PhD Thesis

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Title: Promoting a 'Think Carer' approach in Primary Care/General Practice

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Research Summary

Background: Family carers are known to experience negative consequences to their health and well-being, but despite this, they report having little or no formal health care support. International literature suggests that General Practitioners (GPs) have a critical role to play in the identification and support of family carers, although there are clear gaps in knowledge, awareness, and the provision of appropriate resources and training. A**ims:** The principal aim of this multi-stage, sequential mixed methods research was to address important policy goals concerning the health and well-being of family carers in Ireland, with a specific focus on how they can be better supported by GPs. **Method:** The research involved: **(1)** a national survey of family carers (N=132) and in-depth interviews with family carers and GPs (N=10) *(Study 1)*; **(2)** a scoping review of the international literature to inform the development of guidelines or 'Practice Points' for GPs *(Study 2)*; and **(3)** the development and pilot testing of educational resources for both GPs and carers *(Study 3)*.

Results: ***Study One*** findings suggest that although family carers were experiencing high levels of psychological distress, they were rarely asked about their own well-being and were reluctant to seek help or to discuss the impact of caring on their own health. GPs, although sympathetic to family carers, were uncertain regarding their role (if any) in supporting them. The lack of appropriate resources and information were significant barriers to carer identification and support in primary care. ***Study Two,*** based on an initial review of approximately 4000 papers from across the world (35 of which met the criteria for inclusion), involved a critical synthesis of key strategies for the identification, assessment, and support of carers in primary care. The findings, which are applicable across diverse caring roles, are useful in informing and guiding current policy and practice in this area. ***Study Three,*** completed in collaboration with Family Carers Ireland and a PPI panel of carers, involved the development of guidelines or 'Practice

Points' for GPs, as well as the co-design, co-delivery, and pilot testing of workshops for GPs and family carers respectively.

Conclusion: This timely and important research represents a valuable contribution to the international literature on the identification and support of family carers in general practice/primary care. Crucially, the collective findings increase awareness of the health and well-being needs of family carers, whilst also helping to improve the ways in which they can be better identified and supported, both in Ireland and elsewhere. Additionally, the project outputs provide useful, accessible, and practical evidence-based resources for both GPs and family carers alike. A number of recommendations for policy and practice are highlighted, as well as directions for future research.

List of publications and outputs from the thesis

(including author contributions)

Publications:

1.**Cronin, M.,** McLoughlin K., Foley, T., and McGilloway S. Supporting family carers in General Practice: A scoping review of clinical guidelines and recommendations. *BMC Family Practice* (under review – submitted in Jan, 2023).

Author contributions:

Mary Cronin (Lead author) – Wrote and compiled the initial draft of the manuscript plus subsequent revised drafts, developed and implemented the methodological approach, completed all data analysis, prepared tables and figures and finalised and submitted the final version of the paper.

Kathy McLoughlin (second author/reviewer) – assisted with databases searches and the review of papers.

Tony Foley (Third reviewer/co-author) – Acted as third reviewer and arbiter and contributed to the editing/revision of various drafts of the paper.

Sinead McGilloway (Supervisor and co-author) - Supervised and advised on the methodological approach, manuscript compilation and reviewing and editing of all drafts.

(BMC Primary Care, (formerly, BMC Family Practice) is an open access, peer-reviewed journal that publishes articles on all aspects of primary health care research. The journal has a special focus on clinical practice and decision-making, continuing professional education, eHealth, health services research in primary care settings, and health promotion.)

2. **Cronin, M.** & McGilloway, S. (2022) Supporting family carers in Ireland: the role of the general practitioner. *Irish Journal of Medical Science*. https://doi-org.may.idm.oclc.org/10.1007/s11845-022-03031-9.

Author contributions:

Mary Cronin (Lead author) – Wrote, compiled and revised drafts of the manuscript, conducted the study, completed data analysis, prepared tables and figures.

Sinead McGilloway (Supervisor and co-author) - Supervised and assisted with conceptualisation, manuscript review and drafting/editing.

(The Irish Journal of Medical Science covers all branches of medicine and publishes papers applicable to the daily practice of clinicians.)

3.Cronin, M., Foley T. & McGilloway, S. (2022) Addressing the needs of family carers. *Forum, Journal of the Irish College of General Practitioners, Vol 39, No.9.*

Author contributions:

Mary Cronin (Lead author) – Wrote and compiled the initial manuscript, conducted the study, completed data analysis and revised subsequent drafts.

Tony Foley (member of the scoping review team and co-author) contributed to the editing/revision of various drafts of the paper**.**

Sinead McGilloway (Supervisor/co-author) - supervised and assisted with manuscript compilation, review, editing and finalisation.

(Forum is the professional journal of the Irish College of General Practitioners and circulated to all general practitioners in Ireland. It is also available to GPs through the ICGP website.)

