

#### Quality standards advisory committee 2 meeting

Date: 13 February 2018

**Location:** NICE office, Level 1a City Tower, Piccadilly Plaza, Manchester, M1 4TD

**Morning session:** Cystic fibrosis – review of stakeholder feedback

Afternoon session: Developmental follow-up

- review of stakeholder feedback

Minutes: Draft

#### **Attendees**

## Quality standards advisory committee 2 standing members:

Michael Rudolf (chair), Julie Clatworthy, Corinne Moocarme, Malcolm Griffiths, Arnold Zermansky, Jean Gaffin, Jane Putsey, Steve Hajioff, Allison Duggal, Moyra Amess

## Specialist committee members (SCMs for cystic fibrosis):

Martin Walshaw lolo Doull Janis Bloomer Nichola MacDuff Zoe Elliot

# Specialist committee members (SCMs for developmental follow up):

Nashwa Matta Grenville Fox Joe Fawke Nicola O'Connor Samantha Johnson Phillip Harniess Annemarie Sims

## **NICE staff**

Mark Minchin (MM) Eileen Taylor (ET) Stacy Wilkinson (SW) Julie Kennedy (JK) Rick Keen (notes)

**Apologies** Gillian Baird, James Crick, Guy Bradley-Smith, Jane Bradshaw, Robyn Noonan, Ruth Studley, Mathew Sewell, David Weaver, Michael Fairbairn, Michael Varrow, Helen McCabe (SCM – cystic fibrosis), Tracey Daniels (SCM – cystic fibrosis)

#### 1. Welcome, introductions objectives of the meeting

The Chair welcomed the attendees and the quality standards advisory committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the meeting, which were to review stakeholder comments on the cystic fibrosis and the developmental follow up quality standards.

The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.

## 2. Confirmation of matter under discussion and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the morning session was cystic fibrosis, including specifically:



- Annual reviews
- Preventing cross-infection
- · Treating chronic lung infection
- Choice of mucoactive agent

The Chair asked standing QSAC members to declare verbally any interests that have arisen since the last meeting and all interests specifically related to the matters under discussion. Interests declared are detailed in appendix 1.

#### 3. Minutes from the last meeting

The committee reviewed the minutes of the last QSAC 2 meeting held on 9 January 2018 and confirmed them as an accurate record.

## 4. QSAC updates

MM outlined new policy on declaring and managing interests for advisory committees, highlighting next steps for the next few months, and answered queries from the committee members.

#### 5. Recap of prioritisation meeting and discussion of stakeholder feedback

ET provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the cystic fibrosis draft quality standard.

ET summarised the significant themes from the stakeholder comments received on the cystic fibrosis draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

## Discussion and agreement of amendments required to quality standard

## **Draft statement 1:**

People with cystic fibrosis have a comprehensive annual review

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

- Whether the CF data registry used as a data source for this statement was logging patients who did not attend scheduled annual reviews as attending and if so, that the registry would be difficult to use to measure the quality statement. The committee highlighted that the input criteria for the data registry did allow health professionals to state non-attendance of a scheduled annual review. It was also noted that in collating data, for example in regards to FEV1, professionals consider stand-out trends, rather than just averages.
- Whether the statement should focus on the actions which follow on from the annual review. The committee highlighted that the annual review needed to include specifications about the present and future care of people with cystic fibrosis; this should be reflected in the supporting information.
- Whether the wording of the statement in reference to 'people' put too much emphasis on adults, excluding children and their families.
   The committee agreed that it was vital that the quality standard makes it clear that it includes children with the condition, and their families.
- Whether it was important to include advice in regards to family planning for women with cystic fibrosis within the statement criteria.
   The committee agreed that the definition would be kept as it is,



