



**Cúram Sláinte Phobail, Iarthar**  
**Community Healthcare West**

# **The Pilot Implementation and Evaluation of the interRAI Family Carer Needs Assessment**



**FINAL REPORT**  
**DECEMBER 2023**





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# Foreword

On behalf of Community Healthcare West (CHW), I am pleased to present to you the report of *The Implementation and Evaluation of the interRAI Family Carer Needs Assessment*.

The interRAI Family Carer Needs assessment form is a comprehensive approach to the identification of strengths, preferences and needs of family carers. This is the first time this assessment form has been tested in Ireland and internationally with family carers from five distinct care groups - dementia, older people, physical and sensory disability, intellectual disability and mental health.

CHW acknowledges, appreciates and respects the immense contribution that family carers make in our community. *The Programme for Government: Our Shared Future* acknowledges that family carers are ‘the backbone of care provision in Ireland’. Our healthcare system is very dependent upon the continuing supply of family carers, and this trend is likely to continue into the future as demand for care at home continues to rise, due to improved longevity, advances in medical care and a shift away from institutional care.

With the Irish Longitudinal Study on Ageing (TILDA) showing that almost three-quarters of care in the community is provided by family carers, I am very aware that without family carers, the health service would be adversely impacted. This became even more apparent during the recent COVID-19 pandemic where the family carer’s contribution to the national healthcare response to suppressing the virus was fundamental.

Caring can be rewarding but can also impact negatively on the health and well-being of family carers. Recognition of the role of family carers and the need to make both direct and enabling supports available to carers that are easily accessible, is of critical importance. I acknowledge that too often accessing support can be difficult to navigate and can feel like a further challenge that carers have to overcome.

Family carers are not a homogenous group. Each carer is an individual who has her or his own unique story to tell and particular needs to be met. This highlights the significance of opening the discussion on carer needs assessment’s, and this seminal CHW pilot programme, which is part of an interRAI multinational study led by interRAI International and the interRAI Ireland National Office, will help inform this discussion, bringing new findings

## Community Healthcare West

and reinforcing some previously known.

As we reform, it is essential our health service anticipates, responds and consistently improves the care we deliver. I believe that this pilot programme will help us to better understand the scale and scope of carers needs, and will help inform the development of services and policies which properly recognise, identify and support family carers.

I acknowledge the Government funding received under the Dormant Accounts Fund which made this project possible. I would like to thank the family carers and the health and social care professionals from the HSE and voluntary agencies for their integral participation in the pilot programme. Finally, I would like to thank the project team and the membership of the steering group whose advice and expertise has informed the completion of the pilot programme in CHW.



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**John Fitzmaurice**  
**Chief Officer, Community Healthcare West**

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# Glossary of Abbreviations

<b>ADL</b>	Activities of Daily Living
<b>ADS</b>	Adult Day Service
<b>ASI</b>	Alzheimer Society of Ireland
<b>BoCS</b>	Brothers of Charity Services
<b>CAPs</b>	Clinical Assessment Protocols
<b>CHW</b>	Community Healthcare West
<b>CIPC</b>	Counselling in Primary Care
<b>CMHT</b>	Community Mental Health Team
<b>CREC</b>	Clinical Research Ethics Committee
<b>CSO</b>	Central Statistics Office
<b>DAF</b>	Dormant Accounts Fund
<b>DoH</b>	Department of Health
<b>FCI</b>	Family Carers Ireland
<b>FCNA</b>	Family Carer Needs Assessment
<b>GP</b>	General Practitioner
<b>HCP</b>	Home Care Package
<b>HRB</b>	Health Research Board
<b>HSE</b>	Health Service Executive
<b>ICPOP</b>	Integrated Care Programme for Older Persons
<b>ID</b>	Intellectual Disability
<b>IADL</b>	Instrumental Activities of Daily Living
<b>interRAI</b>	International Resident Assessment Instrument
<b>NCAOP</b>	National Council on Ageing and Older People
<b>NCPOP</b>	National Centre for the Protection of Older People
<b>NIDD</b>	National Intellectual Disability Database
<b>NPSDD</b>	National Physical and Sensory Disability Database
<b>OECD</b>	Organisation for Economic Cooperation and Development
<b>OP</b>	Older People
<b>OT</b>	Occupational Therapy
<b>PHN</b>	Public Health Nurse
<b>POLL</b>	Psychiatry of Later Life
<b>P&amp;S</b>	Physical and Sensory
<b>PwD</b>	People with Dementia
<b>QoL</b>	Quality of Life
<b>SAT</b>	Single Assessment Tool
<b>SCaN</b>	Self-Reported Carer Needs
<b>TILDA</b>	The Irish Longitudinal Study on Ageing
<b>WHO</b>	World Health Organisation

# Executive Summary

## Introduction

Family carers are a vital health, social and economic resource across the world (Hu and Ma, 2018; Pickard, 2015). Care needs are increasing in our society due to improved longevity, advances in medical care and a shift away from institutional care (Oireachtas Library & Research Service, 2019). Eighty percent of long-term care in Europe is provided by family carers (Eurocarers, 2021), while recent figures from Ireland indicate that 1 in 8 people over the age of 15 are providing care to a family member (Family Carers Ireland, 2020).

The most recent Census of Population of Ireland defines a ‘carer’ as someone who ‘provides regular unpaid personal help or support to a family member, neighbour or friend with a long-term illness, health issue, or an issue related to old age or disability’ (Census 2022). Between Census 2016 and the most recent Census 2022, the number of carers increased by 53% to 299,128 or 6% of the population, up from 4% in the previous census. Growth was also recorded in the number of hours of unpaid care provided each week, with the largest increase among persons providing care for 43 hours or more per week, with an intercensal increase of 111%<sup>1</sup> (CSO, 2023). The Irish Longitudinal Study on Ageing (TILDA) has shown that the majority of care to older people living at home was provided by family carers (70%), with 30% receiving either state-provided or private home support (McGarrigle and Kenny, 2020). Family Carers Ireland (2020) has estimated that the financial contribution of family carers is €20bn per year.

It is clear that family carers are vital to supporting older people, children and adults with an illness or a disability, to live with dignity and independence in their own homes and communities. However, family carers in Ireland continue to report having poorer health, less support and feeling worried about the future than their non-carer counterparts (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019). This persists despite the publication of the first ever National Carers Strategy in this country in 2012, and the current ‘Programme for Government: Our Shared Future’ recognising that family carers are the backbone of care provision in Ireland (Government of Ireland, 2020).

Health professionals’ lack of explicit attention to family carers is a serious gap in health care. Carers are hidden patients themselves, with serious adverse physical and mental health consequences, from their physically and emotionally demanding work as caregivers and reduced attention to their own health (Thomas et al, 2015; Reinhard et al, 2008). Demographic and healthcare trends indicate family carer numbers in Ireland will continue to rise, therefore it is critical that a robust process is put in place for the identification, assessment, signposting and support of family carers. The interRAI Family Carer Needs Assessment is designed to help address this.

<sup>1</sup>It should be noted that there were a number of changes to the question on unpaid carers in the 2022 census form compared to previous years which may affect comparability.

## The interRAI Family Carer Needs Assessment

The interRAI Family Carer Needs Assessment is a tool being piloted as part of a larger suite of instruments developed by interRAI, an international collaboration of clinicians and researchers, to support comprehensive assessment and patient-centred care planning. The assessment form is a comprehensive approach to the identification of strengths, preferences and needs of family carers.

The CHW pilot programme is the Irish site of an interRAI multinational study led by interRAI International and the interRAI Ireland National Office. In Ireland, the interRAI suite of assessment instruments has been endorsed by the Department of Health and Sláintecare as the care needs assessment of choice, and is being implemented across the HSE focusing initially on Home Support and across ICPOP teams and long-term care thereafter. The multinational study including this Irish pilot, will help inform the refinement of the Family Carer Needs Assessment form within interRAI standards. From an Irish perspective, the CHW pilot programme will provide key information for service providers and policymakers and will ultimately contribute to increased responsiveness of the health system to best support family carers. Through the interRAI Ireland National Office, work on developing a Carers Assessment will continue after the completion of the CHW pilot.

### Aim and Objectives

The aim of the pilot programme was to test the implementation of the interRAI Family Carer Needs Assessment across various care groups, including, carers of people with dementia (PwD), older people, physical and sensory disability, intellectual disability, and mental health, in CHW.

The six objectives of the pilot programme were:

1. To objectively identify, and assess the needs of family carers, and the differences in needs, across all care groups.
2. To respond to the identified unmet needs of family carers by the provision of supports/ services where feasible within existing services.
3. To track outcomes for family carers with a repeat assessment.
4. To assess the use of the FCNA by health professionals in their respective services.
5. To assess the appropriateness of the FCNA for family carers across all care groups.
6. To support HSE policy decision-making, service planning and service provision.

### Methods

The pilot programme comprised of four phases. In phase 1, eighty-nine family carers from five care groups (i.e. Older People, People with Dementia, Physical and Sensory Disability, Intellectual Disability and Adult Mental Health) were referred to the programme in a sequential manner over a five-month period, by 48<sup>2</sup> health and social care professionals

working in the HSE and in voluntary agencies. These professionals facilitated carers, where necessary, to complete a baseline assessment form. Frequency of the quantitative responses were analysed to determine the extent of needs and supports by the carer and care recipient to establish the areas of unmet needs.

An Additional Feedback Questionnaire was also completed by the same carers at baseline, to determine from the family carers perspective how well the assessment form captured important information, whether the questions were appropriate for their care cohort/ care recipient, and whether pertinent information was missing. Eighty-eight participants completed the Additional Feedback Questionnaire.

In phase 2, completed assessment forms were given to the original referrer by the project manager, who then discussed with the referrers the follow-up actions to address the supports and services identified for both the care recipient and the family carer. Referrers and relevant voluntary agencies and HSE departments notified all of the follow-up actions taken to the Project Office which were entered on an excel database for analysis.

In phase 3, all family carers who participated in completing the baseline assessment form were asked to complete the assessment form again six months later. This was in order to assess the changes in needs across the various care groups at baseline (Time 1) to follow-up (Time 2) for family carers and care recipients, and to determine if providing services to meet unmet needs impacted factors determining well-being, including mood, quality of life and stress. A 70% response rate was achieved at follow-up with sixty-two carers completing the follow-up assessment form.

To gather further information on the appropriateness and usability of the assessment form, all referrers/professionals were invited to complete a survey developed by the project team. Thirty-six of the 52<sup>3</sup> referrers completed the survey, giving a response rate of 69%. This information was collated and was included in the analysis.

Three focus groups were conducted with eighteen referrers from the five care groups on the use of the assessment form by health and social care professionals, and important information was generated and was included in the analysis.

Phase 4 was the project closeout involving aggregation of all data collated, data analysis and compilation of the project report.

<sup>2</sup> Note- three of the 48 referrer's recruited carers from both the PwD and the OP care groups.

<sup>3</sup> Note- although a total of 48 referrers recruited the 89 carers at baseline, 52 referrers were included in the survey, because at the time of the survey being disseminated to referrers, four additional referrers were actively participating in the pilot programme, however they could not recruit any carers.

# Key Findings – interRAI FCNA Baseline and Follow-up

## Demographic Profile

The majority of family carers were female (75%), reside with the person they provide care to (83%), have been caring for more than five years (70%), with an average age of 58 years (range 26 – 86). Fifty-three percent of care recipients were age 65 years or under, and just over one-third were age 81-99 years.

The majority of family carers were:

- the care recipient's child or child in law (35%),
- parent/guardian (34%), or spouse/partner (22%),
- spending 35 hours or more per week taking care of the care recipient (81%).

## Family Carers Health and Wellbeing

### Memory and Cognition

At baseline, 64% of carers reported rarely or never encountering issues with memory. This reduced to 58% at follow-up. Additionally, 45% reported being easily distracted, had trouble paying attention or becoming sidetracked, this proportion was also reflected at follow-up (44%).

### Social participation

Reporting on social participation during the last 90 days, at baseline 55% of carers indicated a decrease in participation levels with half of those distressed by this decrease. At follow-up, 42% indicated a reduction in social participation, with just under a third of those distressed by this reduction. This increase in participation levels was statistically significant.

### Function, Endurance and Stamina

Fifty-two percent of carers at baseline reported feeling so exhausted that they could not carry out their normal day-to-day activities, with just over half of those feeling this in the three days prior to completing the assessment form. At follow-up, 40% of carers felt this way, with the majority of those (68%) feeling this way in the previous three days.

At baseline, 7% of carers reported being unsteady when walking. Worryingly there was a statistically significant increase in instability when walking among carers at follow-up (19%).

### Mood and Major Life Stresses

In the 3 days prior to completing the assessment, mood across all five indicators was poor at baseline, with:

- 41% were anxious,
- 32% were overwhelmed by their loved ones condition,
- 28% were sad or depressed,
- 27% of carers report little interest or pleasure,
- 20% felt they were unable to continue caring.



At follow-up, there were only marginal improvements. However, the exception which is concerning was the number of carers who felt overwhelmed by the care recipients condition which increased to almost half (T1 32%, T2 48%).

At baseline, 33% indicated that they had experienced a major life stress (such as, severe personal illness, death) in the preceding 90 days. This remained constant at follow-up (34%).

### Sleep

Almost half (49%) of carers at baseline experienced problems with sleep within the last three days (33% daily), with only a small improvement at follow-up (42% and 21% daily).

### General Health

At baseline, 55% of carers had seen a doctor or nurse practitioner about their own health in the previous 90 days. Over half (57%) of those had seen a doctor or nurse practitioner between two and five times, with four carers (8%) having six or more consultations for their own health in the 90 days prior to completing the survey at baseline. For carers included in the follow-up segment of the pilot programme, 55% had visited a doctor or nurse practitioner in the 90 days prior, with 35% of those having between two and five visits, with three carers (9%) having six or more consultations.

At baseline, 53% of carers reported pain to some extent, either in the last three days (27%), or often but not in the last three days (26%). One-fifth had pain daily in the last three days at baseline. Carers experiencing pain was mirrored at follow-up (53%).

Thirty percent of carers at baseline reported experiencing acute problems or flare ups of a recurrent or chronic problem. This proportion was reduced slightly at follow-up (29%). Over a quarter (28%) of carers at baseline reported having conditions or diseases that made their health, mood, behaviour or ability to function unstable (24% at follow-up).

### Quality of Life

Over half (53%) of carers at baseline were hopeful for the future most of the time or always (61% at follow-up). However, almost a quarter of carers (22%) were rarely or never hopeful for the future at baseline (13% at follow-up).

During the initial phase of the study, over half of carers (54%) indicated that they felt good about themselves most of the time or always (62% at follow-up), with a further 13% reporting that they rarely or never felt good about themselves, at follow-up, 16% rarely felt good about themselves, with no carer reporting that they never felt this. Approximately half of carers surveyed felt that caring for their relative has improved their relationship, this is consistent across both time points.

Sixty percent of carers at baseline felt listened to by healthcare professionals most of the time or always (56% at follow-up). However, there is still some work to be done by

healthcare professionals in supporting carers, with just under a fifth of carers rarely or never feeling listened to by healthcare professionals. This remains the case at follow-up. The majority of carers felt valued, important and good about their lives. Unsurprisingly, the majority of carers cannot be alone if they wish (50% baseline; 44% follow-up), and are unable to leave on the spur of the moment (85% baseline; 82% follow-up). Of concern is that almost one-third (31%) of carers stated they either never or rarely can get the help they need right away at baseline and this increased to 37% at follow-up.

## Stress

At baseline, 93% of carers were stressed to some degree (79% at follow-up), the majority (63% baseline) indicated that they were stressed but will not change the care they provide (52% at follow-up). A further 20% reported they were stressed and they need to reduce the care they provide (23% at follow-up), with 10% indicating that they are stressed to the point of crisis and will stop providing care (5% at follow-up).

There was no significant difference in stress levels across care groups, however, for carers included across both data collection points, there was a statistically significant reduction in reported stress levels over the time period.

## Supports for Care Recipients

The three greatest support needs identified by carers at baseline were: assistance with personal care (49%), physical rehabilitation (physical and OT) (48%), and day or night care services outside of the home (46%). This priority of supports needed for the care recipient, as identified by the family carer, changed slightly at follow-up: day or night care services outside of the home (40%), assistance with personal care (32%), and mental health services (Social Work, Psychology) (29%).

An analysis of the 62 family carers who completed the assessment form at both time periods found that the highest demanded services for the care recipients across both periods regardless of an increase in provision, were day or night care services outside of the home (respite, day care), physical rehabilitation (physical and OT), assistance with personal care, and mental health services. Between baseline and follow-up, there was a statistically significant decrease in demand for aids and assistive devices, physical rehabilitation and assistance with household tasks.

## Supports for Family Carers

The three greatest support needs at baseline were: carer support groups (78%), episodic relief from caregiving (respite) (62%), and psychological counselling (40%). At follow-up, the greatest supports were: episodic relief from caregiving (56%), education or advice about a specific health problem (21%), and psychological counselling (18%).

An analysis of the 62 family carers who completed the assessment form at both time periods found that persistently across both periods the highest service demand for carers

was also respite, by way of episodic relief from caregiving (T1 66% : T2 56%). Education or advice about a persistent health problem was also in high demand both at baseline (31%) and follow-up (21%). At follow-up there was significantly less demand for counselling for carers, carer support group and financial or legal advice.

### Caring Challenges

The majority of carers (74%) indicated that caring for the care recipient was a major source of stress at baseline. This decreased only slightly at follow-up (71%). Regarding time for themselves, 65% stated at baseline that they have no time to themselves or to enjoy activities they like (58% at follow-up). A further 58% reported that they question their ability to help given the care recipients problems, again there was a small reduction at follow-up (53%).

Of note, carers experiencing financial difficulties and the number of carers for whom their caring role prevents them from working was significantly reduced at follow-up. Worryingly, the proportion of carers that lack support from family and friends increased over the time period (56% baseline; 60% follow-up), as did the carers that found it difficult to use and understand the healthcare system (36% baseline; 39% follow-up).

Carers were asked what they found difficult to manage alongside caring, and over half (56%) reported finding it difficult to care for the care recipient and manage a job or work (42% at follow-up), with 42% indicating they had difficulty managing family and children (32% at follow-up). A substantial number indicated that they found it difficult to care and make enough money to live on (37% baseline; 26% follow-up).

While contingency planning is an important element of family caring, the majority (66%) of carers at baseline indicated they did not have anyone to take over their caring role. This increased slightly at follow-up (68%).

### Summary of carer needs

Memory is an issue for many carers, with many also experiencing difficulties with concentration and a decline in social participation a source of distress for carers. Exhaustion, stress, difficulty sleeping, difficulty finding time for themselves, support with caring when needed, and difficulties juggling work, children and education are major health and well-being risk factors for the majority of family carers included in this study. The supports requested are in line with the challenges that align with the caring role, most notably respite care that would allow the carer take a break from their caregiving responsibilities and attend to their own needs.

# Key Findings – Usefulness and Usability of FCNA Information

## Focusing on the needs of Family Carers

There was general consensus with referrers/professionals that focusing on the needs of the family carer was a valuable and worthwhile exercise, and that it resulted in a more comprehensive understanding of the caring environment and better outcomes for the care recipient. Referrers indicated that carers felt it was a rare experience to be asked about their needs.

## Usefulness of FCNA information generated

Health professionals, who had referred carers to the pilot programme, were asked to rate how useful they found the information that the assessment form generated. The majority of referrers (94%) indicated that the information generated was either 'somewhat' or 'very useful'.

## Use of FCNA information

The majority of professionals found that the information collated by the assessment form benefited and helped inform their work with 96% stating they gained a more holistic perspective of the caring circumstances. **It is noteworthy that 87% of professionals felt that the assessment form gave them information that they otherwise would not have had access to.** Over three quarters (81%) of referrers noted that the assessment complemented other assessments that they already use, and 80% stated that it gave them a better understanding of the impact of caring on the family carer. Similarly, referrers gained a better understanding of the needs of the family carer, to some or a great extent as a result of the information collected (80%).

When referrers were asked how they used the information gathered, the largest number of responses, 38%, were to follow-up on supports in response to reported needs, followed by using it to inform multidisciplinary team meetings 20%, to inform service decisions 16%, and to inform care plans 15%.

## Ease of completion

The majority of health professionals and carers found the assessment form difficult, repetitive, and confusing. Feedback from health professionals and carers indicated that the Carer Needs Assessment form could be improved by digitising the process and form, to improve the flow and to identify sections which could be reduced and/or improved. There was general consensus amongst the professionals that without improvements some family carers may struggle to complete the assessment form.

## Other considerations

One cause of significant frustration amongst professionals was the fact that although family carers were being asked to assess their needs, there were no additional services and supports available to them.

## Summary of the assessment tool evaluation

Overall, the findings from the referrer's survey and the focus groups suggest that professionals felt that the assessment form provided new information on the carers needs and gave them a better understanding of the impact of the caring role on the carer. The use of information generated in the assessment form was crucial in professionals gaining valuable insight and also making informed decisions.

## Key Implications for Policy and Practice

The pilot programme provides important information on family carers in Ireland and findings suggest that while many family carers adapt to the caregiving role and responsibilities, this may harm their own health and well-being and social participation.

There needs to be greater efforts, for example earlier engagement, to support carers who find themselves struggling and adapting with the pressures of the caregiving role and managing their caregiving responsibilities. This should help prevent crises arising for the family carer.

Furthermore, more than half of family carers reported a decrease in social participation with half of those reportedly distressed by this decrease. There is a need for policies that promote greater social participation for carers, create opportunities and develop peer and social networks to enable carers engage in activities outside of their caring role.

Findings also showed that gaps in service provision exist and must be addressed. While family carers indicated that they were in receipt of some services, there were notable gaps. There were unmet needs in areas such as emergency respite, residential respite, in-home respite, day care, physical and occupational therapy, and assistance with personal care. In order for family carers to be supported in the best possible way, these services need a greater allocation of resources, with optimal services that are varied, timely, responsive, flexible and tailored to the carers and the care recipient's needs.

There was unanimous agreement that a comprehensive carer assessment tool is required among all parties involved in this pilot. However, there are some concerns raised about the accessibility of this assessment form for family carers. The volume of information collected and the repetitive nature of series of questions included in the assessment form needs attention. It is noteworthy that many healthcare referrers found both the collection of health and well-being indicator data useful in conjunction with services and supports identified as required by the carer. It was felt this gave a more holistic view of carer needs.



## Conclusions

Comprehensive individualised assessments can be used to capture the varied and multifactorial needs of family carers across various care groups. Future work by interRAI is underway to develop Outcome Scales and/or Clinical Assessment Protocols (CAPs); which are built into digital clinical algorithms that can be used for care planning and identify areas at risk of decline or highlight key areas requiring intervention. This CHW pilot programme is the Irish site of an interRAI multinational study, which will help inform the refinement of the assessment form and the interRAI Ireland National Office will continue this work.

This pilot programme highlights the challenges and benefits in implementing a comprehensive family carer needs assessment. It is important to note that there are many firsts with this pilot programme. This is the first time this version of the assessment form was tested in Ireland (two previous pilot studies tested a former version of the assessment form in Ireland), it is also the first time the assessment form was tested worldwide using a longitudinal component, and the first time the assessment form was tested worldwide across five distinct care groups. It is also the first time the assessment form was tested worldwide using health and social care professionals from statutory and voluntary agencies as referrers.

All of the indications are that family carer numbers in Ireland will continue to rise. Therefore it is critical that a robust process is put in place for the identification, signposting and support of family carers. Caring for family members is essential in our society, yet this role can put social, financial and emotional pressures on carers, and negatively impact their physical and mental health. Carers are hidden patients themselves, and it is important that policies, service providers, health and social care professionals continue to recognise the important role that family carers play in the provision of home care, and that varied and flexible support services for family carers are adequately resourced and easily accessible.



# Chapter 1 - Introduction

The Family Carer Needs Assessment pilot programme in CHW was conducted over a two-year period from September 2021 to September 2023 and involved four phases. Its findings are based on information family carers provided when completing the interRAI Family Carer Needs Assessment. This assessment form of carers needs is in the process of being developed by interRAI International to specifically identify the needs of carers in providing care to their care recipients.

This chapter discusses family caregiving in Ireland, summarises the pertinent demographic trends, and delineates the relevant health policies and strategies for family carers in Ireland. The chapter also outlines the aim and objectives of the pilot programme, and gives an overview of the programme design, data collection methods and data analysis.

## 1.1 Family Caregiving in Ireland

The most recent Census of Population of Ireland defines a ‘carer’ as someone who ‘provides regular unpaid personal help or support to a family member, neighbour or friend with a long-term illness, health issue, or an issue related to old age or disability’ (Census 2022). Between the 2016 Census and the most recent Census 2022, the number of carers increased by 53% to 299,128 or 6% of the population, up from 4% in the previous census (CSO, 2023).

Sixty-one percent of carers are female and 39% are male. The greatest proportion of carers were aged 50-54 years (15%), followed by 14% in each of the 45 to 49 and 55 to 59 years age groups. A further 15% of all unpaid carers were aged 65 years or over (45,878 carers). Growth was also recorded in the number of hours of unpaid care provided each week, with the largest increase among persons providing care for 43 hours or more per week, with an intercensal increase of 111%. Twenty-nine percent of carers in Census 2022 were caring for 43 or more hours per week (86,972 carers), and just over one-fifth (22%) of these were aged 65 years and over (19,377 carers). In fact, looking at age group breakdown for all carers, the highest proportions providing unpaid care for 43 hours or more per week were recorded in the age groups 75-79, 80-84 and 85 years and over, all at 50% or more. <sup>4</sup>

In respect of the three counties in CHW, there were 16,816 unpaid carers in Galway in April 2022, which was 6% of the county’s population compared with 4% in 2016. Females in the county were more likely to be carers than males, with 59% of all carers being female (9,953, 7% of all females), a similar trend to the national figure, and 6,863 were male carers (5% of all males). In Mayo, there were 9,459 unpaid carers, which was 7% of the county’s population compared with 5% in 2016. Similarly, females in the county were more likely to be carers than males, with 59% of all carers being female (5,570, 8% of all females), a similar trend to the national figure, and 3,889 were male carers (6% of all males).

<sup>4</sup> It should be noted that there were a number of changes to the question on unpaid carers on the 2022 census form which may affect comparability with the previous census.





In Roscommon, there were 4,563 unpaid carers, which was 6% of the county's population compared with 5% in 2016. Similarly, females in the county were more likely to be carers than males, with 57% of all carers being female (2,609, 7% of all females), and 1,954 were male carers (6% of all males) (CSO, 2023).

As well as the growth in the number of carers, the period between 2016 and 2022 also saw some notable increases in the hours of unpaid care provided in CHW. The number of carers in Galway providing 43 or more hours of unpaid help each week more than doubled, from 2,141 in 2016 to 4,580 in 2022. The number of carers in Mayo providing 43 or more hours of unpaid help each week also more than doubled from 1,319 in 2016 to 2,702 in 2022. In addition, the number of carers in Roscommon providing 43 or more hours of unpaid help each week also more than doubled, from 666 in 2016 to 1,400 in 2022 (CSO, 2023).

According to the Irish Health Survey 2019 (CSO, 2020), there are now over half a million family carers in Ireland. The survey estimates that 1 in 8 people in Ireland aged over 15 are family carers. Extrapolation to the national population suggests that approximately 516,594 people provide regular unpaid care. Previous estimates had put this figure at 355,000. Family carers Ireland (2020) has estimated that the financial contribution of family carers is now €20bn per year.

