

Epilepsy Quality Standard Topic Expert Group

Minutes of the TEG3 meeting held on 8th November 2012 at the NICE Manchester Office

Attendees	<p><u>TEG Members</u></p> <p>Nick Kosky (chair) (NK), Helen Cross (chair) (HC), Brian Fitzgerald (BF), Sally Gomersall (SG), Michael Harnor (MH), Claire Wrigglesworth (CW), Richard Appleton (RA), Gregory Rogers (GR), Diane Flower (DF), Margaret Jackson (MJ), Colin Dunkley (CD)</p> <p><u>External attendees</u></p> <p>Azim Lakhani (AL)</p> <p><u>NICE Staff</u></p> <p>Brian Bennett (BB), Anna Brett (AB), Beth Shaw (BS), Tim Stokes (TS), Andrew Wragg (AW), Stephen Brookfield (SB), Maxine Adrian-Fleet (MAF), Jenny Harrisson (JH)</p> <p><u>Apologies</u></p> <p>Tony Marson, Tracey Ann Truscott</p>
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Agenda item	Discussions and decisions	Actions
1. Introductions and apologies	NK and HC welcomed the attendees and reviewed the agenda for the day.	
2. Declarations of interest	NK and HC asked the group whether they had any new interests to declare since the last meeting and non were stated.	
3. Review of progress so far and objectives of the day	<p>BS reviewed the progress made on the quality standard (QS) so far. She advised the group that the main objectives of the day were to discuss the results of the consultation and agree the quality statements and associated measures for progression into the final QS. She reminded the group that the QS should only consist of aspirational statements addressing key areas of quality or variations in care. The group was also reminded that the QS should be as concise as possible and it should not include anything that is standard practice.</p> <p>BS also confirmed that the group will have the opportunity to see the final version of the QS before publication.</p>	
4. Support for commissioners and others using the quality standard	<p>SB and MAF outlined the role of the costing and commissioning team and advised the group that they will develop a support document for commissioners and other users to accompany the QS. They stated that the purpose of this document is to help commissioners and service providers consider the commissioning implications and potential resource impact of using the QS. SB and MAF advised the group that they may need to provide input during its development. They also told them that they will have the opportunity to comment on the document. The group were asked to contact them if they have any questions. A number of TEG members volunteered to contribute, JH to pass on contact details to SB and MAF.</p>	<p>JH to pass on contact details of volunteers to SB and MAF.</p>
5. Alignment to national initiatives	<p>The TEG had a brief discussion regarding other national initiatives relating to epilepsy. They highlighted the importance that these products should be aligned for ease of use by Commissioners. It was agreed for the NICE team to take this forward with members of the TEG outside of the meeting.</p>	<p>The NICE team to take forward discussions with members of the TEG concerning alignment of</p>

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		national epilepsy initiatives.
6. Presentation and discussion of consultation feedback	<p>BB and AB gave a brief overview of the consultation comments received and highlighted that there had been positive feedback. BB and AB advised the group that they would consider statement-specific comments received from the consultation as they discussed each statement. They also highlighted that responses will be formulated to comments received from registered stakeholders and these responses will be published on the NICE website alongside the final quality standard.</p> <p>One question asked at consultation was whether the quality standard for children should be merged with the quality standard for adults or whether they should be kept separate. The stakeholder comments showed a range of views and the TEG strongly agreed that the two should be kept separate to aid use by separate services and potentially different commissioners.</p> <p>BS reminded the TEG that further changes may be made to the QS following the meeting, subject to discussion with and agreement of the TEG Chair and following Guidance Executive.</p>	
7. Presentation, discussion and agreement of final statements	<p>Draft Quality Statement 1: Adults/Children and young people presenting with a first unprovoked seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation</p> <p>'a first unprovoked' to be replaced with 'suspected'.</p> <p>Include 'diagnosis and'</p> <p>Definition of specialist from the guideline to be included.</p> <p>Revised quality statement: Adults/Children and young people presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation</p> <p>Draft Quality Statement 2: Adults/children and young people</p>	<p>BB/AB to change wording in the statement</p> <p>BB/AB to include definition</p> <p>BB/AB to change measures accordingly</p> <p>BB/AB to</p>

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	<p>having investigations for epilepsy (and/or their parents and carers) are told the results within 4 weeks of the tests being requested.</p> <p>'having investigations' to be replaced with 'have initial investigations'</p> <p>'are told the results' to be replaced with 'performed'</p> <p>Revised quality statement: Adults/children and young people have initial investigations for epilepsy (and/or their parents and carers) performed within 4 weeks of the tests being requested</p>	<p>change wording in the statement</p> <p>BB/AB to change measures accordingly</p>
	<p>Draft Quality Statement 3: Adults/children and young people who need neuro-imaging for epilepsy have magnetic resonance imaging</p> <p>'need neuro-imaging' to be replaced with 'meet the criteria for'</p> <p>Definition of the criteria (taken from the guideline) to be included.</p> <p>Revised quality statement: Adults/children and young people who meet the criteria for neuro-imaging for epilepsy have magnetic resonance imaging.</p>	<p>BB/AB to change wording in the statement</p> <p>BB/AB to include definition</p> <p>BB/AB to change measures accordingly</p>
	<p>Draft Quality Statement 4: Adults/children and young people with uncontrolled seizures, diagnostic uncertainty or treatment failure are referred to a tertiary care specialist and seen within 4 weeks of referral</p> <p>'with uncontrolled seizures, diagnostic uncertainty or treatment failure' to be replaced with 'who meet the criteria for referral'</p> <p>Definition of the criteria (taken from the guideline) to be included.</p> <p>Revised quality statement: Adults/children and young people who meet the criteria for referral to a tertiary care specialist are</p>	<p>BB/AB to change wording in the statement</p> <p>BB/AB to include definition</p> <p>BB/AB to change measures</p>

