

Partnership in Practice: Research Conference Report

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6th December 2023: Ashling Hotel, Dublin

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We appreciate the invaluable inputs of the conference participants, representing academia, civil society organisations, health and social care practitioners, the Department of Health. We are especially grateful to the family carers and members of FCI's Public and Patient Involvement Panel (**PPI**) who shared their experiences of caring and the challenges and benefits of being involved in research.

Introduction

The 'Partnership in Practice' conference is an annual event hosted by Family Carers Ireland. The conference is designed to engage diverse stakeholders including family carers, researchers, health and social care practitioners and government and non-governmental representatives to work together to unpack some of the challenges in carer-related research. Family Carers Ireland is committed to meaningful Public and Patient Involvement (PPI) so the event focuses on best practices in partnership and the challenges and solutions to meaningful involvement of family carers in research.

The third annual conference was held on 6th December 2023 in the Ashling Hotel, Dublin. Since this was the first time that the conference took place in-person, opportunities to network was critical to the design of the day. Future conferences will build on this work and discuss priority research areas for family carers.

The objectives of the third conference were to:

- Build understanding and awareness of research outcomes and share knowledge gained from research projects to inform policy and everyday practice that affects family carers;
- Show examples of good practice in Public and Patient Involvement;
- Foster networking and collaboration between a wide variety of stakeholders;
- Develop understanding of the challenges of making research relevant in real life and how to overcome these.

Family Carers Ireland convened an advisory panel consisting of family carer, academic and civil society representatives. Panel members co-developed all aspects of the event including event logistics, the agenda for the day, discussion group topics, and dissemination plans. This helped ensure the event space was inclusive while the content of the event was useful and accessible to all invited.

The conference was structured around a morning session where speakers presented on important themes and learnings to consider in better supporting family carers, and a facilitated session where participants reflected on the principles underpinning meaningful Public and Patient Involvement.

The conference engaged over 60 participants including researchers, family carers, charity representatives, health/social care professionals and PPI Ignite members.

The conference agenda included:

- Guest speakers with direct experience and examples of translating research into practice providing tangible outputs;
- Small, mixed discussion groups to brainstorm the barriers and solutions for translating research into practice (and provide networking opportunities);
- Informal networking breaks over refreshments.
- Participants shared their recommendations for planning, managing and financing better carer involvement in research, which were shared in a plenary session and are included in the second part of the report for consideration in progressing PPI and conference follow up activities.

Setting the Scene: Family Carers in Ireland, Dr Nikki Dunne

Informal care, also known as unpaid or family care, is of significant and increasing importance in the context of an ageing population, increasing life expectancy, improved survival rates for chronic conditions and policies to shift the delivery of care towards care in the home. Family carers are the main source of care provision for those in need of care due to a long-term illness, disability or frailty and are estimated to provide between 70 to 95 per cent of all care in the community with an economic value equivalent to 50 to 90 per cent of the overall cost of long-term care across the EU.

Caring for a loved one is associated with a number of benefits, such as emotional rewards, personal growth and a sense of accomplishment. However, caring can also have adverse impacts on carers when they are not adequately supported. There is mounting evidence that unpaid caring should be considered a social determinant of health with caregiving frequently having an impact on the physical and mental health of family carers. Compared to the general population, carers who responded to Family Carers Ireland's State of Caring surveys in 2020 and 2022 were more likely to have poorer health and a longstanding disability, illness or health condition than the non-caring population. Specific adverse effects on physical health include higher rates of back injuries and high blood pressure. Carers are less likely than others to prioritise their own needs which can lead to harmful behaviours such as poor diet or sleep habits and a failure to take preventative health measures. Many carers also find it difficult to balance paid work with caring responsibilities, which can impact on labour force participation. The pressure of combining paid work and care can lead carers (many of whom are working-age women) to give up work or reduce their hours, which can result in financial difficulties and pension disadvantage in later life. In addition, there are potentially considerable indirect or nonfinancial costs of caring, costs such as social exclusion, erosion of personal relationships and psychological wellbeing.

Given the reliance on family carers juxtaposed with the significant financial and personal costs they bear, it is imperative that every effort is made to support them. The presentations in the next section demonstrate different facets of the caring experience, from the experience of caring and resilience in old age to the challenges of balancing unpaid care with paid employment, to the difficulties when experiencing harm in the context of the caring role. These studies are exemplars of partnership in practice between academics, family carers and Family Carers Ireland and provide practical recommendations to support the practical, social, health and wellbeing needs of family carers.