	based on the guideline recommendation.
	The committee agreed that, whilst the data suggests that annual reviews are being conducted by all cystic fibrosis centres, comprehensive annual reviews are not being carried out for everyone with cystic fibrosis.
	Action:
	No change to statement wording. NICE team to edit supporting information for all statements to include children with cystic fibrosis and their families. The supporting information will also highlight that feedback from the annual review should be provided to people with cystic fibrosis, and their family if it is a child, and that the annual review should be used to create a future plan for the person's care.
Draft statement 2: People with cystic fibrosis have individual rooms with	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.
en-suite facilities when admitted to hospital as	The committee discussed the following:
inpatients	<ul> <li>Whether being in an individual room would make people with cystic fibrosis feel isolated and cause them distress, particularly for children. The committee noted that people with cystic fibrosis are aware of the risks of them mixing with others and therefore they understand why it is so important that they have an individual room when they are in hospital.</li> <li>The committee noted that without available facilities to accommodate people with cystic fibrosis there may be a delay in</li> </ul>
	elective admissions.
	The committee noted that individual rooms and en-suite facilities to prevent cross-infection are vital for people with cystic fibrosis.
	Action:
	No change to statement wording.
Draft statement 3: People with cystic fibrosis who have chronic Pseudomonas aeruginosa infection have sustained treatment with an inhaled antibiotic	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.  The committee discussed the following:
	Whether the stakeholder comment that only 30 to 40 percent of patients tolerated the inhaled antibiotics was accurate. The committee felt that most people can tolerate the medication. It was agreed that the statement should not be changed as it directly matches the guideline recommendation.
	The committee agreed that including a definition of 'chronic Pseudomonas aeruginosa infection' would be helpful and it was agreed this would be similar to the definition used by the CF data registry.



	Action:  No change to statement wording. Inclusion of definition of chronic Pseudomonas aeruginosa infection.
Draft statement 4: People with cystic fibrosis who have clinical evidence of lung disease are prescribed rhDNase as the first choice of mucoactive agent.	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.  The committee discussed the following:  RhDNase is licensed for children of five years and above. The committee noted that if prescribed below this age the prescriber should follow relevant professional guidance.  Action:
	No change to statement wording. NICE team to update footnote to make it clear that rhDNase is licensed for children age 5 and over.

## 6. Additional quality improvement areas suggested by stakeholders at consultation

The following areas were not progressed for inclusion in the final quality standard as the committee agreed that the four quality improvement areas already included were the key areas:

1. Transition

This area was discussed at the first committee meeting for this topic and was not progressed as there is a quality standard on transition.

2. Genetic testing and patient journeys

Testing for cystic fibrosis was discussed at the first committee meeting and not progressed as an area for quality improvement. It was noted that genetic testing will becoming more mainstream in the near future and this will include genetic testing for CF and so could be included in updated guidance in future. Patient journeys were also considered by the committee and not progressed.

## 7. Resource impact and overarching outcomes

The committee considered the resource impact of the quality standard. It was noted that whilst there may be an impact on resources to provide individual rooms with en-suite facilities, this is part of the NHS England service specification for cystic fibrosis centres and is included in the payments for this. No other significant resource impacts were identified.

ET requested that the committee submit suggestions to the NICE team relating to the overarching outcomes of the quality standard when it is sent to them for review.

The committee did note the following additional overarching outcomes.

- Lung function
- Incidence and prevalence of infection
- Health related quality of life
- Survival rates

#### 8. Equality and diversity

ET provided an outline of the equality and diversity considerations included so far and requested that the



committee submit suggestions when the quality standard is sent to them for review. The committee noted that for statement 4 it needs to be noted that rhDNase is not licensed for children under 5 years. The committee noted that this can be prescribed to children under 5 if clinically appropriate with the prescriber following relevant professional guidance and obtaining and documenting informed consent.

### 9. Close of morning session

The specialist committee members for the cystic fibrosis quality standard left and the special committee members for the developmental follow-up quality standard joined.

## 10. Welcome, introductions and objectives of the afternoon

The Chair welcomed the developmental follow-up specialist committee members and QSAC members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the afternoon, which was to review stakeholder comments on the developmental follow-up quality standard.

The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.

## 11. Confirmation of matter under discussion and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the afternoon session was developmental follow-up, including specifically:

- Discharge planning
- Single point of contact
- Enhanced developmental surveillance up to 2 years
- Developmental assessment at 4 years

The Chair asked both standing specialist QSAC members to declare verbally all interests specifically related to the matters under discussion during the afternoon session. Interests declared are included in appendix 1.

