

National Institute for Health and Clinical Excellence

Epilepsy

Quality Standard Consultation Comments Table

14th September 2012- 12th October 2012

Notes for completion (NB this is for internal purposes – remove before posting on web)

ID – This is the stakeholder ID from the consultation response spreadsheet. Technical analysts will assign individual comment IDs at a later date.

Stakeholder – Please include the organisation name only.

Statement number – Any comment relating to multiple statements should be duplicated and assigned to each relevant statement. Comments can also be recorded as ‘general’ if they do not relate to a specific statement. If a stakeholder does not specify what the comment relates to then please leave this blank for the technical analyst to complete.

Comment on - Populate this only where stakeholder specifies what element of statement comment relates to, otherwise leave blank. Choose from statement, measure, audience, definitions, equality.

ID	SH ID	Stakeholder	Statement No	QS	Comments Please insert each new comment in a new row.	Response Please respond to each comment
1	013	Epilepsy Action	General		<p>Epilepsy Action welcomes the introduction of a Quality Standard for epilepsy in children. We are encouraged that this Standard is being developed early in the cycle of the Quality Standards initiative, and we welcome the opportunity to input to the process.</p> <p>Overall, we are encouraged by the proposed Quality Statements and believe they form a good basis for the Quality Standard for epilepsy in children. However we would like to propose some additional Statements and some small amends that we believe will further improve the framework. We suggest the following Quality Statement for additional inclusion in the draft Quality Standard for adults.</p> <p>“Adults with epilepsy should have their epilepsy seizure type(s), syndrome, aetiology and co-morbidity determined and be informed upon diagnosis.”</p> <p>We believe that in addition to QS1 (concerning timely diagnosis by a specialist), patient care would benefit from a separate QS regarding accurate diagnosis. We recommend a Statement similar to the one laid out above. This may encourage early, thorough investigations which would</p>	<p>Thank you for your comments. These were noted by the TEG.</p> <p>Thank you for your comments and suggested additional quality statements. The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes. The TEG reviewed all the suggested additional statements and were content that these important issues were covered by the statements included in the quality standard. Additional detail has been added to the definitions and supporting information for a number of the statements to provide further clarification about what the statement covers,</p>

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					<p>increase the likelihood of accurate diagnosis and therefore more targeted and appropriate treatment. Accurate diagnosis can be measured by a reduction in the gap between those who medically could be seizure-free, and those in reality who are.</p> <p>“All women with epilepsy of child bearing potential should be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause (as appropriate).”</p> <p>Epilepsy impacts on the care and treatment choices of women and girls throughout their lives. The anti-epileptic drug a woman takes to treat her epilepsy, could impact on her fertility, the effectiveness of her contraception, the health of an unborn baby. Hormonal changes during pregnancy, menopause or when using hormone replacement therapy could reduce her seizure control, increasing her risk of harm. However quality care, support and information throughout her life, could lead to optimum seizure control with as little impact on her wellbeing as possible. Appropriate outcome measures for this proposed Statement are:</p> <ul style="list-style-type: none"> • A reduction in the number of children born with a major congenital malformation or neurodevelopment impairment following exposure to maternal valproate • A reduction in the number of children born with a major congenital malformation following exposure to maternal AEDs • A reduction in the number of unplanned pregnancies that occur due to an interaction between their AED and their contraceptive <p>We believe this is an appropriate Statement for inclusion as it is already an indicator in the Quality Outcomes Framework.</p> <p>“Adults with difficult to control epilepsy should be advised of and have access to a wide range of treatment</p>	

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					<p>including surgical and non-surgical interventions (as appropriate)."</p> <p>We do not believe the document includes sufficient references regarding access to appropriate treatments (drug and non-drug interventions). We know accessing non-therapeutic treatments can be difficult, and can vary depending on where a person lives. This has meant that many patients who could benefit from these interventions are never considered for them, or are considered far later than they needed to be. A proposed outcome for this indicator is:</p> <ul style="list-style-type: none"> • An increase in the number of people with epilepsy who are seizure-free, or experience a significant reduction in seizure frequency, as a result of resective surgery, vagal nerve stimulation, deep brain stimulation or similar. <p>"Adults with epilepsy should be offered an individualised drug treatment strategy according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual's lifestyle, and the preferences of the individual, their family and/or carers as appropriate."</p> <p>While this may be an obvious statement of treatment, we believe it is important to emphasis a patient's right to NICE approved treatments, and to access to the appropriate medication to treat the causes of seizures, if recommended by an epilepsy specialist.</p> <p>"Adults with epilepsy should, unless there are sound clinical reasons not to, receive information about the risk of epilepsy related deaths (including SUDEP) and methods to reduce that risk."</p> <p>The National Sentinel Clinical Audit of Epilepsy-Related Death (2002)¹ found that there to be around 500 cases of</p>	

¹ Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy–death in the shadows. The Stationery Office.

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					<p>Sudden Unexpected Death in Epilepsy (SUDEP) in the UK every year, and another 500 deaths due to epilepsy related causes. Of the 1,000 epilepsy related deaths in 2001, 54 per cent of the adults had experienced inadequate care. This led to the conclusion that 39 per cent of adult deaths were considered potentially or probably avoidable.</p> <p>There is a quite obvious and acute health outcome associated with this Statement. And this outcome would meet the clinical domain 'Preventing people from dying prematurely' in the NHS Outcomes Framework. This Statement is particularly important for improving the overall quality of care for all people with epilepsy. If the seizures are prevented, then quality of life for these people should increase. One way of demonstrating better seizure prevention is a reduction in the number of epilepsy related deaths, caused by seizures. In some cases, steps can be taken to prevent seizures if people are aware that the consequences of having a seizure can be particularly dangerous.</p> <p>“Adults with epilepsy should have access to psychological services to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory.”</p> <p>This is a potentially important quality of life measure, showing consideration of and addressing the non-seizure impact of epilepsy, in those for whom the condition has a profound and significant impact. This Statement could be measured by Patient Reported Experience Measures (PREMs). It could also be evaluated by non-healthcare outcomes such as increased independent living and participation in the labour market.</p>	
2	010	British Nuclear Medicine Society	Additional statement	Children	Draft quality statement: Children and young people who need neuro-imaging for drug resistant epilepsy may need isotope imaging in case MRI is negative but the seizures are likely to be focal clinically, or the EEG is non-localising, or EEG and the MRI are discordant.	Thank you for your comment. The TEG discussed your suggestion but felt as there is a limit to the number of statements that should be included in a quality standard, your suggestion referred to a very small
3	010	British Nuclear Medicine Society	Additional statement	Children		

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					Structure: provision of isotope imaging services for children with drug resistant epilepsy has to part of the multidisciplinary epilepsy team. The indications and the results of the isotope studies have to be discussed within the multidisciplinary team meeting. The isotope studies have to be reported only in the presence of comprehensive clinical, telemetry and imaging information provided by the epilepsy team. Referrals to isolated Nuclear Medicine units, not part of the epilepsy multidisciplinary team, has to be discouraged. It is envisaged that this type of Nuclear Medicine services may be operational only in centres with an active paediatric epilepsy surgical programme.	group of patients who would be evaluated in tertiary care and that it was too specialised to be included.
7	013	Epilepsy Action	General	Adult	<p>Epilepsy Action welcomes the introduction of a Quality Standard for epilepsy in adults. We are encouraged that this Standard is being developed early in the cycle of the Quality Standards initiative, and we welcome the opportunity to input to the process.</p> <p>Overall, we are encouraged by the proposed Quality Statements and believe they form a good basis for the Quality Standard for epilepsy in adults. However we would like to propose some additional Statements and some small amends that we believe will further improve the framework.</p>	Thank you for your comments. These were noted by the TEG.
8	013	Epilepsy Action	General	Adult	<p>As a general note, we would like the final Quality Standard document to include the additional definitions for the following phrases: “Ongoing access.” (as mentioned under QS7). “Regular structured review” (under QS8) This would help more accurately define the processes that contribute to the best outcomes.</p>	Thank you for your comments. Statement 7 has now been removed as the TEG decided that it would be covered by statement 4 in the final standard concerning care planning. “Structured review” is defined in the CYP quality standard.
9	007	Greater Manchester Neurosciences Network	General	Adults	Some descriptors may be too broad and worth breaking down into more specific matters particularly to ensure that key issues cannot be misrepresented.	Thank you for your comment. Definitions have been added where the TEG agreed that clarification may be required.
10	007	Greater Manchester	General	Adults	Need to ensure that times for access are clinically relevant	Thank you for your comments. The TEG

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		Neurosciences Network			e.g. 4 week timescale for referral to tertiary care, as this may lead to perverse outcomes where some conditions are prioritised above others.	reviewed all the timescales included in the standard and have ensured that they are in line with evidence based recommendations or where these were not available, the expert opinion of TEG members who considered the issue you raised.
11	008	Sheffield Teaching Hospitals NHS Foundation Trust	General	Adults	Tertiary clinics should be defined as having facilities to perform video EEG telemetry, high resolution (3T) MRI, ictal SPECT, cortical mapping, surgical workup and for epilepsy surgery	Thank you for your comment. The TEG were confident that there was national awareness of tertiary services and what they provide.
12	008	Sheffield Teaching Hospitals NHS Foundation Trust	General	Adults	Tertiary centres should have telemetry facilities (acute and planned) with the ability to perform sleep studies, if indicated, to differentiate between epilepsy and sleep disorders.	Thank you for your comment. This was noted by the TEG and they were confident that there was national awareness of tertiary services and what they provide.
13	011	Royal College of Nursing	General	Adults	The Royal College of Nursing welcomes this document. It is comprehensive and timely.	Thank you for your comment. This was noted by the TEG.
14	014	Epilepsy Society	General	Adults	The overview should include in full what is meant by 'specialists'.	Thank you for your comment. Definitions have been added where the TEG agreed that clarification may be required.
15	014	Epilepsy Society	General	Adults	The standards might make more sense if 'chronological' in terms of care pathways - for example, point 6 should come before point 5.	Thank you for your comment. The order of the statements has been reviewed and amended.
16	014	Epilepsy Society	General	Adults	We would like to see the inclusion of a statement about both mortality and A&E episodes (referencing University of Liverpool's 2012 National Audit of Seizure Management in Hospitals study (NASH) and the National Audit of Epilepsy-related Death)	Thank you for your comment. A measure is included concerning hospital admission and A&E attendance in relation to statement 6.
17	015	Epilepsy Bereaved	General	Adults	The overview should include in full what is meant by 'specialists'.	Thank you for your comment. This term is defined under the relevant statements.
18	015	Epilepsy Bereaved	General	Adults	The standards might make more sense if 'chronological' in terms of care pathways - for example, point 6 should come before point 5.	Thank you for your comment. The order of the statements has been reviewed and amended.
19	015	Epilepsy Bereaved	General	Adults	We would like to see the inclusion of a statement about both mortality and A&E episodes (referencing University of Liverpool's 2012 National Audit of Seizure Management in Hospitals study (NASH) and the National Audit of Epilepsy-	Thank you for your comment. A measure is included concerning hospital admission and A&E attendance in relation to statement 6.

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					related Death)	
20	002	NHS Direct	General	Adults and children	NHS Direct welcome the quality standard and have not comments on its content as part of the consultation.	Thank you for your comment. This was noted by the TEG.
21	005	Dept of Health	General	Children	I think this sets high standards as we would hope. I expect that NICE do not wish to enter into the way in which services are commissioned and provided, for example via networks of care, but to meet some of the definitions (such as a specialist in the management of epilepsies requiring peer review), it is difficult to see how this is achieved without paediatric epilepsy networks	Thank you for your comment. As you suggest the purpose of the quality standard is specifying core aspects of what the service requires but leaving flexibility at local level to determine how exactly such services are commissioned and provided.
23	011	Royal College of Nursing	General	Children	The Royal College of Nursing welcomes this document. It is timely.	Thank you for your comment. This was noted by the TEG.
24	011	Royal College of Nursing	General	Children	There does not appear to be a statement in relation to the child/young person's health care needs and support in school and education environments. We would stress that this is something that needs to be considered and measures encompassed which capture impact on school attendance and educational attainment, as well as a health plan which encompasses care in school settings.	Thank you for your comment. The TEG anticipated that these issues would be covered in statement 4 regarding the development of an agreed comprehensive care plan for each child and young person with epilepsy.
25	012	Royal College of General Practitioners	General	Children	The quality standards are generally well thought out and relate well to the NICE guidance and to measurable outcomes (which would need extra funding – one possibility is a GP children and young people's epilepsy QOF standard.	Thank you for your comment. This was noted by the TEG. The TEG will be reviewing the standards for potential indicators for different frameworks, such as the QOF.
28	016	GlaxoSmithKline UK	General	Children	Same comments apply as per adult Quality Standards.	Thank you.
29	016	GlaxoSmithKline UK	General	Children	There is no mention of genetic testing in children (and it did seem to feature quite a lot in the European Congress for Epilepsy recently).	Thank you for your comment. The TEG agreed that if children and young people are being seen in the correct environment by people with appropriate expertise then this should lead to relevant tests being carried out depending on the individual circumstances of each case. Genetic testing was felt to be too specialised to be included as an individual statement.

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30	018	Royal College of Paediatrics and Child Health	General	Children	These standards are very welcome and will hopefully improve the overall standard of care for Children and Young People (CYP) with epilepsies.	Thank you for your comments. These were noted by the TEG.
31	018	Royal College of Paediatrics and Child Health	General	Children	The RCPCH encourages NICE to work collaboratively with RCPCH in helping to ensure that the quality standards can be fed into the Epilepsy12 National Audit.	Thank you for your comment. The TEG was aware of the work being carried out through Epilepsy 12. The primary evidence source used by the TEG to develop this quality standard is NICE Clinical Guideline 137, rather than any national audits. Where the TEG have identified areas for improvement that correlate with the audit criteria used by Epilepsy 12, this has been referenced.
32	018	Royal College of Paediatrics and Child Health	General	Children	We would prefer that the adult and paediatric epilepsy standards are kept separate.	Thank you for your comment. This was noted by the TEG.
33	019	Association of Anaesthetists of Great Britain and Ireland (AAGBI)	General	Children	The AAGBI has no comment on this proposal	Thank you for your response.
34	013	Epilepsy Action	Question 1		<p>We have identified the following healthcare outcomes appropriate for epilepsy:</p> <ul style="list-style-type: none"> • A reduction in non-elective admissions to secondary and acute care. • A reduction in Accident and Emergency episodes and/or paramedic episodes (including logged ambulance/AMT attendances). • An increase in the number of young people and children who are seizure free. • Good scores relating to Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). • An increase in the number of children with epilepsy, parents, carers and teachers who are informed about the main medical and social impact of their conditions [seizure type(s) and syndrome(s)]. • An improvement in the Quality of Life scores for young 	Thank you for your suggestions. As you note, there are challenges with attributing these important outcomes to individual statements, but where the TEG were confident that there was a clear causal relationship between the action described in a statement and an outcome, the outcome has been included.

