

LIBERATING THE NHS: AN INFORMATION REVOLUTION

COMMENTS FROM NICE

Introduction

1. NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE is also responsible for providing Quality Standards for the NHS and for reviewing and developing clinical indicators for the quality and outcomes framework (QOF) for primary care.
2. NHS Evidence is a digital service provided by NICE designed to give professionals easy access to clinical and non-clinical information about health and social care selected from a wide range of sources. NHS Evidence is responsible for digitising NICE's products, an initiative which will have the potential to make an important contribution to the information revolution. We also have a strong interest in improvements in the way data is collected and transformed for use in the NHS, as such data are essential in developing and reviewing guidance, producing commissioning guides and other resources to support implementation, such as costing tools, and in monitoring uptake. We therefore welcome this consultation document.
3. In our comments below we highlight NICE's current and potential contribution and comment on the consultation document's proposals. This consultation response has been informed by a workshop with key stakeholders, and a summary report of this meeting is included in the annex.
4. The sections of our response cover the chapters of the consultation document and conclude with key points summarising the issues we believe are critical for the development of an information strategy to deliver the stated aims and objectives.

An information revolution (chapter 1)

5. We agree with the view expressed that digital technology offers opportunities for efficiency and quality improvement gains in the NHS and social care. Substantial improvements within NICE encompass both the digitisation of our products, building on current web-format

versions on the NICE website, and development of NHS Evidence services. Our overall purpose is to make access easier and to enable more flexible use of evidence and evidence-based guidance, for example, through syndication of content to user systems and by exploiting technology to provide professionals at the point of care with web-based services for desktops, mobile phones and other devices. In addition, the range of information available through NHS Evidence is growing, with the inclusion of resources such as the British National Formulary (BNF). NICE and NHS Evidence can thus play an important role in the provision of quality assured information directly and via 'any willing provider'.

6. Changes resulting from the NHS white paper, such as the switch to commissioning by GP commissioning consortia, the abolition of PCTs and SHAs, new public health functions for local government, and new entities such as the NHS Commissioning Board and Public Health England, will have a major impact on local and regional information support services and will create new information needs. NHS Evidence can play an important strategic and operational role in rationalising information services for health and social care professionals and achieving greater efficiency and quality gains for patients.
7. The focus of the proposals is on data flows and use of data within NHS and social care information systems, starting with data recorded at the point of care. However, there is some inconsistency in use of terms: the information revolution diagram in section 1.13 distinguishes between 'data', 'intelligence', and 'information', and indicates how data can be transformed and given what the glossary calls "'real-world" meaning', but the main text in the document is less careful in using these and others terms, such as 'knowledge' and 'evidence'. We would recommend establishing a clear and consistent terminology that includes the full breadth and scope of information and information transfer domains required for the information revolution. Furthermore we suggest that the type of information provided by NICE/NHS Evidence should be described as 'evidence-based information', as distinct from data and statistics.
8. We strongly support the proposition that data from care records are a resource for research and other purposes that should be better utilised. They are an essential foundation for the evidence-base used by NICE currently and will continue to be so when NICE's role extends into social care.
9. The document does not directly acknowledge the significance for quality improvement of information created mainly outside, but feeding

into, the information cycle depicted in the diagram (section 1.13). NICE Quality Standards, NICE guidance, and other guidance accredited by NHS Evidence depend on secondary research such as systematic reviews and health technology assessments, which often use primary research and evaluations conducted outside the NHS (and the UK). NICE is the prime national resource for this type of material.

10. These proposals could be presented in a broader context, and we recommend that the information strategy should set out connections with the NHS research strategy and the wider biomedical research effort, and, more specifically, the research programmes of the National Institute for Health Research (NIHR), including the infrastructure for systematic reviews. NHS Evidence will support these links by providing clear access to ongoing research alongside published evidence and NICE Quality Standards.

Key points/recommendations (chapter 1):

- The digitisation of NICE guidance and Quality Standards through NHS Evidence and other NICE web services will facilitate access to evidence through third party IT systems and provide a framework of meaning for the data flow throughout the health and social care system. This should be regarded as an important component of the information strategy.
- There needs to be greater recognition of the importance and role of secondary research within the information revolution 'cycle'. How research plays into the information strategy and the role of organisations in prioritisation, appraisal and implementation needs to be considered fully.