## 12.1 Recap of prioritisation meeting and discussion of stakeholder feedback

SW provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the developmental follow-up draft quality standard.

SW summarised the significant themes from the stakeholder comments received on the developmental follow-up draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

## 12.2 Discussion and agreement of amendments required to quality standard

#### **Draft statement 1:**

Parents or carer of a preterm baby agree a discharge plan with maternity services

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

- Whether it was accurate to state that the discharge plan is agreed with 'maternity services'. The committee noted that maternity services do not include neonatal services, which is where most preterm babies will be discharged from. As the key area for quality improvement is that parents or carers have an agreed discharge plan before their baby leaves hospital, they agreed to take the reference to the service out of the statement, and clarify which services are involved in the audience descriptor.
- Whether any of the stakeholder suggestions of detail to add to the definition of the



discharge plan are needed. The committee agreed that signposting to local support services is important and should be added.

Actions: NICE team to re-word the statement to remove reference to maternity services and add signposting to local support services to the definition of the discharge plan.

#### **Draft statement 2:**

Parents or carers of a preterm baby who is eligible for enhanced developmental support are provided with a single point of contact for outreach care within the neonatal service.

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

The committee discussed the following:

- That once the child is discharged from neonatal services at 2 years, it would be inappropriate to use this single point of contact. The committee agreed that it needs to be clearer in the supporting sections of the statement that contact with outreach care within neonatal services will end when contact with the service ends.
- Whether pre-term babies who are born outside of the network they live in should be mentioned. The committee highlighted that having a single point of contact would help if families change location, as they could be signposted to the contact in their area, so no further detail needs to be added.
- Whether any of the stakeholder suggestions of detail to add to the definition of the single point of contact for outreach care are needed. The committee agreed that the point of contact is not for acute illnesses or emergencies and this should be made clearer.
- That the use of the word 'support' would be better than 'reassurance' in the supporting sections of the statement.

#### Actions:

No change to statement wording.

NICE team to make it clearer in the definition of the single point of contact that outreach care is for non-acute issues.

NICE team to clarify in the supporting sections that outreach care should be available until the child leaves the service.

Change 'reassurance' to 'support' in the supporting sections.



#### Draft statement 3:

Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up visits in the first year and an assessment at 2 years that focuses on development.

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

- Whether babies with severe hypoglycemia should be included in the definition of children eligible for enhanced surveillance. The committee agreed that no change is needed as these babies would be covered by the current definition.
- That the supporting sections specify that the assessment at 2 years is at the corrected age, but not that the visits in the first year are at the corrected age. The committee agreed that this should be changed.
- Stakeholder comments on whether the statement could result in children having fewer follow-up appointments. The committee noted that children might have multiple appointments for other issues, such as feeding and growth, not just development, but the developmental assessments can be done at them and does not mean that these should not happen. The committee agreed that the current wording covers this, so no changes are needed.
- The issues with using the PARCA-R questionnaire when parents do not speak English. The committee discussed what would be a suitable alternative and the languages that different questionnaires are available in. The committee agreed that clinicians should use their judgement to choose the most suitable alternative assessment, rather than a questionnaire, and that this should be made clearer in the definition of the assessment and the equality and diversity considerations.
- Whether the process measures
   acknowledge that families might change
   location during the follow-up period. The
   committee noted that this could be achieved
   by adding wording on the booking hospital
   or the service the baby is discharged from. It
   was also raised that it should be made
   clearer that process measure b is
   measuring an additional follow-up visit to the
   visit in measure a.
- Whether the 'red book' is a reliable data source for the process measure. The committee agreed that, as it is a suggested



source and not the only suggestion, it does not need to be changed.

- Whether further clarity is required in the professional audience descriptor about which roles are needed at the assessments. The committee discussed that allied health professionals do not need to be present at the first two checks, but should be at the 2 year check. It was agreed that the current wording covers this and does not need to change.
- Whether parents or carers might think that a follow-up 'visit' means a home visit. The committee agreed that using 'appointment' or 'assessment' would be clearer.

#### **Actions:**

No change to statement wording.