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					<p>people and children with epilepsy.</p> <ul style="list-style-type: none"> • A reduction in (avoidable) deaths as a result of epilepsy. • A decrease in the frequency and severity of the side-effects of anti-seizure medication. • A decrease in the number of children born with birth defects and/or malformations to mothers with epilepsy. • An increase in the number of successful surgical interventions for children with epilepsy (with success defined as increased seizure-freedom rates or a significant reduction in the frequency and severity of seizures). <p>In practice it is difficult to apply these outcomes to specific Quality Statements, as holistically good care (for example reductions in misdiagnosis, optimal seizure-freedom rates, reductions in side-effects, reductions in avoidable deaths) is key to improving and building-upon these measures. The individual processes on the way to achieving this can be measured (such as care planning, annual reviews, number of specialist nurses) but this is a recording of the processes rather than the outcomes patients receive.</p>	
36	007	Greater Manchester Neurosciences Network	Question 1	Adults	<p>Appropriate healthcare outcomes Outcomes should link to those already identified in the Greater Manchester Strategy</p>	Thank you for your comment. This was noted by the TEG. And where the TEG were confident that there was a clear causal relationship between the action described in a statement and an outcome, the outcome has been included.
37	007	Greater Manchester Neurosciences Network	Question 1	Adults	<p>Appropriate healthcare outcomes Outcomes should be considered from two broad perspectives i.e. service outcomes and patient experience outcomes. Most of the outcomes featured relate to patient experience i.e.: Time taken to diagnosis; Time taken to get to medication regimen that is working for the individual; Time to seizures being controlled; Satisfaction for patients and carers. The effectiveness of working to these quality standards should be measured through e.g. effects of patient having a care plan on attendance at A&E, admission</p>	Thank you for your suggestions. Where the TEG were confident that there was a clear causal relationship between the action described in a statement and an outcome, the outcome has been included.

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					and length of stay in hospital; being cared for by a clinical team that provides epilepsy specialist nursing - what impact does the nursing element of the service have on the experience for the patient and does access to specialist nursing prevent the patient accessing outpatient appointments with a neurologist or presenting at A&E.	
38	007	Greater Manchester Neurosciences Network	Question 1	Adults	<p>Appropriate healthcare outcomes</p> <p>Time taken to stabilise condition from referral – draft quality statement 1</p> <p>Decrease in non-elective admissions - draft quality statement 1, 4, 5, 6, 7, 8, 9</p> <p>Decreased mortality rate in under 75's with epilepsy – draft quality statement 1, 4, 5, 6, 7</p> <p>Decreased rate of teratogenicity in children born to women with epilepsy - draft quality statement 1, 6, 7, 8, 9</p> <p>Access to Epilepsy Specialist Nurse - draft quality statement 9</p> <p>Patient satisfaction – all draft quality statements</p>	Thank you for your suggestions. The TEG reviewed these and felt that in many cases other factors would contribute to these outcomes beyond those in the statements. Where the TEG were confident that there was a clear causal relationship between the action described in a statement and an outcome, the outcome has been included.
39	009	Association of British Neurologists	Question 1	Adults	The Association of British Neurologists welcomes any document that aspires to improve the care of people with epilepsy. The scope of the document is limited to process, and the quality standards suggested are sensible and realistic. What are also required to drive up standards of care, are quality outcome measures, which are not included in this document. We would welcome the inclusion of measures such as admission rates for people with epilepsy, number of people being seen in Emergency Departments with epilepsy, number of people admitted with status epilepticus, and number of cases of SUDEP. These would be relatively straight forward to audit on an on-going basis, and provide a measure of the quality of the service being provided.	Thank you for your comment. For each statement, relevant measures have been included that would enable providers or commissioners to assess whether the actions described in the statements have been implemented effectively.
40	014	Epilepsy Society	Question 1	Adults	We would like to see some outcome measures which will incentivise local commissioning to collect and review data on A&E and epilepsy deaths. The two outcomes we consider the most important in terms of driving improvements in services would be reduction in epilepsy deaths and	Thank you for your comments. The quality standard can only include measures that directly relate to the quality statements. For each quality statement relevant structure, process and outcome measures have been

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					<p>reduction in A&E presentations by people with known epilepsy. At the very least we would like an inclusion of measures asking for evidence of a local system in place to review data on deaths and A&E. This would also encourage engagement with voluntary sector organisations that are offering support to local commissioning.</p> <p>We would also like to see outcomes relating to treatment – number of people seizure free and then access to other treatment options if refractory following trial of two AEDs, successful surgery.</p> <p>As noted above, an outcome about family and carers being equipped with appropriate training and support for quality statement 5.</p> <p>We also believe an outcome around individuals being able to effectively manage their epilepsy, going beyond just measuring involvement in their care is important for statement 6.</p>	identified.
41	015	Epilepsy Bereaved	Question 1	Adults	<p>We would like to see some outcome measures which will incentivise local commissioning to collect and review data on A&E and epilepsy deaths. The two outcomes we consider the most important in terms of driving improvements in services would be reduction in epilepsy deaths and reduction in A&E presentations by people with known epilepsy. At the very least we would like an inclusion of measures asking for evidence of a local system in place to review data on deaths and A&E. This would also encourage engagement with voluntary sector organisations that are offering support to local commissioning.</p> <p>We would also like to see outcomes relating to treatment – number of people seizure free and then access to other treatment options if refractory following trial of two AEDs, successful surgery.</p>	<p>Thank you for your comments. The quality standard can only include measures that directly relate to the quality statements. For each quality statement relevant structure, process and outcome measures have been identified.</p> <p>The TEG did consider fully the range of outcomes that could be attributed to each statement, and Where the TEG were confident that there was a clear causal relationship between the action described in a statement and an outcome, the outcome has been included.</p>

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					<p>As noted above, an outcome about family and carers being equipped with appropriate training and support for quality statement 5.</p> <p>We also believe an outcome around individuals being able to effectively manage their epilepsy, going beyond just measuring involvement in their care is important for statement 6.</p>	
42	004	UCB Pharma Ltd	Question 1	Children	<ul style="list-style-type: none"> - A reduction in non-elective admissions to secondary and acute care. - A reduction in Accident and Emergency episodes and/or paramedic episodes - An increase in the number of adults, young people and children who are seizure free. - A reduction in (avoidable) deaths as a result of epilepsy 	Thank you for your comment. Thank you for your comments. Thank you for your suggestions. Where the TEG were confident that there was a clear causal relationship between the action described in a statement and an outcome, the outcome has been included. Hospital admissions and A&E episodes have been included against statement 6.
43	007	Greater Manchester Neurosciences Network	Question 2	Adults	<p>Important areas of care not covered by the quality standards Need to enhance the links with annual review and QOF</p>	Thank you for your comments. Annual review has been referenced in statement 4 concerning the development of a care plan. The TEG noted the reference to QOF.
44	007	Greater Manchester Neurosciences Network	Question 2	Adults	<p>Important areas of care not covered by the quality standards Possibly need to review the length of intervention a patient should receive from a service, record the nature of discharge, numbers of patients engaging in supported self care and patient/carer satisfaction with the care received.</p>	Thank you for your comment. The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and where there is potential to generate measurable indicators. Whilst your suggested areas are important, these were not prioritised for the quality standard, but would be expected to be part of good clinical care.
45	007	Greater Manchester Neurosciences Network	Question 2	Adults	<p>Important areas of care not covered by the quality standards Enhance the need to develop strong relationships between different care providers i.e. primary, secondary and tertiary services</p>	Thank you for your comment. Statement 4 and statement 6 concerning care planning both make reference to integrated care and planning. Statement 5, concerning access to an epilepsy specialist nurse described the

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						role of an ESN including helping liaison between settings.
46	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 2	Adults	No mention of elderly patients, passing mention of pregnancy and learning disabled patients. A QS should be that such patients have demonstrated equality of access to all relevant aspects of the service and that the special needs of these groups be addressed.	Thank you for your comment. Equality of access is essential and there is a specific section in the quality standard stating that all people, including these specific groups, should have equal access to services. Statement 4 concerning a comprehensive care plan is intended to encourage care professionals to consider all the needs of each individual.
47	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 2	Adults	There is no mention of provision of adequate psychiatric or psychotherapeutic care for these patients. This is an important quality standard and availability of psychological care is mentioned in CG137. This should include psychological care for patients with non-epileptic seizures (also mentioned in CG137). The QS should include maximum access time (suggested less than 8 weeks).	Thank you for your comment. Care provision for non-epileptic seizures is outside of the remit of this quality standard. For people with epilepsy, statement 4 concerning the care plan includes the provision of psychological care.
48	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 2	Adults	Specialist preconception counselling should be made available (? Within 6 weeks of referral given by either specialist nurse or consultant with a special interest). Pregnant patients should be seen in a joint obstetric epilepsy clinic by obstetricians and neurologists with training in pregnancy and epilepsy.	Thank you for your comment. The TEG did not identify a specific statement about preconception counselling but have specifically referenced this in statement 4 concerning the development of a comprehensive care plan and statement 8 in the adults standard concerning re- access to specialist services.
49	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 2	Adults	Availability of cardiological investigations (Tilt tables, implantable ECG recording devices) and treatments (pacing etc) should be specified	Thank you for your suggestion. However, following review by the TEG this issue was not prioritised for inclusion in the standard.
50	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 2	Adults	There should be specified quality measures for primary care, including assurance of provision of continuity of supply of antiepileptic medication from a single nominated pharmacy of the patient (or carers') choice. In addition epilepsy care in residential and nursing homes should be subject to a quality standard, including assurance of a common level of service independent of age and disability.	Thank you for your suggestions. However, following review by the TEG these issues were not prioritised for inclusion in the standard.
51	008	Sheffield Teaching Hospitals NHS	Question 2	Adults	There should be specified quality measures for A&E and emergency services which state that patients attending with	Thank you for your comment. These quality statements are relevant to all services under

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		Foundation Trust			a seizure should be notified to the appropriate epilepsy service for review (with the agreement of the patient) rather than relying on primary care to liaise between patient and secondary care to arrange review.	the umbrella of the NHS and would therefore include emergency care settings. Following review by the TEG the issues around communication between A&E and primary care were not prioritised for inclusion in the standard.
52	014	Epilepsy Society	Question 2	Adults	<p>Evidence from the Confidential Enquiry into Maternal and Child Health (CEMACH) demonstrates that women with epilepsy of child-bearing age are a high risk population from the perspective of serious harm or fatality to foetus or mother. We therefore propose an additional standard addressing the specific care needs of women with epilepsy who are of child-bearing age, as follows:</p> <p><i>“All women with epilepsy of child bearing potential should be risk assessed and then given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause (as appropriate).”</i></p> <p>Quality measures for this statement might include ‘decrease in the number of children born with birth defects and/or malformations to mothers with epilepsy’ and ‘A reduction in the number of unplanned pregnancies that occur due to an interaction between their AED and their contraceptive’.</p> <p>We think there is a case for a standard addressing A&E, but at very least that measures relating to other quality standards (as suggested above) should address this. For example, ‘% of people with known epilepsy presenting to A&E discharged with an emergency plan’.</p> <p>The quality statements do not include reference to treatment options (AEDs and other non-drug interventions such as VNS, surgery). As with our comment on A&E admissions above, at the very least there should be measures relating to other quality standards that address treatment options.</p>	<p>Thank you for your comment. The TEG agreed how important information provision is for women with epilepsy and were confident this was dealt with by the included statements, in particular statement 4 on care planning and statement 8 on re-referral to specialist services.</p> <p>A measure has been included regarding A&E attendance for statement 6 regarding emergency care plan for sustained or repeated seizures.</p> <p>The TEG felt the focus in terms of treatment was making sure people saw the right people with sufficient expertise who could then identify the most appropriate treatment for that person, rather than focusing on any specific treatment. This issue is covered in detail in NICE Clinical guideline 137.</p>
53	015	Epilepsy Bereaved	Question 2	Adults	Evidence from the Confidential Enquiry into Maternal and Child Health (CEMACH) demonstrates that women with	Thank you for your comment. The TEG agreed how important information provision

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					<p>epilepsy of child-bearing age are a high risk population from the perspective of serious harm or fatality to foetus or mother. We therefore propose an additional standard addressing the specific care needs of women with epilepsy who are of child-bearing age, as follows: <i>“All women with epilepsy of child bearing potential should be risk assessed and then given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause (as appropriate).”</i></p> <p>Quality measures for this statement might include ‘decrease in the number of children born with birth defects and/or malformations to mothers with epilepsy’ and ‘A reduction in the number of unplanned pregnancies that occur due to an interaction between their AED and their contraceptive’.</p> <p>We think there is a case for a standard addressing A&E, but at very least that measures relating to other quality standards (as suggested above) should address this. For example, ‘% of people with known epilepsy presenting to A&E discharged with an emergency plan’.</p> <p>The quality statements do not include reference to treatment options (AEDs and other non-drug interventions such as VNS, surgery). As with our comment on A&E admissions above, at the very least there should be measures relating to other quality standards that address treatment options.</p>	<p>is for women with epilepsy and were confident this was dealt with by the included statements, in particular statement 4 on care planning and statement 8 on re-referral to specialist services.</p> <p>A measure has been included regarding A&E attendance for statement 6 regarding emergency care plan for sustained or repeated seizures.</p> <p>The TEG felt the focus in terms of treatment was making sure people saw the right people with sufficient expertise who could then identify the most appropriate treatment for that person, rather than focusing on any specific treatment. This issue is covered in detail in NICE Clinical guideline 137.</p>
54	016	GlaxoSmithKline UK	Question 2	Adults	Q2- there is no mention of liaison between primary and secondary care e.g shared care templates, community care including community matrons, learning disability co-ordinators to improve initial diagnosis and accuracy of referral.	Thank you for your comment. Statement 4 and statement 6 concerning care planning both make reference to integrated care and planning. Statement 5, concerning access to an epilepsy specialist nurse described the role of an ESN including helping liaison between settings.
55	020	Chesterfield and North Derbyshire Royal Hospital NHS	Question 2	Adults	The quality statements say nothing about epilepsy care in nursing and residential homes – including access to emergency treatments (ie. rectal diazepam, buccal	The standard is intended to cover all NHS care settings for people with epilepsy. However, settings outside the NHS could

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		Foundation Trust			midazolam), minimum standards for routine GP and hospital appointments involving dependent nursing or residential home residents.	use these standards as appropriate.
56	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Question 2	Adults	There is no statement about commissioners ensuring that all patients with epilepsy (including dependent patients) have equitable access to medications for epilepsy (traffic light systems force some patients to obtain licensed medications from hospital pharmacies to which they do not have any easy access).	Thank you for your comment. Equality of access to care and medication is included as an overarching principle for the standard.
57	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Question 2	Adults	There is no mention of provision of adequate psychotherapeutic care for patients with epilepsy-related psychiatric or emotional problems or patients with psychogenic non-epileptic seizures or maximum waiting times for such services.	Thank you for your comment. Care provision for non-epileptic seizures is outside of the remit of this quality standard. For people with epilepsy, statement 4 concerning the care plan includes the provision of psychological care.
58	004	UCB Pharma Ltd	Question 2	Children	<p><u>What important areas of care, if any, are not covered by the quality standard? (additional quality standard recommended)</u></p> <p>The important and costly areas of non-elective or emergency admissions for people with epilepsy are not covered by the quality standard at present. This is also an identified area for improvement in the NHS Outcomes Framework 2012/13 Part 2. (<i>Reducing time spent in hospital by people with long-term conditions: 2.3.i (Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults) ii Unplanned hospitalisation for epilepsy in under 19s)</i>) A suggestion to improve outcomes and reduce costs associated with these admissions would be to introduce a quality measure related to gaining specialist input through discussion or referral at the point of admission.</p> <p>Proposed quality standard: Adults and young people presenting in the acute setting with seizures should be discussed with or referred to a specialist in the management of the epilepsies within 24hrs of admission.</p> <p>There is currently a recommendation around this topic within the NICE guideline CG137 as described below :</p>	Thank you for your suggestion. The TEG considered these and were confident that issues around admissions and access to specialist care were covered in the statements contained in the standard.