Populations are ageing rapidly worldwide, owing to a combination of advances in healthcare, nutrition and lifestyle changes. According to the World Health Organisation, the number of people aged 60 years and over is projected to more than double, from 962 million in 2017, to 2.1 billion by 2050 (WHO, 2022). In Ireland, latest population projections

indicate a 38% increase in the over 65 population by 2031 and a 68% increase in the over 85 population (HSE, 2021). With this changing demographic structure comes an inevitable rise in the number of older people who require care. Caring for family members is essential in our society, yet this role can put social, financial and emotional pressures on carers, and negatively impact their physical and mental health.

Key findings from analysis examining support to older adults using data from The Irish Longitudinal Study on Ageing (TILDA) showed that family carers (70%) provided the majority of the help, with 30% receiving either state-provided or private home support in Wave 5 which was collected in 2018. The percentage of those who received help (family caring and home support) increased from 45% receiving help with ADL and IADL limitations in Wave 1 (2009), to 60% in Wave 5. The older population continues to contribute substantially to the informal care of their family and friends. To enable family caring to continue, the TILDA report outlines that state-provided home support must also be available to facilitate and support carers to retain their work and leisure in addition to their caring responsibilities (McGarrigle and Kenny, 2020).

## 1.2 Government Policy & Family Carers

A preference for home care over residential care is embedded in many health and related Government policies, such as The National Carers Strategy (Department of Health, 2012), The National Positive Ageing Strategy (Department of Health, 2013), The National Dementia Strategy (Department of Health, 2014), and the current Programme for Government: Our Shared Future (Government of Ireland, 2020). Family carers are vital to the achievement of this objective.

The National Carers' Strategy is a seminal cross-departmental Government strategy, as it was the first strategy of its kind in Ireland, albeit it was published in 2012 during a time of severe economic austerity. It represents an important first step toward recognising the contribution of family carers and supporting them in their role. It sets the strategic direction for future policies, services and supports provided by Government Departments and agencies for family carers (Department of Health, 2012).

Key priority areas were set out in the four National Goals of the National Carers Strategy, including:

- Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for.
- Support carers to manage their physical, mental and emotional health and well-being.
- Support carers to care with confidence through the provision of adequate information, training, services and supports.
- Empower carers to participate as fully as possible in economic and social life.

The current 'Programme for Government: Our Shared Future' in recognising that family carers are the backbone of care provision in Ireland, outlines a commitment to reviewing

and updating the National Carers Strategy. It pledges to deliver a ‘Carers Guarantee’ that will provide a core basket of services to family carers across the country regardless of where they live (p. 51). In recognising the important work of family carers, the Programme for Government commits to developing a pension solution for carers, and extending free GP care to family carers in receipt of the Carer’s Support Grant (Government of Ireland, 2020, p. 76).

One of the key objectives of the HSE National Service Plan 2023 is to “utilise interRAI to determine appropriate care pathways to meet carers needs through completion of the carers needs pilot in Community Healthcare West” (HSE, 2023, p. 46).

### 1.3 Background to the development of the interRAI Family Carer Needs Assessment

In 2013, the HSE established the Carer Needs Assessment Development (CNAD) Working Group, which was a partnership between the interRAI Ireland national team (as part of the Single Assessment Tool (SAT) project), the interRAI consortium (an international not-for-profit organisation who specialise in assessment systems design), and the Family Carer Reference Group who represent a national network of over 200 carer groups across Ireland. Under the direction of the SAT Project Board, the CNAD Working Group was tasked to develop and pilot test a paper-based comprehensive assessment of the needs of an adult carer of an older person, in order to support family carers in their caring role. The CNAD Working Group undertook a literature review of available carer needs assessments and based on this review, several drafts of the Family Carer Needs Assessment form were developed. A final draft was then assessed in a formal pre-piloting scoping exercise both in Ireland and in Belgium, to assess the acceptability of the assessment for carers. As part of this scoping exercise Irish carers participated in testing the draft tool, their needs were identified and they gave their feedback on the tool.

Following changes to the assessment from the scoping exercise, an international pilot research study was then conducted in nine countries (including Ireland). Again Irish carers were identified and invited to participate in the pilot. Findings from all 9 countries were collated and the tool was again refined. This further tested the content and wording of the paper-based Carer Needs Assessment with adult family carers who were caring for older people in the community. In 2017, the final draft called ©interRAI Family Carer Needs Assessment was signed off by the Working Group.

In 2018, the National Dementia Office with support from the Department of Health, was successful in an application for Government funding from the Dormant Accounts Fund (DAF), to pilot the roll-out of the ©interRAI Family Carer Needs Assessment, and CHW was selected for the pilot. In 2021, the Chief Officer, CHW authorised the commencement of the pilot programme, under the direction of the Head of Service - Older People’s Services, CHW.

The pilot programme in CHW is the Irish site of an interRAI multinational study that will allow

the refinement of the assessment form and assist future participating organisations in many countries, including Ireland, to design care plans that considers the unique challenges, strengths and needs of family carers. Ireland is represented in interRAI International and the multinational study through the interRAI Ireland National Office. Work will continue after the CHW pilot on an international level and the Irish data will inform findings.

Subsequently, interRAI International are revisiting this draft assessment form and have changed the FNCA to self-report format and have re-named the form to interRAI SCaN (Self-Reported Carer Needs) Assessment Form.<sup>5</sup>

The assessment form is a comprehensive approach to the identification of strengths, preferences and needs of family carers. The pilot programme will provide key information for service providers and policymakers and will ultimately contribute to increased responsiveness of the health system to family carers.

The assessment form is designed to identify the needs of a family carer in providing care to their care recipient. It looks at the role of the family carer, how caring affects them, and how much care they can realistically provide (while still allowing for involvement in other activities). The assessment aims to identify what types of help or support the family carer may need to support them in their caring role. It provides an opportunity for family carers to:

- Share their experience of caring and to recognise their role as a family carer.
- Discuss and reflect on their own needs as a family carer.
- Be provided with information and advice.
- Identify and discuss any difficulties they may have.
- Make contingency plans if they are ill or unable continue in their caring role.



<sup>5</sup> In February 2022, CHW was informed of this revised name to interRAI SCaN, and permission was granted by interRAI International for Ireland to continue calling the assessment form interRAI FCNA, as the Irish pilot programme had already commenced (of note, only the name of the assessment form changed, all original questions remained unchanged). The SCaN instrument is copyrighted by the interRAI Corporation and the full SCaN instrument is available at <https://catalog.interrai.org/>



## 1.4 Aim and Objectives

Although caring has been reported to have some benefits for family carers, for example a sense of purpose and achievement (Lefranc et al, 2017), greater caring responsibilities have been linked with progressively poorer health outcomes for carers (Thomas et al, 2015), thereby indicating a need for health and well-being supports for family carers. The importance of early identification of carers, effective carer supports, health promotion, monitoring high-risk groups, and timing appropriate interventions is paramount (Shah et al, 2010). The interRAI Family Carer Needs Assessment instrument, which is the subject of the present pilot programme, is designed to help address this.

As such, the aim of the pilot programme was to test the implementation of the assessment form across various care groups, including, carers of people with dementia (PwD), older people, physical and sensory disability, intellectual disability, and mental health, in CHW.

The six objectives of the pilot programme were:

1. To objectively identify, and assess the needs of family carers, and the differences in needs, across all care groups.
2. To respond to the identified unmet needs of family carers by the provision of supports/ services where feasible within existing services.
3. To track outcomes for family carers with a repeat assessment.
4. To assess the use of the assessment form by health professionals in their respective services.
5. To assess the appropriateness of the assessment form for family carers across all care groups.
6. To support HSE policy decision-making, service planning and service provision.

## 1.5 Programme/Study Design

The pilot programme adopted a mixed methods research design, involving the completion of an ©interRAI Family Carer Needs Assessment form with family carers at baseline (Time 1), with longitudinal comparisons conducted with the same cohort six months later at follow-up (Time 2), the completion of an Additional Feedback Questionnaire with the same family carers also at baseline, followed by a survey and focus groups conducted with referrers/health and social care professionals.

As such, a number of methods were employed to determine the usability of the assessment form and the impact of the intervention on the well-being of carers. At baseline the assessment form was completed by a number of carers that were recruited by various gatekeepers in the HSE, Family Carers Ireland and voluntary agencies. The assessment form also records the unmet service needs of carers, as identified by the carer. Where capacity within existing services allowed, carer respondents were referred to the relevant service as appropriate to that indicated in the assessment form. Six months later the assessment form was again administered to the same group of carers to capture changes

in their well-being and to determine if providing services to meet unmet needs identified by carers impact well-being, including mood, quality of life and stress.

Each participant completed the original interRAI Family Carer Needs Assessment, a self-report form gathering information across multiple domains of well-being (physical, social, functional, psychological) with a focus on needs and supports. An overview of the structure of this assessment form is displayed in Table 1.1 below, showing that the majority of the questions focus on identifying the current needs of the carer.

**Table 1.1 Components of the interRAI Family Carer Needs Assessment**

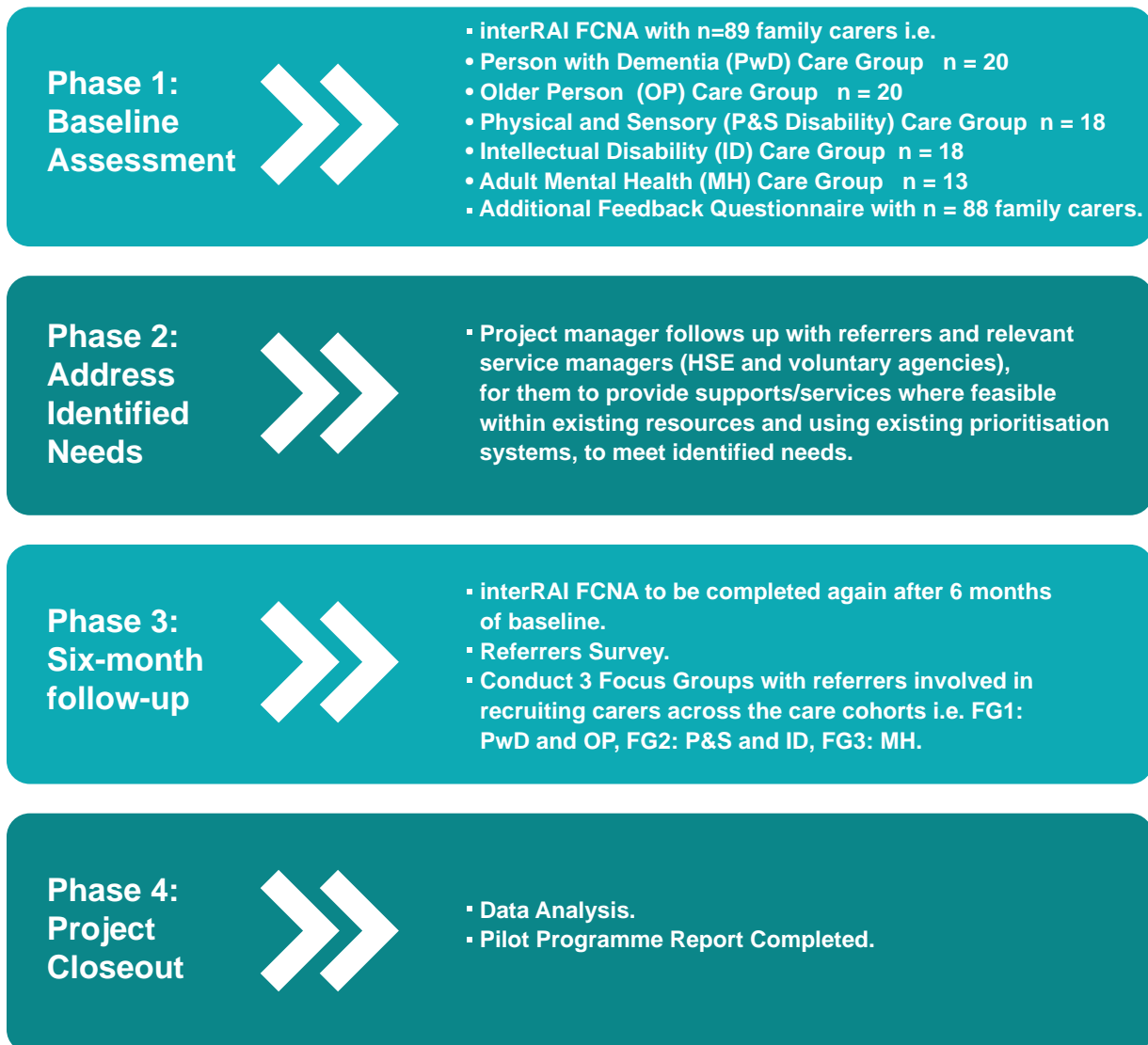
Section	Domains	Number of Questions
Identifying information	Demographic characteristics	13
Carer Health and Well-being	Memory, Social, Functional, Mood, and Physical	36
Family Carer Needs	Needs, supports, challenges, and experiences	58

Only family carers of adult care recipients were included in the pilot programme, as internationally the use of the assessment form has primarily been tested with family carers of adult care recipients.



## 1.6 Data Collection

Figure 1.1 Data Collection Map



## 1.7 Recruitment and Selection

The following methods were used to collect data, figure 1.1 above outlines a map of the data collection process:

1. Assessment form - Baseline data/Time 1 (Phase 1)
2. Additional Feedback Questionnaire (Phase 1)
3. Verbal feedback from family carers to the Project Office (Phase 1 and Phase 3)
4. Follow-up actions on supports/services for family carer/care recipient (Phase 2)
5. Referrers Survey (Phase 3)
6. Focus Groups (Phase 3)
7. Assessment form – Follow-up data/Time 2 (Phase 3)



**In Phase 1**, baseline data was required for the pilot programme where referrers identified family carers to participate. The referrers who were health and social care professionals were issued with a referral pack, which consisted of information leaflets and consent forms for the family carer and the care recipient, the assessment form, the Additional Feedback Questionnaire and a stamped addressed envelope. Written informed consent was obtained by the referrers, who explained the purpose of the pilot programme and were available to answer questions, or referred such questions back to the project manager, who was available to answer questions throughout the process.

Referrers provided assistance in completing the assessment form with family carers if required, while other family carers self-administered the assessment form. The Project Office also provided assistance when required. Completed documentation was returned to the Project Office using the stamped addressed envelope, and all data was recorded on the main excel database.

If information on the assessment form was incomplete or inconclusive, and to clarify the services/supports indicated on Section G. Supports Needed and Received, family carers were contacted by the Project Office. All 89 family carers that participated in the pilot programme had to be contacted by phone by the Project Office for the aforementioned reasons. This provided family carers the opportunity to provide verbal feedback on the assessment form and the assessment process, which was documented and included in the overall analysis.

An Additional Feedback Questionnaire (which was adapted from Stochituiu and Vadeboncoeur, 2020) was provided to family carers at baseline to complete also. The purpose of which was to determine from the family carers perspective how well the assessment form captured important information, whether the questions were appropriate for their care cohort/care recipient, and whether pertinent information was missing. Eighty-eight participants completed the Additional Feedback Questionnaire, one less than the overall baseline sample, as the care recipient was at end of life. Participants were given the opportunity to provide written feedback on the Additional Feedback Questionnaire or verbal feedback to the project office.

In total, 89 family carers completed the assessment form at baseline, and 62 of those were included in the follow-up assessment.

A frequency of the quantitative responses were analysed to determine the extent of needs and supports by the carer and care recipient, and to establish the areas of unmet needs. These items were assessed with carers indicating one of the following responses: not received, not needed, not received, but supports needed, received, no additional supports needed, received, but additional supports needed.

**In Phase 2**, the Project Office forwarded the completed assessment form to the original referrer/health and social care professional. The project manager had phone calls with all referrers to discuss the follow-up actions to be taken to address the services and

supports reported by the carers in the assessment form. To further meet carers needs, the project manager also referred the carers to other HSE departments (such as, the HSE Carers Department, Galway), and to voluntary agencies (such as, Family Carers Ireland) as appropriate. Referrers and relevant voluntary agencies notified all of the follow-up actions taken to the Project Office, which were entered on an excel database for analysis.

**In Phase 3**, all family carers who participated in the baseline data were asked to complete the assessment form six months later. This was in order to assess the changes in needs across the various care groups on health and well-being at baseline Time 1 to follow-up Time 2. Needs recorded by the assessment form were met where feasible from existing supports and prioritisation systems.

Reported unmet needs on the follow-up assessment form were highlighted to the original referrer for subsequent follow-up, and the project manager also made some referrals as appropriate to other HSE departments and voluntary agencies. Sixty-two people completed the follow-up assessment form, with twenty-seven carers lost to follow-up due to care recipients going to Long Term Care, deceased, family carers withdrawing or providing no response to the request. A 70% response rate was achieved for completion of the follow-up assessment form.

To gather further information on the appropriateness and usefulness of the assessment form, all referrers were invited to complete a survey developed by the Project Team (refer to appendix 5), completion of the survey was facilitated by an independent researcher. The referrers survey was initially piloted with three referrers, one from each of the Intellectual Disability, Physical and Sensory Disability and the Older People care groups, and some structural changes were made to the content and wording of the survey. A response rate of 69% was achieved. Data was subsequently collated and analysed.

Invitations were issued to health and social care professionals who had referred family carers across the five care groups to participate in focus groups. In November 2022, an independent researcher conducted three focus groups on the use of the assessment form by health professionals and important information was generated and was included in the analysis. Refer to Appendix 6 for the Focus Group discussion areas.

## Identifying Referrers

Health and social care professionals across CHW in the HSE and voluntary agencies, the later primarily in respect of ID, were integral in recruiting family carers across the five care groups to participate.

Prior to the recruitment of carers for the pilot programme, the project manager and the project lead met with all designated referrers (and their respective line managers). Referrers included HSE staff (i.e. Social Workers, Public Health Nurses and Case Managers), and agreed health and social care professionals from voluntary agencies (i.e. Social Workers, Dementia Nurse Specialists, Carer Support Managers, Instructors and Service Managers).

During these meetings, an explanation was provided of their role as referrer, the project plan, the range of carers required for the pilot, the timeline, the assessment form, and the method of obtaining informed consent.

Following consultation with the HSE Disability Service Managers, it was decided that referrers would recruit participants in the ID care group from three distinct services, i.e. home sharing, day services, and centre based respite as these are the three main service areas provided and would generate a good representation of carers.

### Range of Family Carers

For the purpose of the pilot, family carers were defined as, the primary carer providing the large majority of the home care required, and be a familial relative of the care recipient (albeit this was not a prerequisite).

A range of family carers from the five care groups and the three counties of CHW was required for the programme. The aim was to recruit 100 family carers for the pilot programme based on the most recent Census figures at that time, 54% of carers in CHW were from Galway, 31% were from Mayo, and 15% were from Roscommon (Census 2016). This thus informed the proposed sample for the pilot programme, with 50 carers from Galway (city and county), 30 from Mayo and 20 from Roscommon. Furthermore, for each of the five care groups of 20 carers, it was proposed that 10 would be from Galway, 6 from Mayo and 4 from Roscommon.

In order to gain insight into the needs of carers across the caring spectrum it was important to include a range of carers with varying levels of need. The needs of carers new to the role and had no or little supports in situ and family carers who were caring for a long time and had various supports already in place were targeted for inclusion.

To fully explore the extent of services available in the community, it was imperative to have a mix of rural and urban participants. All family carers and care recipients included in the pilot programme were adults. Carers were also recruited from across all the major care groups in order to test the relevance of the assessment form on the differing groups.

### Engaging Family Carers

Referrers began engaging with family carers to identify and recruit participants, which occurred over a 5-month period, in a sequential manner. The referrer/identifying health and social care professional explained the purpose of the pilot programme using the 'Participant Information Leaflet' and obtained written informed consent.

The assessment form is a paper based self-report tool, and having obtained consent, the referrers provided the assessment form to the family carer to complete independently. However, where the referrer identified that the family carer needed help completing the

<sup>6</sup>Note - three of the 48 referrer's recruited carers from both the PwD and the OP care groups.

assessment form, they provided assistance. Where this was not feasible, the referrer having obtained consent, informed the family carer that the project manager would revert to them directly.



Table 1.2: FCNA Response Breakdown

	Completed the Assessment Form by themselves	Completed the Assessment Form with help	Total
Assessment Form Time 1	51 (57%)	38 (43%)	89
Assessment Form Time 2	46 (74%)	16 (26%)	62

Overall, 48<sup>6</sup> professionals referred participants from the five care groups to the pilot programme. This is not indicative of the number of referrers that were contacted to recruit participants (approximately an additional fifteen referrers engaged with the pilot programme, but could not recruit a carer for reasons outlined below). Referrers undertook this large piece of work for this pilot programme within their current workloads and during the COVID-19 pandemic where Priority 1 systems were in place.

## Completing FCNA Assessment Forms – Baseline data

A total of 100 carers were initially advised for the pilot, with 20 family carers each caring for a Person with Dementia, an Older Person, Physical and Sensory Disability, Intellectual Disability, and Adult Mental Health. At baseline, 89 family carers completed the assessment form and 62 at follow-up. Documentation returned to the Project Office was logged and reviewed to ensure completeness and accuracy. In all of the assessment forms received, information was omitted or was inconclusive, and all 89 family carers were contacted by phone to update the data.

## Barriers to Recruiting Participants

Referrers expressed surprise regarding their difficulty in recruiting participants willing to take part in the pilot, and in some instances, had to approach a number of family carers before they could secure carers to participate.

The primary reasons for family carers not willing to participate, as relayed to the referrers, were grouped into five categories:

### Wellbeing of carer and/or care recipient

- Family carer was too stressed to participate.
- Family carer was too busy with their caring role and did not have the time.
- Families were dealing with illness and bereavements and could not commit to the programme.
- Care recipients not having capacity to give consent and this upset the care recipient and the family carer.
- There was a change in the care recipient's circumstances – admitted to hospital, long-term care or deceased.

### Family Dynamics

- Family issues preventing participation in the programme.
- Care recipients refused to consent, which prevented the family carer from participating, with some carers hesitant to explore this with the care recipient.

### FCNA Form

- Family carers were discouraged by the amount of documentation involved, and expressed that the assessment form was too long and the language was clinical and cumbersome.
- Some family carers found the questions asked were intrusive and very personal.
- Some carers felt the questions related more to the care recipient and/or to older people and were not relevant to their caring circumstances.
- The process for the programme seemed complicated and carers were unsure about it, and some carers felt the process would not benefit them.

### Lack of Services

- Family carers were angry and frustrated with the lack of current services, and felt having to fill out another long form would not be advantageous for them.
- There was no incentive to participate.
- There was little interest in the programme unless new appropriate services identified by the carer could be put in place.
- There was a sense that nothing would be achieved or changed by participating in the programme.



- Some carers were wary about giving information and where it might be used. There was a worry that it might affect services/supports already in place, and/or they may lose benefits.

### Professionals Workloads

- Referrers had to contend with their own workload and found that the process took a significant amount of their time. In one area, due to deficits in social workers, there was only one social worker available.

### Miscellaneous

- Some family carers did not self-identify as a carer.
- Some family carers initially agreed to participate and later decided to withdraw without giving a reason.
- In the Mental Health care group, there were only a small number of family carers available, as many of these clients self-manage their care.

## 1.8 Data Analysis

The Project Office updated the data at baseline following calls with all 89 family carers and the information from the assessment form was then entered into Qualtrics, which was provided by interRAI International. The Qualtrics Survey System is a simple to use web-based survey system to conduct survey research, evaluations and other data collection activities.

Once all data was entered into Qualtrics, interRAI International provided the data to the Project Office in excel format, which was then analysed by an independent researcher. The independent researcher used descriptive statistics to analyse the data. ANOVA and T-tests were also conducted to determine statistical differences over time and between care groups<sup>7</sup>.

When the Project Office received the completed follow-up assessment forms (Time 2) from the family carers, all data was reviewed to ensure its completeness and follow-up calls were made to all carers to clarify information. The follow-up action reports from referrers were reviewed at this stage and where necessary, data was updated on the assessment forms. All queries were verified and data was entered into Qualtrics, and once all follow-up data was entered, interRAI International generated an excel report for the Project Office. This excel report was forwarded to the independent researcher for analysis. The three focus groups were transcribed by an independent researcher.

## 1.9 Ethics

Ethics approval was received from the Clinical Research Ethics Committee (CREC), Galway University Hospitals. Approval for two subsequent minor amendments was also received from CREC. Refer to Appendix 1.

<sup>7</sup> Causal analysis was also conducted but results are not presented in this report as the sample size was not large enough to generate robust results.

## 1.10 Summary

The outcomes from this pilot programme and the wider involvement in the multinational study, will allow the refinement of the assessment form and assist future participating organisations in many countries, including Ireland, to design care plans that considers the unique challenges, strengths and needs of family carers.

This report is structured as follows:

Chapter 2 provides a comprehensive overview of issues arising in the national and international literature on family caring, with a focus on the health impact of caring and carers needs.

Chapter 3 documents the findings from the empirical work undertaken with family carers across five care groups.

Chapter 4 outlines the findings from the empirical work undertaken with health and social care professionals.

Chapter 5 discusses the pilot programmes findings and presents some conclusions and recommendations.





## Chapter 2 - Literature Review

This chapter provides an overview of issues arising in the national and international literature on family caring, with a specific focus on the health impact of caring and the needs of family carers. Research in this area has contributed to reducing the invisibility of family carers and their lived experiences of caring.

### 2.1 Background

Family carers are a vital health, social and economic resource across the world (Hu and Ma, 2018; Pickard, 2015). Care needs are increasing in our society due to improved longevity, advances in medical care and a shift away from institutional care (Oireachtas Library & Research Service, 2019). Eighty percent of long-term care in Europe is provided by family carers (Eurocarers, 2021), while recent figures from Ireland indicate that 1 in 8 people over the age of 15 are providing care to a family member (Family Carers Ireland, 2020).

Worldwide, there are estimated to be 349 million people dependent on family members for their care, the majority of which are women (WHO, 2017). The global challenge of ageing populations and increasing numbers of people requiring care mean that by 2030, it is estimated that one in five Irish people will be a family carer (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019).

Family carers play an integral role in Irish society and contribute enormously to the economy. The current Irish 'Programme for Government: Our Shared Future', acknowledges that "Family carers are the backbone of care provision in Ireland and they deserve support and recognition from Government" (Government of Ireland, 2020, p.76).

Although caring has been reported to have some benefits for family carers, e.g. a sense of purpose and achievement (Lefranc et al, 2017), greater caring responsibilities have been linked with progressively poorer health outcomes for carers (Thomas et al, 2015), thereby indicating a need for health and well-being supports for family carers. The importance of early identification of carers, effective carer supports, health promotion, monitoring high-risk groups, and timing appropriate interventions is paramount (Shah et al, 2010). The interRAI Family Carer Needs Assessment (FCNA) is designed to help address this.

### 2.2 The health impact of caring

The health impact of caring is very evident in Ireland. In a recent Irish national Family Carer Health and Wellbeing Survey (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019), which was a repeat wave of a similar survey undertaken in 2009, found that in the ten year period between 2009 and 2019, carers have poorer health, less support and are more worried about the future. In 2009, over a quarter (29%) of carers reported poor

health. This increased to over a third (36%) of carers in 2019. There was a 70% increase in the number of surveyed carers diagnosed with depression in the ten year period. In 2019, over 1 in 3 (35%) carers were diagnosed with depression, an increase from 1 in 5 (20%) in 2009. The prevalence of anxiety amongst family carers has risen from 3 in 10 (31%) in 2009 to almost 4 in 10 (39%) in 2019. In 2009, 3 in 10 (33%) carers suffered with back injury. In 2019, 4 in 10 (40%) carers had a back injury. The survey also showed that carers reported having less access to vital supports and services. Just over 4 in 10 (43%) had no opportunities for respite in 2009. In 2019, this increased to 7 in 10 (71%) who had no access to respite. Over two-thirds (69%) of carers said they received ongoing support from their GP in 2009. This dropped to just over half (52%) in 2019. Almost 6 in 10 (58%) felt supported by public health nurses in 2009. This dropped to under 3 in 10 (27%) in 2019. Almost 7 in 10 (68%) felt continual support from care workers in 2009. This dropped to less than 2 in 10 (18%) in 2019.

