

**Quality Standards Advisory Committee 3**

**Community engagement: Improving health and wellbeing – prioritisation meeting**

**Transition from children’s to adults’ services – prioritisation meeting**

**Minutes of the meeting held on Wednesday 18 May 2016 at the NICE offices in Manchester**

<p><b>Attendees</b></p>	<p><b><u>Standing Quality Standards Advisory Committee (QSAC) members</u></b>          Jim Stephenson (JS) [Chair], Eve Scott, Malcolm Fisk, Darryl Thompson, David Pugh, Ben Anderson, Lauren Aylott, Ann Nevinson, Susannah Solaiman, Karen Ritchie, Jan Dawson, Deryn Bishop, Madhavan Krishnaswamy, Gillian Parker, Matthew Fay, Rhian Last</p> <p><b><u>Specialist committee members</u></b>  <b>Community engagement: improving health and wellbeing</b>          Chris Nield [agenda items 1-5], Phil Taverner, Steve Tathata, Elizabeth Bayliss, Gerry Stone</p> <p><b>Transition from children’s to adults’ services</b>          Ananta Dave, Alun Williams, Teresa Culverwell, Helena Gleeson, Louise Theodosiou, Debbie Kinsella</p> <p><b><u>NICE staff</u></b>          Items 1 to 11 - Mark Minchin (MM), Christina Barnes (CB)          Items 1 to 6 - Ania Wasielewska (AW), Alison Tariq (AT), Jane Lynn (JL)          Items 7 to 11 - Nicola Greenway (NG), Craig Grime (CG), Ian Mather (IM)</p> <p><b><u>NICE observers</u></b>          Emma Chambers [agenda items1-5], Rachel Neary-Jones [agenda item 5]</p>
<p><b>Apologies</b></p>	<p><b><u>Standing Quality Standards Advisory Committee (QSAC) members</u></b>          Hugh McIntyre, Geeta Kumar, Julia Thompson, Margaret Goose, Ulrike Harrower</p> <p><b><u>Specialist committee members</u></b>  <b>Community engagement: improving health and wellbeing</b>          Jane South</p>

Agenda item	Discussions and decisions	Actions
<p><b>1. Welcome, introductions and plan for the day (private session)</b></p>	<p>The Chair welcomed the attendees and the Quality Standards Advisory Committee (QSAC) members introduced themselves. The chaired welcomed Lauren Aylott as a new member of QSAC3.</p> <p>The Chair informed the committee of the apologies and reviewed the agenda for the day.</p>	
<p><b>2. Welcome and code of conduct for members of the public attending the meeting (public session)</b></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><b>3. Committee business (public session)</b></p>	<p><b>Declarations of interest</b></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><b><u>Standing committee members</u></b></p> <ul style="list-style-type: none"> <li>• Darryl Thompson declared that he has links with an approach called ImROC (Implementing Recovery through Organisational Change), which is underpinned by co-production and community engagement.</li> <li>• Matthew Fay declared that he has helped volunteer organisations, HALE and HOTS (Health On The Streets) both Bradford based charities with grant applications.</li> </ul> <p><b><u>Specialist committee members</u></b></p> <ul style="list-style-type: none"> <li>• Steve Tathata declared that he had undertaken two pieces of consultancy work on the topic of engagement. The first was with West Wakefield Health and Well-being Ltd, a GP Federation, where for a period of approximately 7 months he was the Patient and Carer Engagement Lead under the Prime Minister's Challenge Fund. The second was for a 3 month period with Nova Wakefield District, in the capacity as Community Anchor Development Adviser. He also declared that in January 2016 he joined the Board of Trustees at St George's Community Centre, Lupset, and Wakefield.</li> </ul>	

