

Quality Standards Advisory Committee 3

Coeliac disease – post-consultation meeting

Minutes of the meeting held on Wednesday 20 July 2016 at the NICE offices in Manchester

Attendees	<p><u>Standing Quality Standards Advisory Committee (QSAC) members</u> Hugh McIntyre [Chair], Jim Stephenson, Malcolm Fisk, Darryl Thompson, David Pugh, Lauren Aylott, Ann Nevinson, Susannah Solaiman, Gillian Parker, Geeta Kumar, Ulrike Harrower, Martin Siddorn, Keith Lowe, Karen Ritchie, Jan Dawson, Rhian Last</p> <p><u>Specialist committee members</u> Ruth Quinn, Mike Forrest, Norma McGough, Stephanie France</p> <p><u>NICE staff</u> Items 1 to 8 - Rachel Neary-Jones (RNJ), Craig Grime (CG) Items 1 to 6 – Melanie Carr (MC), Christina Barnes (CB)</p>
Apologies	<p><u>Standing Quality Standards Advisory Committee (QSAC) members</u> Julia Thompson, Ben Anderson, Matthew Fay, Deryn Bishop, Madhavan Krishnaswamy, Eve Scott</p> <p><u>Specialist committee members</u> Peter Gillett, David Sanders</p>

Agenda item	Discussions and decisions	Actions
1. Welcome, introductions and plan for the day (private session)	<p>The Chair welcomed the attendees and the Quality Standards Advisory Committee (QSAC) members introduced themselves.</p> <p>The Chair informed the Committee of the apologies and reviewed the agenda for the day.</p>	

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<p>2. Welcome and code of conduct for members of the public attending the meeting (public session)</p>	<p>The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow. It was stressed that they were not able to contribute to the meeting but were there to observe only. They were also reminded that the Committee is independent and advisory therefore the discussions and decisions made today may change following final validation by NICE's guidance executive.</p> <p>The Chair presented Jan Dawson, public health representative with a card which had been signed by all the committee as a thank you for her contribution to the work undertaken with QSAC3. The committee members wished her well in her future ventures.</p> <p>The Chair advised the committee that Matthew Fay, GP standing member will now be stepping down QSAC 3 due to current work commitments and time pressures. We would like to wish him well with his future ventures. The Chair confirmed that he would write to Matthew to thank him formally for his contributions.</p>	
<p>3. Committee business (public session)</p>	<p>Declarations of interest The Chair asked standing QSAC members to declare any interests that were either in addition to their previously submitted declaration or specific to the topic(s) under consideration at the meeting today. The Chair asked the specialist committee members to declare all interests. The following interests were declared:</p> <p><u>Standing committee members</u></p> <ul style="list-style-type: none"> • None to declare. <p><u>Specialist committee members</u></p> <ul style="list-style-type: none"> • Norma McGough declared that she is employed by Coeliac UK. • Mike Forrest declared that he is currently a governor for Coeliac UK, in a voluntary capacity. He also declared that he has written a module for BMJ which references to the coeliac disease guideline and he declared that he will be speaking at a number of PULSE Roadshows in the future. <p>Minutes from the last meeting The Committee reviewed the minutes of the last meeting held on Wednesday 22 June 2016 and confirmed them as an accurate record subject to the following amendments being made:</p> <p>Page 3: Gillian Parker's declarations to be updated.</p>	