[1] Zigante, Valentina. 2018. 'Informal Care in Europe: Exploring Formalisation, Availability and Quality.' Brussels: LSE Consulting for the European Commission, 2018.

[2] Social Protection Committee and the European Commission. Adequate protection for long-term care needs in an ageing society [Internet]. Luxembourg: Publication Office of the European Commission; 2014 [cited 2020 May 24] Available from: <https://opeco.europa.eu/en/publication-detail/-/publication/71532344-ddf1-4d34-a7aa-f65c701a22a2>

Message from Claire Devlin, Family Carer

The conference opening remarks concluded with a message from Claire Devlin, a family carer and member of FCI's PPI panel. Claire spoke about the value of involving family carers in research, especially involving them from the very outset of research projects. This can lead to research that is relevant to the carer experience. However it is hugely valuable not only for research, but also for family carers themselves who, when PPI is done well, feel like their expertise is recognised and they are making a difference.

Whilst PPI can sometimes feel intimidating for carers, she learned recently that researchers can feel the same. This is reassuring in many ways and needs to be spoken about at the start of a PPI relationship. Claire urged family carers to get involved where they can, for researchers to involve carers where they can and for funders to make it as easy as possible for carers to be involved.



Section 1: Partnerships In Practice - Presentations

An investigation of what protective individual and community level factors are associated with positive well-being outcomes in older family carers in Ireland: evidence from The Irish Longitudinal Study on Ageing (TILDA). Dr Christine McGarrigle, The Irish Longitudinal Study on Ageing (TILDA), Trinity College Dublin, the University of Dublin

Family caring plays an essential role but can place social, financial, physical, and emotional demands on carers. Caring by older people has benefits for health and longevity when providing lower hours of care. Less is known about why some carers maintain their long-term mental health and well-being better than others. Some of these differences observed may be an indicator of how individuals differ in how they adapt to changing circumstances and their ability to maintain or recover their mental health and well-being following an adverse event (psychosocial resilience). It is important to understand how the interrelation of behavioural and social factors may help individuals to emotionally adapt to adverse events such as the stress of being a family carer. This study evaluated patterns of well-being in middle-aged and older caregivers as they transition into and out of caring responsibilities, and identified what may protect the psychosocial resilience; conceptualised as maintaining or recovering well-being, of carers. This study uses data collected from six waves from 2009-2011 to 2021 of The Irish Longitudinal Study of Ageing (TILDA) a prospective biennial nationally representative longitudinal study of older adults aged ≥ 50 in Ireland. It identifies change over time in satisfaction with life (SWL), before and after caring was initiated.

Overall, 731 (12.2%) participants became carers during follow-up. We identified three groups in SWL in carers following initiation of caring, those who were Resilient-Stable (81%), Resilient-Recovery (12%), and Non-recovery (6%). Membership in Resilient-Stable and Resilient-Recovery groups was associated with fewer depressive symptoms and chronic conditions, larger social networks, more close friends and relatives and caring for someone other than a child compared to the Non-recovery group.

Becoming a family carer was associated with a decline in SWL over time in some carers. However, most carers either did not experience a decline in SWL or recovered their SWL over time. We found that both individual and community-level supports may be protective for carers' wellbeing.

This study is part of a joint research project between TILDA and Family Carers Ireland. The next part of the study will investigate, though working with groups of carers, how their well-being may fluctuate depending on the quantity and quality of social supports and formal care service supports received. The study's findings will also provide information to help establish training and advocacy programmes for caregivers. It will inform the priorities for social and community-level services and support for older carers and contribute to the design of new projects and programs to meet these needs.



Advancing our Understanding of Carer Harm: Insights into Carer Harm experienced by Carers of People Living with Dementia and Carers of Children and Adults with Autism.

Dr Sarah Donnelly, UCD

'Carer harm' is when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological and/or sexual harm (Isham et al.2020, p.2). This presentation explored the concept of carer harm from the perspective of family carers of people with dementia and autism and relevant professionals including, social workers, public health nurses, the police and non-government organisations. The project deployed an engaged research approach that produced knowledge in collaboration with family carers and professionals including the development and co-design of information and education resources in order to better understand, prevent and respond to carer harm. Those experiencing carer harm reported 'falling through the cracks' of support services and feeling abandoned by professionals. Key themes included fear, shame, stigma as well as the impact of expectations, responses and systems that harm. Conflicts existed for many professionals in relation to balancing the needs, safety, and protection of all family members.