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					<p><i>Following a first seizure:</i></p> <p><i>1.4.1 Children, young people and adults presenting to an Accident and Emergency department following a suspected seizure should be screened initially. This should be done by an adult or paediatric physician with onward referral to a specialist when an epileptic seizure is suspected or there is diagnostic doubt.</i></p> <p><i>1.4.2 Protocols should be in place that ensure proper assessment in the emergency setting for children, young people and adults presenting with an epileptic seizure (suspected or confirmed).</i></p>	
59	013	Epilepsy Action	Question 2	Children	<p>We suggest the following Quality Statement for additional inclusion in the draft Quality Standard for children.</p> <p>“Children with epilepsy should have their epilepsy seizure type(s), syndrome, aetiology and co-morbidity determined and be informed upon diagnosis.”</p> <p>We believe that in addition to QS1 (concerning timely diagnosis by a specialist), patient care would benefit from a separate QS regarding accurate diagnosis. We recommend a Statement similar to the one laid out above. This may encourage early, thorough investigations which would increase the likelihood of accurate diagnosis and therefore more targeted and appropriate treatment. Accurate diagnosis can be measured by a reduction in the gap between those who medically could be seizure-free, and those in reality who are.</p> <p>“All women with epilepsy of child bearing potential should be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause (as appropriate).”</p> <p>Epilepsy impacts on the care and treatment choices of girls and women throughout their lives. The anti-epileptic drug a woman takes to treat her epilepsy, could impact on her fertility, the effectiveness of her contraception, the health of</p>	<p>Thank you for your suggestions. The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes.</p> <p>All suggestions for additional statements were discussed by the topic expert group who considered that these issues were already covered by existing statements. Additional detail has been added to the definitions and supporting information for a number of the statements to provide further clarification about what the statement covers,</p>

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					<p>an unborn baby. Hormonal changes during pregnancy, menopause or when using hormone replacement therapy could reduce her seizure control, increasing her risk of harm. However quality care, support and information throughout her life could lead to optimum seizure control with as little impact on her wellbeing as possible. Appropriate outcome measures for this proposed Statement are:</p> <ul style="list-style-type: none"> • A reduction in the number of children born with a major congenital malformation or neurodevelopment impairment following exposure to maternal valproate • A reduction in the number of children born with a major congenital malformation following exposure to maternal AEDs • A reduction in the number of unplanned pregnancies that occur due to an interaction between their AED and their contraceptive <p>“Children with difficult to control epilepsy should be advised of, and have access to, a wide range of treatment including VNS, the ketogenic diet and brain surgery (as appropriate).”</p> <p>We do not believe the draft Standard includes sufficient references regarding access to appropriate treatments (drug and non-drug interventions). We know accessing non-therapeutic treatments can be difficult, and can vary depending on where a person lives. This has meant that many patients who could benefit from these interventions are never considered for them, or are considered far later than they should be. A proposed outcome for this indicator is:</p> <ul style="list-style-type: none"> • An increase in the number of children and young people with epilepsy who are seizure-free, or experience a significant reduction in seizure frequency, as a result of resective surgery, vagal nerve stimulation, the ketogenic diet or similar. <p>“Children with epilepsy should be offered an</p>	

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					<p>individualised drug treatment strategy according to; seizure type, syndrome, co-medication and co-morbidity, the individual’s lifestyle and preferences and those of their family and/or carers as appropriate.”</p> <p>While this may be an obvious statement of good practice, we believe it is important to emphasis a patient’s right to NICE approved treatments, and to access to the appropriate medication to treat the causes of seizures, if recommended by an epilepsy specialist.</p> <p>“Parents and carers of children with epilepsy should, unless there are sound clinical reasons not to, receive information about the risk of epilepsy related deaths (including SUDEP) and methods to reduce that risk.”</p> <p>The National Sentinel Clinical Audit of Epilepsy-Related Death (2002)² found that there to be around 500 cases of Sudden Unexpected Death in Epilepsy (SUDEP) in the UK every year, and another 500 deaths due to epilepsy related causes. Of the 1,000 epilepsy related deaths in 2001, 54 per cent of the adults had experienced inadequate care. This led to the conclusion that 39 per cent of adult deaths were considered potentially or probably avoidable.</p> <p>There is a quite obvious and acute health outcome associated with this Statement. And this outcome would meet the clinical domain ‘Preventing people from dieing prematurely’ in the NHS Outcomes Framework. This Statement is particularly important for improving the overall quality of care for all people with epilepsy. If the seizures are prevented, then quality of life for these people should increase. One way of demonstrating better seizure prevention is a reduction in the number of epilepsy related deaths, caused by seizures. In some cases, steps can be taken to prevent seizures if people are aware that the consequences of having a seizure can be particularly</p>	

² Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy–death in the shadows. The Stationery Office.

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					<p>dangerous.</p> <p>“Children with epilepsy should have access to psychological services to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory.”</p> <p>This is a potentially important quality of life measure, showing consideration of and addressing the non-seizure impact of epilepsy, in those for whom the condition has a profound and significant impact. This Statement could be measured by Patient Reported Experience Measures (PREMs). It could also be evaluated by non-healthcare outcomes such as increased independent living and improved outcomes in education.</p>	
60	018	Royal College of Paediatrics and Child Health	Question 2	Children	For CYP with complex disabilities, it is essential that they receive holistic expert care and that the focus is not just on the epilepsy aspects, but equally addresses the breadth and depth of active health concerns.	Thank you for your comment. The TEG agreed and were confident that this would be covered by statement 4 concerning comprehensive care planning.
62	013	Epilepsy Action	Question 3	Adult	<p>We believe the most important Quality Statements proposed are: Statement 1, Statement 4 and Statement 9.</p> <p>QS1 – Misdiagnosis can bring huge social, psychological and medical problems. Diagnosis by a specialist, within a relatively short timescale, helps reduce the likelihood of misdiagnosis. Controlling seizures as quickly and effectively as possible is a vital health outcome. Not doing so poses significant risks and threats to the person with (potential) epilepsy, and could lead to a waste of health service time and resources.</p> <p>QS4 – Reinforcing that even those who are ‘well-controlled’ should be reviewed and assessed for more effective treatment is key principle for improving health outcomes for many people with epilepsy. We believe this targets health inequalities, as many of those patients who have not undergone a treatment review are either older patients (diagnosed many years ago) or patients with learning</p>	Thank you for your comments. Please see statements 1, 7 and 5 in the final quality standard.

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					<p>disabilities. We believe referral for those not fully seizure free for further investigations is an important part of not accepting that seizures 'just happen', and not accepting sub-optimal treatment.</p> <p>QS9 – The “Access to epilepsy specialist nursing” draft Quality Statement is one of the most important because of the integrating role that specialist nurses can play. They liaise between primary and secondary care, and provide a service based on specialist knowledge. They offer a patient centred service and, as far as this framework, they provide a vital means of delivery for at least draft Quality Statements 5, 7, 8 and 10.</p>	
63	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 3	Adults	The issues that make most impact on patient care are: Accurate and expert diagnosis (QS4), provision of adequate support and removal of barriers to care independent of age and disability (no QS), and adequate psychotherapeutic support (no QS).	<p>Thank you for your comments. Please see quality statement 7 in the final quality standard.</p> <p>The topic expert group considered equality issues throughout development of the quality standard. A section on 'Diversity, equality and language' can be found in the final quality standard.</p> <p>The statements apply to all people with epilepsy, and information about the arrangements that may be required for those with additional needs are made explicit in statements 2 and 3 for example. Quality standards are derived from evidence-based recommendations from national accredited guidance, i.e. the NICE clinical guideline 137, which does not include a recommendation on psychotherapeutic support, although it is anticipated that the role of the epilepsy nurse specialist will ensure that people with epilepsy receive all the support they require.</p>
64	014	Epilepsy Society	Question 3	Adults	We think they are all important and none should be prioritised above the others. We would however prioritise	Thank you for your comments. Please see statements 1, 4, 5 and 6 in the final quality

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					standards that are most likely to drive improvement of services. Statement 1 is significant given prompt and accurate diagnosis is an important clinical outcome. Care planning (statements 5 and 6) and safety information (7) are also important. We also strongly support the inclusion of a standard on specialist nursing (statement 9) because of the role ESNs play in integrating care.	standard. The topic expert group considered that the provision of safety information was addressed through care planning, and this aspect is therefore covered in statement 4 in the final quality standard.
65	015	Epilepsy Bereaved	Question 3	Adults	We think they are all important and none should be prioritised above the others. We would however prioritise standards that are most likely to drive improvement of services. Statement 1 is significant given prompt and accurate diagnosis is an important clinical outcome. Care planning (statements 5 and 6) and safety information (7) are also important. We also strongly support the inclusion of a standard on specialist nursing (statement 9) because of the role ESNs play in integrating care.	Thank you for your comments. Please see statements 1, 4, 5 and 6 in the final quality standard. The topic expert group considered that the provision of safety information was addressed through care planning, and this aspect is therefore covered in statement 4 in the final quality standard.
67	012	Royal College of General Practitioners	Question 3	Children	6 (comprehensive care plan) if it included information about epilepsies, emergency treatment plan, details of GP and key worker (such as epilepsy care nurse), details of next review, and DWP benefits available, linked with social care.	Thank you. Please see statement 4 in the final quality standard, where the definitions include these aspects. Statements 5 and 6 cover the areas of epilepsy nurse specialist and emergency care plan in more detail.
68	013	Epilepsy Action	Question 3	Children	<p>We believe the most important Quality Statements proposed are: Statement 1, Statement 4 and Statement 9.</p> <p>QS1 – Misdiagnosis can bring huge social, psychological and medical problems. Diagnosis by a specialist, within a relatively short timescale, helps reduce the likelihood of misdiagnosis. Controlling seizures as quickly and effectively as possible is a vital health outcome. Not doing so poses significant risks and threats to the person with (potential) epilepsy, and could lead to a waste of health service time and resources.</p> <p>QS4 – Reinforcing that even those who are ‘well-controlled’ should be reviewed and assessed for more effective treatment is key principle for improving health outcomes for many people with epilepsy. We believe this targets health</p>	Thank you for your comments. Please see statements 1, 7 and 5 in the final quality standard.

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					<p>inequalities, as many of those patients who have not undergone a treatment review are either older patients (diagnosed many years ago) or patients with learning disabilities. We believe referral for those not fully seizure free for further investigations is an important part of not accepting that seizures ‘just happen’, and not accepting sub-optimal treatment.</p> <p>QS9 – The “Access to epilepsy specialist nursing” draft Quality Statement is one of the most important because of the integrating role that specialist nurses can play. They liaise between primary and secondary care, and provide a service based on specialist knowledge. They offer a patient centred service and, as far as this framework, they provide a vital means of delivery for at least draft Quality Statements 5, 7, 8 and 10.</p>	
69	013	Epilepsy Action	Question 4	Adult	<p>We do not believe that any of the proposed quality measures are ‘inappropriate’. However we have some technical amends to recommend.</p> <p>The most significant amendment concerns Quality Statement 7: “Adults with epilepsy have ongoing access to information about their epilepsy syndrome, seizure type(s) and treatment.”</p> <p>We would like to change this to include a reference to social information at diagnosis. We suggest: “Adults with epilepsy, and their carers, having ongoing access to information about their epilepsy, treatment, and the medical and social implications of their condition.”</p> <p>We believe it is important that patients receive information on these subjects, particularly at diagnosis. We believe the revised Statement above is stronger and clearer, and more</p>	<p>Thank you for your comments. We consider that the social implications of epilepsy are addressed by statement 4 in the final quality standard on care planning.</p> <p>All the statements apply to all people with epilepsy, and as such the quality standard is expected to have a positive impact as the statements promote equality of access to services.</p> <p>Please see revised statement 2 in the final quality standard which focuses on the timeliness of the investigations taking place, to improve clarity.</p> <p>Please see statement 7 in the final quality standard which has been revised to improve clarity.</p> <p>Please see statements 4 and 6 in the final quality standard, which cover the care plan and the emergency care plan respectively.</p> <p>With regards to draft statement 9, this has been reworded to improve clarity; please</p>

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					<p>conducive to better health outcomes (for example, as compliance increases so does the levels of seizure control).</p> <p>With reference to the following Quality Statements: QS1 - We are told by our clinical advisors that older people with probable epilepsy are less likely to be referred to specialist services, for no other reason than their age. We believe it would be beneficial if emphasis was placed in the 'Draft quality measure' section that access to services, in particular epilepsy specialists, should be blind of age, sex, and other disabling issues.</p> <p>QS2 – We also believe the statement can be made a little clearer, that patients and their carers are informed of the results and their implications within four weeks of referral.</p> <p>QS4 - We believe an annual review is an important part of ensuring safe and effective ongoing care; for those whose treatment works and those for whom treatment is not wholly successful. The NICE Clinical guideline for the epilepsies cites seven situations where such a referral should take place (also included in the Definitions section of this Quality Statement). However the wording of this Quality Statement only covers three of these differentials. At a risk of overcomplicating this statement, we would like the Quality Standard development group amending the wording of the Statement to encapsulate the other, relevant additional triggers for referral to an epilepsy tertiary care specialist. In this instance it would be: experiencing, or risk of, unacceptable side-effects from medications.</p> <p>QS5 - While we are aware that some of the information covered in an Emergency Care Plan may be covered by a Care Plan, we believe QS5 and QS6 are both valid Statements for inclusion. Ideally, one Quality Standard would encapsulate both these issues. However because of</p>	<p>see statement 5 in the final quality standard. Please see revised statement 9 in the final quality standard, which has been revised to be more patient-centred by ensuring that the transition period is agreed with the young person. The definitions have also been revised.</p>