4. Cronin, M. & McGilloway, S. (2020) Promoting a 'Think Carer' approach in health and social care services: Identifying as a carer – Why is it important? *Frontline Irish Voice of Intellectual Disability* (online), Issue 116, http://frontline-ireland.com/promoting-a-think-carer-approach-in-health-and-social-care-services-identifying-as-a-carer-why-is-it-important/.

Author contributions:

Mary Cronin (Lead author) - Wrote and compiled manuscript, conducted the study, performed data analysis, prepared tables and figures and revised all subsequent drafts.

Sinead McGilloway (Supervisor and co-author) - Supervised and assisted with conceptualisation, manuscript compilation, review, editing and finalisation.

(Frontline is an online, open access platform publishing articles of interest to people with intellectual disabilities and their families/carers.)

5.Cronin, M. & McGilloway, S. (2019) Promoting a 'Think Carer' approach in health and social care services. *Healthnews* (Online), https://www.healthnews.ie/neurology/promoting-a-think-carer-approach-in-health-and-social-care-services/

Author contributions:

Mary Cronin (Lead author) - Wrote and compiled the manuscript and prepared tables and figures.

Sinead McGilloway (Supervisor and co-author) - Supervised and assisted with manuscript compilation, review and editing.

(Health News is an online, open access platform that publishes healthcare news and information.)

Other outputs:

6.Cronin, M. & McGilloway, S. (2022) 'Communication with doctors - Empowerment workshop for family carers: Facilitator Workshop Guide'. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

Author contributions:

Mary Cronin (Lead author) – Worked with the PPI panel to co-design the workshop and compiled and drafted the final product.

Sinead McGilloway (Supervisor and co-author) - Supervised and assisted with facilitator guide design, drafting and finalisation.

7. Cronin, M., Foley, T. & McGilloway, S. (2022) 'Raising awareness of family carers in General Practice: Facilitator Workshop Guide'. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

Author contributions:

Mary Cronin (Lead author) - Worked with the PPI panel to co-design the workshop and compiled and drafted the final product.

Tony Foley (Co-facilitator and co-author) – Assisted with content, prepared case-based discussion and helped to co-facilitate the workshop.

Sinead McGilloway (Supervisor and co-author) - Supervised and assisted with facilitator guide design/compilation and drafting of content.

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List of Abbreviations

AARP	American Association of Retired Persons
AHA	American Hospital Association
AHRQ	Agency for Healthcare Research and Quality
ANOVA	Analysis of Variance
BC	British Columbia
CPD	Continuing professional development
CSNAT	Carer needs assessment tool
EoL	End of Life
FCI	Family Carers Ireland
GP	General Practitioner
GPR	General Practitioner Registrar
HCA	Health Care Assistant
HCPs	Health Care Professionals
IICGP	Irish College of General Practitioners
ICGP-QiP	Irish College of General Practitioners – Quality in practice committee
LoE	Level of Evidence
LTC	Long Term Care
MeSH	Medical Subject Heading
NICE	National Institute of Care Excellence
NHS	National Health Service
OECD	Organisation for Economic Co-operation and Development
PPI	Public and patient involvement
QoL	Quality of Life
RACGP	Royal Australian College of General Practitioners
RCGP	Royal College of General Practitioners
RCT	Randomised control trial
SCT	Social Cognitive Theory
TPB	Theory of Planned Behaviour
TeamSTEPPs	Team strategies and tools to enhance performance and patient safety
UCC	University College Cork
WONCA	World Organisation of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

Chapter 1: Introduction

1.1 Introduction

Most of us will receive or provide care at some point in our lives because, as relational beings, we live our lives in various stages of dependency and interdependency (Dukelow & Considine, 2017). Despite this, the provision of care is often a contentious issue in health service structures and social policy mainly due to the over reliance on the unpaid work of family carers (Barrett et al., 2014), a lack of appropriate support for those who provide care (Family Carers Ireland, 2022b) and a failure to plan for future care provision (Spotlight, 2019). The research reported in this thesis, focuses on one aspect of care, namely family care and family carers, also referred to as 'informal', 'unpaid' or 'lay' carers/caregivers. A 'family carer' may be defined as someone "who provides unpaid care and supports to a family member, partner or friend because of a disability, health condition, frailty, mental health problem, addiction or other health or social care need" (NICE, 2020, p. 19). This chapter describes the background to family caring, both in an Irish and international context including, in particular, the impact of caring on health and wellbeing. The historical and policy context in Ireland is also outlined, followed by a discussion of the key theoretical frameworks that were used to guide and inform the work. A description of the research aims and objectives and its outputs (i.e. as part of a PhD by Publication), are also provided at the end of the chapter.