Information for patients, service users, carers and the public (chapter 2)

11. From the beginning NICE has involved patients in the development of its guidance and has consistently been an advocate for patient participation in decisions about their care. We publish versions of our guidance and Quality Standards that give patients and carers full information about what NICE has recommended to healthcare and other professionals. The aim is to empower patients and carers in asking for or questioning options for treatment in the NHS. We include contact information of key patient and carer organisations to help the patient or carer have access to all the information they may need about their disease or condition.

12. A section of the NICE website on 'NICE guidance for patients and the public' provides quick access to user-focused documents. The website also gives access to our public health guidance, which supports the aim of providing information for healthier lives and the wider health of the population.
13. We welcome the reference in chapter 4 (on information for professionals) to the role of NHS Evidence. NHS Evidence is primarily designed for NHS and social care professionals, but is also available for patients and other service users and gives them free access to all the available clinical and non-clinical evidence about health and social care, except for commercially-owned material in paid-for databases and journals. These resources include patient information from a variety of sources that meets The Information Standard.
14. NHS Evidence already supports discussions and decisions at the point of care (box in section 4.7). Improvements to the service will add to its value for professionals and will make it more useable for patients. These include a predictive function to make searching easier, topic pages for prioritised information, and the inclusion of a section about the topic of the search as an introduction to the search results, along with tabs giving access to relevant priority information such as NICE guidance and information about medicines.
15. The NICE pathways project will present all that NICE has to say on a given topic by relating it to a coherent and user-friendly visual pathway. This will give commissioners and health and social care professionals access to all NICE guidance (including public health guidance), Quality Standards, and supporting products relevant to each pathway, and should also benefit patient users.
16. Professionals, as well as patients and carers, are interested in access to patient information, including lay versions of NICE guidance. NHS Evidence currently includes only patient information accredited by The Information Standard, but this could be further developed. NHS Evidence recognises the need for trusted sources of information to inform and aid patients' health and social care decisions, and identified by a quality mark. Quality assurance of such information should be based on validated, consistent criteria that focus on the processes used in its development, be sustainable and scalable, and include input from a range of stakeholders, including lay and patient representatives, and health and social care professionals. To embed high quality patient information in health and social care, quality assured patient information could support Quality Standards and essential standards for providers. NHS Evidence is suitably placed to quality-assure patient

information through alignment with its existing quality assurance programmes (specifically accreditation) and linkage with the emerging regulatory framework around commissioning, such as NICE Quality Standards and outcomes frameworks.

17. Professionals have expressed interest in decision aids, which provide a structured way of considering the risk and benefits of treatments in the process of making decisions and choices. NICE could develop decision-support tools based on our guidance and Quality Standards, dependent on resources. We welcome the suggestion in 'Liberating the NHS: legislative framework and next steps' (section 2.33) that use of decision aids could be incorporated in commissioning guidelines and Quality Standards developed by NICE. In any event, NHS Evidence will continue to ensure that decision aids from selected evidence-based providers are made available through the on-line portal.

Key points/recommendations (chapter 2):

- The digitisation of NICE guidance and the increasing remit for NICE and NHS Evidence services will be a strategic enabler for driving efficiencies and continuous improvement in quality and outcomes for patients. This critical role needs to be supported by and embedded in the information strategy for health and social care.

Information for improved outcomes (chapter 3)

18. The consultation document mentions the role of NICE Quality Standards as a source of indicators or measures for the NHS, public health, and social care outcomes frameworks (section 3.2). We agree that these indicators or measures should be developed using approved national informatics standards and we aim to work with the NHS Information Centre and appropriate informatics services to ensure that they are so.
19. The first round of Quality Accounts showed that many providers have already chosen to report on areas of performance using NICE guidance recommendations or audit criteria from NICE's implementation support tools to define markers of quality. We support the proposal in section 3.4 on amending the mandated content of Quality Accounts to make it easier to compare outcomes, including by mandating reporting on the outcomes framework and NICE Quality Standards, once they are established. We welcome the suggestion to providers in the recent letter about Quality Accounts for 2010/11 from the Department of

Health and Monitor that they should use indicators related to NICE Quality Standards where local improvement priorities are covered by these standards.