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					<p>low rates of compliance for Care Plans, and the potentially high-value impact of an Emergency Care Plan, we agree that it is suitable to include both as Quality Statements.</p> <p>QS6 – For information, the NICE Clinical Guideline for epilepsy states that people should be ‘offered’ a care plan, whereas this indicator talks about the number of people who have a plan.</p> <p>QS9 – While we strongly support this Statement, we are concerned that the wording is needlessly ambiguous. We believe the Statement could be misinterpreted, leading to a situation where providers believe they are meeting this Statement and patients are not directly treated by a nurse. By stating “...by a clinical team that provides epilepsy specialist nursing”, the Statement is not mandating that a patient will see the nurse themselves, but could see others in the team or a practitioner that exercises similar ‘nurse’ duties. We do not believe this is the intention of either the Statement or the Quality Standards development group, and so request rewording for clarity. Suggested rewording: “Adults with epilepsy are cared for by a clinical team that includes epilepsy specialist nurses.”</p> <p>QS10 – We are concerned that the wording for this draft Statement might not meet the needs of the young people requiring support during transition between services. Reading both the Statement and the Measure, it is possible to meet this Statement without ever involving the young person directly in the transition (for example, paediatric and adult services meeting to discuss the transition of a young person, excluding the young person from discussions). We believe the value of transition services is to educate and empower the young person to take control of their condition and their treatment, and ensure a smooth move between different clinical teams. These goals can not be achieved if the transition is an internal health service process only</p>	

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					involving the clinical teams. Additionally, we question whether the Definition section of this Statement is overly prescriptive in how this Standard is met (“...a joint clinical action between paediatric and adult services, with at least 2 meetings at a joint consultation...”). We do not know whether this will discourage innovative approaches to transition care.	
70	014	Epilepsy Society	Question 4	Adults	We do not think any of the quality statements are inappropriate but commissioners may find standards 4 and 8 are conflicting priorities. We suggest rewording quality statement 8 to include risk assessment - e.g. the risk of being on unnecessary medications. We suggest that Quality Statement 7 is reworded to include information beyond safety information as follows: <i>“Adults with epilepsy have ongoing access to information, particularly safety information, about their epilepsy syndrome, seizure type(s) and treatment”.</i>	Thank you for your comments. The topic expert group considered that the provision of information was addressed through care planning, and the aspects you mention are therefore covered in statement 4 in the final quality standard.
71	015	Epilepsy Bereaved	Question 4	Adults	We do not think any of the quality statements are inappropriate but commissioners may find standards 4 and 8 are conflicting priorities. We suggest rewording quality statement 8 to include risk assessment - e.g. the risk of being on unnecessary medications. We suggest that Quality Statement 7 is reworded to include information beyond safety information as follows: <i>“Adults with epilepsy have ongoing access to information, particularly safety information, about their epilepsy syndrome, seizure type(s) and treatment”.</i>	Thank you for your comments. The topic expert group considered that the provision of information was addressed through care planning, and the aspects you mention are therefore covered in statement 4 in the final quality standard.
72	013	Epilepsy Action	Question 4	Children	We do not believe that any of the proposed quality measures are ‘inappropriate’. However we have some technical amends to recommend.	Thank you for your comments. We consider that the social implications of epilepsy are addressed by statement 4 in the final quality standard on care planning.

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					<p>The most significant amendment concerns Quality Statement 7: “Children and young people with epilepsy and their parents or carers have ongoing access to information about their epilepsy syndrome, seizure type(s) and treatment.”</p> <p>We would like to change this to include a reference to social information at diagnosis. We suggest: “Children with epilepsy, their parents and carers, have ongoing access to information about the epilepsy, the treatment, and the medical and social implications of their condition.”</p> <p>We believe it is important that patients receive information on these subjects, particularly at diagnosis. We believe the revised Statement above is stronger and clearer, and more conducive to better health outcomes (for example, as compliance increases so does the levels of seizure control).</p> <p>With reference to the following Quality Statements: QS1 - We are told by our clinical advisors that older people with possible epilepsy are less likely to be referred to specialist services, for no other reason than their age. We believe it would be beneficial if emphasis was placed in the ‘Draft quality measure’ section that access to services, in particular epilepsy specialists, should be blind of age, sex, and other disabling issues.</p> <p>QS2 – We also believe the statement can be made a little clearer, that patients and their carers are informed of the results and their implications within four weeks of referral.</p> <p>QS4 - We believe an annual review is an important part of ensuring safe and effective ongoing care; for those whose treatment works and those for whom treatment is not wholly successful.</p>	<p>All the statements apply to all people with epilepsy, and as such the quality standard is expected to have a positive impact as the statements promote equality of access to services.</p> <p>Please see revised statement 2 in the final quality standard which focuses on the timeliness of the investigations taking place, to improve clarity.</p> <p>Please see statement 7 in the final quality standard which has been revised to improve clarity.</p> <p>Please see statements 4 and 6 in the final quality standard, which cover the care plan and the emergency care plan respectively. With regards to draft statement 9, this has been reworded to improve clarity; please see statement 5 in the final quality standard. Please see revised statement 9 in the final quality standard, which has been revised to be more patient-centred by ensuring that the transition period is agreed with the young person. The definitions have also been revised.</p>

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					<p>The NICE Clinical guideline for the epilepsies cites seven situations where such a referral should take place (also included in the Definitions section of this Quality Statement). However the wording of this Quality Statement only covers three of these differentials. At a risk of overcomplicating this statement, we would like the Quality Standard development group amending the wording of the Statement to encapsulate the other, relevant additional triggers for referral to an epilepsy tertiary care specialist. These are: experiencing, or risk of, unacceptable side-effects from medications, and all children under the age of 2 years.</p> <p>QS5 - While we are aware that some of the information covered in an Emergency Care Plan may be covered by a Care Plan, we believe QS5 and QS6 are both valid Statements for inclusion. Ideally, one Quality Standard would encapsulate both these issues. However because of low rates of compliance for Care Plans, and the potentially high-value impact of an Emergency Care Plan, we agree that it is suitable to include both as Quality Statements.</p> <p>QS6 – For information, the NICE Clinical Guideline for epilepsy states that people should be ‘offered’ a care plan, whereas this indicator talks about the number of people who have a plan.</p> <p>QS8 – In the ‘Description’ of this indicator, it states that reviews should be annual. We ask that the Statement be amended to include this within the text, to read ‘an annual structured review’. We believe this makes the Statement clearer.</p> <p>QS9 – While we strongly support this Statement, we are concerned that the wording is needlessly ambiguous. We believe the Statement could be misinterpreted, leading to a situation where providers believe they are meeting this Statement and patients are not directly treated by a nurse.</p>	

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					<p>By stating "...by a clinical team that provides epilepsy specialist nursing", the Statement is not mandating that a patient will see the nurse themselves, but could see others in the team or a practitioner that exercises similar 'nurse' duties. We do not believe this is the intention of either the Statement or the Quality Standards development group, and so request rewording for clarity. Suggested rewording: "Children with epilepsy are cared for by a clinical team that includes epilepsy specialist nurses."</p> <p>QS10 – We are concerned that the wording for this draft Statement might not meet the needs of the young people requiring support during transition between services. Reading both the Statement and the Measure, it is possible to meet this Statement without ever involving the young person directly in the transition (for example, paediatric and adult services meeting to discuss the transition of a young person, excluding the young person from discussions). We believe the value of transition services is to educate and empower the young person to take control of their condition and their treatment, and ensure a smooth move between different clinical teams. These goals can not be achieved if the transition is an internal health service process only involving the clinical teams.</p> <p>Additionally, we question whether the Definition section of this Statement is overly prescriptive in how this Standard is met ("...a joint clinical action between paediatric and adult services, with at least 2 meetings at a joint consultation..."). We do not know whether this will discourage innovative approaches to transition care.</p>	
73	014	Epilepsy Society	Question 5	Adults	Anecdotally - problems with lack of referral and waiting too long for appointments are the main difficulties hence areas for quality improvement.	Thank you. Please see revised statement 7 in the final quality standard.
74	015	Epilepsy Bereaved	Question 5	Adults	Anecdotally - problems with lack of referral and waiting too long for appointments are the main difficulties hence areas for quality improvement.	Thank you. Please see revised statement 7 in the final quality standard.
75	013	Epilepsy Action	Question 6	Adult	We recommend that two Quality Standards remain separate	Thank you. The topic expert group

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					<p>for adult and childhood epilepsies. This is because we believe people with epilepsy, families and carers, and clinicians may find separate documents more accessible for their specific purposes. We believe two Standards may increase the individual impact of each of the Quality Standards. Reducing this to one amalgamated document could diminish their impact and lead to a compromise (or lack of focus) in care for either adults and/or children if combined.</p> <p>We are also unsure how the Quality Standards programme will evolve. Therefore we believe at this stage it is wise to keep two separate Standards, to keep open all future options for application.</p> <p>Specifically regarding the Quality Standards for children with epilepsy, we believe uptake and compliance will be aided by a separate document. We have received clinical advice that suggests paediatricians may be more open to exploring application of the Standards, if it is specifically for their client base.</p>	discussed this issue and agreed that the standards should remain separate.
76	007	Greater Manchester Neurosciences Network	Question 6	Adults	<p>Separate standards for adults and children Merging the standards would ensure coverage of transition for patients from paediatric to adult services</p>	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate because of concern that the paediatric aspects would be lost if the standards were combined, and an acknowledgement that adult and paediatric services and pathways are commissioned differently. The group considered that a statement on transition in both standards would ensure that this aspect is covered (please see statement 9 in the final quality standard).
77	007	Greater Manchester Neurosciences Network	Question 6	Adults	<p>Separate standards for adults and children Merge the documents but highlight issues that are specific to either group as this may assist commissioners and providers as these tend to be managed separately.</p>	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate because of concern that the paediatric aspects would

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						be lost if the standards were combined, and an acknowledgement that adult and paediatric services and pathways are commissioned differently.
78	008	Sheffield Teaching Hospitals NHS Foundation Trust	Question 6	Adults	We can see no advantage in two documents.	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate because of concern that the paediatric aspects would be lost if the standards were combined, and an acknowledgement that adult and paediatric services and pathways are commissioned differently.
79	014	Epilepsy Society	Question 6	Adults	Perhaps two QS are better than one, as specialists involved and diagnosis (eg imaging protocols) are different. However, the issue of transition is really important and so the wording of Quality Statement 10 may need to be tightened to ensure it fully involves the young person directly in the transition.	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate.
80	015	Epilepsy Bereaved	Question 6	Adults	Perhaps two QS are better than one, as specialists involved and diagnosis (eg imaging protocols) are different. However, the issue of transition is really important and so the wording of Quality Statement 10 may need to be tightened to ensure it fully involves the young person directly in the transition.	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate.
81	016	GlaxoSmithKline UK	Question 6	Adults	Q6- having 2 documents for children and adults seems unnecessary given that only 1 quality standard differs between both documents (Standard 8). Regarding adult standard 8 (specific medical or lifestyle issues), would this also be relevant for children? Currently it isn't addressed for children.	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate because of concern that the paediatric aspects would be lost if the standards were combined, and an acknowledgement that adult and paediatric services and pathways are commissioned differently.
82	013	Epilepsy Action	Question 6	Children	We recommend that two Quality Standards remain separate for adult and childhood epilepsies. This is because we believe people with epilepsy, families and carers, and clinicians may find separate documents more accessible for their specific purposes. We believe two Standards may increase the individual impact of each of the Quality Standards. Reducing this to one amalgamated document	Thank you. The topic expert group discussed this issue and agreed that the standards should remain separate.

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					<p>could diminish their impact and lead to a compromise (or lack of focus) in care for either adults and/or children if combined.</p> <p>We are also unsure how the Quality Standards programme will evolve. Therefore we believe at this stage it is wise to keep two separate Standards, to keep open all future options for application.</p> <p>Specifically regarding the Quality Standards for children with epilepsy, we believe uptake and compliance will be aided by a separate document. We have received clinical advice that suggests paediatricians may be more open to exploring application of the Standards, if it is specifically for their client base.</p>	
87	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 01	Adults	General: Not considered realistic to see a Specialist within this timescale without further investment. Neurology SPR assessment is deliverable within 2 weeks. Statement confusing -Is a diagnosis/misdiagnosis of epilepsy expected on the basis of one seizure	Thank you. Quality standards aim to be aspirational but achievable, and this may involve further investment or changes to existing services. The outcomes listed refer to outcomes which the statement may contribute to, which the topic expert group felt was appropriate. In this case it is considered that rapid access to a specialist would contribute to accurate diagnoses; it is not stipulated how soon this might be achieved (and not intended that it would be achieved on the basis of one seizure).
88	007	Greater Manchester Neurosciences Network	Statement 01	Adults	It is vital to improve access to a specialist to get accurate diagnosis	Thank you.
89	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 01	Adults	Meaning of Outcome measures for QS 1 unclear – what is meant by ‘diagnosis’ ? Is this clinical diagnosis at first consultation, diagnosis after review of investigations, diagnosis at the end of the first year? Who decides what the diagnosis is? What does ‘subsequently’ mean? It is difficult to imagine a quality outcome measure which assesses diagnostic quality which seems to be what this measure is	The outcomes listed refer to those outcomes which the statement may contribute to, and which the topic expert group felt was appropriate.