NICE team to amend the definition of the assessment and the equality and diversity considerations to state that a 'suitable alternative assessment' rather than 'questionnaire' should be used instead of PARCA-R.

Amend the wording of the process measures so that hospitals only measure follow-up of children that they are responsible for. Amend process measure b so that it measures an additional visit.

Change follow-up 'visit' to appointment or assessment.

## Draft statement 4:

Children born before 28<sup>+0</sup> weeks' gestation have a developmental assessment at age 4 years.

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

- Whether it is clear what 'at age 4 years'
  means. The committee noted that within
  services follow-up appointments are usually
  within 6 months either side of the specified
  age to allow for scheduling. The committee
  agreed that the supporting sections should
  be amended to say that the developmental
  assessment takes place as close to the
  child's 4th birthday as possible.
- The committee highlighted how not all children would receive their assessment before they start school, so the rationale should be amended to reflect this.



- The same changes should be made in the definition of the assessment and the equality and diversity considerations as for statement 3 regarding suitable alternative 'assessments' instead of 'questionnaires' for people with poor English language comprehension.
- Whether healthcare professionals can ensure that orthoptic vision screening has been offered at the 4 year assessment as it might not be offered until they are 5. The committee agreed that including it in the definition of the assessment would highlight that it should be checked, and if a child has not been offered it yet, they can flag that it needs to be done. The committee agreed that the definition does not need to change.

## Actions:

No change to statement wording.

NICE team to amend supporting sections to state that the developmental assessment takes place as close to 4 years as possible.

Amend rationale to reflect that not all children have the assessment before starting school.

NICE team to amend the definition of the assessment and the equality and diversity considerations to state that a 'suitable alternative assessment' rather than 'questionnaire' should be used for people with poor English language comprehension.

## 12.3 Additional quality improvement areas suggested by stakeholders at consultation

The following areas were not progressed for inclusion in the final quality standard:

- Multidisciplinary team
- Data collection and reporting
- Staff training
- Communication about follow-up
- Developmental assessment practices, use of technology and therapy led groups

## 13. Resource impact and overarching outcomes

The committee considered the resource impact of the quality standard, including the resources required to implement statements 3 and 4, and agreed that there are no resource implications that make the statement unachievable above and beyond those identified during the guideline development process.

The committee confirmed the overarching outcomes are those presented in the draft quality standard. It was noted that many children will have started school at 4 years old and thus may not be ready, or even have their results by this point. NICE team to consider criteria amendments in regards to questionnaires given at assessments – re-wording to 'suitable alternative assessments' instead of 'questionnaires' due to language barriers.

SW requested that the committee submit suggestions to the NICE team relating to the overarching



outcomes of the quality standard when it is sent to them for review.

The committee did note the following additional overarching outcomes.

- Identification of special educational needs
- advice provided to parents and carers

## 14. Equality and diversity

SW provided an outline of the equality and diversity considerations included so far and requested that the committee submit suggestions when the quality standard is sent to them for review. The committee agreed that using suitable alternative assessments when English language comprehension is an issue applies to all assessments, not just PARCA-R, and should be applied to all relevant statements.

## 15. Any other business

As this was Dr Arnold Zermansky's last QSAC meeting, the Chair, on behalf of all the standing members, thanked him for his contribution to the committee's work.

