

Quality Standards Advisory Committee 1

Mental health problems in people with learning disabilities and menopause – prioritisation meetings

Minutes of the meeting held on 2 June 2016 at the NICE offices in Manchester

Attendees	<p><u>Standing Quality Standards Advisory Committee (QSAC) members</u> Bee Wee (Chair), Gita Bhutani, Amanda de la Motte, Sunil Gupta, Steve Hajioff, Gavin Maxwell, Teresa Middleton, Ian Reekie, Hugo van Woerden, Jane Worsley,</p> <p><u>Specialist committee members</u> Mental health problems in people with learning disabilities- Regi Alexander, Umesh Chauhan, Richard Hastings, Sharon Jeffreys, Ian Rogers, John Taylor</p> <p>Menopause- Jane Davis, Linda Parkinson-Hardman, Debra Holloway, Jo Justice, Mary Ann Lumsden</p> <p><u>NICE staff</u> Nick Baillie (NB), Sabina Keane (SK) (1-9), Stephanie Birtles (SB), Nicola Greenway (NG) (10-17), Edgar Masanga (EM), Julia Sus (JS)</p> <p><u>Topic expert advisers</u> none</p> <p><u>NICE Observers</u> none</p>
Apologies	<p><u>Standing Quality Standards Advisory Committee (QSAC) members</u> Ivan Benett, Helen Bromley, Phillip Dick, Phyllis Dunn, Ian Manifold, Julie Millard, Hazel Trender, Alyson Whitmarsh, Arnold Zermansky</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>	
2. Welcome and	<p>The Chair welcomed the public observers and reminded them of the code of conduct that they were</p>	

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<p>code of conduct for members of the public attending the meeting (public session)</p>	<p>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>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 <p><u>Specialist committee members</u></p> <ul style="list-style-type: none"> • <u>Richard Hastings:</u> <ul style="list-style-type: none"> – Member of the British Psychological Society – Advisor to charities and social enterprises: Royal Mencap Society, Sibs, Cerebra, Ambitious about Autism, Brain in Hand, Positive Behavioural Solutions Ltd – Funding for mental health research relating to learning disability/autism to my department from: NIHR HTA, NISCHR in Wales, NIHR RfPB, Autistica, Baily Thomas Charitable Fund, Australian Research Council – Member of the Skills for Health Learning Disabilities Core Skills Education and Training Framework Steering Group – Member of the NHS England Midlands and East Regional Transforming Care Board – Member of the Learning Disability Transforming Care Service Model Reference Group (NHS England, Local Government Association, ADASS) • <u>Umesh Chauhan</u> <ul style="list-style-type: none"> – Member of the Royal College of General Practitioners – Member of the advisory group for the ongoing Learning Disabilities Mortality Review (LeDeR) which is hosted by the University of Bristol <p>Minutes from the last meeting The Committee reviewed the minutes of the last meeting held on 5 May 2016 and confirmed them as an accurate record.</p>	

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4. QSAC updates	None	
5 and 5.1 Topic overview and summary of engagement responses	SB and SK presented the topic overview and a summary of responses received during engagement on the topic.	
5.2 Prioritisation of quality improvement areas	<p>The Chair and SK led a discussion in which areas for quality improvement were prioritised.</p> <p>The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team.</p> <ul style="list-style-type: none"> • Assessment • Annual health check • Psychological interventions • Pharmaceutical interventions • Occupation interventions • Organisation and delivery of support • Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatmentSupport and interventions for family members and carers 	
5.3 Prioritised area – Assessment and Annual Health Check	<p>The committee discussed mental health assessment and annual health checks in people with learning disabilities as potential area for quality improvement. The committee highlighted that merging both of those areas together could be challenging as different healthcare professionals carry out the assessment and health checks. The committee debated if a set of standard questions could be added to the annual health check to ensure mental and physical health questions are included. Moreover, the committee discussed extending annual health checks to include children 14 and over. The committee agreed that annual health checks including mental health questions will reinforce an annual review of medications therefore it is an important area for quality improvement to prioritise.</p> <p>The committee agreed that for the mental health assessment to be accurate, it needs to be conducted by a healthcare professional with knowledge of mental health problems and learning disabilities. The committee agreed that decisions about individuals with learning disabilities taking medication for mental health issues require expertise in both areas. Therefore it was agreed to progress this as a separate area of quality improvement.</p>	<p>NICE to progress a statement on annual health check based on recommendation 1.7.3 in Mental health problems in people with learning disabilities. NICE draft guideline (publication date expected in September 2016)</p> <p>NICE to progress a statement on assessment based on recommendation 1.6.1 in</p>