1.2 Background

Family carers provide care to some of the most vulnerable citizens in our communities including (but not limited to), those with physical and intellectual disabilities, frailty and care of the older person, dementia, cancer, neurological disorders, mental ill health, and substance misuse (Care Alliance Ireland, 2015). Recent estimates suggest that an estimated 20% of the population in Europe (approx. 100 million people) provide care to family members (Carers

World Wide, 2022), while there are currently over half a million family carers in Ireland (Family Carers Ireland, 2022b). *Figure 1.1* below, shows a breakdown, for 2021, of carer numbers in several countries across the world, highlighting the global extent of care provision by informal carers or family members (International Alliance of Carer Organisations (IAC), 2021) (International Carers, 2021).

Figure 1.1

Global carer numbers from IAC (International Alliance of Carers)

In Europe it is estimated that 84% of carers are female, a figure that is consistent with a recent survey of carers in Ireland (*N* = 1,484) where the vast majority of those surveyed (88%) were women (Family Carers Ireland, 2022b). The informal nature of care and the way in which carer numbers are recorded, are key challenges to the availability of accurate data. For example, in Ireland, carer numbers are recorded through the Central Statistics Office (CSO) Census of Population and the National Health Survey, both of which have variations in the phrasing of the question on carers (Family Carers Ireland, 2022a). In addition, many of those providing care do not identify themselves as 'carers' per se, as they see their caring responsibilities as an integral part of their role within the family or close relationship (Barrett et al., 2014). The issue of carer identity will be examined later in this chapter.

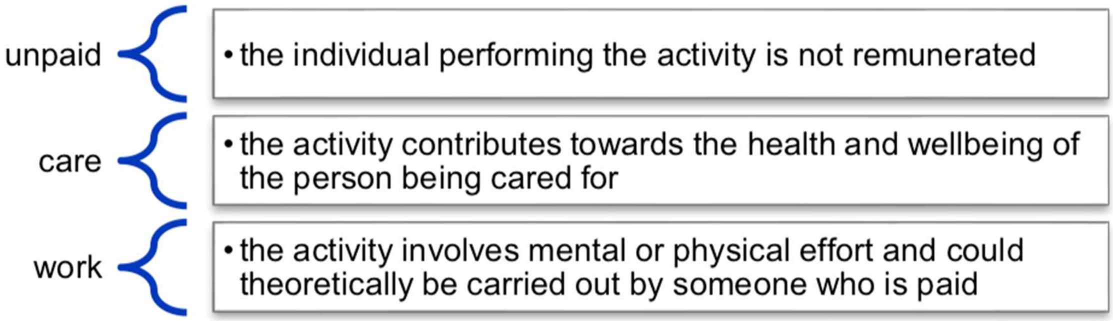
All indicators suggest that these numbers are likely to increase further due to a combination of societal, medical, and health system changes including:

- Improvements in medical care and enhanced treatments for many conditions, resulting in those with complex needs enjoying increased longevity (Barrett et al., 2014);
- An increasing ageing population throughout Europe (Oudijk et al., 2011);
- Changing family structures and later retirement (Broese Van Groenou & de Boer, 2016); and
- A shift away from an institutional model of care (Oireachtas Library & Research Service, 2019) and long-term hospital stays (Barrett et al., 2014), and an attendant increased reliance on care in the community (Verbakel, 2018).

Whilst many of the above explanations for growing carer numbers are positive (e.g. the care recipient living a longer and better quality of life in the community), they also suggest that the type of care being provided in the community is becoming increasingly complex (Barrett et al., 2014). While this care is usually provided in the home, many carers continue to have significant responsibilities following the transition of their loved one to residential care (O'Shea et al., 2017). Indeed, family carers are the main providers of long-term care (LTC) across Europe and their role is distinct from caring in other elements of the healthcare services due to the connection to the person for whom they are providing care and their unpaid status (Figure. 1.2).

Figure 1.2

The nature of 'unpaid' care



- the individual performing the activity is not remunerated
- the activity contributes towards the health and wellbeing of the person being cared for
- the activity involves mental or physical effort and could theoretically be carried out by someone who is paid

Source: (Woods, 2018)

This type of caring role is unplanned for in the life of the carer, and commences when a family member experiences ill health or injury, or when a child with a disability or medical need is born (Barrett et al., 2014). As outlined by O' Shea et al. research suggests that the caregiving experience can be demanding, unpredictable, and often progressive (O'Shea et al., 2017). While most family carers choose to care for their loved one as an expression of love, and can experience satisfaction from the role, there can also be a considerable impact on the physical and mental health of the family carer (Eurocarers, 2018; Family Carers Ireland, 2022b).

Evidence suggests that the health and well-being of family carers across the world is considerably poorer than that of the general population (OECD, 2017). Statistics from Europe (cited in, Carers World Wide, 2022) indicate that, according to the European Quality of Life

Survey, 89% of carers experience depression or anxiety, while 48% have concerns about their physical health.

