



CARERENGAGE

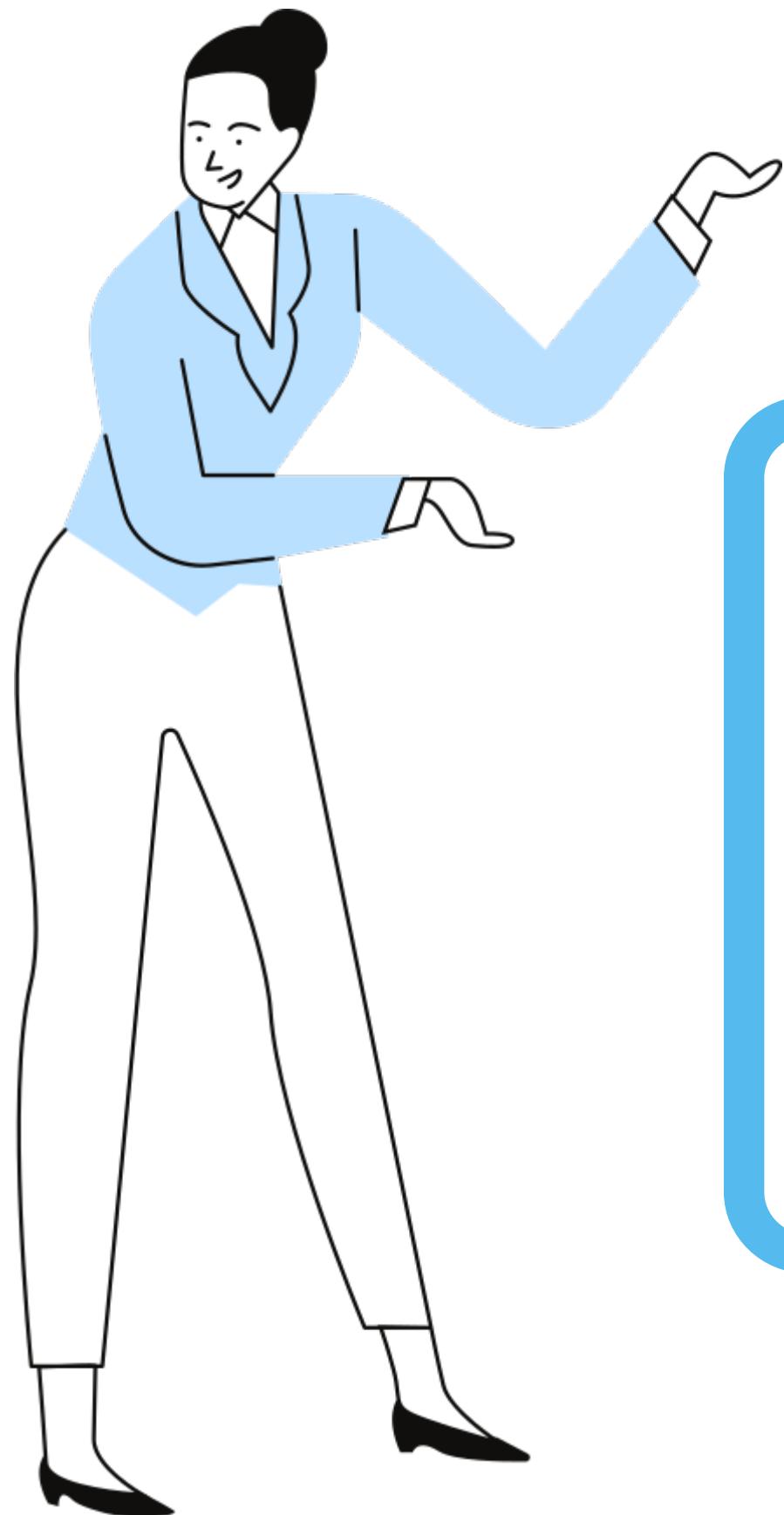
ROUND TABLE 1

PPI IN RESEARCH WITH A FOCUS ON FAMILY CARING

Tuesday 13th October 2020,
11am-1pm



Agenda



- | | |
|--------------------|--|
| 11.00-11.10 | Welcome & Introduction |
| 11.10-11.30 | The Family Carer Response - Aisling Harmon |
| 11.30-11.50 | Panel Discussion/ Q&A |
| 11.50-12 | BREAK |
| 12-12.30 | Breakout rooms |
| 12.30-12.50 | Group feedback |
| 12.50-1 | Conclusion & Next Steps |