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	<p>Page 5 – An action should be added to include a paragraph to the introduction of the older people with social care needs quality standard to clarify the target population.</p> <p>Page 6 – The last line of the first paragraph of draft statement 2 should read ‘definitions’ and ‘includes’.</p> <p>Page 7, statement 3 – following on from the last meeting the chair asked the NICE team whether an outcome had been reached in relation to the discussion around the term ‘social care needs’. The NICE team confirmed that no decision had been made as yet but the Committee will be updated once terminology is agreed across a number of quality standards.</p> <p>Page 11 para 3 – The last line of the third paragraph of draft statement 1 should read ‘elective surgery’ rather than ‘pre-elective’ surgery.</p>	
<p>4. QSAC updates</p>	<p>Cancellation of QSAC 3 Meetings</p> <p>RNJ advised the standing committee members that the reason for cancelling QSAC meetings in October and December 2016 is in response to some concerns that have been raised by committee members, in all committees, about half day meetings. The issue had been discussed at the quarterly chairs meeting and it was felt that half day meetings were not an effective use of committee members’ time and team resources. The programme team has now reviewed the meeting schedule for the remaining year and moved topics around so the committee meetings are full days, where possible.</p> <p>Outcomes of QSAC Chairs meeting</p> <p>The Chair advised that he had taken the QSAC issues forward for discussion at the QSAC quarterly chairs meeting as requested and provided the following update on the areas of discussion.</p> <ul style="list-style-type: none"> • Induction of committee members The Chair informed the committee that the induction of new committee members is currently being reviewed to ensure a thorough induction process for the future. • Public Health and Social Care Topics The Chair identified that public health and social care topics can be challenging to undertake through the quality standards process. It had been suggested that PH and SC topics could be allocated more time for development than clinical topics. It was suggested having longer committee meetings could enable further discussions. However, the chair advised that all SC and PH topics will continue to go through the quality standards process. It was noted that a result of a recent strategic review of quality standards had been to provide example of uptake and implementation in the social care settings. 	

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	<p>A committee member stated that they were currently undertaking a piece of work related to social care settings around crisis care, and had pulled together all necessary guidelines and quality standards for the topic. The Chair suggested this case study could be used to support the work of the field team on how NICE guidance is implemented in practice.</p> <ul style="list-style-type: none"> • Quality standards remit The committee was advised that the number of new quality standards will reduce over the next year. This mirrors a reduction in the number of guidelines being produced. However, no decisions had yet been made on implications for the four QSACs. The Chair assured the committee that they will be kept informed of any developments. <p>The Chair apologised to the specialist committee members for the delay of the post consultation meeting for coeliac disease and advised that this was due to additional time requirements in the development of the skin cancer quality standard.</p>	
<p>5.1 Recap of prioritisation exercise</p>	<p>MC presented a recap of the areas for quality improvement discussed at the first QSAC meeting for coeliac disease.</p> <p>At the first QSAC meeting on 16 December 2015 the QSAC agreed that the following areas for quality improvement should be progressed for further consideration by the NICE team for potential inclusion in the draft quality standard:</p> <ul style="list-style-type: none"> • Serological testing • Patient information about diagnosis • Referral of people with suspected coeliac disease • Dietary Management • Monitoring and follow up • Prescriptions for gluten free foods <p>The rationale for these decisions is available in the prioritisation meeting minutes which can be found here: https://www.nice.org.uk/Media/Default/Get-involved/Meetings-In-Public/Quality-Standards-Advisory-Committee/QSAC3/QSAC3-minutes-16-Dec-15.pdf</p>	

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<p>5.2 and 5.3 Presentation and discussion of stakeholder feedback and key themes/issues raised</p>	<p>MC presented the Committee with a report summarising consultation comments received on coeliac disease. The Committee was reminded that this document provided a high level summary of the consultation comments, prepared by the NICE quality standards team, and was intended to provide an initial basis for discussion. The Committee was therefore reminded to also refer to the full list of consultation comments provided throughout the meeting.</p> <p>The Committee was informed that comments which may result in changes to the quality standard had been highlighted in the summary report. Those comments which suggested changes which were outside of the process, were not included in the summary but had been included within the full list of comments, which was within the appendix. These included the following types of comment:</p> <ul style="list-style-type: none"> • Relating to source guidance recommendations • Suggestions for non-accredited source guidance • Request to broaden statements out of scope • Inclusion of overarching thresholds or targets • Requests to include large volumes of supporting information, provision of detailed implementation advice • General comments on role and purpose of quality standards • Requests to change NICE templates 	
<p>5.4 Discussion and agreement of final statements</p>	<p>The Committee discussed each statement in turn and agreed upon a revised set. These statements are not final and may change as a result of the editorial and validation processes.</p> <p>Draft Quality Statement 1: People at increased risk or with symptoms of coeliac disease are offered a serological test for coeliac disease.</p> <p>The committee discussed the symptoms of coeliac disease and agreed that the condition is an under diagnosed condition, a large number of people are not being diagnosed until they are 50-60 years of age and this can have a negative impact on the individual's quality of life.</p> <p>The committee considered the stakeholder comments suggesting that more emphasis was needed on testing people with symptoms of irritable bowel syndrome (IBS). They agreed that coeliac disease can be misdiagnosed as IBS due to a lack of adequate testing. The committee considered whether IBS should be given more emphasis in the statement. It was agreed that although IBS is the most common group of symptoms that should be tested for coeliac disease, it is not the only group and is not specifically</p>	<p>The NICE team to progress the quality statement ensuring that the definition of people at increased risk of coeliac disease matches the guideline and it is clear that a gluten containing diet is necessary prior to the test. 'Increased' risk should also be removed.</p>

