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Caring beyond **COVID-19:**  
Identifying Research Priorities for  
**Family Carers**



# Project Team

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# Foreword

On behalf of the Interface collaboration committee, I am delighted to provide the foreword to this report.

The Interface project, as the name implies, is the intersection between health and social care community services and family carers. This project sought to provide an understanding of the experiences of individuals who have a shared need and/or navigated caring challenges during the pandemic.

I am very pleased to have been part of the Interface project, Caring During COVID-19: Identifying Research Priorities for Family Carers, undertaken by the University College Cork on behalf of Family Carers Ireland. The Interface project, IdeNtifying prioriTiEs foR FAMily CarErs, established 10 researchable questions which will guide further research to improve the support and wellbeing of family carers, especially when preparing for the next pandemic.

During the lockdowns of 2020 and 2021 wider society had a little taste of what life is like for a typical family carer: social isolation, lack of social support, and grief for one's former way of life, are some of the experiences felt by many. While wider society will have the comfort of coming out of lockdown, social isolation and lack of social support will, unfortunately, remain the daily experience of many family carers.

As a family carer, this priority setting process provided an opportunity to articulate and process my experiences of the changes taken place since March 2020. Thinking back to our various online meetings, several personal stories and moments of raw vulnerability stand out. I am grateful for the honesty of the team and equally thankful for having had the opportunity to be heard myself. **I feel less alone. While the circumstances of family carers vary, the common threads of isolation, lack of support and grief bind us together.**

Hannah Deasy,

Family Carer



# Introduction

A long-standing objective of Government policy for older people and children and adults with an illness or a disability is to support them to live with dignity and independence in their own homes for as long as possible<sup>1</sup>. Family carers are vital to the achievement of this objective and are considered the backbone of care provision in Ireland<sup>2</sup> saving the State some €20 billion each year in avoided health and social care costs<sup>3</sup>. Whilst caring for a family member, friend or neighbour is associated with several benefits, such as emotional rewards and personal growth, there is mounting evidence that unpaid caring should be considered a social determinant of health. Caring, if not adequately supported, can have adverse impacts on a persons' wellbeing, their physical and mental health, quality of life and employment opportunities. However, even before the COVID-19 pandemic, many of Ireland's 500,000+<sup>4</sup> family carers were experiencing financial difficulty, social isolation, and ill-health.

During the COVID crisis many carers were forced to care single-handed without the support of family, day services, home care or respite. Some were made unemployed and faced significant financial pressures while parents of children/adult children with a disability lost their routine and access to day services as well as essential therapies, placing the person at serious risk of regression. Older carers and those with underlying health conditions were expected to cocoon and were reliant on others for their shopping, prescriptions, and essential medical supplies. Social distancing and self-isolation are terms now synonymous with the pandemic, while difficult for us all, are almost impossible for family carers where personal, intimate and hands on care is required. The pandemic has also brought with it significant psychological impacts on carers and those for whom they care, causing fear, anxiety, stress and grave uncertainty about the restoration of health, community and social care services in the months and years ahead.

<sup>1</sup>See: Care of the Aged Report (1968); The Years Ahead-A Policy for the Elderly (1988); Quality and Fairness-A Health System for You (2001); Primary Care-A New Direction (2001); Future Health: Strategic Framework for the Reform of the Health Service (2012); Seanad Report on The Rights of Older People (2012); Slainte Care Report (2017).

<sup>2</sup>Department of Health (2012) National Carers' Strategy: Recognised, Supported, Empowered. Department of Health, Dublin.

<sup>3</sup>13 per cent of the Irish population aged over 15 years provide care (Irish Health Survey 2019). Extrapolation to the national population means Ireland has some 499,904 family carers. Family carers provide a average of 38.7 hours of care each week (Census 2016) which means that collectively, carers provide 19m hours of unpaid care each week. The annual replacement cost of the care provided by family carers is approximately €20bn.

