



**Special Interest Research Group
Profound Intellectual and Multiple Disabilities**

***Report on the 11th Early Career Researchers Meeting
6 February 2023, Leuven***



Preface

On 6th February 2023 we gathered at KU Leuven (Leuven, Belgium) for the 11th Early Career Researchers Meeting. For the first time, the meeting was hosted in hybrid form, both live in Leuven and online. As a result, the ECRM welcomed 51 researchers from all over the world (10 online and 41 in person).

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

Program

After a short welcome word, we began the day with a quick **Mentimeter** survey to find out a bit more about the group. Around half the participants were about to enjoy their first ECRM while the others had attended before. Many of the group were PhD students. Participants were attending from all around the world including Japan, Iceland, Canada, Belgium, the Netherlands, Sweden, Ireland, UK, Bulgaria and several other locations. Participants also shared their diverse views on research into PIMD (Figure 1).

Give us one word to describe research into
Profound Intellectual and Multiple Disabilities



Figure 1 Mentimeter

For our first activity, participants were placed in small groups and given a research-based challenge. Using their shared ideas and respective strengths they had to design a **hypothetical research project**. They then had to represent this creatively on paper and pitch it to the group as a whole. This turned out to be a great way of getting to know each other leading to some serious discussion, adventurous ideas, interesting art work and fair bit of laughter. Study ideas included a 'living lab' carrying out action research to enable people with PIMD to flourish, a 'mind reading' machine to explore their personal perspectives and a study exploring what small differences might make big differences to personhood and individuality.

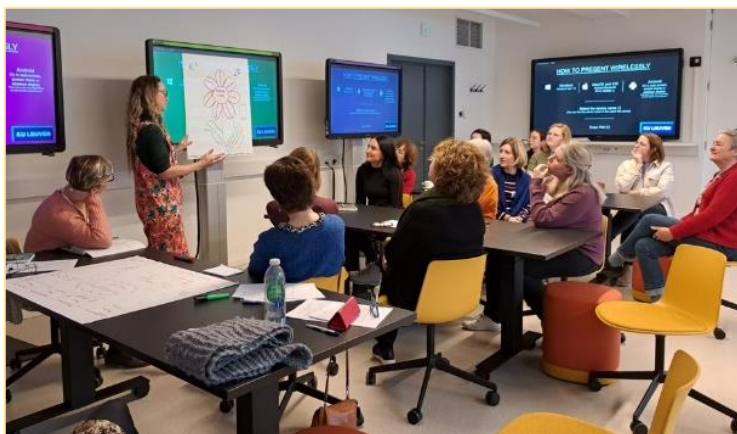


Figure 2 Pitch of a hypothetical research project



Figure 3 Poster

Having got to know each other better, we settled down to listen to the first of two sets of **presentations**. Maartje van Uffelen started the first set by telling us about her study looking at the assessment of motor behaviour in young children with PIMD. Edina Hanley described her PhD work, presenting an integrative review of factors influencing communication partners use of Augmentative and Alternative Communication. Pála Kúld presented the findings of a systematic review and meta-analysis of intervention studies aimed at promoting self-determination of persons with severe or profound intellectual disabilities. Michiru Sasaki joined us (in person) all the way from Japan to tell us about the process of developing a decision aid to facilitate communication between physicians and parents of children with PIMD.

Busy discussion continued over lunch with those attending in person enjoying a university canteen to themselves since the students were on holiday. Lunch was followed by a second set of presentations beginning with an online presentation from Lynn LeVatte and Kristin O'Rourke from Australia, telling us about their project fostering inclusion, communication and engagement through creative & visual arts with youths with Down Syndrome during Covid-19. Sanne Nieuwenhuis & Amber Decoen then shared their experience of taking an interdisciplinary approach to studying personhood of non-verbal participants. Julia Barnes outlined some different methodological approaches to capturing 'photovoice' for people with PIMD. Rosie Rushton concluded the early career research presentations by describing her approach to engaging proxies as co-researchers as a means of developing participatory research.



Figure 4 Edina Hanley



Figure 5 Michiru Sasaki

For the final part of the afternoon, boosted by coffee and some delicious pie, we were entertained and inspired by Professor Dr. Elke Emmers. Elke cleverly used the teachings of Bob Ross (popular artist) to get us thinking about how we might truly engage people with intellectual disabilities in **participatory research**. Her introductory presentation was then followed by some whole group discussion of how we might relate this to a population with PIMD.



Figure 6 Presentation by Prof. Dr. Elke Emmers

Social Program

In the evening we enjoyed a walking tour around Leuven, expertly guided by Gilles followed by dinner at a local restaurant. The evening ended (for those who remained...) enjoying traditional Belgian beer at the 'longest bar in Europe'.



Figure 7 Leffe, a Belgian beer

Summary

The meeting was a productive and inspiring way of sharing ideas with other early career researchers in the field of PIMD. The hybrid model required some technical organisation but it meant we could enjoy the benefits of both face-to-face and remote conference experiences. It was a wonderful opportunity to hear from so many researchers from around the world.

We would like to thank the SIRG PIMD for sponsoring the ECRM and all the participants for making it such an interesting experience. For more information about the SIRG PIMD and ECRM, including newsletters, we refer to the following websites:

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

Kind regards,

The ECRM organising committee of 2023,

Gilles Droogmans Lucy Pepper