In the first study of carers in the former Western Health Board (Galway, Mayo, Roscommon), O'Neill and Evans (1999) found that 40% of carers spent more than 80 hours each week providing care, one in ten carers spent every hour of the week caring, almost all of the carers stated they had to be available on a 24 hour basis, and over half were awakened at night to care. Unsurprisingly, the majority of carer's experienced extreme physical and mental tiredness or exhaustion (67%), almost half got short tempered, over a quarter felt that their physical health had got worse, over half said caring was a financial strain, and almost three-quarters felt they did not have enough time for themselves. Similarly, Harrison (2007) found the mean number of informal care hours per week being provided to home care package recipients in Co. Galway was 113.76, and over one-third of family carers (39%) were providing 168 hours of informal care per week i.e. 24/7 care. The mean quality of life score of family carers was 35.39 out of a maximum score of 100, this is considered very low when compared to scores for other groups as reported elsewhere in the literature.



Notably, research has shown that poor spousal caregiver well-being particularly severe fatigue, is independently and prospectively associated with higher care recipient healthcare expenditure (US) and Emergency Department use (Ankuda et al, 2017). Adelman et al (2014) found that risk factors for caregiver burden included female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a carer. The authors concluded that professionals have a responsibility to recognise caregiver burden and that caregiver assessment and intervention should be tailored to the individual circumstances in which caregiver burden occurs.

The confining and socially isolating impact of full-time caring is especially evident. In Ireland, a 2016 study by the Institute of Public Health, identified carers as being one of five groups particularly at risk of loneliness (Harvey and Walsh, 2016). An Irish Report from the Loneliness Taskforce (Swanick, 2018) states that loneliness must be considered a priority public health risk and there is extensive international research which links experiencing loneliness to significant psychological and physiological difficulties. Loneliness can be worse for people than well known risk factors such as obesity (Christina et al, 2012). The magnitude of health risk associated with social isolation is seen as comparable with that of cigarette smoking (Kharicha et al, 2007). Smoking can decrease life span by up to 10 years (Jha et al, 2013).

Evidence highlights that older people experiencing high levels of loneliness are almost twice as likely to die within six years compared to those who are not lonely (Ye Lou et al, 2012). Loneliness increases the risk of death by 26%, lack of social connections increases the risk of death by 29% (Holt-Lunstad, 2015). Loneliness can increase the risk of heart disease and impede recovery rates from stroke (CARDI, 2012). Loneliness has been linked to a wide variety of mental and physical health outcomes, such as depression, nursing home admission, and mortality (Barrett et al, 2011).



## 2.3 Carers of People with Dementia (PwD)

According to the World Health Organisation, worldwide around 55 million people have dementia. As the proportion of older people in the population is increasing in nearly every country, this number is expected to rise to 78 million in 2030 and 139 million in 2050 (WHO, 2021). The Alzheimer Society of Ireland states that there are 64,000 people with dementia in Ireland, and the number of people with the condition will more than double in the next 25 years to over 150,000 by 2045. There are 11,000 new cases of dementia in Ireland each year - that is at least 30 people every day. One in 10 people diagnosed with dementia in Ireland are under 65. The majority of people with dementia (63%) live at home in the community. Over 180,000 people in Ireland are currently or have been carers for a family member or partner with dementia (ASI, 2021). These demographic changes will put increasing pressure on healthcare resources.

Dementia affects not only the person with dementia but also their family carer. Given the increased demands in caring for a person with cognitive problems, research has shown that carers of people with dementia are more likely to be impacted (Srivastava et al, 2016; Chiao et al, 2015; Wolfs et al, 2012; Bramble et al, 2009; Papastavrou et al, 2007). They are also more likely to experience a decline in their health and quality of life due to difficulties adapting to the role and in developing coping skills (Ducharme et al, 2011; Blieszner and Roberto, 2010). Family conflicts and psychological distress are greatest when carers are transitioning into the role (Lee et al, 2019). This highlights the importance of health professionals capturing the needs of carers early in the caregiving role, and in undertaking repeated carer needs assessments at various stages of the caring trajectory, and therefore not merely at the crisis stage for carers.

Services such as day care, home support and home care packages can assist family carers to continue providing care, but their availability is uneven. Given the intensive nature of caring for someone with dementia, particularly during its later stages, respite services that are responsive and tailored to the needs of the person with dementia, as well as the carer, can make a vital contribution to supporting carers to continue to care (Vandepitte et al, 2016).

## 2.4 Carers of Older People

Research repeatedly shows that older people express a clear preference for care in their own homes provided by family members (Garavan et al, 2001; Callahan, 1981). Poor social support for older people in the community is associated with an increased risk of hospital readmission (Paddock and Hirdes, 2003). In addition, the interaction of caregiver stress and depression were identified as significant predictors of risk of hospital readmission (Schwarz and Elman, 2003). Those with lower levels of social support also have a higher risk of institutionalization (Wolinsky et al, 1992; Steinbech, 1992; Pruchno et al, 1990).

A 2014 Irish study of family carers of older people found that, in general, carers reported caregiving to be a positive experience. However, the study also found that: almost half of





carers provided care for more than 80 hours a week, more than two in every five were at risk of developing clinical depression, approximately a third reported that they experienced moderate to severe burden, more than half reported that they experienced some form of psychological mistreatment, and one in seven carers reported being physically mistreated by the care recipient in the previous three months (NCPOP, 2014).

Sage Advocacy in Ireland asserts that policy continues to be based on the premise that the family has a responsibility to provide for the care needs of their older relatives. However, families' ability to do so is undermined by the fact that community services for older people and people with disabilities are fragmented, with low levels of provision, inadequate needs assessment, geographical inconsistencies, and poor availability of diversified respite care services (Browne, 2016).

Certain cohorts of carers of older people are particularly vulnerable, including, carers who are older themselves, carers living in more isolated rural areas, carers of people with dementia, and, people who find themselves in the caring role 'overnight' as a result of stroke or the sudden onset of illness (Browne, 2016).

## 2.5 Carers of People with Physical and Sensory Disability

Family carers play an important role in the lives of many people with a disability, providing essential supports either in place of, or in addition to, service providers. In Ireland, a total of 20,676 people were registered on the NPSDD (National Physical and Sensory Disability Database) in December 2017, and the majority of people (8,404, 84.4%) lived with family members (HRB, 2017).

More than half of the people with a physical and sensory disability (5,977, 60.0%) registered on the NPSDD, whose records were reviewed in the period 2013-2017, reported having a



primary carer. Ninety-six percent (5,735 people) lived with their primary carer. The majority of primary carers were parent(s), of which, 236 (43.5%) were aged 60-69 years, and 161 (2.7%) were aged 70 years and over.

Chan (2008) identified that person's with acquired brain injury considered the stress level and needs of family carers as one of the most important factors to influence respite use. Mullan et al (2011) found that 71% of persons with MS surveyed, said their main reason for using respite was to give their family carer a break. Approximately two-thirds of carers said that their main reason for using respite was to relieve stress. Parents and carers consistently talk about the need for 'a rest', 'relaxation', 'a chance to go on holiday', 'a chance to spend time with other family members' (Southby, 2018; Robertson et al., 2011; Ryan, 2011; Radcliffe & Turk, 2007). Carers noted that respite gave them time to engage in their own hobbies (Southby, 2018; Ryan, 2011; Wilkie & Barr, 2008). The literature suggests that there may be a reduced likelihood of relinquishing the caring role when caring for a person with a disability when regular respite is available (Nankervis et al., 2011; Mansell & Wilson, 2009; Power, 2009; Wilkie & Barr, 2008).

## 2.6 Carers of People with Intellectual Disability

There were 28,388 people registered on the NIDD (National Intellectual Disability Database) at the end of December 2017. Based on the 2016 Census of Population figures, this represents a prevalence rate of 5.96 per 1,000 population (Hourigan et al, 2017). The majority of adults with intellectual disability (19,599 individuals/69%) continue to live with their families with the aid of additional support services. Almost one third (2,579, 31.6%) of people aged 35 years or over with moderate, severe or profound intellectual disability lived at home in 2017. As their caregivers age, a wide range of additional services such as respite are required for people who wish to continue to live as independently as possible, which has implications for service-planning (Hourigan et al, 2017).





It has been well documented that parents and carers of children with intellectual and developmental disabilities experience higher levels of stress in parenting (Gerstein et al, 2009; Baker et al, 2005; Hauser-Cram et al, 2001), and are at an increased risk of poorer physical health (Allik et al, 2006), than parents of children without intellectual and developmental disabilities. An Irish study of parents of children with intellectual disability, reported that parents had more physical health problems, such as sleep disturbances, headaches, gastrointestinal problems, and respiratory infection episodes, than parents of children without intellectual disability (Gallagher and Whiteley, 2012). In a 2016 Irish study of carers of people with an intellectual disability, a number of statistically significant factors were found to be associated with low carer resilience including, being a compound carer, living with the care-recipient, high levels of psychological distress, poor/fair self-reported general health, and low levels of social connectedness. Low carer resilience was related to high levels of challenging behaviour in care-recipients, and also low levels of support from family, other informal supports, and formal supports (Lafferty et al, 2016).

## 2.7 Carers of people with Mental Health

Embedded within the move away from institutionalised care of people with mental health in Ireland to care in the community, are expectations that family members will take on increased care roles (O’Riordan and Kelleher, 2016). Carer burden increases with more patient contact and when patients live with their families (Lauber et al, 2003). Rose et al (2002: 517) suggest that family members become caregivers, providing ongoing support and practical assistance while struggling with their lack of understanding of the mental illness itself, and they group responses of family carers into three categories: (a) keeping watch/losing trust, (b) being consumed by the illness, and (c) making sense of behaviours as illness symptoms.



Lowyck et al (2004) state that, “family members of schizophrenic patients experience burden on a practical, financial and emotional level and the extent of the burden is closely linked to the amount of symptomatic behaviour of the patient” (p. 395). Caring for patients with eating disorders can be overwhelming for the carer. Available data suggest that the impact on carers of persons with anorexia nervosa may be even higher than for psychoses (Treasure et al, 2001). Research has shown that the impact on family carers of people with mood disorders, includes, significant distress (Sartorius, 2001), marked difficulties in maintaining social and leisure activities, decrease in total family income, considerable strains in marital relationships (Jungbauer et al, 2004; van Wijngaarden et al, 2004), poorer physical health, limited activity, and greater health service utilization than non-caregivers (Baldassano, 2004). In the Irish context, research by O’Riordan and Kelleher (2016) found that a number of family carers felt that living with mental illness continues to be stigmatised, and their experiences had resulted in distancing of friends, neighbours and family members. This of course further isolates the family carer. This evidence demonstrates carers face mental ill-health as a direct consequence of their caring role and experience higher rates of mental ill-health than the general population.

## 2.8 Identifying Family Carers Early – The Role of Health and Social Care Professionals

Identifying family carers as early as possible is of critical importance if they are to be supported to maintain their caring role, particularly given that some do not readily identify themselves as being a carer (such as, parents of a child with a disability or spousal caregiving). Not identifying oneself as a carer may serve as a barrier to accessing services and supports. The National Carers Strategy (Department of Health, 2012) acknowledges that health and personal social service providers are best placed to identify carers through their contact with their patients and families.

Internationally, it is recognised that general practitioners (GPs), public health nurses (PHNs), and other health and social care professionals, have a critical role to play in the identification and support of family carers (Parmar et al, 2020; Chantal et al, 2002). However, to date, no guidelines exist in Ireland to support GPs, PHNs and other health and social care professionals in this role.

Family carers have more contact with their GP than any other health professional (Royal College of General Practitioners, 2014). Two recent scoping reviews of physicians' perspectives of their role in supporting family carers, indicated that primary care was the appropriate context for identifying and supporting carers (Parmar et al, 2020; Peters et al 2020). However, barriers exist in primary care to providing carers with appropriate, effective and timely supports, including, failure of carers to self-identify or to recognise themselves as carers, an ambiguity within primary care services to proactively identify carers, lack of time and reimbursement, focusing on the care recipient to the exclusion of the carer (by both the carer and the health professional), disjointed health and community systems, inadequate services, and a lack of policy and ethical guidance (Parmar et al, 2020; Peters et al, 2020).

In Ireland, a recent study of the role of General Practitioners in supporting family carers (Cronin and McGilloway, 2022), found that the vast majority of family carers (69%) were rarely or never asked how they were, almost two-thirds of carers felt that health care professionals, including GPs, rarely if ever understood the challenges they faced, over half felt the same in relation to concerns about the carers own health and well-being, and over three-quarters of carers felt that professionals were not interested in hearing about their experiences of caring. The study also found that GPs were ambiguous about their role, especially if the carer was not a registered patient of the practice, GPs had little knowledge of services available and/or were frustrated with the lack of available services, carers were reluctant to ask for help as this could further burden GPs or felt unsure about how GPs could help them, and over half of carers did not self-identify as a carer. Cronin and McGilloway (2022) concluded that the findings highlight further, an urgent requirement for the assessment of carer needs, particularly around their capacity to care.

Research and international guidelines has recommended how GPs and other health care professionals might identify carers, including appointing a member of staff to act as carer champion with a primary responsibility for identifying carers (Wangler and Jansky, 2021; NICE, 2020; Carers Trust Wales, 2019), and the provision of carer-focused training (Jones et al, 2012). Moreover, the formal assessment of carer needs in general practice has also been shown to be valuable in identifying overall levels of need and guiding the consultation process (NICE, 2020; Roen et al, 2019; BurrIDGE et al, 2017).

Health professionals' lack of explicit attention to family carers is a serious gap in health care. Carers are hidden patients themselves, with serious adverse physical and mental health consequences, from their physically and emotionally demanding work as caregivers and reduced attention to their own health (Thomas et al, 2015; Reinhard et al, 2008).





## 2.9 Needs and Effective Supports for Family Carers

Carers are a vital source of care for older people and people with disabilities and complex care needs, but often report feeling unprepared and poorly supported in their caregiving role (Burgdorf et al, 2019). Contemporary gerontological policy and practice note that caregivers stress is relieved by community based services (Zarit et al, 1999). In Ireland, research with carers undertaken by the former Western Health Board found that the priority needs of carers included: better financial support, in-home respite care, support groups, information and advice, home help, day centre facilities, residential respite, recognition of their caring role, and more support and time with the public health nurse (O'Neill and Evans, 1999). These findings are supported by further UK research (Banks and Cheeseman, 1999).

### Carer Support Groups

A systematic review of Carer Support Groups in the UK (Victor, 2009), which included nine studies, found many outcomes/benefits of Carer Support Groups, including, improvements to emotional well-being were achieved principally through the mutual support that carers provided to each other within the groups, but also through the development of confidence and a positive self-identity as a carer. Improved well-being was achieved in the groups through carers expression, recognition, validation and normalisation of feelings and situations related to caring. The studies also found that a wide range of types of information and advice was gained both from the input of professional group leaders and other carers to the group. The studies also suggested that there was evidence of the achievement of social support in terms of meeting others, building friendships and participating in social activities. Some limited evidence suggested that support groups can also have outcomes in terms of facilitating access to and improving relationships with service providers. The groups were also found to help carers feel less isolated, to value providing help to others and develop a better self-awareness of their role and needs.

In the US, Adelman et al (2014) found that psychosocial interventions, such as, support groups or psychoeducational interventions for carers were shown to have mild efficacy in mitigating caregiver burden. Similarly, an international systematic review by Hartmann et al (2012) concluded that support groups have shown to have a positive effect on caregivers' coping ability and knowledge, as well as on social support and on caregivers' depression. Moreover, technology-based interventions can reduce caregiver burden, depression, anxiety and stress and improve the caregiver's coping ability.

Larkin (2007) in a research study classified the types of support carers received from carer support groups into four types: Emotional support - sympathy, understanding and value; Instrumental support - practical help with life's daily problems, such as, financial matters/ entitlements; Appraisal support - help with decision making, and agreeing courses of action; Informational support - the provision of advice or information to meet particular needs. Interestingly, the concepts of social integration and social support were found to be factors for carers in finding the support groups beneficial and in continuing to attend.

Based on the evidence presented here, it can be deduced that Carer Support Groups have a myriad of benefits, such as, support groups provide the opportunity for carers to come together, share their experiences and knowledge and learn from one another in a safe, non-judgemental, peer-led setting. Through support groups, carers experience a sense of community, empowerment, improved mental and emotional well-being, reduced feelings of social isolation and increased confidence in their own strengths and abilities.

## Respite

Family care of persons at home can engulf caregivers' lives. From the earliest writings on family care, clinicians and carers have highlighted the need for receiving breaks from the continual demands of caring (Zarit et al, 1985). Respite provides an alternative care arrangement so that the family carer can have time away from care responsibilities, and can be offered in different ways, including in-home care, adult day services and overnight care. Caregivers may use respite time to rest, attend to personal needs or in some cases, continue their employment (Zarit et al, 1998).

Research has found a myriad of benefits of respite, including, lower perceived carer burden, being able to perform tasks, lower stress, and the possibility of carers escaping from their duties enables them to continue in their role (Stirling et al, 2014; Parahoo et al, 2002; Ashworth and Baker, 2000). Using the Caregiver Strain Index (CSI) (Robinson, 1983), Hoskins et al (2005) found that one intervention - respite care, made a significant improvement on the stress levels of carers. The authors concluded that the CSI could serve as a practical function in identifying high levels of stress occurring in carers over a period of time, so that they could be targeted for assistance in their own right (Hoskins et al, 2005). Moderate evidence of respite care in relieving carer's burden has been found in other studies (Knight et al, 1993).

## Day Care

Zarit et al (1999) undertook a major evaluation involving day care for patients with dementia and found that adequate amounts of day care reduced stress indicators among carers compared with a control group not receiving the care. A comprehensive review of the literature on Adult Day Services (ADS) from 2000 to 2011 (Fields et al, 2014), found that ADS attendance can lower caregiver burden and stress and contribute to the overall well-being of caregivers, particularly for those caring for family members with dementia. ADS attendance was associated with significantly less caregiver burden (Mossello et al, 2008), and stress related to family conflict and employment (Schacke and Zank, 2006). Several studies further supported the findings that ADS attendance is associated with higher levels of caregiver well-being (e.g., isolation, worry, guilt), and lower levels of caregiver burden and stress (Sussman and Regehr, 2009; Mavall and Thorslund, 2007; Valadez et al, 2005; Colvez et al, 2002). Zarit et al (2011) found that ADS attendance was associated with decreased levels of stress for dementia caregivers and fewer behaviour and sleep problems in care recipients.

## Counselling

Mittelman et al (1996) found that providing information and counselling reduced stress in carers. Similarly, Mittelman et al (2006) conducted a longitudinal study in New York with spousal caregivers who were provided with sessions of individual and family counselling that were task-oriented. These sessions promoted communication among family members, taught techniques for problem solving and patient behaviour management. It was found that patients who participated in the treatment remained cared for at home for significantly longer than those in the control group.

Comprehensive counselling sessions for spouses caring for a person with dementia helped reduce depression (Jang et al, 2004). Davis et al (2004) found an unexpected reduction in burden and distress for caregivers receiving friendly, socially supportive phone calls that provided some respite from caregiving, even without in-home caregiver skills training. Home visits and enhanced social support have been found to help reduce caregiver depression in other studies (Roth et al, 2005; Teri et al, 2005).

## Training

Evidence suggests that carer education and training can improve health outcomes for family carers and care recipients (Nuckols et al, 2017). However, research has shown that the majority of family carers do not receive training. In the US, a recent study by Burgdorf et al (2019) found that 93% of carers had never received training in caring for older adults. Research suggests that many family carers have no training in care skills and are often expected to carry out caring tasks and technical health procedures with inadequate information or advice as to how to undertake these, how best to use equipment and what to do if problems arise (McDonald et al, 2016; Banks and Cheeseman, 1999).



In a recent Irish National Carer Health and Wellbeing Survey, less than 1 in 5 (18%) carers received training for their role. Manual and People Moving and Handling training was the most common training need identified. Notably however, 4 in 10 carers indicated that they had suffered from back injuries, and two-thirds of these felt their back injury was caused or made worse by their caring role (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019).

Robinson and Yates (1994) found that carers who participated in a caregiver training programme experienced a decrease in objective burden and a more positive attitude toward asking for help and using adult day care. Research has shown that carer training can reduce overall caregiver burden, and particularly among carers of people with dementia. Such training should include an emphasis on problem-focused and action-oriented coping skills (McAtee et al, 2021; Etxeberria et al, 2020; Harvath et al, 2020; Baharudin et al, 2019). A randomised controlled trial by Sotoudeh et al (2019) found a significant reduction in caregiver burden after delivering a carer training programme to carers of haemodialysis patients. Positive outcomes of training for family carers have been found in other research (Jansson et al, 1998; Mittelman et al, 1996).

Saxena et al (2020) found a significant improvement in caregiver burden among carers who were provided with caregiver group therapy which involved psychoeducation of carers about dementia, behavioural management of symptoms, and tips on caring for the carer. The group therapy sessions were helpful in allowing the caregivers to better manage their own stress by feeling supported in the group therapy sessions (Saxena et al, 2020). There is evidence that psychosocial interventions are also beneficial in providing caregivers with strategies to manage their reactions to behaviour problems more effectively (Mittelman et al, 2004). Interventions that focus on caregiving issues are more effective than those that focus exclusively on problematic behaviours in reducing caregiver burden (Burns et al, 2003).

## 2.10 The Compound Carer

A compound carer is defined as a person with multiple caregiving roles (Perkins and Haley 2010). Due to increasing longevity, compound caregiving is likely to increase (Lee et al, 2022). This may be one of the most demanding life situations that a family carer will contend with in their caring role. Research has shown that compound caregivers have significantly poorer health and wellbeing than non-compound caregivers (Wang et al, 2022).

## 2.11 The Sandwich Carer

As people are living longer and the decision to have children is postponed, there is an increase in the number of 'sandwich carers', i.e. who look after their children and ageing parents, parents-in-law or other older relatives at the same time. In some cases, the family carer may be looking after a child with additional needs thus increasing the competitive demands of their situation. Thus carers are pulled in two directions, which is called sandwich carers or dual carers. Sandwich carers are usually people of working age, and therefore their jobs can be affected by their family responsibilities. More than

one in four sandwich carers in the UK report mental ill-health, and are more likely to experience symptoms of mental ill-health, including anxiety and depression, than the general population (Office for National Statistics, 2019). These findings are mirrored in the Irish context (McGarrigle and Kenny 2013) and are especially marked in female carers (McGarrigle et al, 2014).

### 2.12 The Sibling Carer

Often when the health of one or both parents deteriorate and they can no longer provide care, siblings of a care recipient with additional needs are expected to step into the caring role, in the absence of other options. The sibling carer may have other caring responsibilities, such as, their ageing parents/parents-in-law or young children, and must also assume the role of family carer for their sibling. In Ireland, the IDA - TILDA carer's study found evidence of physical, mental and financial toll on sibling carers of older adults with intellectual disability. There was a high prevalence of particular conditions including back pain, aching joints and stress, and sibling carers reported feeling completely overwhelmed by their care responsibilities (Brennan et al, 2023). As the life expectancy of people with ID increases, they may now outlive their parents or their parents' ability to continue to care. Siblings of adults with ID then succeed their parents as primary carers (Brennan et al, 2023).

### 2.13 Conclusion

Family carers should be supported in having their own physical and mental health assessed, so as to enhance their ability to cope with the challenges of caring, and preventive intervention efforts need to focus on alleviating the pressures experienced by many carers. Ultimately, a lack of support for family carers is going to cost the State more in the long run, in that, if carers are unable to provide the level of service required, more people will almost certainly end up in nursing homes – which is contrary to their preference or indeed the preference of their family.

All of the indications are that family carer numbers in Ireland will continue to rise. Therefore it is critical that a robust process is put in place for the identification, signposting and support of family carers. The changing needs along the care trajectory suggest that family carer identification, assessment and supports should be offered from the point of diagnosis of the care recipient, and a regular review process implemented thereafter. Cohorts of carers at particular risk of caregiver burden and adverse health outcomes need particular attention, including, carers of people with dementia, carers of people with an intellectual disability, sandwich carers, sibling carers and compound carers.

# Chapter 3 - Results - interRAI FCNA

## Baseline and Follow-up

This chapter sets out the findings of the interRAI Family Carer Needs Assessment's conducted at baseline (Time 1) and follow-up (Time 2). The first section presents the profile of the family carers by providing a demographic breakdown of the sample. The second section explores the health and well-being of the carers. This is followed in section three with the reported needs of family carers, involving a breakdown of the services required at baseline, services provided in the intervening six-month period, and the services still required as identified by carers at follow-up.

The results presented in this chapter will address objectives 1-3 of the pilot programme as follows:

1. To objectively identify, and assess the needs of family carers, and the differences in needs, across all care groups.
2. To respond to the identified unmet needs of family carers by the provision of supports/ services where feasible within existing services.
3. To track outcomes for family carers with a repeat assessment.

An overview of the participation and referral results is presented in Table 3.1 below. A total of 89 family carers completed a baseline assessment form. A follow-up assessment form was completed six months later by 62 family carers from the original baseline sample. Across all five care groups at both baseline and follow-up, Galway (T1 53%, T2 61%) had the highest number of carers, followed by Mayo (T1 29%, T2 23%), and Roscommon (T1 18%, T2 16%).



Table 3.1 Overview of Participation and Referral Results

Care Cohort	Total No. Referred Baseline FCNAs T1	Total No. Referrers in CHW	Referrers Professional Details	No. Additional Feedback Quest. Returned	Total No. Follow-up FCNAs Returned T2 (*LTFU)
Dementia	20	12	Social Workers POLL Public Health Nurses ASI Dementia Nurse Specialist Western Alzheimer's Dementia Nurse Specialist	19	12 (8)
Older Persons	20	17	Social Worker ICPOP Public Health Nurses Family Carers Ireland	20	11 (9)
Disability - Physical & Sensory	18	4	Case Managers HSE	18	14 (4)
Disability - Intellectual Disability	18	10	BoCS Galway Ability West Western Care BoCS Roscommon St. Hilda's Services	18	15 (3)
Adult Mental Health	13	8	Social Workers CMHTs	13	10 (3)
<b>Total</b>	<b>89</b> (Galway 47; Mayo 26; Roscommon 16)	<b>51<sup>8</sup></b>	<b>A/A</b>	<b>88</b>	<b>62 (27)</b> (Galway 38 (9); Mayo 14 (12); Roscommon 10 (6))

\*LTFU = Lost to Follow-up

## Attrition

Between baseline and follow-up, 27 carers left the pilot programme. The majority of attrition occurred in the older persons (9) and people with dementia (8) care groups, followed by physical and sensory disability (4), intellectual disability (3) and mental health (3) care groups. The majority of attrition were among carers from Mayo (12), followed by Galway (9), and Roscommon (6). Reasons for attrition for the 27 carers included: seven care recipients entered long term care (LTC), five care recipients passed away, three carers felt the form was too long and they did not have the time (one of these carers also felt that there was no point as there were no home support workers available to provide a home support service), one care recipient was in hospital, one carer felt the form asked too much personal information, one carer and their care recipient had medical issues, and one carer indicated that they had other commitments. Eight carers did not respond and therefore a reason could not be established.