The outcome of mandatory reporting concerning the safeguarding of children and mandatory referrals in relation to those defined as 'vulnerable adults' resulted in paperwork and stress for parents/carers but little meaningful action to protect or provide vital services and supports which would help to reduce eliminate risk and harm being experienced. Participants' experiences also suggest that we need to consider the more sophisticated concept of 'human interdependence' (Tronto,1993) and the interdependent nature of everyday living and caregiving when dealing with carer harm.



Towards a workplace intervention for family carers: Emerging findings from the CAREWELL project. Dr Attracta Lafferty, UCD

An increasing number of carers are providing care for a family relative, while also in paid employment (CSO, 2023). It is important that family carers who are working and caring are adequately supported, to help to mitigate some of the challenges associated with juggling work with care responsibilities. The workplace is becoming recognised as a valuable resource for working family carers, as they can benefit from resources that promote good mental and physical health, social interactions, while having ‘personal space’, job satisfaction and greater financial stability (Van Dongen et al., 2014). The HRB-funded CAREWELL project aims to develop an evidence-informed, workplace-based intervention to support family carers to reconcile work and care, while in turn, also helps to enhance their health and wellbeing. PPI was integral to the research throughout, with Family Carers Ireland as co-applicants on the project and an Independent Carer Advisor enlisted to advise and support the project. Family carers were asked to review interview guides and survey materials before fieldwork.

The project adopted a multi-phased sequential research design.

- **Phase 1:** Synthesis of existing evidence on the health and wellbeing of working family carers.
- **Phase 2:** Examination of employers’ and carers’ experiences of health promotion for carers in the workplace
- **Phase 3:** design, develop and co-create a workplace-based health promotion for working family carers.

Working family carers were surveyed and interviewed to examine work-care reconciliation strategies, their balancing of work and care during Covid-19, workplace support needs and the main challenges of balancing work and care. Line managers were interviewed about their perceptions, knowledge and experiences of supporting family carers in the workplace. HR personnel were invited to share their experience of supporting family carers and line managers.

Emergent findings includes:

1. Carers value flexible work options
2. There is a lack of awareness of carers and their support needs
3. Managers play a key role in carers’ experience of balancing work and care
4. Carers value peer support
5. HR and HR policies are perceived mainly as inflexible and inaccessible
6. Caring can negatively impact wellbeing and carers’ self-care behaviour

The emerging key findings, in conjunction with stakeholder validation workshops, will be used to inform the development of a workplace programme that supports family carers. The programme will be rolled out in one workplace site and tested for feasibility. The project is due to complete in June 2024.



Section 2: Values and Principles in Practice:

Small group discussion findings

A shared understanding of the values and principles that underpins the work is helpful for promoting meaningful PPI in practice. The PPI Ignite network has developed a set of values and principles which they ask stakeholders to uphold when engaging in or supporting PPI activity. The roundtable activity, facilitated by Michael Foley (TCD PPI Ignite) focused on how we can apply these values in practice when conducting carer-related research. Each table discussed one principle each, talking about what is currently working well, what is in need of improvement and suggestions to make that improvement a reality.

- 1. Transparency:** Transparency is key to building a trusting environment in PPI. It involves clear communication about the goals, processes, and outcomes of research. Initiatives like PPI Ignite and the need to demonstrate PPI in funding applications alongside a clear plan of action has done a lot to ensure transparency in the PPI space. Transparent guidelines and criteria in funding applications and project selection can enhance trust and collaboration among all stakeholders, including family carers. However, the group identified that the pre-funding stage needs improvement because there is no real process or oversight there. Another key issue is ensuring that research findings are communicated in ways that are accessible and relevant to all users, including charities, family carers, and health and social care professionals. The technical language used in academic reports can be a barrier, making it difficult for non-specialists to understand and apply the findings. 'Knowledge is power' so there should be more proactive strategies to share knowledge beyond academic circles, to allow for opportunities to apply the research in different ways. Overall, transparency is working well in certain phases but improvement is needed in making the entire research process more open and understandable to all involved parties.
- 2. Respect:** Respect is foundational to meaningful PPI. Core to this is the recognition of the value and expertise that each participant brings to the project. This includes not only respecting the knowledge and experiences of family carers but also ensuring equitable treatment in terms of compensation and acknowledgment. Current practices in many research projects of providing reimbursement reflect this respect. Investment in training, particularly for academic researchers in how to do PPI and carers through e.g. FCI's PPI panel, is an acknowledgement and a respect for the process, because not everybody knows how to do it meaningfully. However, there was concern that whilst training had extended to academics and carer contributors, more training is required for other stakeholders that may not be aware how to do PPI meaningfully e.g. HSE, Department of Health committee groups. There is need for broader implementation of respect across all PPI activities, ensuring that every participant's time and contribution is valued and respected appropriately.