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	<p>highlighted in the guideline.</p> <p>The committee discussed the list of conditions and symptoms detailed within the draft quality standard and agreed that the format of the list should match the coeliac disease guideline. Therefore the distinction between symptoms and at risk groups should be removed.</p> <p>The committee discussed stakeholder comments regarding why some at risk groups mentioned in the guideline were not included in the statement and the technical team confirmed that it was because those conditions were ‘consider’ recommendations therefore did not lend themselves to the development of measureable quality statements.</p> <p>The committee discussed the process of serological testing and agreed that the statement needs to specify that the individual should be on a gluten containing diet for 6 weeks prior to the test.</p> <p>It was therefore agreed to progress the statement but to remove ‘at increased risk’ so that the statements covers everyone at risk.</p>	
	<p>Draft Quality Statement 2: People with a positive serological test for coeliac disease are referred to a specialist for further investigation and advised to continue with a gluten containing diet until diagnosis is confirmed</p> <p>The Committee agreed that this statement is important and that the wording should acknowledge the choice and flexibility in further testing for children. They agreed that the focus of this statement should remain on referral to a specialist and advice about a gluten containing diet.</p> <p>The committee discussed the feedback to the consultation question about waiting times for endoscopy and agreed that it would be helpful to include an additional statement to identify a 6 week timescale for an endoscopy to be carried out. They felt that this issue remained key and that there is huge variation in referral for endoscopy and the time to get this.</p> <p>The committee discussed the timescale and stated that there needs to be clarity in the new statement around the starting point of the 6 week process. In some areas the referral is to a specialist but sometimes it would be direct access to endoscopy. The committee agreed that the statement should identify that the endoscopy should be carried out within 6 weeks of referral from the GP. It is important to ensure that the person does not wait to see the specialist and then have to wait another 6 weeks for the endoscopy.</p>	<p>The NICE team to progress the quality statement on referral to a specialist</p> <p>The NICE team to progress the additional quality statement on waiting time for</p>

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	<p>The committee agreed that both statements should be progressed.</p> <p>Draft Quality Statement 3: People diagnosed with coeliac disease are given advice about a gluten free diet by a healthcare professional with specialist knowledge of coeliac disease</p> <p>The committee discussed the intention of this statement and agreed that it should empower the individual to be more informed and enable better self-management of their condition.</p> <p>The committee discussed the consultation comments and noted that the British Dietetic Association did not comment on this statement. The committee agreed that a gluten free diet should be considered a treatment for coeliac disease, albeit not a cure, that can have a significant impact on an individual's health and wellbeing. It was agreed that the advice should include details of naturally gluten free foods.</p> <p>The committee advised that the statement should ensure that individuals have the understanding of which foods can be eaten, how to access them and reinforce the importance of continuing to maintain a healthy diet. It was suggested that the statement wording should ensure the information is understood and that the person is motivated to act on it. It was agreed that the statement should be focussed on people who are newly diagnosed.</p> <p>There was a discussion about which healthcare professionals may give this advice and it was suggested that NICE should consider adding 'such as a dietitian' to the statement wording.</p>	<p>endoscopy</p> <p>The NICE team to progress the quality statement on advice about a gluten free diet for people newly diagnosed with coeliac disease</p>
	<p>Draft Quality Statement 4: People diagnosed with coeliac disease are informed about the gluten free foods available on prescription</p> <p>The committee discussed this statement and agreed that this should not be a standalone statement. The committee suggested that statement 3 and statement 4 could be merged and form part of the information given to newly diagnosed individuals.</p> <p>The committee discussed the availability of gluten free products, the cost and what could be accessed via prescription. The committee agreed there is a substantial price difference for gluten free products such as bread, which can cost 3-4 times more than a standard loaf. It was agreed that the costs alone could affect those in lower socio-economic areas in maintaining a gluten free diet. It was noted that coeliac disease</p>	<p>The NICE team to include this within the statement on advice about a gluten free diet and highlight as an equality issue.</p>