A number of population-based studies also demonstrate the negative impact of caring on health and psychological well-being. For example, the findings from a population-based study in the UK, based on data from the first 10 waves of the British Household Panel Survey (1991 to 2000) (*N* = 17,000) showed that carers providing longer hours of care, reported increased levels of psychological distress, while the risk of onset of psychological distress also increased with the time devoted to caring (Hirst, 2005). A more recent 20-year longitudinal follow-up study in the United States (*N* = 4,024), found an increased risk of developing a mental health problem amongst parents who were caring for a child with a disability when compared to non-carer controls (Hoyle et al., 2021). Likewise, findings from the national Growing Up in Ireland study from 2006 to 2014, found a higher risk of depression in parents who care for a child with a developmental disability when compared with parents caring for typically developing children (after adjusting for underlying chronic health issues) (Gallagher & Hannigan, 2014).

A recent large survey of the health and well-being of family carers in Ireland (Family Cares Ireland, 2019) (*N* = 1,102) indicates that almost half have been diagnosed with mental health problems, while more than two-thirds of family carers suffer with physical ill-health. Similarly, high proportions felt that their health had suffered as a result of their caring role (68%), or that they had no access to home support or appropriate respite care (83%). Eight out of ten family carers provided more than 50 hours care each week.

Interestingly, despite these findings, many population-based studies suggest that carers have lower mortality rates than non-carers (Fredman et al., 2015; Ramsay et al., 2013; Roth et al., 2013), suggesting potential health benefits of caring. However, it has been suggested that other factors may be at play, including selection bias, although Smith and colleagues found no evidence of such bias in their recent study (M. Smith et al., 2018). More recently, Gallagher et al. (2021) suggest that the results of some of the large population-based studies may have been influenced by behaviour and lifestyle factors that were not controlled for and which could potentially have an indirect impact on health outcomes (Gallagher & Bennett, 2021). They used data from the UK 'Understanding Society' Study ($N = 2{,}522$) and controlled for a number of potential confounding factors such as age, gender, relationship status, fruit and vegetable intake and education. The results indicated that carers have an increased risk of illness or disability when compared to non-carers.

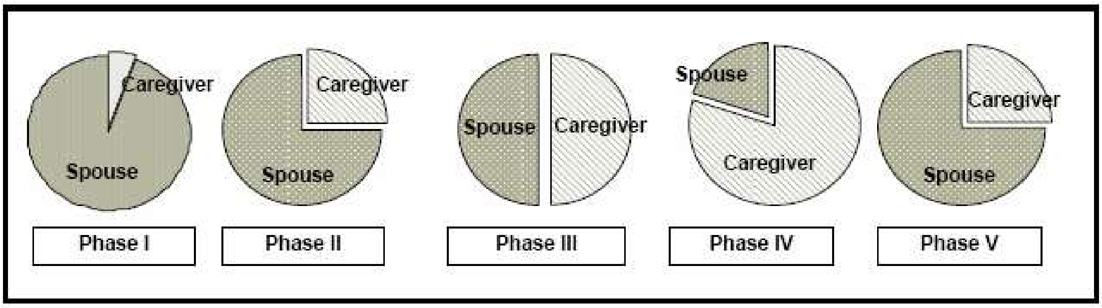
Despite potential risk to carers' physical and psychological health, many countries, including Ireland, do not have systems in place to formally identify, assess, or support family carers. It is particularly important that carers are identified in healthcare settings where appropriate, as many are reluctant to ask for help or to discuss the impact of the caring role on their health and well-being. It has been suggested that one of the primary reasons why carers may not ask for help is that they may not associate themselves with the term 'carer' but rather with the familial bond they hold with the person for whom they provide care (Hughes & O'Sullivan, 2017). This can result in a lack of engagement with available support services and a sense of being 'invisible' in the role. Thus, it is only often at a point of crisis that those who provide care will begin to associate themselves with the role (Eifert et al., 2015), and seek out appropriate support services.

The development of a carer identity may be best understood and explained within the context of Family Caregiver Identity Theory (Montgomery & Kosloski, 2013; Montgomery et al., 2007) which focuses on the process of identity development and formation in individuals who take up a role as carer to a family member or loved one. The theory highlights the ways, in particular, in which the caring role can influence, and often overwhelm, a person's overall sense of self and identity (Montgomery & Kosloski, 2013).

More specifically, Montgomery's original theory suggests that the caregiver identity emerges through a process of five phases (see Figure 1.3). The first of these relates to the onset of the caring role, at which point the carer may be involved in some tasks that signify the beginning of a change from the usual familial role with the family member (e.g. activities of daily living (ADL), such as supporting mobility, dressing or eating). However, carers are often unaware of a carer identity at this stage. In the second phase, the carer may begin to acknowledge that the care provided to the care recipient extends beyond the initial familial relationship with that person, and it is at this juncture that the carer identity begins to emerge. The third phase sees the care recipient's needs progressing significantly, and the intensity of care at this point means that there is a struggle to maintain initial identities. The carer may also struggle during this phase with the option of seeking alternative means of care, such as a nursing home care or residential care. Phase four can be a lengthy period during which the carer role can be all-consuming and other identities are diminished. The final phase of the process relates to a move to residential or other care for the care recipient, whereby the carer may begin to re-assume some of their previously held identities.