20. We welcome the proposed consultation on data returns and the criteria governing what should be collected (section 3.5). We agree about the importance of a criterion on whether a data return helps in achieving a key priority by reference to the outcomes framework or a NICE Quality Standard.
21. NICE has varying information needs. We refer in paragraphs 8 and 9 to the importance of both data-based primary research and secondary research for NICE guidance and Quality Standards, but we also need a range of other data for purposes such as reviewing guidance, analysing guidance uptake, establishing the cost-impact of recommendations and producing commissioning guides and costing tools.
22. NICE guidance sometimes identifies deficiencies or gaps in data and makes recommendations for improvement. Timely access to relevant primary data can only serve to enhance opportunities to identify gaps in information to inform continuous improvement as part of a 'learning system', as implied in the virtuous information cycle of the consultation paper (section 1.13).
23. On patient- and service user-generated information, particularly patient-reported outcome measures (PROMs) (section 3.10), NICE now examines whether there can be standard statements and quality measures relating to patient experience when developing Quality Standards on clinical topics.
24. We welcome the importance attached to joint strategic needs assessment (JSNA) in describing the health and wellbeing needs of communities and how they are to be met, and as a mechanism for linking NHS and local authority commissioning (sections 3.15–3.17).
25. A weakness of current commissioning models is that the term 'evidence' tends to refer to information based on epidemiological and qualitative data on the health problem rather than information on effective and cost-effective solutions. We therefore support the statement that NICE Quality Standards, along with the NHS outcomes framework and the commissioning outcomes framework, will be an important source of information for commissioners. Other essential reference points for the commissioning of high quality, cost-effective – and, where appropriate, joined-up – services are NICE's clinical

guidelines and public health guidance, and other accredited guidance available through NHS Evidence.

26. Commissioners should also be aware of resources provided by NICE and NHS Evidence which support effective commissioning of efficient services (and de-commissioning of ineffective ones), such as:
- Commissioning guides, costing tools and forward planners, which support service re-design.
 - ‘Do not do’ recommendations, which highlight clinical practice that should be discontinued completely or should no longer be used routinely.
 - Referral advice recommendations, which advise on appropriate and timely referral from primary to specialist care.
27. NHS Evidence’s QIPP (quality, innovation, productivity, prevention) specialist collection provides case studies of care-pathway and organisational design that are producing improvements in quality and productivity, and includes Cochrane quality and productivity topics based on Cochrane Collaboration systematic reviews.

Key points/recommendations (chapter 3):

- The links between guidance, standards, evidence based information, outcomes and indicators need to be made explicit within the information strategy; as do clear flows for core information functions (including those that support tariff setting and payment) and responsibilities for organisational roles within the information system.
- The flow of primary data and research data used to inform continuous service improvement and patient outcomes should be expanded to include secondary sources and research and be deployed by NICE to inform the development of standards and guidance as well as commissioning tools and associated evidence-based services for commissioners.

Information for professionals (chapter 4)

28. Evidence-based guidance on effective and cost-effective interventions, whether provided by NICE or other sources accredited by NHS Evidence, should be more explicitly included in the discussion in section 4.6 on the use of evidence by professionals. Use of evidence should also include resources available from NICE and through NHS Evidence’s QIPP page on achieving quality and productivity through commissioning and de-commissioning, and changing professional practice (see paragraphs 26 and 27 above).

29. NHS Evidence is an essential resource for professionals, so we welcome the prominence given to it and the commitment to expanding and improving the service it provides (sections 4.6–4.7). We have already commented in paragraphs 13–15 on the role of NHS Evidence in supporting patients and other service users, and on how improvements in usability and access for professionals will indirectly and directly enhance the service benefits for patients.
30. We strongly support the document’s endorsement of the importance of research in providing the new knowledge needed to improve health and care outcomes and reduce inequalities (section 4.11). NICE’s research recommendations identify important gaps in evidence that become apparent in the process of developing guidance and which need to be filled in the three-year period before the guidance is reviewed. We have arrangements with the NIHR to enable commissioning of a small amount of high priority research and we encourage other research funders to act on our recommendations, but the vast majority of these research questions remain unanswered. They constitute a significant future NHS research agenda.
31. As the document points out (sections 4.11–4.12), research is vital in providing the new evidence needed to improve health outcomes. However, the NHS has to pay for its staff to have access to the journals in which research funded by the NHS or using NHS resources is reported – in effect paying twice for research. We suggest that new arrangements enabling clinical or care professionals to have open access to such material would be preferable to the current licensing arrangements for access. NHS Evidence currently manages the core content contract for the NHS as well as the systems to access this content and is therefore ideally placed to facilitate this change.
32. We support the importance placed on participation in clinical audit (section 4.8). Whilst the drive to increase participation in national clinical audit is welcomed, it is also important to recognise the role local audit can play in addressing priorities and quality improvement at a local level. The inclusion of the cost of subscription to national audits in the tariff is one way to do this, but there is a potential danger that resources currently provided to support local audit are diverted into supporting this national audit. It needs to be made clear that participation in national audit is in addition to local audit.