<sup>8</sup> Note- three of the 51 referrers recruited carers from both the PwD and the OP care groups, therefore the actual sample of referrers was n=48.

### 3.1 Demographic Profile

The demographic details of participants are presented in Table 3.2 below. Of note, the majority of carers were female (75%) and this was consistent across all care groups, reside with the person they care for (83%), with an average age of 58 years (range 26 – 86), mean age 56 at follow-up, and almost three-quarters have been caring for more than 5 years (70%). The majority of carers were the care recipients child or child in law (35%), parent/guardian (34%), or spouse/partner (22%). Fifty-three percent of care recipients were 65 years or under, and just over one-third were age 81-99 years.

**Table 3.2. Sample Descriptive Statistics**

Profile of family carers that participated in the FCNA Pilot Programme	Time 1 (n=89) %	Time 2 (n=62) %	Profile of family carers that participated in the FCNA Pilot Programme	Time 1 (n=89) %	Time 2 (n=62) %
Gender of Family Carer			Caring Relationship to Care Recipient		
Female	75	77	Child or child in law	35	29
Male	24	23	Parent/guardian	34	40
Other	1	0	Spouse/partner	22	21
Gender of Care Recipient			Sibling	6	6
Female	46	47	Other relative	3	3
Male	54	53	Distance to travel to Care Recipient's home		
Other			Live with the CR	83	84
Age Profile of Family Carer (years)			Live 1 – 14 minutes to home of CR	7	6
81-99 years	8	5	Live 15-29 minutes to home of CR	6	5
66-80 years	17	16	Live 30 – 59 minutes to home of CR	2	3
51-65 years	46	45	Live 60 minutes or more to home of CR	2	2
36-50 years	26	31	Care Group		
21-35 years	3	3	Intellectual Disability	20	24
Age Profile of Care Recipient (years)			Physical and Sensory Disability	20	23
81-99	34	24	People with Dementia	22.5	19
66-80	12	13	Older People	22.5	18
51-65	16	21	Mental Health	15	16
36-50	13	13	Hours spent caring for CR (hours in last 3 days, total unpaid care provided by carer and others)		
21-35	22	26	≥36	71	65
18-20 years	2	3	24 to less than 36 hours	7	5
			12 to less than 24 hours	8	11
Marital Status of Family Carer			<12	8	6
Married/partner	56	59	None	6	13
Never Married	22	21	Length of Time Caring for Care Recipient		
Widowed	9	10	>5 years.	70	74
Divorced	8	6	1-5 years	27	24
Separated	4	3	1-12 months	3	2
Primary language of main carer			Sibling, Compound, Sandwich Carers		
English	99	98	Sibling Carers	6	6
Irish	1	0	Compound Carers	35	26
Other	0	2	Sandwich Carers	19	16



In most cases, a significant amount of unpaid care was provided to the care recipients by the informal carer and others. The majority of carers (71%), with other care support in some cases, provided 36 hours or more of unpaid care during the three days prior to completing the survey at baseline, with 23% providing between 1 and 36 hours during the time period. The number of care recipients receiving the highest level of care reduced slightly at follow-up (65%). A substantial number of family carers were a compound carer (35% at baseline; 26% at follow-up), or a sandwich carer (19% at baseline and 16% at follow-up), and a smaller proportion are sibling carers (6% at both time points).

## Time spent on activities

Participants responded to five questions in the assessment form relating to time spent doing specific activities each week, see table 3.3 below.

**Table 3.3 Time Spent on Activities**

	Taking care of the Care Recipient (%)		Unpaid care for other adult(s) (%)		Unpaid care children or youth (%)		Paid work (%)		Education (%)	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
None	0	2	65	74	81	82	56	60	96	98
Less than 4 hours	4	3	3	5	0	2	2	0	2	2
4 to less than 7 hours	3	8	9	5	2	0	1	3	2	0
7 to less than 14 hours	1	5	6	3	3	2	11	11	0	0
14 to less than 21 hours	2	3	1	3	1	2	9	5	0	0
21 to less than 35 hours	8	5	1	2	1	2	7	10	0	0
35 hours or more	81	74	15	8	11	11	13	11	0	0

Most notably, the majority 81% spend 35 hours or more taking care of the care recipient, this reduced to 74% for those included in the follow-up survey. There were 43% in paid work (40% at follow-up) with 13% of the cohort working 35 hours or more, this was slightly reduced at follow-up (11%). Furthermore, at baseline, 35% provide unpaid care to other adult(s) (26% at follow-up), with 15% spending 35 hours or more doing so at baseline. Fewer carers provided care for 35 hours or more per week at follow-up.

## 3.2 Family Carers Health and Well-being

### Memory and Cognition

Providing care to a loved one can be both physically and emotionally demanding with significant negative impacts on the well-being of the carer. The assessment form asks two questions regarding memory and cognition. Participants report on a five-point scale “how often memory is a problem,” and within the previous three days, “have you been easily distracted, had trouble paying attention, or become sidetracked.” At baseline, 64% of respondents report rarely or never encountering issues with memory, 58% at follow-up, and

just over one-third (34%) indicated that they sometimes have memory problems (37% at follow-up), with 2% of carers stating it is a problem most or all of the time (5% at follow-up). Additionally, 45% report being easily distracted, had trouble paying attention or becoming sidetracked, this proportion is also reflected at follow-up (44%). This was also evident in the free text section at the end of the survey where family carers were invited to include any additional comments they felt was important to relay.

*“I work 17 hours per day taking care of my mother and also trying to manage a farm at home. I suffer from back pain, anxiety and stress. I regularly have to cancel hospital appointments, as I have nobody to look after my mother for that length of time. We have a home carer that comes in for 1 hour per day (5 days per week) but it’s not enough as 1 hour will not cover an appointment if I have one. I feel very stressed all the time and my memory is failing. I would love to get some help as it is a very demanding job”. #37*

## Social Participation

Social participation can help carers remain engaged with life outside of their caring role and to retain a healthy work-life balance. Reporting on social participation during the last 90 days, at baseline 55% of carers indicated a decrease in participation levels with half of those reportedly distressed by this decrease. At follow-up, 42% indicated a reduction in social participation in the preceding 90 days, with just over a third of those (35%) distressed by this reduction. This increase in participation levels is significant at the 10% level using a two-sample t-test with equal variance assumed (mean difference 0.132 – confidence interval – 0.004:0.516).

## Function, Endurance and Stamina

Activities of daily living were assessed for family carers by asking them to report abilities over the previous three days. A small minority required assistance with some tasks, see Table 3.4.

Table 3.4 Activities of Daily Living - Family Carers

	I could do it all by myself (%)		I would need some help from others (%)		Others must always do this for me (%)	
	T1	T2	T1	T2	T1	T2
Meal Preparation	98	92	2	8	0	0
Ordinary Housework	89	89	11	11	0	0
Managing Finances	94	94	6	6	0	0
Managing Medications	98	97	2	3	0	0
Shopping	96	94	4	6	0	0
Transportation	96	93	2	5	2	2
Bathing	100	98	0	2	0	0

Respondents were also asked how often they felt so exhausted that they could not carry out their normal day-to-day activities. At baseline, 52% reported feeling exhausted, with just over half of those feeling this in the three days prior to completing the assessment form. At follow-up 40% of survey respondents felt this way, with the majority of those (68%) feeling this way in the previous three days.

At baseline 7% of respondents reported being unsteady when walking, worryingly there was a statistically significant increase in instability when walking among carers at follow-up (19%), determined using a two sided t-test (CI: -0.364:0.009).

## Mood and Major Life Stresses

A significant indicator of general well-being is mood. Questions in the assessment form relating to mood investigate the mood of the family carer during the 3 days prior to completing the assessment form, see Table 3.5.

Table 3.5 Carer’s Mood

	Little interest or pleasure (%)		Anxious, restless, or uneasy (%)		Sad, depressed, or hopeless (%)		Overwhelmed by loved ones condition (%)		Unable to continue caring activities (%)	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
Not in the last 3 days	48	63	34	47	52	61	35	35	55	66
Not in the last 3 days but often feel this way	25	11	26	19	20	11	34	16	25	16
In 1-2 of the last 3 days	12	11	16	16	16	16	8	24	13	6
Daily in the last 3 days	15	15	25	18	12	11	24	24	7	11

In the 3 days prior to completing the assessment form, mood across all five indicators was poor at baseline, with over one-quarter (27%) reporting little interest or pleasure, 41% were anxious, over one-quarter (28%) were sad, depressed or hopeless, almost one-third (32%) were overwhelmed by their loved ones condition, and one-fifth felt they were unable to continue caring. At follow-up, in the last 3 days, three indicators had marginal improvements, i.e. little interest or pleasure 26%, sad, depressed or hopeless 27%, and unable to continue caring activities 17%. However, the exception which is concerning was the number of carers who felt overwhelmed by the care recipients condition which increased to almost half (T1 32%: T2 48%). This finding is also shown in some of the responses provided by carers in the assessment form:

*“I sometimes feel completely overwhelmed caring for my son. Most of the feelings of worry are around myself and my husband getting older and who will care for my son.” #70*

A positive finding however was at baseline, 41% of carers indicated that they felt anxious, restless or uneasy in the last 3 days, and one-quarter felt this way daily. At follow-up, this reduced to 34% of carers who felt this way in the last 3 days, and almost one fifth (18%) felt this way daily. This finding is also reflected in some of the responses provided by carers in

the follow-up assessment form:

*“We got more help with the care recipient over the past 6 months. My mood has improved. Stress still remains.” #70*

Aside from the challenges that family carers have on an ongoing basis in the caregiving role, many experience major life stressors, such as, severe personal illness, death or severe illness of a family member or friend. At baseline, 33% indicated that they had experienced a major life stress in the preceding 90 days, this remained constant at follow-up (34%).

Using an ANOVA test calculated in STATA, there is no significant difference in the mood indicators listed above between the different care groups. This was tested for all those that responded at both time points and there was no difference detected either at baseline or follow-up between the care groups. In addition, using two sample t-tests with equal variance assumed, no significant difference was detected between baseline and follow-up for any of the mood indicators for carers.

## General Health and Health Conditions

Family carers often prioritise the needs of the care recipient over their own which can result in a diffidence to seek help or support for their own health. At baseline, 55% of carers had seen a doctor or nurse practitioner about their own health in the previous 90 days. Of those, over half (57%) had seen a doctor or nurse practitioner between two and five times, with four carers (8%) having six or more consultations for their own health in the 90 days prior to completing the survey at baseline. For carers included in the follow-up segment of this study, 55% had visited a doctor or nurse practitioner in the 90 days prior, with 35% of those having between two and five visits, with three carers (9%) having six or more consultations.

**Table 3.6: Self-Reported Health of Carers**

	% of carers at Baseline (T1)	% of carers at Follow-up (T2)
<b>Excellent</b>	15	16
<b>Good</b>	51	47
<b>Fair</b>	26	32
<b>Poor</b>	8	5

In relation to Table 3.6 above, two-thirds of carers at baseline reported their health as good or excellent (63% at follow-up). Just over one-third (34%) of carers reported their health to be fair or poor at baseline (37% at follow-up).

It is worth noting that a number of carers indicated that while they are in good health now, this was not previously the case. This is not captured by the interRAI assessment form as it only enquires about the health status of the carer over the preceding 90 days (i.e. Section E - Q.2; Section F - Q.7).

This was further evidenced by comments from some family carers:

*“My answers on the form paint a very healthy picture as they refer to the past 90 days only! In the past 11 years as carer I have had severe medical issues which may recur at any time so this may also be the case for others and have a very serious impact on the carers role.”*  
#12

*Family carer advised that she felt that the survey was a snapshot in time as she is in good health now but she has been sick previously. She would be providing a different set of answers if she had been given the survey five years ago. She felt that the survey gave a false picture as she is in good health now but previously has not been, so it depends on what is happening at that point in time. #12 (in conversation with the Project Office).*

Shortness of breath is an issue for a minority of carers (13% baseline; 14% at follow-up), with most of those reporting shortness of breath experiencing it when conducting moderate activities.

At baseline, 53% of carers reported pain to some extent, either “in the last three days” (27%) or “often but not in the last three days” (26%). One-fifth had pain “daily in last 3 days” at baseline. Of those that experience pain, 65% have moderate to excruciating pain. Carers experiencing pain is mirrored at follow-up (53%) with a slightly lower number reporting moderate to excruciating pain (58% of those that experience pain).

Thirty percent of carers at baseline reported experiencing acute problems or flare ups of a recurrent or chronic problem, this proportion was reduced slightly at follow-up (29%). Over a quarter (28%) of carers at baseline reported having conditions or diseases that made their health, mood, behaviour or ability to function unstable (24% at follow-up).

Health issues are a major point of concern with carers:

*“I suffer from back pain, anxiety and stress.”* #37

*“My main problem and concern is getting some cover if I become ill.”* #25

Alcohol consumption – carers were asked what the highest number of alcoholic drinks they had in a single sitting in the last 14 days, there was a slight reduction in alcohol consumption at baseline (54%) to follow-up (52%). Although, of those at baseline who drank in the past 14 days, 10% had five or more drinks, however at follow-up this increased to 34%. Significantly more carers drank more than five or more drinks at follow-up than at baseline, measured using a two-sample t-test (CI -0.22:-0.022).

## Sleep

Regarding sleep quality, specifically, “falling asleep or staying asleep; waking up too early; restlessness; non-restful sleep” during the three days prior to completing the survey, at



baseline 29% of carers reported not feeling this way, 22% stated they often experience this but not in the three days prior to completing the survey. The remaining 49% experienced problems with sleep within the last three days (33% daily). At follow-up the proportion reporting no sleep issues increased to 42%, and there was a small reduction at 42% who had a problem in the three days prior to completing the follow-up survey, 21% daily in each of the preceding three days. There was no statistically significant difference between groups using a two-sided t-test.

This was further enhanced by comments from the family carers themselves:

*“I am stressed and I don’t get enough sleep at night due to my mother being up multiple times a night.” #30*

*“Since I completed the last survey I was offered 2 weeks respite in [name of] hospital which I was happy to avail of. They told me that I can request another respite when I feel the need which I hope to do in 2023 P.G. I have also been offered a weekend respite by [name] Lions club this weekend and have arranged family to cover for me. Respite is excellent for the carer but the patient doesn’t like changes to his routine!! However he will manage for two days P.G.” #12*

## Stress

A significant indicator of well-being is stress, which can be experienced due to the emotional impact and physicality of the caregiving role. Many carers are ‘on call’ almost all day. Their role as a carer can be extremely challenging depending on the needs of the care recipient, and some are providing care at home for 20 years or more and without the requisite supports. This means there is little time for work, other family members or social activities. Many family carers have other commitments like taking care of their own families and they work full-time either in the home or away from the home.

Family carers selected the statement that best describes their level of stress:

- Not stressed;
- Stressed but I will not change the care I provide;
- Stressed and I need to reduce the care I provide (e.g. visit less often, reduce length of visits, cut back on tasks like housework, provide only minimal support);
- Stressed to the point of crisis, and I will stop providing care.

Responses at baseline indicate that 93% of carers were stressed to some degree, the majority (63%) indicate that they were stressed but will not change the care they provide. A further 20% reported they were stressed and they need to reduce the care they provide with 10% indicating that they are stressed to the point of crisis and will stop providing care. At follow-up, 79% of carers were stressed, just over half (52%) were stressed but will continue to provide the same level of care. Over a fifth of carers were stressed to the point of having



to reduce the amount of care they provide (23%), or feel stressed to crisis point and will stop providing care (5%), a reduction of 5 percentage points for this latter group compared to baseline.

There was no significant difference in stress levels across care groups. However, for respondents included across both data collection points, there was a statistically significant reduction in reported stress levels at follow-up compared to baseline levels using a two-sided t-test testing mean difference between the two time periods.

The high level of stress experienced by some carers was further evidenced by responses provided in the assessment form:

*“This caring role I am in is very stressful most of the time. At times I feel I cannot cope.” #84*

*“Covid has been extremely difficult due to the huge disconnect. It has had a huge toll on the family carer. Stress of being alone has given medical conditions that were not previously there.” #2*

*“I don’t have time for self-care needs. I am stressed a lot - carer stress. I have no family support at home. I find it difficult to manage my husband’s care alone. I have been offered a home care package but he won’t allow me to accept carers into our house.” #11*

*“I took early retirement to care for my husband full time (11 years ago). He is now immobile, incontinent and has dementia. We have been very well cared for by all the services, hoist,*

*shower chair, incontinence supplies, home help etc. We have also been offered respite which means my husband leaving home which is extremely stressful for him so I will not avail of it. Also the Alzheimer's society fund a carer to allow me to do shopping etc. for 5 hrs per week. My only fear is that my husband has been given an allocation of two people for personal care, I have taken on one of those two roles and if I get sick there is no one I can call on in an emergency, e.g. if I get a tummy bug, flu or have an accident. Also it would be nice if, like the paid carers, I would be covered to take holidays as presently I have to be available 365 days 1 year! At home, respite would be wonderful for people who are caring for someone who is immobile or bedridden and for whom hospital or nursing home is inaccessible or unsuitable. Thank you for doing this research, I hope the results will lead to some changes for those who need them.” #12*

## Quality of Life

To assess the quality of life of family carers, participants were asked to respond to fourteen statements, results are presented in table 3.7 below.

Over half (53%) of carers at baseline were hopeful for the future most of the time or always (61% at follow-up). However, almost a quarter of carers (22%) were rarely or never hopeful for the future at baseline (13% at follow-up).

During the initial phase of the study, over half of carers (54%) indicated that they felt good about themselves most of the time or always (62% at follow-up), with a further 13% reporting that they rarely or never felt good about themselves. At follow-up, 16% rarely felt good about themselves, with no carer reporting that they never feel this. Approximately half of carers feel that caring for their relative has improved their relationship, this is consistent across both time points.

Sixty percent of carers at baseline felt listened to by healthcare professionals most of the time or always (56% at follow-up). However, there is still some work to be done by



healthcare professionals to acknowledge the insight of carers when it comes to the care recipient, with just under a fifth of carers rarely or never feeling listened to by healthcare professionals, this is consistent across both baseline and follow-up. The majority of carers feel valued, important and good about their lives. Unsurprisingly, the majority of carers cannot find time to themselves when they wish and are unable to act on the spur of the moment. Of concern is that almost one-third (31%) of carers at baseline stated they either never or rarely can get the help they need right away and this increased to 37% at follow-up.

Quality of life questions below are posed on a 0-4 scale, 0 being never, 1 rarely, 2 sometimes, 3 most of the time and 4 for always, hence a higher score indicates a better score in relation to each element. See Table 3.7.

**Table 3.7: Quality of Life**

	Never (%)		Rarely (%)		Sometimes (%)		Most of the time (%)		Always (%)		Average score per domain		Mean Difference (T-Test)
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	
I am hopeful about my future	6	2	16	11	26	26	35	42	18	19	2.37	2.66	0.29
I feel good about myself	3	0	10	16	33	23	42	47	12	15	2.45	2.6	0.15
My relationships with family and friends are good	0	2	2	2	13	8	45	65	39	24	3.16	3.08	-0.08
Caring for the care recipient gives me a sense of self-worth	9	5	12	16	31	16	19	34	28	29	2.44	2.66	0.23
Caring for the care recipient makes me feel needed, useful, loved	11	6	13	13	27	24	18	27	30	29	2.39	2.6	0.21
Caring for the care recipient has improved our relationship	24	15	13	10	16	19	21	32	26	24	2.05	2.42	0.37
I feel listened to by healthcare professionals	7	3	12	13	21	27	43	32	17	24	2.6	2.61	0.03
I have people I can count on	1	8	15	11	19	37	30	18	35	26	2.81	2.44	-0.37*
On the whole, my life is good	3	2	6	6	30	26	43	52	18	15	2.66	2.71	0.05
I play an important role in people's lives	4	3	2	5	18	11	30	44	45	37	3.1	3.1	0.18
If I need help right away, I can get it	7	16	24	21	34	26	17	24	19	13	2.13	1.93	-0.19
I manage the stress in my life	2	3	8	5	36	31	43	53	11	8	2.6	2.6	0.16
I can be alone when I wish	19	23	31	21	27	34	18	18	4	5	1.7	1.6	0.1
I can go where I want 'on the spur of the moment'	69	66	16	16	9	11	3	6	3	0	0.55	0.58	0.03

\* statistically significant at the 90% level.



The above quality of life measures do not vary significantly by the care group to whom the carer provides informal care. Over the time period, the score associated with the majority of the above indicators increased, indicating an increase in quality of life. The score decreased for only three indicators: less carers at follow-up can get help right away if needed; significantly less have people they can count on, and fewer carers felt they have good relationships with family and friends.

### 3.3 Family Carers Needs

#### Supports for Care Recipient

Family carers were asked at baseline and circa six months later to indicate what supports they needed for the care recipient across 14 possible options. The three greatest support needs at baseline were: assistance with personal care (49%), physical rehabilitation (physical and OT) (48%), and day or night care services outside of the home (46%). This priority of supports needed for the care recipient changed slightly at follow-up: day or night care services outside of the home (40%), assistance with personal care (32%), and mental health services (Social Work, Psychology) (29%). See Appendix 7.

Upon initial completion of the assessment form, participants reported what initial supports and services and additional supports they required to continue in their caring role. This was evaluated to determine where extra services could be allocated within current service capacity. Table 3.8 presents additional services required by carers at baseline and follow-up for the care recipient, and also includes the number of people in the sample to whom additional services were provided for the 62 carers who completed the assessment form at both time periods. Table 3.9 outlines the supports provided to care recipients between baseline and follow-up assessments that were partially or fully met<sup>9</sup>.





Table 3.8: Supports for the Care Recipient

Supports for the Care Recipient	Baseline N=62 Supports required	Number that received the support <sup>9</sup>	Follow- up N=62 Supports Required
Assistance with personal care	27 (44%)	27 (100%)	20 (32%)
Assistance with household tasks	22 (35%)	8 (36%)	13 (21%)
Medical or Nursing Care	9 (15%)	9 (100%)	5 (8%)
Mental Health Services	23 (37%)	17 (74%)	18 (29%)
Delivered Meals	6 (10%)	1 (17%)	2 (3%)
Physical rehabilitation (physical or OT)	31 (50%)	18 (58%)	17 (27%)
Day or night care services outside of the home	28 (45%)	18 (64%)	25 (40%)
End-of-life care	0	n/a	0
Housing adaptation	19 (31%)	6 (10%)	15 (24%)
Therapy or assistance to support communication	14 (23%)	7 (32%)	11 (18%)
Aids and assistive devices	19 (31%)	14 (74%)	10 (16%)
Transportation assistance	15 (24%)	5 (33%)	9 (15%)
Financial or legal advice	11 (18%)	6 (60%)	5 (8%)
Educational support, including job training	9 (15%)	3 (56%)	6 (10%)

Table 3.9: Supports for Care Recipient - partially or fully met

Supports for Care Recipient	Number that received the support <sup>10</sup>	Care Recipient supports partially met	Care Recipient Supports fully met
Assistance with personal care	27	13 (48%)	14 (52%)
Assistance with household tasks	8	2 (25%)	6 (75%)
Medical or Nursing Care	9	1 (11%)	8 (89%)
Mental Health Services	17	10 (59%)	7 (41%)
Delivered Meals	1	0	1 (100%)
Physical rehabilitation (physical or OT)	18	6 (33%)	12 (67%)
Day or night care services outside of the home	18	12 (67%)	6 (33%)
End-of-life care	n/a	n/a	n/a
Housing adaptation	6	2 (33%)	4 (67%)
Therapy or assistance to support communication	7	2 (29%)	5 (71%)
Aids and assistive devices	14	1 (7%)	13 (93%)
Transportation assistance	5	1 (20%)	4 (80%)
Financial or legal advice	6	2 (33%)	4 (67%)
Educational support, including job training	3	0	3 (100%)

The highest demanded services across both periods regardless of an increase in provision were day or night care services outside of the home (respite, day care), physical rehabilitation (physical and OT), assistance with personal care, and mental health services. At baseline, we can see that 44% of participants reported needing supports or additional supports for assistance with personal care, all received this service in the intervening period, of which 48% had this need partially met and for 52% this need was fully met, and at follow-up almost one-third still required this support. Carers and referrers in the OP, PwD and P&S care groups, reported to the project manager and to referrers and in the free text question in the assessment form, care recipients being approved for an increase in home support/personal assistant hours, but home support workers/personal assistants could not be sourced to provide these hours, or could only provide a portion of the hours allocated, or could only allocate one home support worker/personal assistant and the family carer was the second person assisting, or there was an inability to source alternative staff if the usual worker was sick or on holidays.<sup>11</sup>

High demand for physical rehabilitation was also identified (physical or occupational therapy) (50% at baseline; 27% at follow-up), and 45% requested supports for day or night care services outside of the home at baseline. Forty percent still requested a need for day or night care services outside of the home at follow-up. Between baseline and follow-up, there is a statistically significant decrease in demand for aids and assistive devices, physical rehabilitation and assistance with household tasks, determined using a two-sided t-test testing mean difference between the two time periods.

## Supports for Carer

Family carers were asked at baseline and circa six months later at follow-up to indicate what supports they needed for themselves across six possible supports. The three greatest support needs at baseline were: carer support groups (78%), episodic relief from caregiving (respite) (62%), and psychological counselling (40%). At follow-up, the greatest supports were: episodic relief from caregiving (56%), education or advice about a specific health problem (21%), and psychological counselling (18%). See Appendix 7.

Family carers identified initial or additional supports that they required from a selection of six options in the assessment form. See table 3.10 overleaf for the 62 carers who completed the assessment form at both time periods.

<sup>9</sup> It is important to note that this information was obtained from various sources including health and social care professionals. It also involved the Project Office checking with carers by phone when they returned the follow-up FCNA form as to what additional services they had received in the interim period between them filling the assessment form up at baseline and follow-up. While every effort was made to ensure complete information is presented regarding allocation of services, there is a chance this may not be completely accurate as carers and healthcare professionals may not have been aware of what additional services had been approved or provided in some instances.

<sup>10</sup> These supports and services were provided based on need identified at baseline, this includes additional support/service provision on top of what they may have been receiving prior to the baseline assessment.

Table 3.11 outlines the supports provided to family carers between baseline and follow-up assessments that were partially or fully met<sup>9</sup>.

**Table 3.10: Supports for the Carer**

Supports for the Carer	Baseline N=62 Supports required	Number that received the support <sup>9</sup>	Follow- up N=62 Supports Required
Carer support group	50 (81%)	47 (94%)	9 (15%)
Psychological counselling	26 (42%)	21 (81%)	11 (18%)
Education or advice about a specific health problem	19 (31%)	17 (89%)	13 (21%)
Episodic relief from caregiving	41 (66%)	22 (54%)	35 (56%)
Financial or legal advice	21 (39%)	13 (62%)	8 (13%)
Transportation assistance	12 (19%)	1 (8%)	7 (11%)

**Table 3.11 Supports for Carer – partially or fully met**

Supports for Carer	Number that received the support <sup>10</sup>	Carer supports partially met	Carer supports fully met
Carer support group	47	2 (4%)	45 (96%)
Psychological counselling	21	2 (10%)	19 (90%)
Education or advice about a specific health problem	17	3 (18%)	14 (82%)
Episodic relief from caregiving	22	12 (55%)	10 (45%)
Financial or legal advice	13	4 (31%)	9 (69%)
Transportation assistance	1	1 (100%)	0

Consistent with required services for care recipients in the previous section, persistently across both periods the highest service demand for carers was also respite, by way of episodic relief from caregiving. Two-thirds of carers requested respite at baseline, this was provided to just over half (54%) of carers in the intervening period, of which just over half (55%) of those had this need partially met and for 45% this need was fully met. At follow-up, over half (56%) of carers still had this need. Education or advice about a persistent health problem was also in high demand both at baseline and follow-up.

