



Family  
Carers  
Ireland

No one should have to care alone

# Overview of Ongoing Research Activities

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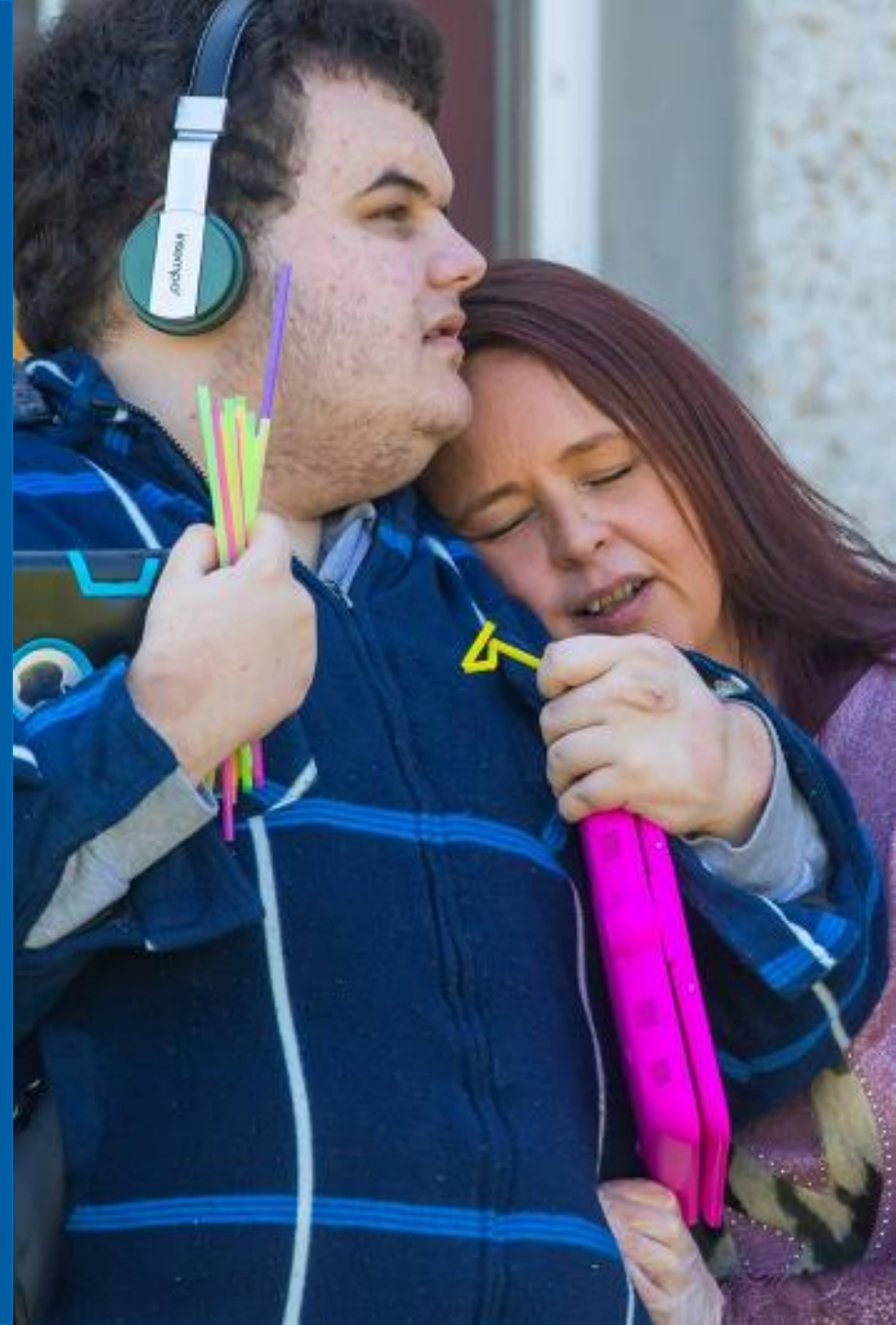
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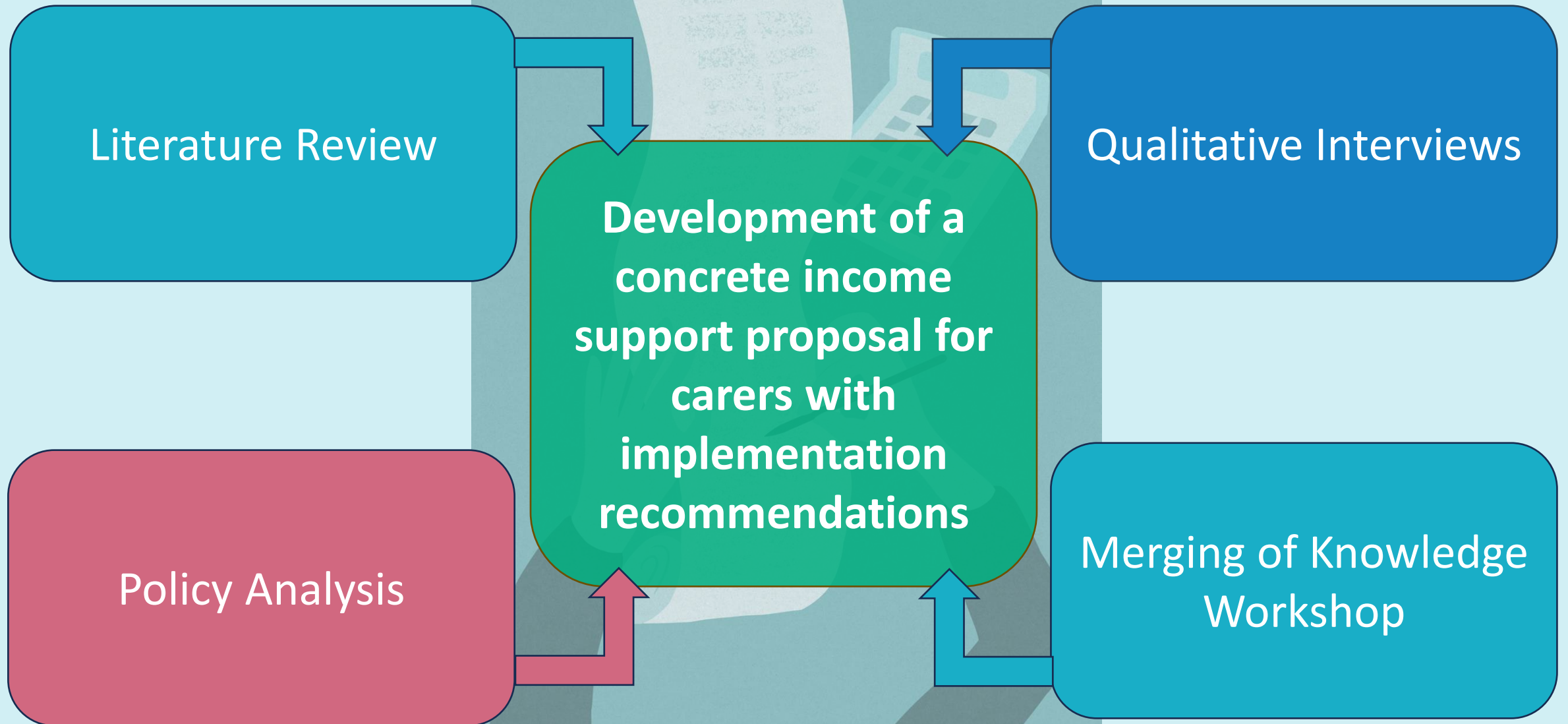
# Towards a Participation Income for Family Carers



