

SPECIAL INTEREST RESEARCH GROUP
PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES

Report of the 2025 Early Career Researchers Meeting

University College Cork, Ireland, April 22, 2025



Profound Partnerships

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

We welcomed over 30 delegates from 13 different countries to Cork, both online and in-person, for the 12th Early Career Researchers' Meeting (ECRM) on 22nd of April. The ECR Meeting was held in The School of Nursing and Midwifery, University College Cork, Ireland.

Together, the ECR 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. The theme for these meetings was Profound Partnerships: Working in partnership to advance research and support of persons with profound intellectual and multiple disabilities. The Early Career Researchers meeting seeks to provide early career ('junior') researchers a welcoming and supportive platform to present their research, discuss challenges and successes, and learn from each other and more experienced researchers.

In this report we would like to give participants or others who were not able to attend a glimpse of how the ECR Meeting proceeded.

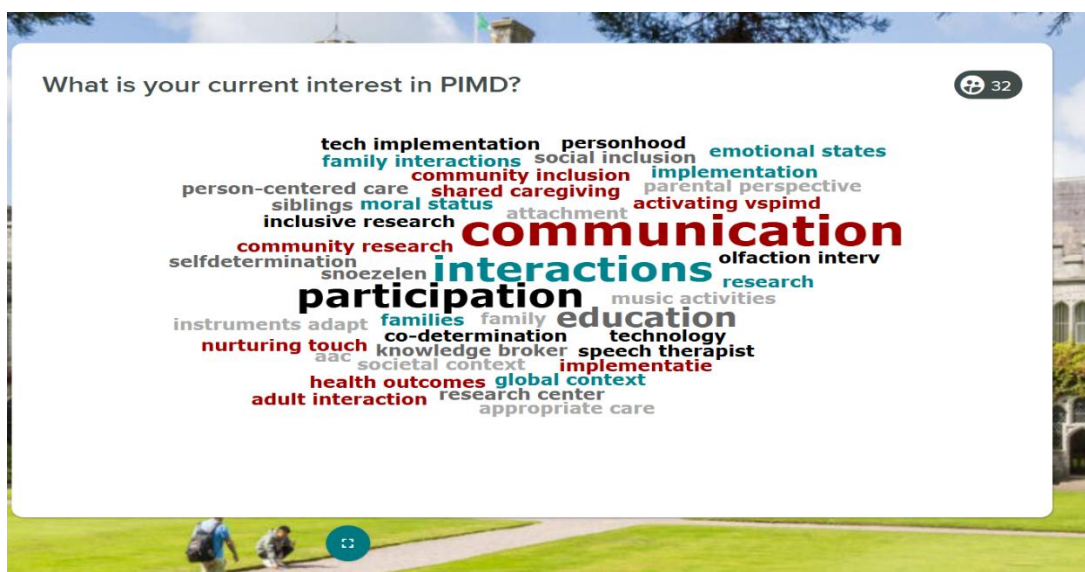
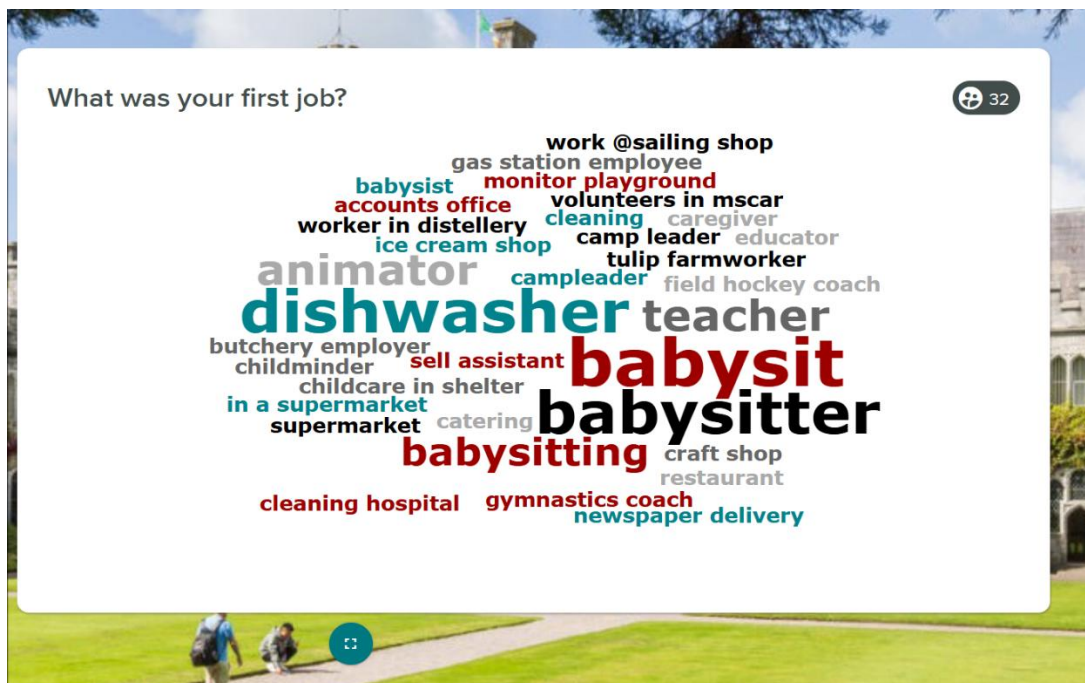
Programme of Events

Early Career Researchers Meeting: Tuesday, April 22nd

After a welcome from Dr. Anne-Marie Martin, we started with an activity to get to know one another, expand our network and to meet and discuss common interests. In person and online attendees were asked:

1. What was your first job?
2. What is your current interest in PIMD?

Attendees shared how their career/life brought them from their first job to their current interest in PIMD which led to interesting discussions! We utilised Vevox to collect responses presented in these wordclouds.



