and detailed record keeping. This would of course not apply only to pain but also to other symptoms.	
365	National Association of Laryngectomee Clubs	Full	10.2.1.3 &10.2.2	73 -74	Establish the most effective way of communicating with each patient and, if necessary, consider ways of making information accessible and understandable (for example, using pictures, symbols, large print, different languages, an interpreter or a patient advocate). Don't think this section meets the needs of Laryngectomees or others who have speech breathing or other additional communications impairments, where is there mention of family members used to assist communications.	Thank you for your comment. This list is not intended to be exhaustive but we have added communication aids and family members to the list. The GDG comment re harms indicates that the GDG did not consider there were harms from making communication more effective.

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					Trade off between clinical benefits and harms The GDG considered no harms were likely No harms were likely – sorry they can be when the professional fails to understand and goes ahead regardless with treatment which adversely affects the Laryngectomee ie rips out the valve leading to numerous repairs operations because they failed to understand someone without speech. Or when they failed to ensure suction is provided for a Laryngectomee with a blocked airway.	
372	National Association of Laryngectomee Clubs	Full	10.3.1.3 & 10.3.2	77	Patients (or home carers) should be given appropriate information to enable them to fully understand the correct use of medications, including oxygen, before discharge. (From 'Chronic obstructive pulmonary disease', R 1.3.11.5) Medications to include indication of need and how to use suction equipment provided to ensure a stoma does not become blocked resulting in entire sole airway failing. Again the "The GDG considered no harms were likely" In this case fatality could and has occurred. If patients families and carers were actively involved in discharge planning many of the problems currently reported would not occur, equipment is in many cases not available at the time of discharge even for someone newly disabled as a direct result of treatment for cancer. Patients and carers should be made aware of the risks presented by a neck stoma:- Infections including pneumonia	Thank you for your comment. The sentence about no harms being likely relates to the GDG view that providing information is not harmful. We accept that the information should be fit for purpose.

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					Damage due to taking in water if not cleared risk of hypoxia, risks during high winds, snow or heated down draughts Risk following radiation treatment during periods of intense sunlight. Recognise the high levels of poor literacy when preparing any written advice. Are forms of statistical evidence the best way to present risk factors? Suggest format of NALCs information may be more readily accepted by many potential patients.	
527	National Association of Laryngectomee Clubs	NICE	QS2	6	"speech" should be added to the list containing sight and hearing so it reads "sight, hearing or speech problems" in both the quality statement and the NICE guidance. The patient communicating their response is just as important as receiving the information. Many laryngectomees will need extra time from the hospital staff to do this especially if they have no carer to help. Through the document it seems there is more attention given to providing information to the patient than to getting the response.	Thank you for your comment. This statement has been replaced with statement 2 which is a more generic communication quality standard. Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.
565	National Association of Laryngectomee Clubs	NICE	1.1.2	8	"speech" should be added to the list containing sight and hearing so it reads "sight, hearing or speech problems" in both the quality statement and the NICE guidance. The patient communicating their response is just as important as receiving the information. Many laryngectomees will need extra time from the hospital staff to do this especially if they have no carer to help. Through the document it seems there is more attention given to providing	Thank you for your comment, the recommendation has been amended accordingly.

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					information to the patient than to getting the response.	
711	National Association of Laryngectomee Clubs	NICE	1.5.4	14	We don't think this section meets the needs of laryngectomees or others who have speech, breathing or other additional communications impairments. Also where is the mention of family members used to assist communications.? Harm is likely when the professional fails to understand and goes ahead regardless with treatment which adversely affects the laryngectomee, e.g. rips out the valve leading to numerous repair operations because they failed to understand someone without speech.	Thank you for your comment. We have added communications aids and family members to the possible methods of help with communication.
739	National Association of Laryngectomee Clubs	NICE	1.5.18	16	This should include indication of the possible need and how to use suction equipment provided to ensure a stoma does not become blocked resulting in entire sole airway failing. In such cases fatality could be the result, and regrettably has been too often. If patients families and carers were actively involved in discharge planning many of the problems currently reported would not occur. Equipment is in many cases not available at the time of discharge even for someone newly disabled as a direct result of treatment for cancer. Patients and carers should be made aware of the risks presented by a neck stoma.	Thank you for your comment. This guidance by nature is generic, with a non population and non setting specific focus, and therefore condition specific application is implicit.
34	National Voices	All	General	General	The guideline discussion and recommendations, and the subsequent Quality Statements, appear to the lay reader to be tilted towards hospital care settings rather than primary or community healthcare.	Thank you for your comment. Some of the recommendations are more appropriate for inpatient settings than primary or community settings. The recommendation you refer to (recommendation 17) refers to the situation when people are admitted to hospital. In this

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					For example, recommendation 16 says that 'when patients in hospital are taking medicines for long term conditions' there should be a discussion about self-management. But patients with long term conditions need such opportunities whether they are in hospital or in the community. This hospital bias may be a natural consequence of the fact that much of the evidence around patient experience, and many of the tools for measurement, have been developed in relation to hospital inpatients in particular. It may also be influenced by the fact that the approved Indicators for Quality Improvement are primarily drawn from the national inpatient survey. However, there is a substantial literature on patient experience in primary care, and a range of instruments that have been developed to measure patient experience generally, and experience of the consultation in particular. Until 2008, the regulator commissioned annual surveys of people's experience of primary care as part of the national patient survey programme. These were superseded by the DH-commissioned General Practice Patient Survey. To date there has been little analysis of the GPPS data for purposes other than monitoring the performance of GP practices. These, and other tools for measuring patient experience in primary care, are discussed in 'The quality of patient engagement and involvement in primary care', Parsons, S et al, Kings Fund, 2010, a report commissioned as part of the Kings Fund Inquiry into the quality of primary care.	situation people routinely have their medicines taken from them and the recommendation is intended to indicate that this should not be routine occurrence. The guidance covers all settings and was not driven by available tools but by the areas the GDG considered important. It is likely that alternative tools will need to be developed to measure some indicators in different populations. Likewise the emphasis on which areas are important is likely to vary according to level of care and to patient condition and need. The GDG included representatives from primary care, community care and maternity care and the GDG were aware of annual surveys of primary care and maternity care surveys. The recommendations include recommendations on listening, involvement in decisions, information, explanation, questions being answered and on kindness and compassion. We agree that the consultation is a key part of care. Issues about consultation length include both actual length and feeling of having enough time. We have recommendations about ensuring patients have adequate time for information and do not feel rushed (recommendation 22). The report 'The quality of patient engagement and involvement in

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					That report concluded, on the basis of a literature review and a review of measurement tools, that the 'key domains' of engagement in primary care consultations are as follows: • listening • involvement in decisions • information, explanation, questions being answered • consultation length • empathy We also note that there have been national surveys of the experience of maternity service users. Although these in part reflect hospital experiences (since the majority of women gave birth in hospital), they also track experience in relation to services provided in the community and in primary care both before and after the birth. This general reflection is relevant because the factors that contribute to overall experience of care in primary and community settings may differ in some respects to those that contribute to experience of hospital care and treatment. For example, they are likely to be less focused on specific single treatment interventions and more focused on maintenance of quality of life in the face of one or more continuing health conditions. In this context, more emphasis may need to be placed on consultations and discussions that help people to manage their health in the context of their general life circumstances. The importance of	primary care', Parsons, S et al, Kings Fund, 2010, states that extended consultation needs to be provided at some point. We do not consider it possible to be more specific about consultation length. Other aspects of your key domains of engagement are captured in the guidance, including the importance of active listening, importance of explanation and empathy.

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					the 'consultation length' factor in the above list indicates that such discussions can either be enabled by (longer) consultations or limited by (shorter) consultations. If these hypotheses are correct, then the guideline recommendations and quality statements should be reviewed to ensure that they properly reflect the importance of techniques and interventions that enable patients actively to manage their situation. These might include, for example: • longer consultations/changed consultation styles • opportunities to learn about, and be supported in, managing one's own condition(s) • use of opportunities to review management, including helping patients to prepare and make use of reviews • participative care planning This general comment leads to our suggestions in comments 2-5 in relation to education for self-management; and to our further comments in relation to revising the recommendations on information provision and decision making in the full guideline. We are aware that the Health Foundation is preparing a submission, drawing on a community of expertise, and considerable research literature in relation to these matters. National Voices also supports that submission and asks the GDG to give its full consideration to the evidence and	

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					arguments therein.	
35	National Voices	All	General	General	National Voices welcomes many of the recommendations and quality statements around the themes of informing patients and engaging them in decisions. In these statements the word 'treatment' is used to cover all treatment interventions. We would ask the GDG to consider whether there should be a specific QUALITY STANDARD on medicines. This is because the decision to prescribe a new medicine is, in many settings, the most frequent treatment decision taken, and yet there is evidence that clinicians may not see medicine prescription as a significant locus for involving patients in the decision. Data from national patient surveys indicates that around 80% of inpatients and 54% of primary care patients say they received a new medicine during the most recent episode of healthcare. However, in 2010 only 37% of inpatients said they were told 'completely' about possible side effects to watch out for; and 44% said they were not told. One quarter of inpatients said they were not told fully told about the purpose of their medicine, or how to take it, in a way they could understand. One third said they were not given full written information about their medicines. (National inpatient survey, Care Quality Commission, 2010) The General Practice Patient Survey does not include questions on medicines. Its predecessor, the healthcare regulator's primary care survey,	Thank you for your comment. Medicines Adherence is included as a topic for development of quality standards in the list proposed by the National Quality Board.

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					found that, while 70% of patients said they were as involved as they wanted to be in decisions overall, this fell to 60% when those prescribed a new medicine were asked whether they were as involved in that specific decision as they wanted to be. 41% of these patients said they did not have enough information about potential side effects and 20% wanted more information about the purpose of the medicine. (National survey of local health services, Healthcare Commission, 2008) In NICE guideline 76 on medicines adherence, the alarming estimate that one third of medicines for people with long term conditions are not taken correctly is linked to the systemic failure of healthcare delivery to involve patients in these discussions and decisions. The guideline recommends that, in order to improve adherence, clinicians should prescribe new medicines in the context of a shared decision making approach. The purpose of a specific quality statement on this issue would be to highlight the need specifically to measure this aspect of patient experience, including the effective provision of information and the extent to which prescribing decisions are made in partnership with patients. Existing indicators that could be used for this purpose include the following questions taken from the inpatient survey 2010 and the regulator's primary care survey 2008: • Were you involved as much as you wanted to be in decisions about the best	

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					medicine for you? (2008) • Were you given enough information about the purpose of the medicine? (2008) or Did a member of staff explain the purpose of the medicines in a way you could understand? (2010) • Were you told how to take your medication in a way you could understand? (2010) or Were you given enough information about how to use the medicine (e.g. when to take it, how long you should take it for, whether it should be taken with food)? • Were you given enough information about any side-effects the medicine might have? (2008) or Did a member of staff tell you about medication side effects to watch for when you went home?	
86	National Voices	Full	General		Accountability for care and treatment may be a relevant factor to patients, especially where they are seeking to rectify deficits in their experience of services. National Voices asks the GDG to consider where, within the draft documents, it may be possible to insert guidance that patients should be informed who is responsible for their current care and treatment. This may sit with other general provisions on information, or with the recommendation on enabling patient feedback, for example.	Thank you for your comment. We have a recommendation (recommendation 38) which states that patients should be informed who is responsible for their care and treatment.
228	National Voices	Full	4.1	25	The recommendations on continuity of care are welcome. We would ask the GDG to consider whether to add an additional point to these, perhaps in recommendation 32. This would be to ensure that the definition of	Thank you for your comment. The recommendations are designed to span all settings and disease areas. The developers agree that this is important, but perhaps not necessary in all circumstances.

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					'healthcare team' includes at least one person specialising in any long term condition the patient may have – irrespective of the reason for any current episode of care and treatment. Thus, for example, a diabetes patient who is hospitalised with a related or unrelated illness should have ready access to a diabetes specialist nurse or doctor.	
253	National Voices	Full	4.1	26 -27	National Voices is concerned about the form of recommendation 58, as part of the section on decision making. This text makes the assumption that the clinician has already made a decision on the most appropriate course of action, and that the patient's role is 'merely' to listen passively to information and explanations. It might belong in the context of trauma or other emergency care where there is self-evidently one single course of action that is appropriate. It does not belong in the realm of patient experience generically of healthcare services. For patient experience generically of healthcare services, the overall approach should be one of shared decision making. This is clearly indicated by the professional codes for all doctors and all nurses and midwives (General Medical Practice 2006, Nursing and Midwifery Code 2008) which place duties on these professionals to work n partnership with their patients; by the regulations for all registered healthcare providers under the Health and Social Care Act 2008, which include requirements to involve people wherever appropriate in discussions and decisions about their care; and by the policy intentions of the current government in its White Paper 'Liberating	Thank you for your comment. We have changed the wording of the recommendation to clarify our intentions. The GDG is advocating an approach to all decisions where patients' values and

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					the NHS' and the subsequent Health and Social Care Bill 2011, which places duties on healthcare commissioners to ensure 'patient involvement'. By contrast to recommendation 58, shared decision making relates to the common situation where there is no single self-evidently 'correct' course of action, and therefore the values and preferences of the patient are an important factor bearing on the choice of the most appropriate course of action for them. A much better formulation is in recommendation 64 – the principles of shared decision making. It is unfortunate that recommendation 64 comes after the recommendation 63 on the use of patient decision aids, and appears to recommend the approach of shared decision making only where there is no available decision aid. This is mistaken – shared decision making is the overarching approach, within which evidence-based patient decision aids may be an enhancement. (We would, in passing, ask the GDG to note that the strong evidence base for the effectiveness of patient decision aids is overwhelmingly from North America, where hundreds of such aids have been developed. Pilots in the UK have found that imported American content is alienating to UK patients, and that there is therefore a need to develop culturally specific aids for patients in this country. See, for example, 'Implementing patient decision aids in urology', Wirrmann E and Ashkam J, Picker Institute Europe, 2006. So far only a very small number of UK-specific decision aids is in	preferences are important. Regardless of how 'shared' the decision is, the GDG considered it important that patients were provided with adequate information. We have changed the order of these recommendations about decision making and use of decision aids.

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					development, and therefore the recommendation to use decision aids ‘where available’ may, at this stage, have little operational relevance.) This section of the recommendations in the guideline is therefore somewhat confused in terms of content and ordering. National Voices would prefer to see a section of recommendations on ‘shared decision making’ clearly separated out from other types of decisions. In such a section: • Recommendation 58 would be excluded (or deleted) • The recommendations would be re-ordered to establish the principle of shared decision making at the start • The formulation used in Quality Statement 15 (with the amendment we suggest in comment 7, above) should be used • Recommendation 64 would precede recommendation 63, and would be amended to reflect the text on p.100 of the guideline which states that ‘Patient decision aids... may act as an adjunct to good clinical practice... [but] are not necessary to deliver good decision making’	
254	National Voices	Full	4.1	26	National Voices welcomes the range of recommendations on the provision of information to patients, and particularly the emphasis on information that is in formats appropriate to each patient. However, we would like to raise two issues	Thank you for your comment. We recognise that the provision of information on its own is not enough. We do however think patients need to have information and have clarified the recommendations to say that patients need information and support to use information.

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					regarding these recommendations. First, we would ask the GDG to recognise that the sheer provision of information, while crucial, is not on its own sufficient to change behaviour or to help patients to be active in their own care and treatment, or to participate in decisions. One way to illustrate this is that, while patients report that the provision of information and explanations by healthcare professionals has improved, there has been no corresponding improvement in the involvement of patients in decisions – see 'Is the NHS becoming more patient-centred? Trends from the national surveys of NHS patients in England 2002-07', Richards N and Coulter A, Picker Institute Europe 2007. Research evidence shows that, contrary to the apparent assumption in recommendation 48, many patients experience difficulty in making active use of the information with which they are provided. It is the patients who most need to improve their health status who also most need help to make use of information with which to do so: people with low health literacy have poorer health status, undergo more hospital admissions, are less likely to adhere to treatment recommendations, experience more drug and treatment errors, and make less use of preventive services (Institute of Medicine. 'Health Literacy: a prescription to end confusion'. Washington DC: The National Academies Press, 2004).	We have added to our recommendations about knowing the patient as an individual to say that patients should be given information or directed to sources of support and information for these aspects of care.

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					For this reason, it has been recommended elsewhere that all strategies to strengthen patient engagement should aim to improve health literacy: see Coulter A and Ellins J. 'Effectiveness of strategies for informing, educating and involving patients'. British Medical Journal 2007;335:24-7 However, information that is delivered by a health professional, with both written and verbal explanations, and tailored to the individual patient, can be much more effective (Haywood K, Marshall S, Fitzpatrick R. 'Patient participation in the consultation process: A structured review of intervention strategies.' PATIENT-EDUC-COUNS 2006;63:12-23). Accordingly recommendation 50 gives a much better account of the role of the healthcare practitioner in providing information, and in this context, recommendation 48 is either superfluous, or should be amended, for example by inserting the words 'consistent support to make use of' before the word 'information'. Second, there is no single recommendation that states explicitly the need to provide patients with information which covers all their holistic needs, and not just clinical. Patients also require information on practical, emotional, social, spiritual and financial matters. Research has shown that it is on these issues where patients experience the greatest information deficits ('Assessing the quality of information to support people in making decisions about their health and healthcare', Coulter A et al, Picker Institute Europe, 2006).	

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					The importance of these non-clinical factors is recognised in recommendations 1 (see the patient as an individual), 3 (consider all factors affecting the patient's condition) and 7 (assess and discuss the patient's physical, psychological, domestic, social, spiritual and financial circumstances on a regular basis), yet there is no corresponding encouragement to help them through the provision of tailored information.	
255	National Voices	Full	4.1	26	National Voices notes, with regard to recommendation 50, that it may be useful to reference sources of evidence-based information, including NHS Evidence, and patient information that is produced by organisations accredited with the Information Standard.	Thank you for your comment. We have added this to the full guideline but the GDG did not consider appropriate to add to an individual recommendation.
256	National Voices	Full	4.1	26	National Voices welcomes recommendation 55 which recognises the value to patient experience of being sign-posted by professionals to extended sources of support. We would wish to see this reflected in the Quality Standard. Patients very often experience gaps in care which these support services can help to close. Moreover, these sources are often the best placed to provide the types of patient information that the NHS itself may not adequately provide, including relevant social, emotional and financial information.	Thank you for your comment. We are unable to include all the recommendations in Quality Standards.
279	National Voices	Full	4.1	27	Evidence from the 'invest in engagement' website reviewing the effectiveness of self-management education suggests that these are most effective when they are a) condition-specific, and b) linked back in to their continuing care under the main professionals involved with them. Linking the patient's learning from self-management education to their goal-setting with clinicians is more likely to	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did not consider however that we could do justice to the topic of self management in its entirety in

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					enable sustained changes in behaviour, and to improve experience. National Voices would suggest the following amendments to recommendation 65 on education programmes: In line 41, after 'taking into account', insert 'their specific condition as well as'... In line 40, after 'objectives', insert ', which are discussed and reviewed with their primary healthcare professional'.	this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.
283	National Voices	Full	4.1	28	In accordance with our comments above, National Voices would suggest strengthening the wording of Recommendation 66. The words 'that are available and meet' should be deleted, and replaced with, 'by providing these in accordance with the criteria listed in recommendation 65'.	Thank you for your comment. This recommendation has been amended for clarity.
407	National Voices	Full	10.5	108 -112	National Voices was surprised that in the section on 'education programmes' the literature search identified only one systematic review and no other high level studies on the effectiveness of education for self-management. We would ask the GDG to reconsider the evidence relating to this section. As part of this we suggest liaising with other experts familiar with this literature. We would also ask the GDG to review the evidence listed at http://www.investinengagement.info/Self-managementOutcomes This is a Department of Health-funded website researched and published by Picker Institute Europe, which identified, reviewed and summarised evidence (systematic	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did not consider however that we could do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.

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					and other high level research reviews) for the effectiveness of patient-focused interventions. The evidence listed here does, in part, support the GDG's view that education programmes fit into disease- or condition-specific guidance – in that it indicates that condition-specific education is more useful to patients than generic self-management courses for long term conditions. However, our assessment of this evidence is that it also shows strong enough benefits across a range of conditions for the GDG to strengthen its support to education interventions; to strengthen the wording of Recommendation 66; to improve the wording of Recommendation 65; and, in the Quality Standard, to include an additional item on education. We make suggestions for these in subsequent lines of this consultation response. According to this evidence review, numerous studies show that self-management education has a positive impact on patients' experience of using health services, including by: • increasing patients' knowledge and recall of relevant information; • improving their satisfaction with services; • improving their coping skills; • increasing their confidence to manage their condition; and • increasing their perception of being socially supported. Like the GDG, we acknowledge some limitations to	

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					these studies, particularly in that they often studied outcomes only in the relative short term (for example, up to six months after participating in education). However, from this review it does seem there is more evidence, albeit patchy, for the cost-effectiveness of education interventions in relation to, for example, diabetes, COPD and asthma.	
847	National Voices	QS	General	General	National Voices is concerned that, while NICE standards are expected to play a key role in helping commissioners and providers across a more decentralised system to maintain best practice, this draft standard contains a number of quality statements for which the GDG have been unable to identify relevant indicators. Commissioners will, under the Health and Social Care Bill 2011, have a duty to ensure the involvement of 'each patient' in their own care and treatment, and will be expected to fulfil this duty 'in the exercise of [their] functions' – meaning in everything they do. Commissioners will also have a duty to work for continuous quality improvement, with the definition of 'quality' including the domain of patient experience. Finally the NHS as a whole will be required through 'mandates' from the Secretary of State to achieve objectives in relation to the five domains of the NHS Outcomes Framework, which includes the domain of patient experience (and the domain of long term conditions, which is relevant to many of our comments above). The NICE Quality Standard on patient experience	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance In addition we expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					of generic services will provide the basis for these commissioning activities. It is therefore essential that it supports commissioners with the fullest possible information about how to measure and assess the experience of patients for whom they are responsible. As noted in our first comment, the Quality Statements are currently overly biased towards hospital settings and towards indicators that have been through the approval of the National Quality Board. The latter process has been extremely slow, and it is regrettable that indicators for primary are in particular have not been assessed and approved, when national survey instruments are available. We would request the GDG to consider the inclusion of indicators for primary care drawn from: • the Healthcare Commission's survey of patients using local health services (2008) • the General Practice Patient Survey (current) • other validated survey tools such as the CARE (Consultation and Relational Empathy) Measure We would also direct the GDG's attention to the fact that the co-ordination centre for the national patient survey programme has provided, for local use, a set of common questions and tools with which commissioners and providers locally could construct their own patient experience surveys. These are at: http://www.nhssurveys.org/localsurveys	

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					The GDG will need positively to consider the viability and appropriateness of enabling commissioners and providers to select from tested indicator sets, where these may not yet have been through NQB or similar approval. Further, we suggest that there are some cases in which the quality statements overlook questions from national patient surveys that are relevant. For example, QS 16 on the provision of evidence-based information could recommend the questions on medicines information suggested in our comment above, knowing that these would be relevant for around 80% of inpatients and 54% of primary care patients (as well as around one quarter of outpatients). We would therefore request a further review of the available survey questions to populate the quality statements.	
892	National Voices	QS	5	3	The quality standard currently does not refer to pain control or relief. As noted in 'Core domains for measuring inpatients' experience of care', Sizmur S and Redding D, Picker Institute Europe 2009, pain control stands out as a single important factor bearing on respondents' satisfaction with the service. Recommendation 17 in the full guideline is "do not assume that pain relief is adequate, ask regularly, provide on time and adjust as necessary". National Voices suggests that 'pain control' should be inserted in QS 5 alongside 'nutrition, hydration and personal hygiene'.	Thank you for your comment. The quality standard has been changed to reflect this.
908	National Voices	QS	16	4	In accordance with our comments 2-4 above, National Voices suggests extending QS 16 to include the provision of education as well as information. An additional paragraph could be added which states:	Thank you for your suggestion. This unfortunately was not addressed through evidence review against the agreed scope for this work.

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					'Patients with an identified long term condition are provided with the opportunity to participate in evidence-based education on how to manage that condition, which takes into account their particular condition and needs, and helps them to set aims and objectives in partnership with their primary healthcare professional'.	
1239	National Voices	QS	15	22	National Voices strongly welcomes the formulation of the 'shared decision making' quality statement. With its emphasis on support to the patient to participate in decisions, this formulation should be reflected back into the recommendations in the full guideline. We further suggest that after the word 'involved' the following text is inserted: 'as much as they wish to be'. The justifications are that: a. Not all patients wish to take an active role in sharing decisions. Around 25% of patients may wish to let health professionals decide for them. b. This additional wording reinforces the thrust of the quality statements generally in requiring that healthcare staff make efforts to elicit from the patient the degree to which they desire and feel confident to take part in decisions. c. The additional wording also reflects the formulation of the tested question on this issue from the national surveys (referred to in the 'relevant existing indicators' box)	Thank you for your comment. The wording has been amended.

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					which asks: 'Were you as involved as you wanted to be in decisions about your care and treatment?'	
1296	National Voices	QS	Appendix 1	25	National Voices considers it important that the list of policy sources should include the NHS Constitution.	Thank you for your comment. This has been directly referenced.
36	NCT	All	General	General	No comment	Thank you for your comment
87	NHS Blackpool	Full	General	General	NHS Blackpool has a PPI Committee, a subgroup of the Trust Board that would normally review a document like this. As the PPI Committee meetings do not fall within the timescale for stakeholder comments, I am responding as the lead for patient experience. The Patient Experience in Generic Terms draft guidance encompasses a variety of aspects of patient care that are determinants of good patient experience. The links to policy documents, such as the Outcomes Framework are explicit. Clinical, communication, patient involvement, family involvement, dignity, comfort and advice for clinicians and managers are all covered. I am pleased that NHS Blackpool is already working on many areas identified in the draft guidance The one area of significant weakness in the guidance is how to monitor progress. There is no explicit reference to benchmarking and suggested models of measuring improvement. Whilst the national in-patient survey, A&E/Cancer/Maternity (3 x 1 year rotation), and national GP survey are available, the guidance would be improved by considering how progress could be monitored locally, and in real time.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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87B	NHS County Durham & Darlington	Full	General	General	GENERAL/ESSENTIAL COMPONENTS OF CARE The only omission that I can potentially see overall is around ensuring some kind of holistic approach to patient reviews/consultations. What I mean by this is not pre-judging, making assumptions etc on the basis of a dominant condition/need. The example that prompts me to mention this is the poor health outcomes that are associated with people with learning disabilities and we know that this is because the learning disability often clouds any objective assessment.	Thank you for your comment. The intent of the Guidance is to ensure a holistic approach and recommendations are included which state that clinicians and others should avoid making assumptions or pre-judging people (recommendation 5).
165B	NHS County Durham & Darlington	Full	4.1.6	23	PATIENT AS AN INDIVIDUAL I would like to see point 6 linked to points 4/5 in the sense that individuals' culture, ethnicity and religion often has a direct bearing on their beliefs and attitude towards health and treatment and therefore an understanding of potential barriers would surely be helpful. A good example is travellers who are often decline routine screening tests and are certainly averse to any conversations about sexual health; all connected to their cultural beliefs.	Thank you for your comment, we acknowledge your point, however, we feel it is too much detail for inclusion in this guideline. If healthcare professionals follow all our recommendations, the example you described should not be an issue anymore.
358B	NHS County Durham & Darlington	Full	10.2	71	COMMUNICATION I would like to see a standard in this section around ensuring patients have the opportunity to ask questions. A standard around ensuring that patients have a key contact/telephone number or simply know who to contact for further information/ask questions etc would be in line with national CQC/CQUIN patient experience standards	Thank you for your comment. This is included in the final version of the quality standard.
88	NHS Direct	Full	General	General	NHS Direct welcome the guidance and have no comment on the contents following consultation.	Thank you for your comment

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89	NHS Hertfordshire	Full	General	General	The use of PALS has been expressed as a fairly new initiative, which is not the case in Hertfordshire	Thank you for your comment and information.
90	NHS Hertfordshire	Full	General	General	Needs to include safeguarding adults, consent / capacity and healthcare associated infections	Thank you for your comment. NICE usually includes standard advice about consent and capacity in the introduction to guidance. We have however added recommendations on consent and capacity (recommendations 30 and 31). While we recognise the importance of healthcare associated infections to patient experience, recommendations about this area are outside the scope of this guideline. NICE are currently developing a guideline on infection control and prevention in primary and community care.
166	NHS Hertfordshire	Full	4.1.3	23	What is meant by domestic	Thank you for your comment. Domestic means: pertaining to the home, the household, household affairs, or the family
167	NHS Hertfordshire	Full	4.1.9	23	Except where this may not be in their best interests	Thank you for your comment. Sharing patient information is addressed in recommendations 34, 35, 36.
196	NHS Hertfordshire	Full	4.1.14	24	Need somewhere to say this includes qualified & unqualified & allied disciplines	Thank you for your comment. This guideline is for all those who have direct contact with patients.
197	NHS Hertfordshire	Full	4.1.25	24	Only if patient has capacity	Thank you for your comment. Patient capacity is now covered in recommendations 25 and 31.
229	NHS Hertfordshire	Full	4.1.29	25	This needs to include that capacity is assessed and documented	Thank you for your comment. A recommendation has been written to address capacity.
257	NHS Hertfordshire	Full	4.1.58	26	Change medical to clinical	Thank you for your comment. The GDG discussed this suggestion and preferred the term 'medical' in this context.
280	NHS	Full	4.1.62	27	Use absolute risk rather than relative risk only if	Thank you for your comment. This

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	Hertfordshire				patient able to understand this concept	recommendation was based on RCT evidence showing absolute risk is better understood that relative risk.
454	NHS Hertfordshire	NICE	General	General	PCT and provider organisations support the aim of the guidance	Thank you for your comment
455	NHS Hertfordshire	NICE	General	General	The aim of the guidance & content of the quality statements should be part of everyday practice for all staff & organisations	Thank you for your comment
456	NHS Hertfordshire	NICE	General	General	The guidance states that the guidance does not cover people using NHS services for mental health or the experiences of carers of people using NHS services, yet it appears to cover all settings	Thank you for your comment. The guidance aims to cover all settings, however, does not take into consideration the carers' point of view, and there is a separate guidance for people using NHS services for mental health
457	NHS Hertfordshire	NICE	General	General	It is not clear how this guidance fits in with CQC registration and Essential Standards	Thank you for your comment. NICE are currently considering what implementation support to provide for this guidance
458	NHS Hertfordshire	NICE	General	General	How will staff be assessed as competent in communication skills	Thank you for your comment. This can only be addressed at a local commissioning level with clear guidance provided by commissioners of service delivery. We suggest that this is incorporated into annual appraisal processes and draws in both pre registration and post registration training.
459	NHS Hertfordshire	NICE	General	General	Need to link to staff surveys	Thank you for your suggestion
460	NHS Hertfordshire	NICE	General	General	Need to be more explicit about education & training	Thank you for your comment. Specific training to implement the guidance is outside the remit of a NICE guideline.
461	NHS Hertfordshire	NICE	General	General	More emphasis on customer care training	Thank you for your comment. Specific training to implement the guidance is outside the remit of a NICE guideline.
462	NHS	NIC	General	General	It needs to be more explicit regarding environment	Thank you for your comment. We agree that

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	Hertfordshire	E				the physical environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would not address physical environment.
463	NHS Hertfordshire	NICE	General	General	Many of the quality statements can be found in Trust welcome packs	Thank you for your comment.
848	NHS Hertfordshire	QS	General	General	There are resource implications to implement & monitor the quality measures	Thank you for your observation.
849	NHS Hertfordshire	QS	General	General	It is not clear how this evidence will be collected and what will happen if organisations are non compliant	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
937	NHS Hertfordshire	QS	1	5	This quality measure has considerable resource issues to gather the evidence and monitor the process	We note your comment.
976	NHS Hertfordshire	QS	2	7	This quality measure has considerable resource issues to gather the evidence and monitor the process	Thank you for your observation. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
359	NIHR King's Patient Safety & Service Quality	Full	10	71	"Health care professionals need to provide a context in which patients feel able to participate and to share decisions if they want to, thus ensuring a good experience for those patients."	Thank you for your comment. We have added a definition of shared decision making to the guideline document to clarify what we mean by "shared decision making".

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	Research Centre				We are not sure how useful the above statement is. It assumes that as long as the health professional explains things in a way the patient understands, the patient will end up agreeing with the health professional and the decision will be "shared". What if the two sides disagree? Can one "share" a decision to disagree? Can the health professional "share" in a decision for the patient to carry on smoking 50 a day, for example? Their "patient experience scoping study" was done on "diabetes" (which kind? - there are huge ethnic and age differences between the type 1 and type 2 populations which have implications for surveys on communication) and included the idea of "acknowledging patient expertise". Yet there were no questions in any of the surveys that assessed this. The closest I could find were questions like: "when you had important questions to ask the doctor, did you get answers you could understand?" and "did the doctor listen to what you had to say?". This isn't adequate and assumes the only thing the doctor could be doing wrong, really, is using too much jargon or complicated explanation. An example to show how this isn't adequate from research in our group: a young diabetic told me how he'd been to his doctor to ask for detailed help in understanding how to get his blood sugar average down. The doctor listened to what he had to say, then told him to "try and play a bit more football". The diabetic understand the doctor's answer perfectly, but the information conveyed	The scoping study covered both types of diabetes. We agree that the survey questions do not cover all the areas important to patients and their health, which is why we commissioned the scoping study and used other sources to inform the development of recommendations. We would hope that appropriate measures will be developed to reflect the complexity of issues such as that you describe.

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					was ludicrously simplistic for someone using insulin. The inadequate response, in this case, actually put the patient off seeking help for several years and caused him serious health problems. But the patient would still answer "yes" to the survey questions above. Snow,R. Fulop,NF. (in press) Understanding issues associated with attending a Young Adult Diabetes Clinic: a case study, Diabetic Medicine.	
417	NIHR King's Patient Safety & Service Quality Research Centre	Full & NICE	general	general	Terms like "dignity", "respect" and "honesty" are vague and intangible moral categories. Practical and observable actions should be stated, such as "All members of the healthcare team will support and facilitate patients' rights to choose, accept or decline treatment".	Thank you for your comment. While we accept that terms such as dignity and respect are difficult to define, patients can usually recognise when they are treated with dignity and respect.
418	NIHR King's Patient Safety & Service Quality Research Centre	Full & NICE	general	general	There appears to be a disproportionate emphasis on the individualised approach to care without I think sufficiently locating the individual in the social context and how social and cultural barriers inhibit in various ways how patients access care and their experience. Discrimination, health and power inequities in the care process are not properly spelt out and I don't think it is enough to mention the need to avoid things such as making assumptions on race, gender culture etc. Patient experience will be affected and determined by embedded structural inequalities at an institutional level often dictated by class, ethnicity, gender etc which will need specific approaches to make sure the individual experience is not compromised. JE.Ocloo ,NJ Fulop (in press) Developing a critical approach to patient and public involvement in patient safety in the NHS: learning lessons from other parts of the public sector? Health	Thank you for your comment. We agree that patient experiences are complex and situated within a wider context. We have included recommendations that encourage health care professionals to consider the wider patient context and have incorporated elements which address wider power issues.

