Quality standards advisory committee 2

Developmental follow-up of babies and young people born pre-term + Cystic fibrosis – Prioritisation meeting

Minutes of the meeting held on 12th October 2017 at the NICE offices in Manchester

Attendees	**Standing Quality Standards Advisory Committee (QSAC) members** Michael Rudolf (Chair), Gillian Baird, James Crick, Guy Bradey-Smith, Arnold Zermansky, Jane Bradshaw, Michael Varrow, Steve Hajioff, Allison Duggal, Moyra Amess, Malcolm Griffiths, Jane Putsey, Jean Gaffin, David Weaver, Corrine Moorcarme **Specialist committee members** **Developmental follow-up** Phillip Harniess, Nashwa Matta, Nicola O'Connor, Grenville Fox, Anne-Marie Sims **Cystic fibrosis** Janis Bloomer, Tracey Daniels, Helen McCabe, Zoe Elliott, Martin Walshaw, Nichola MacDuff, Iolo Doull **NICE staff** Nick Baillie (NB), Julie Kennedy (JK), Stacy Wilkinson (SW) {items 1-5}, Paul Daly (PD) {items 6-10}, Rick Keen (RK) **NICE Observers** Jenny Craven
Apologies	**Quality standards advisory committee (QSAC) standing members** Matthew Sewell, Julie Clatworthy, Ruth Studley, Robyn Noonan and Michael Fairburn **Specialist committee members** Samantha Johnson, Joe Fawke

Agenda item	Discussions and decisions – Developmental follow-up of babies and young people born pre-term	Actions
1. Welcome, introductions and plan for the day (private session)	The Chair welcomed the attendees and the quality standards advisory committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and reviewed the agenda for the day.	
2. Committee business (public session)	**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: **<u>Specialist committee members</u>** <u>Nashwa Matta</u> • Nasha has contributed to published work in regards to the learning environment on preterm and low birth weight babies. • She is a member of the Renfrewshire Community Planning Forum and the Children & Young Peoples Thematic Board. <u>Grenville Fox</u> • None. <u>Nicola O'Connor</u> • Nicola is a trustee for First Touch which supports the Neonatal Unit at St George's Hospital in London <u>Phillip Harniess</u> • Phillip is a member of the APCP Neonatal committee – specialist interest group. • He is also a member of the EI SMART committee – expert therapists developing an early intervention framework for application in the NHS context.	

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	• He has been involved in three relevant research projects: 2011 – Principle investigator on CATCH trial (multisite trial of constraint induced movement therapy) – 2015 – 'Paediatric Physiotherapists' practice in Neurodevelopmental Follow-Up Assessment Programmes of High-Risk Infants (A UK Web-based cross-sectional survey) – 2017 – 'Exploring Parental Experience of Early Therapy for Infants with Emerging Signs of Complex Neurodisability (A local action research project)'. Anne-Marie Sims • She has been part of an international special interest group contributing to a guideline titled 'A guide to support families of children with complex needs and the professionals who care for them'. **Minutes from the last meeting** The committee reviewed the minutes of the last meeting held on 8th June 2017 and confirmed them as an accurate record. Members requested that, on occasions when there was a long gap between QSAC meetings, they should be sent the minutes as soon as they had been approved.	
3. QSAC updates	There were no updates from the NICE team.	
4 and 4.1 Topic overview and summary of engagement responses	SW presented the topic overview and a summary of responses received during engagement on the topic.	
4.2 Prioritisation of quality improvement areas	The Chair and SW led a discussion in which areas for quality improvement were prioritised. The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team. The outcome of discussions is detailed below.	