3. Empowerment and Power Sharing: Empowerment in PPI is about enabling all participants, particularly family carers, to have a meaningful impact on the research process. This involves sharing power, ensuring that decisions are not solely in the hands of researchers or funders. While there have been strides in empowering participants through embedding PPI in the research process with funders requiring evidence of meaningful involvement in grant applications. Involving family carers from the outset can make research more relevant and understandable – having carers and carer organisations sense checking the research findings and being involved in their communication can enable greater impact also. Whilst involving carers in knowledge exchange and inclusive decision-making practices are increasingly evident, there remains a gap in truly balancing power dynamics. Since relationships are at the core of good PPI, this requires time and effort from both carers and researchers. Yet there is no budget at the pre-funding state to allow those relationships to develop and grants with short time-frames do not promote the nurturing of long-term relationships.

Whilst financially compensating family carers for their contributions is important, it can have unintended consequences on means-tested social welfare payments like Carer's Allowance. If people are reluctant to get involved in research because of potential impacts on their finances, then this puts family carers in a difficult situation. This can disempower potential PPI contributors and must be addressed so that PPI contributors are not penalised for their involvement in research. Efforts therefore should be made to provide family carers and patients with the tools and platforms needed to influence research effectively.

4. Trust: Building trust is a cornerstone to good PPI and hinges on creating and maintaining a consistent, open, and respectful dialogue among all stakeholders. Trust is essential to relationships, especially with people who you don't know or where they are coming from. Trust is fostered through confidentiality, respecting diverse perspectives, and ensuring that all voices are heard and considered. Creating safe spaces, where people feel comfortable sharing potentially private matters, is vital for both researchers and carers in building trust. It is critical that the time that building and maintaining trust is acknowledged. While there are examples of good practices in establishing trust, where carers feel that their voices are heard and valued.

However, there is room for improvement, particularly in maintaining ongoing communication, ensuring all stakeholders are kept informed throughout the research process and 'closing the loop' so carers and charities are informed what has happened at the end of the research. Building a dissemination strategy with all stakeholders around the table can mitigate against this so everybody gets an output that is relevant to them. Sometimes research doesn't go to plan and researchers are reluctant to inform family carers about this. Carers suggested that researchers should let them know why it didn't work, what can be done now and how carers can help. A terms of reference developed at the outset can help build the safe space required to establish and maintain trust throughout the research life cycle.



5. Collaboration & Partnership: Collaboration in PPI is not just about working together but about building genuine partnerships where each party's contribution is recognized and valued. This includes acknowledging the unique insights that family carers bring to research. Current practices show an increasing awareness of the importance of PPI in research, with more people understanding what PPI is. Collaboration also allows for the bringing together of a diversity of experience, shifting away from a single narrative about a particular research project. But challenges remain in ensuring that these collaborations are substantive and not merely tokenistic.

Tokenistic PPI can lead to the researcher holding all the decision-making power, without valuing the knowledge of the PPI contributors. Early career researchers also pointed out the difficulty in establishing collaborations and partnerships—as they are often doing their research in isolation, they do not necessarily have wide networks to help find PPI contributors. One way to address this is to look at the funding of PPI in PhD research, which is currently underfunded. The NGO perspective – time and resources to facilitate researchers requests and lack of national guidance on how to quantify and cost that.

6. Flexibility: Flexibility is essential in accommodating the diverse needs and circumstances of all PPI participants. This includes recognizing the different time commitments and logistical challenges faced by family carers. Some initiatives have shown flexibility in terms of travel, recognition for time and commitment, by enabling remote participation or adjusting timelines to allow carers to attend meetings. Access to a dedicated person to liaise with PPI contributors outside of 9-5 hours is another welcome practice enabling flexibility. Nonetheless, there is a need for systemic changes to make flexibility a standard practice in PPI. There was discussion about the inflexibility of the systems in universities, funding organisations and Revenue. A lack of clarity around how these systems worked and interact meant that carers could not make an informed decision about their involvement based on expectations, financial recognition, outcomes and the potential impact on their social welfare benefits.