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	<ul style="list-style-type: none"> <li>• Chris Nield declared that as a Public Health Consultant in Sheffield City Council she sometimes has to apply for research grants in connection to community engagement. She advised that she is an honorary lecturer at Sheffield University for the MPH course and that she is also a member of the FPH mental health committee. Chris stated that she has authored a document which was submitted as evidence to the NICE committee and that she is about to engage in the application process for NIHR funding for public health community engagement research.</li> <li>• Gerry Stone declared she is the Chair of a Community Development Trust, the Seedley and Langworthy Trust (SALT).</li> <li>• Elizabeth Bayliss declared that she is a member of The Guild for Health charity board which promotes health and wholeness. She occasionally undertakes organisation development consultancy work with small charities to help them engage more effectively with their communities and effectively promote self-care. She also stated that she was due to step down as Chief Executive of the Social Action in Health which is a community development charity promoting greater self-determination in health and wellbeing.</li> </ul> <p><b>Minutes from the last meeting</b> The committee reviewed the minutes of the last meeting held on Wednesday 20 April 2016 and confirmed them as an accurate record subject to the following amendment:</p> <p>Page 4 : replace ‘MM suggested that a number of the concerns raised by the SCMs were linked to the time available for the meeting, it was recognised that sufficient time was available to discuss this complex and important topic’</p> <p>Should read ‘MM suggested that a number of the concerns raised by the SCMs were linked to the time available for the meeting, it was recognised that <u>in</u>sufficient time was available to discuss this complex and important topic’</p>	<p><b>NICE Team to make minor revision to minutes prior to publication.</b></p>
<p><b>4. QSAC updates</b></p>	<p>MM informed the committee that following the last QSAC meeting for skin cancer, it was recognised that the committee had progressed as far as they could within the timings of the meeting. However this was not sufficient to pull together a meaningful quality standard and further work was required. It was agreed that the NICE team would work with the specialist committee members and report back to the QSAC. It was noted that this was outside of the standard process and would extend the timescales. MM noted that this will result in a delay to the publication of the skin cancer quality standard.</p> <p>MM advised that skin cancer has been a particularly challenging topic noting that the QS was underpinned</p>	

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	<p>by four NICE guidelines. It was highlighted that a key development source was a guideline first published in 2006 and updated in 2010. MM noted that the quality standards team has learnt from the topic and in the future more time would be allowed for complex topics.</p> <p>Ann Nevinson commented that she was not aware that the revised skin cancer consultation report had been circulated following the last meeting. CB advised that the revised consultation summary report had been attached to the 'thank you' email which had been circulated to all committee members following the last QSAC meeting.</p>	
<p><b>5 and 5.1 Topic overview and summary of engagement responses</b></p>	<p>AW presented the topic overview and a summary of responses received during engagement on the topic.</p> <p><b>Resource impact</b></p> <p>JL presented a slide detailing the resource impact of the community engagement: improving health and wellbeing quality standard.</p>	
<p><b>5.2 Prioritisation of quality improvement areas</b></p>	<p>The Chair and AW 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"> <li>• Effective engagement</li> <li>• Peer and lay roles</li> <li>• Evaluation</li> </ul>	
<p><b>5.3 Prioritised area – Effective engagement</b></p>	<p><b>Effective engagement</b></p> <p><b>Engagement from the start</b></p> <p>The committee discussed the benefits of early engagement and agreed it was important to get the community engaged from the start of the process or initiative. The committee heard of the importance of building relationships with the community and more importantly getting the right members of the community involved in the project or initiative.</p> <p>AW advised the committee of Jane South's comments on this section of the briefing paper</p> <p>'4.1.1 It will be important in the QS to highlight actions for commissioners and strategic planners.</p>	



