

SPECIAL INTEREST RESEARCH GROUP

PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES

Report of the 2025 Roundtable

University College Cork, Ireland, April 23-24, 2025



Profound Partnerships

**Working in partnership to advance research and support of persons
with profound intellectual and multiple disability**

We were delighted to welcome over 74 delegates from 15 different countries (Figure 1) to Cork, both online or in-person, for the SIRG Roundtable Meeting on the 23rd and 24th of April. Together, the ECR (held on the 22nd) and Roundtable Meetings intend to fuel knowledge exchange between researchers and carers interested in advancing the care and support of persons with Profound Intellectual and Multiple Disabilities and their families.

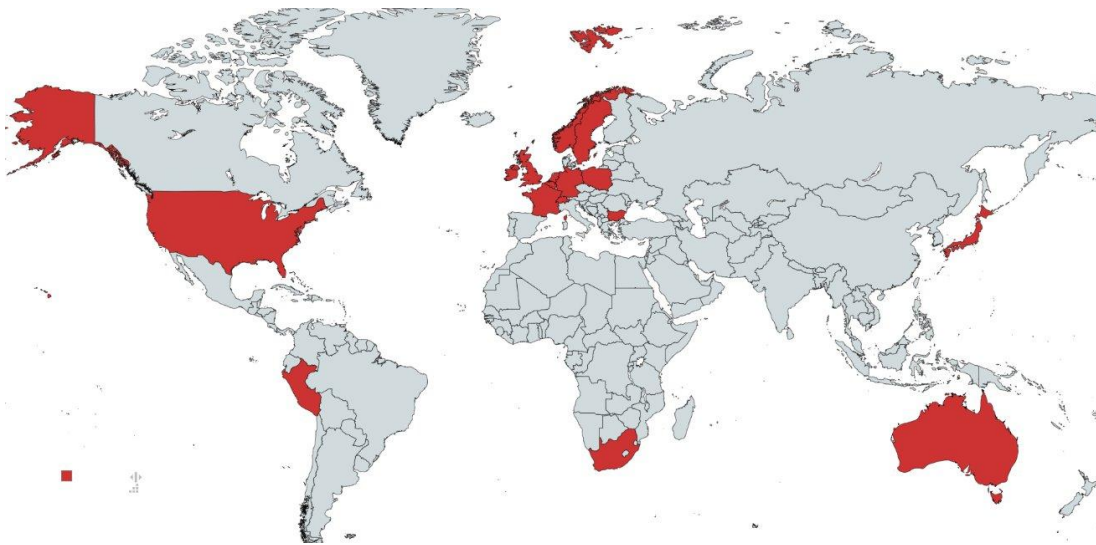


Figure 1 Countries that delegates came from are marked in red

The theme for the meeting was Profound Partnerships: Working in partnership to advance research and support of persons with profound intellectual and multiple disability. In this report summarise how the roundtable proceeded and provide feedback received from delegates. The Special Interest Research Group (SIRG) - Profound Intellectual and Multiple Disabilities (PIMD) is dedicated to advancing knowledge and improving the quality of life for individuals with profound intellectual and multiple disabilities. This was very clear in the range of research and work shared over the two days as outlined below.

On Wednesday evening, we had the third optional social programme event, dinner at Clancy's Bar and Restaurant at 19.00. Attendees had ample time to discuss the events of the day and get to know one another.



On Thursday we continued to share our research and work through a series of in person oral presentations, that stimulated lots of discussion. The oral presentations took place over two sessions. Again, the presentations spanned a diverse range of topics, including a photo-elicitation study of the experiences of siblings, interactions between support staff and people with PIMD, pain, and motor development. The SIRG-PIMD meeting was held from 13.15- 14.15 and the notes will be published at [Profound Intellectual and Multiple Disabilities - IASSIDD](#) later. The day came to a close with a Symposium by Dr. Juliane Dind, who introduced us to the work of Georges Saulus, a French psychiatrist working with people with PIMD, using a film. The programme is included below for reference.

Roundtable Programme Wednesday 23.04.2025

09h00 Welcome address by Prof. Gerry Lee, Professor of Nursing and Chair of Health Service Research

09h10 Opening address by Prof. Bea Maes, Chair of SIRG-Profound Intellectual and Multiple Disabilities

09h20 Keynote: “*Priorities and Perspectives for Impactful Research*” by Mrs. Lorraine Woods and Mr. Damien Douglas, Parents

10h40-11h35 Session 1

10h40 Caren Keeley & Teresa Sansour: Designing participation-orientated services for people with PIMD: Insights from the LINKED research project

10h55 Casey Connor: An exploration of the life-worlds of children with PMLD (profound and multiple learning difficulties) through participatory research involving themselves, their families, carers and school staff.