Suggested quality	Prioritised	Rationale for prioritisation decision	If prioritised, which specific areas to be included?

improvement area	(yes/no)		
Providing enhanced developmental support and surveillance a) Providing enhanced developmental surveillance up to 2 years (corrected age) b) Developmental assessment at 2 years (corrected age) c) Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks gestation	**Yes**	The committee discussed the importance of a 4 year assessment for children born before 28^{+0} weeks' gestation to identify any developmental problems that had not been picked up earlier. Examples were given of children who had difficulties at school that were not identified at earlier assessments. The committee discussed the resource impact of this assessment, but agreed that savings from changes in the 2 year assessment and earlier identification of issues would free up resource. This was agreed as an area for quality improvement and was prioritised for inclusion in the draft quality standard. The committee stated that at least 2 assessments in the first year, followed by another at 2 years (corrected age), are important for the early identification of developmental issues to improve long-term outcomes for children having enhanced support. The committee discussed measurability and whether it is possible to identify the children who should have enhanced developmental surveillance. It was pointed out that neonatologists record the data needed to identify this group for every infant admitted to a neonatal unit on the Badgernet system. The committee therefore agreed that it would be possible to measure a statement on this area and agreed to prioritise it.	• **Infants born preterm who are having enhanced developmental surveillance have at least 2 face-to-face follow-up visits in the first year that focus on development.** • **Children born preterm who are having enhanced developmental surveillance have a face-to-face developmental assessment at 2 years (corrected age).** • **Further developmental assessment at 4 years (uncorrected age) for children born before 28^{+0} weeks gestation.**
Multidisciplinary team	**No**	The committee considered the comments received at topic engagement and discussed the membership of the MDT and the importance of good communication between its members. The potential psychological, financial and logistical burdens placed on families who have to attend multiple MDT assessments was highlighted. The committee	**N/A**

		agreed that the area for quality improvement is the parent and carer experience of the MDT and agreed that this issue would be addressed by the next quality improvement area (information and support).	
Information and support a) Information and support for parents and carers of all preterm babies b) Sharing information with services	**Yes**	The committee discussed that giving tailored information to parents and carers about their child's developmental needs, long-term outcomes of preterm birth, and what follow-up appointments there will be in a sensitive way is important. The committee also discussed emotional and psychological support and key times when support might be needed. The committee agreed that having a statement on providing a single point of contact as part of an outreach service from neonatal services would cover all aspects of this support and this was prioritised for inclusion in the draft quality standard. The committee discussed that there are 2 groups of parents and carers that might need support: those with a baby having enhanced developmental support and those with babies born before 37^{+0} weeks not having enhanced support. The committee discussed having a statement on providing a discharge plan for all parents of preterm babies to cover both of these groups, and agreed that this is not currently happening. The committee agreed to prioritise this area for inclusion in the draft quality standard. The committee discussed information sharing between services and agreed that the key area for quality improvement is on information and support for parents and carers, which is covered by the areas progressed on the single point of contact and the discharge plan. The committee agreed not to prioritise this area.	• **Neonatal services to provide a single point of contact for outreach care for parents or carers of a preterm baby having enhanced developmental support.** • **Provide a discharge plan for all preterm babies.**

Additional areas suggested	Committee rationale	Area progressed (Y/N)
Data collection and reporting	Participation in audit and collation of information are methods by which quality improvement can be evidenced. Quality statements focus on the delivery of care or support, not the methods by which evidence is collated.	**N**
Staff training	Healthcare professionals involved in assessing, caring for and treating children born preterm should have sufficient and appropriate training and competencies. Training may enable quality improvement to take place but is not considered as a quality improvement area.	**N**
Communication about follow-up	The committee agreed that this is not a priority area for quality improvement.	**N**
Developmental assessment practices, use of technology and therapy-led groups	The committee agreed that this is not a priority area for quality improvement.	**N**

5. Resource impact	No resource impact identified.	
5.1 Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on Developmental follow-up of babies and young people born pre-term. It was agreed that the committee would contribute suggestions as the quality standard was developed. The committee suggested parent and carer wellbeing as a possible overarching outcome.	
5.2 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. The committee raised that the Parent Report of Children's Abilities – Revised (PARCA-R) assessment used at the 2 year developmental assessment is not suitable if English is not a first language.	

