



Identifying the top 10 priorities for Family Carers: The INTERFACE project

A TRADITION OF
INDEPENDENT
THINKING



UCC

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Coláiste na hOllscoile Corcaigh

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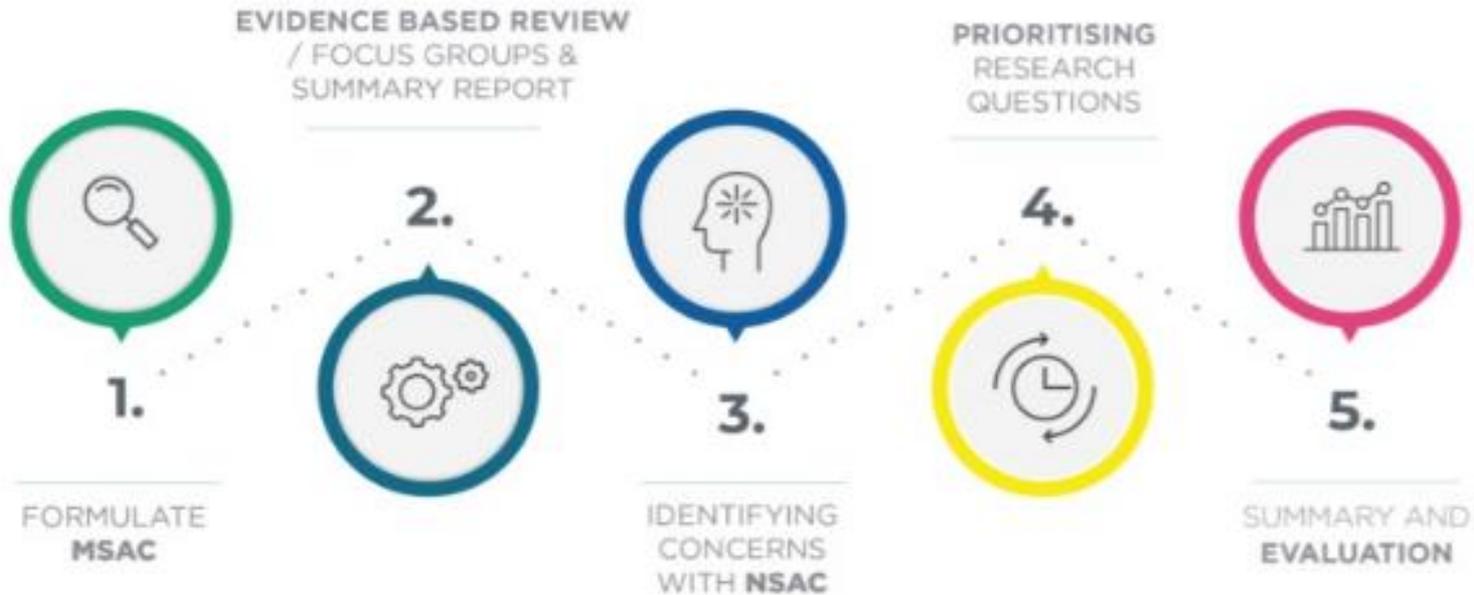


Background:

- Family carers play a vital, yet often invisible role in our society and healthcare system.
- Family Carers Ireland's (FCI) Strategic Plan 2018-2023² demonstrate the primary focus is on supporting Family Carers as individuals, promoting the health and wellbeing.
- We established research priorities for family carers and to shape reform and create awareness in the community regarding the role of family carers.

5 Steps to The Top 10

This **INTEFACE** project followed a five stepwise qualitative exploratory participatory research approach.



Step 1:

We formed a Multi-Stakeholder Advisory Committee (MSAC)