Psychological counselling was provided by the HSE Counselling in Primary Care (CIPC) Service and by Family Carers Ireland, with one carer accessing counselling privately. Education was provided by Family Carers Ireland, the HSE Carer’s Department, the Alzheimer Society of Ireland and the HSE Social Work service. The majority of episodic relief from caring was residential respite with 43% of carers availing of this, 19% received in-home respite and 38% utilised emergency respite services.

<sup>11</sup> It is pertinent to highlight that the extreme shortage of home support workers is evident in all Community Healthcare Organisations, and is not an exclusive problem affecting CHW. CHW have had multiple recruitment campaigns in an effort to address this staffing shortfall, which is now a rolling campaign. CHW are continuing to liaise with the Home Support Tender Providers for 2023 regarding recruitment efforts to address this deficit in home support workers.

At follow-up there was significantly less demand for counselling for carers, carer support group and financial or legal advice. Demand for the other carer supports remained unchanged, despite an increase in service provision across all domains, determined using a two-sided t-test testing mean difference between the two time periods.

These findings are also evident in the free text responses from carers on the assessment form:

*“My main problem is the concern if I became ill getting some cover. Also if I want to go away for a few days. My mum refuses to go into respite; I have managed to get a family member to do it this time.” #26*

*“I have no family support at home. I find it difficult to manage my husband’s care alone.” #11*

*“Respite care in the home rather than the nursing home as patients prefer to stay at home.” #31*

*“Getting respite for my son is a big problem, he has been approved for six days a month respite by HSE in a nursing home. A nursing home is not an ideal setting for a young 30-year-old man but there is nothing else available.” #57*



## Challenges in caring for the Care Recipient

To assess the challenges that family carers face in caring for the care recipient, participants responded to ten statements with Yes or No. See Table 3.12 below.

**Table 3.12: Challenges in Caring for the Care Recipient**

Challenges	Yes (%)	Yes (%)
	T1	T2
I have difficulty finding the time to care for the Care Recipient	44	32
I sometimes question my ability to help given the Care Recipient's problems	58	53
I sometimes find it difficult to provide care in a timely manner (e.g., I live far away, have a job, go to school)	36	24
I have other caring responsibilities (e.g., sick child or partner, child rearing, home duties)	51	50
I have financial difficulties (e.g., have to make trade-offs using funds to cover food, shelter, clothing, or medications)	20	6
I lack enough support from family and friends	56	60
I find it difficult to understand and use the healthcare system	36	39
Caring for the Care Recipient is a major source of stress	74	71
Caring for the Care Recipient keeps me from working, making a living, or getting an education	54	39
I have no time for myself or to enjoy activities I like (e.g., volunteering, visiting friends)	65	58

Most notably, 74% of carers at baseline indicated that caring for the care recipient is a major source of stress, this decreased only slightly at follow-up (71%). Regarding time for themselves, 65% stated at baseline that they have no time to themselves or to enjoy activities they like (58% at follow-up). A further 58% reported that they question their ability to help given the care recipients problems, again a small reduction was observed at follow-up in relation to this. Of note, carers experiencing financial difficulties and the number of carers for whom their caring role prevents them from working is significantly reduced at follow-up using a two-sided t-test for mean difference between the two time periods. Worryingly, the proportion of carers that lack support from family and friends increased over the time period as did the carers that find it difficult to use and understand the healthcare system.



These challenges were further evidenced by responses provided in the assessment form:

*“Reasons that people have to become a family carer, family situations. To me, it’s like having a child back in our house. We have to be here at ‘home’ nearly always. No one really highlights this and the only alternative is nursing home and a rigorous means test on family income - other than the carer automatically getting allowance of some kind for work being done.” #38*

*“Since filling in the previous forms, the care recipient finally got an increase from 5 to 19 hours home help care as the IMND helped with this. We had to fight for this for nearly 9 long months - that was absolutely shocking and added so much more stress to our lives. The carer’s allowance paid each week is still terrible and not a liveable wage for anyone trying to give full time care to a spouse. The system is on its knees and it’s the family care givers suffering because of it and doing it out of love.” #52*

*“I don’t have time for self-care needs. I am stressed a lot - carer stress. I have no family support at home. I find it difficult to manage my husband’s care alone. I have been offered a home care package but he won’t allow me to accept carers into our house.” #11*

## Difficulty caring and managing other areas

Family carers responded to four areas to determine what they found difficult to manage while at the same time providing care to the care recipient.

Over half of the participants, 56% reported finding it difficult to care for the care recipient and manage a job or work (42% at follow-up), with 42% indicating they had difficulty managing family and children (32% at follow-up). A smaller but still a substantial number (37% baseline; 26% follow-up), indicated that they found it difficult to care and make enough money to live on.

*“Time is an issue especially with a fulltime job. Availability of family / friends is not always possible due to their own lives and constraints. Good to talk on the phone but the physical presence of others can help to relieve the strain of being with someone all the time. Paying for care an issue as not entitled to respite grant. Not recognised in system as a carer. Also ‘patient confidentiality’ can be puzzling, especially when it affects your life and caring is part of your day.” #91*

## Adequacy of Community Services & Contingency Planning

Family carers were asked to indicate if the services they received from community agencies were adequate. The majority of carers (baseline 57% and follow-up 60%) said they were either not adequate (baseline 30% and follow-up 34%) or that they did not receive such services (baseline 27% and follow-up 26%).

While contingency planning is an important element of caring for a loved one, even temporarily, many family carers had not addressed this issue as it can be a sensitive and challenging topic. The majority (66%) of participants at baseline indicated they do not have anyone to take over their caring role should they become ill or unable to continue in their caring role, this increased slightly at follow-up (68%).

These concerns were further evidenced by responses provided in the assessment form:

*"I am an 81-year-old widow who is sole carer for my 48-year-old son with special needs. I get no help, no respite and no support. He is becoming more difficult to manage. I am struggling. I worry what will happen to him when I am gone. I don't know what services are available for him in the event of my passing." #71*

*"My concern is long term care of the care recipient when we are old and no longer able to care for him. We will require a full time residential place at some time in the future." #65*

*"My main problem is the concern if I became ill getting some cover. Also if I want to go away for a few days. My mum refuses to go into respite, I have managed to get a family member to do it this time." #25*

*"I became my daughters carer over 20 years ago. She is a lovely girl and it has been my pleasure to look after her... Up to 15 years of age her problems were mostly physical due to being born with a rare syndrome. She developed a mental illness and has also overtime lost her eyesight completely. I feel tied to the house and if I go anywhere she rings me several times. My relationship with my wife and family has suffered... Myself and my wife have not*



*been out alone in years... My daughter is never going to be independent as we are getting older, she will have to go into care. I feel the time remaining with us could be prolonged if we could get a couple of weeks a year respite... I joke I can put the dog into kennel if we go away but where can my daughter go. Respite would be the big thing for me/us in whatever form it comes.” #72 Additional Feedback Questionnaire*

### 3.4 Summary

This chapter presents the findings from the baseline and follow-up interRAI assessments. Most notably the majority of carer participants were female (75%), reside with the person they provide care to (83%), with an average age of 58 years (range 26 – 86). The majority of family carers are the care recipient’s child or child in law (35%), parent/guardian (34%) or spouse/partner (22%), spending 35 hours or more taking care of the care recipient (81%), and have been in the caring role for more than five years (70%). Memory is an issue for many carers, similarly many carers have issues with concentration and the majority of carers indicated a decrease in participation levels in social activities, with half of those reportedly distressed by this decrease.

Overall, family carers struggle to find time to themselves, find it difficult to manage their work or job, family and children, attend school and many report that it is difficult to make enough money to live on.

The supports requested are in line with the challenges that align with the caring role, most notably respite care that would allow the carer take a break from their caregiving responsibilities and attend to their own needs.





# Chapter 4 - Results - Usefulness and Usability of interRAI FCNA Information

This chapter presents the findings from the survey and the focus groups conducted with health and social care professionals, who referred family carers to the pilot programme. It addresses the programme objective, 'To assess the use of the assessment form by health professionals in their respective services'. The findings will include an important appraisal of how useful professionals found the information generated from the assessment form, how they used the information generated in their professional interface with family carers, the relevance of the assessment form to varying care groups, and user's satisfaction of the overall experience.

Sixty-nine percent of referrers ( $n= 36/52$ )<sup>12</sup> completed the survey, with referrers from all five care groups<sup>13</sup> and from all three counties (Galway (50%), Mayo (26%), and Roscommon (21%))<sup>14</sup> participating. A total of 18 referrers participated across the three focus groups, with all five care groups represented.

## 4.1 Focusing on the Needs of Family Carers

There was general consensus in the focus groups that focusing on the needs of the family carer was a valuable and worthwhile exercise. There was agreement that focusing on the needs of the family carer results in a more comprehensive understanding of the caring environment and better outcomes for the care recipient.

A number of participants advised that they would do this as part of their work, while others indicated that their focus is mostly on the needs of the care recipient. Overall, this pilot programme has demonstrated the value of assessing the needs of the family carer and professionals indicated that they would continue with this practice.

During the focus groups, referrers stated that carers felt it was a rare experience to be asked about their needs, and some found it difficult to switch their focus from the needs of the care recipient to their own needs, and found the experience difficult and in some instances upsetting.

<sup>12</sup> Note- although a total of 48 referrers recruited the 89 carers at baseline, 52 referrers were included in the survey, because at the time of the survey being disseminated to referrers, four additional referrers were actively participating in the pilot programme, however they could not recruit any carers.

<sup>13</sup> Thirty-two of the 36 referrers who participated in the survey answered the question on care groups. Nineteen percent referred carers from the PwD care group, 31% from the OP care group, 7% from the P&S care group, 21% from the ID care group, and 21% from the adult MH care group. The smaller percentage that referred overall from the physical and sensory care group is attributed to the smaller number of referrers available in this care group, however of the four referrers in this care group, three of them participated in the survey and the referrer who did not had participated in the pilot testing of the survey.

<sup>14</sup> A further three percent of referrers who participated in the survey indicated that they worked across more than one county. This question was answered by 34 of the 36 referrers who participated in the survey.



This was further evidenced during phone calls between the Project Office and carers who stated that for the most part they found it was a positive experience to be asked how they were feeling and what their needs were. It was difficult for carers to put their needs first, as their thoughts were focused on the needs of the care recipient first and foremost. The process provided them with the opportunity to self-reflect on their caring role, how it affects them and their daily lives and the challenges that accompanies the role. For some, they did not identify as a family carer and that presented a challenge in itself, as they did not recognise that they may have their own needs in the caregiving dyad.

*“We might have relationships with families, and we might have gathered that type of information in a conversation, but the families would never be directly asked specifically for the information. It was definitely a new experience for the families. It is difficult sometimes to reflect on where things are and what you’re worried about, and that would have been the feedback that I would have gotten from the families. They kind of knew about it and worry about what’s going to happen in the future, but once you start answering those questions and putting a label on it, I suppose it makes it more real.” (Participant FG #2)*

*“Looking back now, if I were to do it again, I would actually sit with the person completing the questionnaire, because quite a few people mentioned to me afterwards that they were quite affected by completing it. One woman actually started crying telling me about answering the question about things you do to care for yourself. It had never occurred to her before about self-care and she got quite emotional about that, so if I were to do it again, I think it would be more beneficial for the care recipient to actually be with them.” (Participant FG #2)*



## 4.2 Usefulness of FCNA information generated

Health professionals who had referred carers to the pilot programme were asked to rate in the survey how useful they found the information generated by the assessment form. The majority of health and social care professionals (94%; n=29) indicated the information was either 'somewhat' or 'very useful'.

The usefulness of the information generated was further explored during the focus groups. A number of referrers stated they had access to new valuable information about the needs of the family carer that would not otherwise have been available to them. A positive outcome from the focus groups was a number of referrers learned of services they were heretofore unaware of. The most commonly cited being Family Carers Ireland and the HSE Carers Department, whom they indicated had responded to the carers needs when referred:

*"There was great information about Family Carers Ireland and what they had to offer..."*  
(Participant FG # 2)

*"Another service, the HSE Carers Department, I would not have known about before the project. So, it is another support I have started referring to since. They'd be very supportive as well."* (Participant FG #3)

However, the majority of participants in the focus groups stated that the information gathered about the needs of the family carer was information they already had, and effectively they did not learn anything new about the needs of the family carer or the caring circumstances. This conflicts with the findings from the referrer's survey outlined above. Some referrers feeling this indicated during the focus group discussion that the information from the assessment form corroborated the information they already had and essentially validated their approach, which they found beneficial.

*"I found the information useful, but having worked with the families previously, there was not much I didn't know already."* (Participant FG #1)

*"All I would say is for us, it kind of validated the way we work with people, and also that we probably do more for family carers than we realise because there wasn't really anything new that came out of it for us. I think it was kind of funny that when the calls were coming through, and they identified this need, that need and any other need, we kind of went 'yeah we have done that, we are working on that and we knew about that.' While it may not have surfaced any relatively new information, it did validate that while we are working with the client, we seem to be picking up things while having conversations with the family carers. So, I think, because we are struggling so much at the moment with lack of care staff in the community and there's so much wrong, it was very validating to know that we aren't too far off the mark with supporting the person and their families that support them as well."*  
(Participant FG #1)

Some referrers in the focus groups further postulated that assessing the needs of family carers was beneficial and the extent of assessment form questions gave them a very comprehensive view of the needs of the family carer.

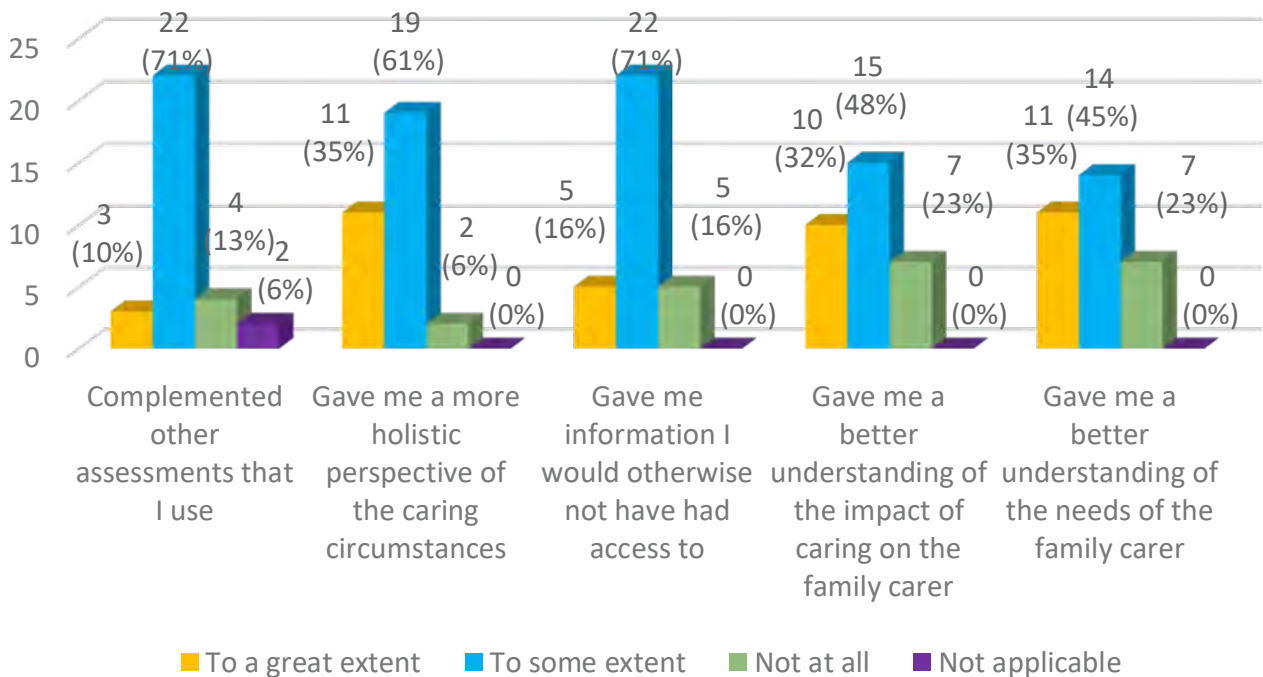
Referrers were surveyed to identify which sections of the assessment form yielded the most helpful information to their professional role in supporting carers. The following four sections were found to be most useful in order of priority: Section G. Supports Needed and Received, Section D. Carer: Function/Endurance/Stamina, Section E. Carer: Mood, and Section F. Carer: Health Conditions.

Overall, the findings from the referrers’ survey and the focus groups suggest that the **professionals felt that the assessment form provided new information on the carers needs, and gave them a better understanding of the impact of the caring role on carers.**

### 4.3 Use of FCNA information generated

The information generated from the assessment form, and how it was used by health and social care professionals was a key area of exploration in the referrers’ survey and the focus groups.

Figure 4.1 Use of FCNA Information Generated (Source: Referrers Survey)

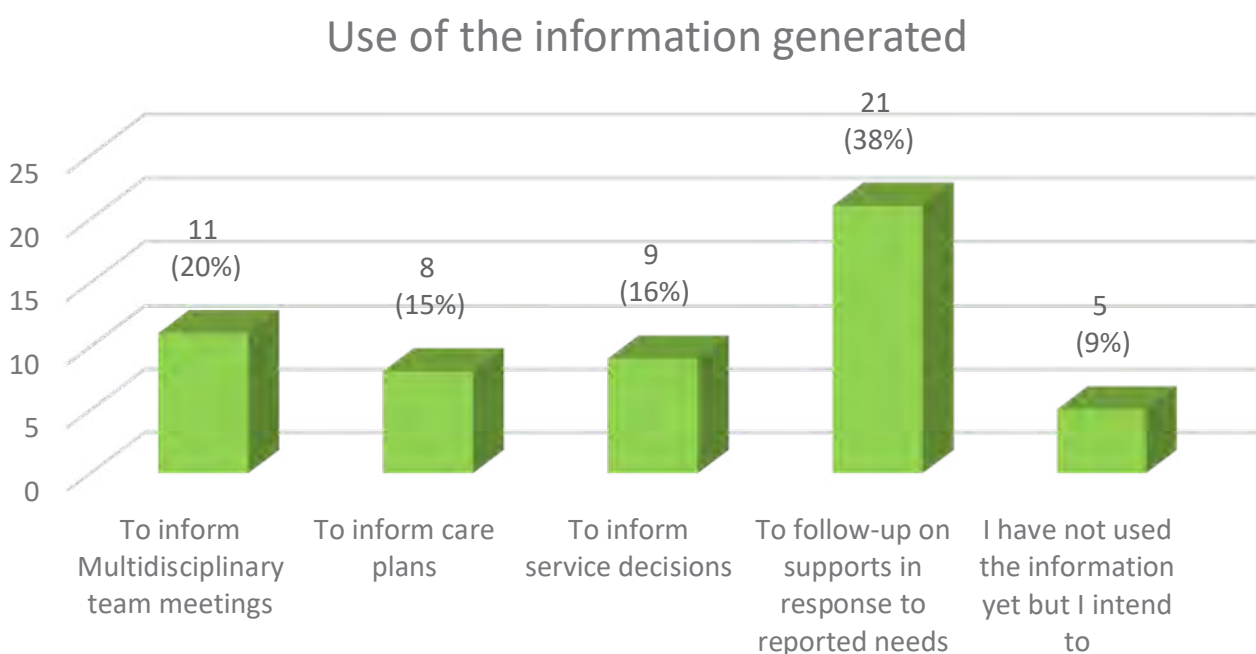


The above figure 4.1 illustrates how the professionals, who had referred carers to the pilot programme, used the information generated, as indicated by responses to the referrers survey. It is evident that the majority of professionals found the information generated benefited and helped inform their work. Ninety-six percent indicated that it gave them a more holistic perspective of the caring circumstances.

**It is noteworthy that 87% of professionals felt that the assessment form gave them information that they otherwise would not have had access to.** Eighty-one percent said it complemented other assessments that they already use. Eighty percent indicated that it gave them a better understanding of the impact of caring on the family carer, and 80% also said that the assessment form gave them a better understanding of the needs of the family carer, to some or a great extent.

The use of information generated in the survey was crucial for gaining valuable insight and also making informed decisions. Participants were asked to indicate specifically how they used the information generated from the assessment form in their respective professional roles.

Figure 4.2 Further use of FCNA information generated (Source: Referrers Survey)



As can be seen from Figure 4.2 above, when asked how the survey participants used the information gathered, the largest number of responses (38%) was to follow-up on supports in response to reported needs, followed by using it to inform multidisciplinary team meetings (20%), to inform service decisions (16%), and to inform care plans (15%). There were no discernible difference to the responses from across the care groups.

A small number of participants had made new referrals as a result of the information gathered, and included it as part of an application for services, for example, home support services. They reported that the survey provided them with the confirmation they needed to ensure that the family carer was able to access a service or services, and the information was used to give importance to carers getting respite care for the care recipient in particular.

*“I’m just thinking of one of mine. Of having the type of information [on the Family Carer] has changed the priority of the need. I didn’t realise that this client had recently been bereaved.*

*Her husband had recently died, and this really changed the urgency of the support that was needed. I would not have had that information if it had been my client rather than the Carer.” (Participant FG #3)*

*“I suppose with the person that I used it with, I probably would have changed my tact to get her to access services. She wasn’t looking for services when she completed this survey, but I felt like services were required due to her age and the age of her son.” (Participant FG #2)*

*“I would have used the information when applying for the service they requested. Like, the carer’s needs would have come into that. What we have applied for, for this family, is home sharing, so we match them with a family in the community. Normally, we would not bring in the Carer’s needs to a huge extent [regularly], where the Carer’s needs prevailed in the matching process.” (Participant FG #2)*

Some referrers informed the focus groups that they already had the information on the family carers needs and had used the information correctly prior to the pilot programme.

*“The role of the social worker in (the care group service) is to link in often with the family members, so, when there is a carer on board, tend to find we already know a lot and already have decent relationships with the carers.” (Participant FG #3)*

One cause of significant frustration was the fact that although family carers were being asked to assess their needs, there were no additional services or supports available to them. Participants stated that they felt that it was unfair to raise expectations of a family carer by asking them about their needs, when they were unable to a large extent to support those needs. A number of the professionals who had referred carers to the pilot programme indicated that they felt uncomfortable asking questions about needs when the supports to address those needs were not available.

*“I found some of the questions in other sections were nearly aspirational, for example ‘what services would benefit?’ those services are not available, or you can apply for them but there are long waiting lists, and it was nearly disconcerting for family members to realize that. I felt nearly guilty telling them about it, about services they didn’t know about but were difficult to get.” (Participant FG #1)*

*“A family carer said that she was long enough at this to know nothing would come of it and she didn’t want to waste her time. There was no shifting that mind-set. Every other family carer agreed.” (Participant FG #3).*

*“I felt that by asking the question there was almost an expectation that something was going to be done or some sort of intervention that could help their situation, but I couldn’t offer anything.” (Participant FG #1)*

## 4.4 Ease of Completing the FCNA

It was important that the pilot programme would capture the experiences of the family carers and the referrers in relation to completing the assessment form. The information generated from the focus groups and the survey provided valuable feedback regarding the referrer's experience.

The survey with referrers asked if they provided support to the family carer to complete the assessment form. Thirty-two percent of the survey respondents stated that they supported the family carer to complete the assessment form, 26% indicated that they provided support to some carers and others did not require their support, while 42% stated that the family carer had completed the assessment form themselves. There were no discernible differences in the responses from across the care groups.

During the focus groups, a number of referrers who had not provided direct support to the family carers to complete the assessment form, stated that if they were to do it again, they would sit with the family carer, both to explain issues as they arose, but also because a number of family carers were quite 'affected' by the process of self-reflection, and some were upset as a result.

**Table 4.1 Level of Difficulty Completing the FCNA**

	I assisted the Family Carer, and I found the form	The Family Carer completed the form, and they found it
<b>Very difficult</b>	17%	26%
<b>Difficult</b>	50%	18.5%
<b>Neither easy or difficult</b>	28%	37%
<b>Easy</b>	0%	18.5%
<b>Very easy</b>	5%	0%

The majority of referrers/professionals (67%) that assisted carers in the completion of the assessment form stated that they found the form difficult or very difficult to complete. Similarly, 44% of carers who completed the form themselves and without the help of the referrer, found the assessment form difficult or very difficult to complete. These findings were also evidenced in the focus groups with referrers:

*"Family carers would have reported back that it felt quite clinical to complete the form, but it was great to get all the information that came from it, but it was very confusing to fill it out as well. I found myself constantly referring back to see what the question was and what number I should be putting in, so, I found that difficult, but the information was great."*  
(Participant FG #1)

*"I have to say, I found it very cumbersome, I didn't find it very user-friendly. I found some of the questions very confusing for me, never mind the carers completing the form."*  
(Participant FG #1)



*“A lot of the questions were repetitious. From a carer’s point of view, it was nearly asking the same question but in a different format, giving, then a very similar answer [as other questions] which I found confusing, let alone the carer.” (Participant FG #1)*

*“The way some questions were phrased were not applicable and appeared more focused towards elderly individuals.” (Referrers Survey Response)*

There was general consensus amongst the professionals that without improvements, some family carers may struggle to complete the assessment form. The project manager contacted all family carers who completed the assessment form at baseline and again at follow-up to ensure completeness and accuracy of responses, and to provide some assistance if required in completing the form. For all 89 carers who completed a baseline assessment form, there were sections of the assessment form that were not completed, or questions answered for the care recipient and not in respect of the carer, such as, Section D. Carer: Function/Endurance/Stamina. In addition, some answers to questions were omitted as the carers and/or the professionals did not understand the question. There was ambiguity regarding services required due to the amalgamation of services in the assessment form, for example, Section G. Supports Needed and Received – Mental Health Services (e.g. social work, psychology), Physical Rehabilitation (e.g. physical or occupational therapy), day or night care services outside the home, and medical or nursing care.

These findings are also evident in the free text responses from carers in the assessment form:

*“I found it difficult to tick boxes because I think my experience of caring is not accurately captured in a survey like this. If other carers have the same difficulty as I have, then the combined results of the survey will not give a true picture of our situation. Perhaps a listening survey would yield better results especially if carers were individualised in facilitating the listening survey. Box ticking does not capture emotion and these questions are the hardest to answer especially as feelings fluctuate all the time. Surveys can capture facts but human experiences cannot be corralled into boxes.” #16 (Additional information provided on the Assessment Form)*

*“I found it confusing in parts. I found the coding and language difficult and cumbersome. No flow to the questionnaire.” (Referrers Survey Response)*

*“The questions need to be brief and to the point. Yes/No answers. Should be no timeframe. I am under 45 and feel this assessment/questionnaire is not relevant to me.” #24 (Additional information provided on the Assessment Form)*

The referrers that supported the family carers to complete the assessment form reported that the process took a substantial amount of their time. These findings were also apparent in the free text responses from referrers in the survey and by referrers during the focus groups:

*“I found the process time consuming and added to workload for the PHN.”* (Referrers Survey Participant)

*“Due to the form not being user-friendly, I found it very difficult to pick the participants.”* (Participant FG #1)

*“Any direct comments I got were about the amount of paper and the amount of words on the paper, and just the sense of time and commitment to filling out the paper and the sense was kind of what were they going to get out of it is probably the feedback. Too many pages, words and questions and they sense that it was a daunting, overwhelming task with no knowledge of the outcome.”* (Participant FG #1)

*“The second family thought it was a mammoth task and didn’t see any benefit arising from it.”* (Participant FG #3)

When completing the Additional Feedback Questionnaire, family carers were asked how long it took them to complete the assessment form. It is important to note that overall 41% of carers stated it took them 30 minutes or less to complete the assessment form, with 40% of carers stating it took them between 31 and 60 minutes (of these, 54% indicated it took them one hour), and a further 19% indicated that it took them more than one hour to complete the form. One carer stated that it took them three hours and 45 minutes to complete the assessment form, and five carers reported it took them two hours.

