

Quality Standards Epilepsy in Adults and Epilepsy in Children and Young People Topic Expert Group

Minutes of the scoping workshop held on Friday 9th March 2012 at the NICE Manchester office

Attendees	<p><u>Topic Expert Group Members</u></p> <p>Nick Kosky (TEG Chair) (NK), Helen Cross (Co-Chair) (HC), Richard Appleton (RA), Michael Harnor (MH), Sally Gomersall (SG), Margaret Jackson (MJ), Greg Rogers (GR).</p> <p><u>Apologies</u></p> <p>Diane Flower (DF), Tracey-Anne Truscott (TT)</p> <p><u>NICE Staff</u></p> <p>Tim Stokes (TS), Andrew Wragg (AW), Beth Shaw (BS), Anna Brett (AB), Brian Bennett (BB).</p> <p><u>Other Attendees</u></p> <p>Paul Cooper (PC)</p> <p><u>Observers</u></p> <p>NA</p>
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Agenda item	Discussions and decisions	Actions
1.Welcome, introductions and plan for the day	NK welcomed the attendees and reviewed the agenda for the day. He advised the group that they were tasked with developing 2 quality standards, epilepsy in adults and epilepsy in children.	
2.Declaration of Interest	NK outlined the declarations of interest policy and the group confirmed they had no additional interests to declare.	
3. Quality standards overview	<p>AW presented the group with an overview of the process for developing NICE quality standards (QS). He highlighted that QS clarify what high quality care looks like. He explained what QS are used for and outlined the current work programme. AW explained how QS are used at present and highlighted that the NHS White Paper <i>Equity and Excellence: Liberating the NHS</i> and the Health and Social Care Bill indicate that QS will be very important in the future. AW advised that we are unsure of the exact mechanisms for this but assured the group that we will bring any updates to future meetings.</p> <p>AW described the role of the TEG and reminded members that they represent themselves rather than a particular organisation. He advised the group that there will be one additional meeting in Spring 2013 where they will reconvene to develop draft Quality and Outcomes Framework (QOF) and Commissioning Outcomes Framework (COF) indicators.</p> <p>AW outlined the role of registered stakeholders in the quality standard consultation process and explained the role of the NICE QS team. He also described the involvement of other NICE teams and external organisations in the development process. AW confirmed that stakeholders registered for CG137 are not required to register again for the QS.</p>	
4.Review of process for developing the quality standard	BS outlined the methods used to develop a QS, highlighting that QS are aspirational but achievable and not intended to reinforce current practice. She outlined NICE's equality commitment and emphasised the need to eliminate unlawful discrimination and promote equality of opportunity within the QS. BS described the relationship between QS and the QOF/COF programmes and advised the group that they will be invited to undertake further work on the QS measures in order to develop valid and clearly worded QOF and COF	

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	indicators.	
5. Quality standard example	AB & BB showed the group an example of a QS. They provided more detail on what a QS looks like and explained the purpose of quality measures and audience descriptors. They emphasised that each individual quality statement must have one concept to ensure clarity. BB showed the group how they will get from a clinical guideline recommendation to a quality statement. BB used the online version of the dementia QS to show the group what a completed QS looks like.	
6. Clinical and policy issues surrounding drug use disorders	PC presented the group with clinical and policy issues surrounding Epilepsy.	
7. Scoping session	<p>The group considered and agreed the proposed scope. They reviewed the included evidence, policy, and audit resources and asked that the following documents were reviewed for inclusion if appropriate / if not already included:</p> <ol style="list-style-type: none"> 1. UK guidance and reports – DVLA (2012) At a glance guide to current medical standards of fitness to drive (February update) ILAE publication 2010 update (children and young people) Assoc. British Neurologists, Local Adult Neurology Services for the Next Decade 2011 NAPC Prodigy (2009) Epilepsy – now CKS Map of Medicine Department of Health Emergency readmission rates: further analysis. 2008 2. UK audits – National Audit of Seizure management in Hospitals (NASH) – include publication reference <p>The group considered the epilepsy in adults areas of care diagram, adapted from the areas identified in CG137 and outlined below:</p> <ol style="list-style-type: none"> 1. Information and involvement in care planning 	

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	<p>2. Assessment</p> <ul style="list-style-type: none"> • Initial assessment • Referral to specialist <p>3. Investigation</p> <ul style="list-style-type: none"> • EEG • Imaging • Other tests • Assessment of psychological, physical and social needs <p>4. Diagnosis</p> <ul style="list-style-type: none"> • Diagnosis by specialist • Classification <p>5. Treatment</p> <ul style="list-style-type: none"> • Pharmacological therapy • Adjuvant treatment • Withdrawal • Convulsive status epilepticus <p>6. Management</p> <ul style="list-style-type: none"> • Review • Self management • Women and girls of childbearing potential • Adults with learning disabilities <p>The group agreed the epilepsy in adults areas of care with changes to the wording of the following areas:</p> <ul style="list-style-type: none"> • Change <i>management</i> to <i>ongoing care</i> • Change <i>review</i> to <i>individualised review of psychological, physical and social needs</i>. <p><i>Review</i> to also include occupational needs</p> <p>The group agreed to include <i>individualised epilepsy care provision</i> as part of the <i>treatment</i> area of care. The group also agreed to consider provision of information on safety/driving and the organisation of services.</p>	<p>Update Areas of care map for Epilepsy in Adults</p>