Key points/recommendations (chapter 4):

- Evidence-based guidance on effective and cost-effective interventions and service improvements, whether provided by NICE or other sources accredited by NHS Evidence, should be more explicitly included in the information strategy for professionals.
- To enable greater standardisation across health and social care services, barriers to providing universal access to evidence-based resources for professionals need to be removed.

Information for autonomy, accountability and democratic legitimacy (chapter 5)

33. We support the proposals on the use of information for purposes of accountability. As an integral part of the NHS outcomes framework, NICE Quality Standards will contribute to such accountability mechanisms.
34. NICE would welcome the provision of a greater range of healthcare related data and research information (sections 5.8–5.9). We support the idea that this information should be accredited and standardised in order to make it meaningful for researchers looking at either national or regional trends.
35. Sections 5.22–5.23 describe the early release of national data sets and we believe that this is an important step in supporting quality improvement. However, there should also be consideration of how new measures and items can be incorporated into these data sets in a timely fashion, rather than current systems which can take months and years. Guidance and Quality Standards from NICE are important in setting context and direction for quality improvement, patient choice etc., but we need to ensure that datasets reflect these in order to provide patients and professionals with the information they need.
36. There is no explicit discussion of the part to be played in accountability mechanisms by annual or periodic national reports that provide an objective comparative analysis and overview of the performance of NHS and social care commissioners or providers, or the experiences of particular patient or population groups. As such overviews provide the context necessary for people to make sense of local data and statistics and take a better informed view of progress and problems in their local system, they should be factored into the information strategy.
37. There is potential for information intermediaries to add value to data and fill information gaps, but also some risk that service users and the

public, as well as voluntary and community sector providers, will be priced out of some areas of the information market.

38. Currently, standards set by the Information Standards Board for Health and Social Care (ISB) apply to information technology systems being used in the NHS, including clinical decision support systems. Compliance with the ISB's DSCN14/2009 standard for clinical decision support systems is dependent on the vendor providing a clinical safety case that clearly demonstrates that the processes used to develop the clinical information in the system are robust and do not place patients at risk.
39. NHS Evidence's accreditation scheme recognises organisations that achieve high standards in producing health or social care guidance by reviewing the guidance development processes against a set of criteria based on a validated, internationally recognised instrument.
40. NHS Connecting for Health (CfH) and the ISB have stated that NHS Evidence accreditation can be used to assure the quality of the clinical information contained within clinical decision support systems that will fulfil the clinical safety case required for compliance with the ISB standard. Accreditation is currently being piloted in this setting with clinical decision support system providers.

Key points/recommendations (chapter 5):

- To ensure the quality of the evidence used in NHS IT systems, consideration should be given to extending the current NHS Evidence Accreditation programme for assurance of information intermediaries.
- With the changes to governance and commissioning structures proposed, the detail regarding reporting frequency, scope and audit processes and the speed of access to information across the system will be critical to success. The information strategy should be clear about data flow across the system and the expected time frames around each key process stage.
- The proposed increased role of information intermediaries presents risks that are potentially counter-productive to achieving greater access and accountability – it will be important to address concerns, such as intellectual property rights (IPR) and audit, in order to prevent barriers to information being re-constructed.

The information strategy (chapter 6)

41. We welcome and support the development of an information strategy as a key enabler to deliver an 'information revolution'. Furthermore, we recognise the critical role of information in delivering 'Greater choice and control' for citizens. The move away from centralised control to a distributed provision model managed via an architecture based on standards, interoperability and market dynamics is pragmatic and more likely to succeed given the complexity of the challenge. However this approach is likely to expose new challenges and barriers that will need to be anticipated and mitigated. Some of these challenges are suggested below.
42. The key issues mentioned in section 6.4 are also likely to include: intellectual property rights (IPR) management; the establishment of a commercial (cost) framework for intermediaries; the establishment of a clear information governance model that includes roles and responsibilities for central agencies such as NICE, the NHS Information Centre, CQC, Monitor and the NHS Commissioning Board.
43. We welcome the suggestion that Quality Standards could be described in ways that computers can understand, so as to minimise the burden of data transcription and mapping associated with implementation and thus improve efficiency (section 6.9). As we said in paragraph 5, digitisation of NICE guidance, Quality Standards, and other products should enable more flexible use. In developing our information management systems we will ensure consistency with standard terminologies and interoperability requirements.
44. We recognise the importance of terminologies and definitions as set out in sections 6.18–6.24 and will support the development of a national strategy to adopt a minimised suite of standardised terminologies – providing definitions used in the development of quality standards and guidance mapped to SNOWMED CT and other agreed standards as appropriate.
45. The digitisation of NICE guidance and the development of the NHS Evidence service will facilitate interoperability as a critical enabler of the information strategy. A key component of the strategy will be how and how quickly standards (in the form of NICE Quality Standards and guidance) can be integrated into decision support and health management systems.

