

Quality Standards Familial Hypercholesterolaemia (FH) Topic Expert Group

Minutes of the TEG2 meeting held on 18th December at the NICE offices in Manchester

<p>Attendees</p>	<p><u>Topic Expert Group Members</u></p> <p>Rubin Minhas (Chair) (RM), Ian McDowell (IMcD), Yvonne Dumsday (YD), Nadeem Qureshi (NQ), Melanie Watson (MW), Helen Stacey (HS), Daphne Austin (DA), Steve Humphries (SH), and Uma Ramswami (UR).</p> <p><u>NICE Staff</u></p> <p>Elizabeth Shaw (ES), Nicola Greenway (NG), Rachel Neary (RN) and Liane Marsh (LM).</p> <p><u>HSC IC Staff</u></p> <p>Azim Lakhani (AL)</p>
<p>Apologies</p>	<p><u>Topic Expert Group Members</u></p> <p>Adie Viljoen (AV), Katherine Kear (KK), Catherine Woodward (CW) and Clare Neuwirth (CN).</p> <p><u>NICE</u></p> <p>Tim Stokes (TS), David Tyldesley (DT).</p>

Agenda item	Discussions and decisions	Actions
1. Welcome, introductions and plan for the day	<p>RM welcomed the attendees, noted the apologies and outlined the agenda for the day.</p> <p>The group reviewed the minutes from the TEG 1 meeting held on 17th September 2012. Members agreed that the minutes were an accurate record of the meeting that took place.</p>	
2. Declaration of Interest	<p>RM asked the group whether they had any new interests to declare since the last meeting. No new interests were declared.</p>	
3. Objectives of the meeting	<p>RM outlined the objective for the day: to discuss and agree the wording of the draft quality statements and measures, which will go out to consultation. RM explained that the group was tasked with developing a small number of key evidence-based statements that focus on high quality care and identify critical markers of challenging but achievable care to drive up quality.</p>	
4. Cascade testing presentation	<p>IMcD gave a presentation on the implementation of the NICE FH guideline in Wales from 2008 – 2012.</p> <p>MW gave a presentation on the adoption of cascade testing by the South Central Cardiovascular Network.</p>	
5. Review of process for developing the quality standard	<p>ES reviewed the process for developing the quality standard (QS) and core principles for development, including their purpose to pick out only critical markers for improvement. She emphasised the need for clear, focused, measurable quality statements and reminded the group that the statements must be aspirational but achievable. It was also stated that the statements need to be in plain English. The quality standard will be informed by recommendations from the published NICE clinical guidelines on Familial Hypercholesterolaemia (FH). Not all recommendations will be represented but this would not mean that they are not important. She also asked the group to highlight any equality issues relating to each statement to the NICE team during the meeting as part of the ongoing equality impact assessment for the quality standards.</p>	

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	<p>NG reiterated that the objective of this meeting was to decide:</p> <ol style="list-style-type: none"> 1. Which statements should be progressed for consultation and the wording and intent of these statements. 2. Which statements would not be progressed for consultation <p>NG gave the group an overview of the key development sources used and confirmed that the TEG would have opportunity to comment on the draft version prior to consultation.</p>	
<p>6, 7 & 8. Draft quality statements (QS) and quality measures (QM)</p> <ul style="list-style-type: none"> • Presentation • Discussion • Agreement 	<p>Draft Quality Statement 1: People with a clinical diagnosis of familial hypercholesterolaemia (FH) are offered DNA/ molecular testing.</p> <p>‘molecular’ to be removed from the statement.</p> <p>Explain in definitions how a clinical diagnosis should be made and that the clinical diagnosis should be made by somebody who has expertise in FH.</p> <p>Convey in the definitions the quality aspect of genetic testing.</p> <p>Revised Draft Quality Statement 1: People with a clinical diagnosis of familial hypercholesterolaemia (FH) are offered DNA testing.</p>	<p>NG to add/remove wording in the statement</p> <p>NG to amend the definitions to reflect the new statement</p>
	<p>Draft Quality Statement 2: Children at risk of familial hypercholesterolaemia (FH) are offered diagnostic tests by the age of 10 years.</p> <p>The TEG agreed that this statement does not need to be revised.</p> <p>The TEG agreed to include a measure on point prevalence at the age of 11.</p>	<p>NG to update the measures.</p>