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					Expectations.	
850	NIHR King's Patient Safety & Service Quality Research Centre	QS	general	general	In the draft quality statements, only the first and last points start with "Healthcare professionals". The first point puts them as object of evaluation. The last is the only point that puts staff in an active role: they "establish and use...", etc.. The guidelines should put staff and managers up front as doers, listeners and supporters in most of the points. Passive verbs – like "Patients are treated", "Patients are given" - do not make it clear who does what to facilitate improved patient experience. The guidelines should emphasise staff and managers' responsibility, agency and accountability throughout.	Thank you for your comment. The quality standards are written in this way to emphasises the importance of the patient.
851	NIHR King's Patient Safety & Service Quality Research Centre	QS	general	general	The quality standards seem to focus on the need for training individual health care professionals and I wonder if this can lead to a real change in organisational culture, particularly when other pressures / targets remain the same.	Thank you for your comment. Aspects of training that is implied in the guidance reflect the current focus in healthcare undergraduate training, and therefore this guidance is related to systems already in place.
852	NIHR King's Patient Safety & Service Quality Research Centre	QS	general	general	I think to focus at an individual level assumes that poor patient experience can be remedied by raising staff awareness and training which we know not to be the case. Also the assumption that we can create a 'shared, positive' culture doesn't take into account hegemony, hierarchies, competing Trust norms e.g. efficiency, throughput.	Thank you for your comment. The cultural shift that we refer to has to start at an individual level, with systems in place to maintain this change at an organisational level.
853	NIHR King's Patient Safety & Service Quality Research Centre	QS	general	general	Measurement is predominantly by patient survey so limited detail and after the event, and non-response by social groups who rarely respond to patient surveys. Perhaps would be useful to consider e.g. PALs data / real time Patient Experience Feedback as well.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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893	Nutricia Ltd	QS	3	3	Include food likes and dislikes to be discussed	Thank you for your comment.
894	Nutricia Ltd	QS	4	3	Include food preferences	Thank you for your comment.
1052	Nutricia Ltd	QS	5	11	Include that nutritional needs are recognised culturally and individuals are screened for nutritional risk	Thank you for your comment. This is too much information to include in the quality standard.
1240	Nutricia Ltd	QS	15	22	Include statement that 'adequate advice is provided to patients relating to nutrition and hydration to facilitate recovery' and 'adequate training being provided to service providers on nutritional screening and how to manage those nutritionally at risk' because nutritional screening should occur in all care settings (NICE CG32 2006); for those found to be at nutritional risk there should be appropriate nutritional intervention and monitoring. Maybe refer to NICE CG32	Thank you for your suggestion. This is a linked piece of guidance to other NICE guidance that fully addresses these points.
91	Pancreatic Cancer UK	Full	General	General	Pancreatic Cancer UK welcomes the development of the patient experience quality standards. The results of the 2010 National Cancer Patients' Experience Survey demonstrated that people diagnosed with pancreatic cancer fare significantly worse that patients diagnosed with other cancers. We hope that the development and implementation of these standards will help to improve care for people affected by pancreatic cancer. Overall we found the standards to be very comprehensive in covering the key issues that need to be addressed to ensure that patients receive a good experience of care.	Thank you for your comment
158	Pancreatic Cancer UK	Full	4.1.21	22	Pancreatic Cancer UK believes that all patients should also be informed about any clinical trials that are available for their condition. In the case of	Thank you for your comment. The remit for the guideline is generic patient experience in the NHS and we were not able to consider

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					pancreatic cancer there is often difficulty recruiting sufficient patients to clinical trials and patients are not always informed about the possibility of participating in a clinical trial. Clinical trials are essential for helping to increase the availability of new effective treatments and patients often report an improved patient experience from participating in trials.	the needs of specific groups within the development of this guideline.
198	Pancreatic Cancer UK	Full	4.1	24	Pancreatic Cancer UK feels this section should address the need to assess regularly whether patients are experiencing any side effects or symptoms from their condition or treatment and provide support to manage these symptoms. This issue is addressed for pain relief, but depending on the condition the patient may experience a range of other physical or emotional symptoms or side effects. For example in the case of pancreatic cancer nausea, diarrhoea, weight loss and fatigue. Patients are not always aware that there may be medications or advice that can help them manage these side effects and improve their quality of life. It is essential that their care team asks about these side effects/symptoms and provides access to appropriate support.	Thank you for your comment. We agree that these needs are important and that attention to them can be a significant influence on patient experience. We had however to limit the areas we were able to consider. Recommendation 1 does look at knowing the patient as an individual.
290	Pancreatic Cancer UK	Full	4.1.55	33	We believe this line should read local and national information and support services. Unfortunately local support groups are not available for all conditions. This may be due to the nature of the disease or size of the patient population. Many national organisations such as charities also provide nationwide support services such as helplines or website discussion boards.	Thank you for your comment. We had altered the recommendation in line with your suggestion.

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854	Pancreatic Cancer UK	QS	General	General	We believe that the quality statements should mention the need for access to support services which can have a significant impact on patient experience of care.	Thank you for your comment. We agree that access is important and can be a significant influence on patient experience. We had however to limit the areas we were able to consider.
1053	Pancreatic Cancer UK	QS	5	11	Standard 5 – We believe that it should be made clearer that this standard also applies to the assessment of symptoms and side effects such as pain. For example in the brackets after physical needs additional text could be added to include symptom relief or pain relief.	Thank you for your comment. The quality standard has been corrected to include this.
37	Parkinson's UK	All	general	general	The guidelines and the quality standard seem to be more directed toward inpatient care. There needs to be more information about guidance about primary care and quality standards drawn up to support this.	Thank you for your comment. The guidance is directed to all aspects of NHS care but primarily concerns staff-patient interactions.
38	Parkinson's UK	All	General	general	We would like to see some detail about complaints and helping people through the complaints system. Unfortunately, this guideline will not always be adhered to and there will be a need for people to complain about the care they have received.	Thank you for your comment. The recommendations cannot provide detailed advice about how people should be helped as this will inevitably vary according to service and locality (Recommendations 32 and 33).
528	Parkinson's UK	NICE	2	6	Draft quality statement 2 has no mention of mental disability (this could include depression or anxiety) that can affect someone's ability to participate in consultations and care. It also makes no clear reference to capacity with relation to someone who could have dementia or psychosis that could affect their ability to participate in consultation or care. This could affect someone who is not using NHS services for mental health. People with Parkinson's can have specific communication difficulties that can have an impact on their ability to participate in their care.	Thank you for your comment. This has been replaced with a more generic communication quality statement. "Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills".

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					Parkinson's leads to people have a very quiet voice, slow speech, slower thought process and other symptoms that can make communication more difficult. There is a lack of awareness about these communication barriers. This quality standard needs to look at wider communication barriers that impact on people taking part in their consultation and care.	
529	Parkinson's UK	NICE	6	6	Draft quality standard 6. This could also include an explanation of how the roles of the healthcare team relate to each other. This would give more idea about how the system is integrated.	Thank you for your comment. System integration is not necessary for all healthcare interactions, thus is not addressed here.
530	Parkinson's UK	NICE	10	6	Draft quality statement 10. This also needs to be shared with relevant social care professionals in the same way.	Thank you for your comment. The statement refers to exchange of information with social care.
531	Parkinson's UK	NICE	11	6	Draft quality statement 11. 'and can expect return contact within a reasonable timeframe' should be added to this statement	Thank you for your comment
566	Parkinson's UK	NICE	1.1.2	8	See earlier comment about draft quality statement 2. This needs to include mental health disabilities and capacity to make decisions.	Thank you for your comment. A separate recommendation about patient's capacity according to the Mental Capacity Act (2005) has been added to the guideline.
595	Parkinson's UK	NICE	1.1.5	9	This is phrased better than the draft quality standard. This includes the words 'listen to' which have a stronger implication than 'discuss' for getting patient centred care.	Thank you for your comment. The wording of recommendations and quality standards is agreed with NICE editors.
596	Parkinson's UK	NICE	1.2	9	Including the words 'physical symptoms' indicates that people won't be presenting with symptoms that are primarily mental health related. Dropping the word 'physical' would show that presenting symptoms can be physically or mentally based.	Thank you for your comment. This section has been changed to say 'health problem'
613	Parkinson's	NIC	1.2.9	10	This is something that is particularly important for	Thank you for your comment.

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	UK	E			Parkinson's. We would like to see added – patients must get their medication at the times they take their medication outside hospital. For Parkinson's it is vital that medication is given at the right time for the patient. If people with Parkinson's don't get their medication on time, their ability to manage their symptoms may be lost, for example they may suddenly not be able to move, get out of bed or walk down a corridor. This means they will be in hospital longer, with significant cost implications for the NHS and a negative impact on their quality of life.	Recommendation 17 addresses this.
614	Parkinson's UK	NICE	1.2.8	10	Medication needs to be included here somewhere. Patients need their medication and if there are difficulties in giving it to them (for example dementia leading to refusal, or swallowing problems meaning they can't take tablets) solutions need to be found.	Thank you for your comment. We agree that the administration of medication is important.. We had however to limit the areas we were able to consider.
643	Parkinson's UK	NICE	1.2.12	11	And that the patient understands this information	Thank you for your comment.
644	Parkinson's UK	NICE	1.3.4	11 /12	See earlier comment about quality statement. It also needs to be explained how the roles fit together.	Thank for your comment. The quality statements have been further refined into 14 for the final quality standard. We believe this has in part been addressed but recognise the importance of local application and establishment of good practice.
759	Parkinson's UK	NICE	1.5.19	17	There should be some reflection of the information and support provided by the voluntary sector. For example services provided by Parkinsons' UK include a free phone help line, on-line and paper based information (to the DH Information Standard) and face to face support and advice from our information support workers. We also	Thank you for your comment. This guidance is generic and not specific to long term conditions. Guidelines on individual conditions will continue to include condition specific information.

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					have over 350 local support group through which people receive mutual support and advice form other people affected by Parkinson's in their area, which they can find hugely beneficial. Anyone who is receiving healthcare, particularly if it is a long term condition should be told about relevant voluntary sector organisations, with where possible both nation and local contact details. This should be a standard and at present it falls far below that.	
938	Parkinson's UK	QS	1	5	If health and social care professionals have to follow this guidance then the statement should be changed to read 'health and social care professionals and all other staff'	Thank you for your comment. This has been amended.
855	Patient Experience Network	QS	General	General	Overall all the statements are good in that they are all required to deliver a standard level patient experience.	Thank you for your comment.
856	Patient Experience Network	QS	General	General	As we read the material and the 17 statements it felt like there should be a 'hierarchy' of statements, possibly similar to Maslow's hierarchy of needs. Essentially there are some statements that if you do not satisfy these then you will fail at the others – i.e. there is a hierarchy of statements potentially.	Thank you for your comment. The quality statements have been listed to reflect the chapters in the guideline.
857	Patient Experience Network	QS	General	General	We felt there is still a risk of this becoming a tick box exercise – which therefore inherently runs the risk of not achieving your objectives of empirical change	Thank you for your comment.
858	Patient Experience Network	QS	General	General	Potentially for those who do go beyond the tick box, even if they did achieve all of the statements they could still potentially deliver a mediocre experience – these statements capture only the 'what' – they do not encapsulate the 'how'. The 'how' is the emotional connections that need to be made to create a great experience	Thank you for your comment. The quality standards are supported by the recommendations in the guideline.
859	Patient	QS	General	General	Finally in summary somehow these do not feel	Thank you for your comment.

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	Experience Network				ambitious enough. If we are going to drive excellence in patient experience and the service they receive these alone will not deliver that – they will, however, establish the base foundations	
92	Patients Association	Full	General	General	We welcome the commitment from NICE to providing comprehensive guidance on improving the experience of care amongst patients. The Patients Association operates a Helpline from which we hear frequently from patients about their dissatisfaction with some NHS services. We hope that by giving a clear and comprehensive steer to healthcare professionals on what is required to provide a good patient experience, this will improve. Furthermore, while this guidance is useful, strong leadership will be needed to ensure that it becomes a reality. Finally, while this guidance is aimed at adult care services, it is also important for there to be a regard to the needs and concerns of younger patients, in particular young adults who may be lost in the gap between children's medicine and adult medicine. It is important that healthcare professionals and the NHS in general recognises that the concerns of young adults may be different to that of adult patient's and these must be addressed accordingly.	Thank you for your comment. Thank you for your comment. Transition from paediatric to adult care is on the list of topics recommended by the National Quality Board for quality standard development. The Guidance covers users of adult services which could include young people.
488	Patients Association	NICE	general	5	We also welcome a commitment to patient centred care. We believe that patients must be at the heart of the health service and should be involved in all decisions about their care. However, genuine involvement can only be accompanied with appropriate and relevant information in an accessible format. Patients need the right information at the right time if they are to be involved in their care.	Thank you for your comment. We have tried to ensure the key elements you mention are a key focus of the Guidance.

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567	Patients Association	NICE	1.1	8	The Patients Association hear frequently on our Helpline that patients want to be treated as individuals but often feel more like a statistic. Patients often tell us that they feel that healthcare professionals only see the disease but do not see the person behind it. Healthcare professionals need to be able to engage and communicate with patients as individuals. This will improve patient trust and ultimately result in a better experience for patients	Thank you for your comment and information.
597	Patients Association	NICE	1.2.1	9	Patients, particularly those who are staying in hospital, are often treated with very little dignity, respect or compassion. There needs to be a firm commitment from clinicians to ensure dignity is extended to all and this needs to be instilled into each ward by strong leadership	Thank you for your comment.
598	Patients Association	NICE	1.2.2	9	Medical information is of the most sensitive and confidential type. There needs to be stronger guidance and details on this.	Thank you for your comment. Areas of confidentiality has been addressed in recommendations 28 and 29.
615	Patients Association	NICE	1.2.4	10	Discussion of sensitive issues needs to be done in a careful and respectful way so as to put patients, particularly elderly patients at their ease. Practical solutions such as drawing curtains around beds and making sure discussions are not overheard on the ward are essential. If possible, moving sensitive discussions to a private room would be advisable.	Thank you for your comment. The area of respect is addressed in recommendation 4.
616	Patients Association	NICE	1.2.7 – 1.2.8	10	Malnutrition continues to be a serious problem for patients, particularly those staying in hospital. While training for professionals on the issue is essential, there also needs to be better information for patients. Work conducted by the Patients Association has found that there is a low level of awareness amongst patients about what constitutes malnutrition and the best way to avoid	Thank you for your comment. We agree that malnutrition is important, however we had to limit the areas we were able to consider. As you noted CG32, nutrition support in adults, addresses some of these areas.

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					it. In addition, we found that very few patients recalled being screened for malnutrition upon admittance to hospital, even though this is set out in NICE guideline CG32 as a requirement for all in patients. Hospital managers must ensure that healthcare professionals are carrying out screening	
617	Patients Association	NICE	1.2.9	10	Patients frequently tell us that they do not feel they understand their medication or its side effects. In a report published by the Patients Association, "Public Attitudes to Pain", patients told us that they often took less of their medication because they were concerned about side effects. They were also afraid of speaking to their doctor about these issues for fear of being rebuked by them. Healthcare professionals need to have a full and honest discussion about side effects so that patients understand the medication and can share their concerns. This needs to be captured here and there should be clearer guidance within this document on the issue. Furthermore, self management can be useful, but there will still be a reliance on healthcare professionals to give patients a clear understanding of their medicines.	Thank you for your comment. The use of medication is covered in recommendation 56.
645	Patients Association	NICE	1.2.10	11	In the Patients Association report, Public Attitudes to Pain, many patients told us that they sometimes took more than their prescribed amount of pain relieving medication because the dosage prescribed did not give sufficient relief. Healthcare professionals need to constantly monitor the levels of pain in patients and ensure that their pain relief is adequate.	Thank you for your comment. We have amended recommendations to reflect the importance of pain relief.
646	Patients Association	NICE	1.3	11	Every patient is different and therefore every patient's care will need to be tailored to be right for them.	Thank you for your comment.

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647	Patients Association	NICE	1.3.1	11	The key phrase here is taking account of each patients personal preferences. Patients have a right to choose what healthcare they want and what types of treatment will be right for them.	Thank you for your comment.
648	Patients Association	NICE	1.3.2	11	In relation to 1.3.1, patient access to meaningful and clear information about services is essential. If patients are to be able to make choices for themselves, they need first to be able to understand the options that are available. This goes beyond just giving patients information leaflets and needs to be at the heart of a consultation with a healthcare professional. Healthcare professionals must guide patients through the information they have been given and answer their questions. In work recently completed by the Patients Association, patients told us that although they may use GPs or other healthcare professionals as a source of information they do not always find this source to be useful. Many patients are relying on information derived from websites. Healthcare professionals should go through information with patients, explaining any points that the patient does not understand and answering any questions they may have on that information. In addition, once information has been given to patients, patients should be given an opportunity to absorb it in order to make a decision that is right for them. A "cooling off" period of a day or two days may be useful here to ensure patients can use the information at their disposal usefully.	Thank you for your comment and information. This is addressed by guidance recommendations.
668	Patients Association	NICE	1.3.5 - 1.3.6	12	We welcome these points. We hear frequently from relatives that they have been shut out of the care of their loved ones, particularly those who are very elderly. 'Shared decision-making' where appropriate, must extend to patients families and	Thank you for your comment. To review this regularly has now been included in the recommendation.

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					carers. The guidance states that they patient must clarify at the outset if they want family members involved but it must be recognised that a patients wishes may change during their treatment journey and healthcare professionals must adhere to this.	
669	Patients Association	NICE	1.3.7	12	Particularly amongst elderly patients, there is still a perception that "doctor knows best" and some may be concerned about speaking up in front of them. Healthcare professionals should take active steps to allay these concerns and make it clear to patients that it is their care and they have the right to decide for themselves.	Thank you for your comment.
685	Patients Association	NICE	1.4	13	Each patient will have different needs with regard to continuity of care in healthcare professional relationships. For many patients who are undergoing treatment, there will be a lot of anxiety and distress. The ongoing presence of a familiar, trusted and reliable healthcare professional can give comfort to patients, improving their confidence and mental wellbeing.	Thank you for your comment. The recommendations are designed to span all settings and disease areas. It is important to acknowledge individual preferences relating to continuity of care and amendments to recommendations we believe have strengthened the guidance.
686	Patients Association	NICE	1.4.2	13	Patients need to understand who is treating them at all times. We have heard from patients undergoing surgery that their surgeon was changed at the last minute and that they did not feel comfortable going forward with the surgery without the healthcare professional who they had built up a relationship of trust with. Many patients also tell us that they sometimes have difficulty distinguishing staff on the ward, particularly porters, doctors and nurses. Whether by a uniform or clear dress code policy it must be clear to patients what the role and function of each member of staff is.	Thank you for your comment. We agree that patients should be informed about the identity and roles of individuals who are caring for them.
712	Patients Association	NICE	1.5	14	Shared decision making is quickly becoming a central part of healthcare and we agree that there	Thank you for your comment. We recognise shared decision making as a process rather

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					does need to be greater shared decisions making and more opportunities for patients to be involved in their care. However, it is vital that the individual needs of the patients are addressed and there needs to be a recognition that some patients may not want to be involved in their care. In a survey conducted by the Patients Association, patients gave very different descriptions of what they understood shared decision making to mean. The individual's preference to decision making needs to be taken into account.	than an outcome and this process needs to be sensitive to the needs and preferences of individual patients.
713	Patients Association	NICE	1.5.4-1.5.11	14 -15	Communication skills need to be an important part of every healthcare professional's training and their needs to be a clear understanding of the need for jargon free, understandable and meaningful communication with patients. Each patient's needs will be different and healthcare professionals need to be in a position to tailor their approach to communication to the needs of the individual in front of them.	Thank you for your comment. We agree that each patient's needs will be different.
740	Patients Association	NICE	1.5.12	16	Information is vital if patients are to be able to make decisions. However, that information must relevant and meaningful. It is also important not to overwhelm patients with information. If patients are to be able to find information useful for decision making, they also need to be given adequate time to consider and absorb that information.	Thank you for your comments. We agree.
741	Patients Association	NICE	1.5.17	16	It should also be recognised that many patients may want time to discuss the options they have been given with their relatives and loved ones to make sure that it is right for them and their loved ones.	Thank you for your comment. It is recommended that people are given adequate time to discuss and arrive at their decision.
760	Patients Association	NICE	1.5.19	17	The Patients Association is part of a group of charities called the Network for Patients. In 2009 the Network published its manifesto, an important	Thank you for your comment. It is not within our remit to put a stronger duty on health care professionals than the current

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					part of which was the "GP duty to refer". In this, the Network for Patients called for there to be a duty on GPs, and indeed other healthcare professionals, to signpost patients to the appropriate disease specific charities for advice, support and information on the condition they had been diagnosed with. We welcome this idea's inclusion within this guidance but would like to see a stronger duty on healthcare professionals to signpost patients to support organisations and third sector groups that would be in a position to provide information and support.	recommendation.
761	Patients Association	NICE	1.5.20	17	We welcome this further emphasis of the need for more opportunities for patients to be involved in decision making about their care but would note that not all patients will want to be involved in these decisions. It is also important where patients may have limited capacity; they are still given appropriate opportunity to be able to make some decisions about their care. We understand that separate guidance is being put together on this issue but feel it is important to establish this principle in the main body of the patient experience guidance.	Thank you for your comment. The GDG agree that not everyone wants to be involved in decisions about their care, and believe this is covered by encouraging people to express their personal needs and preferences. A recommendation has been added pertaining to those who are unable to consent. Capacity issues remain important and are addressed by the guidance.
762	Patients Association	NICE	1.5.21	17	Again, these opportunities for patients to discuss all aspects of their care with their healthcare professional are invaluable. We would further note that those who may have limited capacity should still be given the opportunity to discuss these issues.	Thank you for your comments. A recommendation has been added pertaining to those who are unable to consent.
763	Patients Association	NICE	1.5.22	17	We agree that before any procedure, diagnostic or otherwise, patients must be given ample opportunity and information to understand what is going to happen. Some patient may need extra time to absorb all of the information and time must	Thank you for your comment.

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					be set aside for this as well as giving them an opportunity to ask questions. It is vital that any concern, no matter how trivial it may seem to the healthcare professional, is treated seriously.	
764	Patients Association	NICE	1.5.23	17	Patients should not be allowed to go away from a consultation with a false conception of what will happen and the effects of treatment. It is up to the healthcare professional to establish that the patient has a clear understanding of what the treatment will achieve	Thank you for your comment.
765	Patients Association	NICE	1.5.24	17	It is vital that patients are given enough time to make their decision and should not be rushed into making any decisions they may later regret.	Thank you for your comment. This is reflected in recommendation 22.
773	Patients Association	NICE	1.5.25	18	No two patients will view risks, benefits and side effects in the same way and we agree that it is necessary to recognise and accept this when explaining treatment options to patients.	Thank you for your comment.
774	Patients Association	NICE	1.5.28	18	Different patients will need different levels of support and healthcare professionals must tailor support as appropriate. They also need NICE guidance on how to recognise non-verbal signals for patients wanting support as some patients may be unwilling to voice concerns or ask questions.	Thank you for your comment. The GDG believe that refinement ot recommendations post consultation better reflects the valuable points you raise. That said, it is important to acknowledge the limitations of the guidance as it is dependent on personal and organisational behaviour change. .
780	Patients Association	NICE	1.5.30	19	In the Patients Association report, Public Attitudes to Pain, we found that some patients wanted to have more of an opportunity to self-manage their condition, for example through Expert Patient Programmes. These can be very useful but healthcare professionals must still be ready to give patients extra support where it is needed.	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been

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						assured that this will be raised with the National Quality Board.
784	Patients Association	NICE	4.2	21	We welcome the incorporation of this guidance into a NICE pathway. We hear very often through our Helpline that the routes through the NHS are convoluted and confusing and are not always joined up. We hope a pathway will provide clarity to both patients and healthcare providers alike.	Thank you for your comment
785	Patients Association	NICE	4.3	21	We welcome the conversion of this guidance to an understandable summary for patients and carers. It is important that this is available in a variety of media and formats. We would also be concerned that there are many patients, particularly elderly patients, who will not have internet access, and efforts should be made to ensure this guidance is presented in a format and medium useable to all.	Thank you, your comment will be forwarded to the NICE communications team
947	Patients Association	QS	1	6	We agree that there does need to be an assessment of a healthcare professional's compliance with guidance on patient experience. This also should form part of the revalidation of medical professionals.	Thank you for your comment.
948	Patients Association	QS	2	6	This must be done with care and tact so as not embarrass patients. These are sensitive questions and many patients may not feel comfortable talking about these issues. Healthcare professionals must be able to put patients at their ease so they can feel able to talk about these issues. Further to that, sensitive questions like these should be asked privately to avoid compromising patient confidentiality.	Thank you, we agree with your comment.
949	Patients Association	QS	3	6	This should go beyond being given the opportunity as some patients may not feel able to challenge the views of their healthcare professional and discuss what they want from their healthcare. The emphasis should be on Healthcare professionals	Thank you for your comment. Post consultation wording has been further refined.

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					to take steps to encourage patients to discuss these issues.	
950	Patients Association	QS	4	6	We welcome the inclusion of this in the guidance.	Thank you for your comment.
951	Patients Association	QS	5	6	It must be made clear that the examples given (ie nutrition, hydration and personal hygiene) are not exhaustive and that other issues should be taken into account as well. For example, pain relief.	Thank you for your comment. Pain has now been included.
952	Patients Association	QS	13	6	We would appreciate greater clarity on what "competency" here would mean.	Thank you for your comment. 'Competency' here refers to the person's skill and expertise.
977	Patients Association	QS	15	7	While shared decision making is important in ensuring that patients are happy with their care, some patients will not want to be involved in decision making, preferring to rely on the judgement of their healthcare professional. This needs to be reflected in this standard	Thank you for your comment
978	Patients Association	QS	16	7	Information for patients must be meaningful and easy to understand. It is important that patients are given enough information, but it is equally important that patients are guided through this information by their healthcare professional who should be able to answer their questions and address their concerns. Patients should also be signposted to the appropriate disease specific charity or support group who may be in a better position to provide the kind of support that patients want.	Thank you for your comment. This is too much information for the quality standard however it is covered in the supporting recommendations.
45	Pelvic pain support network	Appendices	General	General	Our comments are as follows : There is very little about chronic pain here and yet it is key to the patient experience	Thank you for your comment. The Guidance includes a reference to the importance of pain management (Recommendations 13 and 15).
321	Pelvic pain support network	Full	7.2.2 Line 8	49	Our comments are as follows: The pain aspects are focussed on hospital staff. The emphasis seems to be on "inpatient" care. What about generalist care and other settings? This needs to	Thank you for your comment. The guidance is generic and therefore all recommendations relate to all settings. This reference is to a question from the NHS survey.

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					follow through. Patients can be discharged from hospital in severe pain without follow up. Suggest change of wording "inpatients" to "all settings "	
325	Pelvic pain support network	Full	7.3 point 17	51	Our comments are as follows : "Omission : please include : "All healthcare professionals who are directly involved in patient care should receive education and training relevant to their post on the importance of assessing and managing pain." Transition from acute to chronic pain occurs rapidly	Thank you for your comment. Assessment has been added to this recommendation.
381	Pelvic pain support network	Full	10.3.2 Recommendation 55	79	Our comments are as follows : need a reference here to organizations that are accredited producers of quality health information ie : the Information Standard	Thank you for your comment. We have added this detail to the Full guideline.
895	Pelvic pain support network	QS	5	3	Our comments are as follows : Patients regularly have their physical needs (such as nutrition, hydration and personal hygiene) assessed …. Why is there no mention of pain here ? What is more important to the patient experience than pain ?This should be included here or added as a separate point.	Thank you for your comment. The quality standard has been changed to reflect this.
93	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	General	General	Hospital signage needs to be improved to help patients navigate to the right places as quickly as possible. Reasonable adjustments needs to be made re: appointment times and where there are long delays identifying an area where patients can go rather than waiting in a busy waiting room. Suggestions have also been made re: systems in which patients with specific needs / conditions which makes it difficult for them to wait for delayed appointments can be prioritised During hospital stays having somebody familiar with you who is supplementary to the nursing staff can be important. Having contact with someone	Thank you for your comments. Physical environment was not part of the Guideline focus. We agree that services need to consider the needs of individual patients and be responsive to them. We cannot make recommendations for specific groups as the Guidance is generic and should be relevant for all patients.

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					who understands the specific needs of a specific condition e.g. Learning Disability Liaison Nurse has been highlighted as being important.	
168	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.1 Recs 1+2	23	[line 4 – 8] Seeing the patient as an individual is crucial to meeting the needs of people with a Learning Disability. Understanding how a physical condition affects the person needs to be extended more strongly to an understanding of what a specific disability or condition such as a learning disability is and how this can affect the individual's ability not only to understand their symptoms, express their symptoms and participate in consultations of care but also how they engage with primary / secondary care prior to a hospital appointment and following the appointment.	Thank you for your comment. We recognise the problems that people with learning disability my have. A recommendation about appropriate assessment of patient's capacity has been added to the guideline and we added recommendations about ensuring that services are alerted to peoples needs before they attend appointments. This is generic guidance and does not address specific conditions.
169	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.5[	23	[line 15] The importance of listening needs to emphasised more strongly. This relates to listening to the patient e.g. a person with a Learning Disability, but also to their carers / family members. Evidence from carers / family members suggest that they feel their views are often disregarded when in fact they could be crucial in helping to understand needs of the person they are supporting which they cannot express themselves.	Thank you for your comment. We have specifically added involvement of family members to our recommendations on communication.
170	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.8	23	[Line 25] This is essential to all care provision. A specific example has been given of a patient having to wait all day for an operation without food and drink and at 6pm was told it was too late. The patient felt that if she had been told that was a possibility, it would have been easier to manage.	Thank you for your comment.
171	Ridgeway Partnership Oxfordshire Learning	Full	4.1.12	23	[Line 30] Actively Listening to concerns needs to be emphasised more strongly. It is important not to dismiss concerns with the line 'trust me….' It is important to note that many patients are frightened	Thank you for your comment, this recommendation has been altered to include this.

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	Disability NHS Trust				or nervous about their visit to hospital which needs to be acknowledged and reassurance provided. Being informed about what is happening is important. A specific example has been given within the organisation where the patient was not asked about their concerns and anxieties following two different Drs marking her before an operation because 1 Dr overruled the other. Nobody noticed the increased anxiety the patient experienced. This demonstrates the importance of observation skills in additional to verbal communication and active listening.	
199	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.17	24	[Line 12] Many patients may not be able to verbally express the need for more pain relief. In addition to asking it is important to be able to observe non verbal cues that may indicate that a patient is in need of pain relief. Verbal questioning could also be supported with using visual scores of pain levels.	Thank you for your comment. Recommendation 15 has been changed to include the use of a pain scale.
200	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.21	24	[Line 22] The format of information needs to be given consideration. Written information may not always be the best option. Language used to explain treatments needs to be a jargon free as possible. Checking understanding of treatment options is crucial .	Thank you for your comment. Please see recommendations 43 to 48 which focus on the format of information.
201	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.23/24/25	24	[Line 26-33] Issues relating to the Mental Capacity Act, Capacity to Consent, Best Interests and Health Care Professionals responsibilities within these areas needs to be addressed formally within the guidance. Gaining consent from people with cognitive difficulties needs time and preparation and cannot always be managed effectively within a short time period. It is important to understand the preparation needed to gain truly informed consent / assess capacity and how to support the individual	Thank you for your comment. Two recommendations have been added to address these issues (recommendations 30 and 31).

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					who lacks capacity. It is important to understand the role of family / carers when supporting the individual who has the capacity to make decisions. Carers are legally on not entitled to speak on behalf of the person they are supporting but may need help in talking about their needs / symptoms. Equally it is important to understand the role of family / carers who are supporting individuals who lack capacity, knowing what information can be shared with whom and when.	
202	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.26	24	[Line 26] Reference should be made to the importance of being able to ask questions in the right way and meaningful to the patient – being specific about the information you need and explaining it in a way that can be understood clearly.	Thank you for your comment. These areas are covered in the Communication section (section 10.2).
230	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1. 32 - 36	25	One of the biggest problems faced by people with a learning disability is the lack of information that is shared between different departments / services prior to, during and following a hospital episode. A lack of understanding about what each other is doing can leave the patient stranded in the middle. It is also important to have an understanding of the home circumstances that patients are being returned to. Cases have been sited where an family member with discharged to the care of their daughter who had a learning disability did not have an understanding of the after care required / medication etc. The guidance does not really address the needs of patient before they reach the hospital, where there is a planned appointment or admission and the importance of appropriate information being provided in a timely way. This is a crucial part of being able to effectively support people with a	Thank you for your comment. The recommendations are designed to span all settings and disease areas. We believe the revised recommendations cover the types of situations that you describe.

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					learning disability but also people with other conditions that affect their cognitive / physical abilities. Ensuring that the right people are given the right information following discharge is also hugely problematic. Having a knowledge of the relevant agencies that are involved to providing continuity of care for each individual is essential.	
231	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.35	25	[Line 18-20] Care should be based where ever possible on agreed care pathways which need to be reviewed on order to ensure that they are meeting need.	Thank you for your comment. The GDG did not believe this level of detail was required.
232	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.38	25	[Line 26-29] Maximising patient participation in communication should also include appropriate preparation for the patient e.g. prior visits to familiarise them to the environment, written / visual about the appointment / stay in hospital e.g. DVD of what happens, linking with relevant agencies e.g. Learning Disability Teams, appropriate preparation for health staff e.g. making sure they have an understanding of key factors that may impact on their ability to communicate, Understanding of learning disability or the condition they have, reading information that has been sent by carers / professional prior to the appointment and using this appropriately to inform discussions / treatment options.	Thank you for your comment. We consider that the recommendations included in other sections e.g. knowing the patient as an individual and tailoring services to the individual include many of these aspects of care you describe.
233	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.43	25	Use of open ended questions can sometimes be challenging for some patients with cognitive difficulties and other conditions . Closed questions can be more effective to open conversations. It is important to know when it is appropriate to use which type of questioning.	Thank you for your comment. We recognise that open- ended questions are not always appropriate but the recommendation is specific in using these to encourage discussion

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258	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.146	26	[Line 5] Who defines the level of competency to be required. How is this assessed and by whom?	Thank you for your comment. Competency falls under the remit of professional organisations and employers.
259	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.49	26	Information before the first visit can be equally important.	Thank you for your comment. We have changed the recommendation to include this.
260	Ridgeway Partnership Oxfordshire Learning Disability NHS Trust	Full	4.1.50	26	[Line 50] This should include what to do if there are any changes in expected waiting times / treatment / investigations.	Thank you for your comment. The list is a suggested list only and cannot be considered exhaustive.
860	RNIB/Action on hearing loss	QS	Scope	General	We welcome the proposed NICE quality standard that is being developed for patient experience in adult NHS services. This should form the very basis of good patient experience, and be both sustainable and attainable. We recognise that there is a tension between a generic quality standard and the need to recognise the needs of specific patient groups. It may therefore be felt that some of the additional wording we are suggesting is inappropriate. If that is the case we would strongly urge the Technical Expert Group to give due consideration to the proposed rewording of the paragraph on diversity, equality and language. As it stands this does not reflect the full remit of the Equality Act 2010 and would benefit from being up-dated in line with the	Thank you for your comment. Changes have been made to reflect this.