## 4.5 Relevance of FCNA to Caring Circumstances

In the referrers’ survey, health professionals were asked to report on the feedback they had received from family carers regarding how relevant the assessment form questions were to their caring circumstances.

Figure 4.3 Relevance of FCNA to Caring Circumstances

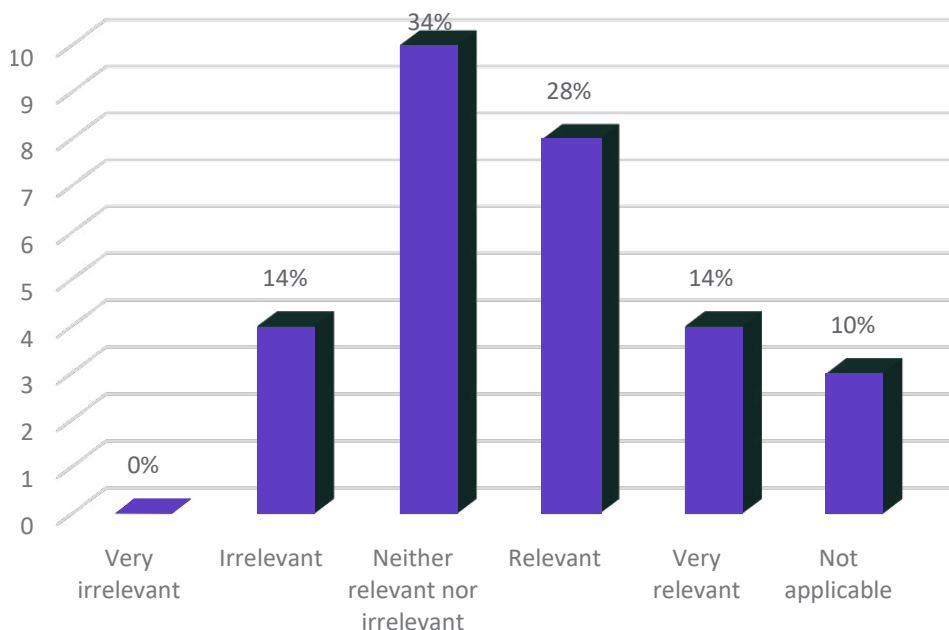


Figure 4.3 illustrates that 42% of referrers stated that the carers felt that the information on the assessment form was either very relevant or relevant to their caring circumstances.

## Recommended changes to the assessment form

Comments given in response to the question in the referrers' survey on the 'relevance of the FCNA to caring circumstances' suggested that some of the health professionals and the carers found the form difficult, long, repetitive, and confusing. This was also the opinion of the Project Team. This was further reiterated by many carers and professionals in telephone conversations with the Project Office. Feedback from health professionals and carers indicated that the Carer Needs Assessment form could be improved by digitising the process and form, and to improve the flow and to identify sections which could be reduced and/or improved.

As such, questions that were perceived to be repetitive include, stress is asked in Section G 3(h), and in Section H 2, and in Section H 3(l). Also, some questions in Section G 3 'Challenges' are similar to Section H 3 'QoL'.

Questions believed to be too long and therefore could be reduced/removed include the 7 follow-up questions of Section D Carer Function/Endurance/Stamina.

Questions that were confusing include, hours caring asked in Section G 4 and asked again in Section G 5, many report that the coding is inconsistent and cumbersome, and the overall volume of questions make the assessment form increasingly confusing and difficult to navigate. Many carers found the various parts to the questions in Section D perplexing. Some carers and professionals found questions 4 and 5 of Section F. Carer Health Conditions complicated. Additionally, the different 'look back' days in various questions caused confusion for many. The assessment is restricted to one care recipient, where many carers may be caring for more than one person. In general there is too much text overall, particularly for people who have literacy difficulties.

Furthermore, in respect of Section D and Section G 2, some carers answered this in error for the care recipient and not the carer. A description of the various supports/services for carer and care recipient in Section G would reduce ambiguity. The questions on hours caring could be more appropriately asked at the beginning of the assessment form under Section A: Identification Information. Section G 3 Challenges, some carers found these questions difficult to complete and did not want to give the impression that they could not cope or were being disingenuous about family and friends. In respect of Section H. Carer: Well-being Q. 1 c. 'Attend school', the project team recommend adding 'university', so as to include adult carers who may be in third level education as opposed to second level/post-primary school.

Regarding Section H.3 Quality of Life, some carers found these questions upsetting and difficult to answer. There is a large component of the form with heading 'I. Carer Health and Wellbeing', and then under a later heading 'II. Family Carer Needs' there is a section

called 'Section H. Carer: Well-being', this is confusing and may be more appropriately placed under 'I. Carer Health and Wellbeing'. Section G 3 Challenges, might also be more appropriately placed under I. Carer Health and Wellbeing.

The way in which some questions were stated created confusion, for example, Section D 3. Stamina and Stability, carers are asked a) How often have you felt so exhausted that you could not carry out your normal day to day activities? Carers are asked to Code 0 not in last 3 days, 1 not in last 3 days, but often feel this way, 2 in 1-2 of last 3 days, and 3 Daily in last 3 days. However, if a carer has not been exhausted in the last 3 days but sometimes feels this way, there was some confusion as to which code to use. Also, there is no definition provided for 'often' and it is therefore open to individual interpretation.

## Relevance of questions in the assessment form and suggested missing questions

The pilot programme invited family carers to complete an 'Additional Feedback Questionnaire', when they were completing the baseline assessment form (see Appendix 4). This additional form asked how well the assessment form captured important information, whether the questions were appropriate for their care cohort/care recipient, and whether pertinent information was missing. Family carers were given the opportunity to provide written feedback on the questionnaire, or alternatively they could provide verbal feedback to the project manager who documented the carers' answers verbatim.

The majority (96%) of carers stated that the assessment form collected important information, with 3% stating that it did not, and one carer indicated both yes and no to signify that some of the information collected was important and other information was not. When asked if there were questions in the assessment form that did not apply to their



caring role, 42% of family carers stated that there were questions that did not apply to their role. The most common questions identified were in *Section D. Carer: Function/Endurance/Stamina*, with almost half of carers (46%) indicating that Section D was not relevant to them, as many family carers felt that they were able to function independently. It is not possible to establish trends in carer groups or age, as this is a small sample, however this may be an area for further investigation. To a lesser extent, *Section B. Carer: Memory and Cognition*, and *Section C. Carer: Social Participation* were also noted as questions that did not apply to a small number of family carers caring roles (i.e. indicated by four carers (5%) respectively).

Some questions that the family carers would like to have included in the assessment form relate to (Refer to Appendix 9):

- Stress caused by the change in dynamic between the carer and the care recipient.
- The cost of living as prices escalate and how difficult it is to survive financially week to week.
- Services/actions that have benefited/helped them as a carer since they started in the caring role.
- Questions that were more specific to particular care groups, e.g. intellectual disability and residential services, and mental health and supported living.
- The impact of caring on other family members, such as on siblings. One carer noted that *“they could only care for their son by neglecting their daughter”*.
- Question in relation to sensory and behavioural support. Sensory disability is not included in the assessment form and there is a need to have sensory stress noted.
- Question regarding carers input on what supports are required from their point of view.
- The accessibility of services and an awareness of what services are available.
- Questions on caring for more than one person.
- Is caring your choice?
- Can the care recipient live independently with supports?
- Question not only on the provision of services but also the quality of such services.
- Assistance for care recipient to live an independent life.
- Questions on coping, such as, what strategies do you have in place to cope?
- Question on future planning of care.
- Availability of services during the COVID-19 pandemic.
- What services/actions have benefited/helped the carer since they started caring?
- What has changed in terms of service provision and how has this impacted on the carers role and on the care recipient.
- Question about worry/worrying.
- The daily medical role requirements/tasks in being a carer.
- Open question on what would make life easier.



## 4.6 Summary

Overall, the findings from the referrers' survey and the focus groups suggest that professionals felt that the assessment form provided new information on the carers needs and gave them a better understanding of the impact of the caring role on the carer. The use of information generated in the assessment form was crucial in professionals gaining valuable insight and also making informed decisions. Many carers indicated that the experience of filling out the assessment form was beneficial for them as it allowed them time to self-reflect on their own needs and experiences as a family carer.

However, one cause of significant frustration amongst professionals was the fact that although family carers were being asked to assess their needs, there were no additional services or supports available to them. The majority of health professionals and carers found the assessment form difficult, repetitive, and confusing. Feedback from health professionals and carers indicated that the Carer Needs Assessment form could be improved by digitising the process and form, and to improve the flow and to identify sections which could be reduced and/or improved. There was general consensus amongst the professionals that without improvements some family carers may struggle to complete the assessment form.

Overall, this pilot programme has demonstrated the value of assessing the needs of the family carer and professionals indicated that they would continue with this practice. However, professionals also indicated that the process took a substantial amount of their time and mentioned the significance of having requisite support and resources.



# Chapter 5 - Discussion and Conclusion

## 5.1 Introduction

In this chapter, we first summarise and interpret the main findings of the interRAI Family Carer Needs Assessment pilot programme in CHW in relation to the primary objectives. This is followed by a consideration of the strengths and limitations of the pilot programme, and the implications of the findings for future HSE policy decision-making, service planning and service provision.

The CHW pilot programme is the Irish site of an interRAI multinational study led by interRAI International and the interRAI Ireland National Office. This pilot programme tested the current interRAI Carer Needs Assessment form in Ireland, which involved administering the assessment form to family carers for completion, and collecting evidence from health and social care professionals to determine the usability of the assessment form by the clients they interact with, and the relevance of the data collected for the purposes of service planning. The assessment form was developed to help identify the unmet needs of family carers of adults requiring services and supports, in order to address the gap in services to this most vulnerable and often invisible cohort. The overall aim of the pilot programme was to test the implementation of the assessment form across various care groups, including, carers of people with dementia, older people, physical and sensory disability, intellectual disability, and mental health, in CHW.

To recap the pilot programme comprised of four phases. In phase 1, eighty-nine family carers from five care groups were referred to the programme in a sequential manner over a five-month period, by referrers who were health and social care professionals working in the HSE and in voluntary agencies. The health and social care professionals facilitated carers, where necessary, to complete a baseline assessment form. An Additional Feedback Questionnaire was also completed by the same carers at baseline.

In phase 2, completed assessment forms were given to the original referrer/health and social care professional by the project manager who then discussed the follow-up actions to address the supports and service needs identified for both the care recipient and the family carer.

In phase 3, six months after having completed the baseline assessment form, a follow-up assessment form was administered to the same group of carers to capture changes in their well-being, and to determine if providing services to meet unmet needs impacted factors determining well-being, including mood, quality of life and stress. Sixty-two carers completed the follow-up assessment form, a response rate of 70%.

To gather data on the use of the assessment form by health and social care professionals, three focus groups (see FG schedule of questions in Appendix 6) were conducted with eighteen referrers from the five care groups, and all referrers were also invited to complete a survey (Appendix 5), a response rate of 69% was achieved.

Phase 4 was the Project Closeout involving data analysis and compilation of the project report.

It is evident from the findings of the assessment form on the health state and healthcare needs of family carers and their care recipients that family carers dedicate a lot of their time to their caring role, often with little support. It is also evident from the focus groups and interactions between family carers and referrers and/or the Project Office when completing the assessment form, that assessing carers needs and supports is not routine practice. Essential care is provided in the home by family and friends, which is central to enabling care recipients to remain at home. As carers experience numerous varying needs along the care trajectory, the challenge is to find accessible and suitable supports for them in order to meet their needs. To enable people to remain living at home for as long as possible and maintain the best possible quality of life for them, informal carers need appropriate and meaningful supports to successfully conduct their caring role.

Traditionally, practical tools to assess carer support needs have been lacking. Testing the assessment form across the five main care groups contributes to the growing body of evidence on the assessment of informal carer needs, with a view to providing pertinent supports to carers.





## 5.2 Profile of Carers

The profile of carers that completed the assessment form align with expectations based on our knowledge of carer profiles generally in Ireland, in that the majority are female (75%) and reside with the care recipient (83%), with an average age of 58 (range 26 – 86). Similarly, the most recent Census of Population of Ireland (Census 2022) evidenced that 61% of carers are female, and people aged between 50 and 59 years are the group most likely to be providing regular unpaid care (CSO, 2023). Significant amounts of the carers time is spent on caring (81% spend 35 hours or more per week caring), this is a cause of stress and burden as it allows little time for other activities, with many carers reporting they struggle to make enough money to live or couple their caring role with managing a job. This is in line with findings from Census 2022 which found 29% of people provide care for 43 hours or more per week, a 111% increase on the 2016 census (CSO, 2023).<sup>15</sup> Research has shown that significant risk factors for caregiver burden are, female sex, residence with the care recipient, and higher number of hours spent caregiving (Cartaxo et al, 2023; Zaalberg et al, 2023; Adelman et al, 2014; Kim et al, 2011) which are factors of concern for our carer cohort based on their demographic profile.

Despite the benefits that working or attending courses outside of the home can have for carer's health, social connections, and financial stability, just 4% of carers in this category were in education and this was for less than 7 hours per week, and 13% were in paid work outside of the home for 35 hours or more per week. In addition to the monetary benefits of working outside the home, there are social and well-being advantages also. While this programme did not collect the employment status of the family carer prior to commencing the caring role, we are aware from conversations with carers when completing the assessment form and informal feedback from referrers, that some family carers have taken early retirement to fulfil caring duties. In some instances, carers took carers leave, gave up work or reduced their hours and commenced social welfare payments such as Carer's Benefit or Carer's Allowance. Others had taken on the role, as they were the only member of their family available to do so, while others did not want or financially could not afford for their family member to go into a nursing home.

Informal caring is associated with a significant reduction in employment and hours of work, especially for people providing high intensity caring, and can also lead to absenteeism, irregular attendance (arriving late and having to leave work) and lack of concentration at work (Gautun and Hagen, 2007). In this context, the 24 hour responsibilities of carers contrast with the improvements over recent years in employment legislation setting limits on working-hours of people in paid employment (Social Justice Ireland, 2023). Forty-three percent of carers in the pilot programme were also in paid work (40% at follow-up). In Census 2022, 57% of unpaid carers (aged over 15) were at work, up from 51% in 2016 (CSO, 2023). Policies which reduce the dual pressure from work and care for employed carers has the potential to improve their employability, making caring a viable option for more potential carers. There needs to be more supportive working environments that offer

<sup>15</sup> It should be noted that there were a number of changes to the question on unpaid carers on the 2022 census form which may affect comparability with the previous census.

flexible working arrangements to family carers and this in turn will lead to more employment options and higher retention within the workforce, especially as carers who retain a working identity often respond better to the demands of caring (Stiell et al, 2006).

People are living longer with the majority living at home which is preferable for most care recipients and carers, however, the implication of this success is that families are likely providing care for longer and in certain situations this can be challenging as the family carer may be a sibling carer (6% at both time points), a compound carer (35% at baseline; 26% at follow-up) or a sandwich carer (19% at baseline and 16% at follow-up). These caring cohorts are important when planning carer needs assessments as they have been shown to have poorer health and well-being (Wang et al, 2022; Officer for National Statistics UK, 2019).



### 5.3 Health and well-being

The health indicators for the carers included in this study identify poor sleep quality and high stress levels as concerns. Just under a half of carers in this pilot programme experienced problems with sleep in the last three days, and one-third had this problem daily. Ninety-three percent of carers were stressed to some degree, with one-fifth reporting they were stressed and needed to reduce the care they provide, and a further 10% indicated they were stressed to the point of crisis and would stop providing care. These are shorter-term health indicators that may lead to longer-term chronic conditions with the potential to negatively impact mental health and general well-being if not addressed.

Health indicators such as memory and cognition, social participation, function/endurance/



stamina, mood and major life stresses, general health and quality of life were also recorded. It is worth noting that while the longer-term health indicators are not a cause for concern in this sample, i.e. self-reported general health, memory and cognition and function, endurance and stamina, the shorter-term health indicators were not as positive. Mood, social participation and major life stressors are all issues of concern when addressing the health and well-being of the family carers captured in the pilot programme. If appropriate supports are not provided for carers, there is a risk that in time the trend observed here in the short-term health and well-being indicators will negatively impact these longer-term indicators which are risk factors for more serious health impairment. This highlights further the importance of health professionals addressing the needs of carers early in the caregiving journey, and in undertaking repeated carer needs assessments at various stages of the caring role, and not merely at the crisis stage for carers.

## 5.4 Carers Needs

The age and medical condition of a loved one can have a significant impact on the requirements of the caregiving role. Generally as people age, or depending on their medical condition, they may require more assistance with daily activities such as bathing, dressing, eating and other tasks related to their health and well-being, which can have emotional and physical implications for the family carer. The impact of this on the family carer will vary depending on a number of factors such as the health status of the care recipient, the availability of other support systems and the carer's own resources and resilience.

Carer needs can be broadly classified into two types: direct (support the carer may need for themselves) and enabling (support the carer may need to enable them to care) (Ewing and Grande, 2013). Both types of needs are assessed in the interRAI assessment form.

The highest demanded services for care recipients across both periods, regardless of an increase in provision, were day or night care services outside of the home (respite, day care), physical rehabilitation (physical and OT), assistance with personal care, and mental health services (social work, psychology). Assistance with personal care for the care recipient was requested by 44% of carers at baseline, all received this service in the intervening period, of which 48% had this need partially met and for 52% this need was fully met. However, at follow-up, almost one-third indicated that they still required this support. This suggests to some degree that the extent of assistance provided was insufficient to meet the need, with inadequate support hours provided. This shortage in homecare is likely indicative of the ongoing personnel constraints in the homecare sector.

Carers and referrers also expressed their particular frustration with the number of home support service hours approved for the care recipient. In some instances a less than optimal number of care hours were allocated despite the referrer and the carer relaying concerns over caregiver burden, owing to the carers age, own medical conditions, sleep disturbance at night, and lack of other informal caring supports, and they felt that these carer factors were not reflected in the hours allocated. Similar findings have been evidenced in other recent Irish research, with almost one-quarter of carers in a survey by Family Carers Ireland



experiencing a delay or reduction in the delivery of home support hours due to a shortage of homecare workers. Over one-third of those on a waiting list for homecare supports or a homecare package said they were waiting over two years for the service (Family Carers Ireland, 2022).

Persistently across both periods, the highest service demand for carers was respite, by way of episodic relief from caregiving. Two-thirds of carers requested respite at baseline, this was provided to just over half (54%) of carers in the intervening period, of which just over half (55%) of those had this need partially met and for 45% this need was fully met. However, over half (56%) still had this need at follow-up. This could be partially attributed to the reduction in respite since the start of the COVID-19 pandemic and the fact that respite has not fully resumed for many who had access to it prior to the pandemic. There is strong evidence that respite is one of the most effective strategies to maintain carer well-being and sustain the informal caring role (Stirling et al, 2014; Lund et al, 2009; Parahoo et al, 2002). The lack of respite, or more specifically the need for sufficient supports to enable the carer to take a break from caring, consistently remains to be a very evident, concerning and ongoing issue for family carers. Similarly to this pilot programme, in 2022, a survey by Family Carers Ireland found that almost three-quarters of carers experienced barriers to accessing respite, namely due to a lack of availability, with two in three carers stating that they had never received respite (Family Carers Ireland, 2022).

At follow-up, there was significantly less demand for counselling for carers, a carer support group and financial or legal advice. These are positive findings and reflects the immense follow-up efforts of referrers/health and social care professionals, the HSE and voluntary agencies in providing 94% of carers with a carer support group, 81% of carers with psychological counselling and almost two-thirds (62%) with financial or legal advice, in the intervening six-month period.

Effective implementation of an evidenced informed and caregiver led tool represents a necessary step forward. This will help care providers better assess and address carers needs, and ultimately reduce or prevent caregiver burden and stress, through the provision of adequate supports and services.

## 5.5 Adaptations of FCNA Form for specific care groups

When determining if adaptations are required to the assessment form, there are a number of factors to consider: validity (does it capture what it needs to assess); reliability (consistency in producing outcomes); fairness (assessed on a level playing field); and accessibility (accessible to all participants). Others include, scoring and interpretation (are the scoring criteria clear and consistent), practicality (is the assessment form feasible to administer), does it align with objectives of the evaluation, and feedback and improvement (from relevant stakeholders) (Oyebode et al., 2003; Wang et al., 2020; Brown & Brown, 2014).

To identify if adaptations were required to the assessment form, opportunities were provided to both the family carers and referrers to facilitate this process. Carers completed an additional feedback questionnaire at baseline, which inquired about how well the assessment form captured important information, whether the questions were appropriate for their care cohort/care recipient, and whether pertinent information was missing. Carers could also provide written feedback on the questionnaire and the assessment form and verbal feedback to the Project Office. Referrers in turn were asked to complete a referrer's survey and attend focus groups.

While it is important that the assessment form captures necessary and relevant information, having an assessment form that is time consuming and difficult to complete can be unappealing to carers. As evidenced in chapter 4, 59% of carers took longer than 30 minutes to complete the assessment form with many requiring assistance from the referrer. The majority of the referrers noted that they found it difficult to complete, confusing and repetitive.

This is further evidenced by the fact that all family carers who completed the assessment form were contacted by the Project Office due to various issues with the completed forms returned. In many instances, sections of the assessment form were not fully completed and very often where completed, information had to be clarified especially where more than one service was listed on the same line (e.g. Section G. Supports Needed and Received).

The usefulness of the information collated from the assessment form, was determined by surveying referrers. Of 31 respondents, 94% indicated that they felt that the information generated was either somewhat or very useful. It is important to highlight that 35% of carers at baseline were caring for more than one person. The assessment form only assesses needs based on caring for one person. It is pertinent to note that some enabling needs in particular may be different for the carer depending on which care recipient they are caring for.



Many participants found the ‘last three days’ time period did not encompass the fluctuating periods of negative and positive caring experiences. Furthermore, some questions related to the last three days, and others, the last 90 days or the last 14 days, and some questions had no time period stated, which some family carers and professionals found confusing. However this is standard interRAI “look back” period assessment methodology and often both assessors and clients need time to adjust to assessment processes. Overall, referrers experience of completing the assessment form was that the family carer found it confusing and they felt it was unclear whether questions related to them or to the care recipient. Other comments included that the form was long, cumbersome, repetitive, did not flow well, and was not user-friendly.

## 5.6 Referral pathways

In this pilot programme, referrers from various disciplines in the HSE and voluntary agencies, including nursing and social work, identified and recruited carers from within their existing caseloads to participate in the pilot programme, and assisted carers to complete the assessment form where necessary.

While the pilot programme has shown that many health and social care professionals indicated that they already assess carers needs as part of their current client caseloads, however, in the absence of a standardised carer needs assessment, carer assessments may still occur but risk taking the form of ‘doorstep conversations’ (Ewing and Grande, 2013). Furthermore, the process of systematic assessment ensures that carers are identified and recognised, and acknowledges the carers own right and entitlement to access supports, to have their own needs documented and for responsive actions to be taken to meet those needs (Thomsen et al, 2017; Aoun et al, 2015).





The findings from the referrers survey and the focus groups suggest that professionals felt that the assessment form provided new information on the carers needs and gave them a better understanding of the impact of the caring role on carers health and well-being. However, professionals also indicated that facilitating the completion of the assessment form and responding to reported needs and arranging supports was very time consuming, given their arduous and extensive client caseloads. Further exploration and consideration is required regarding who should administer carer needs assessments and where is most appropriate for them to be conducted.

## 5.7 Implications of findings for research, policy and practice

This pilot provides important information on family carers in Ireland and findings suggest that while many family carers adapt to the caregiving role and responsibilities, this may harm their own health, well-being and social participation. There needs to be greater efforts, for example earlier engagement, to support carers who find themselves struggling and adapting with the pressures of the caregiving role and managing their caregiving responsibilities. This should help prevent crises arising for the family carer.

There is a need for policies that promote greater social participation for carers, create opportunities and develop peer and social networks to enable carers to engage in activities outside of their caring role in order to address the distressing decrease in social participation experienced by many carers. To ensure the sustainability of family caring, state-provided home support must also be available to facilitate and support carers to retain their work and leisure in addition to their caring responsibilities (McGarrigle and Kenny, 2020). Respite is a key prerequisite however to enable carers to engage socially, especially full-time family carers, who may not have alternative informal caring support structures available.

Gaps in service provision exist and must be addressed, while family carers indicate that they were in receipt of some services there are notable gaps. There are unmet needs in areas such as emergency respite, in-home respite, residential respite, day care, physical and occupational therapy, and assistance with personal care. In order for family carers to be supported in the best possible way, these services need a greater allocation of resources within the HSE and voluntary agencies, so that people in need of care and their families do not have to do without essential supports. Some of the care groups place a great importance in maintaining routines for individuals and providing care in a consistent manner. Therefore in-home supports and services would be more beneficial to the family carer so as to prevent disruption to the care recipient's routine. Feedback received during the pilot programme from family carers indicated that the disruption to the care recipient's routine during a respite break was so disturbing to the cared for person that it was not worth the stress of them taking the break in the first place. The best outcomes for services is that they would be timely, responsive, flexible and tailored to the care recipient's needs.



With the publication of the National Carers Strategy, the Irish Government have recognised the significant role of the family carer. Demographic changes, coupled with an ageing society and the change to family structures, i.e. smaller families, signal that it is important that the caring responsibility is not just the family alone, but should include the remit of social care and health care and indeed wider society. The development of supports and services for the family carer needs to have a multi-disciplinary approach. This will require an evidence-informed, dynamic response which will address the changing needs of family carers and the care recipient in tandem as they age.

## 5.8 Strengths

It is important to note that there are many firsts with this pilot programme. This is the first time this version of the assessment form was tested in Ireland (two previous pilot studies tested a former version of the assessment form in Ireland). It is also the first time the assessment form was tested worldwide using a longitudinal component, and the first time the assessment form was tested worldwide across five distinct care groups. It is also the first time the assessment form was tested worldwide using health and social care professionals from statutory and voluntary agencies as referrers.

The pilot has found important evidence from the perspective of the referrers regarding their perceived role in carer needs assessments, which has implications for policy and practice, and important evidence has been identified in respect of adaptations to be made to the assessment form from the perspective of carers and professionals.

The evidence highlighting gaps in service provision has a crucial role in shaping future policies and in informing funding priorities. By identifying these gaps, policy makers can gain insights into areas where current services fall short of meeting the needs of the population. This evidence underscores the urgency and importance of addressing these gaps, prompting policy makers to develop target strategies and allocate resources to bridge them. The relevance of this evidence lies in its ability to drive informed decision-making, and ensure that policies are tailored to effectively address challenges for family carers. Furthermore, the evidence provides a basis for advocating for increased funding, as it highlights tangible influences that investing in these areas can have on improving overall service delivery and the well-being of the people in the community.