**Maynooth  
University**  
National University  
of Ireland Maynooth



# About the Project



# Carers Views

*"Fighting, fighting for everything, for speech and language, for occupational therapy, for physiotherapy, for school places. You're fighting for everything all the time. That's the most challenging."*

*"It is very invasive."*

*"It's [dealing with services/DSP over the phone] horrible. It's degrading."*

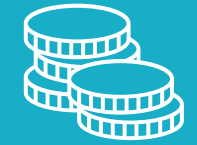
*"There is a really long soul destroying form [for Carer's Allowance]."*

*"You feel like you're begging for something you're entitled to. I worked all my life and paid tax all my life."*

*"You're living in fear of reassessments because the reassessments are made so difficult."*



# Summary of Recommendations



**Introduce a Participation Income (PI) based non-means tested Family Carer's Income Support (FCIS)**



**Establish a PI FCIS Implementation Group**



**Ensure adequacy of PI FCIS by benchmarking and indexing**



**Establish a Navigational Operations Group to improve navigational processes**

# Recommended Timeline





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# Understanding --- Carer Harm



University College Dublin  
Ireland's Global University



# About the Research



Review of Survey Data

State of Caring 2022 data



Individual Interviews

5 carers of autistic people



Focus Group Interviews

4 carers of people with dementia



World Cafés

3 professional/FCl staff focus groups

Representatives from above groups & other organisations  
(one autism specific & one dementia specific)



# Understanding Carer Harm

‘When carers experience violence or become subject to controlling or coercive behaviour resulting in physical, psychological and/or sexual harm’ (Isham et al., 2020)

Carers and professionals struggled to define and understand ‘Carer Harm’ as a term.  
It is not common nor recognisable

Experiences of harm ranged from screaming, destruction of possessions, significant physical violence and resulting emotional distress



*“She would beat down the door, she has broken the door about three or four times. And when she can’t get at me she will break every, and has done it, break everything that you can see” –Autism Carer*

*“Verbally abusive, hitting out that kind of things...most of it was due to frustration”- Dementia Carer*

*I was home on my own, my husband was in work and D came back from school and D had a tremendous meltdown and he pulled my hair even though he doesn't usually do that, but that day he did. He was only eight or nine and he pulled me with such force that he pulled me on the ground and I hit my head on the ground and I was there for a few seconds. And then my eldest child came from school, so imagine D was nine so my eldest was eleven, can you imagine what it's like for an eleven year old child to restrain his brother on the sofa to give me the chance to get up. I'll remember this day to the day I die. Like my eldest was crying, he was saying 'Mammy I don't know for how long more I can restrain him'“*

– Autism Carer

# Protecting Family Carers from Carer Harm

Timely Diagnosis

Transitions and  
Responding to  
Changing Care Needs

Navigating a  
Fragmented and  
Complex Health and  
Social Care System

Early Intervention

Professional  
Helplessness and  
Inability to Respond



# What Helps?

Peer Support

Therapy

Education and  
Training

Assessment

Services

Advocacy

Collaboration,  
Building Links at the  
Community Level  
and Signposting



# World Café Findings



What terminology should we use to define the concept of carer harm/carers hurt?



How can we make the issue of carer harm more visible and what information could it be helpful for family carers to have?



How can professionals and service providers best support family carers experiencing carer harm? What strategies/interventions might be helpful?

# Outputs from the Research



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## Are you experiencing Carer Harm?

**If you are a family carer, ask yourself:**  
Does the person I care for behave in a way that causes me physical injury, emotional pain, or other kind of harm?  
In my engagement with professionals and organisations, is my coping capacity and need for support recognised and responded to?

This leaflet may be useful to any family carer experiencing carer harm

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This leaflet may be useful to carers of autistic adults or children

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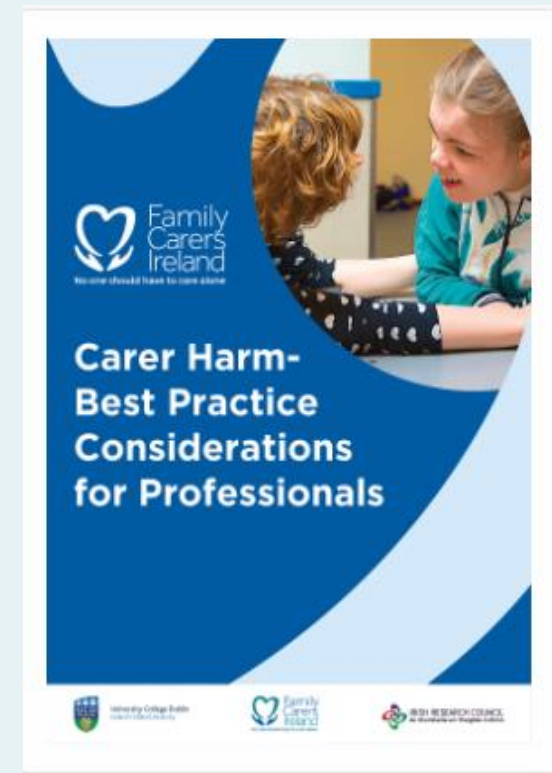
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This leaflet may be useful to carers of people living with dementia

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## Carer Harm- Best Practice Considerations for Professionals

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# Patient & Public Involvement (PPI) Research Advisory Network