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		<p>Mental health problems in people with learning disabilities. NICE draft guideline (publication date expected in September 2016)</p>
<p>5.4 Prioritised area – Intervention</p>	<p>The committee discussed psychological, pharmaceutical and occupational interventions in supporting people with mental health issues and learning disabilities. It was agreed that all the areas are important, however occupational interventions was not a key area for quality improvement.</p> <p>The committee agreed that pharmaceutical interventions are a crucial area for quality improvement. In particular prescribing antipsychotic drugs to people with mental health problems and learning disabilities should be reviewed on a regular basis by experienced healthcare professionals. Moreover, the committee pointed out that optimisation of psychotropic medication is important due to the potential risks, therefore people should be referred to a specialist when the decision is made to continue the treatment.</p> <p>The committee discussed support for parents of children with mental health problems and learning disabilities who need to deal with daily challenges and highlighted parental training as an effective intervention to help them cope with their child’s level of need.</p>	<p>NICE to progress a statement on pharmaceutical interventions based on recommendation 1.9.7 in Mental health problems in people with learning disabilities. NICE draft guideline (publication date expected in September 2016)</p> <p>NICE to progress a statement on psychological interventions based on recommendation 1.9.9 based on in Mental health problems in people with learning disabilities. NICE draft guideline (publication date expected in September 2016)</p>
<p>5.5 Prioritised area – Organisation and delivery of support</p>	<p>The committee discussed support for parents whose children have mental health problems and learning disabilities by providing them with access to a key worker. The committee explained that a key worker is a named professional who coordinates all aspects of care, helps services communicate with the person and their family members, carers or care workers (as appropriate) and monitors the implementation of the care</p>	<p>NICE to progress a statement on organising effective care based on recommendation 1.2.8 in</p>

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	plan and its outcomes. The committee agreed this is an area for quality improvement.	Mental health problems in people with learning disabilities. NICE draft guideline (publication date expected in September 2016)
5.6 Non-prioritised area – Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment	The committee discussed involvement of people with learning disabilities and their family members, carers or care workers in mental health assessment and treatment. The committee highlighted that care takers and parents are already highly involved in decision making of their children’s health and the additional responsibility and stress could trigger mental health issues and worsen their wellbeing. Therefore it was agreed not to progress the statement.	
5.7 Non-prioritised area – Support and interventions for family members and carers	The committee discussed support and interventions for family members and carers and agreed it is not an area for quality improvement.	
6. Additional areas:	<p>The committee discussed the following additional areas that were suggested by stakeholders:</p> <p>A number of suggestions were received from stakeholders about possible additional areas that are not in the scope of this quality standard. The committee discussed them in turn, but agreed that none of the suggested areas should be progressed as new statements, either because the areas were felt to be covered by other quality standards referred or in development, or because there were no source guideline recommendations or because they were more suitable to be developed as measures in the quality standard.</p> <ul style="list-style-type: none"> - Hearing Loss - Autism 	

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	<ul style="list-style-type: none"> - Links between education and health - Dictated mental health liaison nurse for learning disabilities - Dialectical behavioural therapy - Related Qs- look after children (QS31) and learning disabilities: challenging behaviour (QS101) - Provision of support for those with severe and complex mental health disorders and Special Educational Needs and Disability (SEND) - Care and treatment reviews - Designing, planning, delivery and reviewing of services. 	
6.1 Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on mental health problems in people with learning disabilities. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
6.2 Equality and diversity	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.	
7. QSAC specialist committee members (part 1 – open session)	<p>NB asked the QSAC to consider the constituency of specialist committee members on the group and whether any additional specialist members were required.</p> <p>Specialist members: It was agreed that we no further specialist members were required for next meeting.</p>	
8. Next steps and timescales (part 1 – open session)	SK outlined what will happen following the meeting and key dates for the mental health in people with learning disabilities quality standard.	
9. Any other business (part 1 – open session)	<p>There were no items of AOB raised.</p> <p>Date of next meeting for mental health problems in people with learning disabilities: Thursday 6 October 2016</p> <p>Date of next QSAC1 meeting: Thursday 7 July 2016</p>	