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					wording suggested below.	
861	RNIB/Action on hearing loss	QS	Diversity, equality and language	General	We believe that all quality standards should reflect the duties of public bodies under the Equalities Act 2010, not just in relation to communication but in relation to non-discriminatory treatment. We would therefore appreciate specific reference to the Equalities Act in this paragraph. We suggest the following wording: 'Patients have a right to be treated in line with the requirements under the Equality Act 2010. This applies in particular, but not exclusively, to good communication between health and social care professionals, their patients and service users. Treatment and care, and the information given about it, should be culturally appropriate. It should be accessible to people with additional needs such as physical, sensory or learning disabilities as well as those who cannot read standard print or English. Patients should have access to an interpreter or advocate if needed. Every attempt should be made to provide information in a person's requested format at the time of the request. If a requested format is not immediately available every effort should be made to produce and supply it within a reasonable timeframe.	Thank you for your comment. Changes have been made to reflect this. This is supported by the recommendations in the guideline.
896	RNIB/Action on hearing loss	QS	1.	3	We welcome draft quality statement one and agree that healthcare professionals and all other staff who interact directly with patients are assessed, evaluated and mentored for their compliance with the NICE guidance on patient experience in adult NHS services. However we question how immediate any changes will be if staff are only assessed annually.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					If people find themselves in adult NHS care it is because they are in poor health and require good patient care to improve their condition. If patient experience can be assessed and improved on a more regular basis it is possible they will require less time under adult NHS care and receive better quality care. We therefore recommend for the annual one-to-one assessment to be supplemented with more regular audits to ascertain whether departments are achieving the outcomes defined by the Quality Standard on patient experience.	
979	RNIB/Action on hearing loss	QS	2	7	We very much welcome this statement that asks patients about any physical or learning disabilities, sight or hearing problems, difficulties with reading, understanding or speaking English. Since the draft quality standard is meant to maximise participation in consultations and care we feel that the statement would benefit from being strengthened by emphasising the need to ask patients about their needs as soon as they come in contact with a new healthcare team. We would like to suggest the following wording: 'Patients are asked at the first point of contact with each healthcare team about any physical or learning disabilities, sight or hearing problems, difficulties with reading, understanding or speaking English.' We believe this would achieve the proposed outcome. We welcome training for health and social care professionals to establish factors that might affect patient involvement and engagement. We also welcome the structure of the draft quality measure but would like clarification on what	Thank you for your comment. Changes have been made to this Quality statement to reflect that these factors are addressed. The GDG did not wish to restrict this conversation to the first point of contact as circumstances may change over time. The equalities act is now reference and post consultation wording has been further refined.

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					evidence would be provided to show patients are asked about their preferences. We believe this would be a stronger quality statement if staff were required to note in the patient's physical or electronic records any communication needs and preferences raised by patients. These could then be accessed by other members of the healthcare team to avoid duplication of work. This will also enable them to make any necessary arrangements in advance of an appointment, for instance, booking an English-British Sign Language interpreter.	
1008	RNIB/Action on hearing loss	QS	3	9	We welcome this draft quality statement that focuses on the patient as an individual. It is essential that patients are given the opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care. Our concern is that the patient may become irritated that he/she has to discuss preferences at each appointment rather than having them noted acted upon in the first instance. We feel if this were to happen it would save time in future consultations and give the patient confidence that their preferences had been taken onboard. We would therefore welcome a statement that says 'patients are given the opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care. Actions should be taken to ensure these are acted upon and that preferences are confirmed and where necessary adjusted on a regular basis.'	Thank you for your comment. We have made the assumption this will be the case as you suggest. Post consultation wording of the guidance has been further refined.
1023	RNIB/Action on hearing	QS	4	10	We welcome draft quality statement four and would encourage this approach to all patients. We	Thank you for your comment. We recognise the particular needs of those with disabilities.

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	loss				agree that this should be embedded into the service through annual appraisal, performance management, and governance and measurement systems. However it is important to recognise that those with a disability may need more favourable treatment than others in line with the Disability Equality Duty, which assumes that equality of opportunity for disabled people, cannot be achieved by treating everyone the same. Reasonable adjustments will often need to be made to ensure true equality. A change to the generic statement at the beginning of the Quality Standard that makes explicit reference to the Equality Act 2010 would encourage health care providers to make such adjustments.	However, the remit for the quality standards and guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline and quality standards. The equality Act is now referenced within the guidance.
1054	RNIB/Action on hearing loss	QS	5	11	We welcome draft quality statement five and would encourage it to be carried out to the highest standard. An environment that maintains a visually impaired person's dignity and confidentiality is imperative as those with sight loss may not be able to recognise the environment they are in. In order to discuss physical needs and psychological concerns they need to be made aware of their surroundings in order to ensure they have the same privacy as a sighted patient. This is especially important when receiving information such as treatment results in their preferred format. Not only does receiving results	Thank you. We agree with your comment.

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					in accessible format compromise a patient's privacy, it is inexcusable to expect a patient to receive results only verbally. If it is only delivered verbally, too much responsibility is placed on the patient to remember important information accurately. Moreover, people with hearing loss may capture partial or incorrect information. For instance, research undertaken by Action on Hearing Loss found that 33% of British Sign Language users were either unsure about instructions or had taken too much or too little of a medication because of communication problems with their GP or nurse[19]. This can lead to patient issues such as a fear in acting on the wrong information or an anxiety in not knowing exactly what they were told.	
1078	RNIB/Action on hearing loss	QS	6	12	We believe that a requirement for all members of the healthcare team to introduce themselves and give a clear explanation of their role, responsibilities and contribution to patient's care is essential in improving patient care. It will be especially appropriate to people with sensory loss who may otherwise find it difficult to recognise or call on the advice of members of the healthcare team when needed. Staff should also make special allowances for those with sight loss. A visually impaired person may require staff to reintroduce themselves at each appointment as they cannot use their sight to identify them. We believe that an amalgamation of draft quality three and six would be achievable and would	Thank you for your comment. This has been amended to: All staff involved in providing NHS services should ensure that their name, role and responsibilities are known by the patient before any discussions or consultation take place. Where possible the patient should see the same healthcare professional or healthcare team

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[19] A Simple Cure, A national report into deaf and hard of hearing people's experience of the National Health Service. RNID, London, 2006.

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					promote an information-sharing environment. This would allow patient and healthcare team members to become more aware of roles (staff) and preferences (patients).	
1101	RNIB/Action on hearing loss	QS	7	13	We would ask for more clarification on this point. Once patient preference is established, if they alter their preferences will this also be respected? Also if the patient is deemed as having a learning disability when do partners, families and carers have a right to be notified of patient issues?	Thank you for your comment. The final version of the quality standard reflects that continuing opportunities are provided to individualise care. The final version also includes a statement on establishing preferences for sharing information with family and carers.
1104	RNIB/Action on hearing loss	QS	8	14	No comment.	Thank you for your comment.
1119	RNIB/Action on hearing loss	QS	9	15	We welcome this draft quality statement. It is essential patient care is tailored and reviewed regularly so as to improve on the standard of care they receive. Furthermore this allows the patient the opportunity to feed back on their experience. We welcome that 'access,' is taken into account in this draft quality statement but would ask for further clarification on what this would cover. For a person with sight loss this can include accessible environments to enable them to get around confidently, independently and more easily. It can also mean accessible format provision in Braille, large print, email and audio. For many people with hearing loss accessible environment is one where induction loops are available and working so that they can use their hearing aids. They may also benefit from effective lighting, enabling them lipread.	Thank you.

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					Furthermore it is important to recognise that locality, and personal preferences can assist a visually impaired person in having a good patient experience. For example if hospital or GP appointments are made at a time when they can use their disabled bus basses so as not to incur extra charges this will not only improve patient care and confidence, it will also benefit them financially. This is even more important now with sweeping changes to benefits and discretionary elements for local travel, that include reduction of free travel times as well as hospital transport being discontinued for those that previously used it. Access consultancy services offer realistic and helpful on advice making environments more accessible, for example helping organisation to improve their building, streets and signage. In many cases these offer recommendations that not only help disabled people, but also the wider community. For example, providing level access at the main entrance to a building not only provides easier access for wheelchair users, but will also be of benefit to people with walking difficulties, parents pushing prams and visitors pulling wheeled cases or trolleys. Their aim is to help create an inclusive society by improved access for disabled people to the environments and services they use. Because of the specific access issues faced by blind and partially sighted people we would be happy to act as a publication partner for this Quality Standard so that helpful links can be provided to advice on accessibility.	

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1159	RNIB/Action on hearing loss	QS	10	17	We welcome draft quality statement ten but would seek explanation on whether the exchange of information would include information about format preferences for those with sight or hearing loss. We consider it important to share this information with the patients' healthcare team in order to ensure minimal disruption to patient care. For example appointment cards or leaflets made available in a patient's preferred format, such as Braille, large print, audio and electronically.	Thank you for your comment. All quality standards contain specific guidance that information should be provided in an appropriate format.
1172	RNIB/Action on hearing loss	QS	11	18	We welcome this statement and agree that patients should be given clear advice about who to contact, how to contact them and when to make contact about their ongoing healthcare needs. However it is imperative this quality statement is altered to include the following changes: 'Patients should be given clear advice about who to contact, how to contact them and when to make contact about their ongoing healthcare needs. This information should be available in a variety of formats and languages so to as to meet patients' communication needs. We believe this information should be available in alternative formats that include Braille, audio, large print, electronically and British Sign Language clips. Patients with sight or hearing loss need to be confident that they have the relevant information to contact their healthcare professional at short notice to change their appointment or who to contact in an emergency. If this is not available this	Thank you for your comment. All quality standards contain specific guidance that information should be provided in an appropriate format

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					could cause a delay in emergency healthcare or missed updates on treatments or appointments. Data taken from the 2009 Dr Foster report on the availability of health information for blind and partially sighted people said that inaccessible information caused missed appointments. Over a fifth of blind or partially sighted respondents (22 per cent) said they had missed an appointment due to information being sent in a format they could not read themselves.20 Furthermore, 72 per cent of the blind and partially sighted people who were surveyed could not read the personal health information they were given. These figures highlight the widespread issues that those with sensory loss using adult NHS care experience as a result of not receiving their information in the correct format.	
1186	RNIB/Action on hearing loss	QS	12	19	We recognise the positive outcome of a patient seeing the same healthcare professional or healthcare team rather than a different one at each appointment. Not only would this promote and maintain continuity of care, it would also ease patient anxiety for those who have a physical or sensory disability as staff would become familiar with any access and support requirements that patient might have. However, a patient's right to change their health care team must also be recognised and supported to empower patients to act if they feel they are receiving inadequate health	Thank you, please see previous comments.

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[20] Towards an inclusive health service: a research report into the availability of health information for blind and partially sighted people. Executive Summary, Main Findings 1.4: page five.

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					care.	
1212	RNIB/Action on hearing loss	QS	13	20	We welcome this draft quality statement but feel it could be combined with draft quality 14. Please see below for further information.	Thank you for your suggestion
1224	RNIB/Action on hearing loss	QS	14	21	We welcome this statement but believe it should be combined with draft quality statement 13 so as to provide a more substantial statement on accessible communication with patients. Healthcare professionals should be competent in communication skills and demonstrate this by establishing and using the most suitable way of communication. We believe however that there is also a serious lack of communication between primary care trusts/health board and healthcare professionals that affects patient care and ultimately communication between patient and staff. The Dr Foster report into the availability of health information for blind and partially sighted people states 'there was a lack of guidance circulated by PCTs and health boards to support and empower service providers to give accessible information.'[21] This issue needs to be addressed in these guidelines with recommendations for improved policies, processes or systems to ensure healthcare professionals receive sufficient support to allow them to provide health information to people with sensory loss. A patient's agreement and understanding should always be sought as the patient is usually best	Thank you for your comment. The GDG included one statement on training of staff in the final version.

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[21] Towards an inclusive health service: a research report into the availability of health information for blind and partially sighted people. Barriers to health information reaching people who need it. Point 7.3.3 Lack of Guidance for Service Providers.

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					placed to decide on their own communication needs. Communication must include access to alternative formats such as Braille, large print, audio or electronically (email). An ability to listen and establish the correct way of communication will improve doctor-patient relations and ease any anxiety the patient may have over communicating his or her wishes about their treatment. It is also advised that a service be available for those who are deaf-blind and for those who cannot speak English. Note on accessible information Information must be conveyed to patients with sight loss in an appropriate or required format. There are a number of ways to produce information in a format which can be accessed by people who are not able to read printed or electronic documents. Many of these formats are considered specialist by people who do not know or work with individuals with sight loss, but it is important to remember that to the individuals concerned their preferred reading format will be very important, and frequently will hold the key to living an independent life. Data taken from the 2009 Dr Foster report on the availability of health information for blind and partially sighted people said that an overwhelming	

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					95 per cent of people want to receive accessible health information themselves.[22] Alternative formats might take a number of forms. From specialist formats like Braille, audio, Daisy or accessible images through to mainstream documents like printed materials, e-books, spreadsheets, words documents of web pages. RNIB has the largest braille production facility in Europe and our larger scale production services including foreign languages. It has also launched a new online service to help information providers respond to last minute requests such as transcribing hospital appointments etc. Documents can be uploaded online and are returned in alternative formats within 48 hours. In some cases individuals will prefer to have an accessible mainstream format, like good web accessibility, well created printed material or a word processed document. There is no reason for these documents to look any different from the regular version produced for sighted people, so long as simple steps are followed in their creation.	
1241	RNIB/Action on hearing loss	QS	15	22	We very much welcome the inclusion of draft quality statement 15. However we would like clarification as to whether this is through conversing with the patient solely or providing them with decision making tools such as leaflets about their condition. If it involves the latter we	Thank you for your comment. The wording has been amended.

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[22] Towards an inclusive health service: a research report into the availability of health information for blind and partially sighted people. Executive Summary, Main Findings 1.4: page five.

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					would stress how important it is to have alternative formats readily available for blind and partially sighted patient so as not to cause any time delay in making important treatment or 'next step' decisions.	
1268	RNIB/Action on hearing loss	QS	16	23	We acknowledge the importance of this draft quality statement. We again note that format provision is not listed specifically. When making sure the information is 'understandable, personalised and clearly communicated.' Patients with a sight loss condition who cannot read standard print must be able to access the same information as those who are sighted. Similarly, for many British Sign Language users English is a second language and they should be able to access information in British Sign Language. This will eliminate discrimination that is unlawful under the Equality Act by providing reasonable adjustments to format provision. We therefore would welcome a change to the draft quality statement: 'Patients are provided with evidence-based information that is understandable, personalised and clearly communicated. This information should be available in a range of alternative formats to include braille, large print, audio or accessible email and British Sign Language clips.'	Thank you for your comment. Please see previous comments relating to style of presentation of information. We have post consultation referenced directly the Equalities Act.
1290	RNIB/Action on hearing loss	QS	17	24	We concur with draft quality 17 but would ask for clarification on what a decision support tool includes? The aid must be made suitable for those who have a disability such as sensory loss and if not accessible an alternative should be offered. This could be longer patient-healthcare staff appointments and access to information on their	Thank you for your comment. Wording of the quality statement has been further refined post consultation. We refer to guidance available at: NHS Direct website: http://www.nhsdirect.nhs.uk/DecisionAids

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					condition with an emphasis on the patient being able to seek clarification from a healthcare professional if they had any questions.	
862	Roche Products Ltd	QS	general	general	One aspect of this Quality Standard that does not seem to be explicitly captured within the existing quality statement is that of: 'Enabling patients to have realistic expectations from their treatment outcomes and that these are discussed and agreed with the patient'. If patients expectations of their treatment outcomes are not managed this will be reflective in their patient experience surveys.	Thank you for your comment. We are limited in the number of quality standards however, this is reflected in the following recommendation: Clarify what the patient hopes the treatment will achieve and address any misconceptions
1120	Roche Products Ltd	QS	8	15	Audience descriptor: We welcome this statement unequivocally. In order to ensure this patient right is supported we suggest that within the description for each audience it is made more explicit how this is demonstrated. For example allowing adequate time to discuss all options of treatment which should include drugs as well as mode of administration. Relevant existing indicators: We suggest that the national cancer patient experience survey (Q16) is considered as a source for measuring patient experience within this statement.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1242	Roche Products Ltd	QS	15	22	General: We believe this is a critical quality statement and welcome it unequivocally. Further, this quality statement should recommend the use of Patient Decision Aids (PDAs) as a mechanism for delivering shared decision making (in addition to its use in QS 17). PDAs are designed to help patients make difficult decisions about their treatments and medical tests. They are used when there is no clinical evidence to suggest that one	Thank you

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					treatment is better than another and patients need help in deciding which option will be best for them. Research shows that PDAs are really effective in helping patients make informed choices about their healthcare and increase patients' awareness of the expected risks, benefits and likely outcomes. The use of PDAs has already been validated by NHS Direct through their pilot projects (see http://www.nhsdirect.nhs.uk/DecisionAids) In addition we believe that patients should be supported in their decision making in a way which ensures that they can re-access services easily at a later date. For example when a patient is diagnosed with life changing conditions such as cancer or rheumatoid arthritis they may need the time to adjust to their diagnosis before being able to consider the options available and make a sound decision around their treatment plan. Therefore the opportunity and support should exist for patients to reconsider any initial treatment decisions they made at a later date. Relevant existing indicators: We suggest that the national cancer patient experience survey (Q19, Q37, Q39, Q41,Q43) is considered as a source for measuring patient experience within this statement.	
1269	Roche Products Ltd	QS	16	23	Along with Quality Statements 15 and 17, the use of Patient Decision Aids should be recommended as an outcome measure within this statement. In addition this statement should measure access to valuable patient information that is available through patient organisations. For example the National Rheumatoid Arthritis Society (NRAS)	Thank you for your comment. Noted.

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					provide a wealth of publications for patients providing information on choice of drug treatment, who is responsible for providing care, and patient treatment expectations. Relevant existing indicators: We suggest that the national cancer patient experience survey (Q9, Q15, Q18, Q25, Q26, Q31, Q44, Q49, Q51, Q66) is considered as a source for measuring patient experience within this statement. Within the patient experience surveys it will be important to measure whether patients felt information was presented to them in a way they could understand, (for example they realised the potential outcomes from all available treatment choices). In addition the choices offered should not be limited to local healthcare services but also services available nationally highlighting areas of best practice.	
1297	Roche Products Ltd	QS	Appendix 1	25	We would like the Topic Expert Group to consider the following evidence sources within the 'Definitions, relevant existing indicators and other possible national data sources' section: • Department of Health. National Cancer Patient Experience Survey. The latest report indicates direct feedback from 67,000 cancer patients who were admitted inpatients / day patients Jan - March 2010. The patients were drawn from samples provided by 158 Trusts. In addition to this national report, Local Trusts are being provided bespoke reports and some key data is being published on NHS Choices. Report is available at http://www.dh.gov.uk/prod_consum_dh/gr	Thank you for your suggestion.

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					oups/dh_digitalassets/documents/digitalasset/dh_122520.pdf - NHS Improvement. Picker Institute Europe. An evaluation of the National Cancer Survivorship Initiative test community projects. It describes the baseline survey conducted during July – October 2009 and presents the results of analysis of 1284 questionnaires completed by patients receiving care at seventeen test community projects. Report is available at http://www.pickereurope.org/Filestore/PIE_reports/project_reports/NCSI_Questionnaire_Validation_Report_FINAL_for_WEB.pdf - Patient Reported Outcome Measures (PROMs) measure quality from the patient perspective and would be a valuable evidence source for this QS (for clinical procedures where PROMS exist). PROMs are measures of a patient's health status or health-related quality of life. They are typically short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time. The health status information collected from patients by way of PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care delivered to NHS Patients.	
94	Royal College of Anaesthetists, Patient	Full	General	General	As the Patient Liaison Group (PLG) at the Royal College of Anaesthetists (RCoA) we welcome the aspirations this document has to raise standards of patient care. The Guidance appears well	Thank you for your comments, we will answer each point raised. (1) We agree that many of the aspects of the

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	Liaison Group				researched and the patient studies in particular identify many of the concerns that the patients we represent have about the quality of the care they receive. However, we would like to note our serious concern on several fronts: (1) Most of the Recommendations set out in the Full Version of the Guidance, and condensed in the NICE version, are simply a reflection of what a good healthcare practitioner should deliver. It is therefore a sad reflection that such Guidance is required at all. (2) The Guidance states that it is not possible to address specific scenarios, hospitals or conditions. However, our view is that the generalised blueprint this Guidance offers is not sufficient. There needs to be a culture of care, brought about by effective qualification of staff, on-going training, clear lines of responsibility and support from management to ensure that the needs of all individual patients are met in a timely and considerate manner. Care is an on-going process, rather than one that can be identified on a task-by-task or tick-box basis. (3) Whilst the Guidance may provide evidence and direction, we do not feel it is robust enough as regards implementation and on-going quality assurance. The	Guidance do reflect good care, but it is these aspects that emerged from the evidence synthesis which patient identify as important to them and for the GDG not to emphasise these would have devalued patient opinion. (2) The Guidance is generic and cannot consider particular areas of care. However, there may be a need in the future to expand this and look at specific areas of care or specific patient groups. We agree that cultural change if required and it was the intention of the GDG that this Guidance contributes to significant cultural shift within NHS care, indeed this very point is stated in the introduction and scene setting chapter. (3) The Guideline Recommendations are the source evidence for Quality Standard statements, which are designed to inform and shape service delivery commissioning. These recommendations through this route have an increased likelihood at being more fully implemented than previous national guidelines. The NICE pathway project will embed this guidance for easy access by healthcare professionals which should augment its full implementation. (4) Analysis of the cost impact of implementing the recommendations in a guideline for financial planning purposes is undertaken by NICE following guideline development where judged appropriate as part of implementation activities. We expect

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					guidelines are not to be statutorily enforced. We note that the Guidance will form a NICE Pathway for Clinicians but we see nothing in the draft given to us for consultation about how the guidelines are to be followed and what happens if they are not. Will adherence be an element of revalidation? What will be the consequences if they are not adhered to? Our view is that serious explanation needs to be provided on how the Guidance is supposed to work in practice. (4) We note that cost effectiveness is not carried out in the usual way in this draft Guidance (3.1.1, Pages 16/17). However it is impossible to consider the draft properly without querying exactly how the changes proposed will be implemented and monitored with the precious few resources available. (5) The Guidance states clearly that it does not seek to address specific scenarios, patient groups, conditions etc. However, given that the elderly make up such a large proportion of patients and that the low quality of some of their care has recently been identified by the Care Quality Commission (CQC)'s reports, we feel that their needs should be picked up further in this Guidance. We identify specific points below but also feel that	that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board. (5, 6) Thank you for your comments. The focus of the Department of Health referral was to produce generic guidance which was non population and non setting specific. We do anticipate that the NQB will in fact produce guidance around measurement, this maybe a single patient experience measure for providers of NHS care to use. We do believe that the guidance reaches across all adult age groups with recommendations worded carefully to ensure this.

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					their individual concerns should be taken into account throughout the Guidance. It is alarming for example that one Recommendation is ensuring that patient nutrition and hydration are adequate (Full: Page 24: 4.1.15) ; this is a fundamental human right. (6) Your patient group research focuses on conditions (cardiovascular disease, cancer and diabetes) that do affect the elderly but perhaps further studies specifically on the elderly should be included. This would address the highly important care needs of very old people admitted to hospital for age related conditions, who very often remain there for a long stay and some of whom die in hospital.	
127	Royal College of Anaesthetists, Patient Liaison Group	Full	1	11	In "Setting the Scene" the draft Guidance states it is for all those accessing adult services. Other than one reference to quality of care for young adults with ADHD at 9.2.3 on Page 64, the Guidance makes little reference to young people who are at the cusp of using adult services and their specific and particular needs as patients.	Thank you for your comment. Transition from paediatric to adult care is on the list of topics recommended by the National Quality Board for quality standard development.
132	Royal College of Anaesthetists, Patient Liaison Group	Full	2.1	13	The Guidance gives a clear explanation of what a NICE Guideline is but it would also be helpful to have a similar explanation of what, within the framework of NICE Guidelines, a Quality Standard is? How are the Quality Standards expected to be adhered to? How are they monitored? What can a patient do if he/she feels they are not being followed?	Thank you for your comment. NICE quality standards are a set of specific, concise statements that act as markers of high-quality, clinical and cost-effective patient care, covering the treatment and prevention of different diseases and conditions. They are derived from the best available evidence, such as NICE guidance and other evidence

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						sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with the NHS and social care professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
141	Royal College of Anaesthetists, Patient Liaison Group	Full	3.1	15	The Patient Experience Scoping Study focuses on patient needs in 3 disease areas. However, in our view it would have been more comprehensive/useful to have included also literature on care for the elderly and perhaps care for those in emergency and/or ICU care, whose care needs are more acute, complicated and challenging. We acknowledge that reference has been made to other NICE Guidelines in some of these areas but a broader view would give a better picture of the care needs of all patients.	Thank you for your comment. They were selected as three key areas of significant disease burden which include chronic and acute patients likely to have had a range of experiences of the NHS. For example diabetes includes patients with chronic conditions. However. many of the cardiac studies included patients with acute conditions. We aimed to get a spread of experiences across the three areas but do acknowledge some limitations in that the study could not be extended to a wider range of conditions. The aim was to draw from across the three areas to identify the dimensions or aspects of experience that apply to all three patient groups and to extrapolate to all patients. This extrapolation was tested in two main ways – through comparison with other frameworks of patient experience to provide a form of validity check (many aspects were similar) and through the consensus process where the GDG tested the robustness of the Warwick framework

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						through their discussion.
172	Royal College of Anaesthetists, Patient Liaison Group	Full	4.1	23	The patient as an individual The list of Recommendations gives factors that should be taken into account such as language, disability etc. The recent CQC reports into care of the elderly in hospital highlighted the appalling standards of nutrition and dignity in certain hospitals. This serious problem suggests that treating older people as individuals in hospital should be highlighted in this otherwise "general" Guidance. For example, how can these Recommendations address the individuality of a patient with dementia? The draft at present is not robust enough to cover the needs of these vulnerable patients who have a unique and complicated sense of "individuality".	Thank you for your comment. The guideline is non-setting, non-population specific, therefore recommendation about seeing and treating the patient as an individual does apply to older people in hospital. Issues related to nutrition and dignity are addressed in the recommendations in section 'Essential requirement of care'.
173	Royal College of Anaesthetists, Patient Liaison Group	Full	4.1	23 /24	Essential requirements of care We were taken aback that some of these basic human needs (e.g. right to confidentiality (9) and adequate nutrition and hydration (15)) require a Guideline when they should already be good practice. We would add that all staff should be adhering to these guidelines. For example, it would be pointless if ward staff made all efforts to place water on a bedside table in an accessible position, if then, for example, a phlebotomist coming to the bedside to take blood moved the table and failed to put it back or a physiotherapist worked with an infirm patient but failed to return them to a comfortable position where they could reach their water. Similarly, little good will be done by ward staff ensuring hydration/nutrition requirements if those efforts are not accompanied by regular weight checks and malnutrition plans if required.	Thank you for your comment. Recommendations 13 and 14 relate to the management of nutrition and hydration, suggesting education and training to enable healthcare professionals to address this area appropriately. The guidance also provides recommendations on effectiveness of communication.

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203	Royal College of Anaesthetists, Patient Liaison Group	Full	4.1 (16)	24	Where patients are managing their medication themselves for long-term conditions whilst in hospital, initiatives such as the proposed "insulin passport" may help them take responsibility for their regimen whilst in a disorientating environment.	Thank you for your comment. This is a useful tool to facilitate this recommendation.
204	Royal College of Anaesthetists, Patient Liaison Group	Full	4.1 (18)	24	Patients' entitlement to dignity: no reference is made in the Guidance to patients expressing a desire to be in a single sex ward and how dignity is to be respected in areas such as A&E and ICU where this segregation/privacy is not possible.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address issues building issues such as single sex wards. Whilst it is understood that it is difficult to maintain privacy in areas such as A&E, it is hoped that where possible the principle of privacy is upheld. Recommendation 40 addresses this.
205	Royal College of Anaesthetists, Patient Liaison Group	Full	4.1	24	Tailoring healthcare services to the individual Again, we would reiterate that specific care must be taken when communicating with those with specific requirements such as the elderly with dementia. At the same time, the recent CQC reports picked up that the elderly found it insulting to be talked over or talked to "as if they were daft" just because of their age.	Thank you for your comment. We recognise the particular needs of older people. The remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline. The recommendations in the section entitled 'enabling patients to actively participate in their care' address communication issues.
206	Royal College of Anaesthetists, Patient Liaison	Full	4.1 (23)	24	It is welcoming to see a Guideline about always introducing staff. This should be done in "layman's" language and the patient's permission should be asked. It is important to explain who is there and what they are doing even when a patient appears	Thank you for your comment and support for this recommendation. This is further addressed in recommendation 42. In addition recommendation 45 addresses not using jargon.

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	Group				to be unconscious is sedated or otherwise unresponsive. It could be a very frightening experience to be semi conscious and have no idea who is doing what to you.	
207	Royal College of Anaesthetists, Patient Liaison Group	Full	4. (27)	24	Going over information again is very important. For example a patient who has just received a serious diagnosis will be unlikely to be able to absorb all information or be able to make considered decisions in that consultation. In the case of breast cancer, a dedicated breast nurse goes through all the literature with the patient after the consultation and patients are always encouraged to bring another family member or friend to take notes etc. This standard of care for all serious conditions would be a good one for this Guidance to aspire to.	Thank you for your comment. The provision of information is covered in section 10.3, Information.
234	Royal College of Anaesthetists, Patient Liaison Group	Full	4.2	25	Continuity of care and relationships Being in hospital can be a very discombobulating, stressful experience for a patient. Their usual enjoyments and day-to-day control are limited and the daily routines are very different and usually at different times to those at home. Therefore, these recommendations should relate to all the care needs of the patient in hospital, not just their medical needs. For example, does their relative come in and brush their hair/put their teeth in/find their reading glasses or would they like the staff to put their things in reach in the morning? Can they swallow tablets or do they need them crushed and dissolved? These types of personal details will make so much difference to the quality of care a patient experiences in hospital.	Thank you for your comment. The developers agree and refer you to recommendations in the section “knowing the individual”.

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235	Royal College of Anaesthetists, Patient Liaison Group	Full	4.2 (34)	25	Giving a patient/their relative "out of hours" contact (that actually works) is crucial. We have heard much about the introduction of Enhanced Recovery Programmes (ERPs) for certain types of surgery. A patient on an ERP pathway may well be sent home earlier than another patient and will need this type of support in order to make their recovery as safe and stress free as possible.	Thank you for your comment. We agree.
236	Royal College of Anaesthetists, Patient Liaison Group	Full	4.2	25 -28	Enabling patients to actively participate in their care Communication - Again, communication must be tailored to the patient and assumptions should not be made about a patient because of their age. Training must be available to all healthcare practitioners and other staff, including those coming into the ward occasionally (e.g. dieticians, physiotherapists plus staff bringing meals etc.) so that there is a culture of patients being treated with respect and dignity. Patients should also have such sufficient degree of trust in healthcare clinicians that they feel comfortable in asking about what is being done to them, why and whether the member of staff has washed their hands without feeling that they are offending or insulting the member of staff. Staff should also be consistent with what they say. For example, a patient could be very demoralised by one staff member telling them they will be going home later that day whilst another then says they will need to remain in for the next few days. Information – It is good to see this level of care	Thank you for your comment. We are not recommending that patients have overall responsibility for their health or for decisions that are taken. We agree that all staff in contact with patients may require training in these aspects of care. We agree that communication between staff and patients should be open and consistent. We are not advocating that patients have overall responsibility for their care or that they bear all the responsibility for making a decision but that patients are given the information and opportunity to be as involved as they wish. We do not agree that patients should be warned about searching the internet but agree that health care professionals should

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					(provided it is implemented and adhered to) as regards information. We would note however that patients should always be made aware that it is the healthcare practitioners who will be able to advise them and will be in charge of their care. Many patients could feel overawed by feeling they had "overall responsibility" for their care. Decision-making – again patients should not be made to feel that they bear all the responsibility for making a decision, it is a decision made with the guidance of clinicians. It may also be useful to warn patients about the pitfalls of too much internet searching that can worry patients when they read the unfiltered information that is out there. It may be best to guide patients to bring up any concerns they have from reading information on the internet. Education – it is hard to understand what is meant here by education programmes for patients. The	be open to discussing any concerns patients have generated by their access to all information, including information from internet. Education programmes for patients are specific programmes to educate patients about their condition and its management. It should be differentiated from education for staff.

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					key thing from the Guidance is that all staff need to be trained and evaluated on the quality of care they are providing to patients.	
287	Royal College of Anaesthetists, Patient Liaison Group	Full	5.2.1	30	The numbering of the Gerteis dimensions seems to only start at number 2!	Thank you for noticing this- we have corrected this error.
296	Royal College of Anaesthetists, Patient Liaison Group	Full	5.3	36	It is interesting to see that appropriately used humour can make a big difference to some patients' experiences. The patient studies all indicate that staff can do a lot to "normalise" patients' experiences in hospital.	Thank you for your comment.
331	Royal College of Anaesthetists, Patient Liaison Group	Full		53	It comes across quite strongly in the patient studies that those patients with diabetes, a long-term condition with co-morbidities that may require many visits to different departments in a hospital over a long period seem to indicate a lack of being treated as an individual perhaps more than those whose condition (cancer/cardiovascular) may be very serious but often over a shorter length of time and with dedicated teams supporting them. Are the needs of individuals with very long-term conditions fully addressed in the Guidance?	Thank you for your comment. We recognise the particular needs of patients with chronic conditions. The remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline.
463B	Royal College of General Practitioners	NICE	general	General	The ethos of patient centred care, use of decision tools and shared care is to be encouraged and is a stance that the RCGP encourages	Thank you for your comment.
862B	Royal College of General	QS	General	General	However if all of the standards were to be applied to be to primary care they would fall short as not applicable or possible to implement – such as QS	Thank you for your comment. The remit for the guideline is generic patient experience in the NHS, and thus applicable to all areas of

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	Practitioners				5	the NHS.
39	Royal College of Nursing	All	General	General	The Royal College of Nursing welcomes proposals by NICE to make explicit the standards that adult service users can expect when receiving adult NHS services. The guidelines and quality standard for improving experience of care for people using adult NHS services is timely and comprehensive. The RCN actively promotes and actively supports patient-centred care. The RCN in partnership with Department of Health (England), the Nursing and Midwifery Council and other patient and service user organisations, recently developed the Principles of Nursing Practice (www.rcn.org.uk/nursingprinciples. These consist of eight principles describing what the public can expect from nursing practice in any setting. These principles, particularly Principle D, encourages nurses and nursing staff to provide and promote care that puts people at the centre, involves patients, services users, their families and carers in decisions and help them make informed choices about their treatment and care. The guidelines and standard align to the nursing principles.	Thank you for your comment. We are pleased that the guidance and quality standards align with the Principles of Nursing Practice.
174	Royal College of Nursing	Full	4.1 Rec7	23	Line 21:- In assessing these range of issues, the care provider should handle the 'questioning' with sensitivity, i.e. initially by gaining their consent to discuss them, and then with continued consent to each new area/issue	Thank you for your comment. a separate recommendation on consent has been added to the guideline.
175	Royal College of Nursing	Full	4.1	23	Line 25:- Vague and undefined terms are unhelpful; there needs to be an empirical definition of 'kindness', and 'understanding'. It might also be useful to reference agreed and accepted	Thank you for your comment. The technical team feels these are terms that are widely understood.

