National Institute for Health and Clinical Excellence

Quality Standards Familial Hypercholesterolaemia Scoping workshop

Minutes of the meeting held on Monday 17th September 2012 at the NICE offices in Manchester

Attendees	Rubin Minhas (Chair) (RM), Catherine Woodward (CW), Adie Viljoen (AV), Ian McDowell (IMcD), Yvonne Dumsday (YD), Steve Humphries (SH), Nadeem Qureshi (NQ), Katherine Kear (KK), Melanie Watson (MW) Clare Neuwirth (CN), Helen Stacey (HS) **NICE Attendees** Tim Stokes (TSt), Beth Shaw (BS), Nicola Greenway (NG), Rita Parkinson (RP)
Apologies	Daphne Austin, Uma Ramswani

Agenda item	Discussions and decisions	Actions
1. Introductions and apologies	RM welcomed the attendees and the group introduced themselves. RM then reviewed the agenda for the day.	
Business items • Declarations of interest	RM outlined the declarations of interest policy and the group confirmed they had no additional interests to declare.	
2. Quality standards overview and roles & responsibilities	NG presented the group with an overview of the: **Aims of the NICE quality standards programme -** Develop QS for topics selected by the National Quality Board/NHS Commissioning Board. **What a quality standard is** - A set of specific concise statements based on guidance that act as markers of high quality care. NG explained that the DOH had referred a library of 180 topics to NICE in March 2012 which includes 3 public health topics and 2 social care topics. NG reported that the NHS White Paper *Equity and Excellence: Liberating the NHS* and the Health and Social Care Act indicate that QS will be very important in the future. NG advised the group that there will be some 'cross cutting' standards and commissioners/providers will be expected to cross refer across the library of topics. NG asked the TEG to be mindful that when considering areas of care and statements, some issues could potentially be addressed in other related quality standards. **How a quality standard can be used –** To drive up quality of care. NG explained how the QS would link in with other outcome and improvement frameworks including the NHS outcomes framework, commissioning outcomes framework (COF) and quality and	

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	outcomes framework (QOF). The group asked for more detail regarding the COF, Commissioning guidance and payment mechanisms. TSt explained that NICE only had direct involvement with the COF and QOF, other payment schemes including CQUIN are not developed or quality assured by NICE. TSt highlighted the potential issues for inclusion of FH in the QOF. NG described the stakeholder consultation process. Consultations are advertised on the NICE website & notifications are sent to TEG members for network dissemination. NG explained that any organisation's who register are eligible to comment, and all comments are collated with individual responses sent from the team. All of the comments/responses are then published on the website. The group felt engagement with stakeholders to disseminate the QS was important and queried how the endorsement process works. At consultation NICE asks for organisations to endorse the QS. The endorsing organisation logos are displayed on the QS page and in turn help to disseminate the QS. The group asked if pharmaceutical companies could register as a stakeholder. BS stated that they did fall within the NICE stakeholder criteria. NG gave an overview of the role of the TEG members and the role and responsibilities of the NICE team. The group highlighted the Heart UK conference in June 2013 as a potential audience where the QS can be publicised and asked when the QS will be published. NG confirmed the development of the QS will start in September with the final publication expected in August 2013. BS informed the group the draft QS will be publically available at the time of the conference and therefore could be used.	
3. Overview of	BS outlined the methods used to develop QS. BS highlighted that QS are aspirational but	

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methods and processes for developing quality standards	achievable and are intended to drive quality improvements. They are not intended to reinforce current practice. BS advised the group that NICE quality standards are informed by evidence-based recommendations from published NICE guidance or other NICE accredited sources. They do not review or redefine the underlying evidence base. BS described quality statements as descriptive, clear and concise evidence-based qualitative statements. BS informed the group that the statements identify the most important 'markers' or key requirements of high quality care where specific improvements are required and which, if achieved, imply high quality practice in all other areas. BS outlined the need to ensure that the quality statements include only one concept to ensure clarity and measurement. BS gave an outline of NICE's equality commitment and asked the TEG to be mindful of equality issues throughout the development of the QS. Equality impact assessments are developed at three key stages of QS development and the TEG will be asked to consider equalities at each stage. The group highlighted ethnic groups as a potential equality issue BS advised the group that once the QS has been published the TEG will be invited to undertake further work on the quality standard measures in order to develop valid and clearly worded Commissioning Outcomes Framework (COF) and Quality and Outcomes Framework (QOF) indicators. BS explained It is preferable to aim for a smaller number of concise statements, as this will support	Ensure equalities issues are captured in the EQIA

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	providers to utilise quality standards in practice. BS explained that the consensus is 6 – 8 statements, however if the topic is very large then potentially the number of statements could be increased to a maximum of 15. RM reminded the TEG group that the statements are the minimum critically important steps.	
4.Example of a quality standard	NG showed the group the Ovarian cancer QS on the NICE website as an example. RN suggested it may be of use to circulate copies of example quality standards to the group.	NICE to circulate examples of quality standards to the group including patient experience.
5.Scoping session	The group considered the scope from NICE guideline CG17 and agreed the following revisions for the purpose of the QS: **Focus:** Identification and management of FH in individuals and their affected relatives. **Population:** Adults and children with a clinical or molecular diagnosis of familial hypercholesterolaemia. **Excluding:** People with secondary hyperlipidaemia and those with other inherited lipid disorders. **Setting:** Primary, secondary and tertiary care settings. **Area of Care** NG presented an area of care diagram, identified from NICE guideline CG17. The group discussed key areas for quality improvement and agreed that the following areas of care will be considered: ●Diagnosis including diagnosis in children and molecular testing. ●Referral to a specialist services including and referral back to primary care.	NG to update area of care diagram

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	●Cascade testing. ●Access to LDL-lowering apheresis. ●Information for people with familial hypercholesterolaemia and their families on risks including familial risks and cascade testing. ●Annual review including medication review. The TEG were asked to review the evidence sources, national audits and surveys outlined in the topic overview document and highlight any additional sources that could be of use in the development of the QS. The group suggested the following documents to explore: Heart UK publication on 'saving lives, savings families', National service framework for CHD, stroke and children, young people and maternity services, Cardiac Disease NSF for Wales, Putting prevention first - vascular checks: risk assessment and management. The TEG was asked if there were any other QS within the core library that could be referred to. The group acknowledged Medicines adherence & secondary prevention of myocardial infarction and cardiac rehabilitation should be added. The group were asked to consider equality issues surrounding the areas of care. No specific equality issues were identified in relation to specific areas of care however AV raised geographical inequalities. BS confirmed this issue had already been highlighted and was being taken into consideration.	NG to explore further publications. NICE team to send round the primary care commissioning document NG to add additional quality standards
6. TEG Membership and stakeholder list	The group expressed concerns that the views of the NHS Commissioning board were not represented within the group. RM stated there was local commissioner representation but that it might also be useful for an update to be provided at the start of the following meetings.	NICE team to provide an update on the commissioning landscape at TEG2 and TEG3

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7.Next Steps	NG outlined the next steps in the QS development process and highlighted important dates. NG advised the group that they will have a chance to comment on the QS at various stages of development.	
8. AOB	**AOB** RM suggested it may be helpful to the group for IMcD & MW to give an overview presentation at the next TEG meeting on the barriers and facilitators to cascade testing schemes and experiences to date from their respective services. RM thanked the TEG and NICE team and then closed the meeting.	NICE team to add presentations to the agenda for TEG2. IMcD / MW to prepare presentations for TEG2.