Figure 1.3

Phases of carer identity as outlined by Caregiver Identity Theory (Montgomery, 2007)



The progressive nature of the different phases means that, as the caring role intensifies, previously held identities come under pressure (Eifert et al., 2015). Family carers can then experience distress when the carer role begins to conflict with their personal identities and it is at this point that they will seek, or accept the need for, help and support (Montgomery et al., 2007). This theory is grounded in the fact that there is no generic caring role but that each is uniquely defined by the cultural and familial environment (Montgomery, 2016). The theory, as outlined here, also highlights the complexities of the carer identity and provides a useful framework, not only for understanding the emergence of the carer identity, but also its subsequent impact on psychological wellbeing and help-seeking behaviour.

Stigma may also have an impact on carers' help-seeking behaviour. The presence and impact of stigma have been explored in the context of several health conditions, such as neurological disorders (Burgener & Berger, 2008), HIV (Fife & Wright, 2000), lupus (Sehlo & Bahlas, 2013) and dementia (Lion et al., 2020). Those who are caring for individuals with stigmatised conditions such as mental health difficulties and intellectual disability, may also often experience what has been described as 'affiliate stigma' as a result of their caring role (Mak & Cheung, 2008). Affiliate stigma describes instances in which the carer internalises the stigma because of their relationship with the person for whom they provide care. This may have a significant negative impact on the mental health of family carers (Papadopoulos et al., 2019). It has also been suggested that perceived stigma can impact help-seeking behaviours. For example, a systematic review that explored the impact of stigma in those experiencing a mental health illness, found a small to moderate negative effect of stigma on help-seeking (Clement et al., 2015). However, little is known about how perceived stigma may impact family carers' decisions to seek help, or to discuss the impact of their caring role with a healthcare professional.

General Practitioners (GPs) have been reported to be particularly well placed to identify, assess, and refer family carers to community-based supports (Parmar et al. 2020). Internationally, the identification and support of carers in general practice has been encouraged in some countries through the development of guidelines, practice tools, and training for GPs. For example, in the UK, the Royal College of General Practitioners (in collaboration with the Princess Royal Trust) (2013) has developed an ‘action guide’ to assist GPs to better support family carers (Royal College of General Practitioners & The Princess Royal Trust, 2013). Similar resources are available in parts of Australia (Northern Sydney Local Health District, 2019) and Canada (Doctors of BC, 2016).

The barriers and facilitators to GP support of family carers are well documented internationally (Parmar et al., 2020). For instance, existing evidence suggests that GPs find it easier to offer support to family carers: (1) who are their own patients; (2) with whom they have an established relationship; and (3) where practice protocols are in place to support the identification, assessment and referral of the family carer to sources of support (Parmar et al. 2020). Barriers to GPs offering support, on the other hand, include: (1) a lack of time and reimbursement to support family carers within GP practices; (2) failure to identify carers and acknowledge that this group often have very complex needs; (3) a lack of knowledge amongst GPs regarding available supports; and (4) health service systems that focus solely on the care recipient (Carduff et al., 2014; Parmar et al., 2020). These kinds of issues will be explored later in this thesis. As outlined below, there are wider contextual and societal factors that are also at play when it comes to the identification and support of family carers.

1.3 Historical & Policy Context in Ireland

Historically, in Ireland, the care system was structured so that LTC was largely the concern of the workhouses, institutions (O'Shea et al., 2017) and religious orders (Dukelow & Considine, 2017). The de-institutionalisation of care was an enormously positive step in terms of the quality of life (QoL) for people with disabilities and other complex needs, but due to the fact that it has been so inadequately funded, it has resulted in a significant negative impact on families and family carers (Brennan et al., 2022). The work of family carers is an important resource in enabling chronically ill or disabled people to remain at home and in their community (Barrett et al., 2014). However, it is a source of some concern that the move towards community care effectively became "a synonym for family care" (Quin et al., 2005) (p.136). The shift in government policies toward reducing state responsibility for care and reliance on family carers is common across Europe (Verbakel, 2018), yet most countries do not have a system in place to identify and meet the needs of family carers (Courtin et al., 2014). As such, family carers have been largely neglected by policy makers across Europe, although some countries (including Ireland) have some mechanisms to compensate for loss of income.