# Family Carers Ireland and PPI

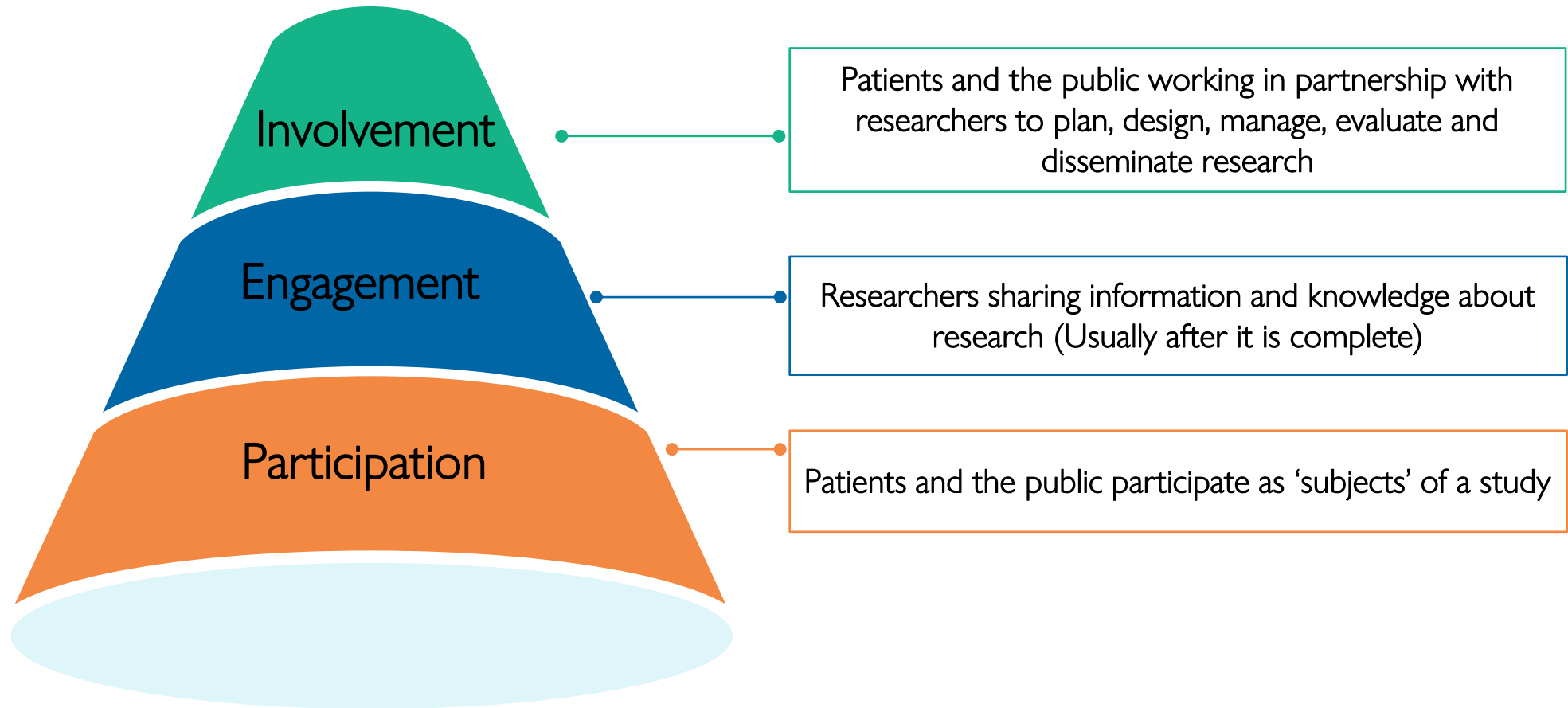
Family Carers Ireland is committed to putting carers at the very heart of what we do. In keeping with this commitment, we are working to embed Patient and Public Involvement (PPI) in our research processes.

*“Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.”*





# Family Carers Ireland and PPI



# Family Carers Ireland's Research Advisory Network



10 carers from different caring backgrounds



Meeting 4 times a year



Completed work on guidance documents and almost half of the members are involved in PPI projects



Continue work on governance and ways of working as well as capacity building and advertising the network's existence

# Other Research Activities

- Internal Evaluations
- Annual Research Conference “Partnerships in Practice” (to be held in person next week)
- 3<sup>rd</sup> State of Caring to be launched in January
- HRB-funded CAREWELL project with UCD
- Irish Research Council New Foundations Grants Scheme
- Building carer involvement and stakeholder engagement
- Research governance