

Quality Standards Topic Expert Group

Epilepsy

Minutes of the meeting held on Monday 2nd July 2012

Meeting held at the NICE offices in Manchester

<p>Attendees</p>	<p>Nick Kosky (TEG Chair) (NK), Richard Appleton (RA), Michael Harnor (MH), Sally Gomersall (SG), Margaret Jackson (MJ), Greg Rogers (GR), Diane Flower (DF), Brian Fitzgerald (BF), Colin Dunkley (CD), Tony Marson (TM), Claire Wrigglesworth (CW), Azim Lakhani (AL)</p> <p><u>NICE Attendees</u></p> <p>Anna Brett (AB), Brian Bennett (BB), Beth Shaw (BS), Andrew Wragg (AW), Tim Stokes (TS), Maxine Adrian-Fleet (MAF)</p> <p><u>Observers</u></p> <p>Alison Tariq</p>
<p>Apologies</p>	<p>Helen Cross (HC), Tracey-Anne Truscott (TT)</p>

Agenda item	Discussions and decisions	Actions
1.Introductions and apologies	<p>The chair, NK welcomed the attendees and reviewed the agenda for the day. Members of the Topic Expert Group (TEG) introduced themselves.</p> <p>NK announced that there were two apologies for the day from HC and TT.</p> <p>The group accepted the minutes from the scoping meeting held on 9th March 2012.</p>	
1.Declaration of Interest	NK asked the group whether they had any new interests to declare since the last meeting and none were stated.	
2.Objectives of the meeting	NK briefly outlined the key objectives of the day: to discuss and agree the wording of the draft quality statements and measures for consultation. NK noted that there was possible room for other areas of care to be prioritised in the afternoon session.	
3.Review of process for developing the epilepsies in adults/children and young people quality standards	BS reviewed the process for developing the quality standard and asked the TEG to think about factors which would have a high impact on outcomes, reducing variation in quality, lead to more efficient use of NHS resources and promote choice and equality whilst maintaining clarity and intent.	
4. Overview and recap	BB stated that 14 potential areas for development were identified at the scoping meeting and 9 of these had since been prioritised and formed into 11 draft quality statements. AB explained the process through which recommendations were prioritised and clarified how the discussions will progress today, reminding members about the rules regarding the wording of quality statements.	

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<p>5 – 7. Draft quality statements (QS) and quality measures (QM) developed from the diagnosis and management of the epilepsies in adults and children in primary and secondary care recommendations</p> <ul style="list-style-type: none"> • Presentation • Discussion • Agreement 	<p>Draft Quality Statement 1: <i>Adults</i> who have had a suspected or confirmed first seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation</p> <p>Draft Quality Statement 1: <i>Children and young people</i> who have had a suspected or confirmed first non-febrile seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation</p> <p>There was some debate around the 2 week timescale and if it was achievable. TEG members felt this was achievable and highlighted it had been achieved in certain areas. The TEG felt this quality statement would help commissioners drive change and noted that 2 weeks was an aspirational but achievable target.</p> <p>The TEG asked if the term first unprovoked seizure could be used (as this would exclude for example, alcohol withdrawal seizure).</p> <p>The group discussed potential outcomes related to this statement. It was agreed that this could impact on rates of misdiagnosis – though this would be a secondary outcome.</p> <p>Revised statement: <i>Adults</i> who have had a suspected or confirmed first unprovoked seizure are initially seen by a specialist in the management of the epilepsies within 2 weeks of presentation</p> <p>Revised statement: <i>Children and young people</i> who have had a suspected or confirmed first unprovoked seizure are initially seen by a specialist in the management of the epilepsies within 2 weeks of presentation</p>	<p>Include the term unprovoked seizure</p>

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	<p>Draft Quality Statement 2: <i>Adults</i> undergoing investigations for epilepsy receive investigative tests within 4 weeks of them being requested.</p> <p>Draft Quality Statement 2: <i>Children and young people</i> undergoing investigations for epilepsy receive investigative tests within 4 weeks of them being requested</p> <p>The TEG discussed the need for the results to be fed-back to clinicians and patients within this time frame rather than just the test being completed. Therefore it was agreed to amend the statement to be explicit about the time frame within which the results should be reported. It was noted some tests can take longer to complete and would not be able to adhere to these timescales (for example, video telemetry which takes 5 days) and it was agreed to cover this issue in the definitions section – recognising that some specialist tests would need a longer reporting timeframe.</p> <p>Revised statement: <i>Adults</i> undergoing investigations for epilepsy are informed of the results within 4 weeks of the tests being requested</p> <p>Revised statement: <i>Children and young people</i> undergoing investigations for epilepsy are informed of the results within 4 weeks of the tests being requested</p>	<p>Include information on tests which may take longer in the definitions section</p>