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	<p>The committee discussed the importance of identifying community assets and agreed its importance as it would help inform commissioners and strategic planners where initiatives were needed.</p> <p>The committee agreed to progress a quality statement around the guideline recommendations 1.4.2.</p>	
<p><b>5.3 Prioritised area – Peer and lay roles</b></p>	<p><b>Peer and lay roles</b></p> <p><b>Volunteering and peer support</b> The committee discussed the challenges of defining a volunteer. They agreed that a volunteer should not be defined as it is important to get volunteer roles integrated into the community as part of ordinary life rather than trying to professionalise it.</p> <p>The committee highlighted the importance of establishing bridging roles which will link back to the establishment of early relationships between the commissioners of the initiatives and getting the community involved from the beginning of the process. The bridging role will also facilitate the community in identifying the outcomes that are important to them and also identify the population of community that should be involved in the initiative.</p> <p>The committee agreed to progress a quality statement around the guideline recommendation 1.3.1</p> <p><b>Skills / capacity building</b> The committee discussed the guideline recommendation around skills and capacity and they agreed that it was not specific enough to be progressed into a quality statement.</p> <p><b>Parity between lay and profession knowledge</b> The committee discussed the parity between lay and profession knowledge and agreed that this could be incorporated into the volunteering and peer support in recommendation 1.3.1 and the bridging roles.</p>	<p><b>NICE Team to progress a statement around recommendation 1.3.1</b></p>
<p><b>5.3 Prioritised area – Evaluation</b></p>	<p><b>Evaluation</b></p> <p><b>Evaluation from the start</b> The committee discussed evaluation and stressed the importance of identifying the outcomes at the start of the process. A committee member identified Evaluation Support Scotland (ESS) an organisation that provides an evidence based approach working with community organisations to enable them to provide</p>	<p><b>NICE team to progress statement around recommendation 1.1.2</b></p>

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	<p>measurable outcomes.</p> <p>The committee agreed that if outcomes are identified at the beginning of the project or initiative it informs volunteers of the start and end of the process and is a way of communicating the results throughout the duration of the initiative. Evaluation the work from the start could also help to reduce the burden of engagement at the end of the project or initiative.</p> <p>The committee identified that evaluation could feed back to the funder of the initiative or project but would not necessarily help meet the needs of the local community. A specialist committee member suggested reviewing some research undertaken by UCLAN around the engagement of people in the evaluation of the projects they are working on. It states that doing this has a greater impact on the individual personally and their community.</p> <p>The committee agreed to progress a quality statement around the guideline recommendation 1.1.2.</p> <p><b>Cost effectiveness</b> The committee briefly discussed cost effectiveness and agreed that it was not always about the cost of a project or initiative but the impact it could have on the health and wellbeing of the community. It was also highlighted that this is the subject of a research recommendation. The Committee agreed not to progress a quality statement on this area.</p>	
<p><b>5.4 Additional Areas</b></p>	<p><b>Additional areas</b></p> <p><b>Hearing loss</b> AW advised the committee that the community engagement for groups of people with specific health conditions are outside the scope of this quality standard it was agreed not to progress a quality statement in this area.</p> <p><b>Visual assessment</b> AW advised the committee that community engagement for groups of people with specific health conditions are outside the scope of this quality standard programme and therefore has not been progressed.</p> <p><b>Healthy diets among young people</b> AW advised the committee that there is a weight management quality standard which addresses healthy diets in young people and therefore it was agreed not to progress a further quality statement in this area.</p>	

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	<p><b>Taboo issues</b> AW advised that the taboo issues identified were dying including end of life care; AW noted that end of life care is the subject of a separate quality standard. A committee member asked whether these suggestions would be fed back to the development team for the end of life care topic, the team advised it would.</p> <p><b>Complementary healthcare therapies</b> AW informed the committee that complementary healthcare therapies are outside the scope of this quality standard and a statement will not be progressed.</p> <p><b>Terminology</b> AW advised the committee the quality standard title was changed to Community engagement: Improving health and wellbeing to align itself with the guideline terminology and it was agreed that a specific quality statement on terminology was outside the remit of the topic.</p>	<p><b>NICE team to feedback comments around taboo issues to development team of the end of life care quality standard.</b></p>
<p><b>5.5 Overarching outcomes</b></p>	<p>The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on Community engagement: Improving health and wellbeing. It was agreed that the committee would contribute suggestions as the quality standard was developed.</p>	
<p><b>5.6 Equality and diversity</b></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><b>5.7 QSAC specialist committee members (part 1 – open session)</b></p>	<p>MM asked the QSAC to consider the constituency of specialist committee members on the group and whether any additional specialist members were required.</p> <p>It was agreed that membership was sufficient for this topic.</p>	
<p><b>6. Next steps and timescales (part 1 – open session)</b></p>	<p>MM outlined what will happen following the meeting and key dates for the Community engagement: Improving health and wellbeing quality standard.</p>	