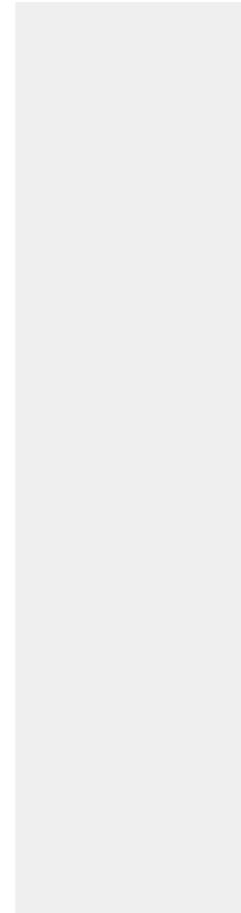
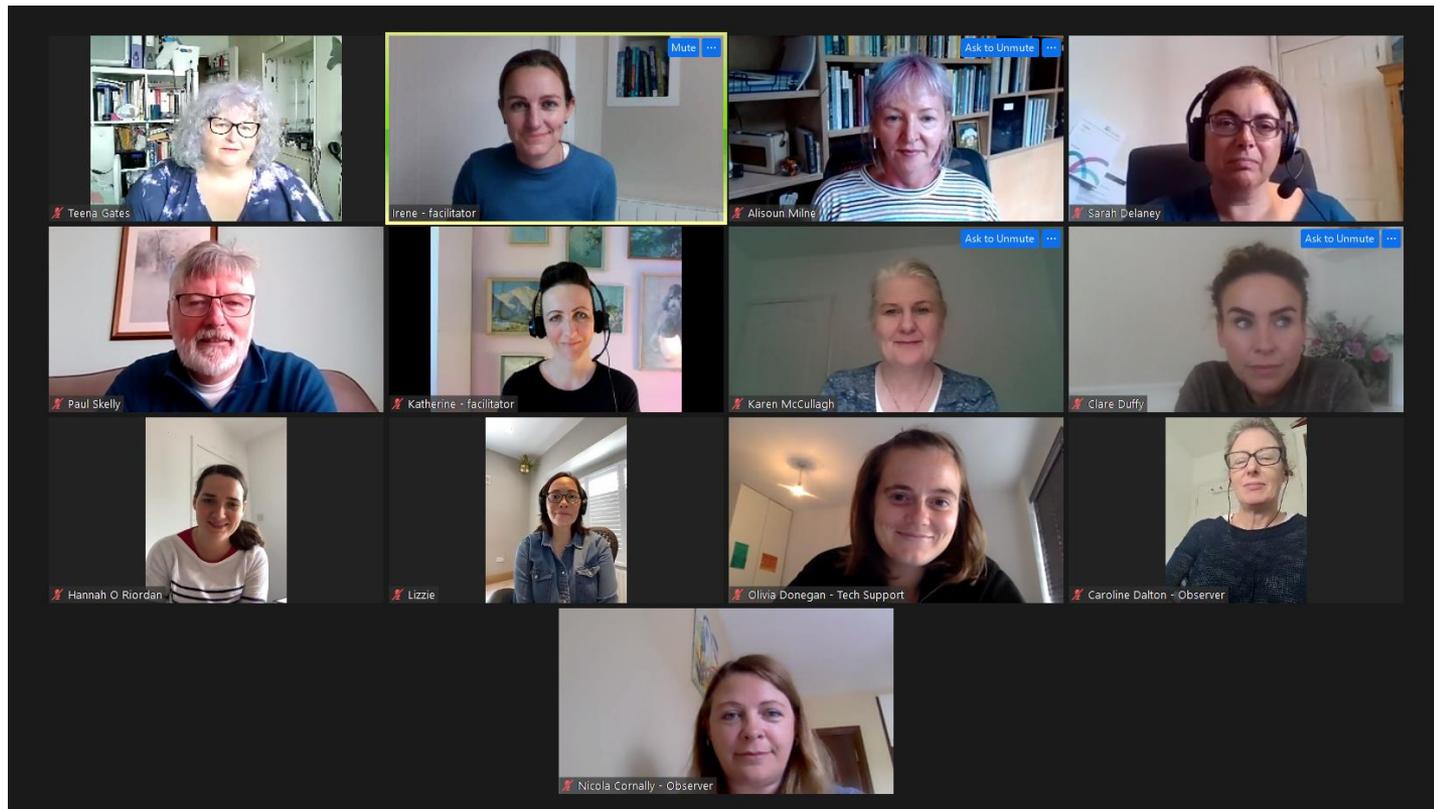


The purpose of MSAC was

- 1) Identify questions and concerns about providing care in the context of a pandemic and beyond
- 2) Agree which questions and concerns are top priorities for research
- 3) Rank research priorities.



PPI in research ~ Co-Creation!



Step 2:

Gathering Evidence and Questions



Step 3:

Synthesis of the list of concerns and uncertainties

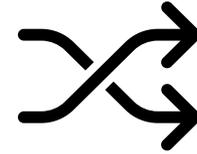


- Synthesis of concerns and a summary of indicative questions was carried out through a consultation meeting using online video conferencing facilities. This enabled a focused discussion and translation (grouping) of concerns into an indicative list for prioritisation or research topics from step 2.
- The aim of this consultation was to work collaboratively with key representatives to agree, by consensus, a prioritised list of concerns for identification of research priorities. These were then checked against the evidence to ensure questions that had been fully answered by research were not included in the prioritisation process.
- An agreed method or threshold criteria informed this process. From the original 34 areas identified these were reduced to 16.



Step 4:

Prioritisation of Questions



- As part of the iterative participatory process the Multi-Stakeholder Advisory Committee took part in the fourth and final online video conference.
- During this conference, members were asked to discuss the questions, hear different points of view about the priorities for research, and vote via google forms in order to establish the top 10.
- Once the 10 areas for priority were identified a process of editing in consultation with the group took place to ensure each statement was worded correctly to aid finalise the wording of each question.