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	<p>runs in some families and therefore the cost impact can be very significant. It was requested that these issues are outlined in the equality assessment. The committee agreed that the key quality improvement issue is the variation in what gluten free products are available on prescription across the country however acknowledged that a national prescribing scheme is beyond the remit of NICE quality standards. They felt that the statement as currently drafted did not address this quality improvement need.</p> <p>It was noted that you can eat naturally gluten free meals but it may not be as nutritionally sufficient.</p> <p>The committee agreed not to progress this statement as a standalone statement but this is to be incorporated as an equality issue into statement 3.</p>	
	<p>Draft Quality Statement 5: People with coeliac disease are offered an annual review</p> <p>The committee discussed the statement and agreed the intent of the statement is to encourage people to attend an annual review and enable them to self-manage their condition better. As suggested by stakeholders, it was agreed that the annual review did not need to be with a GP but could take place in primary or community settings eg, community pharmacists. The committee suggested that this should be emphasised more within the statement.</p> <p>The committee discussed the rationale of the statement and agreed further information was required in the rationale as to why individuals should attend the annual review. It should also stress the importance of adherence to a gluten free diet in order to ensure children thrive and to optimise health and wellbeing for all ages.</p> <p>The committee agreed that this statement should be progressed.</p>	<p>The NICE team to progress the statement on annual review</p>
	<p>Additional areas suggested by stakeholders</p> <p>Detection of asymptomatic patients MC advised the committee that this area was not identified within the recommendations of the guideline and therefore could not be progressed. It was agreed that some people who are asymptomatic will be included within the at risk groups included in the statement on serological testing.</p> <p>Vitamin D testing and supplementation MC advised the committee that this area was discussed at the prioritisation meeting however was not prioritised. The committee agreed that vitamin D testing and supplementation is covered in the general</p>	

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	<p>approach to the management of coeliac disease. It was therefore agreed not to progress a statement in this area.</p> <p>Screening people with coeliac disease for neurological signs and symptoms A committee member advised that research around neurological screening is currently being developed. The committee agreed not to progress a statement in this area as they felt that the guideline clearly outlined those individuals at risk.</p>	
<p>5.5. Overarching outcomes</p>	<p>The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on coeliac disease. It was agreed that the Committee would contribute suggestions as the quality standard was developed.</p> <p>It was suggested that ‘years without a diagnosis’ could be an additional outcome.</p>	
<p>5.6. Equality and diversity</p>	<p>The NICE team explained that equality and diversity considerations should inform the development of the quality standard, and asked the Committee to consider any relevant issues. It was agreed that the Committee would contribute suggestions as the quality standard was developed.</p>	
<p>7. Next steps and timescales (part 1 – open session)</p>	<p>MC outlined what will happen following the meeting and key dates for the coeliac disease quality standard.</p>	
<p>8. Any other business (part 2 – Private session)</p>	<p>The following items of AOB were raised:</p> <ul style="list-style-type: none"> • No items to address <p>The Chair thanked the specialist committee members for their input into the development of this quality standard,</p> <p>Date of next QSAC3 meeting: Wednesday 21 September 2016 – Transition from children’s to adults’ services and community engagement: improving health and wellbeing</p>	

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<p>9. Quality standard for skin cancer</p>	<p>CG presented an update on the quality standard for skin cancer. He explained that some changes had been made to the QS since the committee last reviewed it, however they were not extensive.</p> <p>Several members of the committee expressed ongoing concern with statement 2 which focusses on appraisal and revalidation of GPs and GPwSI undertaking BCC removal in the community. It was felt that this statement related to competency – an area usually outside of NICE quality standards remit.</p> <p>Furthermore it was unclear whether this related to generic medical revalidation and appraisal or was a separate clinical governance arrangement. The committee asked CG to raise their concerns with the NICE senior team</p>	<p>CG to raise the concerns with the NICE senior team.</p>