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					definitions of dignity, which may actually embrace the other reference terms.	
176	Royal College of Nursing	Full	4.1	23	Line 28:- This must be done with sensitivity (as per line 21)	Thank you for your comment.
208	Royal College of Nursing	Full	4.1	24	Line 1:- We are unsure that as this is written it adequately explains what is being proposed, in that it makes no differentiation between out-patient and in-patient care, which each presents very different issues.	Thank you for your comment. This recommendation is relevant to any patient for whom nutritional care is necessary.
209	Royal College of Nursing	Full	4.1	24	Line 3:- As in line 1 above, we consider that this point needs to create a differentiation between what should be done for in-patients and for out-patient care.	Thank you for your comment. This recommendation is relevant to any patient for whom nutritional care is necessary.
210	Royal College of Nursing	full	4.1	24	Line 10:- This must be at point of admission. However, this may contradict individual establishments' codified practices.	Thank you for your comment.
211	Royal College of Nursing	Full	4.1	24	Line 14:- What does promptly mean? This needs to be specific. We would recommend substituting with 'at time of asking or need'.	Thank you for your comment. The recommendation has been altered as suggested.
212	Royal College of Nursing	full	4.1	24	Line 19:- What is meant by locality? If to patient's place of residence then this needs to be made explicit. Reviews of the patients' needs should be discussed with them at all times.	Thank you for your comment. 'Locality' has been removed from the recommendation.
213	Royal College of Nursing	Full	4.1	24	Line 24:- Patients should be 'supported' rather than 'encouraged' to access preventative health service, on the principle that a patient's autonomy must be respected at all times.	Thank you for your comment. 'Support' has been added to this recommendation.
214	Royal College of Nursing	full	4.1	24	Line 26:- At each opportunity introduce all professionals (health or other, e.g. social care) involved in the patients care to the patient…	Thank you for your comment. This recommendation has been revised with a further recommendation added to inform the patient of the roles of the healthcare team (recommendation 38).
215	Royal	Full	4.1	24	Line 31:- Only if the patient agrees. There are	Thank you for your comment.

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	College of Nursing				already guidance codes on whom to share information about a patient with, e.g. No one Knows me..	
216	Royal College of Nursing	Full	4.1	24	Line 34:- 'Using a style' is vague; all discussions with the patients should be conducted in a way that allows the patient to express their personal needs…	Thank you for your comment. This has been changed as you have suggested.
217	Royal College of Nursing	Full	4.1	24	Line 36:- the beginning of this sentence would read better if starts like this - Review with the patient their knowledge of their condition and treatments…	Thank you for your comment. This suggestion has been incorporated into the recommendation.
237	Royal College of Nursing	Full	4.1	25	Line 1:- There are already codes regarding capacity requirements for giving consent; these should be referenced here.	Thank you for your comment. Recommendations have been written to address capacity and consent.
238	Royal College of Nursing	Full	4.1	25	Line 6:- Feedback should be given either immediately, or in a timeframe agreed with the patient	Thank you for your comment. It was felt that timeframe did not need to be included.
239	Royal College of Nursing	Full	4.1	25	Line 18:- What does this actually mean; what is it trying to achieve? Patients in need of multiple services should be provided with a lead care-co-ordinator (e.g. Specialist Nurses?), and the utmost priority should be given to ensuring that in planning service provision the patient should be placed at the centre, e.g. no to multiple appointments on the same site on different days or at times at either end of the day…	Thank you for your comment. The recommendations are designed to span all settings and disease area. The need for a lead care co-ordinator might vary by disease area.
240	Royal College of Nursing	Full	4.1	25	Line 21:- This needs to be illustrated with examples, e.g. information about test results should be with the healthcare professional in advance of any appointment to discuss them with the patient	Thank you for your comment. This recommendation has been reworded for clarity.
241	Royal College of Nursing	Full	4.1	25	Line 26: Re linguistic and cultural needs – may be more detailed guidance is needed here? We know for example that in some cultures e.g. people from	Thank you for this comment. We have added to the recommendation to ensure that the actions are culturally appropriate.

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					Africa, South East Asian and some Arab countries do not like sustained eye contact as a mark of respect. The guidance recommends that one maintains eye contact – maybe a catch-all sentence is needed here recognising the importance of and sensitivity to cultural issues, so as to embrace the individual and respond appropriately.	
242	Royal College of Nursing	Full	4.1	25	Line 30:- This will read better if it starts like this - Ask the patient how they wish to be addressed...	Thank you for your comment. We have altered the recommendation as you suggest.
243	Royal College of Nursing	Full	4.1	25	Line 35:- This needs to be simplified; ensure that there is equity of communication between patients and professionals	Thank you for your comment. We have worked with the editor to agree the final wording of the recommendation.
244	Royal College of Nursing	Full	4.1	25	Line 38:- Without being patronising!	Thank you for your comment. We agree!
245	Royal College of Nursing	Full	4.1	25	Line 40:- This needs illustrative examples	Thank you for your comment. It was not felt necessary to include examples.
261	Royal College of Nursing	Full	4.1	26	Line 5:- All letters from health professionals should be copied to patients. This is a right/obligation given in the NHS Constitution: The NHS also commits: to share with you any letters sent between clinicians about your care (pledge).	Thank you for your comment.
262	Royal College of Nursing	full	4.1	26	Line 3:- How should that competence be demonstrated, and what are relevant communications skills? E.g. Makaton for people working with people with LD?	Thank you for your comment. It is beyond our scope to indicate how competency should be assessed.
263	Royal College of	Full	4.1	26	Line 7:- This probably needs to be linked to line 3 above, with an explicit requirement for revalidation	Thank you for your comment. This recommendation has been removed following

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	Nursing				and CPD.	stakeholder comment.
264	Royal College of Nursing	Full	4.1	26	Line 7:- This probably needs to be linked to 46, with an explicit requirement for revalidation and CPD.	Thank you for your comment. This recommendation has been removed following stakeholder comment.
265	Royal College of Nursing	Full	4.1	26	Line 8: The guidance seems to have neglected advice on how to share important information; it suggests staff should ask patients about what information other staff have about them (this seems not to have been covered in the continuity of care section either). Maybe there needs to be some more detailed recommendations/guidelines/best practice about how best to share patient information with all staff involved in their care so that staff are aware of patients' preferences and needs?	Thank you for your comment. The reference for your comment does not appear correct. We do not suggest that patients should inform staff what information other staff have about them and do include a recommendation about sharing of information with all staff involved in care.
266	Royal College of Nursing	Full	4.1	26	Line 9:- Need to be mindful of different demands and needs of individual patients for information, e.g. information overload at diagnosis. This needs to be re-written to encompass responding to patient need appropriately, and supporting people to be able to better manage their condition and health, for instance through accessing self-management courses.	Thank you for your comment. Recommendations about communication with patients, and education programmes and self management are included in other recommendations.
267	Royal College of Nursing	Full	4.1	26	Line 11:- Key point here should be that information given to patients is given in a suitable format for them to be able to make use of it, e.g. written, audio-visual, large print or Braille	Thank you for your comment.
268	Royal College of Nursing	Full	4.1	26	Line 14:- This needs to be linked (fused with) Line 9, or at least reference the key principles outlined there	Thank you for your comment. The GDG preferred two separate recommendations to emphasis these points.
269	Royal College of	Full	4.1	26	Line 24: Does not this echo previous points, specifically line 9?	Thank you for your comment. The GDG wished to emphasise that patient differ in how

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	Nursing					they process information and both oral and written information should be given if possible.
270	Royal College of Nursing	Full	4.1	26	Line 25:- Ask the patient… explore is too vague a term	Thank you for your comment. We have changes the recommendation in line with your suggestion.
271	Royal College of Nursing	Full	4.1	26	Line 27:- Add point that any prescription for medicines or treatment is accompanied by information to enable patients to use any medicines and equipment correctly. This point would also benefit from referencing something about encouraging patients to report side-effects or adverse experiences to the healthcare professional.	Thank you for your comment. NICE has produced guidance on Medicines Adherence which covers these points
272	Royal College of Nursing	Full	4.1	26	Line 30:- Ensure that patients are sign-posted to all suitable information sources, e.g. via use of Information Prescriptions and Care Planning. It might be useful here to reference the DH Informational Standard Scheme.	Thank you for your comment. We have added information about the Information Standard scheme to the Full guideline.
273	Royal College of Nursing	Full	4.1	26	Line 35: Obviously we appreciate the suggestion that staff should ask patients what their preferences are at every possible opportunity, however, there should also be a statement about how to manage explaining why the individual cannot have what they would wish to have?	Thank you for your comment. The GDG did not consider it appropriate to include this level of detail in a recommendation.
281	Royal College of Nursing	Full	4.1	27	Line 27:- Change to: where available and suitable, make use of PDAs, and ensure that all staff are trained in their use.	Thank you for your comment. The recommendation has been amended.
282	Royal College of Nursing	Full	4.1	27	Line 29:- Shared Decision-Making (SDM) should be the baseline for all decision making within healthcare, as per the Government's Health and Social Care Bill proposals. Decision Aids sit above SDM as a means to facilitate SDM.	Thank you for your comment. We agree and the title of this section is now "shared decision making" and this has been emphasised where possible throughout the document.
419	Royal	Full	General	General	Re-implementation:- It is not clear when healthcare	Thank you for your comment. The

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	College of Nursing	& NICE			professionals will refer to these guidelines and use them on a regular basis as they do with other guidelines. Would it not be more appropriate for these recommendations to be incorporated into all NICE guidelines, rather being a separate document?	recommendations will be included in all other NICE guidance.
537	Royal College of Nursing	NICE	QS4	6	Draft quality statement: We are not sure that 'culture of kindness' is translatable into actual measures and as such seems at odds with courtesy, respect, understanding and honesty. It is also somewhat subjective and would seem to fall under the same exclusion rule criteria as 'satisfaction'	Thank you for your comment. The word 'culture' has been removed.
538	Royal College of Nursing	NICE	QS5	6	Draft quality statement: Needs should be both assessed and met	Thank you for your comment. Changes to the statement have been made.
539	Royal College of Nursing	NICE	QS6	6	Draft quality statement: This needs to be extended to the care team, to include non-medical professionals working in healthcare settings	Thank you for your comment.
540	Royal College of Nursing	NICE	QS9	6	Draft quality statement: Locality needs to be defined, i.e. is it locality to patient's place of residence?	Thank you for your comment. This change has been made.
541	Royal College of Nursing	NICE	QS10	6	Draft quality statement: Prioritisation of care needs to be explained, i.e. care should be provided in a manner that meets a patient's needs in a co-ordinated and organised manner	Thank you for your comment. The statement has been changed to reflect this.
542	Royal College of Nursing	NICE	QS13	6	Draft quality statement: This needs to be made more explicit; what equates to a demonstrated competency, should this relate to an external measure or regulatory requirement?	Thank you for your comment. The quality standard does not prescribe the manner in which organisations assess the competency of their staff in communicating with patients. Local decisions should be made on how to

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						assess this.
543	Royal College of Nursing	NICE	QS14	6	Draft quality statement: Establish with the patient the most suitable way of communicating with them…	Thank you for your comment. This statement has been altered to further reflect shared decision making.
940	Royal College of Nursing	QS	1	5	Measure: - What is the end calculation here, .i.e. 50% of all staff, 75%... Should we also be asking for proportion of staff that has been trained in the NICE guidance as part of their CPD?	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
941	Royal College of Nursing	QS	1	5	Description: - It is not clear what is being proposed in the patient's paragraph?	Thank you for your comment, this section has been reviewed.
942	Royal College of Nursing	QS	1	5	Indicators: - Could this be fitted into Quality Accounts reporting?	We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1024	Royal College of Nursing	QS	4	10	Measure: - 'culture of kindness' is hard to measure or quantify, and thus difficult for staff to demonstrate; this also applies to compassion	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1025	Royal College of Nursing	QS	4	10	Description:- As above fostering a culture of kindness is a term that is impossible to translate effectively into practical application	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1055	Royal College of	QS	5	11	Measure:- This should be assessed and met	Thank you for your comment. The quality standard has been amended to include this.

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	Nursing					
1056	Royal College of Nursing	QS	5	11	Indicators: Could also reference CQC reports on provision of care, e.g. hydration	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance.
1160	Royal College of Nursing	QS	10	17	Measure:- Prioritisation of care needs to be explained further	Thank you for your comment.
1187	Royal College of Nursing	QS	12	19	Measure:- Needs to be re-written: patients were given the choice to see the same healthcare professional or healthcare team, and those that wished to were enabled to do so	Thank you for your comment. The statement is not intended to remove patient choice. The focus of the GDG is that most patients do wish to see the same healthcare professional and this should be supported.
1188	Royal College of Nursing	QS	12	19	Description: - As above: patients who wish to were able to see the same…	Thank you for your comment. The statement is not intended to remove patient choice. The focus of the GDG is that most patients do wish to see the same healthcare professional and this should be supported.
1213	Royal College of Nursing	QS	13	20	Measure:- There needs to be a better definition of what is meant by communication skills	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1214	Royal College of Nursing	QS	13	20	Description:- As above	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
95	Royal College of Physicians	Full	4	General	This section lists a number of recommendations: The patient as an individual – this theme includes points which relate to the health care professional's individualised approach to the patient. The need for healthcare professionals to be mindful of the impact of their personality and	Thank you for your comment. The Guidance aims to ensure that health care professionals treat patients as individuals and avoid assumptions about them. The need to consider their own behaviour underpins many of the recommendations in the Guidance

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					their own behaviour during the consultation should be more explicit. Essential requirements of care This theme sets out the many responsibilities of health care professionals when caring for and treating patients. However, there is ambiguity and generalisation around the location of responsibility for this, which should be made more explicit. This responsibility brings many challenges, which should also be explored. Tailoring health care services to individuals Paramount to this theme is the need for health care professionals to communicate effectively by whatever medium is necessary. The importance of rigorous record-keeping and documentation in communications should be emphasised. Enabling patients to actively participate in their care It would be helpful to set out characteristics of an environment that is conducive to active patient participation.	As the Guidance is generic and applies to all patients, the GDG felt it appropriate to avoid comments about specific locations for treatment or care. We agree that rigorous record-keeping and documentation is important. However this Guidance primarily focuses on the nature of interactions between patients and health care professionals rather than organisational recording and transfer of information. We did not look at environment issues as this was outside the scope of this work.
96	Royal College of Physicians	Full	General	General	Other comments: It is noted that patient safety is not described either as a stand-alone aspect of the key themes within this draft consultation or, more explicitly, within one of the themes. This is a very important aspect of care from a patient perspective and should be addressed. Similarly, access to, and control of, personal health records by patients is a key quality area which	Thank you for your comment. We agree that patient safety is important but it did not emerge as a key theme within the Warwick scoping study or as a chapter heading within the Guidance, which emerged for the GDG consensus process. We agree that patient safety would be an important area for future consideration. We did not address access or control of personal health records as the guidance is generic across all settings and patient populations.

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					should be explored.	
863	Royal College of Physicians	QS	General	General	The RCP is grateful for the opportunity to respond to the above consultation. Overall, we welcome this timely piece of work and would like to endorse the response of the British Society of Gastroenterology (BSG). We would also like to make the following comments. Our experts believe that the aspirations of the draft quality statements are unarguable but that the implementation is unclear in many places. For example, it is asserted in 'Setting the scene' that for patients' experiences to play a role in shaping services in health care, a big culture shift in many hospitals is needed. In what way is it anticipated that these guidelines will contribute to making this culture shift happen? What are the characteristics of the new culture? For example, do the main themes of this consultation document encapsulate the core aspects? We note that many of the statements are not within the control of the individual health professional. How individual performance will be monitored is therefore another barrier. We believe that it will take some time before systems are in place to ensure that the statements are implemented and can be monitored. In the meantime, the standardised patient record can be the place where definitive statements about quality statements 2, 3, 5, 7, 8, 9, 10, 11, 12, 16 and 17 are recorded.	Thank you for your comment. The recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
544	Royal College of Radiologists	NICE		6	The RCR suggests that the draft quality statement no 4 should be moved up to no 2.	Thank you for your comment.

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545	Royal College of Radiologists	NICE		6	With reference to draft quality statement no 6, it would be helpful to indicate the meaning of a 'healthcare team'. What are the boundaries of such a team?	Thank you for your comment. This statement aims to ensure that patients are informed of the names and designations of those involved in their care. The constitution of the teams may vary in different localities and service models.
546	Royal College of Radiologists	NICE		6	With reference to draft quality statement no. 13, the RCR suggests that there should be some indication of how skills in communication are to be demonstrated. Is it supposed that these skills will be uniform amongst all health care professionals? The RCR questions whether or not there can be a single standard here.	Thank you for your comment. This is a current focus in healthcare undergraduate training, and therefore this guidance is related to systems already in place.
653	Royal College of Radiologists	NICE	1.3	11	The RCR suggests that some mention should be made of the tension between recognising the individuality of the patient and the often general responses of patients to treatments. It may be misleading for patients to suppose that their case is both individual and different.	Thank you for your comment.
670	Royal College of Radiologists	NICE	1.3.5 and 1.3.6	12	The RCR suggests that it might be useful to indicate recognition of the problems/disagreements that can arise between patients and their relatives/carers.	Thank you for your comment. Recommendations have been refined and in part recognise the point raised here, and provides guidance on how to manage such an event effectively.
716	Royal College of Radiologists	NICE	1.5	14	The RCR suggests that the title for this section might be amended to read "...to participate actively in their care'	Thank you for your comment. The wording has been agreed with the NICE editors.
742	Royal College of Radiologists	NICE	1.5.18	16 /17	It might be useful to add a comment here about obtaining and storing medication	Thank you for your comment. We believe this is covered by the wording of the existing recommendation.
40	RSM	All	General	General	No comment	Thank you for your comment
864	Sanofi	QS	general	general	Sanofi welcomes the opportunity to participate in this consultation and would like to submit the following comments in response.	Thank you for your comment. Thank you for your comment. Timeframes for

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					- The document provides a comprehensive set of measures that we hope will be effective in promoting excellence in patient experience in adult NHS services. - We understand that Quality Standards are aspirational. However, we believe that a time frame should be set by which the statements become a standard requirement to embed improvement in these areas. In particular, we would wish to see the following statements become a requirement; 2, 3, 4, 8, 9, 10, 11, 14, 15 and 17. - As a general principle, the Quality Standard should be relevant to all care settings including community, hospital and tertiary centres. It should focus on the patient, rather than focus on individual locations of care delivery. The draft standards clearly reflect this approach; it is important to maintain this intent when these are finalised. - Implementation of these statements should be supported by appropriate measurement and incentivisation mechanisms. Information on achievement/performance should be readily accessible in the public domain.	100% achievement would depend on local baseline, therefore we do not include suggested timeframes. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
943	Sanofi	QS	1	5	Sanofi welcomes the focus on patient experience and the need to ensure that all staff who interact with patients should be assessed for compliance with the standard, not just healthcare professionals. However, it is essential that this	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from

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					does not become a 'tick-box' exercise where simple processes are followed. Assessment should be based on the patient's actual experience and, therefore, we would suggest that patient feedback is included in the evaluation process.	the NHS Commissioning Board.
980	Sanofi	QS	2&3	7 -9	Sanofi welcomes the inclusion of these statements (QS2 and QS3), however we are concerned that the wording is more appropriate for a standard requirement and is not stretching, as an aspiration should be. We believe that all patients should be supported to fully engage in decisions around their care. In QS 2, the outcome measures suggest that there should be 'evidence that patients felt involved in consultations and their care from patient experience surveys and feedback.' We believe it is essential that patients are 'actively' listened to. A recent survey by the Patients Association found that whilst nearly 75% of patients felt involved in decision making about their care to some extent, patients still feel that they are not being listened to. In QS 3, the focus is more on the impact of listening to the patient: 'evidence that patients felt they were given the opportunity to discuss their health beliefs, concerns and preferences in order to in order to individualise their care'. Where possible, the statements should be focused on the outcome for the patient (such as individualising their care) rather than a process action by the healthcare professional.	Thank you for your comment.
1026	Sanofi	QS	4	10	Sanofi welcomes the inclusion of this statement.	Thank you for your support for this quality standard.
1079	Sanofi	QS	6	12	Sanofi fully supports this statement, but also believes that the Quality Standard should include	Thank you for your comment

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					appropriate statements for occasions when a carer is the key point of contact.	
1102	Sanofi	QS	7	13	Sanofi fully support this statement but would also call for the development of a separate standard on the quality of experience carers should expect.	Thank you
1121	Sanofi	QS	8	15	Sanofi welcomes this statement but would call for an additional sentence outlining that patients should be made aware of the available treatment options and have the opportunity to discuss these with a suitable professional. Evidence suggests that by giving patients more information on treatment choices and allowing patients, with appropriate guidance, to assess the risks of treatment, and what treatment will be best for them, patients are ultimately more satisfied with their treatment.23 Sanofi also believes that a quality statement on the need for patients to be made aware of all their rights under the NHS Constitution should also be included. In order for patients to have the highest quality experience of the NHS, they should be made aware of what level of care and treatment they can expect – this can only be reinforced by an understanding what rights they have under the NHS Constitution.	Thank you for your comment
1140	Sanofi	QS	9	16	Sanofi welcomes this statement and calls for it to be expanded to include treatment and information. The statement should read: Patients receive care, information and treatment that is tailored to their needs and circumstances…' Although this may be implied, to ensure this is truly aspirational and	Thank you for your comment.

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[23] Geest, TA; Wetzels, R; Raposo, V; Lopes Ferreira, P; Baker, R; Wensing, Michel, Elderly patients' and GPs' views on different methods for patient involvement: an international qualitative interview study, Family Practice, Vol 22, Number 2, pp. 184-191(8), 2005

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					aimed at improving quality of experience for patients, we believe it should be explicit on these areas.	
1161	Sanofi	QS	10	17	Sanofi proposes that the statement reads: 'On agreement with the patient, information about patient care is exchanged in a timely, appropriate, clear and accurate manner…', Currently the actual quality statement does not include patient agreement, although this is stated in the outcome measure. We believe it needs to be more explicit in the initial statement in order to fully protect patient confidentiality. We would also note that infrastructure needs to be put in place to support the sharing of patient information across the different care sectors. The integration of information systems would allow for improved sharing of information across primary, secondary, acute and care sectors and, therefore, improve the patients experience of care across the entire health and social care system.	Thank you for your comment.
1173	Sanofi	QS	11	18	Sanofi welcomes the inclusion of this statement.	Thank you for your comment.
1189	Sanofi	QS	12	19	Sanofi fully supports this statement. However, we also understand that continuity of care may not always be possible, such as if a patient has to access urgent care in a different area. When this is the case an explanation of the systems in place to protect the patient experience is required.	Thank you
1215	Sanofi	QS	13&14	20 -21	Sanofi welcome these Statements (QS13 and QS14) and believe they are vital to improving patient experience and, therefore, care. We believe both statements could be combined. There is an imperative to ensure that a healthcare professional has the appropriate training to enable them to communicate effectively with patients.	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.

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					However, the true success measure is the patient feedback and we believe the two statements are inextricably linked – a training programme to support healthcare professionals in their communication skills should be a standard element of Continuing Professional Development, as opposed to an aspirational statement of high quality care. The important aspect of the statement should be the experience of the patient, not the training in itself. Therefore, we propose that these statements should be joined with the outcome measure being: Evidence from experience surveys and feedback that patients felt they were communicated with effectively.	
1243	Sanofi	QS	15	22	Sanofi welcomes the inclusion of this statement.	Thank you for your comment.
40B	Sheffield Teaching Hospitals NHS Foundation Trust	All	General	General	We do however feel that the nice document provides a very useful best practice guide for medical staff – that may be a very helpful training resource particularly to newly qualified medics. We have recently been approached by a Consultant about producing customer care standards for medics using a similar approach to that taken to support Reception Staff across the Trust. If we were to do this, I think the Nice Guidance would be a very useful starting point.	Thank you for your comment
419B	Sheffield Teaching Hospitals NHS Foundation Trust	Full & NICE	General	General	We welcome the guidance as it is helpful that Nice has started to explain and define what Patient Experience is about and set out some core quality statements relating to patient experience.	Thank you for your comment.
419C	Sheffield Teaching Hospitals	Full & NIC	General	General	The guidance is however too long. This may explain why we didn't receive any individual comments from other colleagues who have a	Thank you for your comment. We believe that the length of this guidance is appropriate for a clinical guideline. The NICE version is a

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	NHS Foundation Trust	E			patient experience responsibility.	summary of the full guideline, and also a version for patients is produced.
464	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	General	General	Overall – the NICE guidance document covers what we would be expecting HCP's to do an a day to day basis but does seem just a little too biased towards what patients want and perhaps this is as a result of how they collected their evidence base (in the full guidance document). Should it include something about what we, as an NHS organisation think our patient experience strategy should look like?	Thank you for your comment. In order to capture the ethos and content of patient experience, it was important to view experiences from the perspective of the recipient of care. The GDG included health care professionals who work in the NHS and also had a view on patient experience. The consensus process enabled these different elements and views to be discussed.
618	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	1.2.7	10	This is not always everyone's role in MDT. I think it's important to recognise poor nutrition and to know who to refer to	Thank you for your comment. Through training staff, it is felt that they should understand when to refer.
619	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	1.2.8	10	This is the part that is more important than 1.2.7	Thank you for your comment.
654	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	1.2.10	11	Make sure that there is a tool and staff know how to use it for patients who cannot communicate easily e.g., dementia, LD patients who are in non-specialist services e.g., patients on an acute ward	Thank you for your comment. Pain measurement tools has been added to this recommendation
655	Sheffield Teaching Hospitals NHS	NICE	1.3.1	11	Does this mean when patients are under services or after they have been discharged? - not totally clear	Thank you for your comment. This is in relation to utilisation of adult NHS services in primary or secondary care.

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	Foundation Trust					
688	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	1.4.2	13	Could be linked to 1.3.4	Thank you for your suggestion.
743	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	1.5.12	16	Consider phrasing to include 'if appropriate'	Thank you for your comment. The GDG acknowledge that not all patients wish to be actively involved in their care, however they should be given the opportunity.
744	Sheffield Teaching Hospitals NHS Foundation Trust	NICE	1.5.18	16	At what point is this to be applied?	Thank you for your comment. This recommendation states a general principle of practice and is not intended to be formulaic in how it is applied.
865	Sheffield Teaching Hospitals NHS Foundation Trust	QS	General	General	We are in general agreement with all the statements and feel that they have value to patient experience, but overall, feel that some degree of clarification is needed on how we would demonstrate compliance	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
865B	Sheffield Teaching Hospitals NHS Foundation Trust	QS	General	General	Because of the extent of the guidance, and also the fact that much of the evidence used to measure against these standards might be subjective, we felt that the guidance and standards will be difficult to monitor and evidence against in a manageable way. For example, with CQC standards, we are understandably finding that Patient Experience is relevant to many of the	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					standards, and that therefore there is a huge amount of work to evidence and cross reference evidence	
944	Sheffield Teaching Hospitals NHS Foundation Trust	QS	1	5	If this is the case, should all NICE guidance relevant to services be looked at in PDRs?	Thank you for your comment. We note your observation and feel that this will be addressed through local service delivery commissioning.
953	Sheffield Teaching Hospitals NHS Foundation Trust	QS	2	6	It is not always appropriate to ask these things. The wording on this statement needs changing	Thank you for your comment.
1080	Sheffield Teaching Hospitals NHS Foundation Trust	QS	6	12	It is not always appropriate to do this for everyone, it should be up to all Health Care Professionals to make it clear to the patient who they are and what they do.	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1141	Sheffield Teaching Hospitals NHS Foundation Trust	QS	9	16	Who would be responsible to do this? Should they be identified so patients can inform them? It sounds like every patient needs case managing from this statement	Thank you for your comment. This is a challenge for all health care providers but is designed to 'improve the patient experience'.
1216	Sheffield Teaching Hospitals NHS Foundation Trust	QS	13	20	How formal is this, are we talking KSF level? What happens if this has not been demonstrated?	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.

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1270	Sheffield Teaching Hospitals NHS Foundation Trust	QS	16	23	This statement could be combined with QS14, perhaps?	Thank you for your suggestion. The GDG reduced the number of statements in the final quality standard.
465	SignHealth	NICE	General	General	Implementation of this guidance would lead to a dramatic and important change in the experience of patients. SignHealth fully support the recommendations and the assumptions that underlie them. It is refreshing to see a document that really does value the patient's experience.	Thank you for your comment.
466	SignHealth	NICE	General	General	SignHealth is particularly pleased to see the importance placed on communication and some of the barriers faced by deaf patients.	Thank you for your comment.
570	SignHealth	NICE	1.1.2	8	Delighted to see recognition that a patient may not be able to fully participate because of a hearing difficulty. This, to me, implies that the health professional will then need to take steps to ensure maximum participation, e.g. get an interpreter. I hope others do not interpret it as, "You can't expect a deaf person to be fully involved in a consultation." Experience suggests this is just how some people may see it.	Thank you, the recommendation has been reworded so that all the factors (including hearing problems) are 'addressed' rather than just 'considered'.
717	SignHealth	NICE	1.5.4	14	It is great to see that communication needs have been included here. It is also very welcome that the section recognises the diversity of possible methods of communication. My only worry would be that a hearing health professional may not be able to "establish" the best communication method. Ideally, the patient would say what their preferred method of communication is. That should be the starting point. The patient and professional need to collaborate to establish what will work best. All too often clinicians are misguided and	Thank you for your comment. We recognise that these issues are complex and a variety of approaches may be required. The recommendations and quality standard are intended to signpost the importance of these issues and patients' rights to have them addressed but are unable to provide detail to cover every eventuality.

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					think that if they shout or write things down a deaf person will understand and there will not be a communication problem. This highlights a lack of deaf awareness. A deaf aware clinician would realise that a Deaf person may have very limited written English skills, and may not feel confident about saying what communication method they would prefer.	
726	SignHealth	NICE	1.5.8	15	This is a very valuable step. Hopefully professionals will not rely on asking, "Do you understand everything?" In some cases it is far better to ask the patient questions which test their understanding.	Thank you for your comment.
727	SignHealth	NICE	1.5.10	15	Communication skills training for professionals is extremely important. We welcome this recommendation and hope that health organisations will consider communication with deaf patients when providing training.	Thank you for your comment.
745	SignHealth	NICE	1.5.13	16	This is very welcome. It would have been nice to see British Sign Language explicitly mentioned. It is extremely easy and cheap to get information put into BSL and provided on a website or DVD. There is no reason why Deaf people whose first language is BSL should not receive this same level of service. Hopefully "different languages" will suffice.	Thank you for your comment. This recommendation is not intended to be exhaustive and states possible formats as examples only.
866	South Staffs and Shropshire NHS Foundation Trust	QS	general	General	very appropriate very clear	Thank you for your comment.
1122	South Staffs and Shropshire	QS	QS 8	15	may be issues with the legal frameworks and the ministry of justice	Thank you for your observation

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	NHS Foundation Trust					
1142	South Staffs and Shropshire NHS Foundation Trust	QS	QS 9	16	what about including issues around risk	Thank you for your comment. Information about relevant risks has been included in the final version of the quality standard.
1225	South Staffs and Shropshire NHS Foundation Trust	QS	QS 14	21	our service users said - Any material provided for information or decision making, whether paper-based or online, should meet readability and accessibility standards. E.g, not so photocopied it is faded or blurred, text should be large enough and the use of jargon avoided. Patients should be asked whether they understand the material and if they need help to understand it. If material is to be accessed online the patient must be asked if they need any help – for example it is not always easy to use a mouse or a keyboard if you have a tremor or anxiety may be a factor. Material provided in this way should be for supporting the relationship between the health care professional and the service user rather than replacing it.	Thank you for your comments.
177	Southampton University Hospitals NHS Trust	Full	4.1	23	In the “patient as individual” guidance section or elsewhere in the proposed guidance, there appears to be a lack on recognition of the importance of spiritual care.	Thank you for your comment. Spiritual circumstances are mentioned in recommendation 7.
178	Southampton University Hospitals NHS Trust	Full	4.1	23	There is no mention of the importance of securing same sex accommodation or privacy (e.g. type of gowns and nightwear used) in the section relating to patient privacy and dignity. We feel this is	Thank you for your comment. We agree that same sex accommodation has a significant impact on patient experience. It was agreed with NICE that because of time constraints

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					worthy of specific inclusion given the high priority the DoH have placed on the NHS delivering this agenda over the past 2 years.	the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and not address building issues. Recommendation 41 addresses privacy in relation to clothing.
218	Southampton University Hospitals NHS Trust	Full	4.1	24 /25	One of the aspects of inpatient care which has a significant impact on patient experience relates to the number of non clinical moves they are required to undergo. This affects both continuity of care and in turn safety as well as destroying relationships with the healthcare team. We feel the standard should include a specific item in relation to the need to minimise patient moves ("right bed first time").	Thank you for your comment. We agree that this is an important area and can be a significant influence on patient experience. We had however to limit the areas we were able to consider.
219	Southampton University Hospitals NHS Trust	Full	4.1	24	Guidance no. 19 relates to the provision of accurate information to patients about delays. To enable staff to clearly link the themes, we suggest this would be better placed in the continuity or information sections.	Thank you for your comment. This recommendation has been moved to the information section of the guideline.
220	Southampton University Hospitals NHS Trust	Full	4.1	24	Guidance no. 21 related to the provision of information about treatment options may be better placed in the information section.	Thank you for your comment. The GDG decided to leave this recommendation in this section.
221	Southampton University Hospitals NHS Trust	Full	4.1	24	Guidance no. 23 relates to staff introducing themselves and appears to be a repetition of no. 33. We feel it would be better placed in the continuity of care and relationships section.	Thank you for your comment. These recommendations have been amalgamated and remain in this section.
246	Southampton University Hospitals NHS Trust	Full	4.1	25	Guidance no. 31 relates to patient feedback about their care. We feel this important aspect of patient experience needs strengthening or is even worthy of a section on its own. At present there is nothing included about feedback loops i.e. informing patients what has changed as a result of their	Thank you for your comment. Local complaints procedures would address this.