<sup>4</sup>Central Statistics Office, 'Irish Health Survey 2019 – Carers and Social Supports' (Dublin: Central Statistics Office 2020) <https://www.cso.ie/en/releasesandpublications/ep/p-ihsc/irishhealthsurvey2019-carersandsocialsupports/>

# Background

Since the onset of the global pandemic, the essential role that research plays in tackling the COVID-19 pandemic has been well illustrated. Identification of research needs and gaps from current evidence generates relevant questions and involving service users strengthens this process. Recognising the importance of addressing the needs of family carers, University College Cork and Family Carers Ireland began working in partnership on the INTERFACE project to identify research priorities relating to family caring, in relation to the COVID-19 pandemic.

Inspired by the well-established James Lind Alliance Priority Setting Partnerships (JLA PSP)<sup>5</sup>, the research team implemented a collaborative process with family carers and those who work closely with them, aiming to identify research priorities relating to caring in the context of COVID-19. Whether the experiences were on a personal or a professional level, the views of carers, those who worked with them, and academics were given equal attention throughout the project. The nine-month collaborative process resulted in a ranked list of ten research priority areas in the context of the ongoing COVID-19 pandemic.

The research priorities identified through the INTERFACE project are predominantly related to the experience of caring during COVID-19. However, some of the research priorities identified reiterates systemic issues related to caring for family carers in Ireland. Also, new burdens related to caring during the pandemic emerged. Further work is needed to identify more specific research priorities relating to particular caring situations.

The ten priorities identified through the INTERFACE project will help to inform future research on caring in the context of the continuing COVID crisis or future pandemics. This can focus efforts on achieving improvements in the areas of policy and practice that are of greatest concern to carers.

This report has been developed in two sections. The first section outlines the five steps taken to reach consensus on the top ten research priorities. The second section sets out the context for considering the specific research priorities.

<sup>5</sup>James Lind Alliance (JLA) 2021 The James Lind Alliance Guidebook available at <https://www.jla.nihr.ac.uk/>  
Accessed on 10th February 2022

# Carers at a glance

## Who Is a Carer?

Someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability<sup>6</sup>

### Who Cares?

499,000 **12.5%** of the adult population  
**86%** of family carers are family members. Most are caring for an ageing parent or a child with high support needs<sup>7</sup>

## How Much?

### How Much Care Is Provided?

Average of **44.6 hours** of care provided per week<sup>7</sup>

### How Do We Financially Support Full-time Family Carers?

**89,000** carers receive the Carers Allowance Over **116,000** receive the annual Carer Support Grant<sup>8</sup>

### Is the Role Challenging?

**88%** of carers feel stressed trying to balance caring with other family and work responsibilities<sup>9</sup>

## What Is the Health Impact?

**68%** of carers feel their health has suffered as a result of caring<sup>9</sup>

**48%** of family carers have been diagnosed with mental ill health<sup>9</sup>

**70%** increase in the number of carers diagnosed with depression from **2009 to 2019**<sup>9</sup>

## Ethnicity, Gender & Children

### Ethnic Background

**5%** of family carers in Ireland are from an ethnic background other than 'white Irish'<sup>6</sup>

### What's the Gender Mix?

Women account for the majority of family carers in Ireland; however, the number of male carers is increasing - currently nearly **40% of all carers are male**<sup>7</sup>

### Do Children Provide Family Care?

**11%** of school-age children report providing care<sup>11</sup>

## Percentages

How Many Home Support Service hours are provided each year? **24.26m**<sup>10</sup>

What share of the Social Welfare Pie do Family Carers Get? **6.7%**<sup>8</sup>

### Are there more older Carers now?

The number of older carers has increased by over **50%**<sup>7</sup>

<sup>6</sup>Central Statistics Office (2020) Irish Health Survey 2019 - Carers and Social Supports. CSO, Dublin.

<sup>7</sup>Central Statistics Office (2017) Census 2016 Profile 9 - Health, Disability, and Carers. CSO, Dublin.

<sup>8</sup>Department of Social Protection (2021) Annual Report 2020

<sup>9</sup>Family Carers Ireland, College of Psychiatrists of Ireland & University College Dublin (2019) Paying the Price: The Physical, Mental and Psychological Impact of Caring, Ireland: Family Carers Ireland. <https://familycarers.ie/wp-content/uploads/2019/05/Paying-the-Price-The-Physical-Mental-and-Psychological-Impact-of-Caring.pdf>

<sup>10</sup>Health Service Executive (2020) National Service Plan 2021.