## Close of meeting



# **Appendix 1: Declarations of interest**

Name	Membership	Declaration
Helen McCabe	Specialist	None.
Iolo Doull	Specialist	lolo gave three educational lectures on paediatric asthma, for which he received a fee from Astra Zeneca.  He attended a paediatric advisory board on paediatric asthma, and received a fee from Boehringer Ingelheim.
Janice Bloomer	Specialist	None.
Martin Walshaw	Specialist	None.
Nichola MacDuff	Specialist	None.
Tracey Daniels	Specialist	Tracey has previously completed paid consultancy work for Philips. She have also completed paid advisory boards for Raptor, Forest pharmaceuticals, Novartis, Gilead and Pharmaxis. She have given paid presentations for Pharmaxis and for Roche.  She have received educational grants/sponsorship or travel expenses from Philips, Raptor, Zambon, Forest pharmaceuticals, Actavis, Novartis, Pharmaxis and Roche.
Zoe Elliott	Specialist	Zoe has been paid for the communication & marketing work she did for the James Lind Alliance Priority Setting Partnership in Cystic Fibrosis.
		Accepted for European CF Conference June 2017 Presenting posters: #questionCF - The use of social media to engage the CF community in research Question CF: A James Lind Alliance Priority Setting Partnership in Cystic Fibrosis (the project is paying for my flights and hotel to attend the last day of the conference, everything else is self funded).
		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 <a href="http://www.eurordis.org/content/eurordis-summer-school-patient-advocates#c">http://www.eurordis.org/content/eurordis-summer-school-patient-advocates#c</a>
		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.
Anne-Marie Sims	Specialist	None.
Grenville Fox	Specialist	None.
Joe Fawke	Specialist	Consultant Neonatologist, University Hospitals Leicester NHS Trust     Honorary Senior lecturer, University of Leicester     Paediatric Training Programme Director, Health Education East



#### Midlands

- 4. Chair, NICE Parenteral Nutrition in Neonates guideline committee
- 5. Chair, Advanced Resuscitation of the Newborn Infant Working Group, Resuscitation

Council (UK)

- 6. Member of NICE Developmental Follow up of Preterm Babies guideline committee
- 7. Member, Newborn Life Support Working Group, Resuscitation Council (UK)
- 8. Co-Director Leicester Neonatal Simulation Team which runs neonatal simulation

instructor courses. All proceeds from these courses are paid to the Leicester

Neonatal Service and I receive no remuneration from these courses.

9. Invited Faculty for the European Resuscitation Congress September 2017, travel

expenses / accommodation covered but no remuneration.

10. Invited to the Neonatal Discussion Forum, conference & travel costs met, no

remuneration.

11. Invited faculty to RC(UK) scientific symposium, no remuneration.

#### **Relevant Publications:**

## Pending peer review with Archives of Disease of Child Health

- Duley L, Dorling J, Pushpa-Rajah A, Oddie S, Yoxall CW, Schoonakker B, Bradshaw L, Mitchell E, **Fawke J**. Randomised trial of cord clamping and initial stabilisation at very preterm birth.
- Batey N, Yoxall B, **Fawke J**, Duley L, Dorling J. Fifteen Minute consultation: Bedside stabilisation of the high risk newborn infant. Commissioned article by Archives.
- Duley L, Dorling J, Pushpa-Rajah A, Oddie S, Yoxall CW, Schoonakker B, Bradshaw L, Mitchell E, **Fawke J** on behalf of the Cord Pilot Trial Collaborative Group. Randomised trial comparing two policies for cord clamping and initial neonatal stabilisation at very preterm birth.

## Published:

 $\bullet$  Fawke J, Cusack J. Advanced Resuscitation of the Newborn Infant 2015 guidelines

addendum. Resuscitation Council (UK) 2015.

• Fawke J, Cusack J. Advanced Resuscitation of the Newborn Infant. 1st edition,

Resuscitation Council (UK) 2014.

• Bolton C, Stocks J, Hennessey E, Cockcroft J, **Fawke J**, Lum S, McEniery C, Wilkinson I,

Marlow N. The EPICure study: association between hemodynamics and lung function at 11

years after extremely preterm birth. J Pediatr. 2012; 161(4): 595-601.

• McEniery CM, Bolton CE, **Fawke** J, Hennessy E, Stocks J, Wilkinson IB, Cockcroft JR,

Marlow N. Cardiovascular Consequences of Extreme prematurity. J Hypertens. 2011;

29(7): 1367-73.