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					feedback?	
247	Southampton University Hospitals NHS Trust	Full	4.1	25 /26	Recs 37-47: In the section about enabling patients to actively participate in their care, there are 10 statements about communication. We believe there to be 2 important omissions in this section – one about listening and the 2nd about staff delivering consistently positive customer care to patients in terms of their attitudes and beliefs.	Thank you for your comment. We have reviewed the recommendations as a whole to ensure that listening and that the patient does not feel rushed are included. The GDG preferred not to use the term 'customer care'.
248	Southampton University Hospitals NHS Trust	Full	4.1	25	Guidance 42 relates to avoiding the use of jargon and we feel this should also include the use of abbreviations.	Thank you for your comment. We include abbreviations in jargon.
274	Southampton University Hospitals NHS Trust	Full	4.1	26	Recs 48 onwards: The subsection of "Enabling patients to actively participate in their care" on information is included but there are also other statements about information giving scattered throughout the other standards. We feel that staff would find the guidance simpler to follow if all the statements about information were housed in one section.	Thank you for your comment. The current arrangement of the recommendations reflects the areas under which they were developed. It does not preclude the order being changed for implementation.
275	Southampton University Hospitals NHS Trust	Full	4.1	26	Guidance 52 relates to the provision of verbal and written information. We feel this should include a requirement to document accurately the provision of any information.	Thank you for your comment. The GDG discussed this and disagreed about the need to document on all occasions.
276	Southampton University Hospitals NHS Trust	Full	4.1	26 -27	The section on decision making does not currently include specific guidance about end of life care or advanced care planning decision making. We feel this important element of care should be recognised and included in the guidance,	Thank you for your comment. NICE are currently developing quality standards for End of Life care which was published in November 2011.
301	Southampton University Hospitals	Full	5.5	42	The model of patient experience proposed does not relate to the guidance headings/themes and this may make it difficult for staff to follow. Could	Thank you for your comment. We have added a table to clarify the GDGs view of relationships between model of patient

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	NHS Trust				this be aligned in some way? We feel it is important we use the categories which demonstrate good experience from the patients perspective.	experience and the themes. We have provided themes so it is clear to staff what they should do.
420	Southampton University Hospitals NHS Trust	Full & NICE	General	General	We are very concerned that there is a separate set of standards and guidance for patient experience in mental health organisations. The needs of patients with acute and chronic mental health issues in acute care do not seem well catered for in the current division of standards between acute and mental health – in reality there are so many overlapping areas, we are concerned that the needs of these patients (who form such a large percentage of the acute care patient profile nowadays) will be missed, if the mental health statements are not applicable in acute care and vice versa.	Thank you for your comment. As with all guidance that may be population specific, the intention is that it is applied in other care settings when appropriate and we believe that this will be the case with both the mental health and adult care guidance on patient experience.
421	Southampton University Hospitals NHS Trust	Full & NICE	General	General	Whilst we recognise the separation of PROMS issues from patient experience measures, we are concerned that there are many areas of overlap which need to be made reference to in this document if we are to avoid unhelpful reductionism in gaining more understanding of the complete patient experience.	Thank you for your comment. Measures ofr patient experience are different to PROMS, which tend to be outcome of care led rather than experience led. We are aware that a single measure is in development which we anticipate will be sued to measure use and implementation of this guidance.
467	Southampton University Hospitals NHS Trust	NICE	General	General	The guidance would benefit from clearer explanations about the connections between the draft quality statements and the 66 elements of the guidance.	At the end of each quality statement, the source recommendations are noted.
468	Southampton University Hospitals NHS Trust	NICE	General	General	There is no reference to patients who are unable to communicate their needs or hear their options e.g. patients who are critically unwell or who have disabilities. The importance of the role of advocacy and the role of the family and significant others in care planning and treatment decisions is	Thanks you for your comment We have considered both advocacy and significant others and family involvement in several recommendations.

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					paramount.	
601	Southampton University Hospitals NHS Trust	NICE	1.2	9	There is no reference to hygiene or skin care needs in this section – both of these issues have been highlighted in recent reports detailing quality failings so we feel it would be helpful to make these issues more explicit.	Thank you for your comment. We agree that hygiene and skin care are important, we had however to limit the areas we were able to consider.
620	Southampton University Hospitals NHS Trust	NICE	1.2.8	10	The nutrition standard does not consider the needs of those patients who are critically unwell/unable to move, and who have requirements for alternative methods of feeding e.g. enteral or parenteral nutrition.	Thank you for your comment. We recognise the particular needs of those who need enteral feeding, however the remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline. CG32, nutrition support in adults, addresses this.
767	Southampton University Hospitals NHS Trust	NICE	1.5.22	17	Consideration is required of the needs of emergency and/or critically unwell patient and consent – does the guidance assume best interest decision making, or should this overall aim be clearer? i.e. stating best practice is to hold best interests meeting/decision discussions BEFORE starting any screening, investigations or treatment?	Thank you for your comment. A recommendation has been added about the capacity to consent.
97	Stonewall Equality	Full	General	General	Stonewall are a national charity campaigning for the rights of the 3.6 million lesbian, gay and bisexual people in England, Scotland and Wales. Stonewall work with over 600 employers to improve sexual orientation equality in the workplace and the home and, over 50 Local Authorities to tackle homophobic bullying in schools. Stonewall work with over 50 NHS organisations throughout England promoting equality for lesbian, gay and bisexual staff and improving services for	Thank you for your comment

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					lesbian, gay and bisexual people.	
98	Stonewall Equality	Full	General	General	Stonewall would like to refer NICE to the recent Cancer Patient Experience Survey produced for the Department of Health which highlighted the much poorer experiences of lesbian, gay and bisexual patients across 14 domains including dignity and respect. In addition, the most recent GP Patient survey highlighted that lesbian, gay and bisexual respondents reported poorer experience of being able to access their preferred GP.	Thank you for your comments. We have included recommendations about the need for health care professionals to avoid making assumptions about patients in providing care. The nature of the guidance is generic across all populations and we believe this particular recommendation addresses this.
137	Stonewall Equality	Full	2.5.32	14	Stonewall believe this guidance should cover those people, including lesbian, gay and bisexual people, who have poorer experiences of care to encourage and improve the experience of all patients who access NHS services	Thank you for your comment. . We have replaced this recommendation with reference to the Equalities Act to ensure we have not omitted any individuals or groups.
179	Stonewall Equality	Full	4.1.6	23	This section should reference sexual orientation alongside religious beliefs, age, gender, educational level etc… Stonewall research (Serves You Right, 2008) has found that 1 in 14 lesbian, gay and bisexual people expect to be treated worse than heterosexuals when accessing healthcare. In addition, 50% of lesbian and bisexual women reported negative experiences of healthcare in the past year (Prescription for Change, 2008) and, 70% felt negative comments had been made about their sexual orientation by a healthcare worker, despite the fact this is against the law. Assumptions about a person's sexual orientation can impact negatively on their care and treatment. For example, 1 in 5 lesbian and bisexual women	Thank you, we agree with your comment. We have replaced this recommendation with reference to the Equality Act to ensure we have not omitted any individuals or groups.

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					have been told they are not at risk of cervical cancer by their healthcare worker, despite this not being the case.	
602	Stonewall Equality	NICE	1.1.6	9	Stonewall believe this paragraph must include avoid making assumptions based on a person's sexual orientation	Thank you for your comment. . We have replaced this recommendation with reference to the Equality Act to ensure we have not omitted any individuals or groups.
867	Stonewall Equality	QS	General	General	Stonewall welcome the 17 draft quality standards and believe that if applied appropriately can improve the experience of lesbian, gay and bisexual people who use services	Thank you for your comment.
868	Stonewall Equality	QS	General	General	However, Stonewall believe the standards could be strengthened by reference to the Equality Act and the Public Sector Duty reinforcing the rights of patients with protected characteristics, including lesbian, gay and bisexual people and, the responsibilities of health and social care staff. The Government Equalities Office LGBT Action Plan states a commitment to ensure medical staff can work sensitively with their lesbian, gay and bisexual patients. One effective method of achieving this would be, in part, through the Quality Standards set out in this document.	Thank you for your comment. The beginning of the quality standard has been changed to reflect this. The Equalities Act 2010 is also incorporated into the guidelines.
981	Teenage Cancer Trust	QS	2	7	Teenagers and young adults with cancer from age 19 will be treated in teenage and young adult specialist facilities or adult NHS services, so their experience is important to capture as part of this quality standard. NICE Improving Outcomes Guidance on Children and Young People with Cancer (2005) clearly sets out that communication with children, young people and families needs to be tailored to their needs in order to have successful outcomes.	Thank you for your comment. We agree that the needs of young adults are important and that age appropriate care has a significant influence on patient experience. These quality standards are derived from the recommendations of the guideline which are designed to span all adult NHS services. The equalities act is now referenced within the guidance.

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					It is acknowledged in this guidance that "There is considerable evidence that there are problems with communication and information-giving (both inter-professional and between patients/parents/carers)." (p.121) Teenage Cancer Trust's survey showed that 45% young people we surveyed felt that information was not designed for their own age group. Age, therefore, is one of the barriers to participation, and we believe that age appropriate communication is as valid for young people as it is for older people. We suggest that draft quality statement No.2 adds in that patients are also asked about "age-appropriate needs" to maximise their participation in consultations and care.	
571	Teenagers and Young Adults with Cancer	NICE Full	1.1 6.3	8 45	There is little mention of the patient's family in this area. This is a key area for many young adults (usually those <21yrs, but variable). It is unclear if representatives from the GDG included teenage/young-adult patients or if they sought the views of this small but often distinct group.	Thank you for your comment. The guideline is for all people who use adult NHS services. Family involvement was not considered a priority by the GDG for this general guideline. Involvement of family/carers is mentioned later on in the 'Enabling patients to actively participate in their care' section. The developers are mindful of the need for ensuring that a broad range of experience and knowledge is represented on the group. This has to be balanced with the need to ensure that the GDG is workable size and such enables individuals to contribute effectively. When convening the GDG the developers have followed the principles outlined in the NICE technical manual.

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621	Teenagers and Young Adults with Cancer	NICE	1.2	10 /11	While pain and anxiety/depression are important aspects of ill health and addressing them is key to quality of care, there are other unpleasant sensations which may also be experienced but not directly: these include nausea, itch, and fatigue. Nausea in particular may be under-rpeorted and under-addressed.	Thank you for your comment. We agree that these are important areas and can be a significant influence on patient experience. We had however to limit the areas we were able to consider.
718	Teenagers and Young Adults with Cancer	NICE Full	1.4.4 9.3	14 68	Could consideration be given to identifying which patients would benefit from a single-named worker (Key Worker) appointed for them; a model which the GDG identified as effective with midwifery and has been used in cancer care.	Thank you for your comment. The recommendations are designed to span all settings and disease areas.
775	Teenagers and Young Adults with Cancer	NICE Full	1.5.26 10.4.2	18 105	The consideration of the psychological impact of diagosis and appropriateness of quantititive information probably need highlighting in the text of the recommendation, not just the LETR paragraph.	Thank you for your comment. We recommend that patients are referred for psychological support if this is required in the section titled "knowing the patient as an individual".
776	Teenagers and Young Adults with Cancer	NICE Full	1.5.26 10.4.2	18 105	When communicating risk information, there is no mention of the communication of uncertainties in the information. It is almost never known that 3 / 100 will do better, and 7 / 100 have a side effect. Everything will have both mathematical imprecision (reflected in the 95% confidence interval) but also structural imprecision (uncertainty about the biases in the underlying studies, and uncertainty in how to extrapolate from the information source to the patient's specific situation).	Thank you for your comment. The GDG acknowledge your point but consider it is not possible to offer guidance on conveying uncertainties and suggest this is picked up under the bullet point that asks people to "personalise the risks and benefits as much as possible".
781	Teenagers and Young Adults with Cancer	NICE Full	1.5.29 10.5.2	19 111	'Ensure programmes are evidence based' seems like a very wooly recommendation. What could count in this may be interpreted as something as weak as 'Did you like our course' questionnaires to deonstration of patient-relevant outcome improvements within an RCT.	Thank you for your comment. We consider that programmes should be developed using the principles of sound evidence-based practice.

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99	The British Pain Society (Patient Liaison Committee)	FULL	GENERAL	General	Our comment is as follows: Throughout the document it is vital that all recommendations show 'that ' the patient comes first'. Every patient is an individual and should be treated as such. It is important to recognise that while many patients (through poor literacy ,numeracy, linguistic skills etc.) may have difficulty understanding complex terms or data, but so is it important to recognise that a well-educated, literate, and/or numerate patient is likely to quickly become an expert and they then may feel demeaned by oversimplification.	Thank you for your comment. Guidance recommendations address these aspects.
326	The British Pain Society (Patient Liaison Committee)	Full	4.1.	51	(15)Our comment is as follows : Add phrase "and/or drinking"	Thank you for your comment. This has been added to the recommendation.
327	The British Pain Society (Patient Liaison Committee)	Full	7.3	51	(17)Our comment is as follows: Be aware patients may well play down their level of pain. They may do so because they know that the degree to which they say they have pain could affect health care provider's perception of them as a 'difficult' patient.	Thank you for your comment. Recommendation 14 has been written to assess pain as accurately as possible.
342	The British Pain Society (Patient Liaison Committee)	FULL	8.3	56	(29) Our comment is as follows: Insert after word 'treatment' the phrase 'make an alternative choice or seek a second opinion'	Thank you for your comment. Recommendations 25 and 26 address this.
355	The British Pain Society (Patient Liaison Committee)	FULL	9.3	68	(32) Our comment is as follows: A patient should be guaranteed continuity of care – the phrase ' may involve seeing the same health care professional' is too uncertain. It leaves a	Thank you for your comment. Loss of notes is a failure of a mechanism used to ensure continuity of care and cannot be recommended against. Some patients prefer to see a different health care professional

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					convenient loophole for a patient to find there is no continuity. If patient moves to another address and must see a new health care professional, then the said patient should be confident his/her notes are transferred quickly and efficiently. Loss of notes (or other mechanism in the of continuity of care can result in distress)	who has a shorted waiting period, while others might prefer to wait to see their regular practitioner – they should be given the choice.
366	The British Pain Society (Patient Liaison Committee)	FULL	10.2.2	73	(40)Our comment is as follows; How will the form of communication needed by the patient be established? At the first visit the patient may not bring sufficient information about their need to the communication process. For example, a deaf patient may not be able/remember to bring an interpreter. These patient needs should be established by the primary care physician/health care provider and stated when sending out (further treatment/ investigation) consultation request letters.	Thank you for your comment. We have clarified in the recommendations that systems should be in place to ensure that patient requirements are indicated prior to such appointments.
368	The British Pain Society (Patient Liaison Committee)	FULL	10.2.2	74	(44) Our comment is as follows: Patients should be encouraged to have a friend or relative accompany them to ensure that someone takes in all that has been discussed- and makes notes. A frightened patient (e.g., cancer or other life threatening/limiting disease), may have such heightened anxiety that they do not remember (cortisol effect) what was said after the consultation - even if they appear to do so at check back!	Thank you for your comment. We agree that there are circumstances where being accompanied by a family member or friend may be helpful but do not think that this should be applied to all patients.
369	The British Pain Society (Patient Liaison Committee)	FULL	10.2.2	74	(46) Our comment is as follows: By what criterion will this be measured to ensure "across-centres/ health care providers" reliability? Considerable differences could result from a vague	Thank you for your comment. We anticipate that the National Quality Board will be providing guidance on how to measure the quality of patient experience.

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					recommendation.	
373	The British Pain Society (Patient Liaison Committee)	FULL	10.3.2	77	(50) Our comment is as follows: Spell out where and by whom more definitively. Patients may feel very vulnerable if this isn't clearly done.	Thank you for your comment. We believe the recommendations are supportive of your comment.
382	The British Pain Society (Patient Liaison Committee)	FULL	10.3.2	79	(55) Our comment is as follows: Add 'patients should be advised about the dangers of internet research' Many sites give unreliable information that may be confusing and unhelpful.	Thank you for your comment. We do not agree that patients should be warned about searching the internet but agree that health care professionals should be open to discussing any concerns patients have generated by their access to all information, including information from internet.
394	The British Pain Society (Patient Liaison Committee)	FULL	10.4.2	104	(58) Our comment is as follows: Add something to the effect that this whole issue must be sensitively managed- patient's resilience and existing knowledge should be taken into account.	Thank you for your comment. The GDG believe this is covered by existing recommendations in the section titled "knowing the patient as an individual".
395	The British Pain Society (Patient Liaison Committee)	FULL	10.4.2	104	(59) Our comment is as follows: A patient's misconceptions may be coloured by their own prejudices and cultural views. This should be taken into account, especially in a multicultural society.	Thank you for your comment. We believe this is addressed by the recommendations in the section titled "knowing the patient as an individual".
400	The British Pain Society (Patient Liaison Committee)	FULL	10.4.2	105	(62) Our comment is as follows: Just as it is important to ensure patients with possibly low levels of numerical understanding can access the data, so is it important not to demean an educated patient by using what may to them seem as ' overly simplified numerical data'. N.B., this also applies to verbal or written communications.	Thank you for your comment. The recommendation requires the information to the personalised as far as possible and this would include pitching it at the correct level for the patient – see recommendations in communication section also.

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869	The British Pain Society (Patient Liaison Committee)	QS	GENERAL	General	Our comments are as follows: In the measures there is much reference to the responsibilities of commissioners, but it is not clear to us that they are able to deliver on all the areas suggested. For example, who is responsible for HCP training? The measures suggest that this is commissioners, but it is not clear. Similarly are commissioners really able to ensure good exchange of information between professionals? We feel it might be important to refer to professional bodies, such as the Royal Colleges Finally throughout the QS there seems to be an emphasis on patient surveys. These are one part of an approach to measuring the patient experience –and they can certainly be objectively analysed statistically. However, a more open-ended (if more subjective) measure of whether patients are involved in establishing local priorities of care and support ought also to be considered. For example, patients attending pain clinic could be interviewed (with their consent). about their pain experiences and their opinions/experiences verbalised and recorded to fully inform the QS	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
897	The British Pain Society (Patient Liaison Committee)	QS	10	3	Our comment is as follows: The standard could be too aspirational in that while it may be the ideal situation, it could frequently fail in practice. For example, one of our members of the PLC observed at pain clinic visit, that patient files were missing, possibly because they were at another hospital. It was also observed that while patient	Thank you for your comment. We expect the guidance to inform best practice and believe that recommendations will guide commissioning and measurement of performance against these. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					notes were made at the consultation, by the time they were ready for filing the patient's file was missing (gone to another hospital perhaps). In fact our member observed that there was a big pile of unfiled notes indicating this was not an isolated incident. As a consequence the consultant involved struggled to carry out his responsibilities effectively. Another member of the PLC, who moved from one area of the country to another, did not get an appointment for continuity of care despite the GPs letter. What happened to the letter? We feel the measure at 10 should reflect reality rather than a frequently unattainable ideal.	.
909	The British Pain Society (Patient Liaison Committee)	QS	16	4	Our comment is as follows: The need to commission self-management courses should be mentioned. In short there should be a measure that relates to self-management e.g., trend of GP consultation attendance rates. Given the emphasis on self-management in current health policy we would see this as a positive point to make.	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We considered that we could not do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.
100	The Health and Care Infrastructure Research and Innovation Centre	Full	general	general	This document is concerned with the definition of a generic standard for patient experience and the methods, evidence and recommendations for applying generic outcome measures. As such this document is not concerned with the underlying physical and engineered infrastructure supporting patient experience, such as "technology" or the	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational

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	(HaCIRIC)				"built environment". This accounts for their relatively infrequent mentioning (7 and 24 times respectively) compared to more clinical or patient derived terms. Other infrastructure related terms such as "setting" and "access" get further prominence, however the evidence base to support them is not drawn on.	issues and not address building (environment/access)
101	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	general	general	HaCIRIC welcome the opportunity to comment, as we feel that it is unlikely that the Guideline Development Group (GDG) will have considered the full impact of the physical environment and broader engineered infrastructure on outcomes. Prominence is given to the built infrastructure by other clinical institutions such as the British Medical Association (2011), which raise the impact of the built environment in addressing the psychological and social needs of patients. There are now over 1,000 sources of evidence and 15 notable major systematic reviews demonstrating the credible causal impact of buildings on health outcomes and gain.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address building and environment.
102	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	general	general	The importance of evidence based design (EBD) has increased since Ulrich (1997) first showed the measurable effects of views of nature on patient health outcomes; post-operative patients recovered faster and took fewer analgesic medications when windows faced a natural view rather than a brick wall. Since then, very many studies have supported and added to knowledge in this area. Phiri (2006), Lawson and Phiri,(2000), Rubin et al., (1998) and Ulrich et al., (2008) proposed a theory of supportive design for healthcare that emphasised reduction of stress, provision of personal choice, positive distraction and attention to nature. By now it is widely	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address environment.

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					acknowledged that the quality of the hospital environment has a major impact on the well-being of patients as well as on staff.	
103	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	general	general	The effect of the built environment on patient health outcomes and patient experience continues to be collected (amongst others) by various institutions that have been supported by HaCIRIC, these include: Sheffield University (Phiri, 2006), Loughborough University (Mills et al., 2010, Price et al., 2009) and Salford University (Codinhoto et al., 2008). The most significant collection of these has been made by Sheffield University over the past 10 years, all of which will soon to be available from: www.spaceforhealth.nhs.uk. We believe that high quality built environments are important to patient experience and that this NICE report should make a clearer statement of the impact of the built environment.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address building.
104	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	general	general	We support the use of the term "environment" throughout, however would like to see a more deliberate defining paragraph that would acknowledge the role of healthcare built infrastructure in providing the setting for care, in delivering economies of scale, scope and distribution and in contributing to various patient experience outcomes.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address building.
105	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	general	general	We commend the development of a new outcome framework and would support its use to evaluate the impact of the built environment, particularly against the following NICE outcomes: dignity and respect (e.g. the impact of single rooms), comfort (lighting, ventilation and heating), self management (building setting and accessibility), co-ordination (building amalgamation, co-location, space use and lean practice) and continued care	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address building (environment/access…...)

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					(space adjacency, consistency of care location and capacity planning and patient movement), and social, personal and psychological factors (healing, considerations for families and therapeutic design). There is a need for clear roles to be defined with regards to the built infrastructure environment along with explicit understanding of patient related outcomes and measures.	
106	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	general	general	It is important to note the practical value of the provisional recommendations and it would be useful if the document was explicit about its intended audience.	Thank you for your comment. We include a reference to the intended audience in the Setting the scene chapter.
142	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	3.1	15	This guidance was developed using "a pragmatic approach" to ensure the consideration of multiple sources of evidence/information in line with the expertise of a multidisciplinary Guideline Development Group (GDG). Could NICE provide a description of who in this group represents the view of estates, facilities and broader infrastructure?	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address broader infrastructure.
152	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	3.6	18	It was stated that a limited number of systematic literature reviews were undertaken in areas prioritised by the GDG and that systematic literature reviews were carried out against specific economic evidence areas (such as Health Technology Assessment). Given the significant cost and financial constraints imposed by large built infrastructure investments, could the way the economic impact of the built infrastructure has been incorporated into this report be made more	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address environment.

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					explicit?	
298	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	5.4.1	37	This guidance makes no explicit mention of the policy, organisation or institutional structure that supports the evidence based outcomes and standards for the physical built environment.	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.
298	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	5.4.1	37	Only one indirect mention of the importance of the physical environment is made in relation to the Care Quality Commission's NHS patient surveys (L22). Given this stated importance, please could NICE explain which organisation or institution is tasked with defining these environmental outcomes and collecting supporting evidence on the impact of infrastructure on outcomes? It would be helpful for a clear definition to be included in this NICE document to demonstrate the accountability and links between Care Quality Commission Essential Standards document, with this clinical guidance. As CQC Outcome 10 in their Essential Standards document (Care Quality Commission, 2010) refers to "currently valid DH Estates and Facilities publications (like Health Technical Memoranda and Health Building Notes)" is used by providers to demonstrate conformity with regulations, how will "current..." and "valid" standards be maintained and provider outcome performance be measured by the CQC and NICE against a backdrop of the diminishing role of the DH to produce and maintain these built infrastructure standards? As such the role of a national independent estates and facilities expert	Thank you for your comment. NICE are currently considering what implementation support to provide for this guidance We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board with the Department of Health, and, when it is established, from the NHS Commissioning Board.

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					and/or institution that contributes to the existing evidence and puts in place a clear quality assurance mechanism should be detailed within this report.	
350	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	9.2.3	59	This guidance peripherally deals with responsibilities of healthcare commissioners but no direct mention is made of the engineering guidance and standards for non-clinical components of the healthcare system, such as infrastructure (e.g. BSI, or the role of DH Estates and facilities guidance and standards) in defining the minimum standard for infrastructure related outcomes.	Thank you for your comment. We agree that the built environment has a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address the non-clinical components of car such as infrastructure.
353	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	Full	9.2.4.2	63	Although the guidance recognises that patient focussed outcome measures considered within this document are limited within clinical interventions within complex models of care, it must be noted that similar patient focussed outcome measures must be developed to seek the effect of the physical built healing environment.	Thank you for your comment. The developers agree.
469	The Health and Care Infrastructure Research and Innovation Centre (HaCIRIC)	NICE	general	general	We acknowledge the recognition of patient safety throughout; however, we believe that this is more about clinical safety and thus we suggest to clarify more how should the built environment and its supporting services contribute patient, and staff, safety.	Thank you for your comment. We agree that the physical environment is important in terms of patient safety. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would not address physical environment.
870	The Health and Care Infrastructure Research and Innovation	QS	general	general	The quality statements are aimed to cover three dimensions of quality: safety, effectiveness and experience. Safety is mentioned relatively rarely and it seems to be assumed that safety is a “given” and therefore is not detailed further.	Thank you for your comment. We agree that safety is an important area and can be a significant influence on patient experience. We had however to limit the areas we were able to consider.

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	Centre (HaCIRIC)					
107	The Health Foundation	Full	General	General	Mechanism for incorporation into existing and future NICE guidance The Health Foundation warmly welcomes the decision to create this guideline. Its development demonstrates an appreciation of the importance of patient experience as a core aspect of good clinical care, rather than an "add-on". However, our preference would be that guidance on how to deliver care so that it reliably delivers a good patient experience is common to every piece of guidance issued by NICE. Our concern is that by separating patient experience guidance from the rest of NICE's guidance, it may have the potentially unintended consequence of suggesting that future NICE guideline development groups do not need to pay attention to issues around patient experience. For example, we know that NICE develops each clinical guideline based with the aim of achieving high optimum effectiveness, efficiency, safety and timeliness of care in relation to the guideline topic. We would therefore like to see: - the guideline amended in order that it is much clearer about how it will be implemented - clarity about how existing and future guidelines will incorporate the good practice set out within this document consistently - clarity about how the linking will be achieved between condition specific guidelines and this generic one, such that this generic guideline is	Thank you for your comment. The intention is that this Guidance should link to other NICE Guidance in the future. We envisage that future Guidance will also consider particular patient experiences issues that have relevance for specific groups. Implementation of the Guidance is currently being considered. This guidance will be featured within the NICE pathways project, designed to link guidance. The cross cutting nature of this guidance applies across many guidelines.

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					recognised and measured as an integral aspect of all other guidelines and is truly regarded as such by health professionals.	
108	The Health Foundation	Full	General	General	Scope, exclusions and search strategy We welcome the ambition of creating a single guideline setting out what a patient in any aspect of the healthcare could expect in terms of the service provided to them. We believe that this is important because it defends against arguments that certain communities, people, or services should be exempted from these essential levels of quality care. However, the challenge of working at this scale is ensuring that all the relevant evidence has been taken into account in the development of the guideline. In later sections of this response we comment on the paucity of the evidence cited in relation specifically to self-management support. This is one example of a weakness which stems from a more fundamental problem, namely the search strategy underpinning the whole guideline. In other NICE guidelines, it is possible to map included and excluded search terms onto inclusions and exclusions in the scoping section of the guideline. However in this guideline (sections 2.4 and 2.5), the scope of the search strategy is not clarified with sufficient rigour; search terms (inclusions and exclusions) are not stated. It is not possible to ascertain the basis on which the guideline development group identified the important constituents of patient experience. Whilst we appreciate the challenge of the task, it is	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could not do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board. The GDG did not codify their experience. The Warwick Scoping study synthesised qualitative research, and from this research activity high level themes emerged. It is these high level themes that provide structure to this guidance. It is the nature of evidence that has determined what is important to patient experience, and not GDG experience. The role of the GDG is to interpret evidence sources and translate these into recommendations for practice. he themes are broadly in agreement with published frameworks, Whilst acknowledging the limitations of the work which were shaped by the amount of

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					difficult to avoid the conclusion that the group codified their experience according to the interests and expertise of the members of the guideline development group. Given that the membership didn't include, for example, a health psychologist or a sociologist, the current guideline views patient experience through an inadequately narrow lens. As a result of this problem, the guideline omits a great deal of relevant evidence that ought to be reflected within the theme of "Enabling people to actively participate in their care". We recommend that recommendations 37-66 need redrafting based on a much more coherent and comprehensive literature review. We would expect that this review would identify relevant evidence of the effectiveness of: - Self-management support - Patients' ability to access and interact with their own health records - The provision of information to patients using video, audio or interactive formats - Providing access for communication with health professionals via media other than face-to-face consultations, including e-mail, telephone and web-based consultations.	development time made available to the NCGC and the GDG, the guidance acknowledges the importance of self management and has where possible provided examples from evidence reviewed. We have also discussed with NICE the importance of this literature and proposed that it should be addressed through core library topic discussions between NICE and the NQB. We have been assured by NICE that they will seek to explore this.
109	The Health Foundation	Full	General	General	Tone and emphasis: paternalism, bio-medical approach and inconsistency with the guideline for Service User Experience in Adult Mental Health The underlying framework of this document is the traditional biomedical perspective. The guideline is therefore likely to deliver a professionally-led approach which does not improve the patient	Thanks you for your comments. The guideline has been reviewed to ensure the tone is appropriate. We disagree that the framework is a biomedical model, especially given that guidance themes emerged from qualitative research synthesis. The GDG recognise the importance of self-

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					experience because it fails to change the relationship of dependence, deference and power imbalance between professional and patient which so negatively impacts on the patient experience. This weakness is thrown into relief by the differences between this guideline and the one for Adult Mental Health. There are significant inconsistencies between the generic guideline for adult health services and the separate guideline for mental health services. It is clear that the two documents were developed entirely separately and consequently there are significant differences of emphasis and tone between the two documents. In particular, the mental health guideline is underpinned by a recognition missing in the generic document that: - The experience of ill-health, or any engagement with health services, is significantly improved if health services are underpinned by a bio-psycho-social approach. This approach involves a recognition of the psycho-social context in which healthcare is delivered, particularly the patient's functional goals and roles within family and community and the need for decisions about healthcare to be driven not only by biological concerns but also psychological and social issues, such as the ability to plan and manage a palliative stage of care so that it optimises psychological and emotional processes for both patient and carers. Equally, in the	management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.

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					context of long term conditions, the importance of a philosophy of recovery, support and hope and support for managing the psychological and social impacts of a long term condition. - The outcomes of treatment are maximised when the patient is supported to play an active role in managing their own health. Indeed, the mental health guideline well reflects the lived experience of people as it emerges from NICE's own qualitative research and evidence reviews undertaken for these processes: the living of a daily life within which, for most people, healthcare is an event of greater or lesser frequency within the wider context of life. From this perspective, a "good patient experience" is not only an experience which is inherently positive – though that is vital; but also an experience from which people emerge feeling supported and equipped, mentally and physically, to live their wider life. The generic guideline however reads entirely as though it comes from the perspective of the health professional and its scope is therefore significantly limited to the time spent directly within the clinical encounter. The scope of the guideline is consequently limited to 'improving a person's experience of what we do to them', rather than 'improving a person's health experience, and what we do with them'. We recommend that the guideline development	

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					group for the generic patient experience guideline considers which aspects of the mental health guideline should be incorporated into the generic guideline.	
305	The Health Foundation	Full	5.5	43	Welcome for the theme "Enabling patients to actively participate in their care". The Health Foundation welcomes and supports the inclusion of the theme "Enabling patients to actively participate in their care". This is a critical aspect of high quality health services and one that has been much neglected; consequently it is particularly important that the guideline is clear and achievable in relation to this domain as this NICE guideline should be an important driver of change. As currently drafted, however, we think that the level of expectation placed on health services around this domain within the guideline is limited and does not reflect the strength of the evidence. We provide further detailed comment and recommendations for revision below. These comments focus on the recommendations related to the theme of "Enabling patients to actively participate in their care", specifically: - Communication (Recommendations 37-47) - Information (Recommendations 48-55) - Decision making (Recommendations 56-64) - Education Programmes (Recommendations 65 and 66).	Thank you for your comment. We have responded to your comments in the individual sections as listed in your comment.
360	The Health Foundation	Full	10.2	71 -74	Communication: the effectiveness of interventions to prepare patients prior to the consultation	Thank you for your comment. We acknowledge that the areas we reviewed were limited and did not include all possible

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					One important omission from the recommendations about communication is the value of systems to prepare people for the consultation. For example, we recommend Paul Kinnersley's review of a very heterogeneous literature[24], which produced mixed results overall but clearly demonstrated that interventions prior to the consultation improved satisfaction ie patient experience. We therefore recommend that the guideline development group reviews the literature with regard to pre-consultation preparation and patients' access to their records, with a view to adding a further recommendation along the following suggested lines: Maximise the opportunity for people to be prepared in advance of consultations and/or decisions, through providing agenda setting prompts, access to their health records, coaching, relevant information or biomedical results in an appropriate and understandable format.	areas that might improve patient experience. We did original reviews in areas prioritised by the GDG.
361	The Health Foundation	Full	10.2	71 -74	Communication: Closing the Loop The section on communication contains a number of well-made recommendations for improving the patient experience. We suggest that there is a further technique which has been shown to improve the patient experience and to improve clinical outcomes, namely "closing the loop". This is a technique designed to improve	Thank you for your comment. We acknowledge that the areas we reviewed were limited and did not include all possible areas that might improve patient experience. We did original reviews in areas prioritised by the GDG.

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[24] BMJ 2008;337:a485, doi:10.1136/bmj.a485

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					the experience of many patients of being overwhelmed with a great deal of information during a consultation that they don't understand or remember. Schillinger D et al (2003) showed that HbA1c levels were lower in patients whose care had included this communication technique than those who had normal care[25]. This is an important addition in order to address patients' concern surfaced through NICE's qualitative work that they want clinical staff to communicate information about their illness and treatment "in a way that they can understand".	
374	The Health Foundation	Full	10.3.2	77 -78	Information provision – ineffectiveness in leading to behaviour change/self-management The Health Foundation strongly welcomes the requirement to provide information to patients and agrees that this is a basic pre-condition for people to play an active role in their care. However, we are disappointed to see that the recommendation suggests that information should be provided "in order to promote active participation in [their] care and self-management of their condition" (Recommendation 48). Whilst there is some evidence that written motivational leaflets or letters improve knowledge, and can help people feel more confident to raise their concerns and discuss their symptoms [26], there is sparse evidence that verbal or written information improve	Thank you for your comment. We agree that information is a necessary element but not necessarily sufficient for behaviour change. We did not however consider that we were making recommendations for self care and self management and behaviour change. We could not do justice to such a topic in this generic guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.