<sup>11</sup>Family Carers Ireland (2020) Young Carers in Ireland: Insight into the Prevalence and Experiences of Young Carers in Ireland using data from the Health Behaviour in School-aged Children (HBSC) 2018 Study. <https://familycarers.ie/media/2126/young-carers-in-ireland-family-carers-ireland.pdf>



# 5 Steps to the Top 10 Research Priorities

The INTERFACE project collaborated with family carers to explore what research is needed to support carers.

A collaborative process between Family Carers Ireland and family carers was coordinated by the research team to ensure the correct conditions were in place to identify research priorities relating to caring in the context of COVID-19.

This collaborative approach enabled personal and professional experiences to be shared by the committee over the course of six months. The 5 steps, known as the 5 Cs, entailed coordinating conditions, establishing a collaboration committee, identifying common concerns, choosing the top concerns and communicating change. This collaborative process also entailed an evidence-based review of the literature and focus group discussions resulting in a long list of concerns. Together, with the research team, common concerns were grouped into an indicative list for prioritisation. Following further consultation, the top 10 concerns were chosen which provided unique insight into care circumstances during the pandemic. These were then ranked to communicate the research priorities for carers by carers to help enact change.



# Step 1:

## Coordinate conditions for identifying research priorities



To ensure the interface project was reflective of key stakeholders, the research team drew on the well-established James Lind Alliance Priority Setting Partnerships (JLA PSP) methods. The research team implemented a collaborative process with family carers and those who work closely with them, aiming to identify research priorities relating to caring in the context of COVID-19.

To that end a Multi-Stakeholder Advisory Committee (MSAC) was established.

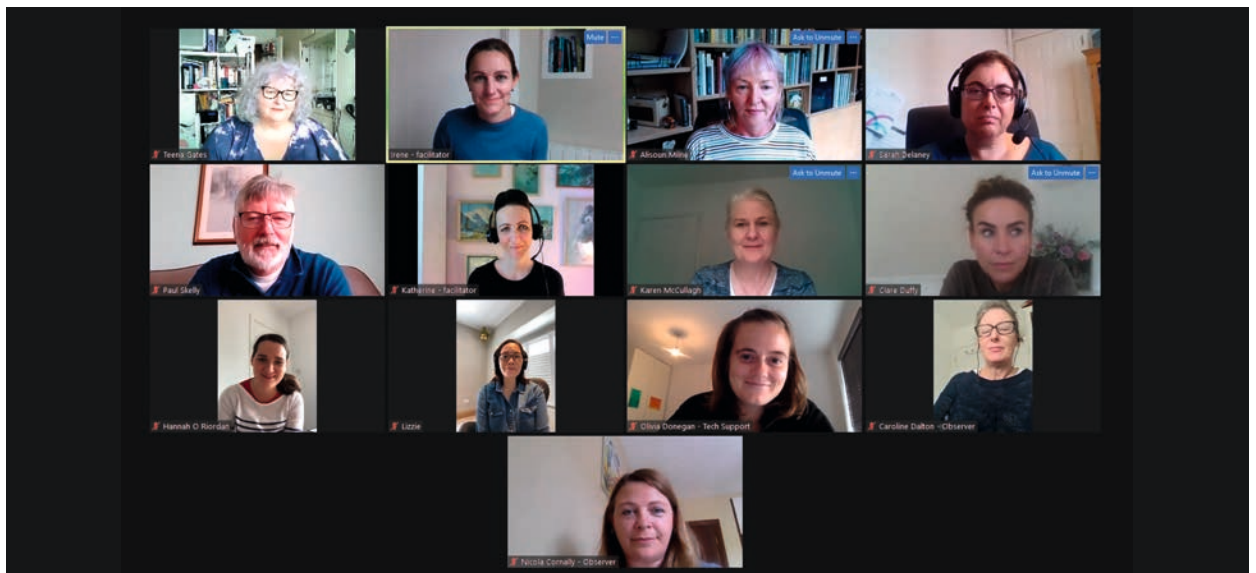
This collaboration committee was integral to guiding the researchers' direction and prioritisation process. The committee was made up of thirteen members from different backgrounds each providing a unique perspective to the project.