Welcome & Introduction

01 Project Overview

02 Purpose of today

03 Key Points from Video
Presentations

Dr. Jon Salsberg

Meaningfully Involving Patients, Carers and other Members of the Public in Health Research

Video link: <https://youtu.be/uS-SZHc4Olc>

- 01** Research WITH or BY members of the public, rather than ON, ABOUT, or FOR them
- 02** Different ‘levels’ of participation - from engagement to involvement (words interchangeable)
- 03** Importance of meaningful engagement and working together
- 04** If nowhere else, beneficiary involvement at very beginning (setting topic and questions) and very end (interpretation of results and dissemination)
- 05** Those at the heart of the research never removed from any stage

Dr. Nikki Dunne & Jo Bergin

Family Carers Ireland

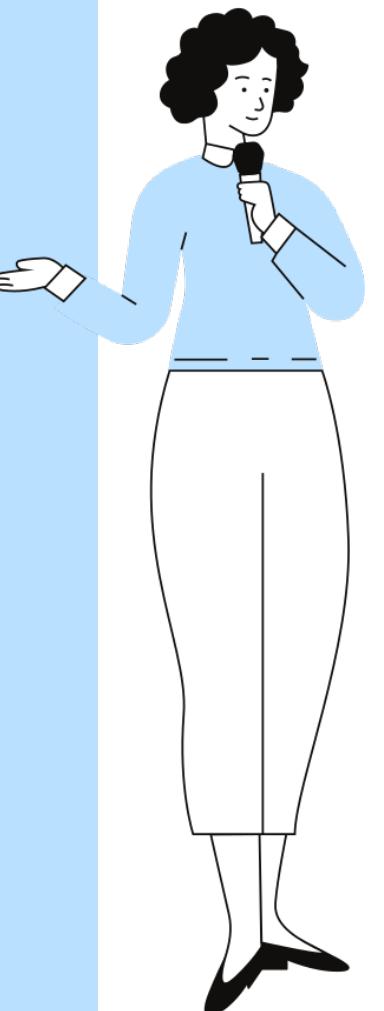
A reflection on the development of the Family Carers Research Advisory Network

[Video link: https://youtu.be/TJdihhVp01M](https://youtu.be/TJdihhVp01M)

- 01 Creation of a panel to ensure the family carer voice is included in research
- 02 FCI seeing an increase in request for PPI involvement
- 03 Mutually beneficial for family carers and researchers
- 04 Formalising the way FCI work with regards to PPI requests
- 05 Terms Of Reference of the group: Respect; openness & transparency; reciprocity; flexibility

Aisling Harmon

The Family Carer Perspective



- 01** Critical that carer is recognized and validated as expert at the centre of the PPI process. Be open minded to the solutions being presented. Ensure there is meaningful involvement throughout.
- 02** Research team needs to show respect and be professional and empathetic throughout. Last minute crises will occur due to caring commitments.
- 03** Avoid sanitization of PPI research. Can devalue it. Remember the importance of policy change
- 04** Recognise the PPI research is an overwhelming, emotional, vulnerable and/or cathartic experience for carers. Can increase sense of isolation as carer. Need someone to ask 'Are you OK?'
- 05** Worthwhile experience and opportunity to positively impact and influence policy

Panel Q&A

What duty of care do researchers have towards family carers?

- The earlier family carers are brought into the research/PPI process, the better.
- Carer participation should definitely be included in the terms of reference stage.
- Have exploratory discussions with family carer from the outset of the research.
- Stay in touch with family carers throughout the process.
- Researchers need to be empathetic - as PPI is an emotional process for family carers.



Panel Q&A

Can the panel give examples of lessons from a really good PPI project?

- Projects with excellent governance structures and practice.
- Make sure the voice of the patient and/or carer is always the biggest and heard throughout the project.
- The patient or carer sets the standard of how the project knows that it has met its deliverables.



How can diversity be addressed or ensured in PPI panels?