The 'Care of the aged report', in 1968, was the first policy paper in Ireland to refer to older people remaining in their own homes (O'Shea et al., 2017). The first welfare payment in respect of caring, issued the same year and described as the 'Prescribed Relatives' Allowance', was payable to those aged over 70 requiring full-time care. The care was to be provided by a female relative and the payment was made to the care recipient (Dukelow & Considine, 2017). In 1972, this was extended to male carers and could be paid directly to the carer (Quin et al., 2005), and by 1973, the ‘Domiciliary Care Allowance’ was introduced in respect of children up to 16 with significant needs. In 1990, the Carer’s Allowance replaced the ‘prescribed relatives’ allowance’ and consisted of a means tested payment (Dukelow & Considine, 2017). Currently, there are a number of variations to this allowance, including carers’ benefit (for carers who take time off work to provide care), half-rate carers allowance (for those not meeting the requirement of a full payment), and a carer’s support grant (payable annually to those in receipt of carer allowances). In recent years, carers in Ireland who are in receipt of carers allowance or carers benefit may visit their GP free of charge (International Carers, 2021).

Although these allowances are considered by government to be important in supporting carers, Ireland’s overall response to supporting its carer population has been the subject of much criticism. Indeed, expenditure on LTC in Ireland is considered to be low by international standards (Brennan et al., 2022), despite the fact that carers are reported to save the state an estimated €20 billion per year in care costs (Family Carers Ireland, 2022b). Indeed, it has been suggested that an underlying policy goal with respect to supporting family carers, is to keep them in their role as long as possible, thereby minimising the cost to the state (Barrett et al., 2014).

Aside from the previously mentioned means tested income supports and GP card, family carers in Ireland do not receive any additional health service entitlements, despite the potential risks to their physical and psychological health. By contrast carers in the UK have a legal entitlement to an assessment of their needs through the health and social care system (Dukelow & Considine, 2017). It is interesting to note that while the UK government launched its first national strategy for carers in 1999 (Courtin et al., 2014), many countries across Europe and internationally do not have policy or legislation in place to support family carers (International Carers, 2021).

In an Irish context, the first National Carers Strategy (NCS), which recognised the role and contribution of family carers, was launched in 2012 (Department of Health, 2012). Although it has been criticised for being developed on a cost neutral basis (Dukelow & Considine, 2017) and with an underlying suggestion of family caring as ‘normative’ (Brennan et al., 2022), it was nonetheless an important first step in advancing the needs and rights of family carers. The most recent draft Programme for Government (2020), referred to family carers as “the backbone of care provision in Ireland” and deserving of support and recognition, prompting a commitment to an updated NCS (still pending at time of writing in 2023). A key component of the NCS mission statement is that carers “will be supported to maintain their own health and well-being and to care with confidence” (National Carers Strategy, 2012, p.2). A number of specific objectives of the strategy address how carers are identified and supported in healthcare services. These include:

- Promoting more proactive approaches to the identification of carers and to addressing their needs among staff and organisations that are likely to encounter individuals in caring situations (e.g. health and personal social service providers, and particularly primary care team members, community and education professionals) (*Objective 1.1.6*, p.20).
- Raising awareness among health and personal social service providers of the physical and emotional health issues that carers may experience (*Objective 2.1.1*, p.21).

Crucially however, these specific objectives relating to the health and well-being of family carers (along with many other objectives) have remained largely unmet in the 10 years since the publication of the strategy. Therefore, the not-for-profit sector has become the primary provider of services for family carers (Dukelow & Considine, 2017). The largest of these organisations is Family Carers Ireland (FCI), the national charity supporting Ireland's 500,000+ family carers, which operates 22 resource centres and over 60 support groups, while engaging directly with more than 20,000 carers each year. FCI makes a range of supports available to family carers including: the provision of respite, education and training; information and advice; access to small grants for respite equipment; support groups; social events; counselling; intensive assessment; action planning to support the family caregiver to maintain a sustainable caring routine; and the development of an emergency care and support plan (familycarers.ie).

Other national health policies have also incorporated objectives for family carers; for example, the Irish National Dementia Strategy (Department of Health, 2014) calls for "as much support as possible" for family carers of people with dementia and suggests an integrated response by primary care, secondary care, and community services. Importantly, Care Alliance Ireland, an umbrella organisation working with and supporting condition-specific organisations, such as The Alzheimer Society, The Irish Heart Foundation, and the Irish Cancer Society, assists these groups in providing better information and supports to family carers (carealliance.ie).