This is further evidenced with information relating to the age cohort of family carers and care recipients, and provides information for service planning in the future to anticipate needs of this target population. Data gathered around contingency planning, identifies the need to focus on emphasising this type of planning for carers who do not have it in place. In Ireland, Cronin and McGilloway (2022) postulated an urgent requirement for the assessment of carer needs, particularly around carers capacity to care.

## 5.9 Limitations

As we look at the analysis of the pilot programme, it is essential to acknowledge the limitations that may impact our understanding and evaluation. Identifying these limitations is crucial to ensure a balanced perspective and to interpret the findings accurately. Here we will discuss the specific constraints, challenges and potential areas where there may be limitations. By recognising and addressing them, it will provide a more comprehensive view and make informed recommendations for improvement.

When we commenced this programme, initially it had aimed to recruit 100 family carers across five care groups. At baseline, we recruited 89 participants and had a drop-out rate of 30% achieving a sample size of 62 participants at follow-up. It was difficult to recruit participants due to a number of factors outlined in Chapter 1 including (a) the amount of literature involved, (b) the family carer already being under stress and overburdened in the caring role, and (c) the family carer not willing to participate as the programme was conducted without additional resources and within existing prioritisation systems.

Family carers engaged in this pilot programme were invited to participate primarily by health and social care professionals, thus implying they are known to health services. This likely introduces selection bias to our sample as family carers that are not known to healthcare services are predominantly not represented in our sample and may have different characteristics and needs than those included here. Additionally, some carers that were invited to participate declined as they felt there is an extreme deficit of services in their locality, therefore carers with higher health service need may not be fully represented in our sample. As a result of this selection bias, it is probable that our service need estimations may be an under-representation of the true demand for health services in CHW.

Another limitation of this pilot programme was the number of participants in the care groups. The scope of this pilot allowed for recruitment of 20 carers in each of the five care groups. This was achieved in two of the care groups, two further groups almost reached their target numbers. The Adult Mental Health care group had fewer numbers than anticipated, due in part to there being fewer family carers involved as many care recipients were self-managing their condition. The numbers participating in the programme were small, therefore it was difficult to generate meaningful analysis between the care groups. The recruitment of participants for the pilot programme was undertaken during the COVID-19 pandemic and referrers were prioritising cases with greater needs and this limited their access to recruit family carers.

While the assessment form itself is a self-report tool, there is a risk of response bias where the carer could under or over report on the questions asked, particularly if the carer believes that this may make them more likely to receive additional supports. Also the assessment form does not capture that the family carer may be looking after more than one care recipient and this in turn would not capture the needs and supports in totality. Some family carers may have an informal caring support network, such as from other family members, which would be important for the future to understand the differences in carers needs depending on the involvement from others in the caregiving role.

## 5.10 Recommendations

As we conclude this report and our comprehensive analysis, it is evident that there are key opportunities to provide actionable recommendations to influence the strengths identified and address the limitations we have noted above. By implementing these suggestions, the assessment form can capitalise on its advantages and navigate the challenges that lie ahead with its potential implementation.

### 1. Changes need to be made to the interRAI Assessment Form

The assessment form in its current format needs to be amended as it is too long, cumbersome, repetitive and is not user-friendly, the multiple choice options are confusing, it is unclear if some questions relate to the family carer or the care recipient, the various time-periods attributed to many questions is confusing, the 'last 3 days' time period does not encompass fluctuating experiences, the amalgamation of some services in the supports needed question is ambiguous, and the assessment form does not capture the needs of carers caring for more than one person. All of which may deter a family carer from accurately completing the assessment form in whole or in part.

Furthermore, the data collected regarding services for the carer and care recipient do not capture carer preferences for services. A carer may indicate that they wish to avail of all services listed but have a greater need for one over the other in the immediate term, and this is not evident from the data collected in the current version of the assessment form.

A digital version of a refined assessment form is advisable. Once the interRAI SCan



(formerly interRAI FCNA) is finalised, it will be digitised into the interRAI Ireland system. Once finalised, the information provided by the assessment form could be used by health and social care professionals to make informed decisions around services and care plans and will provide a more holistic view of family carer circumstances.

## **2. Carers (and health and social care professionals) need an assurance that the services and support needs identified in a Carer Needs Assessment will be available and provided**

This should include direct supports for the carer themselves and enabling supports to enable carers to care, including, respite, information, training, carer support groups, counselling, physical rehabilitation (physical and OT), assistance with personal care, day care, and mental health services (social work and psychology).

Health and social care professionals need to be supported to identify carers early, which could then be followed up with an identification of the supports and services that carers require. Integral to this is assisting carers to make contingency plans in the event that they are unable to provide care in the future. This is particularly concerning for older parents caring for adult children. Health and social care professionals need to be provided with the



necessary resources to enable them to assess and address carer's needs.

### 3. Carers need access to high quality, diversified and flexible Respite

Respite or more specifically the need to take a break from caring, is the most effective strategy to maintain carer well-being and sustain the informal caring role. Respite is the single most important need of carers, however the lack of respite consistently remains an ongoing and concerning issue for most carers. Taking regular breaks is a necessary and effective way for carers to self-care, avoid burnout and invest in other areas of their life.

Efforts to address this paucity in respite services needs to be urgently actioned. A menu of high quality, diversified and flexible respite, including, emergency respite, in-home respite, residential respite and day care, that is age appropriate and suitable for the care recipient's needs and interests is of paramount importance.

## 5.11 Conclusion

Family carers providing informal care in the care recipient's home is both cost effective and allows the care recipient to remain in familiar surroundings with people that they know and trust. Family carers have been referred to in the literature as a "shadow workforce" constituting an all too often unseen, unsupported, untrained and unrecognised cohort. To future-proof the sustainment of informal caring and the continuing supply of family carers, it is essential that the requisite supports and services for family carers are provided. The caring role itself is an onerous one which can impact immensely on family carers socially, financially, psychologically, physically, and emotionally.





This pilot programme has offered a greater insight of the role and needs of family carers, which will help inform policies and services to address the paucity in appropriate supports to meet the needs of families now and into the future. Testing the implementation of this interRAI assessment form, reveals a multi-faceted landscape where strengths and limitations co-exist. While we have acknowledged the limitations, the recommendations are aimed at capitalizing on the strengths while mitigating the impact of the limitations.

In most countries, including Ireland, family carers provide the bulk of care, and the estimated economic value significantly exceeds expenditure on formal care. A continuation and expansion of informal caring is essential, given future demographic and cost pressures facing long-term care systems across the OECD. This is also what care recipients themselves prefer. Continuing to seek ways to support and maintain family carers appears therefore a potentially mutually beneficial approach, for the care recipients, the family carers and for the public services.

Family carers are hidden patients themselves and we need to have a collaborative and supportive structure that addresses and emphasises their integral role, and it is of fundamental importance that policies, service providers and health and social care professionals continue to recognise the important role that family carers play in the provision of home care, and that varied and flexible support services for family carers are appropriately resourced and are easily accessible to ensure informal caring can be sustained and be valued by all.

Without family carers our health system would be significantly adversely impacted. It is important that all sectors of society are cognisant of this and consider the potential impact on this vital sector of our population when developing and implementing policies and services.



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# Appendices

## Appendix 1 - Ethical Approval



Ospidéal na h-Ollscoile, Gaillimh  
University Hospital Galway  
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee  
Room 59  
1<sup>st</sup> Floor  
HR Building  
Merlin Park Hospital  
Galway.

20<sup>th</sup> January, 2022.

Ms. Michelle Harrison  
Coordinator  
Care Department  
25 Newcastle Road  
Galway.

*Ref: C.A. 2728      interRAI Family Carers Needs Assessment Pilot Programme in  
Community Health West September 2021 to September 2023*

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Dear Ms. Harrison,

The Clinical Research Ethics Committee approved and ratified the above submission at its meeting on Wednesday 19<sup>th</sup> January, 2022.

The date of this letter is the date of authorization of the study.

Please keep a copy of this signed approval letter in your study master file for audit purposes. The study must be carried out in accordance with General Data Protection Regulation and Health Research Regulation 2018.

You should note that ethical approval will lapse if you do not adhere to the following conditions:

1. Submission of an Annual Progress Report/Annual Renewal Survey (due annually from the date of this approval letter). **We would encourage you to keep note of this date as the CREC will not issue a reminder.**
2. Report unexpected adverse events, serious adverse events or any event that may affect ethical acceptability of the study.

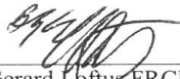
Ospidéal na h-Ollscoile, Gaillimh, UNIVERSITY HOSPITAL GALWAY,  
Galway, Ireland.



3. Submit any change to study documentation (minor or major) to CREC for review and approval. Amendments must be submitted on an amendment application form and revised study documents must clearly highlight the changes and contain a new version number and date. Amendments cannot be implemented without written approval from CREC.
4. Notify CREC of discontinuation of the study
5. Submit an End of Trial Declaration Form and Final Study Report/Study Synopsis when the study has been completed.

***This application has been reviewed from an Ethical perspective. It remains the responsibility of the Principal Investigator to ensure that data processes are compliant with National Data Protection Regulations and local policies.***

Yours sincerely,



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B. Gerard Loftus FRCPI, MD  
Emeritus Professor of Paediatrics, NUI, Galway  
Chair, Galway Clinical Research Ethics Committee.

c.c. Ms. Geraldine Collins, Project Manager, Care Department, 25 Newcastle Road  
Galway.



Ospidéal na h-Ollscoile, Páirc Mheirlinne  
Merlin Park University Hospital  
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee  
Room 59  
1<sup>st</sup> Floor  
HR Building  
Merlin Park Hospital  
Galway.

8<sup>th</sup> June, 2022.

Ms. Michelle Harrison  
Coordinator  
Care Department  
25 Newcastle Road  
Galway.

**Ref: C.A. 2728**     *interRAI Family Carers Needs Assessment Pilot Programme in  
Community Health West September 2021 to September 2023  
Amendment Submitted 31<sup>st</sup> May, 2022 – Compliance with Item No.3  
Amendment to ACS*

Dear Ms. Harrison,

I have considered and reviewed the above amendment and I wish to confirm that I am happy to grant Chairman's approval to proceed.

*Chairman's approval is normally ratified at the next Clinical Research Ethics Committee meeting. If any issues with your application are identified at the meeting we will contact you again*

Yours sincerely,

B. Gerard Loftus FRCPI, MD  
Emeritus Professor of Paediatrics, NUI, Galway  
Chair, Galway Clinical Research Ethics Committee.

c.c. Ms. Geraldine Collins, Project Manager, Care Department, 25 Newcastle Road  
Galway.

Ospidéal na h-Ollscoile, Páirc Mheirlinne, MERLIN PARK UNIVERSITY HOSPITAL,  
Galway, Ireland. Tel: 00 353 (0)91 757631



Ospidéal na h-Ollscoile, Páirc Mheirlinne  
Merlin Park University Hospital  
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee  
Room 59  
1<sup>st</sup> Floor  
HR Building  
Merlin Park Hospital  
Galway.

19<sup>th</sup> July, 2022.

Ms. Michelle Harrison  
Coordinator  
Care Department  
25 Newcastle Road  
Galway.

**Ref: C.A. 2728**      ***interRAI Family Carers Needs Assessment Pilot Programme in  
Community Health West September 2021 to September 2023  
Amendment Submitted 18<sup>th</sup> July, 2022 – Additional Questionnaire***

Dear Ms. Harrison,

I have considered and reviewed the above amendment and I wish to confirm that I am happy to grant Chairman's approval to proceed.

*Chairman's approval is normally ratified at the next Clinical Research Ethics Committee meeting. If any issues with your application are identified at the meeting we will contact you again*

Yours sincerely,

B. Gerard Loftus FRCPI, MD  
Emeritus Professor of Paediatrics, NUI Galway  
Chair, Galway Clinical Research Ethics Committee.

c.c. Ms. Geraldine Collins, Project Manager, Care Department, 25 Newcastle Road  
Galway.

Ospidéal na h-Ollscoile, Páirc Mheirlinne, MERLIN PARK UNIVERSITY HOSPITAL,  
Galway, Ireland. Tel: 00 353 (0)91 757631

## Appendix 2 - Project Information Leaflets



*'This project was approved by Government with support from the Dormant Accounts Fund'*



### Project Information Leaflet – Family Carer

**Title: interRAI Family Carer Needs Assessment Pilot Programme in Community Healthcare West.**

#### **Invitation**

You are being invited to take part in a pilot programme - a pilot is essentially a test. We are testing the use of a new assessment form for family carers in Counties Galway, Mayo and Roscommon. Before you decide, it is important for you to understand why the pilot programme is being done and what it will involve. This information leaflet will tell you about the purpose, risks and benefits of this pilot. If you agree to take part, we will ask you to sign a consent form. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only consent to participate in this pilot programme when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

#### **Who is doing the pilot programme?**

The pilot programme is being done by a team of professionals from the HSE in an area of the HSE called Community Healthcare West, which covers Counties Galway, Mayo and Roscommon. We got some funding from Government under the Dormant Accounts Fund, to do this pilot programme, and we must report back to this department regularly on our progress. A Steering Group made up of experienced Managers, health professionals and family carers will oversee the pilot programme. Some members of the team are for example qualified nurses and social workers.

#### **Purpose of the pilot programme**

You have been asked to participate as you are a family carer looking after an older person, a person with dementia, a person with a disability (this could be a physical and sensory disability or an intellectual disability), or a person with mental health.

The aim or purpose of this pilot programme is to test the use of an assessment form, called 'interRAI Family Carer Needs Assessment', which has never been used in Ireland before. The assessment form is used to help identify what your needs are as a carer. It also looks at your role as a family carer, how it affects you, and how much care you can realistically provide, while still allowing you to be involved in other activities, and the assessment should also help identify what types of help or support you may need.



**Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

**How do I take part?**

If you wish to take part you will be given this information leaflet to keep and asked to sign a consent form by a professional who knows you and the person you care for well, such as a public health nurse or social worker. This professional will return your consent form to me. I have asked for your contact telephone number on the consent form so I can contact you about the pilot programme and the carer assessment.

**What will happen to me if I take part?**

If you choose to take part, the professional who gave you this information leaflet and the consent form (the Referrer), will then give you the Assessment Form, which is called 'interRAI Family Carer Needs Assessment'. This form might take approximately 30 minutes for you to complete, so you can complete it in your own time, which doesn't have to be all at once. If you feel you might need some help filling up the form, the professional such as the social worker who gave you the form, will either help you to complete it, or they will leave the form with you and will contact me, and I will then arrange to meet with you to complete the form or we can do this over the phone.

When the form is completed, I will then go through it with the Referrer and any of the needs you have identified in the form, we will follow up on, and we will discuss these needs with the various health professionals supporting you, to try to meet some or all of these needs where possible and from within existing resources. A copy of the completed form will be given to the professional who identified you in the first place (the Referrer), such as the social worker or public health nurse, and the form will also be given to other professionals such as the home support/home help service or disability services etc. Your completed assessment form may also be brought by the Referrer to multidisciplinary team meetings to discuss your caring needs and the needs of the person you are caring for with the other professionals present. The reason for this is so these health professionals will use what you have said in the assessment form to help them make decisions on services being delivered to support you and the person you are caring for.

Six months later, the health professional who gave you the form or me will contact you and will ask you to complete the assessment form one last time. The reason for this is that we want to see if we were able to provide you with any of the supports/services you had asked for the first time you filled it out, or if your health and wellbeing had changed in any way since the first time you completed it.

We will also ask you to complete an additional short form called a questionnaire, with some questions about how long it took you to complete the assessment form, whether the questions were appropriate and if the assessment form missed some important information. Again you can complete this questionnaire in your own time by yourself or I will complete it with you over the phone or in person, whichever you would prefer.

**How long will my part in the pilot programme last?**

You will be asked to complete the Assessment Form two times, the form will take approximately 30 minutes to complete each time you complete it. You will complete the form for the second time about 6 months after the first time.

The additional short form/ questionnaire will take about 5-10 minutes to complete and you complete that form once.

**What do I have to do before the pilot programme?**

There are no special requirements/ restrictions prior to taking part.

### **What are the benefits of taking part?**

Taking part in this pilot programme will provide valuable information on family carers' experiences and needs in caring at home for an older person, a person with dementia, a person with a disability or with mental health. It will allow us to understand carers needs better, and to follow up where possible on some of the services and supports you felt you needed. It will show us in the HSE what supports and services we possibly could not put in place that you may have requested and this will then be highlighted in the final report, which will be given to the Department of Health. This type of Carer Assessment has never been done in Ireland before, so we hope to learn a lot from testing it in our area.

### **What are the possible disadvantages/risks of taking part?**

Any needs you have reported in the assessment form will have to be provided, where possible, from within existing resources. Therefore, some (or all) supports you have asked for may not be able to be provided to you or to the care recipient, which you may find upsetting. Also, the assessment form asks you some questions about your own health and wellbeing, such as about your mood, memory, pain, and about your quality of life and the challenges you face in caring. You may become upset while completing it. If this should happen when a professional is helping you complete the form such as a social worker, the completion of the form will be immediately stopped and will only recommence if you are happy to do so. If you are filling the form out by yourself and this should happen, please contact me.

### **What happens at the end of the pilot programme?**

Each time you complete and return the form to me, I will fill in all of your answers on my computer- your name will not be put beside these answers on the computer so as to protect your identity. I may give this information to another colleague outside of my department or to a private organisation to help me with analyzing the results- again your name will not be given so there is no way of tracing the answers back to you. Because we are using an assessment form which is copyright to an organisation called interRAI, we will need to give your answers to them also- but again there will be no way of them knowing that the answers belong to you. The reason for this is that interRAI are testing this assessment form in other countries such as Canada and they want to compare the needs and other information from the assessment with what was found in other countries. Your answers will therefore be included in this international study of the assessment form being undertaken by this interRAI organisation. After two years I will write up a report on the pilot programme and I will give this to the Department of Health. I may also publish some research articles about this pilot programme and no answers will be traced back to you or to any of the other carers taking part. Essentially, you and your care recipient's personal details will be de-identified.

### **What happens if I change my mind during the pilot programme?**

If at any time you wish to withdraw your participation from this pilot programme you may do so, if this is following the completion of one or both assessment forms that you have completed, they will be confidentially destroyed and will not be included. Please note that once the final programme report is published you cannot withdraw your consent however.

### **What if I have a complaint during my participation in the pilot programme?**

If you have any concerns about this pilot programme and wish to contact someone independent and in confidence, you may contact the Chairperson of the local Clinical Research Ethics Committee- Professor Brendan Loftus, as follows: Contact, The Administrator Clinical Research Ethics Committee, Room 2, 2nd Floor, HR Building Merlin Park Hospital, Galway. Tel: 091 775022 (Tuesday-Friday- 8.00 a.m. - 1.00p.m.). I applied for and was granted ethical permission from this Committee before contacting you to take part.

Many thanks for taking the time to read this. If you have any further concerns or queries please contact me:

**Geraldine Collins**

**Project Manager**

**interRAI Family Carer Needs Assessment Pilot Programme, Community Healthcare West.**

**Telephone:**

**Email:**



*'This project was approved by Government with support from the Dormant Accounts Fund'*



## **Project Information Leaflet – Care Recipient**

**Title: interRAI Family Carer Needs Assessment Pilot Programme in Community Healthcare West.**

### **Invitation**

Your Family Carer is being invited to take part in a pilot programme - a pilot is essentially a test. We are testing the use of a new assessment form for family carers in Counties Galway, Mayo and Roscommon. Because we will be asking your Family Carer about their caring role and for some personal information about you - whom they are caring for, such as, for your name, your date of birth and your gender, it is important that we also explain the pilot programme to you and ask you for your consent. **You are therefore consenting for your personal information (your name, date of birth, gender) to be given to us by your family carer. You will not be asked to take part in the pilot programme, only your family carer will be taking part.** Before you decide, it is important for you to understand why the pilot programme is being done and what it will involve. This information leaflet will tell you about the purpose, risks and benefits of this pilot. If your family carer agrees to take part, we will ask you to sign a consent form also. If there is anything you are not clear about, we will be happy to explain it to you. Please take as much time as you need to read it. You should only give your consent when you feel that you understand what is being asked of you, and you have had enough time to think about your decision. Thank you for reading this.

### **Who is doing the pilot programme?**

The pilot programme is being done by a team of professionals from the HSE in an area of the HSE called Community Healthcare West, which covers Counties Galway, Mayo and Roscommon. We got some funding from Government under the Dormant Accounts Fund, to do this pilot programme, and we must report back to this department regularly on our progress. A Steering Group made up of experienced Managers, health professionals and family carers will oversee the pilot programme. Some members of the team are for example qualified nurses and social workers.

### **Purpose of the pilot programme**

Your family carer has been asked to participate as they are either looking after an older person, a person with dementia, a person with a disability (this could be a physical and sensory disability or an intellectual disability), or a person with mental health. The aim or purpose of this pilot programme is to test the use of an assessment form, called 'interRAI Family Carer Needs Assessment', which has never been used in Ireland before. The assessment form is used to help identify what the needs of the family carer is mostly, but also asks one question about your needs as the person receiving the care.

### **Do I have to take part?**

It is up to your family carer to decide whether or not to take part. They can only take part if you also agree to this and give your consent. If your family carer decides to take part they (and you) are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way. You as the person receiving the care, do not have to complete the assessment form, it is only your family carer who completes this form.

### **How do I take part?**

If your family carer wishes to take part, you will be given this information leaflet to keep and asked to sign a consent form by a professional who knows you and your family carer well, such as a public health nurse or social worker. This professional will return your consent form to me.

### **What will happen to me if I take part?**

If your family carer chooses to take part, and you give your consent also, the professional who gave you this information leaflet and the consent form (the Referrer), will then give your family carer the Assessment Form, which is called 'interRAI Family Carer Needs Assessment'. When the assessment form is completed by your family carer, I will then go through it with the Referrer, and any of the needs your family carer has identified in the form, we will follow up on, and we will discuss these needs with the various health professionals supporting you and your family carer, to try to meet some or all of these needs where possible and from within existing resources. A copy of the completed form will be given to the professional who identified your family carer in the first place (the Referrer), such as the social worker or public health nurse, and the form will also be given to other professionals such as the home support/home help service or disability services etc. The completed assessment form may also be brought by the Referrer to multidisciplinary team meetings to discuss your needs and your family carer's needs, with the other professionals present. The reason for this is so these health professionals will use what your family carer has said in the assessment form to help them make decisions on services being delivered to support you and your family carer.

Six months later, the health professional who gave your family carer the form or me will contact your family carer and will ask them to complete the assessment form one last time. The reason for this is that we want to see if we were able to provide you and your family carer with any of the supports/services they had asked for the first time they filled it out, or if their health and wellbeing had changed in any way since the first time they completed it.

We will also ask them to complete an additional short form called a questionnaire, with some questions about how long it took them to complete the assessment form, whether the questions were appropriate and if the assessment form missed some important information. Again they can complete this form in their own time by themselves or I will complete it with them over the phone or in person, whichever your family carer would prefer.

### **How long will my part in the pilot programme last?**

You as the care recipient will not be asked to complete any forms or questionnaires. Your family carer will be asked to complete the Assessment Form two times, the form will take approximately 30 minutes to complete each time your family carer completes it. Your family carer will complete the form for the second time about 6 months after the first time.

The additional short form/ questionnaire will take about 5-10 minutes to complete and your family carer completes that form once.

### **What do I have to do before the pilot programme?**

There are no special requirements/ restrictions prior to taking part.

### **What are the benefits of taking part?**

Taking part in this pilot programme will provide valuable information on carers' experiences and needs in caring at home for an older person, a person with dementia, a person with a disability or with mental health. It will allow us to understand carers' needs better, and to follow up where possible on some of the services and supports your carer felt they/you needed. It will show us in the HSE what supports and services we possibly could not put in place that your carer may have requested and this will then be highlighted in the final report, which will be given to the Department of Health. This type of Carer Assessment has never been done in Ireland before, so we hope to learn a lot from testing it in our area.



### **What are the possible disadvantages/risks of taking part?**

Any needs your family carer has reported in the assessment form will have to be provided, where possible, from within existing resources. Therefore, some (or all) supports your carer has asked for may not be able to be provided to you or to your carer, which they/you may find upsetting. Also, the assessment form asks your family carer some questions about their own health and wellbeing and the challenges they face in caring, which they may find upsetting. If this should happen when a professional is helping your family carer complete the form such as a social worker, the completion of the form will be immediately stopped and will only recommence if they are happy to do so. If your family carer is filling the form out by themselves and this should happen, they should contact me.

### **What happens at the end of the pilot programme?**

Each time your family carer completes and returns the form to me, I will fill in all of their answers on my computer- your family carers name (and your name) will not be put beside these answers on the computer so as to protect your identity. I may give this information to another colleague outside of my department or to a private organization to help me with analyzing the results- again you and your family carers name will not be given so there is no way of tracing the answers back to them. Because we are using an assessment form which is copyright to an organisation called interRAI, we will need to give your family carers answers to them also- but again there will be no way of them knowing that the answers belong to your family carer. The reason for this is that interRAI are testing this assessment form in other countries such as Canada and they want to compare the needs and other information from the assessment with what was found in other countries. Your family carers answers will therefore be included in this international study of the assessment form being undertaken by this interRAI organisation. After two years I will write up a report on the pilot programme and I will give this to the Department of Health. I may also publish some research articles about this pilot programme and no answers will be traced back to your family carer or to any of the other carers taking part. Essentially, you and your family carers personal details will be de-identified.

### **What happens if I change my mind during the pilot programme?**

If at any time you wish to withdraw your consent and therefore withdraw your family carers participation from this pilot programme you may do so, if this is following the completion of one or both assessment forms by your family carer, these completed forms will be confidentially destroyed and will not be included. Please note that once the final programme report is published you cannot withdraw your consent however.

### **What if I have a complaint during my participation in the pilot programme?**

If you have any concerns about this pilot programme and wish to contact someone independent and in confidence, you may contact the Chairperson of the local Clinical Research Ethics Committee-Professor Brendan Loftus, as follows: Contact, The Administrator Clinical Research Ethics Committee, Room 2, 2nd Floor, HR Building Merlin Park Hospital, Galway. Tel: 091 775022 (Tuesday-Friday- 8.00 a.m. - 1.00p.m.). I applied for and was granted ethical permission from this Committee before contacting you to take part.

Many thanks for taking the time to read this. If you have any further concerns or queries please contact me:

**Geraldine Collins, Project Manager,**

**interRAI Family Carer Needs Assessment Pilot Programme, Community Healthcare West.**

**Telephone:**

**Email:**

	<p><b>Project Information Leaflet</b></p>
<p><b>Family Carer Needs Assessment Project</b></p>	
	<p>We want to improve the lives of family carers and the people they care for in Ireland.</p>
	<p>We want to understand about the impact of caring on your family carer's health and wellbeing.</p>
	<p>Your family carer can help us by telling us about their story and talking with us.</p>



We want to know about your relationship with your family carer.





We want to know how your family carer takes care of you and about their needs.



We want to know about your family carer's social connections and free time.



## What Will We Do With Your Information

<p><b>Examples of what worked well:</b></p> <p>We hope to provide family carers with supports and services where possible and from within existing resources that they have asked for to help them to continue to care for you at home.</p>	
<p><b>Examples of what didn't work:</b></p> <p>We want to make sure family carers are not stressed and do not have poor health and wellbeing.</p>	

Many thanks for taking the time to read this.

If you have any further concerns or queries please contact me:

Geraldine Collins.