5.3 Next steps and timescales	The NICE team outlined what will happen following the meeting and key dates for the developmental follow up quality standard. MR thanked the specialist committee members for their input into the development of the quality standard.	
	Discussions and decisions – Cystic fibrosis	**Actions**
6. Committee business (public session)	**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: **<u>Specialist committee members</u>** <u>Martin Walshaw</u> • None <u>Iolo Doull</u> • Iolo gave three educational lectures on paediatric asthma, for which he received a fee from Astra Zeneca. • He also attended a paediatric advisory board on paediatric asthma, and received a fee from Boehringer Ingelheim. <u>Janis Bloomer</u> • None. <u>Nichola MacDuff</u> • None. <u>Tracey Daniels</u> • Tracey has previously completed paid consultancy work for Phillips. • She has also completed paid advisory boards for Raptor, Forest Pharmaceuticals, Novartis,	

	Gilead, Pharmaxis. • She has given paid presentation for Pharmaxis and for Roche. • She has received educational grants/sponsorship or travel expenses from Phillips, Raptor, Zambon, Forest pharmaceuticals, Actavis, Novartis, Pharmaxis and Roche. <u>Helen MacCabe</u> • None. <u>Zoe Elliot</u> • Zoe has been paid for the communication and marketing work she did for the James Lind Alliance Priority Setting Partnership in Cystic Fibrosis. • She was accepted for European CF Conference in June 2017. • She is attending the EURORDIS Expert Patient and Researcher summer school in Barcelona. This is funded by the charity with help from the European Medicines Agency; the health programme of the European Union; Malalties Minoritaries http://www.eurordis.org/content/eurordis-summer-school-patient-advocates#c • She spoke at the CF Trust conference in September - The event was sponsored by: Vertex; Mylan; Pari Medical Ltd; Raptor Pharmaceuticals; PTC Therapeutics, Inc; Gilead Sciences; Concert Pharmaceuticals; Galapagos; SPS Medical and Chiesi. She did not receive any payment or financial inducement for speaking at the event.	
7 and 7.1 Topic overview and summary of engagement responses	PD presented the topic overview and a summary of responses received during engagement on cystic fibrosis (CF). PD emphasised that the presentation was a summary, but all stakeholder suggestions were included in full in the briefing paper; and that all references to the guideline relate to the draft consultation version of the guideline.	
7.2 Prioritisation of quality improvement areas	The Chair and PD led a discussion in which areas for quality improvement were prioritised. The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team. The outcome of discussions is detailed below.	

Suggested quality improvement area	Prioritised (yes/no)	Rationale for prioritisation decision	If prioritised, which specific areas to be included?
Diagnosis a) Sweat testing and gene testing	**No**	Specialist committee members gave committee an overview of the sweat and gene testing processes and their importance before discussing these areas. Committee concluded that testing is already occurring, and that there are no recommendations in the underpinning guideline to support the specific areas suggested by stakeholders.	• **Not prioritised**
Monitoring, assessment and management a) Annual and routine reviews b) Nutritional assessment and interventions c) Exercise d) Psychological assessment e) Liver disease f) Cystic fibrosis related diabetes	**Yes**	PD gave committee a summary of stakeholder suggestions for each of the sub-areas, along with an overview of relevant recommendations and current practice data. Current practice data suggest that a high proportion of cystic fibrosis patients have an annual review recorded. However, committee discussed the extent to which patients were receiving a comprehensive assessment. Committee discussed the nature and content of the annual review, including the different ways that the patient is involved; the involvement of MDT members; differences between arrangements for children and adults; and the different approaches to timing (the annual review as a single, one day event versus a continuous process). Committee agreed to progress a statement on annual reviews based on recommendation 1.5.2. Members agreed that there should be flexibility in terms of when each component of a review takes place, but there needs to be an annual review	• **People with cystic fibrosis have a comprehensive annual review. Statement needs to include components set out in guideline.**

		involving all MDT members. It was also noted that the results and outcomes need to be discussed and shared with the person with cystic fibrosis. Members discussed the other areas suggested by stakeholders, and noted that each of them would be a component of an annual review. Committee concluded no statements were needed to cover these other suggested areas.	
Pulmonary management a) Airway clearance (access to adjuncts, nebulisers, airway clearance devices) b) Treatment of infection (antibiotic therapy) c) Inhaled therapies	**Yes**	Each of the sub-areas were considered by committee. The committee discussed the differences in effectiveness of the various airway clearance techniques and devices on offer for CF patients; the need to take patient preference into account, and the potential resource impact. The committee agreed that whilst there were issues, they could not be addressed by the guideline recommendations. Committee then discussed treatment of infection and considered the key area to be use of inhaled antibiotics to address chronic *Pseudomonas aeurignosa*. Specifically, the focus should be chronic infection where eradication treatment had not been successful. Committee noted that the proportion of patients receiving inhaled antibiotics is relatively high nationally, but that there is variation between cystic fibrosis centres and networks. They also recognised that not all people offered inhaled antibiotics will actually take them. Committee also discussed other inhaled therapies and agreed to progress a statement on offering people with cystic fibrosis who have respiratory symptoms, or other evidence of lung disease, a mucoactive agent with rhDNase as first line	• **People with cystic fibrosis who have chronic Pseudomonas aeruginosa infection are offered an inhaled antibiotic.** • **People with cystic fibrosis who have respiratory symptoms are offered rhDNase as the first choice of mucoactive agent.**