Members comprised of family carers and representatives from family carers Ireland, Eurocarers, Health Research Charities Ireland, Community Healthcare.

The purpose of MSAC was three-fold:

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.

<sup>11</sup> James Lind Alliance (JLA) 2021 The James Lind Alliance Guidebook available at <https://www.jla.nihr.ac.uk/> Accessed on 10th February 2022.





# Step 2:

## Collaboration Committee



The work of the committee began with assimilating and contemplating research evidence from various sources. The research team conducted an evidence-based review of published primary studies. Sequentially, consultation with Family Carers Ireland staff members and Health and Social Care Professionals helped gather 'questions and concerns' about family care.

In addition, an audit report prepared by FCI provided a summary of concerns raised in 2020 from its members. This audit report provided data from Freephone Careline calls and social media. Two additional relevant reports used to inform the priority areas were Caring Through COVID: Life in Lockdown (2020)<sup>12</sup> and The State of Caring (2020)<sup>13</sup>.

Once compiled, the data was analysed and cross referenced to provide themes and potential questions for verification by the MSAC. From analysis of the data the committee produced a list of concerns and uncertainties to be further refined. Figure 1 provides an overview of the sources of data.

<sup>12</sup> Family Carers Ireland (2020) Caring through COVID - life in lockdown. Family Carers Ireland. Dublin Ireland. <https://familycarers.ie/media/1394/caring-through-covid-life-in-lockdown.pdf>. Accessed 13th May 2021

<sup>13</sup> Family Carers Ireland (2020) The state of caring. <https://familycarers.ie/media/2022/family-carersireland-state-of-caring-2020.pdf>. Accessed 20th May 2021



Figure 1: Sources of Evidence

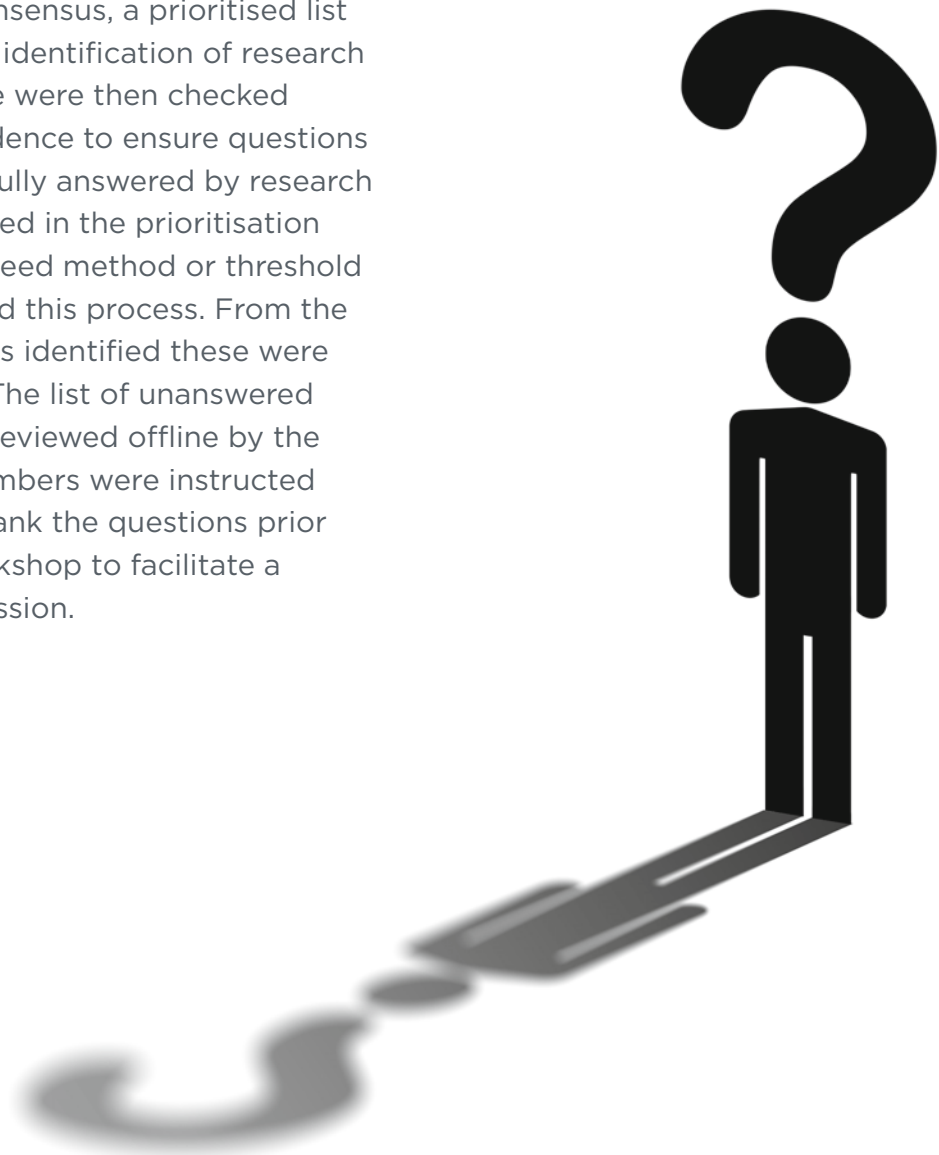
# Step 3:

## Common Concerns



Synthesis of concerns and potential questions was conducted through an online video consultation with the committee. 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. The list of unanswered questions was reviewed offline by the committee. Members were instructed to review and rank the questions prior to the final workshop to facilitate a thorough discussion.



## Step 4: Choose Top Concerns



The final meeting involved the difficult decision making process to agree on the top concerns or research priorities for family carers. This process involved a three hour group discussion, where members heard different points of view about the priorities across two breakout online rooms before voting or ranking their top 10.

Once the ten areas for priority were identified and agreed, a process of editing in consultation with the group took place to finalise the wording of each question.



## Step 5: Communicate Change



The Interface project communicates change needed to improve the support and wellbeing of family carers in the context of a global pandemic. However, research investigation is needed, firstly, on the ten research priorities to examine systemic issues and new burdens identified by key stakeholders. This project allowed the 'ground-up' development of research priorities for carers by carers. The priorities for research are grouped into five categories.

1. Adequate & appropriate support services
2. Mental health and wellbeing of the carer
3. Employment
4. Economic wellbeing
5. Recognition and acknowledgement of the family carer



# Top 10 Research Priorities

The research priorities identified through the INTERFACE project are predominantly related to the experience of caring during COVID-19. The pandemic brought with it significant physical and psychological impacts on carers and those for whom they care.

The opportunity to engage in relevant research with stakeholders enabled understanding the experiences of carers and highlighted key concerns.

The partnership approach of this project allowed the 'ground-up' development of research priorities for carers by carers and is central to impactful research. The COVID-19 pandemic served to magnify systemic issues already present related to caring for family carers in Ireland. The identification of 10 researchable questions will guide further investigation to improve the support and wellbeing of family carers. Research priorities can help shape reform and create awareness in the community regarding the role of family carers.

The top 10 research priorities would not have been possible without the involvement of services users and various organisations. We would sincerely wish to thank key organisations, such as Eurocarers and Health Research Charities Ireland for their involvement as well as PPI Ignite Network @UCC for advising on how to include the voices of carers. The wealth of experience that came from family carers and the participatory process enabled different perspectives to be heard and understood with the end result of them being translated into an indicative list for prioritisation.

## ADEQUATE & APPROPRIATE SUPPORT SERVICES



Category one was adequate and appropriate support services and three research priority questions were developed under this category. Key to supporting carers is ensuring that services are available if and when they are needed. The COVID-19 pandemic has exacerbated many pre-existing challenges in accessing supports and services, with help remaining limited, restricted eligibility criteria and a lack of choice. Family carers who took part in the research and members of the MSAC emphasised that they had no choice but to take on more care responsibilities as appropriate resources and supports were simply not available. Fears about what would happen in the event they or their loved one contracted COVID-19 was a central concern for those involved. The vital role that adequate and appropriate support services play in sustaining family carers' was identified as priority research area. Three research questions were developed.