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	<p>The group discussed whether there needs to be a specific area concerning older people. It was discussed and agreed that this was not necessary.</p> <p>The group reviewed the equality issues but could not identify any at this stage.</p> <p>The group considered the epilepsy in children and young people areas of care diagram, adapted from the areas identified in CG137 and outlined below:</p> <ol style="list-style-type: none"> 1. Providing treatment in child and young person friendly environments 2. Assessment <ul style="list-style-type: none"> • Initial assessment/screening • Referral to specialist in paediatric epilepsies/neurologist 3. Investigation <ul style="list-style-type: none"> • Use of relevant diagnostic test/assessment to inform aetiology • Assessment of any cognitive development delay • Assessment of psychological, physical and social needs 4. Diagnosis <ul style="list-style-type: none"> • Diagnosis by specialist • Classification of epilepsy type 5. Treatment <ul style="list-style-type: none"> • Pharmacological therapy • Adjunctive/alternative intervention in refractory/complex patients • Withdrawal • Convulsive status epilepticus 6. Management <ul style="list-style-type: none"> • Review 	

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	<ul style="list-style-type: none"> • Self management • Girls and women of childbearing potential • Children and young people with learning disabilities <p>The group agreed the epilepsy in children areas of care with changes to the wording of the following areas;</p> <ul style="list-style-type: none"> • Reword <i>providing treatment in child and young person friendly environments</i> to <i>providing treatment and information by people trained and skilled in working with children in a child friendly environment.</i> • Change <i>management</i> to <i>ongoing care</i> • Change <i>initial assessment/screening</i> to <i>initial assessment</i> • Change <i>classification of epilepsy type</i> to <i>classification of seizure type and epilepsy syndrome</i> • Change <i>adjunctive/alternative Intervention in refractory/complex patients</i> to <i>adjunctive/alternative intervention.</i> • Remove <i>withdrawal</i> • Include <i>transition in ongoing care</i> • Remove <i>review</i> and replace with <i>individualised plan to include educational needs</i> • Change 'assessment of psychological, physical and social needs' to holistic reviews of physiological, psychological and educational needs. This would include assessment of cognitive developmental delays. <p>The group also agreed to consider access to epilepsy specialist nursing.</p> <p>The group made a general observation concerning the use of the term "epilepsy" and that it would be more accurate to refer to 'the epilepsies'. This is to be considered by the NICE team and Chairs.</p>	<p>Update Areas of Care map for Epilepsy in Children and young people.</p> <p>Consider using the term 'the epilepsies' instead of 'epilepsy'</p>
<p>8. TEG membership and stakeholder list</p>	<p>AW advised the TEG that NICE are currently recruiting the following additional members:</p> <ul style="list-style-type: none"> • Lay member with an interest in paediatric epilepsy 	

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	<ul style="list-style-type: none"> • Consultant adult neurologist • Learning disabilities consultant with an interest in epilepsy • Paediatrician with an interest in epilepsy • Commissioner • Emergency Medicine Consultant with an interest in adult and paediatric epilepsy <p>GR will supplement the commissioner role in the interim.</p> <p>The group discussed the possible inclusion of a chief executive or business manager to the group, particularly in the current NHS climate, NICE noted this for future QS development. The group also discussed recruiting a community pharmacist to the TEG but decided the current membership was sufficient and that additional input could be covered via the stakeholder consultation.</p> <p>The NICE team advised the group of the need for registered stakeholder input into the development of the QS to ensure all relevant bodies have an opportunity to comment on the QS.</p> <p>The group discussed equality issues and were mindful of issues regarding chronic/disabling accessibility to ensure equal care for all.</p>	
9. Next steps and timescales	<p>The NICE team outlined the next steps in the QS development process and highlighted important dates. AW advised the group that they will have chance to comment on the QS at various stages of development and asked the group to set aside some time during these periods.</p> <p>The group agreed to change the TEG 2 meeting to take place over 1 day on 2nd July, the group will keep TEG 3 as a 2 day meeting and will evaluate this at the next meeting.</p> <p>The COF review group meeting date will take place in Spring 2013, date to be confirmed.</p>	<p>Send list of confirmed meetings to TEG</p> <p>Send slides to TEG</p>
10. Group	<p>Following the formal agenda items the group produced a list of possible quality</p>	

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<p>discussion</p>	<p>statements which may inform the development of the briefing document which will be the basis for discussions at TEG 2:</p> <ol style="list-style-type: none"> 1. Urgent assessment – timely accessibility to appropriate levels of expertise 2. Timely investigation 3. Provision of information on safety and driving 4. Individualised management plan 5. Women’s issues – child bearing potential 6. Status epilepticus 7. Review and referral 8. Psychology and mental health 9. Pathways and networks of care 10. Unscheduled admission 11. Multidisciplinary review of epilepsy related death 12. Appropriate training in EEG, imaging and paediatric investigation. 13. Medicines adherence 14. Educational and occupational management and broader quality of life 15. Access to specialists / most appropriate person in a timely manner 16. Provision of information concerning how to access relevant epilepsy charities and voluntary organisations. <p>The following suggestion was sent via email after the meeting:</p> <ol style="list-style-type: none"> 17. Transition - 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>NK thanked the group and closed the meeting.</p>	