		treatment. Current practice data showed variation in practice. Members recognised that rhDNase does not have UK marketing authorisation for use in children. However, they wanted the statement to cover all ages which would align with the guideline recommendations. Committee considered the key guideline recommendations to be 1.6.17 and 1.6.18.	
Preventing cross-infection	**Yes**	Committee considered transmission of infection between people with CF, transmission between people with CF and those who care for them, and cross infection in different settings. Committee agreed the focus was organising care within hospital environments. Specifically, the need to make sure that inpatients have individual rooms with en-suite facilities was considered fundamental to preventing cross infection. Committee heard that this practice is not occurring fully at the moment and thus a statement was required to ensure improvement. It was noted that there could be potential resource issues in regards to this, as some hospitals may not have access to a sufficient number of facilities.	• **People with cystic fibrosis have individual rooms with en-suite facilities during inpatient care.**
Service delivery a) Access to care b) Transition to adult services	**No**	Committee considered the sub-areas within access to care as suggested by stakeholders. Some members felt there was some variation in terms of access to home based IV antibiotics, but recognised that there was no statement in the guideline that could be used to build a statement to address it.	• **Not prioritised**

		Committee highlighted that transition from child to adult services for CF patients was an area for concern for parents. Committee discussed whether this area could be measured appropriately, though. They also recognised there are only a small number of recommendations in the CF guideline and whether the area was sufficiently covered by an existing quality standard (Transition from children's to adults' services QS140). Committee agreed not to progress a statement on transition due to challenges with measurability and overlaps with existing statements on transition.	

Additional areas suggested	Committee rationale	Area progressed (Y/N)
Lung transplant	No recommendations in source guidance	**N**
Management of CF-SPID (Screen Positive, Inconclusive Diagnosis) group	No recommendations in source guidance	**N**
Management of the upper airway in CF patients	No recommendations in source guidance	**N**
Monitoring adherence to treatments	Nice guideline on medicines adherence (CG76) but this does not cover specific area suggested	**N**
Palliative care in CF	Joint working between services / across settings already covered by QS13	**N**
Physiotherapist's role in relating to CFTR channel modulators	No recommendations in source guidance	**N**
Registers and audits	Participation in audit and collation of information are methods by which quality improvement can be evidenced. Quality statements focus on the delivery of care or	**N**

	support, not the methods by which evidence is collated.	
Technology in airway clearance	No recommendations in source guidance.	**N**
Time to diagnostic assessment	No recommendations in source guidance.	**N**
Listed in meeting – pregnancy planning and contraception with people with CF – premature deaths	No recommendations in source guidance.	**N**

8. Resource impact	It was suggested that: • making individual rooms with en-suite facilities available for all inpatients with CF could have a resource impact at a local level • making such rooms available could also prevent the costs associated with treating cross infection	
8.1 Overarching outcomes	The NICE team presented overarching outcomes that could be improved by implementing a quality standard on cystic fibrosis. Committee did not make any amendments to the list suggested, but members were informed they can contribute suggestions as the quality standard is developed.	
8.2 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.	
9. Next steps and timescales (part 1 – open session)	PD outlined what will happen following the meeting and key dates for the cystic fibrosis quality standard. MR thanked the specialist committee members for their input into the development of the quality standard.	
10. Any other business	**Date of post-consultation meeting for Developmental follow-up of babies and young people born pre-term and for cystic fibrosis: 13 February 2018** **Date of next QSAC 2 meeting: 14 December 2017**	