- Hard to do. Panels can just do their best.
- Key thing is to ensure carers' and the cared for legitimate lived experience is represented in the project.

Breakout Group Questions



What are the challenges that different groups involved in PPI research experience?

- a) Family Carers
- b) Academic institutions/ researchers

a) Family Carers

- Resourcing - Time and money
- Confidence, Can feel uncomfortable being around a table of 'experts' or professionals.
- Can family carers be 'equal' if they are the only one at the table not being remunerated? "Only some researchers get in touch with you to tell you the results of the research"
- Language of research - can be technical. Meeting with academics can be overwhelming.
- Feeling of being "talked at", particularly where the researcher is inexperienced
- Selection criteria. Emotional intensity - need to be prepared for it.
- Longer term follow up after the project for those carers who may be traumatised or re-traumatised by participation



Breakout Group Questions

b) Academic institutions/ researchers

- HEIs and researchers under-resourced and are not trained in PPI.
- Lack of adequate funding for PPI in HEIs
- Translating PPI into accessible terms - for all stakeholders.
- Eliminating "hierarchy" of knowledge, recognise the expertise of every person.
- Can be difficult or uncomfortable to approach topics sensitively for researchers/academics.
- Influencing the decision makers with the researched evidence showing impact for practical purposes.



Breakout Group Questions

What are the solutions to those challenges, and who should be involved in those solutions?

(e.g. If family carers experience difficulties being involved in research because of time spent caring, what are ways to overcome that, and who has responsibility for that?)

- Have carers involved at every stage of the PPI process and recognise and validate them as experts.
- Don't sanitise carer experience or research items.
- Communication - Researchers should get in touch with carer participants when the research is finished.
- PPI should be honored/value in research.
- Resourcing (see next slide). Make funds available so that family carers who are part of a PPI research team are financially renumerated.
- Accessible language



Breakout Group Questions

What are the solutions to those challenges, and who should be involved in those solutions?

(e.g. If family carers experience difficulties being involved in research because of time spent caring, what are ways to overcome that, and who has responsibility for that?)

- Recognise carer contributions through formal recognition of participation, esp. as many carers may have gaps in their CV. One example is a digital badge.
- Provide PPI training for researchers - e.g. PPI may be difficult for early career researchers, they may lack confidence. Perhaps they could shadow researchers?
- Training for researchers/academics around approaching and dealing with topics around family care provision, sensitively and empathically.
- Embedding PPI in research takes time. As well as PPI ignite initiatives, have a 10-year PPI strategy
- Stakeholder responsibility of the decision makers that influence policy and procedures to engage with research projects as team members. A flat team structure for specific research rather than hierarchical feeding in one direction from researchers to policy makers. Common agenda.



Breakout Group Questions

How can family carers be adequately compensated for their expertise as part of PPI projects?

What are some of the difficulties, challenges with compensation, and how can they be addressed?

- Remuneration for carer participation, can depend whether the project/researcher is being remunerated.
- Ask the carer what they want i.e. one size does not fit all. Examples include voucher, payment towards replacement care, payment of a broadband bill etc.
- Hours of care support equivalence. Care4care model of skill banking and reciprocating, monetary agreement of payscale equivalent, as per professional pay if bringing professional skills.
- Compensation can be non-monetary. Recognise carer contribution through formal recognition of participation, esp. as many carers may have gaps in their CV. One example is a digital badge.





References & Links

CarerEngage- <https://www.ucc.ie/en/iss21/researchprojects/researchprojects/carerengage/>
Care Alliance Ireland – www.carealliance.ie
ISS21 UCC - <https://www.ucc.ie/en/iss21/>
Family Carers Ireland – www.familycarers.ie
PPI Ignite @ UL - <https://www.ul.ie/hri/themes/public-and-patient-involvement-ppi>
PPI Research Team UL - <https://www.ul.ie/medicine/public-and-patient-involvement-ppi-research-unit>
Making A Start: A Toolkit for research charities to begin a PPI relationship (HRCI & PPI Ignite TCD) - <https://hrci.ie/a-new-ppi-toolkit/>
PPI In Research: Case Studies - <https://www.hrb.ie/funding/funding-schemes/public-and-patient-involvement-in-research/ppi-stories/>