		• Fawke J, Lum S, Kirkby J, Hennessey E, Marlow N, Rowell V, Thomas
		V, Stocks J.
		Lung Function and Respiratory Symptoms at 11 Years in Children born extremely preterm.
		The EPICure Study. Am J Crit Respir Care Med. 2010; 182: 237-245.
		• Kirkby J, Welsh L, Lum S, <b>Fawke J</b> , Rowell V, Thomas S, Marlow N, Stocks J. The
		EPICure Study: Comparison of Pediatric Spirometry in Community and
		Laboratory settings. Pediatric Pulmonology 2008; 43:1233-1241.
		International Awards:
		2008 Recipient of the Bengt Robertson Award from the European Academy of Paediatrics for research on the neonatal lung.
		National Awards:
		2008 recipient of the Dr. Michael Blacow Memorial Prize, RCPCH for presentation on 11 year neurodevelopmental and respiratory outcomes of the 1995 EPICure cohort.
Nashwa Matta	Specialist	1. Speaking at Neonatal MCN Scotland on Educational and Developmental needs of children born preterm 8/8/2017 Invited by the East MCN
		2. Speaking at Aberdeen on and Developmental needs of children born preterm and NICE guidelines 16/8/2017
Nicola O'Connor	Specialist	Nicola is a trustee for First Touch which supports the Neonatal Unit at St George's Hospital in London.
	Specialist	Phillip is a member of APCP Neonatal committee – special interest group
		Member of EI SMART committee – expert therapists committee developing an early intervention framework for application the NHS context
		Previous research:
Phillip Harniess		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 – An Local Action Research Project'
	Specialist	Specific, personal, non-financial interests:
Samantha Johnson		Johnson S, Waheed G, Manktelow BN, Field D, Marlow N, Draper ES, Boyle EM. Differentiating the preterm phenotype: Distinct profiles of cognitive and behavioural development following late and moderately preterm birth. Journal of Pediatrics, doi: 10.1016/j.jpeds.2017.10.002. [Epub ahead of print].
		Linsell L, Johnson S, O'Reilly H, Wolke D, Morris J, Kurinczuk J, Marlow N. Cognitive trajectories from infancy to early adulthood following birth



- before 26 weeks of gestation: a prospective population based cohort study. Archives of Disease in Childhood doi: 10.1136/archdischild-2017-313414. [Epub ahead of print].
- Johnson S. Foreword in Occupational therapy in neonatal services and early intervention. Practice Guideline. Royal College of Occupational Therapists 2017.
- Johnson S and Wolke D. 'Prematurity and low birthweight' pages 705 to 716. In Hopkins B, Geangu E, Linkenauger S. (Eds) The Cambridge Encyclopaedia of Child Development 2<sup>nd</sup> Edition. Cambridge University Press, 2017.

#### 2) She has given 8 presentations that relate to the topic area:

- The outcomes of prematurity. Small Steps Big Changes & Nottingham University Hospitals Neonatal Study Day, City Hospital Nottingham, UK, November 2017.
- Improving developmental outcomes after very preterm birth: The efficacy of early intervention. 12<sup>th</sup> Mater Growth and Development Unit Conference, Brisbane, Australia, October 2017.
- Understanding the nature and causes of very preterm children's mathematics learning difficulties: Implications for intervention. 12<sup>th</sup> Mater Growth and Development Unit Conference, Brisbane, Australia, October 2017.
- Long term psychological outcomes after extremely preterm birth: Evidence from the EPICure Studies. Mater Mothers' Hospital Grand Rounds, Brisbane, Australia, October 2017.
- Outcomes following late and moderately preterm birth: An extension of the very preterm phenotype? Mater Mothers' Hospital Neonatal Grand Rounds, Brisbane, Australia, October 2017.
- Looking beyond IQ in preterm children. 3<sup>rd</sup> Summer Conference on Neonatology, Avignon, France, September 2017.
- Understanding very preterm children's difficulties with mathematics: Implications for intervention. Centre for Early Brain Development, Norwegian University of Science and Technology, Trondheim, Norway, September 2017.
- Lifespan mental health outcomes following preterm birth. Current Issues in Clinical Neuroscience: The Neonatal Brain. University Medical Centre, Utrecht University, Utrecht, The Netherlands, June 2017.

## Specific, non-personal, financial interests:

She have been awarded the following research grant as chief investigator. All funds are awarded to her employing institution (University of Leicester), no funds are received personally.

Action Medical Research, £70,698; for 12 months commencing April 2018. Standardisation of the Parent Report of Children's Abilities-Revised for use as a developmental screening tool and clinical outcome measure. Samantha Johnson, Louise Linsell, Dieter Wolke, Neil Marlow, Peter Brocklehurst & Bradley Manktelow.