11h10 Vera Munde: emPOWERment - for individuals with trisomy 18 or 13 and their families

11h25 *Poster Pitches*

Myrthe Dilling: Defining participation: A conceptual model of participation for adults with profound intellectual and multiple disabilities (PIMD).

Karsten Knol: Faces of loneliness: how to decrease loneliness in a heterogenous group of informal caregivers of people with chronic or lifelong conditions?

Allison (A.J.) van de Kreke: Seeing the trees and the forest: A study describing and clustering existing (evidence based) knowledge and interventions.

11h45-12.30 Panel Discussion “Research Partnerships for Advancing Care & Support”

14h00-15h00 Session 2-Around the World in 60 minutes!

14h00 Edina Hanley: Communication partners’ behavioural intention to use augmentative and alternative communication with individuals with severe or profound intellectual disability

14h15 Mona Pihl: Discussion group for relatives of people with PIMD

14h30 Daisuke Hirano: Relationship between hand stereotypies and purposeful hand skills and factors causing skin injuries and joint contractures in individuals with Rett syndrome

14h45 Arine Kuylar: Co-designing a communication partner training programme for children with profound intellectual and multiple disabilities (PIMD) with special educators

15h30-16.30 Group Activity

Thursday 24.04.2025

09h05-10h35 Session 3

09h05 Sien Vandesande: A photo-elicitation study of sibling experiences on the stay of their sibling with a moderate to profound intellectual disability in a residential care facility.

09h20 Jean Ware: Academic progress in learners with profound intellectual disabilities; analysis of a Routes for Learning dataset

09h35 Ines Van keer: The dynamic DPE-model: a grounded theory study on parents as developmental partners building a development-promoting environment for their child with PIMD

09h55 Helena Wandin: "I think that's freedom for her" How access to gaze-controlled devices impact sense of self in individuals with Rett syndrome according to communication partners

10h10 Gilles Droogmans: Unravelling the multifaceted interplay of factors influencing staff client quality interaction: Insights from a survey study in group homes for people with severe to profound intellectual disabilities

10h25 Wieneke Penninga: Situational experiences of meaningfulness of support staff during their interactions with people with profound intellectual disabilities: an explorative study

11h00-12h30 Session 4

11h00 Christine Pacitti: Investigating pain related medication use and contribution to polypharmacy in adults with intellectual disability: A systematic review

11h15 Kathleen Julia Barnes: Sensorily-ableist notions of personal and intimate space

11h30 Linn Johnels: Musical interaction with students with severe/profound intellectual and multiple disabilities

11h50 Martien Rienstra: Effective elements of the Active Learning intervention and their relationship with the exploratory behaviour of persons with severe/profound intellectual and multiple disabilities, a multiple case study.

12h05 Anne-Marie Martin: Family carers experiences of supporting people with profound intellectual and multiple disabilities around pain management in the home: A mixed methods systematic review

12h20 Marleen Wessels: Motor development and mechanisms of change of young children with PIMD

13h15 SIRG member meeting

14h15-15h15 Symposium: Juliane Dind: In-depth reflections with Georges Saulus on PIMD issues

Feedback from Delegates

A feedback request was sent to all delegates following the meeting. There was positive feedback regarding communication, location and organisation. The programme was also received favourably with some recommendations for future events:

- Some people requested more discussion time around presentations. A suggestion is that presenters are advised to prepare a 10 minute presentation with 10 minutes for discussion.
- Earlier communication of the meeting details to enable arrangement of supports in the 'home' university.
- A clearer distinction between the ECRM and Roundtable meeting

In terms of 'definitely do again next year' the following were identified:

- Keep it friendly and lowkey, like it always is. That's so nice about this conference.
- The hybrid format to increase accessibility, including online presentations
- Increased voice of parents was welcomed.

Summary

We wish to thank you all for your input and contributions to the roundtable whether by presenting, chairing, asking questions or just simply the opportunity to meet and chat over the two days. We hope you enjoyed the event whether you joined us in person or online.

The roundtable enabled knowledge exchange among people from many different countries with a common goal of improving the lives of people with profound intellectual and multiple disabilities and their families. Importantly, we were reminded about the need to partner with individuals with PIMD, their family and caregivers.

We would like to thank the SIRG PIMD and the Health Research Board Ireland Conference and Event Sponsorship Scheme 2024 for sponsoring both events.

We look forward to seeing you in the future.

Best wishes,

Anne-Marie Martin, Edina Hanley, Sanne Nieuwenhuis, Caroline Egan, Laura Leahy

The 2025 ECRM/Roundtable Organising Committee