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					aimed at.	
90	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 01	Adults	It is not always possible to make an accurate diagnosis of a seizure disorder at the first consultation. Therefore the outcome measures (diagnosis of epilepsy subsequently found to be incorrect, diagnosis of a condition that is subsequently found to be epilepsy) are not optimal because it is unclear how long after first consultation this would be sampled.	The outcomes listed refer to outcomes which the statement may contribute to, which the topic expert group felt was appropriate. In this case it is considered that rapid access to a specialist would contribute to accurate diagnoses; it is not stipulated how soon this might be achieved as this would differ on a case by case basis (and not intended that it would be achieved on the basis of one seizure). The methodology for measuring this outcome would be determined locally.
91	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 01	Adults	C) is a more reliable outcome measure than the other two variables which rely on a gold standard 'diagnosis'	Thank you.
92	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 01	Adults	Unclear how the term 'specialist' is to be defined. The description seems to exclude nurse specialists, which may be controversial. The stipulation that a specialist in epilepsy has to be a medical practitioner with at least one session a week devoted to epilepsy is ambiguous – does this mean a clinic in which patients with epilepsy are seen, or a session devoted to patients with epilepsy or a session partly devoted to patients with epilepsy or a session with patients presenting with blackouts which could be epilepsy, etc.	Thank you. The definitions section is used to broadly define or clarify particular terms used in the quality statement and uses the definition from the clinical guideline. Interpretation may depend on local service configuration and it would be inappropriate for the topic expert group to be any more prescriptive.
93	011	Royal College of Nursing	Statement 01	Adults	Could include: "This should (when appropriate) include consultation with an Epilepsy Specialist Nurse".	Please see statement 1 in the final quality standard which has been revised to clarify that the person should be seen by a specialist in the diagnosis and management of the epilepsies.
94	014	Epilepsy Society	Statement 01	Adults	As noted above, what is meant by 'specialists' needs to be defined here.	Please see the definitions section of statement 1 in the final quality standard.
95	015	Epilepsy Bereaved	Statement 01	Adults	As noted above, what is meant by 'specialists' needs to be defined here.	Please see the definitions section of statement 1 in the final quality standard.
96	020	Chesterfield and North Derbyshire Royal Hospital NHS	Statement 01	Adults	Meaning of Outcome measures unclear – what is meant by 'diagnosis' ? Is this clinical diagnosis at first consultation, diagnosis after review of investigations, diagnosis at the end	The outcomes listed refer to those outcomes which the statement may contribute to, and which the topic expert

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		Foundation Trust			of the first year? What does 'subsequently' mean?	group felt was appropriate.
97	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 01	Adults	It is not always possible to make an accurate diagnosis of a seizure disorder at the first consultation. Therefore the outcome measures (diagnosis of epilepsy subsequently found to be incorrect, diagnosis of a condition that is subsequently found to be epilepsy) are not optimal because it is unclear how long after first consultation this would be sampled.	The outcomes listed refer to those outcomes which the statement may contribute to, and which the topic expert group felt was appropriate.
98	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 01	Adults	Unclear how the term 'specialist' is to be defined. The description seems to exclude nurse specialists, which may be controversial. The stipulation that a specialist in epilepsy has to be a medical practitioner with at least one session a week devoted to epilepsy is ambiguous – does this mean a clinic in which patients with epilepsy are seen, or a session devoted to patients with epilepsy or a session partly devoted to patients with epilepsy or a session with patients presenting with blackouts which could be epilepsy, etc.	Thank you. The definitions section is used to broadly define or clarify particular terms used in the quality statement and uses the definition from the clinical guideline. Interpretation may depend on local service configuration and it would be inappropriate for the topic expert group to be any more prescriptive.
99	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 01	Adults	(Perhaps deliberately) this statement does not make any difference between adults of different ages. We have demonstrated that younger people with epilepsy are currently 20 times more likely to be referred to a specialist service than older people. The overwhelming majority of older people with epilepsy is currently not being referred (despite the NICE guidelines). If it is the intention of these quality standards to ensure that adults of all ages get the same care, this should be explicitly stated.	Thank you. The topic expert group considers equality and diversity throughout the development of the quality standards. The statements apply to all people with epilepsy and a positive impact is therefore expected on the equality of access to specialists.
100	001	Alder Hey	Statement 01	Children	Quality Statement 1. At the current time, I would think that very few children/young people with a first unprovoked seizures are seen by a specialist in epilepsy management. I have some doubts as to whether this is necessary. I would not usually arrange any investigations in such children, rather counsel and advise parents what to do if they have another seizure (first aid etc). It could be that locally, a nurse is trained to run such a service, rather than a doctor.	Thank you for your comments. The statement is in line with the underpinning evidence-based recommendations from NICE clinical guideline 137, from which the quality standard is derived.
105	017	Cambridge Community Services NHS Trust	Statement 01	Children	Comment: Agreed that this is gold standard. Feedback suggests that this is often not achievable. Locally, for some patients as an experienced nurse I offer a triage assessment	Thank you for your comments.

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					that aims not to diagnose but at least to ensure first aid and safety measures are in place, support further collection of evidence as well as requesting investigations following discussion with Consultant specialist. Whilst this does not meet the standard, it is an alternative to providing nothing at all within the time frame.	
106	018	Royal College of Paediatrics and Child Health	Statement 01	Children	Perhaps the input of an epilepsy specialist nurse would be better at this point. The visit might be considered unnecessary for the family if they saw the epilepsy specialist doctor before the EEG. If however, an EEG is not considered necessary, then seeing within 2 weeks might be appropriate if parents are willing to come to clinic in that time frame.	Thank you for your comments. The statement is in line with the underpinning evidence-based recommendations from NICE clinical guideline 137, from which the quality standard is derived.
107	018	Royal College of Paediatrics and Child Health	Statement 01	Children	The number of patients that are referred to tertiary care should be included in the outcome measure, as 20-30% of children with epilepsy, broadly speaking would be refractory and need to be seen in a tertiary service.	Outcome measures are stated where the topic expert group felt these were appropriate. The topic expert group considered that this aspect is covered by statement 7 in the final quality standard.
109	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 02	Adults	General: Unrealistic with variation in current service levels to complete the process within 4 weeks	Thank you. Please see statement 2 in the final quality standard which has been revised to improve clarity and focus on the timeliness of the investigations taking place. However, quality standards are intended as being aspirational but achievable in order to improve patient outcomes.
110	007	Greater Manchester Neurosciences Network	Statement 02	Adults	It is vital to improve access to a specialist to get necessary investigation to support accurate diagnosis	Thank you.
111	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 02	Adults	The waiting time to access the relevant investigations is impracticable, providing no opportunity for patient choice of date and time. We suggest a maximum 6 week wait for basic investigations such as MRI, CT, EEG, video EEG telemetry and ECG with additional time for communication. It is unclear if MRI under GA or neuropsychological assessment is included, but these would certainly be very challenging to achieve.	Thank you. Please see statement 2 in the final quality standard which has been revised to improve clarity. The definitions section describes which investigations the statement includes.

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112	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 02	Adults	There is no mention of the provision of equipment for patients to record seizures at home to aid diagnosis, which is a useful tool.	Please see statement 2 in the final quality standard which focuses on the timeliness of investigations. The topic expert group have defined which investigations are included within this timescale, in line with the underpinning evidence-based NICE clinical guideline 137.
113	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 02	Adults	Being “told the results” does not represent quality. Quality is about supporting the patient to understand the implications of the results and the options available. The QS should specify that the patient should be supported in their understanding of the results, a joint role between specialist medical practitioner and an Epilepsy Nurse	Thank you. Please see statement 2 in the final quality standard which has been revised to improve clarity.
114	014	Epilepsy Society	Statement 02	Adults	The focus of this statement is on the time (4 weeks) with no indicator of need. The NASH findings identified problems at A&E in terms of unnecessary investigations - this is an expense which would be better placed in addressing improvements in care.	The topic expert group prioritised areas of care where practice is variable, or where implementation could have a significant impact on patient care and improved outcomes, and agreed to focus on the timeliness of investigations in this statement. However, any investigations should be appropriate and based on the recommendations in the NICE guideline.
115	014	Epilepsy Society	Statement 02	Adults	This section might specifically include that adults in later life should also have access to appropriate tests (listed as a special group in section 1.18 of the clinical guideline).	The statements apply to all people with epilepsy and as such a positive impact is expected on equality of access to services.
116	015	Epilepsy Bereaved	Statement 02	Adults	The focus of this statement is on the time (4 weeks) with no indicator of need. The NASH findings identified problems at A&E in terms of unnecessary investigations - this is an expense which would be better placed in addressing improvements in care.	The topic expert group considered that the period between the suspected seizure occurring and diagnosis can be a particularly anxious time for patients and families, and that the earlier a correct diagnosis is made, the sooner tailored therapy can be initiated, therefore the focus of the statement is timely investigations. However, any investigations should be appropriate and based on the recommendations in the NICE guideline.
117	015	Epilepsy Bereaved	Statement	Adults	This section might specifically include that adults in later life	The statements apply to all people with

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			02		should also have access to appropriate tests (listed as a special group in section 1.18 of the clinical guideline).	epilepsy and as such a positive impact is expected on equality of access to services.
118	016	GlaxoSmithKline UK	Statement 02	Adults	<ol style="list-style-type: none"> 1. Patients should have the results of investigations within 4 weeks of the test being requested- shouldn't this read 'within 4 weeks of the patient having the test'? Many investigations do not happen within 4 weeks. 2. Ensure quality measure emphasises for all tests results to be conveyed to the patient, not just abnormal results. 	Thank you. Please see statement 2 in the final quality standard which has been revised to improve clarity and focus on the timeliness of the investigations taking place.
119	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 02	Adults	Four weeks is an ambitious time frame to request and organise a test, generate a report and communicate the findings to the patient. In many cases patients will not be able to find time to tests requiring trips to the hospital or stays in hospital (such as video-EEG). Consideration should be given to the utility of opting for a timeframe which will only be achieved in a minority of locations and cases	Thank you. Please see statement 2 in the final quality standard which has been revised to improve clarity.
120	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 02	Adults	The framework should be more explicit on whether MRI under general anaesthesia (for instance for patients with LD or anxiety disorders) needs to be provided within the same time frame.	The statements apply across to all people with epilepsy. Please see statement 2 in the final quality standard where the equality and diversity section confirms that the same services and investigations should be offered to adults with learning disabilities as are offered to the general population.
121	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 02	Adults	Would neuropsychological testing be included here?	Please see statement 2 in the final quality standard where the definitions section describes which tests are included within this timeframe.
122	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 02	Adults	The statement does not specify what "told" means – does a letter to the patient's GP qualify, do patients have to be seen, can the result be described in a letter to the patient?	Please see statement 2 in the final quality standard which has been revised to improve clarity.
123	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 02	Adults	Currently some trusts run separate policies for patients on the 16 week pathway and patients in follow-up. It may be helpful to clarify whether this statement only refers to investigations in newly referred patients or patients with epilepsy having tests in relation to their seizure disorder at any time.	Please see statement 2 in the final quality standard which has been revised to improve clarity.
124	001	Alder Hey	Statement	Children	Results within 4 weeks. This is rather optimistic and in some	Please see statement 2 in the final quality

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			02		cases, just not possible as it depends on the exact nature of the investigations being ordered. In an ideal world, an EEG and an MRI (if needed) would be available within this time frame. But other investigations may take longer eg genetic tests etc. Even getting the MRI results back within this time frame may be difficult, as sometimes they need to be discussed with other colleagues before giving results to parents (eg radiologists).	standard which has been revised to improve clarity.
126	010	British Nuclear Medicine Society	Statement 02	Children	See paragraph “definitions”: “Investigations for epilepsy include electroencephalogram (EEG), magnetic resonance imaging (MRI) and blood tests, as appropriate”. I would suggest to add: “For drug resistant epilepsy, in the case the clinical features suggest a focality of the seizures, the MRI is negative, the EEG findings are discordant with the MRI, or the EEG is not localising but the MRI shows a lesion, further evaluation with either positron emission tomography (PET) or ictal single photon emission computerized tomography (SPECT) is recommended.”	Thank you. Please see statement 2 in the final quality standard which has been revised to clarify that it refers to initial investigations only.
127	012	Royal College of General Practitioners	Statement 02	Children	“Being informed of results” alone is inadequate – it needs “explanation of results and management plans” to cover the 40% who do not have diagnosed epilepsies.	Please see statement 2 in the final quality standard which has been revised to improve clarity and focus on the timeliness of the investigations taking place. Any diagnoses that were not epilepsy would fall outside the remit of this quality standard.
128	018	Royal College of Paediatrics and Child Health	Statement 02	Children	Neither quality statement is realistic or required, there will be some cases that are clearly not urgent and will not require urgent investigations or treatment.	The topic expert group considered that the period between the suspected seizure occurring and diagnosis can be a particularly anxious time for patients and families, and that the earlier a correct diagnosis is made, the sooner tailored therapy can be initiated, therefore the focus of the statement is timely investigations.
129	018	Royal College of Paediatrics and Child Health	Statement 02	Children	In the experience of one of our contributors, EEGs are done 3 weeks after referral and it takes a further 3 weeks for the results to come through. This is not in the hand of clinicians in a district general hospital.	Please see statement 2 in the final quality standard which is consistent with the underpinning NICE guidance. Quality Standards aim to be aspirational but achievable.

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130	018	Royal College of Paediatrics and Child Health	Statement 02	Children	The waiting times of EEG and MRI, will make the 4 week target of providing results to family difficult. To achieve this there would need to be expansion of EEG and MRI capacity. 6-8 weeks may be more pragmatic and achievable currently.	Please see statement 2 in the final quality standard which is consistent with the underpinning NICE guidance. Quality Standards aim to be aspirational but achievable. NICE has produced a support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard and patient information to explain to patients and carers what the quality standard means to them, both available from www.nice.org.uk .
132	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 03	Adults	General: Agree	Thank you.
133	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 03	Adults	MRI is not an appropriate investigation for all patients, including those poorly tolerant of the procedure, the very obese, the claustrophobic, those with metal foreign bodies in their heads. In many patients a CT scan is a better option. The quality statement should be revised to reflect this. Whilst the statement is aimed to minimise exposure to ionizing radiation, which is laudable, as drafted might also push patients into being offered MRI under sedation or general anaesthetic rather than CT when the latter may be safer. Patients may refuse investigation, including imaging, so it would be more appropriate to word the statement to patients 'are offered MRI' rather than 'have MRI'.	Thank you. Please see statement 3 in the final quality standard, where the definitions section has been expanded to acknowledge this point.
134	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 03	Adults	Patients should have a choice and be involved in the decision, this needs acknowledgement.	Patient choice and shared decision-making are important themes for all NHS care. The NICE quality standard on patient experience in adult NHS services (available from www.nice.org.uk) covers this in more detail.
135	014	Epilepsy Society	Statement 03	Adults	This statement should say 'as imaging of preference'. Although MRI is the preferred method of neuro imaging,	Please see statement 3 in the final quality standard, where the definitions section has

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					there might be times when CT is the only available option. The statement also does not include anything about when imaging is indicated.	been expanded to acknowledge this point, and include criteria for neuroimaging.
136	015	Epilepsy Bereaved	Statement 03	Adults	This statement should say 'as imaging of preference'. Although MRI is the preferred method of neuro imaging, there might be times when CT is the only available option. The statement also does not include anything about when imaging is indicated.	Please see statement 3 in the final quality standard, where the definitions section has been expanded to acknowledge this point, and include criteria for neuroimaging.
137	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 03	Adults	MRI is not an appropriate investigation for all patients, including those poorly tolerant of the procedure, the very obese, the claustrophobic, those with metal foreign bodies in their heads, or those acutely unwell and presenting with seizures. In some cases a risk benefit evaluation (for instance in patients with LD and epilepsy) may conclude that it is less distressing and risky for the patient to have a CT scan (despite the lower pick up of epileptogenic abnormalities) than an MRI scan under GA. It should also be made clear that patients should have a say in this – they may refuse investigation, including imaging.	Please see statement 3 in the final quality standard, where the definitions section has been expanded to acknowledge this point, and include criteria for neuroimaging.
139	012	Royal College of General Practitioners	Statement 03	Children	Some thought also needs to be given to the increasing ability of GPs being able to order MRI scans where they liaise with the radiologist. In future the GP may be able to order these tests while awaiting paediatric specialist advice.	Thank you. The definitions section is used to broadly define or clarify particular terms used in the quality statement. Interpretation may depend on local service configuration and it would be inappropriate for the topic expert group to be any more prescriptive. The statement is not considered to preclude different methods of ordering the scans.
140	018	Royal College of Paediatrics and Child Health	Statement 03	Children	General anaesthetic for MRI scans is not available in many hospitals sedation is often provided instead.	Please see the definitions section of statement 3 in the final quality standard which includes mention of sedation.
141	018	Royal College of Paediatrics and Child Health	Statement 03	Children	All MRIs should be carried out with standard epilepsy protocol and reported by a neuroradiologist	Thank you for your comment.
143	013	Epilepsy Action	Statement 04	Adult	We agree that a referral to a tertiary care specialist is not being made quickly for people with uncontrolled seizures, diagnostic uncertainty or treatment failure. The NICE Clinical Guideline states that referrals for refractory epilepsy should	Thank you. Please see revised statement 7 in the final quality standard. The definitions section sets out the circumstances in which a referral to tertiary care is required.