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<p><b>7. Welcome and code of conduct for members of the public attending the meeting (public session)</b></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><b>8. Committee business (public session)</b></p>	<p><b>Declarations of interest</b> 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"> <li>Gillian Parker declared the research unit she works in has carried out research on transitions from child to adult services for disabled children and that her colleague, Prof Beresford provided expert advice to the NICE Guideline Development Group.</li> </ul> <p><u>Specialist committee members</u></p> <ul style="list-style-type: none"> <li>Teresa Culverwell declared she is the interim chair of Sandwell parents voice parent forum, supported by Action for Children's as an unpaid volunteer. She is a volunteer member of Wolverhampton success group. She was a member of the NICE Guideline Development Group for Transition from children's to adults' services. She is also a volunteer member of the Sandwell ambassadors' forum. Teresa confirmed that she is a trustee of the Sandwell parents for disabled children charity and KIDS where is also non-executive director. She confirmed that she was also a non-executive and trustee at Healthwatch in Sandwell.</li> <li>Louise Theodosiou declared that she has spoken on the theme of transition at industry sponsored events, and her trust has worked with industry sponsorship to develop possible ADHD pilots.</li> </ul>	
<p><b>9 and 9.1 Topic overview and summary of engagement responses</b></p>	<p>NG presented the topic overview and a summary of responses received during engagement on the topic.</p> <p>NG highlighted there had been a good response from stakeholders during topic engagement. However it was noted the majority of stakeholders represented health care services. The committee were informed that several key stakeholders representing social care had been contacted but were unable to input into the development of the quality standard at this stage, these stakeholders were encouraged to comment during consultation.</p>	<p><b>QSAC to email any suggestion for key stakeholders to CB at NICE to encourage specified organisations to register as stakeholders for this topic.</b></p>

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	<p>NG asked the committee for any suggestions for key stakeholders representing social care who should be encouraged to comment at consultation to email CB after the meeting. The committee suggested that the Department for Education and children hospices are encouraged to register as stakeholders for this topic and submit comments during consultation.</p> <p><b>Resource Impact</b></p> <p>IM presented a slide detailing the resource impact of the Transition from children's to adults' services quality standard.</p>	
<p><b>9.2 Prioritisation of quality improvement areas</b></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"> <li>• Timing and review</li> <li>• Named worker</li> <li>• Building independence</li> <li>• Involvement</li> <li>• Support before transfer</li> <li>• Support after transfer</li> <li>• Services</li> </ul>	
<p><b>9.3 Prioritised area – Timing and review</b></p>	<p><b>Timing and review</b></p> <p><b>Timing of transition planning</b></p> <p>The committee discussed the current quality of transition planning and noted that there is variation throughout the country. They highlighted that although there may not be any recent published current practice there are lots of examples of good practice that could be used to support the quality standard.</p> <p>The committee suggested the introduction to the quality standard should outline the legal responsibilities for each group of children. For example, the Health and Social Care Act for those children with special educational needs. It was also suggested that the introduction include clear definitions of transition and transfer.</p> <p>The committee identified the importance of the timing of transition and that it should be reflective and</p>	