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	<p>seen within 4 weeks of referral.</p>	<p>accordingly</p>
	<p>Draft Quality Statement 5: Adults/children and young people with a history of prolonged or repeated seizures have a personalised written emergency care plan.</p> <p>Statement to stay the same</p> <p>Include in definitions that the plan should have a 12 monthly review</p>	<p>BB/AB to include definition</p>
	<p>Draft Quality Statement 6: Adults/children with epilepsy have an agreed, comprehensive, personalised written epilepsy care plan.</p> <p>'personalised' to be removed from the statement</p> <p>'comprehensive' to be defined</p> <p>Recommendation of what a care plan should include in terms of safety (currently under statement 7) to be included in the definition.</p> <p>Revised quality statement: Adults/CYP with epilepsy have an agreed and comprehensive written epilepsy care plan</p>	<p>BB/AB to remove wording in the statement</p> <p>BB/AB to include definition</p> <p>BB/AB to include recommendation 1.3.1</p> <p>BB/AB to change measures accordingly</p>
	<p>Draft Quality Statement 7: Adults/CYP with epilepsy have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment</p> <p>The TEG agreed to remove this statement as after moving recommendation 1.3.1 to statement 6 this statement is superfluous.</p>	<p>BB/AB to remove this statement</p>
	<p>Draft Quality Statement 8: Adults with well-controlled epilepsy are referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p>	<p>BB/AB to change/ remove wording in the</p>

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	<p>'well controlled' to be removed</p> <p>Replace reference to secondary care and review by specialist with 'specialist epilepsy services'</p> <p>Revised quality statement: Adults with epilepsy who have medical or lifestyle issues requiring review are referred to specialist epilepsy services.</p> <p>Draft Quality Statement 8: Children and young people with epilepsy have a regular structured review with a paediatric epilepsy specialist</p> <p>'regular' to be removed from the statement</p> <p>'at least annually' to be included at the end of the statement</p> <p>Holistic needs to be included under review in the definitions</p> <p>Revised quality statement: Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually</p>	<p>statement</p> <p>BB/AB to include definition</p> <p>BB/AB to change measures accordingly</p>
	<p>Draft Quality Statement 9: Adults / children with epilepsy are cared for by a clinical team that provides epilepsy specialist nursing</p> <p>Statement changed to focus more on a person's ability to access the epilepsy nurse specialist when they need to, rather than universal access at all times.</p> <p>Revised quality statement: Adults / Children with epilepsy are seen by an ESN and have access to a named ESN who they can contact between scheduled reviews</p>	<p>BB/AB to change wording in the statement.</p> <p>BB/AB to change measures accordingly</p>

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	<p>Draft Quality Statement 10: Young people with epilepsy who are due to transfer to adult services have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services</p> <p>The TEG agreed that for measurement purposes an age range should be included in the definitions for when the majority of young people are ready to transfer. The TEG suggested that the wording 'who are due to transfer to adult services have a transition period' to be replaced with 'have an agreed transition period'. The inclusion of 'agreed transition period' included an age range of 16-19 when this should occur. However it was noted that this needed to be adaptable in certain circumstances such as people with learning disabilities who may require a longer / later transition period dependent on the capacity and ability of the young person. to be involved</p> <p>Definitions of 'agreed' and 'transition period' to be included</p> <p>Revised quality statement: Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services</p>	<p>BB/AB to change wording in the statement.</p> <p>BB/AB to include definitions</p> <p>BB/AB to change measures accordingly</p>
<p>8. Equality impact assessment</p>	<p>BB advised the group that an equalities impact assessment would be completed, for the following reasons:</p> <ul style="list-style-type: none"> • To confirm that equality issues identified have been considered and appropriately addressed. • To ensure that the outputs do not discriminate against any of the equality groups • To highlight planned action relevant to equality • To highlight areas where statements may promote equality <p>BB asked the group to highlight any specific issues and the TEG asked to ensure there is some text in the introduction of the quality standard around epilepsy in different groups e.g. older people, learning disabilities etc.</p> <p>The TEG agreed to make slight changes to the order of the statements moving round statements 4, 5 and 6 so they aligned more</p>	<p>BB/AB to include introductory text.</p>

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	closely with the care pathway.	
9. Next steps	<p>AW outlined the next steps, including key dates in the QS development process. He gave a brief outline of the endorsement process and advised the group that a number of organisations have expressed an interest in endorsing the QS. The TEG members were urged to make use of their contacts to encourage organisations to express an interest in endorsing the standard. A number of members explained they had organisations in mind and were asked to email AW with expressions of interest.</p> <p>The group was reminded that the date for the next meeting, to begin working on QOF and COF indicators, will be on Monday 8th April 2013 in the NICE Manchester office.</p>	TEG members to email AW expressions of interest
10. AOB	<p>GR highlighted to the group that in April 2013 Epilepsy will become one of the RCGP's key areas for priority and that a multidisciplinary diploma for epilepsy is currently being developed.</p> <p>The TEG and NICE team were thanked for their hard work and the meeting was closed.</p>	