Key points/recommendations (chapter 6):

- The proposed strategic approach to decentralise information management and responsibility will raise challenges and dependencies in addition to those mentioned in the consultation document – such as IPR issues and the associated commercial/cost risks. It will be critical to mitigate these factors in the information strategy with clear drivers for uptake and measures for achieving goals.
- The digitisation of NICE guidance and the development of NHS Evidence will support the implementation of standard terminologies and interoperability across the system. There needs to be a clear governance and operational model in the information strategy that will ensure the stated goals for standardisation are implemented speedily.

National Institute for Health and Clinical Excellence (NICE)

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Liberating the NHS: Potential implications for NICE and NHS Evidence Report

Background

The Government's White Paper, *Equity and Excellence: Liberating the NHS*, and its associated documents – *Greater Choice and Control* and *An Information Revolution* – set out proposals to give patients control over access to information and the care they receive and to empower all professionals to be able to access high quality information to deliver high quality care.

Liberating the NHS: Greater Choice and Control

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120613.pdf

Liberating the NHS: An Information Revolution

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120598.pdf

NHS Evidence is a service provided by NICE to give access to quality assured clinical, public health and patient information. These proposals could therefore have implications for the future development of NHS Evidence and the services it provides.

As a result NICE ran a short workshop at BMA House on 10 December 2010 which brought patient organisations and royal colleges together to discuss how the new vision could impact the future development of NHS Evidence.

The workshop included discussions around:

- What role NHS Evidence could have in providing access to more patient information/patient leaflets
- How NICE/NHS Evidence could better support joint decision making
- How the NHS Evidence Accreditation Scheme could be expanded
- How NICE/NHS Evidence could help people identify treatments of 'proven clinical value'
- How NHS Evidence could facilitate access to related information, such as ongoing trials and healthcare data?

Organisations invited to the workshop

- Arthritis Care
- Information Centre
- Sue Ryder Care
- CQC
- Royal College of Physicians (Health Informatics Unit and PCSG)
- Royal Pharmaceutical Society of Great Britain
- Royal College of Paediatrics and Child Health
- Royal College of Obstetricians and Gynaecologists
- Royal Pharmaceutical Society of Great Britain
- National Association for Colitis and Crohn's Disease
- RNIB
- Royal College of Midwives
- Royal College of Radiologists
- The Carers Resource
- Terrence Higgins Trust
- Macmillan Cancer Support
- EMIS
- Arthritis Care
- Multiple Sclerosis Society
- NHS London
- The Prostate Cancer Charity
- Royal College of Nursing
- RNIB
- Patient Association
- KSS Library and Knowledge Services

Following some background and scene setting the workshop broke into five discussion groups which considered at least two of the key questions below.

Discussion questions and key themes

Q1 What role should NHS Evidence have in providing access to more patient information/patient leaflets?

There did not appear to be a general consensus within the groups around this question. However, whilst there was initial uncertainty (from patient organisation representatives) about whether there was a role for NICE, there was a general acknowledgement that there is a need for one place for access to quality assured information for patients, to cut costs and confusion – and that this might be a role for NICE/NHS Evidence.

There was a concern about duplication with the work of NHS Choices.

There was also a question mark over the usefulness for certain service users of information on its own without the opportunity for face-to-face help from a specially trained individual and a concern that NHS Evidence couldn't facilitate engagement of patients with relevant interest groups in the way the specialist websites of patient organisations could. Therefore, NICE could work more closely with patient and carer organisations.

As NICE is seen as an independent assessor of quality information, some groups mentioned the possibility of NICE/NHS Evidence quality assuring patient information (and if so that it would need to assess under different criteria to the current Accreditation Scheme) which raised the question of how that would affect the DH Information Standard.