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	<p>developmentally appropriate for the young person. It was stressed that an end point of the process needed to be identified within the descriptor of the quality statement for clarity to ensure users were aware the process continues past the point of transfer and doesn't stop when the young person is being seen by adults' services.</p> <p>The committee agreed to progress a statement around recommendation 1.2.1.</p> <p><b>Annual review</b> The committee agreed to prioritise a quality statement around annual review based on recommendation 1.2.4.</p>	<p><b>NICE team to progress a quality statement based on recommendation 1.2.1</b></p> <p><b>NICE team to progress a quality statement on annual review based on recommendation 1.2.4</b></p>
<p><b>9.3 Prioritised area – Named worker</b></p>	<p><b>Named worker</b></p> <p><b>Named worker</b> The committee discussed the importance of having a named worker throughout the transition process and agreed that due to the length of time it may take for the transition to happen, this may not be the same person. It needs to be a key person who helps to coordinate to transition and ensure that the young person's views and choice are taken into consideration.</p> <p>The committee agreed to progress a statement around recommendation 1.2.5</p> <p><b>Named GP</b> The committee was aware that it is now a contractual obligation for all patients to have a named GP, effective from early 2016 and therefore is not an area for quality improvement and does not need to be progressed into a quality statement.</p>	<p><b>NICE team to progress a quality statement based on recommendation 1.2.5</b></p>
<p><b>9.3 Prioritised area – Building independence</b></p>	<p><b>Building independence</b></p> <p>The committee discussed the importance of building independence and suggested that this could be included within the quality statement on having a named worker. The named worker was identified as somebody who could signpost to other services, help explore the young person's confidence so they could aim to be the best they can be and to move to the next stage of independence and for some, moving to</p>	

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	<p>self-management of their condition. It was also discussed that there should be a robust assessment process to identify whether an individual could and should manage their own condition. This could possibly form part of the details held within annual review.</p> <p>The committee agreed that this should be outlined in the introduction of the quality standard and agreed that this should not be progressed as a separate statement.</p>	
<p><b>9.3 Prioritised area - Involvement</b></p>	<p><b>Involvement of parents and carers</b></p> <p>The committee discussed the involvement of parents and carers and whether it was an area for quality improvement. They felt it was important that parents and carers should be involved, taking into account the young person's wishes, as they may have to coordinate future services especially for those with complex needs. It was suggested that recommendation 1.2.20 would be appropriate to underpin a statement as this covers the expectations and anxiety parent and carers may have during the transition process. The committee were asked to specify when this should happen and agreed it should be part of the annual review. The committee agreed that a quality statement should be developed with reference to mental capacity of the young person and Gillick competency.</p> <p>The committee agreed to progress a statement around recommendation 1.2.20.</p>	<p><b>NICE team to progress a quality statement based on recommendation 1.2.20 about involving with parents and carers</b></p>
<p><b>9.3 Prioritised area – support before transfer</b></p>	<p><b>Support before transfer</b></p> <p><b>Introduction to adult services</b></p> <p>The committee discussed the importance of the young person being introduced to adult services prior to transfer as this would help to ensure that the transfer is managed properly. This would bring together the hand over from one service to another and pre-empt any issues that may occur.</p> <p>The committee agreed to progress a statement around recommendation 1.3.1.</p> <p><b>Personal folder</b></p> <p>The committee discussed the proposal of the personal folder during the transition process. The committee were advised that this was a consider recommendation and quality statements were not usually based on these type of recommendations because of issues with consistent measurement.</p> <p><b>Expectations</b></p> <p>The committee agreed that this area had been covered in the statement progressed on involving parents and carers and therefore did not need to be a standalone statement.</p>	<p><b>NICE team to progress a quality statement based on recommendation 1.3.1 about meeting adult services</b></p>