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					be made 'soon', which is then further defined as 4 weeks. However we also believe that establishing a patient's right to a tertiary care referral is also an area for Quality Improvement. We believe this QS should emphasise both the situation and circumstances whereby a referral should be made, and the time by which the referral process has to be 'completed', We believe it would be wrong for the Quality Standard to prioritise one of these important principles over the other, and we believe it is important that neither of these principles of good patient care should be compromised.	
144	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 04	Adults	General: Unrealistic within current service provision. Some services act as both secondary and tertiary centres in their respective areas	Please see revised statement 7 in the final quality standard which is consistent with the underpinning NICE guidance. Quality Standards aim to be aspirational but achievable; this may require the provision of services to change in order to improve patient care.
145	007	Greater Manchester Neurosciences Network	Statement 04	Adults	Access to a tertiary care specialist within 4 weeks of referral may be unrealistic leading to patients being seen by a less experienced medical practitioner – better to wait and see a consultant with the right skills and experience	Please see revised statement 7 in the final quality standard which is consistent with the underpinning NICE guidance and includes a definition on the level of skills and experience needed. Quality Standards aim to be aspirational but achievable.
146	007	Greater Manchester Neurosciences Network	Statement 04	Adults	Transfer of care between different levels of specialist care needs to be clearer.	Interpretation may depend on local service configuration and it would be inappropriate for the topic expert group to be any more prescriptive. Please see revised statement 7 in the final quality standard, where the focus is timely access to the right level of expertise.
147	007	Greater Manchester Neurosciences Network	Statement 04	Adults	There may not be any clinical value in having patients seen in tertiary services within 4 week other than obviously patient satisfaction	Please see revised statement 7 in the final quality standard, which is consistent with the underpinning NICE guidance. Appropriate access to tertiary services is important in terms of diagnostic certainty, specialist drug advice etc, and the topic

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						expert group considered that timely access is important not only in terms of patient satisfaction, but also other outcomes such as timely diagnosis and initiation of treatment (so prevention of further seizures).
148	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 04	Adults	The distinction between ‘secondary’ and ‘tertiary’ care specialists is unclear and unhelpful – instead the services and competences offered by staff at the centre should be defined, e.g. access to inpatient video telemetry for diagnosis. Therefore instead of a statement about Referral to Tertiary Care, the QS should state ‘referral to a centre with expertise in complex epilepsy and facilities for 3T MRI, EEG video telemetry, epilepsy surgery etc....’.	Thank you. Please see revised statement 7 in the final quality standard, where the focus is timely access to the right level of expertise.
149	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 04	Adults	Patient satisfaction is a weak indicator of quality of service, and is likely insensitive and unspecific to the service (i.e. can be influenced by unrelated issues such as accessibility, clinic wait and referral patterns.) Patients with non-epileptic seizures may initially express dissatisfaction independent of the quality of the diagnostic service despite high level of clinical expertise.	Thank you for your comment. The topic expert group reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard. Patients with non-epileptic seizures are outside the remit of this quality standard.
150	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 04	Adults	There is no mention of provision of adequate psychotherapeutic care for patients with seizures. This is an important quality standard as a third of patients have significant psychiatric morbidity.	Quality standards are derived from evidence-based recommendations from national accredited guidance, i.e. the NICE clinical guideline 137, and it is anticipated that the statement will contribute to ensuring the person with epilepsy receives the support they require.
151	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 04	Adults	The key element in QS4 is that patients who are dissatisfied with their epilepsy control or adverse effects of medication should have the opportunity to be referred to an expert centre with comprehensive diagnostic facilities.	Thank you. Please see revised statement 7 in the final quality standard which aims to address this point.
152	014	Epilepsy Society	Statement 04	Adults	The focus here is on uncontrolled epilepsy but there is no definition of this. We would suggest a definition of ‘uncontrolled epilepsy’ includes those with known refractory epilepsy, but also include people whose seizure frequency	Please see statement 7 in the final quality standard, which has been revised to improve clarity.

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					changes as identified through annual review and also people with nocturnal generalised-tonic seizures that are not seizure-free and who are at risk of SUDEP.	
153	014	Epilepsy Society	Statement 04	Adults	Treatment failure needs to be defined earlier on than in definitions section. We would also like to see the inclusion of measure ‘% of people with known epilepsy attending A&E discharged with an emergency plan’ as a measure for this standard.	The definitions section is used to broadly define or clarify particular terms used in the quality statement. The topic expert group reviewed all measures in the draft quality standard and have prioritised and refined those they considered most important to measure the quality statements in the final standard.
154	015	Epilepsy Bereaved	Statement 04	Adults	The focus here is on uncontrolled epilepsy but there is no definition of this. We would suggest a definition of ‘uncontrolled epilepsy’ includes those with known refractory epilepsy, but also include people whose seizure frequency changes as identified through annual review and also people with nocturnal generalised-tonic seizures that are not seizure-free and who are at risk of SUDEP.	Please see statement 7 in the final quality standard, which has been revised to improve clarity. A definition is provided of the people with epilepsy who would “meet the criteria” for referral to a tertiary care specialist.
155	015	Epilepsy Bereaved	Statement 04	Adults	Treatment failure needs to be defined earlier on than in definitions section. We would also like to see the inclusion of measure ‘% of people with known epilepsy attending A&E discharged with an emergency plan’ as a measure for this standard.	The definitions section is used to broadly define or clarify particular terms used in the statement. We consider emergency care plans to be covered by statement 6 in the final quality standard.
156	016	GlaxoSmithKline UK	Statement 04	Adults	Q4 – diagnostic uncertainty is an area requiring quality improvement. The rate of incorrect referrals to epileptologists/neurologists is a problem. Non-epileptic attack disorder and syncope often result in incorrect referrals. Greater triage is required	Thank you. We believe revised statement 7 in the final quality standard addresses this.
157	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 04	Adults	The distinction between ‘secondary’ and ‘tertiary’ care specialists is obscure and unhelpful – instead the services and competences offered by staff at the centre should be defined, e.g. access to inpatient video telemetry for diagnosis.	Thank you. Please see revised statement 7 in the final quality standard, where the focus is timely access to the right level of expertise.
158	020	Chesterfield and North Derbyshire Royal Hospital NHS	Statement 04	Adults	What about patients requiring specialist advice but not covered by the proposed triggers for referral (eg. patients with controlled epilepsy but facing decisions about treatment	Thank you. We believe revised statement 8 in the final quality standard addresses this issue.

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		Foundation Trust			of other conditions, patients planning pregnancy)?	
159	004	UCB Pharma Ltd	Statement 04	Children	<p><u>Comment about quality statement 4. (Define what a tertiary service is under the definitions section)</u></p> <p>Adults with uncontrolled seizures, diagnostic uncertainty or treatment failure are referred to a tertiary care specialist and seen within 4 weeks of referral. We propose the issue is that patients should be seen by an appropriate specialist with training in the epilepsies therefore it is important to define within the quality standard what a tertiary service is as described in the NICE guideline CG137: <i>A tertiary epilepsy specialist is an adult or paediatric neurologist who devotes the majority of their working time to epilepsy, is working in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review</i></p>	Please see revised statement 7 in the final quality standard which now includes this definition.
161	013	Epilepsy Action	Statement 04	Children	<p>We agree that a referral to a tertiary care specialist is not being made quickly for people with uncontrolled seizures, diagnostic uncertainty or treatment failure. The NICE Clinical Guideline states that referrals for refractory epilepsy should be made 'soon', which is then further defined as 4 weeks. However we also believe that establishing a patient's right to a tertiary care referral is also an area for Quality Improvement. We believe this Quality Standard should emphasise both the situation and circumstances whereby a referral should be made, and the time by which the referral process has to be 'completed',</p> <p>We believe it would be wrong for the Quality Standard to prioritise one of these important principles over the other, and we believe it is important that neither of these principles of good patient care should be compromised.</p>	Thank you. Please see revised statement 7 in the final quality standard. The definitions section sets out the circumstances in which a referral to tertiary care is required.
162	017	Cambridge Community Services NHS Trust	Statement 04	Children	<p>Comment: Of the two points, there needs to be a timely referral to a tertiary care-if there is more than a 4 week wait, there should be a way of escalating concern where required</p>	Thank you. Please see revised statement 7 in the final quality standard.
163	018	Royal College of Paediatrics and Child Health	Statement 04	Children	<p>Is this achievable? The waiting list for paediatric neurology in many areas appears to be very much longer than this.</p>	Quality Standards aim to be aspirational but achievable, and revised statement 7 in the final quality standard is consistent with the underpinning NICE guidance. However, it is

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						recognised that some standards may be more challenging than others and may require changes in services in order to achieve them.
164	018	Royal College of Paediatrics and Child Health	Statement 04	Children	Neither quality statement is realistic or required, there will be some cases that are clearly not urgent and will not require urgent investigations or treatment.	The topic expert group considered that tertiary referrals were vital for a number of reasons, and that timely and appropriate access was a key area for quality improvement.
165	018	Royal College of Paediatrics and Child Health	Statement 04	Children	In the experience of one of our contributors, tertiary neurology clinics in their area take place once every 2 months. As such, the 4 week timescale might mean families travelling further unnecessarily.	Quality Standards aim to be aspirational but achievable, and revised statement 7 in the final quality standard is consistent with the underpinning NICE guidance. However, it is recognised that some standards may be more challenging than others and may require changes in services in order to achieve them.
166	018	Royal College of Paediatrics and Child Health	Statement 04	Children	Appropriate referral to tertiary service should be better emphasised, with reducing waiting time to see tertiary expert being secondary. Our Epilepsy 12 audit has demonstrated that not all children who should see a tertiary care epilepsy specialist are doing so and therefore the emphasis should be on appropriate referral.	Please see revised statement 7 in the final quality standard. The definitions have been extended to set out the criteria for referral to tertiary care.
167	018	Royal College of Paediatrics and Child Health	Statement 04	Children	The outcome (of tertiary care) evaluation should include revision of diagnosis, further diagnostic investigations and new treatment options considered as suitable in each case, not just patient satisfaction.	Thank you for your suggestions. Outcome measures are stated where the topic expert group felt these were appropriate, measurable and specifically attributable to the action stated in the statement. In addition to this, each statement is now followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to.
168	018	Royal College of Paediatrics and Child Health	Statement 04	Children	Tertiary care epilepsy specialists currently have waiting times longer than 4 weeks. Significant additional resources (consultant numbers etc.) will be needed to achieve this.	Please see statement 7 in the final quality standard which is consistent with the underpinning NICE guidance. Quality

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						Standards aim to be aspirational but achievable. However, it is recognised that some standards may be more challenging than others and may require changes in services in order to achieve them. NICE has produced a support document to help commissioners and others consider the commissioning implications and potential resource impact of this quality standard and patient information to explain to patients and carers what the quality standard means to them, both available from www.nice.org.uk .
170	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 05	Adults	General: Agree	Thank you.
171	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 05	Adults	This concentrates on hospital and emergency care. A key issue in avoiding prolonged or repeated care is prompt and adequate access to urgent advice and rescue medication. Possible quality standards should include: That the patient can obtain all antiepileptic medication from a single pharmacist of their choice; that prescriptions should be supplied without the necessity of the patient reminding or prompting the practice; that the patient or carer has access to patient-specific advice (e.g. from a specialist nurse) on a daily basis; and that special adjustments are made for patients with learning disabilities or difficulties using transportation to facilitate delivery of antiepileptic medications	Thank you. The definitions section is used to broadly define or clarify particular terms used in the quality statement. Interpretation may depend on local service configuration and it would be inappropriate for the topic expert group to be any more prescriptive.
172	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 05	Adults	There should be a QS concerning provision for training of staff and carers for administration of emergency medication.	It is recognised that appropriate training is a generic issue that underpins all quality standards. Please see section 2 (overview) for specific reference to this.
173	008	Sheffield Teaching Hospitals NHS	Statement 05	Adults	A useful outcome measure would be a record of repeat attendances at A&E where seizures were terminated by	Thank you for your suggestion. Outcome measures are stated where the topic expert

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		Foundation Trust			administration of a single antiepileptic drug (e.g. midazolam) which could have been delivered in the home.	group felt these were appropriate, measureable and specifically attributable to the action stated in the statement. In addition to this, each statement is now followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to.
174	014	Epilepsy Society	Statement 05	Adults	The point about training and support for family and carers is really important, and should be a measurable outcome for this standard not just included in the definitions.	Thank you for your suggestion. Outcome measures are stated where the topic expert group felt these were appropriate, measureable and specifically attributable to the action stated in the statement. In addition to this, each statement is now followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to. The topic expert group felt that the focus of the specific outcomes referenced should be the person with epilepsy.
175	015	Epilepsy Bereaved	Statement 05	Adults	The point about training and support for family and carers is really important, and should be a measurable outcome for this standard not just included in the definitions.	Thank you for your suggestion. Outcome measures are stated where the topic expert group felt these were appropriate, measureable and specifically attributable to the action stated in the statement. In addition to this, each statement is now followed by a rationale section which provides a brief explanation for why the statement is important with some reference to the outcomes that the action referred to in the statement has a potential causal link to. The topic expert group felt that the focus of the specific outcomes referenced should be the person with epilepsy.