**Q1**

*To what extent has the pandemic amplified existing systemic failures in the care system, and/or created new challenges for family carers?*

**Q2**

*How can access to respite services for service users be designed to support family carers in the event of another health crisis?*

**Q3**

*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 WELL-BEING OF THE CARER



Category two was mental health and wellbeing of the carer and two research priority questions were developed under this category. Caring often entails significant psychosocial risks that are heightened when confined to the home during a global pandemic. Family carers have faced unprecedented levels of uncertainty since the onset of the pandemic: both for the people they care for and for their own health and well-being. Many carers have had to increase the hours and intensity of the care they provide, and significant numbers of people have taken on caring responsibilities for the first time. Given that many carers experience poor health and well-being, there is a significant risk that health inequalities will be increased by this pandemic, particularly for high-risk groups such as carers. Those participating in the project emphasised that carers' health and wellbeing needed to be better supported in the event of a future crisis or emergency. Although there is already a significant range of interventions to support carer well-being, evidence based resources specific to a future emergency or crisis situation (such as a pandemic) is paramount.

**Q4**

*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?*

**Q5**

*How has the COVID-19 pandemic impacted on family carers' resilience and ability to self-care?*

## EMPLOYMENT



Category three was employment and one research priority question was developed under this category. Family Carers Ireland estimate that as many as 1 in 9 employees juggle paid work alongside a caring role. Taking on caring responsibilities while also working in paid employment can present significant challenges for carers and their families. Pre-COVID-19, many carers were forced to reduce their working hours, forgo promotion opportunities, taking a job with less responsibility or leaving their job entirely to provide care. Since the onset of the pandemic, the worlds of both employment and caring have been dramatically altered. Family carers are facing unique and unprecedented challenges in addition to the many pressures already associated with balancing work and family care.

**Q6**

*How can employers and government better support family carers to balance paid work with caring?*



## ECONOMIC WELL-BEING



Category four was related to economic well-being and one research priority question was developed under this category. 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. Moreover, significant life changes are often required to cope with the practical aspects of caring, e.g. moving house, practical adaptations to your home or purchasing an accessible vehicle. The economic impact of caregiving is not only experienced during the active years of caring, but can last a lifetime, as years spent on a low income or out of the workforce mean carers can't repay debt, build savings or contribute to a pension. If caring comes to an end while the carer is of working age, barriers to returning to work often result in carers being 'locked out' of the labour market. Even working carers, who manage to remain in employment, are likely to see their working lives adversely affected by having to reduce their hours of work, accept low-paid, precarious work options or sacrifice promotion and career opportunities.

**Q7**

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



## RECOGNITION AND ACKNOWLEDGEMENT OF THE FAMILY CARER



Category five was recognition and acknowledgement of the family carer and Three research priority questions were developed under this category. Care is part of the human condition – it will come to us all one day, whether as recipient, provider or arranger of the support that everyone needs when faced with illness, accident, frailty or the end of life. Yet despite the centrality of care to our everyday lives and the enormity of carers' unpaid contribution, care work in the home has been undervalued and has often remained invisible with little official recognition of its significance to the everyday functioning of society. The COVID-19 pandemic has illuminated our collective reliance on the informal care provided in families and communities.

**Q8**

*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?*

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**Q9**

*How has the role of 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?*

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**Q10**

*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?*

# FAMILY CARERS IRELAND TOP 5 RESEARCH CATEGORIES FOR CHANGE



## Adequate & Appropriate Support Services

**Q1** To what extent has the pandemic amplified existing systemic failures in the care system, and/or created new challenges for family carers?

**Q2** How can access to respite services for service users be designed to support family carers in the event of another health crisis?

**Q3** 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 Well-being of the Carer

**Q4** 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?

**Q5** How has the COVID-19 pandemic impacted on family carers' resilience and ability to self-care?



## Employment

**Q6** How can employers and government better support family carers to balance paid work with caring?



## Economic Well-being

**Q7** What financial implications has the pandemic had for family carers (including impact on household income, benefits, and entitlements)?



## Recognition and Acknowledgement of the Family Carer

**Q9** 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?

**Q10** How has the role of 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?

**Q11** 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?



The top 10 research priorities for carers were chosen by carers, through a collaborative process in partnership with University College Cork and Family Carers Ireland to help enact change. Research priorities can help shape reform and create awareness in the community regarding the role of family carers.