We had special guests join us on the morning of the ECR Meeting, the university dogs from MCC PAWS (**M**y **C**anine **C**ompanion **P**romoting **A**cademic **W**ellbeing and **S**upport @UCC). The MCC PAWS project is funded by the University's Mental Health Group and saw the introduction of MCC canines across campus for students and staff. The aim of the project is to enhance the overall wellbeing of UCC students and staff, with regular dog-based activities being held on campus to foster a sense of belonging and promote social connections.

A series of Early Career Researcher presentations took place over three sessions and included interesting discussions between presenters and delegates. There was an opportunity to review poster presentations while networking with delegates.

09h30-10h45 Session 1

Session one began with Casey Conner, who presented their work on developing new ways of researching with children with profound and multiple learning disabilities through an exploration of doing what you like to do. Gemma Testerink presented their work on how interventions and implementation strategies can be designed and further developed in co-creation: what we learn from multiple research projects. Diana Aksamit presented their research about shaping decisions together: A model of co-determination for people with profound intellectual disabilities. Naomi Dorsman completed the first session with their presentation on adult siblings of individuals with pervasive support needs and intellectual disabilities: Roles and experiences over the life course.

10h30 Poster pitches

We enjoyed three poster pitches by Myrthe Dilling: Defining participation: A conceptual model of participation for adults with profound intellectual and multiple disabilities (PIMD); Ally Peabody Smith: Identifying the resources necessary to improve clinician comfort-levels when serving non-speaking intellectually disabled patients: Challenges across the pond and Allison (A.J.) van de Kreke: Seeing the trees and the forest: A study describing and clustering existing (evidence based) knowledge and interventions.

11h00-12h00 Session 2

The second session of presentations commenced following a tea/coffee break. Catherine de Haas commenced the session with their presentation about creating belonging around living with profound intellectual and multiple disabilities. Arletta Iwan presented their mixed methods systematic review on communication partners' experiences and/or perspectives of being sensitive to expressive behaviours of persons with profound intellectual disabilities. K. Julia Barnes presented their research on considering touch as a channel for joint attention with people with PIMD and visual

impairment. Emma Vanroye presented The Mandala Project: unraveling the role and mechanisms of stress and stress regulation in children with profound intellectual and multiple disabilities.

12h15-13h00 Session 3

The third session began with Lotte Piekema presenting TechChange: exploring how the implementation of technology in people with profound intellectual and multiple disabilities can be optimised. Maren Hüffmann followed with their presentation on “Broken plates and spilled soup”: Fractured personhood and structural vulnerability– profound and multiple disability/UK. Finally, Karsten Knol presented their research on Faces of loneliness: understanding loneliness among informal caregivers.

14h00-15.30

In the afternoon Dr Emmy Racine, Project Manager of *PPI Ignite @UCC* delivered a workshop on Public and Patient Involvement (PPI). Due to the nature of the workshop, the afternoon session was held in person only.

After an introduction in PPI by Emmy, Anne Marie Martin presented a project called PPI POWER (Planning Our Work with Equity and Respect) as a case study. Afterwards, we had different discussion tables, discussing our thoughts about meaningful involvement of people with PIMD, what we need to involve people with PIMD and what should the role of support networks, families, and advocates look like?

Social Programme

A social gathering was held at the Flying Enterprise with a BBQ and time to connect.

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:

- The hybrid format was useful allowing online participants to join when they could.
- There was a suggestion that relevant practitioners would be invited to the ECRM to answer questions or concerns.
- A deep dive into some methods or particular research strategies.

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

- A workshop on specific themes, with parents, and/or on methodological/ethical themes

Summary

The meeting provided a platform for early career researchers in the field of PIMD to exchange ideas and insights. The hybrid format allowed us to experience the best of both in-person and virtual conferencing. It was truly inspiring to hear from researchers across the globe, contributing diverse perspectives to our discussions.

We extend our sincere appreciation to SIRG PIMD and the Health Research Board Ireland Conference and Event Sponsorship Scheme 2024 for sponsoring the ECRM, and to all participants for making the event such an engaging experience. For more information about SIRG PIMD and ECRM, including newsletters, please visit the following websites:

- iassidd.org/profound-intellectual-and-multiple-disabilities
- ecrmpimd.weebly.com

Kind regards,

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

The 2025 ECRM/Roundtable Organising Committee