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176	016	GlaxoSmithKline UK	Statement 05	Adults	Standard 5- all patients with epilepsy should have a personalised written emergency care plan (not just those with a history of prolonged or repeated seizures)	We consider care plans for all people with epilepsy to be covered by statement 4 in the final quality standard.
177	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 05	Adults	This concentrates on hospital and emergency care. A key issue in avoiding prolonged or repeated care is prompt and adequate access to urgent advice and rescue medication. There should be an indicator that the patient can obtain all antiepileptic medication from a single pharmacist of their choice, that prescriptions should be supplied without the necessity of the patient reminding or prompting the practice, that the patient or carer has access to patient-specific advice on a daily basis (for instance from epilepsy specialist nurses), and that special adjustments are made for patients with learning disabilities or difficulties using transportation to facilitate delivery of antiepileptic medications.	Thank you. The definitions section is used to broadly define or clarify particular terms used in the quality statement. Interpretation may depend on local service configuration and it would be inappropriate for the topic expert group to be any more prescriptive.
179	017	Cambridge Community Services NHS Trust	Statement 05	Children	Comment: The measure should state that a review date is on the emergency plan and be clear what treatments/management are required in the community and what requires transfer to acute services	Please see statement 6 in the final quality standard, where the definitions section has been extended to this effect.
180	018	Royal College of Paediatrics and Child Health	Statement 05	Children	Rather than simply assess whether a plan exists, a better outcome would be to measure the percentage where the plan was available in the event of an emergency and also the percentage where the plan was followed.	The topic expert group stated outcome measures where they felt they were appropriate, and considered that these issues were covered by the outcome measures included against this statement.
181	018	Royal College of Paediatrics and Child Health	Statement 05	Children	Provision of individualised care and emergency care plans are very important. However, this is not happening even in tertiary centres. The drug management plan in the clinic letters are often the only source of information for patients.	Thank you. The topic expert group prioritised areas of care for quality improvement, where practice is variable or where implementation could have a significant impact on patient care and this is such an area.
183	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 06	Adults	General: Agree	Thank you. This was noted by the TEG.
184	007	Greater Manchester	Statement	Adults	Emphasis on care planning should be increased	Thank you for your comment. There is a

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		Neurosciences Network	06			statement on the existence of a care plan that is agreed and comprehensive.
185	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 06	Adults	No point in having a care plan unless it's up to date and can be reviewed by a specialist when the need arises. The provision of a Epilepsy nurse specialist telephone helpline where the plan can be reviewed and revised which has close working communication links with the medical specialist is vital and should be part of the QS	Thank you for your comment and suggestion. The TEG recognised the need for the care plan being reviewed and have added reference to this in the supporting information for statement 4 in the final quality standard for adults.
186	011	Royal College of Nursing	Statement 06	Adults	Could include "and an annual review undertaken by an Epilepsy Specialist Nurse".	Thank you for your comment. Reference has been made in statement 4 of the final quality standard for adults for at least an annual review of a person's care plan. The TEG did not state specifically that this should be done by an ESN as different care professionals could do this.
187	014	Epilepsy Society	Statement 06	Adults	The word 'comprehensive' is ambiguous – care plans can vary widely – it would be good if the definition was about a care plan which includes a risk assessment (safety and quality of life measures). A risk assessment is a central element of a high quality care plan.	Thank you for your comment. Please see the definitions section for statement 4 in the final quality standard for clarification concerning the definition of comprehensive care plan.
188	014	Epilepsy Society	Statement 06	Adults	Although patient satisfaction is important, there are also outcomes around individuals being able to effectively manage their epilepsy, which goes further than just measuring involvement in their care. There might also be an outcome about being effectively timely and effective communication with patients (e.g. within primary and secondary care, any appropriate links to social care)	Thank you for your comment. The TEG recognise these areas as important outcomes. However, they felt that there would be some difficulty in measuring these either due to data collection being difficult or because some of the outcomes are beyond the control of care professionals. They have therefore not been included in the standard.
189	015	Epilepsy Bereaved	Statement 06	Adults	The word 'comprehensive' is ambiguous – care plans can vary widely – it would be good if the definition was about a care plan which includes a risk assessment (safety and quality of life measures). A risk assessment is a central element of a high quality care plan.	Thank you for your comment. Please see the definitions section for statement 4 in the final quality standard for clarification concerning the definition of comprehensive care plan.
190	015	Epilepsy Bereaved	Statement 06	Adults	Although patient satisfaction is important, there are also outcomes around individuals being able to effectively manage their epilepsy, which goes further than just measuring involvement in their care. There might also be an	Thank you for your comment. The TEG recognise these areas as important outcomes. However, they felt that there would be some difficulty in measuring these

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					outcome about being effectively timely and effective communication with patients (e.g. within primary and secondary care, any appropriate links to social care)	either due to data collection being difficult or because some of the outcomes are beyond the control of care professionals. They have therefore not included them in the standard
191	004	UCB Pharma Ltd	Statement 06	adults	<p><u>Quality Statement 6 (stipulate regularity of review of care plan and draft content)</u></p> <p>Adults with epilepsy have an agreed, comprehensive, personalised written epilepsy care plan. We propose that it is important that there is annual review of this care plan and also that the content of the care plan is stipulated within the quality standard. We would therefore propose that the quality statement reads: Adults with epilepsy have an agreed, comprehensive, personalised written epilepsy care plan that is reviewed annually with a specialist in the management of the epilepsies. The care plan content should be stipulated within the definitions section.</p>	Thank you for your comment. The TEG wanted to ensure that the statement focused on the existence of the care plan as the primary concept for the statement. Please see the definition section for statement 4 in the final quality standard for adults that includes reference to an annual review.
193	012	Royal College of General Practitioners	Statement 06	Children	It needs to be explained for whom the care plan exists – the parents and carers or the child or young person themselves?	Thank you for your comment. The care plan is concerned with the care provided to the child and young person. The provision of care will involve information and advice for the parents and carers, but should be intended for the child or young person primarily. It is envisaged that the care plan for a child or young person would be agreed with the family as appropriate, and depending on the age/capacity of the child. The definition section stipulates that a care plan should be discussed and agreed between the child or young person with epilepsy, their parents and/or carers and their primary and secondary health and social care professionals.
194	012	Royal College of General Practitioners	Statement 06	Children	The appropriate dose of medication is so important and varies throughout childhood and adolescence and depends on the GP's co-operation – perhaps some mention should	Thank you for your comment. Please see statement 4 in the final quality standards. The definition section provides list of the

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					be made particularly of this. The care plan seems too narrow - perhaps some link with the information section – support dogs, support agencies, disability aids and so on.	areas that should be considered.
195	017	Cambridge Community Services NHS Trust	Statement 06	Children	Comment: the care plan should identify a review date. In addition, some brief guidance should include a definition of 'comprehensive'	Thank you for your comment. Please see the definition for statement 4 in the final quality standard that provides a definition of comprehensive and includes reference to a minimum annual review.
196	017	Cambridge Community Services NHS Trust	Statement 06	Children	Area of care to consider-the minimum training requirements to carers other than parents, particularly staff giving rescue medication. If there is not appropriate training for different staff, even the best care plan cannot support a child or young person's needs.	Thank you for your comment. Statement 6 in the final quality standard makes references to supporting parents and carers to manage emergency care plans in cases of prolonged or repeated seizures.
197	018	Royal College of Paediatrics and Child Health	Statement 06	Children	For those CYP with complex health care needs, the epilepsy may be part of a range of other health care needs, which also must be addressed in any written health care plan, including any emergency health care plans. Epilepsy is of course very important, but it is also important to ensure there are robust plans for other aspects of health care for those with complex disabilities and that the epilepsy plan does not overshadow these needs. The plan should be shared with schools and training needs to be provided for school staff when appropriate.	Thank you for your comments. The TEG agreed that any care plan should be broad enough to take into account any relevant issues that should be considered when providing care for children or young people with epilepsy.
198	018	Royal College of Paediatrics and Child Health	Statement 06	Children	Provision of individualised care and emergency care plans are very important. However, this is not happening even in tertiary centres. The drug management plan in the clinic letters are often the only source of information for patients.	Thank you for your comment. Both of these issues are included in the quality standard, please see statements 4 and 6 in the final standard respectively.
200	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 07	Adults	General: Agree	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan.
201	007	Greater Manchester Neurosciences Network	Statement 07	Adults	Access to information is very important to patients and families	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a

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ID	SH ID	Stakeholder	Statement No	QS	Comments Please insert each new comment in a new row.	Response Please respond to each comment
						comprehensive care plan.
202	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 07	Adults	This statement is vague. It could be argued that it is met simply by GP practices existing and signposting patients to information providers at the patient's request. The statement could be made more specific by referring to particular materials (such as leaflets, helplines or websites). Advice is only meaningful if it is individualised. Should healthcare providers be pro-active in providing written information materials or making explicit referrals to specific online information resources? Should healthcare providers provide evidence of active collaboration with information providers (such as epilepsy charity groups or helplines or epilepsy nursing services)? All patients newly diagnosed with epilepsy should be informed explicitly about the range of information resources available including national patient organisations. Patients with an existing diagnosis of epilepsy should be reminded at regular intervals (to ensure they know where to access information about work, driving, sports, pregnancy, diet, travel, co-medications, contraception...).	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan which covers some of the issues you raise.
203	014	Epilepsy Society	Statement 07	Adults	This statement should be more comprehensive than safety information alone and should cover lifestyle issues such as work, driving, and leisure (in addition to the lifestyle points covered in Quality Statement 8). Additionally something might be included around individualised safety information around risk. As Quality Statement 7 is the only standard that references information provision, we would like to see reference included for families affected by SUDEP and other seizure-related mortality. NICE clinical guidelines support the need for care pathways to address after death care.	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan.
204	014	Epilepsy Society	Statement 07	Adults	It would be helpful if signposting charities and other sources of information were included as part of the quality measure. We note that compliance is left to local level. Would it be possible for commissioners to think of information provision as something where 100% performance is expected, because it is such a cost effective measure and would sign post people with epilepsy to resources outside of the NHS.	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan. Outcome measures have also been drafted to support this statement.

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ID	SH ID	Stakeholder	Statement No	QS	Comments Please insert each new comment in a new row.	Response Please respond to each comment
					Another important outcome measure for this statement would be ‘% presenting to A &E discharged with safety information and follow-up.’	
205	015	Epilepsy Bereaved	Statement 07	Adults	<p>This statement should be more comprehensive than safety information alone and should cover lifestyle issues such as work, driving, and leisure (in addition to the lifestyle points covered in Quality Statement 8). Additionally something might be included around individualised safety information around risk.</p> <p>As Quality Statement 7 is the only standard that references information provision, we would like to see reference included for families affected by SUDEP and other seizure-related mortality. NICE clinical guidelines support the need for care pathways to address after death care.</p>	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan.
206	015	Epilepsy Bereaved	Statement 07	Adults	<p>It would be helpful if signposting charities and other sources of information were included as part of the quality measure. We note that compliance is left to local level. Would it be possible for commissioners to think of information provision as something where 100% performance is expected, because it is such a cost effective measure and would sign post people with epilepsy to resources outside of the NHS. Another important outcome measure for this statement would be ‘% presenting to A &E discharged with safety information and follow-up.’</p>	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan. Outcome measures have also been drafted to support this statement.
207	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 07	Adults	<p>This statement is very vague. It could be argued that it is met simply by GP practices existing and signposting patients to information providers at the patient’s request. The statement could be made more specific by referring to particular materials (such as leaflets, helplines or websites). Advice is only meaningful if it is individualised. Should healthcare providers be pro-active in providing written information materials or making explicit referrals to specific online information resources? Should healthcare providers provide evidence of active collaboration with information providers (such as epilepsy charity groups or helplines or epilepsy nursing services)? All patients newly diagnosed with epilepsy should be informed explicitly about the range</p>	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan, which covers some of the issues you raise.

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ID	SH ID	Stakeholder	Statement No	QS	Comments Please insert each new comment in a new row.	Response Please respond to each comment
					of information resources available including national patient organisations. Patients with an existing diagnosis of epilepsy should be reminded at regular intervals (to ensure they know where to access information about work, driving, sports, pregnancy, diet, travel, comedications, contraception...).	
208	004	UCB Pharma Ltd	Statement 07	Children	<p><u>Quality Statement 7 (Define content of information checklist, with focus not only on safety information)</u></p> <p>Adults with epilepsy have on-going access to safety information about their epilepsy syndrome, seizure type (s) and treatment. We propose that the information is not solely 'safety' based but is the right information to allow for patients to be fully informed and supported in managing their condition. We would therefore propose that the quality statement reads: Adults with epilepsy have on-going access to up to date information about their epilepsy syndrome, seizure type (s) and treatment, including relevant safety information. We also propose within the definitions section that it is stipulated what information and in what format is made available to the patient. An example would be as defined in the SIGN guideline DIAGNOSIS AND MANAGEMENT OF EPILEPSY IN ADULTS Page 32 part 6.1.1 EXAMPLE INFORMATION CHECKLIST http://www.sign.ac.uk/pdf/sign70.pdf</p>	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan.
210	012	Royal College of General Practitioners	Statement 07	Children	Appropriate adjustment for understanding and developmental needs (for example through Medikidz approach) could be mentioned to clarify this.	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan.
211	018	Royal College of Paediatrics and Child Health	Statement 07	Children	Having a SUDEP discussion should be a mandatory part of information given to CYP with epilepsy and their parents	Thank you for your comment. The content of this statement has now been incorporated into statement 4 in the final quality standard concerning a comprehensive care plan.
212	003	Nottinghamshire Health Care NHS Trust in partnership	Statement 08	Adults	General: Agree	Thank you.

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		with Nottingham University Hospitals Trust				
213	007	Greater Manchester Neurosciences Network	Statement 08	Adults	For some patients review could be undertaken by ESNs based with primary or community services rather than secondary care services	Thank you for your comment. The wording of the statement has been amended slightly and refers to specialist services. This could include a community based ESN for example.
214	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 08	Adults	It is unclear why patients with epilepsy and medical or lifestyle issues have to be referred to a medical practitioner rather than an epilepsy specialist nurse, who could probably provide a better service.	Thank you for your comment. The wording of the statement has been amended slightly and refers to specialist services. This could include a community based ESN for example.
215	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 08	Adults	The equality measures here will be hard to measure, as the definition of medical and lifestyle issues will be problematic	Thank you for your comment. We have provided some examples of the type of issues that this includes. This is not an exhaustive list and the main focus of the statement is around accessing specialist support.
216	014	Epilepsy Society	Statement 08	Adults	Could the wording show that this can be at any time or repeatedly? For example, 'at any such time.'	Thank you for your comment. This is implied in the wording of the statement and the supporting information.
217	015	Epilepsy Bereaved	Statement 08	Adults	Could the wording show that this can be at any time or repeatedly? For example, 'at any such time.'	Thank you for your comment. This is implied in the wording of the statement and the supporting information.
218	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 08	Adults	It is unclear why patients with epilepsy and medical or lifestyle issues have to be referred to a medical practitioner rather than an epilepsy specialist nurse.	Thank you for your comment. The wording of the statement has been amended slightly and refers to specialist services. This could include a community based ESN for example.
219	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 08	Adults	It should be made explicit that this sort of advice could be provided by epilepsy specialist nurses (with a definition of what this is).	Thank you for your comment. The wording of the statement has been amended slightly and refers to specialist services. This could include an ESN.
220	004	UCB Pharma Ltd	Statement 08	Adults	<u>Quality Statement 8 (Define 'well controlled')</u> Adults with well-controlled epilepsy are referred to secondary care if they have specific medical or lifestyle	Thank you for your comment. Please see statement 8 in the final quality standard. The wording has been amended and there

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					<p>issues that require review by a specialist in the management of the epilepsies. We propose that the term 'well-controlled' should be replaced by 'seizure free' within the quality statement. We would therefore propose that the quality statement reads: Adults with epilepsy who are seizure free are referred to a specialist in the management of the epilepsies if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p> <p>Within the definitions it states that epilepsy that is 'well controlled' in adults can usually be managed within primary care. We propose that the term well-controlled is open to misinterpretation and may lead to variability of care across the country dependant on peoples definition of 'well-controlled', patients who are not seizure free should not be managed within primary care, leaving this statement open may lead to patients being kept in primary care with poor control un aware that seizure freedom could be a potential goal.</p>	is no longer reference to well controlled or seizure free epilepsy as this caused some unintended confusion during consultation.
221	018	Royal College of Paediatrics and Child Health	Statement 08	Children	For those with complex disabilities that include epilepsy the regular structure must also address the individual's holistic needs, not just the epilepsy. These draft standards do not state where this review should take place which is entirely correct.	Thank you for your comment. The definitions section for the review does cover a wide range of potential areas that the review should cover. The TEG noted your comment about not being prescriptive about the place for the review.
223	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 09	Adults	General: Agree	Thank you for your comment
224	007	Greater Manchester Neurosciences Network	Statement 09	Adults	Involvement of ESNs is crucial to improving patient care	Thank you for your comment
225	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 09	Adults	The term epilepsy specialist nurse may need to be defined more clearly, i.e. a nurse with specialist training who spends at least 50% of clinical time in epilepsy.	Thank you for your comment. The TEG have reviewed and amended the definition.

