

National Research Oversight Board for Children and Young People's Gender Services

Notes of the meeting held on 16 September 2024
Microsoft Teams Meeting

Chair:

Professor Sir Simon Wessely

Decision-making members:

Dr Michael Absoud
Baroness Dr Hilary Cass
Professor John Chester
Dr Rachel Elvins
Professor Peter Fonagy
Dr Lindsay Neil
Professor James Palmer
Beth Scott
Stephen Tomlin
Dr Troy Tranah

[REDACTED]

Attendees:

[REDACTED]

[REDACTED] (attending on behalf of Dr Julie Alderson)
[REDACTED] (NIHR observer)

Meeting notes

Item	Items	Presenter
1.	Welcome and Introductions	
<p>██████████ informed members that representatives of NHS Wales and NHS Scotland will be joining future meetings as observers; individuals to be confirmed shortly. Apologies were noted from Professor Emily Simonoff; and Dr Julie Alderson (██████████ is deputising for Dr Alderson).</p>		
2	Draft Notes of the Previous Meeting	
<p>The notes of the previous meeting on 8 July 2024 were agreed as accurate and complete.</p>		
3.	Gender Programme Update	
<p>Professor Palmer described the overall approach to the implementation of the Cass Review recommendations, including the establishment of the National Provider Network that will assume responsibility for management of many of the workstreams on a phased basis, once it is established from October 2024. The overarching governance group, the National Portfolio Board, holds its inaugural meeting on 24 September.</p>		
4.	Implementing the Cass Review Research Recommendations	
<p>██████████ updated members on the various strands of work relating to the Review recommendations that relate to research activities. Members received a copy of a letter from the Secretary of State for Health and Social Care to parliamentarians (September 2024).</p>		
5.	Update on Gender Research Communications	
<p>Members received a copy of a published summary that gives a broad overview of the key elements of current and joint research programme activities. Baroness Cass referred members to her recently published papers that she will share with the group.</p>		
6.	Puberty Suppressing Hormones Study Application Update	
<p>Members received an update from ██████████. The formal 'stage 2' application has been received from the Chief Investigator and has been peer-reviewed; a workshop is planned for September 2024 which will provide an opportunity for feedback received as part of the peer review stage to be further considered and addressed by the study team.</p>		

Members discussed the role of the Research Oversight Board in the study approvals process, noting that whilst regular high-level updates were being provided to them, they had not yet seen the detailed study application. The Chair confirmed that the role of Oversight Board was in confirming the original study commission into the National Research Collaboration Programme, through which the study was being progressed, and to consider a formal endorsement once NIHR had completed its usual peer review and scientific review and a positive funding recommendation had been reached. It was seen as important that the Oversight Board did not duplicate these 'business as usual' review stages which fell within NIHR's responsibilities, expertise and process. The Chair concluded that the role of the ROB was around priority setting, oversight and assurance, and that it had to properly restrict its role to a high-level overview of the study design process at this point.

██████████ confirmed that oversight board members would receive a full study briefing ahead of their endorsement being sought. Depending on the funding recommendation reached by NIHR, and timings, there may be a need for an additional Oversight Board meeting to enable approvals to progress in a timely way.

6.	Progress on the Common Core Dataset
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Members received a presentation from Dr Absoud and Dr Neil on progress in collecting the agreed core data set as part of service delivery.

Dr Neil outlined a potential additional project to build outcome measures. ██████████ suggested that ideally a joint proposal should be brought to the Research Oversight Board by all of the commissioned providers, including University Hospitals Bristol and Weston NHS Foundation Trust and Cambridge University Hospitals NHS Foundation Trust.

7.	Data Linkage Study Update
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██████████ updated members on legal advice received in relation to the linked statutory instrument.

Professor Palmer will shortly be meeting with NHS England's Chief Data and Analytics Officer to explore how NHS England can take the study forward using internal data analytic teams, and an update will be shared at the next meeting.

8.	Any Other Business
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Baroness Cass asked for an update on the Living Systematic Review. ██████████ said that she has shared details of the previous six reviews with members, and with clinical reference group colleagues, for comment, with the aim of updating the review topics if required. NIHR would subsequently be taking these reviews forward as part of their work programme.

9.	Next Meeting
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18 November 2024, 3.30pm to 5pm

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