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<p><b>9.3 Prioritised area – support after transfer</b></p>	<p><b>Support after transfer</b></p> <p><b>Non attendance</b> The committee discussed the issue of young people who do not attend adults’ services following transfer and agreed it is a problem that needs to be addressed. The committee heard how there is inconsistency around how non-attendance is managed within different service areas. However if the individual goes into crisis then there is a high cost associated with this. The committee discussed how non-attendance could be the outcome of poor planning and agreed that engagement of the individual is important and should be individualised where possible. The committee agreed that an agreed plan in advance should be in place for those who do not attend. It’s important that individuals are informed as this will empower an individual to remain engaged.</p> <p>The committee agreed to progress a statement around recommendation 1.4.1</p>	<p><b>NICE team to progress a quality statement based on recommendation 1.4.1</b></p>
<p><b>9.3 Prioritised area - services</b></p>	<p><b>Services</b></p> <p><b>Joint Planning</b> The committee discussed the importance of joint planning between children’s and adults’ services and agreed that it is a key principle for this quality standard. The committee agreed reference to joint planning should be included in the introduction of the quality standard.</p> <p><b>Developmentally appropriate service provision</b> The committee had previously discussed developmental appropriate transition and its importance in the design and monitoring of a service. It was agreed that this should be included in the introduction of the quality standard.</p>	<p><b>NICE team to include reference to joint planning and developmentally appropriate service provision in the introduction</b></p>
<p><b>9.4 Additional Areas</b></p>	<p><b>Additional areas</b></p> <p><b>Ownership</b> The committee had previously discussed ownership as part of providing effective services but from a strategic perspective. The committee were advised that quality standards should be person-centred.</p> <p><b>Data</b> NG advised the committee that it is not within the remit of quality standards to propose audit questions for national audits. Any stakeholder suggestions of outcomes will be considered for potential inclusions in the</p>	

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	<p>introduction to the quality standard.</p> <p><b>Scope</b> NG advised the committee that the quality standard will cover any individual regardless of their condition and therefore a quality statement was not required and therefore will not be progressed. NG highlighted to the committee that there had been several comments on the scope of the quality standard and which clinical conditions were included. NG stated that in line with the guideline, the quality standard is applicable for all young people who will need to transition to adults' services regardless of the condition.</p> <p><b>Funding</b> NG advised the committee that setting national tariffs is outside the remit of quality standards.</p> <p><b>Research</b> NG advised the committee that quality standards do not address areas for research.</p> <p><b>End of life care plans</b> NG highlighted that there will be a separate quality standard on end of life care for children and young people.</p>	
<b>9.5 Overarching outcomes</b>	<p>The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on transition from children's to adults' services. It was agreed that the committee would contribute suggestions as the quality standard was developed.</p>	
<b>9.6 Equality and diversity</b>	<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>The committee identified the following groups that may need to be added to the equality impact assessment:</p> <ul style="list-style-type: none"> <li>• Those young people in a secure setting</li> <li>• Those young people in a care setting</li> <li>• Those young people with gender dysphoria</li> </ul>	<p><b>NICE team to incorporate the additional areas into the equality impact assessment.</b></p>

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	<ul style="list-style-type: none"> <li>• Those young people with limited mental capacity</li> <li>• Those young people who are pregnant</li> </ul>	
<b>9.7 QSAC specialist committee members (part 1 – open session)</b>	<p>MM 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 the current membership was sufficient for this topic.</p>	
<b>10. Next steps and timescales (part 1 – open session)</b>	<p>MM outlined what will happen following the meeting and key dates for the transition from children's to adults' services quality standard.</p>	
<b>11. Any other business (part 1 – open session)</b>	<p>The following items of AOB were raised:</p> <ul style="list-style-type: none"> <li>• No items to address.</li> </ul> <p><b>Date of next meeting for Transition from children's to adults' services:</b> Wednesday 21 September 2016.</p> <p><b>Date of next QSAC 3 meeting:</b> Wednesday 22 June 2016 Older people with social care needs and multiple long-term conditions Intravenous fluid therapy in children and young people in hospital.</p>	