

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

**Notes of meeting held on 29 May 2024  
Via MS Teams**

## Chair:

Professor Sir Simon Wessely

## Decision-making members:

Michael Absoud  
Julie Alderson  
Indi Banerjee  
Hilary Cass  
John Chester  
Rachel Elvins  
Peter Fonagy  
Elizabeth (Lizzie) Fussey (*deputising for Steve Turner*)  
Helen Griffiths  
Bidisha Lahoti  
Stuart Logan  
Grainne McAlonan  
James Palmer  
Beth Scott  
Stephen Tomlin  
[REDACTED]  
Tom Voit  
Eloise Wyke (*deputising for Julie Alderson*)

## Attendees:

Michael Chapman  
[REDACTED]

## Apologies:

Apologies were received from:

Dr Julie Alderson, Clinical Psychologist, Bristol (*Eloise Wyke was welcomed as a deputy*)

Steve Turner, President of the Royal College of Paediatric and Child Health (*Elizabeth Fussey, Policy Manager for Child Protection and Ethics (RCPCH), was welcomed as his deputy*)

## Agenda Item 2: Minutes of the Previous Meeting

The notes of the previous meeting, held on 13 March 2024, were agreed as accurate and complete.

## Agenda Item 3: Matters Arising

It was noted that Dr Hilary Cass will now take over from James Palmer as the Chair of the Research Sub-group, which meets approximately bi-monthly.

Early preparatory work continues for the planned James Lind Alliance Priority Setting Partnership (PSP) which will take a systematic approach to engagement with a wide range of stakeholders to identify and prioritise future gender research topics. The PSP is likely to formally go live towards the end of 2024 or early 2025, which will enable stakeholders to engage with the benefit of experience and learning from the first months of delivery of new services.

**Action:** *Members were asked to consider potential PSP steering group membership and forward any suggestions to [REDACTED]*

Good progress had been made in recruiting to additional research and evaluation capacity within the south hub, following additional funding support endorsed by the Research Oversight Board.

**Action:** *[REDACTED] to provide additional assurance on the available funding to north and south-west hub colleagues to support progress on recruitment in this important area.*

Professor Palmer gave an update on the establishment of the National Youth Advisory Network, with whom Professor Simonoff is now engaging on trial design for the planned puberty suppressing hormone study.

## Agenda item 4: Publication of the Independent Review Final Report

Members noted the publication of the final report on 10 April and discussed associated media and stakeholder coverage. Dr Cass particularly highlighted that she had had to refute incorrect assertions that were becoming widespread on social media that the Review had excluded relevant evidence. She reiterated that the method for evidence review was robust and described transparently in the report.

Members discussed the research specific recommendations in the report and noted other potential research priorities, including:

Gender Affirming Hormones – noting the need to define the question to be answered  
Patients not on a medical pathway – noted that outcome measures would need to be defined, and that this would be difficult given lack of clarity on the range of

interventions; would require voluntary long-term follow into adulthood. Professor Fonagy suggested that the TIDieR checklist could be helpful, which focuses on psychosocial interventions.

Dr Cass described her ambitions for the establishment of the National Provider Collaborative, and said it was critical that the new services established a consistent data set, and approach to research activities.

### Agenda item 5: Update on the Progress of the Data Linkage Project

Members were referred to the supporting paper, previously circulated.

Members noted the issues currently impacting on progress with the study. The permissive approach was still preferred but members also noted the potential option that a Direction could be made by the Secretary of State if the gender clinics did not voluntarily collaborate in relation to the opt out and data sharing requirements. A Direction would result in a compulsory Data Provision Notice issued to the NHS Trusts that host the adult gender clinics. All options were continuing to be explored to enable the study to progress.

### Agenda item 6: Progress Update Puberty Suppression Hormone Study

Professor Simonoff provided a verbal update on the good progress that was being made in completing recruitment to the study team, on the draft study application and in early engagement on study design and potential outcome measures. The National Children's Bureau would be supporting ongoing patient and public engagement. Michael Absoud has been confirmed as deputy Chief Investigator and [REDACTED] [REDACTED] has joined the study team to provide a lived experience perspective. The current goal is to complete and submit the stage 2 study application for NIHR peer review and committee consideration in late July. NIHR were planning a further study workshop for September to enable a round table approach to any remaining design issues requiring further consideration at that stage.

### Agenda item 7: Establishing a Core Clinical Data Set

Members welcomed Dr Absoud's presentation and thanked him for his work and that of other colleagues in making progress in this area. Members endorsed the proposed consent / assent forms and the core clinical data set to now be consistently collected by all commissioned providers. It was noted that it was largely agreed that REDcap would be used in terms of data reporting tool, but this needed to be further discussed at a forthcoming meeting with the Liverpool team.

**Action:** John Chester to check in with north hub colleagues the proposed use of REDcap and to provide an update at the next meeting.

### Date of the Next Meeting:

It was noted that the next meeting would be held, via MS Teams, on Monday 8 July 2024, 15:00 – 16:30.

Members were reminded that the 16 September meeting would provide an opportunity to meet in person.