1.4 Theoretical frameworks

Two key theories were used to inform and guide the current research. The first, Social Cognitive Theory (SCT) (Bandura, 1986), provides a useful framework for understanding carer health and well-being behaviour due to its focus on the interaction between personal, environmental and behavioural factors. Secondly, the Theory of Planned Behaviour (TPB)

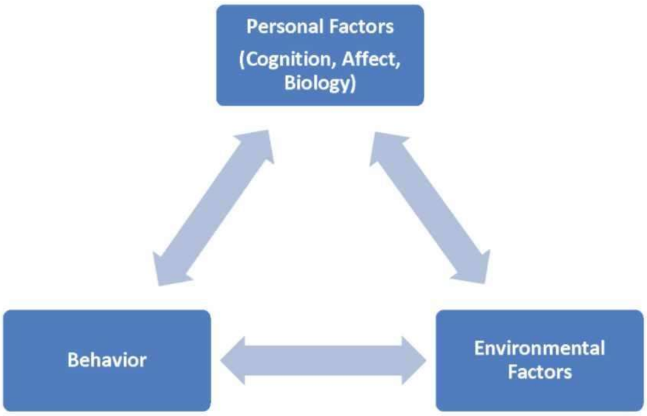
(Ajzen, 1985) helps us to better understand behaviour/behaviour change in health care settings such as general practice/primary care. Each of these is described below.

1.4.1 Social Cognitive Theory

SCT has its origins in Social Learning Theory (SLT) (Bandura and Walters, 1963) which was founded on principles of social modelling, observational learning, and vicarious reinforcement (Nabi & Oliver, 2009). In 1986, Bandura updated and renamed his theory to acknowledge the role of cognition in our ability to construct reality, self-regulate, encode information, and take subsequent action (Bandura, 1986). The revised theory was based on the central construct of reciprocal determinism which refers to the interaction of personal, environmental and behavioural factors (Bandura, 1998) (see Figure 1.4). This interaction provides a useful lens for understanding and promoting health-related behaviours (Bandura, 1998).

Figure 1.4

Social Cognitive Theory – Reciprocal determinism.



According to SCT, there are four core determinants of health-related behaviours (Stacey et al., 2016) including: (1) knowledge of health risks; (2) perceived self-efficacy that we can exercise control over our health; (3) outcome expectations about costs and benefits; and (4) perceived facilitators and barriers to making positive changes to our health (Bandura, 2004). The first of these refers to the fact that knowledge regarding our susceptibility or predisposition to health issues is necessary to enable us to be sufficiently motivated to change our health-related behaviours (Bandura, 2004). The second determinant, self-efficacy, refers to our belief in our ability to engage in a particular behaviour, a factor that is central to motivation and action (Bandura, 1998). Thirdly, outcome expectations can be divided into physical, social, and self-evaluative outcomes. The first of these refer to positive or negative consequences of the behaviour, while social outcomes are concerned with the perceived wider social approval or disapproval. In contrast, self-evaluative outcomes are the result of our sense of self-satisfaction or self-dissatisfaction (Bandura, 2004). Finally, perceived facilitators and barriers, such as a lack of access to services and supports, can influence health-related behaviours (Bandura, 2004).

The interplay of cognitive, psychological and social factors within SCT has been useful in improving our understanding of patient behaviour outcomes in health settings (Painter et al., 2008; Stacey et al., 2016). For example, the theory has been used to inform studies that have examined perceptions of personalised nutrition (Rankin et al., 2017), activity and dietary behaviours in patients with diabetes (Sebastian et al., 2021), as well as protective behaviours during the COVID-19 pandemic (Trifiletti et al., 2021). A recent scoping review indicated that SCT has been widely and successfully used to better understand and evaluate health interventions in primary care (Islam et al., 2023). For example, it has been used for designing exercise programmes for cancer survivors (Basen-Engquist et al., 2013), and an empowerment programme for carers of dialysis patients (Rabiei et al., 2020). More specifically, self-efficacy, a key component of SCT, is thought to be crucial in determining whether someone will engage in a particular health behaviour (Martin et al., 2016). Therefore, this construct is commonly employed in health research and when designing and testing health-related interventions. For example, Au and colleagues (2009) examined the mediating role of self-efficacy on the impact of social support on the well-being of dementia family caregivers (Au et al., 2009). Self-efficacy has also been used to understand the behaviours of family caregivers of older adults with cognitive impairment (Khan et al., 2020).

Thus, SCT provided a useful lens in the context of the current study, to explore carers' health and wellbeing behaviours and experiences due to its focus on the reciprocal interaction between cognitive processes (i.e. carers' knowledge, beliefs and expectations regarding their health and wellbeing), environment (i.e. the caring role, level of support, support for health care professionals) and behaviour (i.e. help-seeking and health-related activities). All of these were carefully considered when designing the three separate but related studies on which this research is based.