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[25] Schillinger D. et al, (2003) *Closing the Loop: Physician Communication with Diabetic patients who have low health literacy*, Archives of Internal Medicine 163(1): 83-90

[26] Glasgow NJ, Ponsonby AL, Yates R, et al (2003) *Proactive asthma care in childhood: general practice based randomised controlled trial* BMJ 327(7416): 659

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					self-management behaviours or clinical outcomes27. Consistently, studies have shown that printed materials can improve knowledge28, but generally do not impact on behaviour when used alone29. The practice of providing information, either orally or in written form, on the assumption that it will lead to behaviour change, is a critical area of practice that needs to be updated in the light of overwhelming evidence. This NICE guideline must, in this context, provide health professionals with clear direction about evidence-based practice around how to promote self-management. The Health Foundation undertook a review of the literature about what works to support self-management, Helping People Help Themselves, published earlier in 2011. We recommend that NICE draw on the results of this review in amending the guideline around information provision. The key relevant issues within the evidence that should be reflected in the guideline and accompanying quality standards are:	

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[27] Little P, Dorward M, Warner G, et al (2004) *Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care* BMJ 328(7437): 441; Fleissig A, Glasser B, Lloyd M (1999) *Encouraging out-patients to make the most of their first hospital appointment: to what extent can a written prompt help patients get the information they want?* Patient Educ Couns 38(1): 69 - 79

[28] Dally DL, Dahar W, Scott A, et al (2002) *The impact of a health education program targeting patients with high visit rates in a managed care organization* AMJ Health Promot 17(2): 101 – 11;
van Boeijen CA et al (2005) *Efficacy of self-help manuals for anxiety disorders in primary care: a systematic review* Fam Pract 22(2): 192 – 196;
Roberts L, Little P, Chapman J, Cantrell T, Pickering R, Langridge J (2010) *The back home trial: general practitioner-supported leaflets may change back pain behaviour* Spine 27(17): 1821 - 8

[29] Morrison A (2001) *Effectiveness of printed patient educational materials in chronic illness: a systematic review of controlled trials* J Manag Pharm Care 1(1): 51 – 62;
Gibson PG, Powell H, Coughlan J et al (2004) *Limited (information only) patient education programs for adults with asthma (Cochrane Review)* The Cochrane Library, Issue 2, Chichester: John Wiley & Sons

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					- Combining written information with lectures or other educational activities can be more effective than written information alone[30]. - The most effective written information tools are those that are personalised to the individual, for example, based on their own test results, goals or BMI[31]. For example, a randomised trial in Scotland compared posting four personalised asthma education booklets versus conventional oral education at outpatient or surgery visits. Personalised booklets improved self-management and reduced hospital admissions[32]. Other studies have reinforced these findings[33].	
375	The Health Foundation	Full	10.3.2 10.4.2	77 -78 104	Information: fundamental approach to shared decision making - "proposed care" vs "options" The Health Foundation welcomes the emphasis upon patients' involvement in decision making about their treatment and care and the recognition of the importance of information within this	Thank you for your comment and pointing out some of the inconsistencies in our language. We did not intend to be paternalistic and altered the wording as you suggest.

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[30] Forster A, Smith J, Young J et al (2004) *Information provision for stroke patients and their caregivers (Cochrane Review)* The Cochrane Library, Issue 2, Chichester: John Wiley & Sons;
Seals TD, Keith MR (1997) *Influence of patient information leaflets on anticonvulsant drug compliance in prison* Am J Health Syst Pharm 54(22): 2585-7

[31] Kennedy A, Robinson A, Hann M et al (2003) *A cluster-randomised controlled trial of a patient-centred guidebook for patients with ulcerative colitis: effect on knowledge, anxiety and quality of life* Health Soc Care Community 11(10): 64 – 72;
Lafata JE, Baker AM, Divine GW et al (2002) *The use of computerized birthday greeting reinders in the management of diabetes* J Gen Intern Med 17(7): 521 – 30;
Sethares KA, Elliott K (2004) *The effect of a tailored message intervention on heart failure readmissions rates, quality of life, and benefit and barrier beliefs in persons with heart failure* Health Lung 33(4): 249 – 60;
Enwald HP, Huotari ML (2010) *Preventing the obesity epidemic by second generation tailored health communication: an interdisciplinary review* J Med Internet Res 12(2): e24

[32] Osman LM, Abdalla MI, Beattie JAG et al (1994) *Reducing hospital admission through computer supported education for asthma patients* BMJ 308(6928): 568 – 71

[33] Azrin NH, Teichner G (1998) *Evaluation of an instructional program for improving medication compliance for chronically mentally ill outpatients* Behav Res Ther 36(9): 849 - 61

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					process. Much of the guideline constitutes an important step forward in positioning shared decision making based on high quality patient information as a crucial element of a good patient experience. We believe however that there are important inconsistencies within the full guideline with regard to the intent of the guidance. This inconsistency runs throughout the document, but is best exemplified in Recommendation 50, which contains within it the requirement to provide information about "proposed care" and also, only a few words later, about "any treatment options". This inconsistency is repeated in the set of recommendations about decision making, within which Recommendation 58 again sets out a requirement to "explain the medical aims of proposed treatment", as opposed to Recommendation 64, which requires that the health professional "ensure[s] that the patient is aware of the options available and explain[s] the risks, benefits and consequences of these". Similarly, Recommendation 54 is based on an assumption that the patient's role is to do what they are told. What this reveals is that the guideline and accompanying quality statements seem unclear about a fundamental issue: whether the aim of information provision (and shared decision making) is about setting out options and allowing the patient to make an informed choice about which option they select; or about setting out "proposed care", having followed the traditional	

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					practice from the biomedical perspective, where collecting ideas, concerns and expectations from the patient is for the purpose of the professional making a better plan for the patient. We believe that the model of decision-making suggested is more appropriate to a process of ensuring that the patient provides informed consent, which comes at a later stage of the shared decision making process, once a specific course of action has been selected by the patient. Whilst informed consent processes should, we believe, be seen as the second stage of a shared treatment decision process, it is vital to separate out the two and to ensure that at earlier stages, the professional is presenting options rather than "proposed care". The Health Foundation recommends that as a minimum, in order for this guideline to reflect the well-established clinical evidence around best practice in providing information and shared decision making, the term "proposed care" should be removed from the document and consistently replaced by the term "options".	
408	The Health Foundation	Full	10.5	108 -112	Absence of self-management support; Difference between Education programmes and Self-Management Support The most significant weakness of the guideline, from our perspective, is the almost total absence of self-management support from the guideline beyond passing reference within the Patient Education section. There are a number of problems with the current draft guideline in this regard:	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the

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					The evidence cited within this section is both incomplete and extremely out of date. This may have resulted from a flawed search strategy, using terminology around patient education, whereas the internationally used term for this critical aspect of patient experience is "self-management support". As a result, NICE's literature review is reported to have identified only one systematic review, undertaken in 1985 (reference 48, p.109). However, since then the self-management support literature has grown very substantially and it is therefore wholly inappropriate to base a NICE guideline on such a partial understanding of the current state of the evidence. We recommend, as sources of further evidence, two recent meta-reviews: - Helping People Help Themselves, a review of the evidence considering whether it is worth supporting people to self manage. The Health Foundation, 2011, at http://www.health.org.uk/publications/evidence-helping-people-help-themselves/. - Invest in Engagement – a review of 124 systematic reviews on self-management support, 2010, by Picker Institute Europe, at http://www.investinengagement.info/45. Furthermore, we recommend: - The body of peer reviewed work published by Professor Kate Lorig of Stanford University, which demonstrates the effectiveness of generic self-management support programmes and is a particularly surprising omission from the evidence considered by the guideline development	National Quality Board. This section did not aim to review the literature on self-management, but rather the generic components of patient education programmes. This section of the guideline has been amended to clearly reflect this.

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					group, given that it is about a particularly effective form of patient education; - The body of peer reviewed published work by Professor Tom Bodenheimer MD of UCSF, which emphatically makes the case for self-management support being an intervention of common benefit and requiring a common set of generic skills across all long term conditions. - Incorporation of the evidence which underpins Ed Wagner's Chronic Care Model, which is based on the evidence of what works to obtain optimum outcomes (including patient experience) for people with long term conditions. We also recommend searching using the related term of "care planning", which should for example lead to consideration of key evidence reviews such as "Personalised care planning for diabetes: policy lessons from systematic reviews of consultation and self-management interventions, J Graffy, S Eaton, J Sturt and P Chadwick, Primary Health Care Research & Development (2009) 10(3); 210-22"; and http://www.kidneycare.nhs.uk/Library/Care_Planning_Mini_Topic_Review_April_2011.pdf. Secondly, the inclusion of self-management support within a section entitled Patient Education reflects a fundamental failure to understand the aims of self-management support and how it is broader than patient education. Whereas patient education generally aims to improve knowledge and understanding, and sometimes skills (e.g. the	

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					very well-evidenced DAFNE programme for people with diabetes), self-management support additionally includes collaborative decision making, with the aim of producing measurable improvements in self-efficacy (confidence and motivation to self-manage). Furthermore, self-management support is provided as an integral aspect of clinical care, within each clinical encounter between clinician and patient, and not solely within the format of patient education programmes. The Health Foundation uses the definition of self-management support produced by Professor Tom Bodenheimer, Self-management support is the assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health-related behaviours and clinical outcomes[34]. In this context, we recommend that the guideline development group and NICE reconsider the current section 10.5 and that instead there should be a section entitled "self-management support", with patient education as a sub-section of this section. Further, and based on the evidence of what is important to patients with long term conditions about their care and the evidence about what characteristics of a healthcare experience lead patients to make the challenging behaviour changes required to optimise their health, we urge that two additional recommendations are included within the self-management support section,	

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[34] Bodenheimer T, et al, *Helping Patients Manage their Chronic Conditions*, California Health Foundation, 2005

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					setting out the approach expected of health professionals working with people with long term conditions, as follows: "Accept and respect that people with long term conditions are in charge of their own lives and self-management of their condition , and are the primary and risk takers, about the actions they take in relation decision makers to their management" "High quality services for people with long term conditions should support and encourage people to develop confidence and competence in managing the challenges of living with their condition(s) in order to have a better quality of life, better clinical outcomes and make more appropriate use of resources" This level of direction is, we recognise, prescriptive; however, it reflects and is no more detailed or prescriptive than the many recommendations in other sections of the guidance which relate to clinicians' attitudes, beliefs and consultation styles, eg Recommendations 1.1.5, 1.3.9, 1.3.10, 1.5.7 (NICE guideline numbering).	
777	The Health Foundation	NICE Full	1.5.28 10.4.2	18 106	Absence/low prominence of Shared Decision Making within the Full and NICE Guidelines and poor incorporation of the evidence about the clinical skills of shared decision making Unlike the Quality Statement, the NICE Guideline and Full Guideline do not explicitly require shared decision making to be the over-arching philosophy and method brought to decision making. Indeed, Recommendation 64 positions shared decision	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of

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					making as something which should be done "if a patient decision aid or other decision support tool is not available" (p.106 Full, p.19 NICE). This reflects a poor understanding of the literature and extremely clear evidence base. In this regard, we echo the important comment of the one member of the guideline development group reference in the final paragraph on page 107 of the full guideline about decision aids being only one part of effective shared decision making, which appears to have been overlooked by the rest of the guideline development group. That comment however reflects a much more accurate account of the literature about what works for effective decision making than the current guideline conveys. Furthermore, we think that the large number of separate recommendations within the Decision Making section is confusing; that they are presented in a confusing order (for example, the first reference to the requirement to use shared decision making principles is in the final recommendation, after a very detailed recommendation about communicating risk) and contain duplication and inconsistency. One aspect of this is that there is an inconsistency between the report of NICE's own review of the literature around decision aids as reported on p.100 of the full guideline, and Recommendation 64. On p.100 the guideline states "Patient decision aids do not replace, but may act as an adjunct to good clinical practice. Patient decision aids are not necessary to deliver good decision making …".	self management as a topic and have been assured that this will be raised with the National Quality Board.

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					In this context, we urge that Recommendations 56-64 are amended. As a suggestion, we offer the following wording which better reflects the evidence on best practice in implementing shared decision making[35] [36] [37]. First recommendation (replacing current Recommendation 56): Support patients to be involved in shared decision making to ensure that they understand that they have choices and that there are options. Use clinical shared decision making skills, as well as decision aids where appropriate and available, to help patients to make decisions which are based on understanding all the options, their risks and implications, and which are consistent with what is important to them. (This is a new drafting based on the good framing in the Quality Statement). Detailed recommendation (replacing recommendations 58, 59 and 64): "Offer support to the patient when they are making and reviewing decisions, using the principles of shared decision making: • Ensure that the patient understands that they have a right to make their own choice, that there are options, and that their preference will be unique to them (additional bullet)	

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[35] Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. Br J Gen Pract. 2000 Nov;50(460):892-9. PubMed PMID: 11141876; PubMed Central PMCID: PMC1313854

[36] *BMJ* 319 : 766 (1999), Towle A, Godolphin W., Framework for teaching and learning informed shared decision making

[37] Makoul, G. and Clayman, M. (2005). An integrative model of shared decision making in medical encounters. *Patient Education & Counseling*, **60**, 301–312.

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					• Encourage the patient to clarify what is important to them (bullet moved up the list – this is the 3rd bullet in current draft; second half of bullet dropped, second half used later below) • Ensure that the patient is aware of the options available and explain the risks, benefits and consequences of these (no change to current draft). Use short, simple decision aids within the consultation to convey key information about the options (additional sentence) • Offer advice about how the patient could access further decision support (either a decision aid or a person who can offer decision coaching), where these exist (additional bullet) • Check that the patient understands the information (no change to current draft) • Support the patient to review whether their decision is consistent with what is important to them (additional bullet)	
782	The Health Foundation	NICE	1.5.29 1.5.30	19	Difference between Education Programmes and Self-Management Support The comments made above in relation to the full guideline apply also to the NICE guideline, which needs substantial revision to reflect the strength of the evidence identifying self-management support as an effective intervention to improve the patient experience, of which Education Programmes are only one important but small part.	Thank you for your comment. The GDG recognise the importance of self-management for many patients, especially those with long-term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We did consider however that we could do justice to the topic of self management in its entirety in this guideline. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the

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						National Quality Board.
871	The Health Foundation	QS			Absence of a Quality Statement reflecting Recommendations 65 and 66 It is not clear why there is no Quality Statement at all reflecting section 10.5 of the full guideline (Patient Education), nor sections 1.5.29-1.5.30 of the NICE Guideline (Education Programmes). Its omission from the Quality Standard further suggests that NICE has failed to understand the strength of the evidence around self-management support and critically weakens the power of the guideline with regard to its ambition of "Enabling patients to actively participate in their care". We urge that the Quality Statements are revised to include an additional Quality Statement which reflects the evidence around self-management support, including Education Programmes as one delivery mechanism.	Thank you for your comment. A statement on use of evidence based information was written to reflect these recommendations.
1244	The Health Foundation	QS	15	22	Sparse use of the term Shared Decision Making within the Full and NICE guidelines, but prominence in the Quality Statement The Health Foundation welcomes the prominence of the term Shared Decision Making within Quality Statement 15. This is the best framing of shared decision making within the suite of documents (relative to the Full Guideline, NICE Guideline). We support and welcome the requirement not just to "involve" patients in decisions but to "support them to be involved". In any revisions made as a result of this consultation process, we would urge that this important distinction is not lost. The use of the term shared decision making will also help	Thank you for your comment. We acknowledge the need for clarity around this issue and we have addressed this in both the full guideline and its related impact on recommendations and quality statements.

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					health professionals to understand how this new guidance fits with other pressures on them, as it is the consistent term being used within key policy documents emanating from the Department of Health during for example the 2010 White Paper and related consultation documents such as Liberating the NHS: Greater choice and control.38	
872	The Hepatitis C Trust	QS	General	General	The Hepatitis C Trust is supportive of the development of a Quality Standard on patient experience in adult NHS services. The measurement of patient experience should be a key contributor to the measurement of overall outcomes and the proposed Quality Standard sets high standards that should be followed. In order to measure patient experience effectively, tailored questions should be developed for specific conditions or modelling should be introduced that will ensure that data can be disaggregated down for a specific group of patients. This will ensure that the specific needs of patients with hepatitis C for example can be addressed.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
982	The Hepatitis C Trust	QS	2	7	In some parts of the UK South Asian population, the prevalence of hepatitis C is five times that of the wider population39. In light of this, it is vital that steps are taken to assess potential barriers to participation in consultations and care, particularly	Thank you for your comment. The equalities act is now referenced within the guidance.

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[38] Department of Health (2010). *Equity and Excellence: Liberating the NHS*, London: Department of Health p.13 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf; Department of Health (2010). *Liberating the NHS: Greater choice and control*, London: Department of Health p.4 & pp 25-30 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120613.pdf

[39] G R Foster, Improving understanding and knowledge of chronic hepatitis C in ethnic minority groups from Pakistan and Bangladesh in London, Research from the Hepatitis C Trust and the lead investigator Professor G R Foster , Queen Marys University of London, 2010

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					in relation to language. There may also be cultural barriers that should be assessed – for example, we know that people from South Asian communities are less likely than the wider population to come forward for diagnostic tests. In this way, steps should be taken to ensure that healthcare professionals adapt the provision of services so that, where relevant, people are targeted in their own community.	
1057	The Hepatitis C Trust	QS	5	11	The physical and psychological impact of receiving hepatitis C treatment can be large, thus any assessment of physical and psychological concerns should include a full assessment of the possible impact of treatment and the support that may be required by an individual in order for them to complete treatment. Given the fact that a large proportion of hepatitis C patients are former or current injecting drug users, it is vital that the physical and psychological needs of this group are fully assessed. Ongoing research suggests that by treating patients who are injecting drug users, the spread of hepatitis C can be reduced and overall outcomes of those receiving treatment are improved. Assessment of physical needs and psychological concerns should be coupled with additional support where this need is identified.	Thank you for your comment. This quality standard has been changed to state that needs are met. Within this context the areas you have highlighted would be covered by an appropriate psychological assessment.
1081	The Hepatitis C Trust	QS	6	12	The healthcare team is vital to ensuring that people with hepatitis C have a positive experience of their care. Through ensuring that patients have a direct contact with specific members of the team, it should be possible for patients to know who to talk to if they are experiencing negative psychological effects as a result of their condition	Thank you for your comment. Amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".

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					or treatment.	
1123	The Hepatitis C Trust	QS	8	15	Informed patient choice should be at the heart of hepatitis C services – in this way, all patients should be offered the opportunity to undergo treatment and have the benefits and disadvantages explained to them. Evidence has shown that in some areas, patients are denied treatment if they are injecting drug users[40] – decisions about whether to treat a patient or not should be based on clinical evidence[41] and patient choice, not a blanket ban among certain groups.	Thank you for your observation
1143	The Hepatitis C Trust	QS	9	16	As many groups affected by hepatitis C are from groups with multiple needs such as injecting drug users, it is important that care is tailored to specific needs. This could include the delivery of hepatitis C treatment alongside drug treatment programmes. There is also a high prevalence of hepatitis C among those in prison – this group should still be provided with tailored care to support individuals in becoming clear from the virus during their time in prison.	Thank you for your comment.
1162	The Hepatitis C Trust	QS	10	17	In order to ensure that effective treatment and care of patients with hepatitis C, it is vital that information is shared between those working in the community and healthcare professionals. If those operating drug treatment programmes are in a position to offer hepatitis C testing, it should be possible for them to provide this type of information to healthcare professionals who may be providing support to this group.	Thank you for your observation.

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[40] All Party Parliamentary Hepatology Group, In the Dark: An audit of hospital hepatitis C services across England, August 2010

[41] NICE, TA200: Hepatitis C - peginterferon alfa and ribavirin, September 2010

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					In all instances, patient confidentiality should be maintained and the consent of these patients should be secured.	
1174	The Hepatitis C Trust	QS	11	18	As certain groups infected with hepatitis C may have complex lifestyles, it will be important that they are provided with contact details of a service or individual that they know can be contacted at any time. This means that if an individual is diagnosed with hepatitis C and then becomes disconnected from the health services, they know who to contact if they choose to re-engage with the health service to commence treatment or to get additional support to help them to manage their condition.	Thank you for your comment. We agree
1190	The Hepatitis C Trust	QS	12	19	Whilst efforts to ensure that patients can access the same healthcare professional or healthcare team to promote and maintain continuity of care, this should not prevent patients who may have lost contact with their original team in accessing support from a different provider. Measures should be in place to ensure that the healthcare records can be shared quickly between different providers to support continuity of care in these instances.	Thank you for your comment. We agree.
1245	The Hepatitis C Trust	QS	15	22	Shared-decision making for hepatitis C is vital in ensuring that patients are offered a number of options in relation to treatment and care. All patients should be offered the opportunity to undergo treatment and have the benefits and disadvantages explained to them. Evidence has shown that in some areas, patients are denied treatment if they are injecting drug users42 –	Thank you for your observation

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[42] All Party Parliamentary Hepatology Group, In the Dark: An audit of hospital hepatitis C services across England, August 2010

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					decisions about whether to treat a patient or not should be based on clinical evidence43 and patient choice, not a blanket ban among certain groups.	
41	The King's Fund	All	General	General	Overall the guidance and draft quality standards are very good and comprehensive and will be valuable for patients, commissioners and professionals.	Thank you for your comment
133	The King's Fund	Full NICE?	1.4	13 -14	Following on from the above - In particular, information about medication is very important and often poorly communicated between professionals in different parts of the service (eg at discharge) and to patients. Often not understood by patients at discharge. See: Keeping patients safe when they transfer between care providers - getting the medicines right. Good practice guidance for healthcare professions. July 2011 Royal Pharmaceutical Society, endorsed by Academy of Medical Royal Colleges. This guidance aims to increase the priority given to medicines information transfer and promote best practice in line with existing national initiatives. It has been developed in collaboration with pharmacy, medical, nursing and allied health professional bodies, plus patients, national agencies and health and social care professionals. This however does not appear in any of the Quality Statements about Continuity of Care.	Thank you for your comment. This has been addressed following public consultation.

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[43] NICE, TA200: Hepatitis C - peginterferon alfa and ribavirin, September 2010

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					Indicator: national inpatient survey	
180	The King's Fund	Full	2	23	There is no mention of cognitive impairment or dementia, both of which are likely to affect the patient's ability to participate. It is and will be in the future a significant co-morbidity for many patients	Thank you for your comment. A separate recommendation about patient's capacity according to the Mental Capacity Act (2005) has been added to the guideline.
249	The King's Fund	Full NICE	Rec 35 1.4.4	25 14	This is a crucial point and we include coordination of care within our definition of 'continuity of care' (forthcoming King's Fund report - scheduled for September contact Lara Sonola l.sonola@kingsfund.org.uk) A particularly important point for patients is discharge from hospital which if not managed in a coordinated way can mean patients are readmitted unnecessarily. (Holzhausen E. "You can take him home now": carers' experience of hospital discharge. 2001. London, Carers National Association.) Could further emphasis be put on the importance of smooth transition between services, particularly discharge, as part of QS10?	Thank you. We agree and the recommendation has been amended for clarity.
294	The King's Fund	Full	5.3	35	Despite the physical environment being recognised as a factor in three of the preceding models (tables 3, 4 and 5) and in the following section which details factors that are important to NHS patients (5.4.1, 6.4.2, and fig.2) it is not included in the chosen model developed from the scoping study at table 6 or in table 8. It is unclear why this important component of patient experience has been omitted. The King's Fund's Enhancing the Healing Environment programme over the last 11 years indicates that specific and explicit recognition needs to be made of the importance of the environment in which care is delivered to patients' wellbeing and recovery. See also R Ulrich (2004) The role of the physical	Thank you for your comment. We agree that the built and physical environment have a significant impact on patient experience. It was agreed with NICE that because of time constraints the scope of the guideline needed to be constrained and would focus on clinician/patient interaction and organisational issues and not address physical environment.

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					environment in the hospital of the 21st century and B Lawson (2003) The architectural healthcare environment and its effect on patient health outcomes.	
328	The King's Fund	Full	17	51	An excellent recommendation. There is strong evidence that this is very important from the patients' point of view and that pain relief is a dignity issue - see Help the Aged. (2008) On our own terms: the challenge of assessing dignity in care	Thank you for your supportive comment.
1027	The King's Fund	QS	4	10	The words used in this statement "…kindness, compassion, courtesy, respect, understanding and honesty" cover everything - excellent!	Thank you for your support for this quality standard.
1058	The King's Fund	QS	5	11	Realise that NICE not covering carers but it is seems a strange omission at times - this is one example where involvement of family and friends (a component of patient-centred care in all pcc frameworks) would make sense. It would be good practice for the discussion with patients about what extra support needed to include their family/carer. (Similar point for QS14)	Thank you for your comment. We agree that the involvement of carers is important and that attention to carers can be a significant influence on patient experience. We had however to limit the areas we were able to consider.
1144	The King's Fund	QS	9	16	Patient organisations such as the MS Society have produced information about caring for patients with coexisting conditions in hospital	Thank you for your comment.
1246	The King's Fund	QS	15&16	22 &23	Should this make it clear that information should be provided verbally but also written (as recommended in the full document)	Thank you for your comment. Noted
873	The Medical Technology Group	QS	General	General	The MTG is pleased to see that NICE is developing a quality standard for patient experience. The MTG believes that patient choice and patient information are necessarily at the heart of a health service that puts the patient first. Nevertheless, these principles are not mutually exclusive as there is no choice without knowledge.	Thank you for your comment. It is hoped that final version of the quality standard has been written to reflect this.

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					The MTG would like to see quality standards developed which more closely tie together patient choice and patient information.	
874	The Medical Technology Group	QS	General	General	An important piece missing from the draft QS is explicit reference to a patients right to be treated in a clean environment with minimal risk from healthcare associated infections. Patients should have access to information regarding a hospital's rate of HCAI and hospitals should provide a written statement of their Infection Prevention and Control policy in a patient friendly format. This should include their policy on screening for elective patients. Patients should expect all NHS institutions to have a zero tolerance policy on HCAIs.	Thank you for your comment. We agree that a clean environment is important. We had however to limit the areas we were able to consider.
1124	The Medical Technology Group	QS	8	15	The MTG is pleased to see a quality standard for patients' rights to choose, accept or decline treatment are respected and supported.	Thank you for your comment.
1163	The Medical Technology Group	QS	10	17	Statement: The MTG agrees that information about patient care should be exchanged in a timely, appropriate, clear and accurate manner between healthcare professionals.	Thank you for your comment. This has been reworded. See above.
1164	The Medical Technology Group	QS	10	17	Measure: Patients need to be given a choice at all stages when there is a choice to be made. Patients should be given the information they need to make a choice at all stages i.e. if a woman is suspected of having fibroids, a common health problem, they are normally diagnosed by ultrasound scan. However, the information this gives will only be detailed enough if the treatment is to be hysterecomy. If the woman does not wish to have a hysterectomy, but wants embolisation or myomectomy they will need an MRI to show where the fibroids are and how many there are, so it would save time and money if the woman had a	Thank you for your comment. We agree.

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					choice at the beginning.	
1247	The Medical Technology Group	QS	15	22	Statement: There is no choice without knowledge. Patients must be given full information on all the treatments available for their disease, and must be given full information on providers and their health outcomes results down to clinician level.	Thank you for your comment. We agree
1248	The Medical Technology Group	QS	15	22	Audience descriptors: Clinicians, especially GPs need training in listening to patients and entering into shared decision making rather than making decisions and assumptions on their behalf. This is a critical step towards the personalisation of care and making it most appropriate for the patient. Can clinicians be incentivised to ask the right questions of their patients to prompt a dialogue rather than making assumptions about what they think is best? GPs need to be kept up to date with new treatments and delivery schemes i.e. the insulin pump for type 1 diabetes and uterine fibroid embolisation for women with fibroids. As many older patients will not have access to the internet, hard/paper copies of information must be made available at the GP surgery and any other provider. Patient groups act as advocates for many patients helping them through the system. Providing more information on advocacy services available would be useful to help personalised treatments. There is also a task for commissioners to work more closely with providers, service users and	Thank you for your observations.

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					individual clinicians to ensure that services are structured around the patient rather than a patient to fit the service approach.	
1271	The Medical Technology Group	QS	16	23	Measure: The provision of choice and information needs to be regularly audited through patient satisfaction (experience) questionnaires. There needs to be plenty of space to provide feedback on how this could be improved. In the past patient questionnaires have lacked space for feedback.	Thank you for your comment. Noted
1291	The Medical Technology Group	QS	17	24	Measure: There is no choice without knowledge. Patients must be given full information on all the treatments available for their disease, and must be given full information on providers and their health outcomes results down to clinician level. As many older patients will not have access to the internet, hard/paper copies of information must be made available at the GP surgery and any other provider.	Thank you for your comment. We agree
110	The Mid Yorkshire Hospitals NHS Trust	Full	General	General	The quality statements and guidance are welcomed. The detail appears appropriate although potentially onerous to measure. There needs however, to be a more explicit and logical framework. High Quality Care for All stated "It is important that we have a national quality framework that enables us to publish comparable information on key measures". Whilst, comparable patient experience data is available through the national survey programme, there is no common approach to thematic analysis of qualitative data captured from comments, complaints, websites etc. In order to support the development of comparable information the development of a more logical and	Thank you for your comment. The National Quality Board will aim through this publication align systems of care and service delivery to improve the quality of patient experience. We agree that robust methods of measurement are required and we expect the NQB to produce measures for service commissioners and providers following the launch of this guidance.

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					explicit Framework with well defined domain headings would support thematic analysis, benchmarking and triangulation of data for Trust's composite patient experience reports. The sub headings (Domains) within the guidance do not appear to clearly define themes which could be used to aid analysis e.g. 'The patient as individual' and Tailoring healthcare services to the individual' lack clarity of definition and appear to overlap in many aspects. Whilst it is recognised there is a need for a new Framework which could apply throughout the NHS and encompass the areas of most importance to patients, the Picker Institute Europe care domains and the DOH themes identified from NHS patient surveys have much more tangible and succinct headings. Many reports at national and local level have highlighted 'Attitude' as a key theme of complaints. Domain headings such as 'Access and waiting' or 'Environment' would be much more tangible and likely to be adopted. The quality measures and mapping to relevant existing indicators is welcomed. Further development to rationalise this with the codes available within Trust risk management databases e.g. (Datix – which supports thematic analysis of issues identified from complaints/incidents/claims/PALs /appreciations) would further support robust and systematic triangulation of information. The proposed Framework and its potential to	

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					support systematic analysis of patient experience data should be detailed clearly within the guidance. More explicit direction regarding the expectations on organisations including who and how the guidance should be implemented and monitored would support its prioritisation.	
1082	The Mid Yorkshire Hospitals NHS Trust	QS	6	12	The 'Relevant existing indicators' section states "Questions on involvement in decision –making" however the Quality statement and example indicator relate to "introducing" rather than involving.	Thank you for your comment. Reworded
111	The National LGB&T Partnership	Full	General	General	Throughout the document potential differences due to sexual orientation and gender identity are not considered at all. This is despite evidence that lesbian, gay bisexual and trans (LGB&T) patients experience is poorer than that of the general population: • One in five trans people have found their GP to be unhelpful (Whittle, S. Turner, L. and Al-Alami, M. (2007), Engendered Penalties: Transgender and Transsexual People's Experiences of Inequality and Discrimination) • 20% of health care professionals admit to being homophobic (Stonewall (2007), Sexual Orientation Research Review) • Only 1 in 3 older LGBT individuals believes their health professionals to be positive towards them (Heaphy B., Yip A. and Thompson D. (2004), Shaping futures: LGBT people growing older, p5)	Thank you for your comment. We acknowledge the issues faced by lesbian, gay, bisexual and transgender people and have added a recommendation about the need for services to recognise comply with the Equalities Act.

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					NICE and all relevant agencies must start addressing the poorer health and social care experiences and outcomes of LGB&T people.	
181	The National LGB&T Partnership	Full	4.1	23	On point 6 - Sexual orientation and gender identity should be included in this list. Given that all other relevant protected characteristics from the Equality Act 2010 are included, the exclusion of sexual orientation and gender identity is very alarming and must be rectified.	Thank you, we agree with your comment . We have replaced this recommendation with reference to the Equality Act to ensure we have not omitted any individuals or groups.
112	The Picker Institute Europer	Full	General	General	The Picker Institute commends the amount and quality of work undertaken to review available evidence to inform the Guideline Development Group's work. The minimal consultation period does not however provide for detailed scrutiny or comment. Our response focuses on the draft quality standards/statements (below).	Thank you for your comment.
470	The Picker Institute Europer	NICE	General	General	The Picker Institute has very substantial concerns about the number, construction and practicability of the draft quality standards/statements. They need, in our view, substantial distillation and tightening-up to be capable of measurement, to allow valid comparisons of performance and to provide data that is useful for planning quality improvement initiatives. In this context, while entirely endorsing the overview and direction of travel set out in the NICE version, we suggest that the standards/statements (and consequently all associated documents) require more work.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and when it is established from the NHS Commissioning Board. The guidance has been refined to reflect consultation feedback.
875	The Picker Institute Europer	QS	General	General	The Picker Institute's overall view is that the patient experience (generic) quality standard requires substantial revision in order to be fit for	Thank you for your comments.

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					purpose and capable of implementation. We wish to emphasise that we entirely endorse the intentions, ideas and principles underlying the draft quality statements. Our reservations, as expressed below, reflect our very substantial experience of developing instruments to measure patients' experiences of care and of coordinating and conducting national and local surveys, bespoke quantitative patient experience measurement and quality improvement work with the NHS. The observations within this section (your order number 3) apply to all or most of the 17 draft quality standards/statements. Otherwise, specific comments on individual draft standards/statements are provided in subsequent order numbers. The consultation period does not allow for exhaustive analysis and development of alternatives, but we would very much welcome the opportunity to discuss our overall and specific concerns and our recommendations in detail with the Guideline Development Group. Our overall concerns on the draft quality standard include, but are not confined to, the following: • The status of 'quality statements' should be explained in all documents in the set. If the terms 'standard' and 'statement' are interchangeable, 'quality standard' should be used in every case. • There are, in our view, far too many quality	Please see: http://www.nice.org.uk/usingguidance/commissioningguides/aboutcommissioningguides.jsp The quality standard has been changed to reflect this.