Step 5:

Identifying Research Priorities



- 1) economic impact and financial strain
- 2) systemic issues, education, resources and policy
- 3) technology
- 4) support services and infrastructure
- 5) mental health and wellbeing of the carer
- 6) carers in society
- 7) recognition and acknowledgment of the family carer.

Key themes within these priorities relate to:

- Valuing carers in terms of their economic and societal contribution
- Economic impact and the financial strain of caregiving
- Provision and access to support services and infrastructure in Ireland

ECONOMIC IMPACT - FINANCIAL STRAIN



1. **TITLE:** How can employers and government better support family carers?

2. **EXPLANATION OF THE QUESTION:** Family carers often juggle employment with the demands of caring. Whilst government grants are available these are dependent on the hours of work an individual completes. Usually, employers will seek employees to complete a 20-hour week contract however to avail of social care support they can only work 18 hours a week, this disconnection leads to a 'poverty trap'. In addition, the pragmatic barriers present a barrier to caring. For example, inflation, using sick days to care, requiring certain hours of work to be completed, and the cost of care itself.

3. **PRIORITY POPULATION (S):** All family carers

4. **RATIONALE FOR PRIORITY:** For care to be sustainable, carers must be supported to care, this includes government and employer support.

- 'Its's all about support and this includes from employers. People don't really understand your role and employers try give support but they think an hour to drop home will help – but it might not be an hour – caring is unpredictable'.

ECONOMIC IMPACT - FINANCIAL STRAIN



1. **TITLE:** What financial implications has the pandemic had for family carers (including impact on household income, benefits, and entitlements)?

2. **EXPLANATION OF THE QUESTION:** The COVID-19 pandemic has presented unique restrictions to financial income, including job loss/furlough and restriction on financial benefits. For many families, taking on caring responsibilities results in long-term financial hardship, with the loss of income from employment exacerbated by higher household costs. Covid-19 has exacerbated those challenges for many carers.

3. **PRIORITY POPULATION (S):** All family carers

4. **RATIONALE FOR PRIORITY:** For care to be sustainable, carers need to be supported to care. This includes government and employer support.

'The 'poverty trap' is the only way to describe it, we are often faced with financial strain and are now with COVID-19 there are additional money pressures'

Conclusion:

- The partnership focus of this project allowed the 'ground-up' development of research priorities for carers by carers.
- The COVID-19 pandemic served to magnify systemic issues already present in society, as well as highlight new burdens.
- The development of 10 researchable questions will guide further investigation to improve the support and wellbeing of family carers.

Priority Research Questions

Economic Impact - Financial Strain

- A. How can employers and government better support family carers?
- B. What financial implications has the pandemic had for family carers (including impact on household income, benefits, and entitlements)?



Systemic issues, education, resources and policy

- C. To what extent has the pandemic amplified existing systematic failures in the care system, and/or created new challenges for family carers?
- D. What aspects of the policy response to the pandemic were effective in meeting the additional needs of family carers?
- E. How have other nations supported family carers during the pandemic and what lessons can be learned from them?



Technology

- F. What was the impact of technology on the experience of family carers and the care relationship during the pandemic? What benefits and limitations need to be accounted for when designing future virtual support systems?



Support services and infrastructure

- G. In accordance with post-pandemic restrictions, how can essential support services for service users be designed to maintain the health and safety of family carers?
- H. How can access to respite services for service users be designed to support family carers in the event of another health crisis?
- I. How do family carers plan for future care, in the event of their own sickness, frailty, death or another change in their circumstances?



Mental health and wellbeing of the carer

- J. How did the pandemic impact on the mental health and wellbeing of family carers? How can carers' mental health be protected from the effects of intensive caring (e.g. burnout) during potential future periods of lockdowns or service withdrawal?
- K. What are the key support interventions (for both the carer and the person being cared for) that can help family carers sustain their caring role in a meaningful way?
- L. How has the COVID-19 pandemic impacted on family carers' resilience and ability to self-care?



Carers in society

- M. How has the role of the family carers changed during the COVID-19 pandemic, and what impact has this had on carers, their families, and relationships? Is there an ethical limit to what we can expect from family carers in the event of another health crisis?



Recognition and acknowledgement of the family carer

- N. How have the public perceptions of, and empathy towards, the 'family carer' changed during the pandemic, and what impact has this had on family carers themselves?
- O. How can the value of family carers' work be better recognised in terms of its societal contribution, and by carers themselves, and how can this increase the inclusion and involvement of carers within their communities?
- P. How can partnerships between family carers and healthcare professionals be improved or developed to better support the person being cared for and to support family carers?



Thank You