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	<p>Draft Quality Statement 3: People with familial hypercholesterolaemia (FH) are referred to a specialist with expertise in FH. ‘with a clinical diagnosis of’ to be added to the statement.</p> <p>Definition for clinical diagnosis to be added.</p> <p>Revised Draft Quality Statement 3: People with a clinical diagnosis of familial hypercholesterolaemia (FH) are referred to a specialist with expertise in FH.</p>	<p>NG to add/remove wording in the statement</p> <p>NG to amend definitions</p>
	<p>Draft Quality Statement 4: Relatives of people with a clinical diagnosis of familial hypercholesterolaemia (FH) are offered cascade testing.</p> <p>‘clinical’ to be replaced by ‘confirmed’ in the statement.</p> <p>‘cascade testing’ to be replaced with ‘testing through a nationwide, systematic cascade process.’</p> <p>The TEG agreed that that the measures relevant for second and third degree relatives should only include those at risk and who are untested.</p> <p>Revised Draft Quality Statement 4: Relatives of people with a confirmed diagnosis of familial hypercholesterolaemia (FH) are offered testing through a nationwide, systematic cascade process.</p>	<p>NG to add/remove wording in the statement.</p> <p>NG to update the measures.</p>
	<p>Draft Quality Statement 5: People with familial hypercholesterolaemia (FH) receive care/ treatment to achieve a reduction in LDL-C concentration of greater than 50% from baseline.</p> <p>‘People’ to be replaced with ‘Adults.’</p> <p>‘lipid modifying drug’ to be added to the statement.</p>	<p>NG to add/remove wording in the statement.</p>

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	<p>'care' to be removed from the statement.</p> <p>The following process measure to become an outcome measure: 'The proportion of people with FH who receive a high-intensity statin to achieve the reduction in LDL-C concentration of greater than 50% from baseline' and changed to 'number of adults achieving the reduction in LDL-C concentration of greater than 50% from baseline'</p> <p>Revised Quality Statement 5: Adults with familial hypercholesterolaemia (FH) receive lipid-modifying drug treatment to achieve a reduction in LDL-C concentration of greater than 50% from baseline.</p>	<p>NG to update measures.</p>
	<p>Draft Quality Statement 6: Children with familial hypercholesterolaemia (FH) are offered lipid-modifying drug treatment by the age of 10 years.</p> <p>This statement to be developed to incorporate specialists and setting issues.</p> <p>The TEG agreed to include a measure on the proportion of children offered lipid-modifying drug treatment as well as received treatment.</p> <p>Revised Quality Statement 6: Children with familial hypercholesterolaemia (FH) are offered lipid-modifying drug treatment by the age of 10 years (specialist/setting).</p>	<p>NG to develop this statement to incorporate specialists and setting issues.</p> <p>NG to update the measures.</p>
	<p>Draft Quality Statement 7: People with familial hypercholesterolaemia (FH) are offered advice on the risks of smoking and, if appropriate, information on smoking cessation services.</p> <p>The TEG agreed to remove this statement and incorporate it into statement 8.</p>	<p>NG to remove this statement and incorporate into statement 8.</p> <p>ES to check if</p>

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	<p data-bbox="678 432 1619 528">Draft Quality Statement 8: People with familial hypercholesterolaemia (FH) are offered a structured review at least annually.</p> <p data-bbox="678 568 1525 600">The TEG agreed that this statement does not need to be revised.</p> <p data-bbox="678 639 1122 671">Insert checklist into the measures.</p>	<p data-bbox="1641 217 1856 408">FH will be covered under existing conditions in the QS on smoking cessation.</p> <p data-bbox="1641 639 1827 703">NG to update the measures.</p>
<p data-bbox="378 759 647 919">7. Other guideline recommendations potentially suitable for QS development</p>	<p data-bbox="678 759 1536 823">The TEG considered other guideline recommendations potentially suitable for QS development.</p> <p data-bbox="678 863 1603 1023">Members felt that a national information system is vitally important as it would prevent patients from falling through the net. Members felt that it would be appropriate to include this in the definitions for statement 4 as this data needs to be collected and linked up at a national level as the relatives of people with FH could live anywhere in the country.</p>	<p data-bbox="1641 863 1856 951">NG to update the definitions in statement 4.</p>
<p data-bbox="378 1078 636 1142">8. Consultation on the draft QS</p>	<p data-bbox="678 1078 1581 1174">RN outlined the consultation process and advised the group that only registered stakeholders can comment on the draft QS. TEG members to email with any stakeholder suggestions.</p> <p data-bbox="678 1214 1603 1310">RN explained the process around endorsement partners, explaining that any interested organisations should send expressions of interest to the Quality Standards team.</p>	<p data-bbox="1641 1078 1850 1238">TEG to email NICE team with any other stakeholder suggestions.</p>
<p data-bbox="378 1366 624 1430">8. Next steps and AOB</p>	<p data-bbox="678 1366 1603 1430">RN outlined the next steps, including key dates in the QS development process, and asked the group to hold time in their diaries to comment</p>	

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	during the relevant periods. RM thanked the group and closed the meeting.	