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					standards/statements for implementation in practice. With 17 separate items, each requiring structure/process and outcome data collection, involving multiple questions and analyses, there is a very substantial risk that the NHS front-line and management will simply disregard the NICE document. The Picker Institute strongly recommends that there should be circa five high-level quality standards in the first instance, and that these should be selected on the basis of a) importance to patients (and carers, where relevant) according to best available evidence, and b) the availability of genuinely relevant existing indicators and data sources. • The patient experience quality standards are, in effect, objectives and as such they should all be 'smart' (specific, measurable, achievable, etc). They should not be so complex as to require multiple questions in order to measure and monitor performance. • The quality standard indicators should comply with established criteria for 'good' indicators (understandable, robust, reliable, etc), and performance data should allow valid comparisons between providers, services and over time. • With regard to the previous point, there are multiple examples within the draft document where NHS survey programme questions are cited as 'relevant existing indicators' when the questions cited in fact bear no direct	The number of Quality statements has been reduced to 14. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board. Thank you for your comments. The references to the national patient survey questions have been included to highlight where current questions exist that go some way to measuring the quality statement. The specific references have been reviewed for appropriateness to the statements.

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					relationship to the proposed quality standard/statement or its measurement and are certainly not good indicators. This must be resolved to avoid undermining the credibility of the patient experience quality standard as a whole. For example: ◦ the national inpatient survey core question 44 “Did you find someone on the hospital staff to talk to about your worries and fears?” is not an indicator of ‘patients are given the opportunity to discuss their health beliefs, concerns and preferences in order to individualise their care’ (draft quality statement three); ◦ the national inpatient survey core questions 45 and 45 (were you given enough privacy when discussing your condition or treatment and when being examined or treated) are not indicators of whether ‘patients regularly have their physical needs (such as nutrition, hydration and personal hygiene) and psychological concerns (such as fear and anxiety) assessed in an environment that maintains their dignity and confidentiality (draft quality statement five); ◦ the national inpatient survey core questions 51, 52, 53 and 54 (before an operation or procedure, did a member of staff explain risks and benefits in you could understand, explain what would be done, answer your questions in a way you	

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					could understand, and were you told how you could expect to feel afterwards) provide absolutely no information about whether patients' rights to choose, accept or decline treatment are respected and supported (draft quality statement eight). • The patient experience quality standards and indicators should describe the goal (the outcome for patients as reported by patients), not the means of achieving it (the providers' processes/activities as reported by providers). • Quality standards should only ask patients things that they can reasonably be expected to know. For example, it is not clear how patients could know whether or not they had been introduced to all members of the healthcare team (draft quality statement six). • With regard to measuring and monitoring, numerators and denominators should in all cases reflect data collection methods and capacities, and should be realistic and fit for purpose. As currently drafted most would require a census of all NHS patients and/or all NHS front-line staff, which is neither possible nor necessary. • The quality standard should be readily understandable, comply with established plain language criteria and minimise 'wiggle room'. The requirement that 'commissioners ensure that services establish at the outset, a	

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					respectful approach in ensuring that the patients' preferences for involving and sharing information with partners, family members and/or carers are prioritised', for example, could mean anything or nothing, depending on interpretation.	
945	The Picker Institute Europer	QS	1	5	The Picker Institute supports the principle of evaluating and performance-managing the NHS staff contribution to ensuring a positive patient experience, informally within day-to-day management and within formal appraisal processes. We do not however consider the statement, as drafted, to be appropriate as a quality standard for all the reasons set out under order number three (above). In particular, we perceive an overlap with the requirements of professional codes of practice, and question how and by whom evidence would be collated. We recommend, rather, a high level indicator based on patient-reported data regarding the quality of their interactions with health professionals and their overall assessment of the quality of their care.	Thank you for your comment. We agree that the recommendations and standards overlap both with professional codes of practice and regulatory bodies such as the Care Quality Commission. NICE are currently considering what implementation support to provide for this guidance
983	The Picker Institute Europer	QS	2	7	The Picker Institute does not consider the statement, as drafted, to be an appropriate quality standard for all the reasons set out under order number three (above). In particular, it is process and provider focused. We recommend, rather, a high level indicator based on patient-reported data regarding the extent to which they understood information	Thank you for your comment. The statement has been reworded.

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					provided and were involved, as much as they wanted to be, in decisions about their care and treatment.	
1009	The Picker Institute Europer	QS	3	9	The Picker Institute does not consider the statement, as drafted, to be a useful or appropriate quality standard for all the reasons set out under order number three (above). In particular, it is process and provider focused. Further, 'given the opportunity' is capable of very diverse interpretation and so incapable of measurement in a way that allows valid comparisons. We recommend, rather, a high level indicator based on patient-reported data regarding the extent to which patient were involved, as much as they wanted to be, in decisions about their care and treatment.	Thank you for your comment..The statements have been revised and now include whether patients have been asked about their health beliefs and also if they feel able to make decisions.
1028	The Picker Institute Europer	QS	4	10	The Picker Institute largely supports this draft quality statement, though has methodological concerns about the conflation of seven different concepts (dignity, kindness, compassion, courtesy, respect, understanding and honesty) into one standard. Although, intuitively, these concepts 'belong together', it would be necessary empirically to confirm, via factor analysis of existing data, whether they can legitimately be combined to create a single high level indicator. It may be that the concepts cannot usefully be grouped into a single item and that more than one indicator is required.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1059	The Picker Institute Europer	QS	5	11	The Picker Institute has methodological concerns regarding the complexity of this draft quality statement, which conflates the assessment of	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used

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					physical needs, the assessment of psychological concerns, the assessment environment, and the maintenance of dignity and confidentiality. Further, the proposed statement and measures require only the assessment of physical needs and psychological concerns – not that patients' needs and concerns should be met/addressed by health professionals.	by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1083	The Picker Institute Europer	QS	6	12	The Picker Institute does not consider the statement, as drafted, to be a useful or appropriate quality standard for all the reasons set out under order number three (above). In particular, it is unclear how or why being introduced to team members is a function of service tailoring, or how patients would know whether or not they had been introduced to all members of the health care team (which can be variously defined/understood). The NHS survey programme question 'Were you involved, as much as you wanted to be, in decisions about your care and treatment?', cited as a 'relevant existing indicator' in fact bears absolutely no relation to the quality statement.	Thank you for your comment. This has been amended to: "Patients are introduced to all healthcare professionals involved in their care and are made aware of the roles and responsibilities of the members of the healthcare team".
1103	The Picker Institute Europer	QS	7	13	The Picker Institute supports this draft quality statement although, as noted, there are no relevant existing indicators. Again, as drafted, the quality statement is complex and would require multiple questions to gather all the required items of data. We recommend simplifying to focus on partner, family and carer involvement (given that	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					presupposes adequate information) and redrafting so that the quality standard matches the existing 'involvement in decisions' patient experience question: 'Patients' partners, families and carers are involved in decisions about care and treatment as much as the patient wants them to be.'	
1125	The Picker Institute Europer	QS	8	15	The Picker Institute wholeheartedly endorses the principle of respecting and supporting patients' rights to choose, accept or decline treatment. We do not however consider the statement, as drafted, to be appropriate as a quality standard for all the reasons set out under order number three (above). In particular, 'respecting' and 'supporting' are non-specific and capable of diverse interpretation, while 'feeling respected and supported' is highly subjective and would be highly influenced by individual expectations. As such, performance would be impossible to measure in ways that provide genuinely comparable data. Further, we cannot comprehend why the NHS inpatient survey questions on information provided before surgical treatment are considered to be relevant existing indicators – but the 'involvement in decisions as much as you wanted to be' question is not.	Thank you for your comment. Thank you for your comment. The GDG felt it possible to ask a patient whether their rights to choose, accept or decline treatment had been respected. The reference to the questions on information provision were included as the patients right to choose, accept and decline treatment will be affected by the correct provision of information prior to treatment. However following your comment these have been removed. The questions on involvement in decisions have been used as possible sources of information for the statement on shared decision making.
1145	The Picker Institute Europer	QS	9	16	The Picker Institute wholeheartedly endorses the principle of personalised care We do not however consider the statement, as drafted, to be appropriate as a quality standard for all the reasons set out under order number three	Thank you for your comment. This has been amended to: Patients receive care that is tailored to their needs and circumstances, taking into account their ability to access services, personal preferences and coexisting conditions.

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					(above). In particular, the quality statement is very complex, and would require multiple questions in order to provide all the data required to measure and monitor performance and to provide actionable data to inform quality improvement work.	
1165	The Picker Institute Europer	QS	10	17	The Picker Institute does not consider the statement, as drafted, to be a useful or appropriate quality standard for all the reasons set out under order number three (above). In particular, the draft quality statement focuses on the means (information exchange) rather than the outcome for patients (coordinated care). We are not clear what 'prioritisation of care' means in this context.	Thank you for your comment. The statement has been reworded.
1175	The Picker Institute Europer	QS	11	18	Picker Institute Europe supports this draft quality statement, though again strongly recommends that it should be focused on the outcomes for patients rather than provider processes. We strongly recommend that it should be redrafted to read 'Patients know who to contact about their ongoing health needs, and how to contact them.'	Thank you for your comment. We believe this is implicit in the statement and wording consistent with NICE style.
1191	The Picker Institute Europer	QS	12	19	The Picker Institute does not consider the statement, as drafted, to be a useful or appropriate quality standard for all the reasons set out under order number three (above). In particular, 'healthcare team' and 'throughout their care' can be variously interpreted (depending on care setting, for example) and patients will not necessarily know which staff members are in which teams.	Thank you for your comment. This has been addressed in the reconfiguration of 17 statements into 14 statements.

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1217	The Picker Institute Europer	QS	13	20	The Picker Institute does not consider the statement, as drafted, to be a useful or appropriate quality standard for all the reasons set out under order number three (above). In particular, the draft quality standard focuses on 'what providers do' rather than outcomes for patients. We are not clear what 'trained in communication skills' means in practice, and in our view the requirement is likely to be interpreted variously at local level. We are also unclear regarding how, when and to whom communications competency should be demonstrated. Though not cited, there are several relevant questions used within the NHS patient experience programme, pertaining to, for example understanding of information, understanding of responses to questions, and involvement in decision making. The quality standard should be derived from these.	Thank you for your comment. See above comments relating to agreements between commissioners and providers of healthcare.
1226	The Picker Institute Europer	QS	14	21	The Picker Institute does not consider the statement, as drafted, to be a useful or appropriate quality standard for all the reasons set out under order number three (above).	Thank you for your comment.
1249	The Picker Institute Europer	QS	15	22	The Picker Institute supports this draft quality statement, but it is unnecessarily complex and again focuses on provider activities rather than patient outcomes. We strongly recommend redrafting to create a strong and very simple high level quality standard:	Thank you for your comment. See new wording in previous response above.

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					'Patients are involved, as much as they want to be, in decisions about their care and treatment'.	
1272	The Picker Institute Europer	QS	16	23	The Picker Institute supports this draft quality statement, except that it focuses on provider activities rather than patient outcomes. Though not cited, there are several relevant questions used within the NHS patient experience programme, pertaining to, for example understanding of information, understanding of responses to questions, and involvement in decision making. The quality standard should be derived from these.	Thank you for this helpful suggestion. The references have been reviewed to further utilise the patient survey programme.
1292	The Picker Institute Europer	QS	17	24	The Picker Institute's view is that access to decision aids should be regarded as an indicator of patient involvement in decisions, not as a quality standard in its own right. This is principally because we hold that generic quality standards should be applicable to all patients, in all settings, whereas validated decision aids are only available for relative few conditions/patient groups.	Thank you for your recommendation.
42	The Prostate Cancer Charity	All	General	General	The Prostate Cancer Charity welcomes the development of the Clinical Guideline and quality standards for patient experience in generic terms. Historically, men with prostate cancer had reported a worse patient experience than those with other types of cancer. The 2010 National Cancer Patient Experience survey found that, while the experience of men with prostate cancer has improved, it lags behind other tumour groups in key areas such as the provision of information about treatment side effects and financial support. The Charity welcomes the chance to respond to	Thank you for your comment.

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					the consultations on the Clinical Guideline and quality standards as the UK's leading charity working with people affected by prostate cancer.	
113	The Prostate Cancer Charity	Full	General	General	NICE state that one of the aims of clinical guidelines is to "help patients to make informed decisions1." In order to make such decisions, patients need clear information. The Charity believes that the draft structure of the clinical guideline needs to be improved to ensure clarity for patients who may use the document as a guide to the quality of care they should receive. For example, currently the draft guideline is not very well organised. The sections overlap significantly which has led to repetition throughout the recommendations. Often, where a point is mentioned for the first time, not enough detail is given. For example, recommendation 21 stresses the need for giving the patient information about treatment options but does not mention supporting them in decision making or providing information in different formats. The recommendations could be made clearer if other relevant sections were referenced where they are alluded to. In addition, similarly-worded recommendations are sometimes given under different sections. This is likely due to the fact that some themes, such as communication and information, underpin all of the recommendations, so it can be difficult to discuss them as separate issues.	Thank you for your comment. The structure of the Guidance was reviewed to enhance clarity and minimise repetition

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					Listing all of the types of information that a patient should receive throughout their care in a quick-reference guide would help clinicians and patients check their information provision. This could be done in an appendix to the clinical guideline. Recommendations for clinicians to consider a particular element of care are listed separately from recommendations for clinicians to take action. This makes the guideline seem repetitive. For example, recommendation 2, which states that clinicians should, "consider the extent to which factors such as physical or learning disabilities, sight or hearing problems...may affect the patient's ability to participate in consultations and care," is listed under the section "The patient as an individual." However, recommendation 40, which gives advice on how to overcome difficulties in understanding by, "using pictures, symbols, large print, Braille, different languages, an interpreter or a patient advocate," is given under the section "Enabling patients to actively participate in their care." It might make the guideline more user friendly to deal with "consider" and "action" points together. If this is not possible, then points for consideration should refer to relevant "action" points. It would also be valuable for NICE to pilot the draft Clinical Guideline with patients in order to assess how practical it is for them. Reference 1) NICE website:	

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					http://www.nice.org.uk/aboutnice/whatwedo/aboutclinicalguidelines/about_clinical_guidelines.jsp	
114	The Prostate Cancer Charity	Full	General	General	The recommendations vary in style. Some are specific, which is helpful, but others are open ended. The latter would benefit from some concrete examples to contextualise them. these have been provided in a few places, but not throughout the guideline. For example, recommendation 62 gives helpful examples of the principles to use when discussing risks and benefits with patients. However, recommendation 48 does not offer examples of the types of information patients might need to "promote active participation in their care."	Thank you for your comment. We provide examples where it is felt to be helpful in providing greater context and follow the advice of the NICE editorial team.
115	The Prostate Cancer Charity	Full	General	General	It is widely accepted that patient information should be written in plain English so that patients are able to easily understand it and act upon it the first time they read it. The draft clinical guideline is not easy to read and understand and the wording is not consistent with plain English guidelines2. Specifically, some recommendations use NHS jargon without explaining it. Some recommendations use passive language. In other instances, overly complex language is used which affects the clarity of the recommendation. For example: • in recommendation 20, it is unclear what "locality" and "access" mean • recommendation 35, "ensure effective coordination and prioritisation of care" uses	Thank you for your comment. The language of the Guidance has been reviewed to ensure clarity and appropriate tone.

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					both jargon and passive language which affects the clarity of the recommendation - recommendation 38, "maximise patient participation in communication," could be more clearly written as "ensure patients are able to fully participate in conversations and communicate effectively." It is especially important that the guideline is easy for both clinicians and patients to understand and interpret. This will be the only guideline that outlines the level of care patients can expect while using NHS services. Although there will be patient version of the guideline, it will be extensively based on the final clinical guideline. The patient version will not go out for consultation before it is published, so it is important to make sure the language of the clinical guideline is as clear and meaningful as possible. Reference: 2) Plain English Campaign: http://www.plainenglish.co.uk/	
116	The Prostate Cancer Charity	Full	General	General	The full guideline includes 66 recommendations about patient experience. It is likely that consultation times for some clinicians may need to increase to implement the guideline. It is important to ensure that the associated cost implications do not lead to the guideline not being fully implemented. Clinicians will need support and training to fully implement the guideline. Making the document easier to read and follow by	Thank you for your comment and points made. Recommendations made by the GDG will form the basis of good practice and will inform the development of 'patient experience' measurement which commissioners will be expected to use and ensure that service delivery facilitates the implementation of this guidance. Following consultation on this draft, editing and reshaping of the guidance will improve its presentation.

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					re-organising it to avoid repetition would also make it easier for clinicians to implement.	
117	The Prostate Cancer Charity	Full	General	General	The Charity would like to see this guideline implemented as widely as possible and recommend that NICE fully evaluate the uptake of the guideline at an appropriate time after its publication. In order to fully evaluate the implementation of the guideline, robust data will need to be collected on patient experience across disease areas.	Thank you for your comments. The Guidance produced from the evidence synthesis is the primary source evidence for the Quality Standard on Patient Experience. This means that it will provide the framework for commissioning and will inform how effective this is in changing practice/improving patient experience through measurement.
309	The Prostate Cancer Charity	Full	6 & 8	44 -47 & 53 -57	There is significant overlap between the sections "The patient as an individual," and "Tailoring healthcare services to the individual." The guideline could be made less repetitive, and more user friendly by combining these sections under the heading "Tailoring care to the individual patient."	Thank you for your comment. This reflects the complexity of care, highlighting that several themes fall into a number of major categories of experience.
318	The Prostate Cancer Charity	Full	7	48 -52	The title "Essential requirements of care" is not clear and could also suggest that other sections of the guideline are not essential. A title such as "Essential clinical requirements of care" might be more straightforward.	Thank you for your comment. The GDG felt that this title was appropriate for the section and has therefore not been altered.
319	The Prostate Cancer Charity	Full	7	48 -52	The section "Essential requirements of care" could be made more user friendly by sub-dividing the points which focus on hospital and in-patient care from the points which are relevant to all types of patient care.	Thank you for your comment. The GDG felt that it was not necessary to make this distinction as the recommendations are also valid outside of the hospital environment.
332	The Prostate Cancer Charity	Full	8	53 -57	The Charity believes there should be a recommendation in this section for clinicians to support the patient's right to seek a second opinion and right to complain if they do not feel they are receiving an appropriate level of care. The NHS Constitution states that patients have the	Thank you for your comment and information. A recommendation about a second opinion has been added (recommendation 27). Recommendation 33 addresses informing patients how to complain.

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					right to be involved in their care and the right to make a complaint. However, The Prostate Cancer Charity has found that some men with prostate cancer feel that their clinicians do not support their right to be involved in their treatment and care. Just over 30 per cent of men surveyed by the Charity reported that they could not provide any examples of when they had been effectively involved in decisions about their treatment or care. A number of men said they felt their care only improved after they proactively pushed for a second opinion, while others felt they had to exert pressure to become involved6. We also hear anecdotally through the Charity's Helpline7 that some men have difficulty accessing information about the local complaints procedure. A recommendation for clinicians to support a patient's right to a second opinion and right to complain will help patients become more involved in their treatment and care. Reference 6) Between 25th August and 8th September 2010, The Prostate Cancer Charity surveyed people affected by prostate cancer living in England for their views to the proposals in "Equity and excellence: liberating the NHS". 145 people responded to an online and paper survey. 7) The Prostate Cancer Charity offers a UK-wide confidential Helpline, staffed by specialist nurses.	
333	The Prostate Cancer Charity	Full	8 & 10	53 -57 & 71	The Charity believes there should be a specific recommendation for clinicians to ensure patients do not feel rushed so that they are able to ask questions about their care and possible treatment	Thank you for your comment and information. Recommendation 22 states that adequate time should be allowed for discussions.

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				-108	options. We hear anecdotally through our Helpline8, and through our research, that men sometimes do not feel able to ask questions. Some men have commented that they did not have enough time, while others said that clinicians do not seem to encourage questions. For example, some responses to a survey conducted by the Charity9 included: "Oncologist/Urologist need to ...be more open and informative with their patients. More time should be allocated for each consultation." "There never seems to be time to cover all of the options when looking in to what treatments are available." "It would be more reassuring if a little more time could be given in a one to one talk." A survey conducted with callers to the Charity's Helpline10 found that most men and their partners access the Helpline so they can receive expert and detailed advice immediately from the Charity's Information and Support Specialist Nurses. Many compared their experience using the Helpline with their experience seeing Healthcare professions, saying that their experience with the Helpline was more favourable. Many respondents said they felt they had little time to ask questions or absorb information when talking to healthcare professionals during appointments.	

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					For example, some responses to the survey included: "The Helpline nurses were very professional, but I felt I could talk as long as necessary and also on both occasions the phone call was answered immediately, which with other professionals was not the case." "They gave me time to consider the questions and ask for further information without any pressure. At hospital appointments I always feel time is limited." References 8)The Prostate Cancer Charity offers a UK-wide confidential Helpline, staffed by specialist nurses for anyone concerned or affected by prostate cancer. 9) Between 25th August and 8th September 2010, The Prostate Cancer Charity surveyed people affected by prostate cancer living in England for their views to the proposals in "Equity and excellence: liberating the NHS". 145 people responded to an online and paper survey. 10) 201 callers who contacted The Prostate Cancer Charity's Helpline between September 2010 and January 2011 responded to a hardcopy survey.	
333	The Prostate Cancer Charity	Full	8 & 10	53 -57 & 71 -108	The Charity believes there should be a specific recommendation for clinicians to ensure patients do not feel rushed so that they are able to ask questions about their care and possible treatment options.	Thank you for your comment. We agree and this has been added to recommendation #22 which reads: "Hold discussions in a way that encourages the patient to express their personal needs and preferences for care,

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					We hear anecdotally through our Helpline8, and through our research, that men sometimes do not feel able to ask questions. Some men have commented that they did not have enough time, while others said that clinicians do not seem to encourage questions. For example, some responses to a survey conducted by the Charity9 included: "Oncologist/Urologist need to ...be more open and informative with their patients. More time should be allocated for each consultation." "There never seems to be time to cover all of the options when looking in to what treatments are available." "It would be more reassuring if a little more time could be given in a one to one talk." A survey conducted with callers to the Charity's Helpline10 found that most men and their partners access the Helpline so they can receive expert and detailed advice immediately from the Charity's Information and Support Specialist Nurses. Many compared their experience using the Helpline with their experience seeing Healthcare professions, saying that their experience with the Helpline was more favourable. Many respondents said they felt they had little time to ask questions or absorb information when talking to healthcare professionals during appointments.	treatment, management and self management Allow adequate time so that discussions do not feel rushed"

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					For example, some responses to the survey included: "The Helpline nurses were very professional, but I felt I could talk as long as necessary and also on both occasions the phone call was answered immediately, which with other professionals was not the case." "They gave me time to consider the questions and ask for further information without any pressure. At hospital appointments I always feel time is limited." References 8)The Prostate Cancer Charity offers a UK-wide confidential Helpline, staffed by specialist nurses for anyone concerned or affected by prostate cancer. 9) Between 25th August and 8th September 2010, The Prostate Cancer Charity surveyed people affected by prostate cancer living in England for their views to the proposals in "Equity and excellence: liberating the NHS". 145 people responded to an online and paper survey. 10) 201 callers who contacted The Prostate Cancer Charity's Helpline between September 2010 and January 2011 responded to a hardcopy survey.	
335	The Prostate Cancer Charity	Full	8	54	The Charity welcomes recommendation 21, "Give the patient information about relevant and available treatment options, even if these are not provided locally." This information is important to men with prostate	Thank you for your comment and information.

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					cancer. Over 90 per cent of respondents to a survey conducted by The Charity stated that they want more information and choice about the treatment and care they are offered. Of these, over half wanted more choice and information about the types of treatment available. This included more information about the treatments available at other hospitals and more choice over which hospital they attended3. Reference 3) Between 25th August and 8th September 2010, The Prostate Cancer Charity surveyed people affected by prostate cancer living in England for their views to the proposals in "Equity and excellence: liberating the NHS". 145 people responded to an online and paper survey.	
336	The Prostate Cancer Charity	Full	8	54	The Charity welcomes recommendation 22, "Tell the patient about health and social services that are available (for example, smoking cessation services), and encourage them to access these according to their individual needs." However, the recommendation could be made stronger by stating that responsibility should lie with the clinician to proactively tell patients what services are available. Many patients will not know what services are available or what services they may need. Hearing about them from a clinician will be the only way for many patients to find out what is available. Many patients will not know what is available in their area or what services they may need and will	Thank you for your comment and information. Recommendation 20 addresses this.

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					therefore not be able to ask their clinician. Research conducted by The Charity found that over 40 per cent of men diagnosed with prostate cancer do not receive the support they needed to cope with the effects of prostate cancer and its treatment4. However, the Charity found that in many areas support services were available5 but men were not finding out about them. It is therefore important that this recommendation is written to ensure that clinicians proactively provide information about the services available and how to access them. References 4) 156 UK men who had been diagnosed with prostate cancer and had experienced side effects from treatment within the last two years completed an online and postal survey for The Prostate Cancer Charity in January and February 2010. 5) A Freedom of Information Request was sent to every PCT in England and Health Board in Scotland asking them a series of specific questions about the support services they provide or fund for men with prostate cancer experiencing urinary incontinence, erectile dysfunction and psychological problems. Approximately 60% responded.	
356	The Prostate Cancer Charity	Full	9	68	The recommendations in this section are not clear. Specifically, more information is needed to help clinicians implement the following: • recommendation 32 "consider each patient's requirement for continuity of	Thank you for your comment. The recommendations are intendeds to be generic. We have included examples e.g. seeing the same health care professional in these recommendations. The GDG considered that both professionals and

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					care," - recommendation 35, "ensure effective coordination and prioritisation of care" for patients who require a number of different services and - recommendation 36, "ensure clear and timely exchange of patient information between healthcare professionals." Specific recommendations or examples of best practice would help make the recommendations more applicable.	patients could judge what was timely but that this would vary depending on patients and conditions.
357	The Prostate Cancer Charity	Full	9	68	Recommendation 35, which stresses the importance of effective coordination for patients who require a number of different services, should specifically include patients who have been discharged from hospital. It is important that patients who have recently been discharged have appropriate follow up care and support. Additionally, a recommendation to ensure all patients with a long-term condition have a personalised care plan would help ensure that their care is coordinated.	Thank you for your comment. We believe your points are now addressed in recommendations 34-36 in a manner that spans all settings and conditions.
362	The Prostate Cancer Charity	Full	10	71 -112	The subdivision of this section, "Enabling patients to actively participate in their care," is clear and works well.	Thank you for your comment.
370	The Prostate Cancer Charity	Full	10.2	74	The Prostate Cancer Charity welcomes recommendation 46, which states that all members of the healthcare team should have a demonstrated competency in relevant communication skills.	Thank you for your comment. The GDG considered that the need for demonstration of competency would drive training if required.

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					The recommendation could be made stronger by including a requirement that members of the healthcare team should receive training in communication skills.	
376	The Prostate Cancer Charity	Full	10.3	77	Recommendation 50, "give the patient...clear, consistent, evidence-based, contextualised, tailored information throughout all stages of their care," should also state that the patient should be provided with comprehensive information to cover all of their options.	Thank you for your comment. The GDG discussed the wording and did not consider that adding comprehensive to the recommendation was necessary.
377	The Prostate Cancer Charity	Full	10.3	77	The Charity strongly believes that recommendation 50, that patients should be given information about "their condition, proposed care and any treatment options," should be amended to include giving patients information about all short and long term side effects they may experience from the treatments they receive. Information about treatment side effects is important for a range of conditions, but it is especially important for men with prostate cancer as the treatments often have life-changing side effects. Men treated with radiotherapy, for example, can experience significant side effects years after their treatment finishes. These men will need information about the side effects to help them cope effectively if and when they appear. Men treated with hormone therapy can experience a range of side effects including fatigue, erectile dysfunction, mood swings and depression. Despite the considerable distress and discomfort experienced by many men who are receiving	Thank you for your comment. The GDG did not consider it appropriate to change the wording of the recommendation but the information needs to reflect the condition being treated.

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					hormone therapy, the Charity's research shows that too many men are not given adequate information about side effects prior to treatment. This means that they are not prepared for what could be ahead of them and do not know that the side effects they go on to experience can be an expected result of treatment12. All patients should receive verbal and written information about the side effects they may experience as a result of treatment. They should be told about appropriate interventions that can help prevent or alleviate side effects and should be regularly assessed by clinicians to ensure they are receiving adequate support. Reference 12) "Hampered by hormones? Addressing the needs of men with prostate cancer. Campaign Report." The Prostate Cancer Charity, 2009. Available at: http://www.prostate-cancer.org.uk/media/49198/htcampaignreport.pdf	
378	The Prostate Cancer Charity	Full	10.3	77	Clinicians should be aware that patients with long-term conditions may need to be signposted to information about financial support, and that patients will not always know to ask about this.	Thank you for your comment. We have included a recommendation which includes asking if the patient needs financial support.
379	The Prostate Cancer Charity	Full	10.2	78	The Charity welcomes recommendation 52, "give the patient both verbal and written information." The provision of verbal and written information is especially important for men with prostate cancer. The 2010 National Cancer Patient Experience Survey found that 1 in 4 prostate cancer patients are not given written information. There are also	Thank you for your comment. The guidance is generic and applies to all NHS settings so specifically including 'take home' in the recommendation would not be appropriate. We do suggest however that people are told about local and national support groups and information.

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					significant variations between the best and worst performing health Trusts. Prostate cancer patients are also less likely than patients from other common tumour groups to be given an explanation of treatment side effects or receive written information about side effects11. The Charity believes that this recommendation could be strengthened by stressing that clinicians should give patients information to take home from the consultation (in an appropriate format). This will give patients time to digest complex information. Patients should also be given the opportunity to contact their clinician or other nominated healthcare professional after consultations if questions arise, even if no follow up appointments are scheduled. Reference 11)National Cancer Patient Experience Survey Programme. 2010 National Survey Report. Department of Health. 10 December 2010.	
383	The Prostate Cancer Charity	Full	10	79	Recommendation 55, "Tell the patient where they might find reliable high quality information and support after consultations, from sources such as: local support groups and networks, local and national information services," should also specifically include referring patients to charities. Many charities, such as The Prostate Cancer Charity, already produce high quality tailored information, which is certified by the Department of Health's Information Standard. Referrals to	Thank you for your comment and this information. The Information Standard has been added to the Full guideline.

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					charities would help the NHS save money and avoid duplication of effort.	
384	The Prostate Cancer Charity	Full	10.3	79	Recommendation 55 should also include the use of Information Prescriptions in England. The Prostate Cancer Charity is concerned that there are no references in the draft clinical guideline to the Information Prescription programme. Information Prescriptions can be effective in guiding patients to relevant and reliable sources of information to help them manage their condition. Full use of the programme would also help cut down on duplication of effort as sources of high quality information would already be identified and made easily accessible. The Prostate Cancer Charity strongly recommends the inclusion of Information Prescriptions for use in England in the clinical guideline to present the best practice in patient experience. In Wales and Northern Ireland, where the Information Prescription Programme is not available, clinicians should refer patients to other reliable sources of information such as charities or support groups.	Thank you for your comment. The GDG did not wish to include this in a generic guideline relevant for England and Wales.
396	The Prostate Cancer Charity	Full	10.4	104	The Charity believes that recommendation 58, "Before starting any screening, investigations or treatment...openly discuss and provide information about the risks, benefits and consequences of the investigation or treatment..." should be reworded to say "provide balanced information about risks, benefits and consequences..."	Thank you for your comment. We agree and have added a sentence to the link from evidence to recommendation section of the guideline.

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					It is vital that clinicians provide patients with balanced information. However, evidence suggests this does not always happen as it should. For example, the Charity is aware anecdotally that some GPs do not provide balanced information about the pros and cons of the PSA test to men who are concerned about prostate cancer and deny the test to men who have made an informed decision to have one13. Government policy states that all men over 50 are entitled to have a PSA test on the NHS - once they have received balanced information and fully considered its pros and cons. Despite this, 1 in 10 GPs do not support men's right to access the test even after they have considered its pros and cons14. References 13) Kantar Health conducted web based interviews on behalf of The Prostate Cancer Charity with 505 GPs from across the UK drawn from TNS healthcare professional panels in February 2011. 14) The Prostate Cancer Charity offers a UK-wide confidential Helpline, staffed by specialist nurses for anyone concerned or affected by prostate cancer.	
397	The Prostate Cancer Charity	Full	10.4	104 -106	The Charity believes that supporting patients throughout decision making should be given a higher priority in the recommendations. Currently, offering patient support while making decisions is the last of the 9 recommendations in this section.	Thank you for your comment. The order of recommendations in a section does not indicate priority and the GDG consider they are of equal importance. We agree that it is important to support people through decision making and this is explicit in the

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					The Prostate Cancer Charity welcomes recommendations to increase patient choice, but it is important to support them through decision making. For some patients the additional responsibilities associated with greater choice, as outlined in the Government's proposed NHS reforms, may place too high a burden on them at an already difficult time (i.e. having just received a cancer diagnosis). This is particularly important for men with prostate cancer. Due to the complex nature of the disease, men with early stage prostate cancer often have to make difficult treatment decisions . Research conducted by the Charity15 and anecdotal evidence received through the Charity’s Helpline16 suggests that some men feel pressured to make a decision about their treatment without enough support from healthcare professionals. Clinicians should also be aware that patients may need emotional support, especially when making complex decisions. Clinicians should proactively refer patients to sources of emotional support if it is necessary. References 15) Between 25th August and 8th September 2010, The Prostate Cancer Charity surveyed people affected by prostate cancer living in England for their views to the proposals in "Equity and excellence: liberating the NHS". 145 people responded to an online and paper survey. 16) The Prostate Cancer Charity offers a UK-wide confidential Helpline, staffed by specialist nurses	recommendations.

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					for anyone concerned or affected by prostate cancer.	
403	The Prostate Cancer Charity	Full	10.4	106	The Charity welcomes recommendations 63 and 64 which support the use of decision aids. However, the Charity believes that these recommendations should be worded more strongly to actively promote the use of decision aids. Specifically recommendation 63 which says, "be aware of the value and availability of patient decision aids..," could be re-worded to say, "Suitable high quality decision aids should be offered to the patient where available."	Thank you for your comment. The developers consider that the wording reflects the intended meaning and evidence base.
411	The Prostate Cancer Charity	Full	10.5	111	The recommendations about patient-education programmes are not clear. More information about the types of education programmes that should be offered and when and to whom they should be offered would help make the recommendations more applicable.	Thank you for your comment. As the content of patient education programmes vary by condition, this review set out to assess the likely components of a programme rather than the types of programmes, per se.
876	The Prostate Cancer Charity	QS	General	General	Quality standards are meant to be patient facing documents. However, the draft quality standards are not easy to understand or follow. The sentences are often too long and overly complex, which decreases their clarity. Breaking each quality statement up into shorter sentences would make them easier to understand without affecting their impact. NHS jargon, medical and academic terms are also used without explanation. It is unlikely that most patients will fully understand the following: NHS guidance; annual performance assessment; commissioned; integrated approach; co-existing	Thank you for your comment. The quality standards have been reviewed.