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	<p>Draft Quality Statement 3: <i>Adults</i> undergoing imaging investigations for epilepsy receive magnetic resonance imaging.</p> <p>Draft Quality Statement 3: <i>Children and young people</i> undergoing imaging investigations for epilepsy receive magnetic resonance imaging.</p> <p>The TEG noted some audits show that CTs may be used inappropriately and that in some areas it is difficult to access MRI scans. It was agreed to retain these quality standards. The quality statement was reworded 'for people who require imaging' as to capture the quality of requesting tests also.</p> <p>BF also highlighted issues regarding access to investigations like MRI for people with challenging behaviour. It was agreed this issue would be referenced in the equality and diversity considerations, stating that reasonable adjustments should be made to ensure all people requiring access to MRI are able to have it in some form. This includes open bed MRI and if required MRI under general anaesthetic.</p> <p>Revised statement: <i>Adults</i> requiring imaging investigations for epilepsy receive magnetic resonance imaging</p> <p>Revised statement: <i>Children and young people</i> requiring imaging investigations for epilepsy receive magnetic resonance imaging</p>	<p>Amend wording of quality statement to include 'for people who require imaging..' as to capture the quality of requesting tests also.</p>

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	<p>Draft Quality Statement 4: <i>Adults</i> whose diagnosis of epilepsy cannot be confirmed in secondary care are referred to a tertiary epilepsy specialist</p> <p>Draft Quality Statement 4: <i>Children and young people</i> whose diagnosis of epilepsy cannot be confirmed in secondary care are referred to a tertiary epilepsy specialist</p> <p>The TEG discussed the need for a timeframe to be added to this as it was important that people were seen in a timely fashion. There were discussions about the difficulty in accessing tertiary care for people who live far from a specialist centre – though outreach services should be able to deal with this. The TEG agreed that 4 weeks (in line with the NICE guideline) should be inserted into the statement. The TEG discussed the importance of any referral to tertiary care being part of a smooth care pathway and that the tertiary care will be an extension to their care package rather than a new care package. The TEG discussed the importance of having recognised referral criteria for tertiary care. The TEG agreed that those included in recommendation 1.10.2 in the NICE guideline should be referenced in the definitions section of the statement. In addition, the TEG requested the QS be changed from ‘..whose diagnosis of epilepsy cannot be confirmed’ to ‘with uncontrolled seizures, diagnostic uncertainty or treatment failure’. They felt this was clearer and in line with recommendations.</p> <p>Revised statement: <i>Adults</i> with uncontrolled seizures, diagnostic uncertainty or treatment failure are seen within 4 weeks of a referral to tertiary care</p> <p>Revised statement: <i>Children and young people</i> with uncontrolled seizures, diagnostic uncertainty or treatment failure are seen within 4 weeks of a referral to tertiary care.</p>	<p>Change ‘..whose diagnosis of epilepsy cannot be confirmed’ to ‘with uncontrolled seizures, diagnostic uncertainty or treatment failure’</p>

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	<p>Draft Quality Statement 5: <i>Adults with convulsive status epilepticus are treated in emergency care settings by clinicians or family members/carers with appropriate training using agreed protocols</i></p> <p>Draft Quality Statement 5: <i>Children and young people with convulsive status epilepticus are treated in emergency care settings by clinicians or family members/carers with appropriate training using agreed protocols</i></p> <p>There was some discussion around the intent of these statements and it was agreed the statements should aim to drive up the quality of emergency care in the community and accident and emergency departments.</p> <p>The TEG believed these quality statements should focus on both care plans and adherence to protocols noting that some patients often receive the same drug twice during emergency situations and in transfer between the community and acute settings. In light of TEG discussion it was agreed that the focus needs to be on how emergencies are managed initially in the community and that people need individualised care plans for any emergency that takes into consideration previous incidents and how they were best managed. The quality statements were therefore amended as below.</p> <p>Revised statement: <i>Adults with a history of seizure clusters or prolonged seizures have an individualised emergency care plan for managing such events beginning in the community</i></p> <p>Revised statement: <i>Children and young people with a history of seizure clusters or prolonged seizures have an individualised emergency care plan for managing such events beginning in the community</i></p>	<p>Amend quality statement to focus on emergency care plans to manage emergencies beginning in the community and transferring to emergency care.</p>