Project Manager,

interRAI Family Carer Needs Assessment Pilot Programme,

Community Healthcare West.

Telephone:

Email:

## Appendix 3 - Consent Forms



Participant Identification Number: \_\_\_\_\_

### CONSENT FORM

#### **interRAI Family Carer Needs Assessment**

#### **Pilot Programme in Community Healthcare West**

Project Title: interRAI Family Carer Needs Assessment Pilot Programme in CHW.

Name of Project Manager: Geraldine Collins.

I \_\_\_\_\_ [PRINT NAME] confirm that I have read the information leaflet for the above pilot programme. I hereby consent to participating in the pilot programme regarding the interRAI Family Carer Needs Assessment in Community Healthcare West.

I understand that:

1. Assessment Forms and Questionnaires will be retained for a period of seven years, after which time they will be destroyed.
2. My identity will be totally protected in any written reports or publications or research resulting from the pilot programme.
3. I am free to withdraw at any time.
4. I am aware that a decision to withdraw at any time, will not affect my rights or services in any way.
5. I am aware that there may be some/all support services that I have asked for in the assessment form that may not be able to be provided to me or to the care recipient.
6. I am aware that the completed assessment form will be shared with the Referrer and with other health professionals such as during multidisciplinary team meetings.
7. I have been given the opportunity to ask any desired questions, and all such questions have been answered to my satisfaction.

The above has been explained to me by \_\_\_\_\_

(Professional obtaining Consent to sign here stating Professional Title also)

Signed by Family Carer \_\_\_\_\_ Date \_\_\_\_\_

Family Carer's Contact Telephone Number: \_\_\_\_\_



Participant Identification Number:
------------------------------------

## CONSENT FORM

### interRAI Family Carer Needs Assessment Pilot Programme in Community Healthcare West

Project Title: interRAI Family Carer Needs Assessment Pilot Programme in CHW.

Name of Project Manager: Geraldine Collins.

I \_\_\_\_\_ [PRINT NAME] confirm that I have read the information leaflet for the above pilot programme. I hereby consent to participating in the pilot programme regarding the interRAI Family Carer Needs Assessment in Community Healthcare West.

I understand that:

1. Assessment Forms and Questionnaires will be retained for a period of seven years, after which time they will be destroyed.
2. My identity will be totally protected in any written reports or publications or research resulting from the pilot programme.
3. I am free to withdraw my consent at any time.
4. I am aware that a decision to withdraw my consent at any time, will not affect my rights or services in any way.
5. I am aware that there may be some/all support services that my family carer has asked for in the assessment form that may not be able to be provided to me or to my family carer.
6. I agree for my family carer to share my personal information for this pilot programme.
7. I am aware that the completed assessment form will be shared with the Referrer and with other health professionals such as during multidisciplinary team meetings.
8. I have been given the opportunity to ask any desired questions, and all such questions have been answered to my satisfaction.

The above has been explained to me by \_\_\_\_\_


(Professional obtaining Consent to sign here stating Professional Title also)

Signed by Care Recipient \_\_\_\_\_ Date \_\_\_\_\_






Participant ID Number: \_\_\_\_\_

**ACCESSIBLE CONSENT FORM**

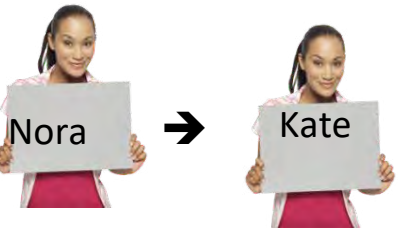




***[interRAI Family Carer Needs Assessment Pilot Programme in Community Healthcare West]***

<b>Consent Form</b>	
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**My name is:** \_\_\_\_\_

	<b>Please Tick the Yes or No Face</b>		
	I have enough information about the project.	☺ Yes	☹ No
? 	I was able to ask questions about the project.	☺ Yes	☹ No
	I understand that what my family carer says will be kept on a computer.	☺ Yes	☹ No
	I am happy for the things my family carer says to be used in the project. To writing a report or for research and telling other people so needs can be followed up on.	☺ Yes	☹ No



	<p>I understand that my name and my family carers name will <b>not be</b> used.</p>	<p>😊 Yes</p>	<p>☹️ No</p>
	<p>I understand that I am free to withdraw my consent at any time and it <b>will not</b> affect my rights or services.</p>	<p>😊 Yes</p>	<p>☹️ No</p>
	<p>I understand that other people will <b>not know</b> what my family carer said.</p>	<p>😊 Yes</p>	<p>☹️ No</p>
	<p>I understand that taking part means my family carer will be having a chat. They will answer a few questions and complete a form.</p>	<p>😊 Yes</p>	<p>☹️ No</p>
	<p>I agree for my family carer to share my personal information.</p>	<p>😊 Yes</p>	<p>☹️ No</p>



The above has been explained to me  
by \_\_\_\_\_

*(Professional obtaining Consent to sign here stating Professional Title also)*



Date \_\_\_\_\_



Sign \_\_\_\_\_

*(Signed by Care Recipient)*

## Appendix 4 - Additional Feedback Questionnaire

### Additional Feedback Questionnaire For Family Carers

*(Adapted from Stochitoui and Vadeboncoeur, 2020)*

1. Today's Date \_\_\_\_\_
2. Your Name \_\_\_\_\_
3. Your Date of Birth \_\_\_\_\_
4. How long did it take you to complete the form? \_\_\_\_\_ minutes
5. Did the form collect important information? Yes  No
6. Were there items that do not apply to your caring role? Yes  No
7. Please write out the questions asked on the Family Carer Needs Assessment form that do not apply to your caring role?

8. Were there questions that you would have liked to be asked that were not on the Family Carer Needs Assessment form? Yes  No
9. If you answered Yes to Question 8; Please write out the questions you thought were missing from the Family Carer Needs Assessment form?

**Thank You. Please return the completed form to: Geraldine Collins, Project Manager, interRAI FCNA Pilot Programme, Community Healthcare West, Carers Department, 25. Newcastle Road, Galway, H91 RW28. Telephone: Email:**

## Appendix 5 - Referrers Survey



### interRAI Family Carer Needs Assessment Pilot Programme in Community Healthcare West

Thank you for participating in the interRAI Family Carer Needs Assessment Pilot Programme in Community Healthcare West.

Family Carers provide approximately 70% of care in the community but their needs often go unrecognised. The interRAI Family Carer Needs Assessment (FCNA) form being piloted in CHW is a comprehensive approach to the identification of strengths, preferences and needs of Family Carers.

The pilot programme will provide key information for service providers and policy- makers and will ultimately contribute to increased responsiveness of the health system to Family Carers.

This pilot programme in CHW is part of a multinational research study in ten countries, including Ireland, led by interRAI Canada. The outcomes from this multinational study will allow the refinement of the Family Carer Needs Assessment form and assist future participating organisations in many countries, including Ireland, to design care plans that considers the unique challenges, strengths and needs of Family Carers.

**The aim of the pilot programme in CHW is to test the implementation of the interRAI Family Carer Needs Assessment across various care groups, including, carers of people with dementia (PwD), older people, physical and sensory disability, intellectual disability, and mental health, in Community Healthcare West.**

**One of the key objectives of the pilot programme is to assess the use of the Family Carer Needs Assessment by health professionals in their respective services. As a referrer of Family Carers to this FCNA pilot programme, your contribution has been integral, and your feedback on the Family Carer Needs Assessment form is very important to the FCNA Project Team and the FCNA Steering Group. In that context, we would very much value and appreciate your time in completing this brief questionnaire.**

If you have referred more than one Family Carer and/or supported more than one carer to complete the FCNA form, and the experience was different, please use the final text box in this questionnaire to provide some information on this.

Please note that your responses will remain anonymous and confidential. They are being returned to an independent researcher and will not be viewed by any member of the HSE.

View the [Family Carer Needs Assessment](#) form. Please complete the survey by September 12th 2022. Thank you.

\* 1. I agree to provide feedback as a referrer to the Family Carer Needs Assessment pilot programme and understand all returned questionnaires will be anonymous and confidential and returned directly to an independent researcher for data analysis.

I consent to the above and agree to participate

Yes

No

\* 2. From which Care Group(s) did you refer Family Carers? (Please tick all that apply)

People with Dementia

Older People

Physical and Sensory  
Disability

Intellectual Disability

Mental Health

3. I work mainly in:

Galway

Mayo

Roscommon

Other

(please  
specify)



4. How useful have you found the information that the Family Carer Needs Assessment generated?

I found the information:

Not at all useful	Somewhat useful	Very useful
★	★	★

5. Did you find that the Family Carer Needs Assessment form:

	To a great extent	To some extent	Not at all	Not applicable
Complemented other assessments that I use	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave me a more holistic perspective of the caring circumstances	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave me information I would otherwise not have had access to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave me a better understanding of the impact of caring on the Family Carer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave me a better understanding of the needs of the family carer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

6. Please indicate how you used the information generated from the Family Carer Needs Assessment form. (Please tick all that apply)

- To inform Multidisciplinary team meetings
- To inform care plans
- To inform service decisions
- To follow-up on supports in response to reported needs

I have not used the information yet but I intend to

Other (please specify)

7. Which sections of the Family Carer Needs Assessment form yielded the most helpful information for you as a health professional supporting Family Carers?

- 1.
- 2.
- 3.

8. Did the Family Carer:

- Receive support from you to complete the Family Carer Needs Assessment form
- Complete the Family Carer Needs Assessment form themselves
- Both - I gave support to some and others completed the Family Carer Needs Assessment form themselves

9. If you assisted the Family Carer to complete the Family Carer Needs Assessment form, how easy or difficult did you find it?

I found the Family Carer Needs Assessment form:

		Neither easy nor		
Very difficult	Difficult	difficult	Easy	Very easy

Please provide a little more detail

10. What sort of feedback (if any) did you get from Family Carers on how easy or difficult they found the Family Carer Needs Assessment form to complete?

The Family Carer found the Family Carer Needs Assessment form:

		Neither easy nor			
Very difficult	Difficult	difficult	Easy	Very easy	N/A
					<input type="radio"/>

Please provide a little detail

11. What sort of feedback (if any) did you get from Family Carers on the relevance of the Family Carer Needs Assessment questions to their caring circumstances?

The Family Carer found the questions:

		Neither relevant				
Very irrelevant	Irrelevant	nor irrelevant	Relevant	Very relevant	N/A	
★	★	★	★	★	○	

Please provide a little detail

12. Is there anything else you would like to add?

## Appendix 6 - Focus Group Schedule of Questions

- Welcome and introductions.
- Confidentiality and permissions.
- General experience of using the tool.
- The importance of assessing the needs of Family Carers.
- Usefulness and relevance of data obtained for the referrer service/service provision.
- What use did the referrers make of the information.
- Future use of the FCNA.

## Appendix 7 - Descriptive Statistics Section G: Supports Needed and Received

### Supports for the Care Recipient (Baseline)

Care Recipient Supports	Supports not received, not needed	Supports received, no additional supports needed	Supports not received, but supports needed	Supports received, but additional supports needed	Subtotal: Supports needed to some extent
Assistance with Personal Care (e.g., bathing, grooming)	27 (30%)	18 (20%)	14 (16%)	30 (34%)	44 (49%)
Assistance with Household Tasks (e.g., cleaning, laundry)	46 (52%)	7 (8%)	28 (31%)	8 (9%)	36 (40%)
Medical or Nursing Care	31 (35%)	39 (44%)	7 (8%)	12 (13%)	19 (21%)
Mental Health Services (e.g., social work, psychology)	34 (38%)	21 (24%)	11 (12%)	23 (26%)	34 (38%)
Delivered Meals	71 (80%)	8 (9%)	7 (8%)	3 (3%)	10 (11%)
Physical rehabilitation (e.g., physical or occupational therapy)	28 (31%)	18 (20%)	21 (24%)	22 (25%)	43 (48%)
Day or night care services outside of home	37 (42%)	11 (12%)	21 (24%)	20 (22%)	41 (46%)
End-of-life care	86 (97%)	2 (2%)	1 (1%)	0 (0.0%)	1 (1%)
Housing adaptation (e.g., wider doors, ramps, downstairs toilet, central heat, gas or flood detector, adaptation grants)	40 (45%)	16 (18%)	27 (30%)	6 (7%)	33 (37%)
Therapy or assistance to support communication (e.g., speech-language therapy, translation services)	64 (72%)	4 (4%)	13 (15%)	8 (9%)	21 (24%)
Aids and assistive devices (e.g., walking aid, falls alert, personal alarm, GPS wandering device hearing aid, communication board, electronic speech device)	32 (36%)	29 (33%)	24 (27%)	4 (4%)	28 (31%)
Transportation assistance	47 (53%)	17 (19%)	21 (24%)	4 (4%)	25 (28%)
Financial or legal advice	70 (79%)	5 (6%)	13 (15%)	1 (1%)	14 (16%)
Educational support, including job training	71 (80%)	5 (6%)	11 (12%)	2 (2%)	13 (15%)



**Supports for the Care Recipient (Follow-up)**

	Supports not received, not needed	Supports received, no additional supports needed	Supports not received, but supports needed	Supports received, but additional supports needed	Subtotal: Supports needed to some extent
Assistance with Personal Care	22 (35%)	20 (32%)	3 (5%)	17 (27%)	20 (32%)
Assistance with Household Tasks	37 (60%)	12 (19%)	8 (13%)	5 (8%)	13 (21%)
Medical or Nursing Care	20 (32%)	37 (60%)	1 (2%)	4 (6%)	5 (8%)
Mental Health Services	24 (39%)	20 (32%)	6 (10%)	12 (19%)	18 (29%)
Delivered Meals	51 (82%)	9 (15%)	2 (3%)	0 (0%)	2 (3%)
Physical rehabilitation	18 (29%)	27 (44%)	8 (13%)	9 (15%)	17 (27%)
Day or night care services outside of home	24 (39%)	13 (21%)	8 (13%)	17 (27%)	25 (40%)
End-of-life care	60 (97%)	2 (3%)	0 (0%)	0 (0%)	0 (0%)
Housing adaptation	34 (55%)	13 (21%)	14 (23%)	1 (2%)	15 (24%)
Therapy or assistance to support communication	44 (71%)	7 (11%)	7 (11%)	4 (6%)	11 (18%)
Aids and assistive devices	24 (39%)	28 (45%)	5 (8%)	5 (8%)	10 (16%)
Transportation assistance	37 (60%)	16 (26%)	8 (13%)	1 (2%)	9 (15%)
Financial or legal advice	52 (84%)	5 (8%)	3 (5%)	2 (3%)	5 (8%)
Educational support, including job training	51 (82%)	5 (8%)	5 (8%)	1 (2%)	6 (10%)

**Supports for the Carer (Baseline)**

	Supports not received, not needed	Supports received, no additional supports needed	Supports not received, but supports needed	Supports received, but additional supports needed	Subtotal: Supports needed to some extent
Carer support group	13 (15%)	7 (8%)	63 (71%)	6 (7%)	69 (78%)
Psychological counselling	47 (53%)	6 (7%)	29 (33%)	7 (8%)	36 (40%)
Education or advice about a specific health problem (including end-of-life care)	57 (64%)	5 (6%)	22 (25%)	5 (6%)	27 (30%)
Episodic relief from caregiving (e.g., emergency respite care)	23 (26%)	11 (12%)	41 (46%)	14 (16%)	55 (62%)
Financial or legal advice	51 (57%)	9 (10%)	26 (29%)	3 (3%)	29 (33%)
Transportation assistance	63 (71%)	6 (7%)	17 (19%)	3 (3%)	20 (22%)

**Supports for the Carer (Follow-up)**

	Supports not received, not needed	Supports received, no additional supports needed	Supports not received, but supports needed	Supports received, but additional supports needed	Subtotal: Supports needed to some extent
Carer Support Group	9 (15%)	44 (70%)	9 (15%)	0 (0%)	9 (15%)
Psychological counselling	28 (45%)	23 (37%)	3 (5%)	8 (13%)	11 (18%)
Education or advice about a specific health problem	39 (63%)	10 (16%)	11 (18%)	2 (3%)	13 (21%)
Episodic relief from caregiving	16 (26%)	11 (18%)	10 (16%)	25 (40%)	35 (56%)
Financial or legal advice	40 (65%)	14 (23%)	4 (6%)	4 (6%)	8 (13%)
Transportation assistance	53 (85%)	2 (3%)	6 (10%)	1 (2%)	7 (11%)

## Appendix 8 - Descriptive Statistics Time 1 & Time 2 Carer Health and Well-being

Table - Descriptive Statistics – Baseline (T1) &amp; Follow-up (T2) Carer Health and Well-being

<b>PROFILE OF FAMILY CARER HEALTH &amp; WELLBEING</b>	<b>Time 1 (n=89) (%)</b>	<b>Time 2 (n=62) (%)</b>
<b>Memory and Cognition</b>		
<b>Has problem with memory</b>		
Never	30	26
Rarely	34	32
Sometimes	34	37
Most of the time	1	5
Always	1	0
<b>Been easily distracted/ trouble paying attention (last 3 days)</b>		
No	55	56
Yes	45	44
<b>Social Participation</b>		
<b>Participation in social, religious work has decreased (last 90 days)</b>		
No less participation	45	58
Participated less, but was not distressed	28	27
Participated less, but was distressed	27	15
<b>Function/Endurance/Stamina</b>		
<b>Meal preparation capability (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	98	92
I would need some help from others	2	8
Others must always do this for me	0	0
<b>Ordinary housework capability (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	89	89
I would need some help from others	11	11
Others must always do this for me	0	0
<b>Managing finances capability (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	94	94
I would need some help from others	6	6
Others must always do this for me	0	0
<b>Managing medications capability (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	98	97
I would need some help from others	2	3
Others must always do this for me	0	0
<b>Shopping capability (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	96	94
I would need some help from others	4	6
Others must always do this for me	0	0
<b>Transportation capability (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	96	93
I would need some help from others	2	5
Others must always do this for me	2	2
<b>Assistance required with bathing (last 3 days)</b>		
I could do it by myself without needing someone to keep an eye on me	100	98
I would need some help from others	0	2
Carer did not bathe/shower in last 3 days	0	0
<b>Frequency carer felt so exhausted they could not carry out normal day-to-day activities</b>		
Not in last 3 days	48	60
Not in last 3 days, but often feel this way	24	13
In 1-2 of last 3 days	12	8
Daily in the last 3 days	16	19

<b>Frequency carer felt unsteady when walking</b>		
Not in last 3 days	92	82
Not in last 3 days, but often feel this way	3	11
In 1-2 of last 3 days	2	5
Daily in the last 3 days	2	2
<b>Mood</b>		
<b>Felt little interest or pleasure in things</b>		
Not in last 3 days	48	63
Not in last 3 days, but often feel that way	25	11
In 1-2 of last 3 days	12	11
Daily in the last 3 days	15	15
<b>Felt anxious, restless or uneasy</b>		
Not in last 3 days	34	47
Not in last 3 days, but often feel that way	26	19
In 1-2 of last 3 days	16	16
Daily in the last 3 days	25	18
<b>Felt sad, depressed or hopeless</b>		
Not in last 3 days	52	61
Not in last 3 days, but often feel that way	20	11
In 1-2 of last 3 days	16	16
Daily in the last 3 days	12	11
<b>Felt overwhelmed by the Care Recipient's condition</b>		
Not in last 3 days	35	35
Not in last 3 days, but often feel that way	34	16
In 1-2 of last 3 days	8	24
Daily in the last 3 days	24	24
<b>Felt unable to continue caring activities</b>		
Not in last 3 days	55	66
Not in last 3 days, but often feel that way	25	16
In 1-2 of last 3 days	13	6
Daily in the last 3 days	7	11
<b>Experienced any major life stresses (illness, death) (last 90 days)</b>		
No	67	66
Yes	33	34
<b>Health Conditions</b>		
<b>Difficulty falling/staying asleep, waking too early, non-restful sleep (last 3 days)</b>		
Not in last 3 days	29	42
Not in last 3 days, but often have this problem	22	16
In 1-2 of last 3 days	16	21
Daily in the last 3 days	33	21
<b>Shortness of breath (last 3 days)</b>		
No shortness of breath	87	85
Had shortness of breath doing moderate activities (climbing stairs)	10	11
Had shortness of breath doing normal day-to-day activities (getting dressed, housework)	2	3
Had shortness of breath when resting	1	0
<b>Pain (last 3 days)</b>		
No pain	47	47
Not in last 3 days, but often have pain	26	18
In 1-2 of last 3 days	7	16
Daily in the last 3 days	20	19
<b>Most intense level of pain experienced (last 3 days)</b>		
No pain	55	50
Mild	16	21
Moderate	20	23
Severe	6	5

Excruciating	3	2
<b>Had acute problems or flare ups of a recurrent or chronic problem</b>		
No	70	71
Yes	30	29
<b>Have any conditions or diseases that make health, mood, behaviour or ability to function unstable</b>		
No	72	76
Yes	28	24
<b>Highest number of alcoholic drinks in a single sitting (last 14 days)</b>		
None	46	48
1	13	11
2-4	35	23
5 or more	6	18
<b>How often they saw a doctor or nurse about their health (last 90 days)</b>		
None	45	45
1	19	31
2-5	31	19
6-9	2	3
10 or more	2	2
<b>Reported rated health</b>		
Excellent	15	16
Good	51	47
Fair	26	32
Poor	8	5
<b>Reported level of stress</b>		
Not stressed	7	21
Stressed but I will not change the care I provide	63	52
Stressed and I need to reduce the care I provide (e.g., visit less often, reduce length of visits, cut back on tasks like housework, provide only minimal support)	20	23
Stressed to the point of crisis, and I will stop providing care	10	5
Subtotal: Stressed to some extent	93	79
<b>Carers COVID-19 experience and health care received</b>		
No positive test result or diagnosis	58	37
Tested positive, but not hospitalised	40	61
Tested positive, was hospitalised, but not in ICU	1	2
Tested positive, was hospitalised in ICU	0	0
<b>When carer first tested positive or had diagnosis of COVID-19</b>		
No positive test result or diagnosis	58	37
Last 30 days	8	0
31-90 days ago	16	6
91-180 days ago	13	11
More than 180 days ago	4	45
<b>Care Recipients COVID-19 experience and health care received</b>		
No positive test result or diagnosis	63	53
Tested positive, but not hospitalised	28	35
Tested positive, was hospitalised, but not in ICU	7	8
Tested positive, was hospitalised in ICU	2	3

## Appendix 9 - Questions family carers would like to have been asked that were missing from the interRAI FCNA form

*Lack of Community Supports / Social Supports.*” #2 Additional Feedback Questionnaire

*“Psychological effect of caring needs to be looked at.”* #4 Additional Feedback Questionnaire

*“How much has been spent privately to support care for our loved ones and keep them in the family home.”* #15 Additional Feedback Questionnaire

*Carer would like to have been asked about the times that home help come to the house - this does not always suit - and the times that Respite is received - she would like to choose the times herself but she feels she has to go with the times that are offered. She would like to have been asked about her journey as a carer and the changing dynamic between the carer and the care recipient. She would like to have been asked about the times that the carer is pushed to the limit and can give no more.* #16 In conversation with Project Office

*“Maybe around some long term plans if I cannot give care anymore.”* #17 Additional Feedback Questionnaire

*“Perhaps one that relates to the accessibility of services available and having an awareness of what services are there for supports.”* #18 Additional Feedback Questionnaire

*“Cost of laundry/Cost of Heating as prices escalate/Cost of transport to and from hospital/ doctors appointments.”* #23 Additional Feedback Questionnaire

*“Individualised and maybe one to one interview regarding different age group of carer and how impacts individual lifestyles.”* #24 Additional Feedback Questionnaire

*“Question on Carers allowance and means testing or financial aid for carer.”* #31 Additional Feedback Questionnaire

*“Did not capture that I also care for my mother, they both need full nursing care and I provide 24/07 care for both with home help.”* #32 Additional Feedback Questionnaire

*“Reasons that people have to become a family carer, family situations. To me, it’s like having a child back in our house. We have to be here at ‘home’ nearly always. No one really highlights this and the only alternative is nursing home and a rigorous means test on family income - other than the carer automatically getting allowance of some kind for work being done.”* #38 Additional Feedback Questionnaire



“Caring for the care recipient is my choice: Code - 0 No or 1 Yes / Could the care recipient live independently with appropriate supports in place: Code - 0 No or 1 Yes.” #41 Additional Feedback Questionnaire

*“I think that there should be a question asking about the impact of caregiving responsibilities on other family members. I am only able to care for my son by neglecting my daughter. The focus should not only be on the impact of the care recipient but also on the impact of others.”* #42 Additional Feedback Questionnaire

*“Questions that related not only to the provision of services but more importantly to the quality of such services.”* #44 Additional Feedback Questionnaire

*“Something about assistance for the care recipient to run their life independently as possible. Contacting agencies etc. is very stressful especially these days when carers are few.”* #46 Additional Feedback Questionnaire

*“Just about general income and how hard it is to survive week to week financially.”* #52 Additional Feedback Questionnaire

*“Questions representing services that could be available.”* #55 Additional Feedback Questionnaire

*“Respite for Carers, Extra P.A. hours, More Carer Allowance, Freedom to work more hours.”* #56 Additional Feedback Questionnaire

*“Maybe links with GP services to support family carers.”* #58 Additional Feedback Questionnaire

*“More questions about the care duties/medical role requirements on daily basis. More questions about the carers supports and time away/break from caring.”* #60 Additional Feedback Questionnaire

*“Question in relation to sensory and behavioural support absent. Nothing about sensory disability at all – need to have sensory stress noted. Question re carers input on what supports required from their point of view. Impact that being a carer has on the siblings/ children.”* #61 Additional Feedback Questionnaire

*“The questions were very broad – perhaps phrase it ‘Due to lack of sleep’ – did you..... or If you do not get a full nights sleep, how does this impact you?’ The questions need to be put in context.”* #61 Additional Feedback Questionnaire

*“Need to have a question on strategies – ‘What strategies do you have in place to cope?’.”* #61 Additional Feedback Questionnaire

*“Open ended questions about what would make life better/easier for carer at this time.” #62 Additional Feedback Questionnaire*

*“Maybe if questions were more specific to areas/group e.g. Intellectual Disability and resources locally.” #69 Additional Feedback Questionnaire*

*“If questions could be more specific to everyday life with a mentally challenged child/adult. Easy to get child minders when my son was very young - very difficult when he is 28\*. Questions around coping more specifically when son not at services. Some questions felt too broad.” #70 Additional Feedback Questionnaire*

*“Feel questions re older carers and future plans/programs not mentioned.” #71 Additional Feedback Questionnaire*

*“See is there anything else you (carer) wish to tell us.” #72 Additional Feedback Questionnaire*

*“Future planning for a loved one.” #74 Additional Feedback Questionnaire*

*“Availability of Respite, provision of independent living and provision of services during COVID.” #79 Additional Feedback Questionnaire*

*“Not asked about residential support.” #80 Additional Feedback Questionnaire*  
*“Believe more flexibility is needed with questions as my experience as a carer is ongoing, forever changing and cannot be narrowed down to the past three days. Would have liked questions on how to give more insight into how caring role has impacted me. Did not take into account some days are better than others and my son “three days” can be better than others.” #84 Additional Feedback Questionnaire*

*“How closely my son’s medical team liaise with me as his carer.” #86 Additional Feedback Questionnaire*

*“1. What services/actions have benefited/help me as a carer since I started in this role. 2. What has changed in terms of service provision and how has this impacted in my role and on recipient. 3. I think it might be useful to have a questions about worry/worrying.” #93 Additional Feedback Questionnaire*







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