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					conditions; continuity of care; coordination and prioritisation of care; demonstrated competency or maximise their participation. The statements should be redrafted using simplified language, using plain English guidelines17. Where particular phrases cannot be simplified, they should be explained with additional information. Reference 17) Plain English Campaign: http://www.plainenglish.co.uk/	
877	The Prostate Cancer Charity	QS	General	General	The organisation of the quality standards is not clear. It would be more effective to group the quality statements in line with a patient's care pathway, in the same way that existing disease-specific quality statements are organised. If this is not possible, the organisation could still be improved by grouping them by topic in a more consistent manner. For example: • the quality statement on supporting a patient's decision making (QS 15) should be grouped with the statement on a patient's right to choose treatments (QS 8); • the quality statement on assessing patient's disabilities or difficulties (QS 2) and the statement on assessing a patient's health beliefs (QS 3) should be grouped with, QS 14, which says that healthcare	Thank you for your comment. The quality standards cover adult services in the NHS and therefore a care pathway in this instance is not possible as the pathways vary so much. Your suggestions have however been considered.

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					professionals should establish and use the most suitable way of communicating with each patient (please see comment 32, below); - quality statements 1 and 13 should be grouped together, or combined, as they both refer to requirements for healthcare professionals to follow the guideline on patient experience; - quality statements 15 and 17 should be together as they both deal with decision making.	
898	The Prostate Cancer Charity	QS	QS1	3	The Charity welcomes this quality statement, which says that NHS staff will be evaluated for compliance with the NICE guideline on patient experience. However, the statement is not especially relevant for patients. While patients should know what is expected of healthcare professionals, the statement will not have meaning for them unless they are able to find out whether or not clinicians have implemented it. Publishing this data on the NHS Choices website will help patients use this information to help them choose the highest quality services.	Thank you for your comment. Post consultation this has been further refined.
899	The Prostate Cancer Charity	QS	QS3	3	This statement is not clear and would not make sense to a patient. (Please see comment 32, below)	Thank you for your comment
900	The Prostate Cancer Charity	QS	QS2, 3 & 14	3 -4	These statements could be combined to better contextualise them. The Charity's suggestion is:	Thank you for your comment. These quality standards have been reviewed.

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					"Patients are asked about: • any physical or learning disabilities; • sight or hearing problems; • difficulties reading, understanding or speaking English; and • their beliefs, concerns and preferences. Healthcare professionals use this information to tailor communication to individual patients so they can be fully involved in their care."	
901	The Prostate Cancer Charity	QS	QS5	3	This statement should include regular assessments of a patient's level of pain and experience of physical and emotional side effects of treatment. This statement should also state that the assessments should be acted upon. The phrase "in an environment that maintains their dignity and confidentially" is not specific enough to be meaningful for patients, or to be measured. QS 4 mentions patients being treated with dignity, so it is repetitive to include it again here. The Charity's suggestion for this statement is: "Patients regularly have their physical needs (such as nutrition, hydration, personal hygiene, pain relief and side effects from treatment) and psychological concerns (such as fear and anxiety) assessed and acted upon."	Thank you for your comment. Pain has been incorporated into this quality statement.
902	The Prostate	QS	QS8	3	This statement should be expanded. It should include a requirement for patients to be offered all	Thank you for your comment. This detail is in the corresponding recommendations to this

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	Cancer Charity				appropriate and available treatment options for their condition. This statement should also include clinicians supporting a patient's right to seek a second opinion or make a complaint if their treatment is not adequate.	quality statement.
903	The Prostate Cancer Charity	QS	QS9	3	The way that this statement is worded is confusing. In this context, it is unclear what the words "access" and "locality" mean. The statement is also contradictory to the recommendations in the draft clinical guideline on patient experience. The guideline states that patients should be offered all available treatments, even if they are not available locally. However, this statement says that patients should receive care that is "tailored to their needs and circumstances...taking into account locality..." This seems to suggest that patients should only be offered treatments available locally, which is not what the guideline suggests.	Thank you for your comment. 'Locality' has been removed from the statement and the wording has been clarified.
910	The Prostate Cancer Charity	QS	QS10	4 & 17	This quality statement should include a patient's right to access information on their own care, including access to their own care record. The statement also seems difficult to measure and assess. The draft quality measure says, "evidence from experience surveys and feedback that patients were asked whether they wanted their information shared with relevant healthcare professions." However, this does not ensure that information	Thank you for your comment. This area has not been covered in the guideline as we had to limit the areas we covered. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.

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					was actually shared between relevant healthcare professionals and services.	
911	The Prostate Cancer Charity	QS	QS11	4	This statement could be strengthened by including the use of personal care plans for people with long term conditions.	Thank you for your comment. We recognise the particular needs of people with long term conditions; however the remit for the guideline is generic patient experience in the NHS.
912	The Prostate Cancer Charity	QS	QS13	4	This statement will not be meaningful for patients on its own. It could be grouped with statement 1 to give it more context. It should also include a requirement for clinicians to proactively engage in frank and open discussions about all elements of a patient's care, especially when discussing difficult issues such as end of life care.	Thank you for your comment. Following consultation this has been further refined.
913	The Prostate Cancer Charity	QS	QS15	4	This statement would be clearer if broken up into shorter sentences. It should also include patients having enough time to make decisions. The Charity's suggestion is: "When making decisions about screening, investigation, treatment and care, patients are given support to make informed choices. Patients are given information to help them understand the pros and cons of all relevant options to make the best decision for them. Patients are given adequate time to reflect and make decisions, including the opportunity to have follow up appointments."	Thank you for your comment. The quality statement has been reworded to make it clearer.
914	The Prostate Cancer Charity	QS	QS16	4	This quality statement needs to be expanded to more fully explain the information a patient should receive. The Charity's suggestion is:	Thank you for your comment. The quality statement has been reworded to make it clearer.

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					"Patients are given balanced, evidence-based and comprehensive information about their diagnosis, treatment options, risk and benefits of treatments, treatment side effects, support services and their care pathway. The information is provided in both verbal and written formats and is clear and understandable. Patients are signposted to relevant charities and support services."	
43	The Rotherham NHS Foundation Trust	All	General	General	Whilst a focus on Patient Experience is always welcome there is a danger of the whole (how patients feel) being outweighed by the sum of the parts and we are concerned that there does not appear to be any consideration of how these will be utilised though this may be because there were only 3 practicing health care professionals on the Guideline Development Group e.g. how could QS 1 be undertaken meaningfully? The quality standards could easily be refined to just 4, 5 and 15 (or 16). If those happened all the rest would almost certainly have occurred or at least the core issues would have been addressed.	Thank you for your comment. The guideline group had 6 members involved in day to day clinical care as well other professionals and patient members who have clinical experience. The quality standards have been distilled to 14 statements following consultation.
1192	The Rotherham NHS Foundation Trust	QS	12	19	Whilst continuity of care is important this does not need to rely on continuity of staff nor is that always possible - the former can be achieved through good communication and performance leadership NB Continuity of poor care = worst care	Thank you for your observation.
422	The Royal College of Surgeons of England (Patient Liaison Group)	Full & NICE	General	General	The RCS (Eng) PLG welcomes the new guidelines for patient experience in generic terms. The standards outlined are clear, positive and show respect for the patient. The full version shows that a lot of thought has gone into this document, with thorough justification and openness in methodology which provide the guidelines with integrity and honesty, which as a patient group we	Thank you for your comment

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					value and appreciate.	
547	The Royal College of Surgeons of England (Patient Liaison Group)	NICE		6 -7	We support the draft quality statements as 'aspirational'. They are clear and make sense to our members and if adhered to in every case then the patient experience will be very good. We are aware, however, that it may be easy for this to be used as a 'tick-sheet' to assess clinicians conduct, in which case the generic terms of the statements may be considered to be so general as to include a huge variety of conduct. The guidance notes (see point below) become very important in this respect.	Thank you for your comment.
548	The Royal College of Surgeons of England (Patient Liaison Group)	NICE	1	6 -19	However, our members express some concern over lack of detail in the guidance for some specific needs groups, in particular vulnerable elderly patients, for example with dementia, teenagers who are being cared for in adult care and gender-related issues. Whist we understand the guidance needs to be generic, we feel that examples for these groups within the guidance notes would be useful and allow for the 'tailored care' referred to in the document.	Thank you for your comment. We recognise the particular needs of vulnerable patients. However, the remit for the guideline is generic patient experience in the NHS and we were not able to consider the needs of specific groups within the development of this guideline.
572	The Royal College of Surgeons of England (Patient Liaison Group)	NICE	1	8 -19	As patients we appreciate thoughtful and respectful care. To this end the guidance notes appear to be well-considered and the examples very much appreciated, so that clinicians can actually consider their own conduct. For example, as patients we do appreciate clinicians who get on our level (literally and metaphorically) to talk to us (1.5.2); guidance on giving statistical propabilities is welcome as this often varies (1.5.26); finding out how a person wishes to be addressed (and using that name) is	Thank you for your comment. The Implementation strategy will concentrate on the recommendations.

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					also worth reminding clinicians (1.5.3). This is just a flavour; all the examples given in sections 1.1, 1.2, 1.3, 1.4 and 1.5 of the report were useful, therefore we consider these examples invaluable and ask that it be made clear in the guidelines that the guidance given is as valuable as the quality statements. It is easy for busy clinicians to simply look at the table alone.	
689	The Royal College of Surgeons of England (Patient Liaison Group)	NICE	1.4	13	Consider inclusion in the section a statement on discharge. This statement could include 'Discharge to be to a named GP in Primary Care' and 'Provision as part of the discharge package of a Patient Passport for future use containing post hospital clinical needs and medications in a form to be updated (and carried) by the patient'.	Thank you for your comment. Discharge to a named GP may not be appropriate for all patients and primary care services. The use of a patient passport is a specific intervention which may aid continuity but we did not look at this in detail and therefore cannot make a specific recommendation to use this.
1298	University Hospitals Birmingham NHS Foundation Trust	QS	general	general	There are already quality standards that apply to the experience of patients contained within the Care Quality Commission Essential Standards, in particular standard 1. Rather than have a separate set of standards, it would be good to refer to, and incorporate, compliance with the Essential Standards as a way for Trusts to demonstrate that they are providing a quality patient experience. This would reduce the duplication that having another set of standards will bring about.	Thank you for your comment. Noted
1299	University Hospitals Birmingham NHS Foundation Trust	QS	QS 1	5	Not sure 'mentored for compliance' is the appropriate term	Amended
1300	University Hospitals Birmingham	QS	QS 1	5	It is not practically possible to incorporate compliance with NICE guidance into annual performance assessment for all staff who directly	Thank you for your comment. This will be determined through commissioning of services at a local level.

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	NHS Foundation Trust				interact with patients. There are Trust values and standards that are already incorporated. A better way of having a direct impact on staff would be to have a measure of how NICE guidelines are incorporated into the Trusts and individual service policies and procedures. For those who have responsibility of staff, implementation and ensuring that appropriate NICE guidelines are incorporated into service development could be included in their job descriptions.	
1301	University Hospitals Birmingham NHS Foundation Trust	QS	QS 2	7	This needs to be included in patient assessment documentation and a 'flag' included on patient electronic and paper records to alert staff to the additional patient needs.	Thank you for your comment. Noted
1302	University Hospitals Birmingham NHS Foundation Trust	QS	QS 4	10	There is currently only one question in the National Patient Surveys which relates to dignity. The survey needs to be reviewed to include questions on kindness, compassion, courtesy and honesty. Evidence is also available from other methods of feedback from patients and carers including PALS, Compliments, Complaints, NHS Choices and Patient Opinion.	Thank you for your comment. We expect that further advice about how quality standards and the associated measures should be used by the NHS will come from the National Quality Board and, when it is established from the NHS Commissioning Board.
1303	University Hospitals Birmingham NHS Foundation Trust	QS	QS 7	13	Involvement of carers needs to be reassessed at various points in the patient journey, not just on first contact as this standard suggests. The level of involvement may change as the patient's condition improves or deteriorates, or as they become more or less dependent. The outcome cited may not always be possible, as not all patients are able to provide feedback, therefore an audit of patient records should also be used a method of assessment of compliance.	Thank you for your comment. This guidance is about Patient Experience and we believe that we have incorporated where appropriate.

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					For the relevant existing indicators, there is a question in the National Inpatient Survey (43) which asks if family / carer had an opportunity to speak to the doctor.	
1304	University Hospitals Birmingham NHS Foundation Trust	QS	QS 7	13	Amend this section to include "…..are established at the first point of contact and continuously reviewed and respected throughout their care"	Thank you for your comment. Reworded.
1305	University Hospitals Birmingham NHS Foundation Trust	QS	QS 8	15	Service providers should incorporate the guidelines into their consent policy and procedures.	Thank you for your observation
1306	University Hospitals Birmingham NHS Foundation Trust	QS	QS 8	3	Add in something about ensuring they are given detailed and accurate information to enable them to "choose, accept or decline treatment"	Thank you for your comment. Please see amended statement
1307	University Hospitals Birmingham NHS Foundation Trust	QS	QS 9	16	This statement appears to be an outcome of the other standards rather than a standard i.e. QS 2, 3, 5,7, 8, 15, 16 & 17.	Noted, statements have been distilled, reworded and in some cases amalgamated.
1308	University Hospitals Birmingham NHS Foundation Trust	QS	QS 9	16	Amend to "…. tailored to their individual needs and circumstances	Thank you for your comment. Noted

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1309	University Hospitals Birmingham NHS Foundation Trust	QS	QS 10	17	Description of what this means for Health & Social Care Professionals: obtaining consent from the patient is impractical and unnecessary. We have a duty to share information with those health and social care professionals who are providing care, and do so under the legal requirements of the data protection act and Caldicott. This is essential to ensure the patient receives timely, safe care. To withhold information whilst waiting to gain patient consent would be immoral and could cause a delay to essential care. All NHS Trusts have a legal duty which is monitored by the NHSLA for compliance and so introducing this QS is an unnecessary duplication. The timely sharing of information could be monitored so that information is shared effectively reducing any delays in care.	Thank you for your comment. We agree
1310	University Hospitals Birmingham NHS Foundation Trust	QS	QS 12	19	Whilst the idea may be sound this is not always practically possible in an acute setting. Teams of medical staff provide the care to patients and so, as an example, a patient coming for OPD appointments may not always see the consultant, but one of their team. As junior staff rotate as part of their training and development, they may not see the same person again. It is far more important that the healthcare professional is fully appraised of the patient and their on-going care needs, and that the information they give does not conflict with information the patient has been given previously. Anecdotally this is what patients are most concerned about hence the question (40) in the National Inpatient Survey.	Noted. Please see amended wording.
1311	University Hospitals Birmingham	QS	QS 13	20	"…..demonstrated competency in communication skills" To what standard and how will this be measured	Please see previous comments.

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	NHS Foundation Trust					
1312	University Hospitals Birmingham NHS Foundation Trust	QS	QS 14	21	Most suitable for who? Need to clarify if this means suitable for the patient, the healthcare professional, the type of information being exchanged etc It will be difficult to measure whether specific episodes of communication have been suitable or not unless the understanding is robustly assessed and clearly documented.	Thank you for your comment. Please see amended wording
1313	University Hospitals Birmingham NHS Foundation Trust	QS	QS 15	22	? should be situated near to statement 8 as along similar theme	Thank you for your comment.
1314	University Hospitals Birmingham NHS Foundation Trust	QS	QS 16	23	Add on "……in a way that meets their individual requirements"	Thank you for your comment. Noted
1315	University Hospitals Birmingham NHS Foundation Trust	QS	QS 17	24	Add on "…..and are given any necessary information, assistance and support to access and use the tools to their optimum capability	Thank you for your comment. Noted
904	University of Glasgow	QS	QS 9	3	Our comments are as follows We feel that the standard should be amended to take account of 'treatment burden'. Treatment burden can be defined as the self-care practices that patients must perform in response to	Thank you for your comment. We agree that 'treatment burden' is important and can be a significant influence on patient experience. We had however to limit the areas we were able to consider. Furthermore, the GDG recognise the importance of self-management for many patients, especially those with long-

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					the requirements of their healthcare providers as well as the impact that these practices have on patient functioning and well being. A range of treatment burdens or workload factors for those with chronic disease have been described which include: logistical burdens, for example organising appointments or visits from health professionals, organising rehabilitation, arranging transport; technical burdens, for example enacting lifestyle changes, performing rehabilitation exercises, modifying environments, taking medications; relational burdens, for example enrolling family, friends and health professionals for support, initiating interactions with possible carers and supporters; and sense making burdens, for example conceptualising problems, understanding and learning about management strategies, knowing when to seek help, differentiating between treatments1-4. It has been posited that treatment burden is important because for many people with complex, chronic, comorbidities it may reduce their capacity to collaborate in their care (5). It is therefore a key factor that merits attention when trying to tailor healthcare treatments to the individual. (1) Gallacher K, May C, Montori VM, Mair FS. Understanding Treatment Burden in Chronic Heart Failure Patients. A Qualitative Study. Annals of Family Medicine 9:235-243 (2011) (2) Granger BB, Sandelowski M, Tahshjain H, Swedberg K, Ekman I. A Qualitative Descriptive Study of the Work of Adherence to a Chronic Heart Failure Regimen. J Cardiovasc Nurs 2009;	term conditions. We recognise the role of healthcare professionals and the NHS in supporting self-management. We have indicated to NICE the importance of self management as a topic and have been assured that this will be raised with the National Quality Board.

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					24(4):308-315. (3) Russell LB, Dong-Churl S, Safford MM. Time requirements for diabetes self-management: Too much for many? Journal of Family Practice 2005; 54(1):52-56. (4) Hart E. System induced setbacks in stroke recovery. Sociology of Health and Illness 2001; 23(1). (5) May C, Montori V, Mair F. We Need Minimally Disruptive Medicine. British Medical Journal 2009; 339:b2803.	
118	Urology User Group Coalition	Full	General	General	The Urology User Group Coalition (UUGC) represents the estimated half a million continence appliance users who rely heavily on urology products and services to maintain their health and wellbeing. We are also representative of many people with the vast range of clinical diagnoses that usually require continence management to be integrated into care and treatment pathways. These include the long term conditions of cancer, stroke, spinal cord injury, MS, spina bifida, Parkinson's disease and other neurological conditions.	Thank you for your comment.
119	Urology User Group Coalition	Full	General	General	We welcome the opportunity to respond to this consultation. Throughout our response, we are keen to emphasise that, for patients with continence problems, it is essential that they have as much choice as possible over the devices they use to help them manage this condition at and away from home. This includes catheters, but also products such as urinary sheaths, drainage bags and other continence products	Thank you for your comment. The guidance is based on the premise of patient choice where appropriate (and within existing guidance from NICE.
120	Urology User Group Coalition	Full	General	General	We strongly feel that efforts to improve "patient experience" should include efforts to prevent healthcare acquired infections. This is mentioned	Thank you for your comment. We recognise the importance of healthcare acquired infections to patient experience. NICE is

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					on page 76 with reference to surgical site infections. However, it is vital that there should be mention of efforts to reduce urethral catheter and device related infections, MRSA, etc and the facilities for hand cleansing and the importance of patient involvement around these issues.	currently developing specific guidance on infection prevention and control in primary care and community settings.
121	Urology User Group Coalition	Full	General	General	Although some general points are raised about equality issues, we feel that there could have been a strong focus on these throughout the document, as this would do more to improve equality for many people covered by disability equality legislation. NICE has a duty to promote equality of opportunity and access to care. This is not talked about a great deal in the guidance, e.g. the lack of mention of access to healthcare for people with mental health conditions. While we understand that there is separate guidance on patient experience for those using mental health services, efforts need to be made to improve their experience across the range of NHS care. In addition, there ought to be wider equality awareness training for all NHS staff to ensure that they realise who is covered by disability legislation and that all people are able to access services. Many of those whose interests are covered by the UUGC face huge challenges, including accessing screening, as services fail to take account of their needs. Issues encountered include problems with disposal of continence products in patient toilets and issues such as stepped entrances stopping patients from accessing clinic or screening appointments.	Thank you for your comment. NICE recommendations are developed in line with current Equality and Diversity legislation. We have added a recommendation about the Equality Act to ensure we have not omitted any individuals or groups.

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					There is also a need to ensure the dignity of patients at all times, e.g. some patients have been told to bring a week's worth of used incontinence pads to a clinic so that their need for them can be reassessed.	
311	Urology User Group Coalition	Full	6.3	45	We agree with recommendation 1 on seeing the patient as an individual. Many of the people we represent have complex long term conditions which affect them in individual ways, and understanding their individual circumstances and needs is vital in ensuring that they receive the right treatment which allows them to manage their condition in the most effective way.	Thank you for your comment
312	Urology User Group Coalition	Full	6.3	45	We agree with recommendation 2 that healthcare professionals should consider the extent to which factors such as physical or learning disabilities, sight or hearing problems and difficulties with reading, understanding or speaking English may affect the patient's ability to participate in consultations and care. However, this should also include people with mental health problems, who are just as likely to have continence and urology problems.	Thank you for your comment. The list is intended as an example and is not exhaustive.
315	Urology User Group Coalition	Full	6.3	46	We agree with recommendation 3 that healthcare professionals should consider factors such as the patient's domestic, social and work situation in deciding on the best treatment. It is vital that individuals with continence needs are able to use the most appropriate products for their individual needs in order to allow them to live independently, manage their care for themselves and maintain a job and social life.	Thank you for your comment
316	Urology User Group Coalition	Full	6.3	46	We agree with recommendation 7, that healthcare professionals should assess and discuss patients' needs and regularly review their need for support.	Thank you for your comment

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					As mentioned, many people with continence problems have complex long term conditions and their needs change over time; it is importance to ensure that they are using the most appropriate products to allow them to manage their condition effectively.	
322	Urology User Group Coalition	Full	7.3	50	We agree with recommendation 11, that healthcare professionals should be prepared to broach sensitive subjects – this should include continence care, something which patients are often reluctant to talk about. On average a person has a continence problem for 7 years before they seek treatment, and more pro-active engagement from healthcare professionals may reduce this.	Thank you for your comment. This has been included in this recommendation.
329	Urology User Group Coalition	Full	7.3	51	In terms of recommendation 16, that when patients in hospital are taking medicines for long-term conditions, healthcare professionals should consider and discuss with them whether they are able to, and would prefer to, manage these medicines themselves, this should also include continence and stoma care. Apart from allowing the patient dignity and independence, this is likely to reduce infection risk in those who rely on catheters. It is vital they are provided with products that they are used to and allow independent care. Many hospitals fail to stock such products and those admitted as emergencies or have longer stays than planned may not have their own prescribed supplies. Patients who manage their continence care by intermittent self catheterisation or urinary sheath and/or pads often unnecessarily end up with indwelling urethral catheters because it is convenient for staff.	Thank you for your comment. The update of the Infection Prevention Control guideline addresses this concern. It will be published in March 2012.
330	Urology User Group	Full	7.3	51	We agree with recommendation 18, that healthcare professionals should address the	Thank you for your comment, we agree with your observations.

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	Coalition				patient's personal needs, including continence care. Incontinence can be a side effect of many complex conditions. It is important to ensure that sufficient attention is paid to this as part of the care process, in order to ensure that patients are able to remain independent and ensure their dignity.	
337	Urology User Group Coalition	Full	8.3	54	We agree with recommendation 20, that healthcare professionals should adopt an individual approach to healthcare services, tailored to the needs and circumstances. It is important that this includes lifestyle needs and independence. Many people with continence issues end up housebound because the products they are provided with are not suitable for use away from home, at work etc without loss of dignity or help from another person This means, for example, that individuals in need of continence products should have access to all products listed on Part IX of the Drug Tariff, and not be limited by local use of tenders or formularies, to ensure that their individual needs are met.	Thank you for your comment. It is felt that this is covered in the recommendation under the area of tailoring to the 'patient's needs' and circumstances.
338	Urology User Group Coalition	Full	8.3	54	We agree with recommendation 21 that all patients should have access to information on all relevant and available treatment options, even if not available locally. As mentioned, many local PCTs make use of tenders or formularies for continence products; although they do not technically restrict access to products that are not listed, in practice these off-formulary products are difficult to obtain and there is little information about the full range of available products. In order to be able to choose the best product to meet their individual needs,	Thank you for your comment and information.

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					patients should have access to information about all products listed on Part IX of the Drug Tariff, which the Secretary of State for Health has already approved as clinically effective, safe and value for money for the NHS. It is also important that healthcare professionals ensure that they are informed about patient's rights and the available products, so that they can assist them in making a decision.	
343	Urology User Group Coalition	Full	8.3	56	We agree with recommendation 26 that discussions should be held in a way which allows the patient to express their personal needs and preference. This is essential in allowing a patient to find the right products to help them meet their individual needs.	Thank you for your comment.
344	Urology User Group Coalition	Full	8.3	56	We agree with recommendation 27 that healthcare professionals should review the patient's knowledge, understanding and concerns about their condition and treatments. This is particularly important for complex long-term conditions.	Thank you for your comment.
345	Urology User Group Coalition	Full	8.3	56	We agree with recommendation 28 that healthcare professionals should accept that the patient may have different views about the balance of risks, benefits and consequences of treatments. This relates to the points about formularies mentioned above; patients should be able to access the products which they feel best meet their needs and not just pick from a limited list set by a PCT.	Thank you for your comment.
346	Urology User Group Coalition	Full	8.3	56	We agree with recommendation 30 that healthcare professionals should respect and support patients in their choice of treatment.	Thank you for your comment.
398	Urology User Group Coalition	Full	10.4.2	104	We agree with recommendation 56 that when discussing decisions about investigations and treatment, healthcare professionals should do so	Thank you for your comment.

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					in a style and manner that enables the patient to express their personal needs and preferences. This is very important in allowing the patient to talk about their individual needs and find the treatment which best allows them to manage their condition.	
878	Urology User Group Coalition	QS	General	General	The Quality Standard should make reference to the principle of "no decision about me, without me" in order to reinforce the importance of patient choice in improving patient experiences.	Thank you for your comment.
471	Walsall Healthcare NHS Trust	NICE	General	General	The documents describes what information needs to be included and utilised by the patients and careers, it does not talk about using different formats. I accept that it says in ways that are appropriate for people with learning difficulties, poor vision etc but there is no advice about what that format could or should be. For inexperienced staff they may not consider electronic, forums etc and I think it would be useful to expand this	Thank you for your comment. While we agree this is important, the generic focus of the guidance means it was not possible to provide such specific recommendations for particular groups.
472	Walsall Healthcare NHS Trust	NICE	General	General	It would be helpful to describe the use of different languages and the fact that some are usually verbal rather than written so it would be helpful to have a tape, DVD etc for this group to access	Thank you for your comment. While we agree this is important, the generic focus of the guidance means it was not possible to provide such specific recommendations for particular groups.
473	Walsall Healthcare NHS Trust	NICE	General	General	Whilst the guidance describes the need to talk to people and offer them things, I did not find consistent advice to document this information. My understanding is that the CQC would like to see this information documented.	Thank you for your comment. Documentation is an important issue and this is embedded into this guidance in both recommendations and quality statement. By nature it is implicit.
122	Yorkshire Ambulance Service NHS Trust	Full	General	General	Although a very comprehensive set of sources have been used, they appear to be mostly related to care provided by hospitals or by professionals who have an ongoing relationship with the patient. It would be helpful to have reference within the guideline of the specific challenges faced by ambulance clinicians and others providing	Thank you for your comment. The Guidance would apply to emergency care, but as suggested, would need to be balanced with the context.

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					emergency care. For some aspects of care (for example in the 'decision making domain') the patient's right to make decisions, have the options/risks explained to them and have time to consider them, needs to be balanced against the need to provide rapid access to emergency care.	
323	Yorkshire Ambulance Service NHS Trust	Full	7.3(2)	50 -51	Ambulance clinicians do not usually play a role in patients' nutrition and hydration other than to make initial observations about patients and to report these as part of their handover to community/hospital clinicians.	Thank you for your comment. The technical team are aware that some recommendations will not be applicable in all circumstances.
347	Yorkshire Ambulance Service NHS Trust	Full	8.3	56	Participating in ongoing review of a patient's knowledge of their condition and views on their care is not usually part of emergency clinicians' roles.	Thank you for your comment.
367	Yorkshire Ambulance Service NHS Trust	Full	10.2.2	73	Providing an environment that is conducive to discussion and protects privacy may in some cases not be possible when attending a patient in response to a 999 call (although clinicians would take all possible measures to do so).	Thank you for your comment. The GDG considered that in all cases staff should endeavour to provide the best environment possible, while recognising that situations such as emergency situations may make this more difficult.

These stakeholder organisations were approached but did not respond:

Abbott Diabetes Care
Abbott Laboratories Limited
African Health Policy Network
Alder Hey Children's NHS Foundation Trust
Arthritis Research UK
Association of British Clinical Diabetologists
Association of British Health-Care Industries
Association of British Neurologists
Association of Directors of Adult Social Services (ADASS)
Association of Surgeons in Primary Care
Bard Limited
Barnsley Hospital NHS Foundation Trust
Beating Bowel Cancer
Birthchoice UK
Blackburn with Darwen Teaching Care Trust Plus
BMJ
Bradford District Care Trust
Brighton and Sussex University Hospitals Trust
British Association for Parenteral & Enteral Nutrition (BAPEN)
British Association for Sexual Health and HIV
British Association of Critical Care Nurses
British Dental Association
British Heart Foundation
British Liver Trust
British National Formulary (BNF)
British Orthopaedic Association
British Psychological Society, The
Cambridge University Hospitals NHS Foundation Trust (Addenbrookes)

Camden and Islington Mental Health and Social Care Trust
Cancer Network User Partnership
Cancer Research UK
Central Lancashire PCT
Central London Community Healthcare
Central North West London NHS Trust
Cochrane Pain, Palliative and Support Care Group
Compass
Connecting for Health
Covidien UK Commercial
Crohn's and Colitis UK (NACC)
Crossroads Association
Department for Communities and Local Government
Department of Civil and Building Engineering
Department of Health Advisory Committee on Antimicrobial Resistance and Healthcare Associated Infection (ARHAI)
Department of Health, Social Services & Public Safety, Northern Ireland (DHSSPSNI)
Dept of Primary Health Care Sciences, University of Oxford
Derby Hospitals NHS Foundation Trust
Derbyshire Healthcare NHS Foundation Trust
Derbyshire Mental Health Services NHS Trust
Dorset Mental Health Forum
Downs Syndrome Research Foundation
Dr Foster Intelligence
Dudley Group of Hospitals NHS Trust
Dudley PCT
Ealing Hospital NHS Trust
Eli Lilly and Company Ltd
Equalities National Council
Faculty of Dental Surgery
Faculty of Pain Medicine of the Royal College of Anaesthetists
Federation of Ophthalmic & Dispensing Opticians (FODO)
Ferring Pharmaceuticals Ltd

Fibroid Network Charity
Flintshire County Council
FPA
Gender Identity Research & Education Society
George Eilot Hosptal Trust
Gilead Sciences Ltd
Great Western Hospitals NHS Foundation Trust
Greater Manchester and Cheshire Cardiac and Stroke Network
Greater Manchester West Mental Health NHS Foundation Trust
Greater midlands cancer network
Healthcare Improvement Scotland
Healthcare Quality Improvement Partnership
Heart UK
Heatherwood & Wexham Park Hospitals NHS Trust
Help and Care
Hereford Hospitals NHS Trust
Hindu Forum of Britain
HIV Scotland
Humber NHS Foundation Trust
Ipswich Hospital NHS Trust
James Whale Fund for Kidney Cancer
James Whale Fund for Kidney Cancer
Johnson & Johnson Medical
King's College London
Leukaemia & Lymphoma Research
Lewisham Healthcare NHS Trust
Lewy Body Society, The
Liverpool Women's NHS Foundation Trust
Liverpool Community Health
Luton & Dunstable Hospital NHS Foundation Trust
Lymphoma Association
Medicines and Healthcare Products Regulatory Agency (MHRA)
Medway Community Centre
Mental Health Foundation

Milton Keynes NHS Foundation Trust
Ministry of Defence (MoD)
Multiple System Atrophy Trust
Narcolepsy UK
National Association for Patient Participation
National Children's Bureau (NCB)
National Council for Palliative Care
National Kidney Federation (NKF)
National Lung Cancer Forum for Nurses
National PALS Network
National Patient Safety Agency (NPSA)
National Rheumatoid Arthritis Society, The
National Treatment Agency for Substance Misuse
NEt (North East Together)
NETSCC, Health Technology Assessment
Newcastle Upon Tyne Hospitals NHS Foundation Trust
NHS Bradford & Airedale
NHS Clinical Knowledge Summaries Service (SCHIN)
NHS Confederation
NHS County Durham and Darlington
NHS Institute for Innovation and Improvement
NHS Plus
NHS Sheffield
NHS Somerset
NHS Western Cheshire
NHS Western Cheshire
North East London Cancer Network
North Staffordshire Cancer Service User Forum
Northumberland, Tyne & Wear NHS Foundation Trust

Nottinghamshire Healthcare NHS Trust
NUH Trust
Outer North East London Community Services
Patient Information Forum
Patient Liaison Committee
Pelvic Partnership, The
Peninsula Heart & Stroke Network
Pilgrim Projects
Pilgrims Hospices in East Kent
Polycystic Kidney Disease Charity
Portsmouth Hospitals NHS Trust
Positively Pregnant
Public Health Wales
RCPCH Allergy Care Pathways Project
Royal Berkshire NHS Foundation Trust
Royal College of General Practitioners
Royal College of General Practitioners Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Psychiatrists
Royal Devon and Exeter NHS Foundation Trust
Royal Free Hospital NHS Trust
Royal National Institute of Blind People
Royal Pharmaceutical Society of Great Britain
Samaritans
Sarcoma Information Services Ltd.

Scottish Intercollegiate Guidelines Network (SIGN)
Sefton Link Support
Sensory Integration Network
Sheffield Children's NHS Foundation Trust
Shropshire & Mid Wales Cancer Forum
Sickle Cell Society
Skin Care Campaign
Social Care Institute for Excellence (SCIE)
Society and College of Radiographers
Solent Healthcare
South East Coast Ambulance Service
South London and Maudsley NHS Foundation Trust
South London Cardiac and Stroke Network
South West London Acute Commissioning Unit
South West Yorkshire Partnership NHS Foundation Trust
Southport & Ormskirk Hospital NHS Trust
Specialised Healthcare Alliance
Step4Ward Adult Mental Health
Stryker UK Ltd
Surrey Heart & Stroke Network
Sussex Partnership NHS Foundation Trust
Swansea University
Teva UK Limited
The Society and College of Radiographers
The Stroke Association
Tourettes Action
Turning Point
UCL Partners
UK Clinical Pharmacy Association (UKCPA)
UK National Screening Committee
United Kingdom Clinical Pharmacy Association (UKCPA)

Urostomy Association
Walton Centre for Neurology and Neurosurgery NHS Trust
Weight Concern
Welsh Assembly Government
Welsh Scientific Advisory Committee (WSAC)
West Essex Community Health Services
West London Gay Men's Project
Wirral University Teaching Hospital NHS Foundation Trust
WISH - Women in Secure Hospitals
Wye Valley NHS Trust
York Teaching Hospital NHS Foundation Trust