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	<p>Draft Quality Statement 6: <i>Adults</i> with epilepsy and their family and carers are given and have access to [information] about their condition, its treatment and the [implications] it has on their health and lifestyle choices</p> <p>Draft Quality Statement 6: <i>Children and young people</i> with epilepsy and their family and carers are given and have access to [information] about their condition, its treatment and the [implications] it has on their health and lifestyle choices</p> <p>The TEG considered if these draft quality statements were covered in the patient experience quality standard. The TEG felt the impact epilepsy and its treatment can have on wide ranging lifestyle issues means that it is particularly important that there is a statement concerned with the importance of understandable information for people. The TEG discussed and agreed some key areas that should be included in the statement, and agreed to retain the quality statements with the revisions noted below.</p> <p>Revised statement: <i>Adults</i> with seizures or epilepsy should have access to timely information in a form they can understand about their syndrome or seizure type(s), prognosis, risk, benefit and harm of treatments, acute seizure management, education / employment and driving and available support</p> <p>Revised statement: <i>Children and young people</i> with seizures or epilepsy and their family and carers should have access to timely information in a form they can understand about their syndrome or seizure type(s), prognosis, risk, benefit and harm of treatments, acute seizure management, education / employment and driving and available support</p>	<p>Amend to include information on prognosis, risk, benefit and harm of treatments, acute seizure management, education/employment, driving and available support.</p>

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	<p>Draft Quality Statement 7: <i>Adults</i> with epilepsy have a [comprehensive] [individualised written care plan] that includes both medical and lifestyle issues, that has been agreed between the person, family / and or carers where appropriate and the primary and secondary care providers</p> <p>Draft Quality Statement 7: <i>Children and young people</i> with epilepsy should have a [comprehensive] [individualised written care plan] that includes both medical and lifestyle issues, that has been agreed between the person, family / and or carers where appropriate and the primary and secondary care providers</p> <p>The TEG felt these were important quality statements. It was acknowledged care plans need to be written and comprehensive plans. It was also noted that some patients do not currently have written care plans. It was agreed that this issue was not already covered in the patient experience QS and therefore should be included here. A minor amendment was suggested to include 'epilepsy care plan'.</p> <p>Revised statement: <i>Adults</i> with epilepsy have a [comprehensive] individualised written epilepsy care plan that includes both medical and lifestyle issues, that has been agreed between the person, family / and or carers where appropriate and the primary and secondary care providers</p> <p>Revised statement: <i>Children and young people</i> with epilepsy have a [comprehensive] individualised written epilepsy care plan that includes both medical and lifestyle issues, that has been agreed between the person, family / and or carers where appropriate and the primary and secondary care providers</p>	

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	<p>Draft Quality Statement 8: <i>Adults</i> with epilepsy are offered a care package that is supported by an epilepsy specialist nurse.</p> <p>Draft Quality Statement 8: <i>Children and young people</i> with epilepsy are offered a care package that is supported by an epilepsy specialist nurse</p> <p>The TEG agreed to change the draft quality statements as they believed the term 'supported' is not strong enough and they wanted to ensure access to an epilepsy specialist nurse. They also noted the original recommendation for these quality statements was from 2004 and that the landscape had changed since then. There was a discussion about whether the statement should focus on the specific role that an ESN delivers rather than specifying who should deliver that role. However it was agreed that just the presence of ESN should drive improvement and that the statement should be widened to specify a clinical team that included epilepsy specialist nursing</p> <p>Revised statement: <i>Adults</i> with epilepsy should be cared for by a clinical team that includes epilepsy specialist nursing.</p> <p>Revised statement: <i>Children and young people</i> with epilepsy should be cared for by a clinical team that includes epilepsy specialist nursing.</p>	<p>Amend quality statements to clarify patients should be 'cared for' by a clinical term that includes epilepsy specialist nursing.</p>

