HRCDC
Health Research Consent Declaration Committee

Minutes of the Meeting – APPROVED

Date: 26th May 2026
Location: The Health Research Board and online

HRCDC Attendance:

Aideen Hartney
Evelyn Mahon
Paul Stynes
Aisling McMahon
Sarah Barnes Aabo
Jonathan Briody
Jim Blighe
Barbara Clyne
Brid Burke (Secretariat)
Jonny Barrett (Secretariat)
Caroline Byrne (Secretariat)

Quorum for Decisions

YES

Opening

The Chair opened the meeting and welcomed the members.

Apologies

Ross McMullan, John Woods, Mary Tumelty, Antoinette O'Connor, Fionnuala Gough

Disclosure of Interest

There were no disclosures of interest for this meeting.

Minutes of the last meeting

Draft minutes of 28th April 2026 were circulated in advance of the meeting and were approved by the HRCDC.

New Applications

Reference ID:

26-010

Lead Applicant:

Daniela Tropea

Lead Data Controller:

Trinity College Dublin and St James Hospital (SJH)

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Title:
EEG-Based Analysis of Brain Activity in patients with rare neuropsychiatric disorders and typical development (TD) controls (EBABArare)

Research Objective:
This study uses EEG (brain wave recordings) to understand brain activity patterns in adults with rare neuropsychiatric disorders like Rett syndrome, Kleefstra syndrome, and Fragile X syndrome, compared to healthy controls. Participants (50 participants and 50 controls) will have sensors (electrodes) on their scalp applied for about one hour while their natural brain activity is recorded. No injections, blood tests, or medications are involved. Family caregivers complete a short questionnaire about basic health information. The goal is to identify measurable brain activity markers that could help doctors better diagnose these rare conditions and understand if different disorders share similar brain patterns. All personal information is protected by unique codes managed by the PI. Pseudonymised EEG data will be stored securely. This study aims to improve diagnosis and awareness for patients with rare brain disorders through research publications.

Reason for Declaration:
Explicit consent cannot be obtained from all the research participants because the study includes adults with rare neuropsychiatric disorders. They often suffer from cognitive disabilities and lack the decision-making capacity needed to provide informed explicit consent due to their condition; their parents/caregivers will provide proxy assent on their behalf.

HRCDC Comments:
The Chairperson requested the primary and secondary reviewers who were assigned to this application to outline the proposal contained in the application and any issues arising. There was then a discussion on the application by the HRCDC. Following detailed discussions, it was the consensus of the HRCDC that, while there is a public interest in the study, additional information will need to be provided about the study before a final decision is made by the HRCDC.

HRCDC Decision:
The consensus of the HRCDC was that a formal decision would be deferred pending receipt of further information.

Further information requested:
The HRCDC recognises that there is public interest in this study; however, it raised a number of concerns on the responses provided in the application form and to the Secretariat's pre-review questions. Therefore, the HRCDC is of the view that these matters need to be addressed to the satisfaction of the committee before it can make a decision on the application for a consent declaration.

Annual Reviews
The Secretariat has received 3 annual reviews in advance of the meeting which were deemed satisfactory:

- **Ref ID:** 23-003 (MACE)
- **Ref ID:** 19-021 (National Self-harm registry)

- **Ref ID:** 21-003 (Investigating the Epidemiology of Mycobacterium bovis infection in humans)

Activities report and events of interest

The Secretariat circulated a report of its activities to the HRCDC in advance of the meeting.

Any Other Business

- The HRCDC were reminded that the next meeting is scheduled for 23rd June 2026.

The Chair closed the meeting

Prior to the meeting commencing, there was a presentation on Artificial Intelligence in health research.