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<p>10. Welcome, introductions and plan for the day (private session)</p>	<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>	
<p>11. 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>12. Committee business (public session)</p>	<p>Declarations of interest</p> <p>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 <p><u>Specialist committee members</u></p> <ul style="list-style-type: none"> • <u>Mary Ann Lumsden</u> <ul style="list-style-type: none"> – Chair: Consortium Board for the National Collaborating Centre in Women's and Children's Health – Vice Chair: Women's Health Expert Advisory Group to the MHRA. – Advisor: NeRRe Biotechnologies, on potential new molecules for treating menopausal symptoms. (non-personal). – President Elect of International Menopause Society – Member of the Council of the British Menopause Society • <u>Debra Holloway</u> <ul style="list-style-type: none"> – Chair of RCN women's health Forum- ongoing – Consultant on guide line for nurses – paid position Jan 16 – Session on menopause for Lambeth practice nurses Dec 15 not paid and via Trust. – Chair RCN women's health conference November 15- not paid. – Chair RCN endometriosis nurse conference November 15 not paid 	

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	<ul style="list-style-type: none"> – 2015 -Menopause session at de Montfort University – 2015 BMS- hysteroscopy and peri- menopause bleeding and menopause café on primary care consultations – Yearly gynaecology nursing course for KCI level 6- 2015- session on menopause and module co lead. – RCN congress- chair fringe event endometriosis and fertility- june 2015 – BSGE- invited speaker for satellite nurses meeting- RCN endometriosis project and co-chair of nurse hysteroscopy session- may 2015 – RCN launch of CNS endometriosis document- chair and speaker march 2015 <p>Publications</p> <ul style="list-style-type: none"> – 2015 Oxford handbook of women’s health nursing. Gupta, Holloway, Kubba (translated into Greek) – 2015- the Role of the CNS in endometriosis- RCN publication (chair of group and author) – 2015 endometriosis fact sheet- RCN publication (chair of group and author) – 2015- iron deficiency and anaemia in adults- RCN guidance for nurse. RCN (working party) – 2015 managing the menopause at work- Carmel Bagness and Debby Holloway. Practice Nursing 26.11 	
<p>13 and 13.1 Topic overview and summary of engagement responses</p>	<p>NG presented the topic overview and a summary of responses received during engagement on the topic.</p>	
<p>13.2 Prioritisation of quality improvement areas</p>	<p>The Chair and NG led a discussion in which areas for quality improvement were prioritised.</p> <p>The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team.</p> <ul style="list-style-type: none"> • Diagnosis • Information • Managing short term menopausal symptoms • Review • Premature ovarian insufficiency • Referral 	

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<p>13.3 Prioritised area – Diagnosis</p>	<p>The committee discussed diagnosis of menopause and agreed with stakeholder comments that there is an issue with an over-reliance on blood tests in women over 45, diagnosis should be based on clinical symptoms. The committee highlighted that to make a potential statement measurable we should base it on the population of women who are presenting to various health care practitioners, such as practice nurse, contraceptive services and not just GPs. The committee agreed that the statement would focus on diagnosis of menopause based on menopausal symptoms rather than a blood test.</p> <p>It was therefore agreed to progress a statement on diagnosis.</p>	<p>NICE to progress a statement on diagnosis based on recommendation 1.2.1 from NG23.</p>
<p>13.4 Prioritised area – Information</p>	<p>The NICE team highlighted that general information provision is included in the patient experience quality standard and therefore any areas on information progressed would have to be specific to this population and not overlap.</p> <p>The committee discussed information given to women about menopause and agreed that it will need to differ depending on their individual needs but that this is the same for any condition. The committee agreed that women’s awareness of the risks and benefits of various treatments is essential specifically in relation to the prescribing of hormone replacement therapy (HRT). Also the committee highlighted there is a reluctance of primary care to prescribe HRT. For these reason the committee agreed that this is a key area for quality improvement and to progress a statement in this area.</p> <p>The committee agreed that contraception was an important area however it is covered by another guideline and is not key area for quality improvement.</p> <p>Finally, the committee discussed information given before treatment and agreed that it was an important area for quality improvement especially around information given to women who might develop premature ovarian insufficiency (POI), therefore it was agreed to incorporate it into the statement on the treatment of POI.</p> <p>It was therefore agreed to progress a statement about HRT.</p>	<p>NICE to progress a statement about giving information on the risks and benefits of taking HRT based on recommendation 1.3.3 from NG23</p>
<p>13.5 Prioritised area – Review</p>	<p>The committee discussed the importance of the review process and agreed that follow-up is crucial in reassessing suitability of their treatment or need for treatment. Moreover, the committee pointed out that it gives an opportunity for healthcare professionals to look at whether the treatment is working, the long term risks and overall health and decide whether referral is needed.</p>	<p>NICE to progress a statement on treatment review based on recommendations 1.4.19</p>