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	<p>Draft Quality Statement 9: <i>Adults</i> with epilepsy have a [regular] [structured] review with their GP or with a specialist covering all aspects of their individualised care plan</p> <p>Draft Quality Statement 9: <i>Children and young people</i> with epilepsy have a [regular] [structured] review with a specialist covering all aspects of their individualised care plan</p> <p>The TEG agreed to not progress the adult quality statement and noted this is to some extent covered in the Quality and Outcomes Framework. The TEG did however agreed to consider a quality statement on re-referral from primary to secondary care (see section 8).</p> <p>It was noted the QOF only covers people aged 16 and over and that nearly all children are managed in secondary or tertiary care. The TEG therefore agreed to retain the children and young people's quality statement. The TEG asked that specialist was defined as stated in the briefing paper.</p> <p>Revised statement: Adult statement not progressed</p> <p>Revised statement: <i>Children and young people</i> with epilepsy have a [regular] [structured] review with a [specialist] covering all aspects of their individualised care plan</p>	

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	<p>Draft Quality Statement 10: <i>Women</i> with epilepsy and their partners, as appropriate, are offered (information / a review) and counselling concerning potential risks associated with epilepsy/ the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding and menopause.</p> <p>Draft Quality Statement 10: <i>Young women or girls</i> of child bearing age with epilepsy and their parents/carers as appropriate are offered (information / a review) and counselling concerning potential risks associated with epilepsy/ the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding</p> <p>The TEG agreed that both statements should not be progressed as the issues can be covered in the information and care planning quality statements.</p> <p>Revised statement: Not progressed</p> <p>Revised statement: Not progressed</p>	<p>Include information on contraception, conception, pregnancy, caring for children and breastfeeding in the definitions section of quality statements 6 and 7</p>

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	<p>Draft Quality Statement 11: Young people with epilepsy have their transfer to adult services managed by a named clinician</p> <p>There was some concern that the draft statement was too generic.</p> <p>The TEG considered an alternative quality statement suggested at the first TEG meeting:</p> <p>In adolescence, all young people with epilepsy should be offered a period of transition during which their continuing epilepsy care should be reviewed jointly by paediatric and adult medical and nursing specialists to optimise their care and to facilitate their move into adult services.</p> <p>The TEG agreed to progress the alternative statement above, subject to editing by the NICE team, acknowledging this is aspirational but achievable, and can be done in any manner of ways to allow for local circumstances and innovations.</p> <p>Revised statement: In adolescence, all young people with epilepsy should be offered a period of transition during which their continuing epilepsy care should be reviewed jointly by paediatric and adult services to optimise their care and treatment to facilitate their move into adult services</p>	<p>Amend quality statement to ensure a period of review by paediatric and adult medical and nursing specialists</p>

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<p>8. Other recommendations potentially suitable for QS development</p>	<p>AB/BB asked the group for recommendations for further statements. The following areas were discussed:</p> <p>People should be looked after as part of clinical networks to enable access to multi-disciplinary care and relevant expertise. The TEG members and NICE team agreed to draft a quality statement on this for consideration.</p> <p>Criteria for referral and re referral from primary care to secondary care. The TEG asked the NICE team to draft a quality statement on this for consideration.</p> <p>Training in EEG interpretation in paediatrics – It was agreed this would be covered by quality statement 2, with a definition added to the statement regarding the need for relevant expertise to translate investigative test results.</p> <p>Access to services for learning disabilities (LD) and mental health (MH) patients – It was discussed that this should be covered within the equality and diversity considerations for the whole standard. The NICE team agreed to look at this and decide how best to progress.</p> <p>Medicines adherence – the group were advised medicines adherence was a topic in the core library and it was agreed this would cover adherence issues.</p>	<p>Draft quality statement on clinical networks</p> <p>Draft quality statement on clinical networks</p> <p>Build into the definitions section of QS2</p> <p>Cover access to services for LD and MH patients in equalities section of quality standard</p>
<p>9. Summary of agreed quality statements</p>	<p>BB concluded by guiding the TEG through the draft quality statements compiled during the day. There are a total of 10 statements to go to consultation with the possibility of a further 2 areas being developed into statements. Therefore a possible 12 statements.</p>	

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10. Consultation on the draft Quality standard	<p>AW explained the consultation process and discussed stakeholders with the group. He explained that to comment on the draft quality standard an organisation must register as a stakeholder on the NICE website. The TEG was asked for any organisations they had in mind that could be approached to register as a stakeholder.</p> <p>AW explained the role of endorsing organisations and asked TEG members to inform any organisations that may interested in registering as an endorsing organisation.</p>	<p>TEG to identify additional stakeholders and endorsing organisations.</p>
11. Next steps	<p>TEG members were given an update on the next steps, including key dates in the development process.</p>	
12. AOB	<p>NK thanked AB/BB and the TEG for their work so far and closed the meeting.</p>	