It was suggested that NICE could focus on assessing the quality of decision-making tools – these are different from the type of information currently covered by the Information Standard.

There was agreement from more than one group that NHS Evidence could do more on patient information but that it should have a signposting role only. Those groups felt that NHS Evidence should signal information accredited under the Information Standard and ingest the sources but not accredit the information itself. They believed that the Information Standard was regarded as the most relevant quality mark for patient information.

Other benefits:

- NHS Evidence could be a convenient additional resource for patients.
- It could forward people to more relevant sites.
- Its role in establishing a baseline of quality controlled information could be useful.
- It could have an indirect effect by signalling to GPs (who were often poor at referrals for particular conditions) the important points on care pathways.
- There might be benefits to organisations from syndication of NHS Evidence.

Q2 How could NICE/NHS Evidence better support joint decision making?

There was general consensus that patients want the safest care. They trust their healthcare professional and this is where NHS Evidence would be key – in helping healthcare professionals to make the best decision.

However, there was agreement that if a patient is involved in the decisions around their care that they generally experience better outcomes. To make the right decision a patient needs to ask the right questions.

It was felt that what is required is to ensure the patient has all the right information without overloading them.

There is a need to facilitate access to evidence, patient information and data through a single portal - currently provided through three different routes.

NICE/NHS Evidence need to minimise complexity and uncertainty of information:

- Much information to support decision-making is highly complex and can be difficult to understand – for clinicians as well as patients.
- Data on quality of care is often either unreliable (incomplete/inaccurate) or difficult for patients to interpret (e.g. SMRs).

Groups again acknowledged that there is still a substantial part of the population who cannot access the internet. And of those who can, many don't know how to interpret the information. It was agreed that patients need support in using and interpreting information.

An IT solution alone was not deemed suitable. A couple of groups felt that it would be important to train healthcare professionals to access the relevant quality assured information and share it with patients in a face-to-face environment.

Another group believed the community pharmacist to be 'an untapped resource,' that many patients will seek information from rather than their GP and that there might be an opportunity for NHS Evidence to target this audience to facilitate joint decision making.

EMIS selects relevant information for GPs during patient consultation – is there any scope for somehow linking in with this system?

Whilst patient organisations provide resources that enable patients to engage with clinicians they responded positively to the idea that there could be interoperability between patient organisation's decision support resources and the NICE guidance-linked pathway model that NHS Evidence was developing – for example, at key decision points or 'nodes' on the pathway.

Groups also wanted more decision support aids believing that what is wanted is a balanced view that clearly lays out all the choices/options and a pathways style of presentation to help patients and carers to visualise and understand the options.

Good practice of information prescriptions was also discussed and seen as a very useful tool to identify information needs/sources at key points in the care pathway.

Q3 how should the NHS Evidence accreditation scheme be expanded?

Note was made of the fact that all NHS Evidence information sources have been selected based on an assessment of their quality/relevance and that this should be made clearer for users.

Groups that discussed this question felt that NHS Evidence could usefully bring all the decision aids together and accredit them.

There was agreement that national standards are needed and that they should be used to develop local standards and processes.

One group asked: Can NICE help to promote standards that apply in the NHS across all parts of the UK –for example, through reciprocal accreditation? They believed this would promote equality in standards of care across the whole of the UK.

This group also suggested accrediting the process for collecting data rather than quality assuring individual datasets and suggested that NHS Evidence accredit processes for developing clinical pathways.

It was further suggested that NHS Evidence should accredit decision-making tools for patients and the public.

Q4 How can NICE/NHS Evidence help people identify treatment of ‘proven clinical value’?

The points that came out of the group discussion were that ‘proven clinical value’ is not always clear. For example the choice can be too great – three choices for prostate cancer.

There needs to be better use of experiential evidence – e.g. one group discussed outputs of EMIS’ primary care research tool.

It was clear that more work needs to be done around social care. It was noted that there is often a gap in the care pathways for long term conditions and end-of-life care.

How data are analysed is important – you need to give the full picture so that people can make an informed choice.

Knowing the review date for information is important, and the risks need to be presented clearly.

Q5 How can NHS Evidence facilitate access to related information such as ongoing trials and healthcare data?

It was felt it would be helpful if NHS Evidence could improve data accessibility for patients and professionals. But, the data required is often not available.

Patients and patients' charities need access to trial information as part of the decision making process.

NHS Evidence could have a role in helping to recruit patients to trials via their patient group / charity.

NHS Evidence could also have a role in bringing all the trials information together in one place.