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	<p>It was therefore agreed to progress a statement in this area.</p>	<p>and 1.4.20 from NG23</p>
<p>13.6 Prioritised area – Premature ovarian insufficiency</p>	<p>The committee discussed diagnosis and management of premature ovarian insufficiency (POI) and agreed that information given about menopause to this specific group of women is essential. The committee pointed out that there is variation in primary care in identifying women with potential POI; younger women presenting with menopausal symptoms often undergo other tests without a diagnosis of POI being considered. Moreover, wrong or late diagnosis can have big implications on their health. Surgical removal of ovaries is likely to result in early menopause and women’s awareness of the effects of this treatment is a key area for quality improvement.</p> <p>It was therefore agreed to progress two statements in this area, one on the diagnosis of POI and a second on information provision and treatment options.</p>	<p>NICE to progress a statement on diagnosis of premature ovarian insufficiency (POI) based on recommendation 1.6.2 from NG23</p> <p>NICE to progress a statement on the provision of information for women who may develop POI and the treatment options based on recommendations 1.3.6 and 1.6.6 from NG23</p>
<p>13.7 Non-prioritised area – Managing short term menopausal symptoms</p>	<p>The committee discussed the following areas relating to the management of various short term menopausal symptoms (vasomotor symptoms and HRT, individualised treatments, altered sexual function, complementary products, urogenital atrophy)</p> <p>The committee pointed out that altered sexual function is experienced far more by women than they might admit. However developing a statement is problematic due to the lack of recommendations addressing this specific area. There is also no licenced treatment for women which results in them being referred to secondary care.</p> <p>The committee discussed individualised treatments and agreed it would not be possible to develop a measurable statement as every individual might find a different treatment more effective.</p> <p>The committee debated vasomotor symptoms and HRT treatment and agreed that the use of HRT decreased in 2002 due to its risks and the reluctance of primary care to prescribe it. It was highlighted that prescribing levels are increasing but not to the levels seen prior to 2002. The committee agreed the first step was to ensure women were receiving the correct information about the risks and benefits of HRT</p>	

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	<p>which is captured in the proposed statement on information.</p> <p>The committee discussed and agreed that urogenital atrophy and complementary products are not areas for quality improvement.</p> <p>It was therefore agreed not to progress a statement in this area.</p>	
<p>13.8 Non-prioritised area – Referral</p>	<p>The committee discussed referral to specialist healthcare professionals and raised concerns about the lack of menopause services and healthcare professionals with the appropriate expertise. The intent of this statement would be to drive the increase in menopause services so more referrals can be made for women with more complicated symptoms. The committee felt strongly that this should be an area for quality improvement however it is hard to specify the population who should be referred and there is no appropriate recommendation available to support this. It was agreed to incorporate referral issues into the statement about review, recognising that this will only include a subset population.</p> <p>It was therefore agreed not to progress this as a separate statement.</p>	
<p>14. Additional areas</p>	<p>The committee discussed the following additional areas that were suggested by stakeholders:</p> <p>A number of suggestions were received from stakeholders about possible additional areas that are not in the scope of this quality standard. The committee discussed them in turn, but agreed that none of the suggested areas should be progressed as new statements, either because the areas were felt to be covered by other quality standards referred or in development, or because there were no source guideline recommendations or because they were more suitable to be developed as measures in the quality standard.</p> <ol style="list-style-type: none"> 1. Length of appointments 2. Research 3. Training 4. Service specification 	
<p>14.1 Overarching outcomes</p>	<p>The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing the quality standard on menopause. It was agreed that the committee would contribute suggestions as the quality standard was developed.</p>	

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14.2 Equality and diversity	<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.</p> <p>The committee highlighted that women with a disability, refugees and asylum seekers should be included as they may have difficulties accessing healthcare.</p> <p>It was agreed that the committee would contribute further suggestions as the quality standard was developed.</p>	
15. QSAC specialist committee members (part 1 – open session)	<p>NG asked the QSAC to consider the constituency of specialist committee members on the group and whether any additional specialist members were required for the next meeting.</p> <p>Specialist members: It was agreed that no further specialist members were required.</p>	
16. Next steps and timescales (part 1 – open session)	<p>NG outlined what will happen following the meeting and key dates for the menopause quality standard.</p>	
17. Any other business (part 1 – open session)	<p>There were no items of AOB raised.</p> <p>Date of next meeting for menopause: Thursday 3 November 2016 Date of next QSAC1 meeting: Thursday 7 July 2016</p>	