

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

**Notes of meeting held on 8 July 2024
Via MS Teams**

Chair:

Professor Sir Simon Wessely

Decision-making members:

Michael Absoud
Julie Alderson
Hilary Cass
Rachel Elvins (*from item 5*)
Peter Fonagy
Helen Griffiths
Bidisha Lahota
Lindsey Neil
James Palmer
Beth Scott
Emily Simonoff
Troy Tranah
Steve Turner
Thomas Voit

Attendees:

[REDACTED]

Apologies:

John Chester
[REDACTED]

Agenda Item 1: Welcome and Introductions

Professor Steve Turner (President of the Royal College of Paediatric and Child Health) and Dr Julie Alderson, Consultant Clinical Psychologist, representing the planned south west service, were welcomed to their first meeting.

Peter Fonagy was congratulated on the award of a CBE and Hilary Cass was congratulated on her peerage.

Agenda Item 2: Minutes of the Previous Meeting

The notes of the previous meeting, held on 29 May 2024, were agreed as accurate and complete.

Agenda Item 3: Matters Arising

Research and Service Evaluation Team Resource: Updates were provided on the progress of recruitment to new team roles supporting research and service evaluation, after additional funding had been confirmed following the south and north hub's joint proposal being endorsed by the Research Oversight Board in January. Michael Absoud confirmed that, other than a planned appointment to a deputy clinical lead role, appointments were otherwise complete in the south hub. The clinical lead role was still to be progressed in the north team. A standard operating procedure was now in place with the Band 6 roles expected to be key in supporting work on data completeness and initial analyses.

Action: [REDACTED] to confirm with Julia Anderson the linked funding available for the south west service to aid forward planning.

Consistent Data Collection: Following sign off at the last meeting, the agreed core data set is now being consistently collected across both hubs. The use of REDCap in the north hub was pending the necessary informational governance approvals, with data in the meantime being recorded in the patient's electronic record. Michael Absoud would be meeting with the south west team to support their preparations for the agreed single data approach.

Action: Lindsey Neil to progress information governance approvals and associated consent requirements within the north hub service to support consistent use of REDCap for data collation.

Living Systematic Review: [REDACTED] noted the need to secure an approach to maintain regularly updated evidence reviews, following initial work undertaken by York, to inform future clinical practice and policy.

Action: Beth Scott will make an introduction to colleagues to explore a review option via the NIHR evidence synthesis team.

Agenda Item 4: Establishment of the CYP National Gender Youth Advisory Network

[REDACTED] joined the meeting to provide an update on the recently established national gender Youth Advisory Network, which had now met five times and had already supported engagement on the planned puberty suppressing hormone study design and outcome measures. Currently invitations to join the Network are for children and young people aged 11 to 18 years (and their parents or carers) from the active caseload, although this may be expanded in the future. Patient and public voice leads from the north and south hubs were thanked for their very positive contributions in supporting the initial meetings, together with lived experience

representatives who kindly shared their experience of involvement with the NHS England CYP gender programme. Future engagement topics may include the development of the new CYP service specification, shaping the work programme of the CYP clinical reference group (CRG) and testing draft comms and survey approaches for the James Lind Alliance Priority Setting Partnership. The hubs are setting up local engagement networks in parallel.

Agenda Item 5: Update on the Development of the Puberty Suppressing Hormone Study

Emily Simonoff provided an update on the proposed study design and the membership of the study team. [REDACTED]

[REDACTED] is now providing expert advice on the cognitive elements of the study.

The second stage study application to NIHR is likely to be slightly delayed, and is now expected to be submitted by the end of August. Emily does not currently believe this will impact on the estimated timeline for the study to open to recruitment in early 2025, but this will depend on peer and committee review.

The National Children's Bureau is supporting the study's plans for ongoing patient and public engagement. An easy access version of the protocol is being planned based on feedback from the Youth Advisory Network engagement sessions.

Agenda Item 6: Data Linkage Study

James Palmer provided a brief update, noting ongoing discussions with York on taking forward the next phase of the study, and that legal advice was being sought on whether any update is required to the statutory instrument post the completion of the Cass Review.

Agenda Item 7: Progress Update – James Lind Alliance Priority Setting Partnership (PSP)

Michael Absoud has now taken over as clinical lead for the PSP, and a further meeting has been held with the James Lind Alliance team, including psychology representation from the north and south hubs, to plan the preparatory work for the PSP to go live in late 2024, or early 2025, as planned.

A key next step will be to define and agree the scope of the PSP, for example the age group to be covered, and whether to extend the scope beyond 'late onset gender dysphoria' as initially proposed.

Proposals also need to be developed on membership of the steering group, which is expected to meet monthly and would typically include 10-15 members. The JLA has advised that members would typically be aged 18 or above. Membership is likely to include individuals with lived experience, clinicians working directly in gender

services and wider representation from education and social care. Members of the national Youth Advisory Network might, subject to their agreement, act as a key reference and testing group for the project.

Action: *Michael Absoud to bring a draft PSP scope proposal to a future meeting for the Research Oversight Board's review and endorsement.*

Action: *Research Oversight Board members to contact Michael with potential steering group membership nominations..*

Date of the Next Meeting:

The next meeting will be held in person on Monday 16th September 15:30 – 17:00 in London (venue TBC).