

## National Children and Young People's Gender Dysphoria Research Oversight Board

**Notes of meeting held on 13 March 2024**  
**Microsoft Teams Meeting**

### Chair:

Professor Sir Simon Wessely

### Decision-making members

Dr Indi Banerjee

Dr Hilary Cass

Professor John Chester (from agenda item 5)

Dr Helen Griffiths

Dr Camilla Kingdon

Dr Bidisha Lahoti

Dr Gail Marzetti

Dr Lindsay Neil

Professor James Palmer

Beth Scott

Professor Emily Simonoff

Stephen Tomlin (from agenda item 5)

Dr Troy Tranah

### Attendees



## Meeting notes

Item	Items	Presenter
1.	<b>Welcome and introductions</b>	
<p>Dr Kingdon informed members that this was her last meeting, as Professor Steve Turner assumes the role of President of the Royal College of Paediatrics and Child Health in April. The Chair thanked Dr Kingdon for her contribution to the board's work.</p> <p>The Chair welcomed Beth Scott, Head of Research Programmes at Department of Health and Social Care as a new member, replacing Gail Marzetti.</p>		
2	<b>Draft minutes of previous meeting</b>	
<p>The notes of the previous meeting were agreed as accurate and complete.</p>		
3.	<b>Clinical commissioning policy: Puberty Suppressing Hormones</b>	
<p>Professor Palmer informed members that following an extensive review of the evidence, on 12 March NHS England had confirmed that Puberty Suppressing Hormones would not be a routinely commissioned intervention for children and young people with gender incongruence, effective from 1 April. The review had concluded that there was not sufficient evidence of safety, effectiveness and outcomes. Dr Lahoti welcomed the clarity the policy provided for new service providers.</p> <p>NHS England's decision does not relate to prescribing for Central Precocious Puberty, for which GnRHAs are licensed. NHS England is exploring with Department of Health and Social Care the issues around prescribing through private practice and unregulated providers.</p>		
4.	<b>Update on proposed study on Puberty Suppressing Hormones</b>	
<p>Members received an update from Professor Simonoff:</p> <ul style="list-style-type: none"> <li>• An outline protocol has been developed.</li> <li>• Most Principal Investigators (PIs) are in place and a number of meetings have been held with them, though a PI has not yet been identified for paediatric endocrinology, which might ideally be filled by an expert from outside of the UK. There is a diversity of opinion between the PIs about the feasibility of an RCT approach.</li> <li>■ On 8 March the National Institute for Health and Care Research (NIHR) had hosted a study development workshop, chaired by ■</li> <li>• Wales were likely to formally join the study.</li> <li>• The planning assumption is that a full stage 2 application will be made to NIHR by July 2024, with – subject to subsequent approvals - the study potential recruiting participants early-mid 2025.</li> </ul> <p>■ reminded members that work with stakeholders to begin to identify other research priorities, including in the later onset cohort, would begin once the Phase 1 providers were operational. This would be commissioned from the James Lind Alliance using their established priority setting partnership (PSP) approach. Further details will be brought to a future meeting.</p> <p>Dr Cass remarked that use of a core data set by the new providers was the key to future research efforts; Dr Neil assured members that the providers have a consistent, though</p>		

limited data set agreed for initial use, and that work continues to develop a more detailed data set once work to standardise the providers EPR systems is complete. Professor Palmer said that this was unlikely to be before July 2024, and that he wanted to explore with the providers the expertise that was necessary to establish a common data repository. **Agreed: Update on work to develop a core dataset to be an agenda item for the next meeting.**

Dr Cass remarked that her report is likely to recommend that there should also be a formal evaluation of non-medical interventions as a response to paediatric gender incongruence. While members were supportive of the proposition, Professor Simonoff's view was that the group's efforts should be focused on establishing the PSH study before reaching to other elements of the pathway.

Members noted that the proposed James Lind Alliance Priority Setting Partnership work is still planned, with NIHR's support; aiming to start during the autumn 2024.

**5. Update from the Cass Review**

Dr Cass informed members that she expects her final report to be published in April.

Dr Cass will write to NHS England on the Data Linkage Study. Professor Palmer reassured members that NHS England would make all efforts to put the Data Linkage Study into place.

**6. Next meeting, 29 May 2024**

[REDACTED] is now leading NHS England's work to establish a Patient and Public Voice framework for its work around children and young people's gender incongruence services. An update will be provided at the next meeting.

**7. Future meeting dates**

- 8 July 2024, 3pm to 4.30pm
- 16 September 2024, 3.30pm to 5pm (in person)
- 18 November 2024, 3.30pm to 5pm