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226	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 09	Adults	Definition of a “clinical team” is required (a commissioning group? a GP practice? a group of hospital consultants?).	Thank you for your comment. Please see statement 5 in the final quality standard where the wording has been amended and no longer refers to a clinical team.
227	016	GlaxoSmithKline UK	Statement 09	Adults	<ol style="list-style-type: none"> 1. This seems to contradict section 8 above which states that well-controlled epilepsy in adults can usually be managed in primary care- how will these patients access an epilepsy nurse, who are in the hospital setup? 2. Should there also be a quality measure for the number of epilepsy patients per epilepsy specialist nurse in each locality? With it capped at a certain number? 	Thank you for your comment. Please see statement 5 in the final quality standard as the wording has been amended to aid clarification. With regard to recommending a ESN to patient ratio, there is not currently an evidence based up-to-date ratio that can be published.
228	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 09	Adults	This is a hugely ambitious statement likely to encourage commissioners to create “pseudoservices”. At present the vast majority of people with epilepsy in the UK have no access to an epilepsy specialist nurse. This statement needs to define clearly what a “clinical team” is (a commissioning group? a GP practice? a group of hospital consultants?) and what an “epilepsy specialist nurse” is (how much training, what kind of training, how much time dedicated to work with epilepsy).	Thank you for your comment. Please see statement 5 in the final quality standard where the wording has been amended and no longer refers to a clinical team. An ESN is defined in the definition section for the statement.
230	011	Royal College of Nursing	Statement 09	Children	<p>This should be access to a children’s epilepsy nurse specialist.</p> <p>The recent 2012 national audit highlighted that 46% of children/young people did not have access to a children’s epilepsy nurse specialist. Yet the audit in relation to sudden unexpected deaths in 2002 noted that this was key in providing specialist advice and supporting families and children to manage their condition.</p>	Thank you for your comment. The definition of an ESN in the quality standard for children and young people makes reference to this being a children’s ESN.
233	003	Nottinghamshire Health Care NHS Trust in partnership with Nottingham University Hospitals Trust	Statement 10	Adults	General: Agree	Thank you for your comment.
234	008	Sheffield Teaching Hospitals NHS	Statement 10	Adults	In Sheffield we have found no advantage in more than one joint consultation of the adult and child epilepsy teams	Thank you for your comment. Please see statement 9 in the final quality standard.

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		Foundation Trust			during the transition period. The evidence that at least 2 are needed should be stated or the stipulation changed to 'at least one joint meeting'.	The definition has been amended to at least a single joint meeting.
235	008	Sheffield Teaching Hospitals NHS Foundation Trust	Statement 10	Adults	The current statement is too prescriptive, as the benefit of concurrent care by two consultants introduces risks (for instance in terms of emergency care provision). Transition can be achieved well by epilepsy specialist nurses (paediatric and adult) having joint appointments.	Thank you for your comment. Please see statement 9 in the final quality standard. The definition has been amended and is now less prescriptive.
236	011	Royal College of Nursing	Statement 10	Adults	Could include "and an agreed handover of nursing care, be undertaken by both the paediatric and adult specialist nurse"	Thank you for your comment. Please see statement 9 in the final quality standard. The definition has been amended and is now more general about what professionals should be involved.
237	020	Chesterfield and North Derbyshire Royal Hospital NHS Foundation Trust	Statement 10	Adults	The benefit of concurrent care by two consultants is not clear. Concurrent care by two teams introduces some risks (for instance in terms of emergency care provision). Transition can be achieved well by epilepsy specialist nurses (paediatric and adult) having joint appointments. I think the proposed statement is too prescriptive.	Thank you for your comment. Please see statement 9 in the final quality standard. The definition has been amended and is now more general about what professionals should be involved.
240	018	Royal College of Paediatrics and Child Health	Statement 10	Children	Suggesting at least two joint appointments at transition has huge resource implications. In some areas there are joint transition clinics where one joint appointment appears to be adequate. Where is the evidence that two joint appointments are required?	Thank you for your comment. Please see statement 9 in the final quality standard. The definition has been amended to at least a single joint meeting.
241	018	Royal College of Paediatrics and Child Health	Statement 10	Children	General Practitioners could be used in the transition for uncomplicated epilepsies. Transition clinics are so few in number at present that compliance with this quality statement will be difficult.	Thank you for your comment. Please see statement 9 in the final quality standard. The definition has been amended and is now more general about what professionals should be involved.
242	018	Royal College of Paediatrics and Child Health	Statement 10	Children	Two joint clinics before transfer seems superfluous. This can also cause confusion about who exactly is in charge of seizure management. It can be a struggle to have one joint clinic as this is not encouraged by hospital Trusts.	Thank you for your comment. The TEG reviewed the definitions and have been less prescriptive but do reference at least one joint consultation. It does not suggest a joint clinic as such.

These organisations were approached but did not respond:

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2gether NHS Foundation Trust
Allocate Software PLC
Anglesey Local Health Board
Arrhythmia Alliance
Ashton, Leigh & Wigan Community Healthcare
Association of British Healthcare Industries
Association of Child Psychotherapists, the
Association of Clinical Pathologists
Association of Educational Psychologists
Association of Neurophysiological Scientists
Association of Paediatric Emergency Medicine
Autism Alliance UK
Autism West Midlands
Autistic People Against Neuroleptic Abuse
Barnet Primary Care Trust
Barts and the London NHS Trust
Beacon Pharmaceuticals
Betsi Cadwaladr University Health Board
Birmingham and Solihull Mental Health NHS Foundation Trust
Black Country Partnership Foundation Trust
Bolton Primary Care Trust
Bradford District Care Trust
Brainstrust
Brighton and Sussex University Hospital NHS Trust
Britannia Health Products Ltd
British Academy of Childhood Disability
British Acupuncture Council
British Association for Community Child Health
British Association for Psychopharmacology
British Association of Art Therapists
British Association of Behavioural and Cognitive Psychotherapies
British Association of Neuroscience Nurses
British Association of Prosthetists & Orthotists
British Association of Social Workers
British Dietetic Association
British Geriatrics Society
British Maternal & Fetal Medicine Society
British Medical Association
British Medical Journal
British National Formulary
British Paediatric Mental Health Group
British Paediatric Neurology Association
British Psychological Society
British Society for Clinical Neurophysiology

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British Society for Human Genetics
British Society of Neuroradiologists
Buckinghamshire Primary Care Trust
BUPA Foundation
Calderdale and Huddersfield NHS Trust
Calderstones Partnerships NHS Foundation Trust
Cambridge University Hospitals NHS Foundation Trust
Camden Link
Capsulation PPS
Care Quality Commission (CQC)
Carers Trust
Central London Community Healthcare
Centro de Terapia Familiar
Cephalon UK Ltd
Cerebra
Children living with Inherited Metabolic Diseases
Children's Commissioner for Wales
Children's Epilepsy Workstream, Trent
Citizens Commission on Human Rights
Cochrane Epilepsy Group
Coeliac UK
College of Emergency Medicine
College of Occupational Therapists
Commission for Social Care Inspection
Community Psychiatric Nurses' Association
Confidential Enquiry into Maternal and Child Health
Co-operative Pharmacy Association
County Durham Primary Care Trust
Craegmoor
Cyberonics
David Lewis Centre, The
Department for Communities and Local Government
Department for Education
Department of Health, Social Services and Public Safety - Northern Ireland
Derbyshire Mental Health Services NHS Trust
Devon Partnership NHS Trust
Dorset Primary Care Trust
Dravet Syndrome UK
Ealing Hospital NHS Trust
East Midland Ambulance Services NHS
East Midlands Ambulance Service NHS
Eisai Ltd
English Community Care Association
Epilepsy Footprint

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Epilepsy Nurses Association
Epilepsy Wales
Equalities National Council
Faculty of Dental Surgery
Faculty of Public Health
Fair Play for Children
Federation of Ophthalmic and Dispensing Opticians
First Person Plural
Five Boroughs Partnership NHS Trust
Foundation for People with Learning Disabilities
Friends of Landau Kleffner Syndrome
General Medical Council
George Eliot Hospital NHS Trust
Gloucestershire Hospitals NHS Foundation Trust
Gloucestershire LINK
GP Care
Great Western Hospitals NHS Foundation Trust
Greater Manchester West Mental Health NHS Foundation Trust
Hafan Cymru
Hammersmith and Fulham Primary Care Trust
Hampshire Partnership NHS Trust
Hayward Medical Communications
Health Protection Agency
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Herpes Viruses Association
Hertfordshire Partnership NHS Trust
Hindu Council UK
Humber NHS Foundation Trust
Independence Homes Ltd
Independent Children's Homes Association
Independent Healthcare Advisory Services
Institute of Sport and Recreation Management
International Brain Tumour Alliance
International League Against Epilepsy UK Chapter
International Neuromodulation Society
Janssen
Joint Epilepsy Council
Kent and Medway NHS and Social Care Partnership Trust
King's College London
Kingston Primary Care Trust
Knowsley Primary Care Trust
Lancashire Care NHS Foundation Trust
Leeds Community Healthcare NHS Trust

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Leeds Primary Care Trust (aka NHS Leeds)
Leeds Teaching Hospitals NHS Trust
Liverpool Community Health
Liverpool PCT Provider Services
Lothian University Hospitals Trust
Luton and Dunstable Hospital NHS Trust
Matthews Friends
MBB Connections Healthcare
Medicines and Healthcare products Regulatory Agency
Medicines for Children Research Network
Medtronic
Medtronic International Trading Sarl
Medway NHS Foundation Trust
Mersey Care NHS Trust
Ministry of Defence
National Autistic Society
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Hospital for Neurology & Neurosurgery
National Institute for Health Research Health Technology Assessment Programme
National Offender Management Service
National Patient Safety Agency
National Public Health Service for Wales
National Treatment Agency for Substance Misuse
Neonatal & Paediatric Pharmacists Group
Nester Healthcare Group Plc
Neuromodulation Society of UK & Ireland
NHS Bath & North East Somerset
NHS Bournemouth and Poole
NHS Clinical Knowledge Summaries
NHS Connecting for Health
NHS Dudley
NHS Forth Valley
NHS Norfolk Primary Care Trust
NHS Nottingham City
NHS Pathways
NHS Plus
NHS Plymouth
NHS Sefton
NHS Sheffield
NHS South Birmingham
NHS South West Essex

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NHS Warwickshire Primary Care Trust
NHS Worcestershire
NICE - Centre for Evidence based Purchasing
NICE - CPHE
NICE - CPHE Methodology - Simon for info
NICE - Guidelines Coordinator - for info
NICE - Guidelines HE for info
NICE - Medicines and Prescribing Centre
NICE - NHS Evidence
NICE - PPIP
NICE - R&D for info
NICE - Technical Appraisals
NICE technical lead
NICE TLOC GDG
Niger Delta University
Norfolk and Norwich University Hospital
NORTH EAST LONDON FOUNDATION TRUST
North of England Cardiovascular Network
North Somerset Primary Care Trust
North Tees and Hartlepool NHS Foundation Trust
North West Blackouts Group
Northumberland, Tyne & Wear NHS Trust
Nottingham City Hospital
Novartis Pharmaceuticals
Nutricia Clinical Care
Offender Health - Department of Health
Partneriaeth Prifysgol Abertawe
Patients Watchdog
Pembrokeshire NHS Trust
PERIGON Healthcare Ltd
Pharmaceutical Services Negotiating Committee
Pharmametrics GmbH
Pottergate Centre for Dissociation & Trauma
Public Health Wales NHS Trust
Retreat, The
Ridgeway Partnership
Rotherham Primary Care Trust
Royal Berkshire NHS Foundation Trust
Royal Brompton Hospital & Harefield NHS Trust
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Pathologists
Royal College of Physicians

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Royal College of Physicians of Edinburgh
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Speech and Language Therapists
Royal College of Surgeons of England
Royal Pharmaceutical Society
Royal Society of Medicine
Royal West Sussex NHS Trust
Salford Primary Care Trust
Samantha Dickson Brain Tumour Trust
SANAD trialists group
Sandwell Primary Care Trust
Sanofi
Scottish Intercollegiate Guidelines Network
Sheffield Childrens Hospital
Sheffield Health and Social Care NHS Foundation Trust
Sheffield Primary Care Trust
Shire Pharmaceuticals Ltd
Sky Medical Technology Ltd
Sleep-Safe Products
Social Care Institute for Excellence
Society for Acute Medicine
Society of British Neurological Surgeons
Solent Healthcare
South Asian Health Foundation
South East Coast Ambulance Service
South Essex Partnership NHS Foundation Trust
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
South West Yorkshire Partnership NHS Foundation Trust
South Western Ambulance Service NHS Foundation Trust
Special Products Ltd
St Andrews Healthcare
St Andrew's Hospital
St Jude Medical UK Ltd.
St Mary's Hospital
STARS - Syncope Trust And Reflex anoxic Seizures
Sue Ryder Care
Sussex Ambulance Services NHS Trust
Sussex Partnership NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Trust
Teva UK
The Association for Clinical Biochemistry
The Association of the British Pharmaceutical Industry
The British In Vitro Diagnostics Association

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The Children's Trust
The Fostering Foundation
The Neurofibromatosis Association
The Neurological Alliance
The Rotherham NHS Foundation Trust
The Walton Centre for Neurology and Neurosurgery
Treating Autism
Tunstall Healthcare UK Ltd
UK Clinical Pharmacy Association
UK group of consultant epileptologists
UK Pain Society
Ultrasys plc
United Lincolnshire Hospitals NHS
University College London Hospital NHS Foundation Trust
University Hospital Birmingham NHS Foundation Trust
University Hospital of North Staffordshire NHS Trust
University Hospital Of South Manchester NHS Foundation Trust
ViroPharma Ltd
Warrington Primary Care Trust
Welsh Government
Welsh Scientific Advisory Committee
West Herts Hospitals NHS Trust
West Midlands Ambulance Service NHS Trust
Western Cheshire Primary Care Trust
Western Health and Social Care Trust
Westminster Local Involvement Network
Wirral University Teaching Hospital NHS Foundation Trust
Wishaw General Hospital
Wockhardt UK Ltd
Worcestershire Acute Hospitals Trust
Worcestershire Health and Care NHS Trust
Wrightington, Wigan and Leigh NHS Foundation Trust
Wyre Forest Primary Care Trust
York Hospitals NHS Foundation Trust
Young Epilepsy

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