7. Equity & Inclusion: Equity and inclusion are about ensuring that all individuals, regardless of their background or circumstances, have equal access to participate in PPI. This involves actively working to remove barriers that might prevent people from engaging, such as language, cultural, socioeconomic, or logistical challenges. What is seen to be working well is co-design in dissemination phases, perhaps because this stage is easier to understand as it is more tangible to PPI contributors and researchers are more likely to take the time to ask what is the best approach, which doesn't necessarily happen at other stages. The group felt that one of the most important areas for improvement was assumptions about people's lives, so there needed to be much more time taken to understand the different factors that were needed to be more inclusive. Due to a number of and better understanding in certain research stages. However, there was a need for greater consideration of real-life factors and reduction of categorization that may lead to inequity. While there have been efforts to promote inclusivity in certain stages of research, more comprehensive strategies are needed to ensure that all voices are heard and valued equally.

In summary, while there are areas where PPI practices are working well, there are significant opportunities for improvement. Researchers, funders, and charities all play a crucial role in driving these improvements, ensuring that PPI is genuinely inclusive, effective, and respectful of family carers.

Specific Recommendations for Improvement

The set of recommendations provided here illustrates the significant overlap among the principles underpinning public and patient involvement, highlighting their interrelated nature and the impracticality of implementing any single principle in isolation. Across all themes, the common thread is the importance of meaningful engagement and recognition of all stakeholders in the research process. This interconnection suggests that these principles are not discrete entities but rather form a cohesive framework of practices with substantial overlap. Despite this, we have categorised the recommendations by theme for clarity, while acknowledging that many of them address several principles concurrently and were the subject of discussion across various groups.

1. Transparency

- **Clarifying PPI's Value:** Explicitly communicate the purpose and benefits of PPI to all stakeholders, ensuring alignment with the real-world needs of family carers. This promotes transparency about the research's goals and its relevance.
- **Closing the Loop:** Implement clear and ongoing communication strategies with PPI contributors about research progress, challenges, and outcomes, fostering an environment of open dialogue.

2. Respect

- **Facilitate Participation:** Provide prompt and fair compensation to family carers at the grant's pre-application stage, recognising their contributions as valuable and essential.

3. Empowerment & Power-Sharing

- **Co-Created Agreements:** Develop collaborative agreements that clearly outline roles, expectations, and processes, ensuring all voices are heard and valued equally in the research process.
- **Expectation Management and Training:** Offer targeted training to manage expectations and foster mutual understanding among researchers, PPI contributors, and funders.

4. Trust

- **Designated Communication Roles:** Establish roles within the research team specifically focused on maintaining open lines of communication with PPI contributors, ensuring they feel informed and heard throughout the project.

5. Collaboration & Partnership

- **National Best Practice Guidance:** Advocate for and utilise national guidelines on best practices for PPI, drawing on successful models to strengthen collaborative efforts.
- **Compulsory PPI Training:** Ensure all academics receive mandatory training on PPI, akin to research integrity training, to build a foundation for effective collaboration.

6. Flexibility

- **Adapting Research Processes:** Adjust research methodologies and schedules to accommodate the diverse needs and circumstances of PPI contributors, demonstrating a commitment to inclusive and adaptable research practices.

7. Equity & Inclusion

- Early and Thorough Engagement: Tackle inclusion and equity issues from the onset, dedicating time and resources to understand and remove barriers to participation.
- Language Accessibility: Make communication more accessible by simplifying language, thereby lowering barriers for participation, especially for family carers.
- Community Networks: Strengthen local community networks to provide essential support, enabling broader and more meaningful participation in research.
- Meeting Contributors Where They Are: Customize approaches to meet potential PPI contributors in their environments, ensuring genuine inclusion by recognizing and accommodating their unique needs.

Learnings for Specific Stakeholders

- Researchers should focus on building relationships, respecting diverse perspectives, and involving stakeholders throughout the research process.
- Charities and Funders need to facilitate transparent processes, support equitable participation, and recognise the value of diverse contributions.
- Family Carers should be empowered to participate fully in research, with their contributions acknowledged and respected.
- All parties should strive for continuous improvement, embracing flexibility and inclusivity to ensure research is relevant, impactful, and ethically sound.

These recommendations underscore the importance of a holistic approach to PPI, where principles of transparency, respect, empowerment and power-sharing, trust, collaboration and partnership, flexibility, and equity and inclusion are not only acknowledged individually but are also interwoven throughout the research process.

This approach ensures that PPI is implemented effectively, ethically, and inclusively, with a focus on building mutual respect and understanding among all stakeholders.





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