1.4.2 Theory of Planned Behaviour

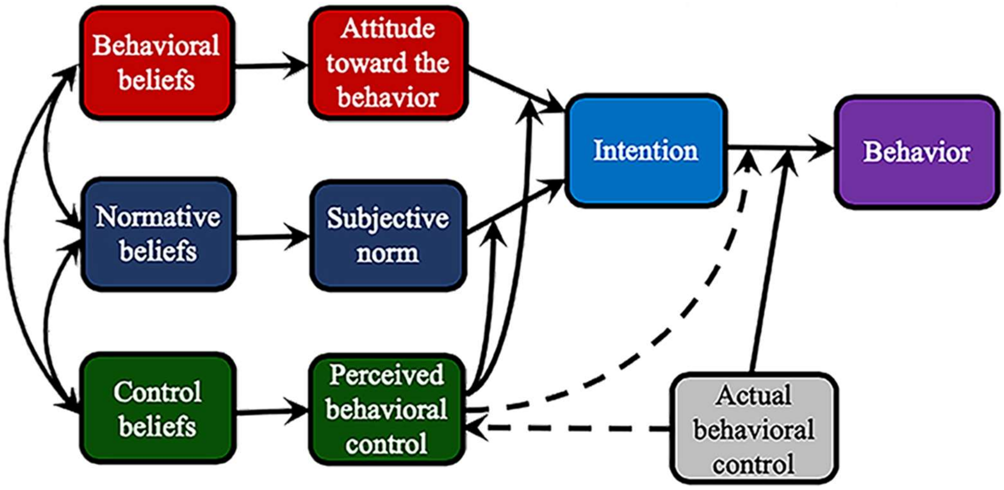
The TPB was developed by Icek Ajzen in the 1980s (Ajzen, 1985) as an extension of his earlier work based on the Theory of Reasoned Action (TRA) (Ajzen and Fishbein, 1975), which suggests that human behavior is determined by a combination of attitudes and subjective norms (Hale et al., 2002). The key additional component in the extended TBP was the development of the construct of perceived behavioural control which is described below.

The TPB adopts an essentially cognitive approach to explaining behaviour that focuses on three factors: (1) attitudes; (2) subjective norms; and (3) perceived behavioural control. According to the TPB, all three components interact to influence the development of a behavioural intention. ‘Attitudes’ refers to an individual’s positive or negative evaluation of a behaviour. ‘Subjective norms’ reflect the perceived social pressure to engage in, or avoid, a behaviour while ‘perceived behavioural control’ reflects the individual’s perception of their ability to perform the behaviour (Munro et al., 2007). The last of these, perceived behavioural control, considers internal factors, such as self-efficacy and perceived difficulty, as well as external or environmental factors, such as resources and opportunities.

Thus, it captures or explains actions or behaviours that are not completely under an individual’s control, but which can, nonetheless, influence behaviour (Ajzen & Driver, 1991). For example, an individual may intend to engage in a particular behaviour, but external factors such as the environment may prevent them from doing so. Thus, according to TPB, attitudes, subjective norms and perceived behavioural control influence the intention to perform a behaviour which, in turn, predicts the likelihood of engaging in the behaviour (Archer et al., 2008) (see Figure 1.5). Generally, the more favourable the attitude and subjective norm, the greater the perceived control and the stronger the likelihood of performing the behaviour (Ajzen, 2011).

Figure 1.5

The Theory of Planned Behaviour



The TPB has been widely and successfully used to predict a range of health-related behaviours, such as smoking cessation (Moan & Rise, 2005), physical activity (Boudreau & Godin, 2007) and weight management (Mazloomy-Mahmoodabad et al., 2017; McConnon et al., 2012). Although the early application of the TPB in health research largely focused on patient or population health behaviours rather than the behaviours of health professionals in relation to the health of patients (Walker et al., 2001), it quickly became more widely used with regard to its application in understanding and predicting the behaviour of healthcare professionals. Thus, it has been used to understand and predict the behaviours of healthcare professionals in many settings including, for example, nurses' intention to use research in clinical decision-making (Côté et al., 2012) and pharmacists' views of drug misuse (Fleming et al., 2019). Indeed, in a systematic review of healthcare professionals' intentions and behaviours, the TPB was the most commonly used theory (Godin et al., 2008). TPB has also been applied in the context of general practice to dementia management (Jiwa et al., 2014), prescribing and referral behaviour (Rashidian & Russell, 2012; Webb, 2017), GPs' intentions to use clinical guidelines (Kortteisto et al., 2010) and GP behaviour regarding the referral of cancer patients to social supports (Kam et al., 2012).

The TPB can also be used to inform the development and evaluation of interventions by identifying beliefs that underpin intentions and either modifying these beliefs or reinforcing new ones (Ajzen, 2006; Walker et al., 2001). For example, the theory was found to be effective in informing the development of a pilot educational intervention to address the irrational prescribing behaviours of GPs in relation to over-the-counter medications (Lionis et al., 2014). Thus, the theory was used in the context of the current study, to better understand the underlying beliefs, motivations and barriers that can influence GP behaviour when family carers present in clinical practice and to help inform the development of appropriate resources for GPs to support them in this role. Further information on how both of the above theories were applied in the context of this research, is provided later in the thesis.

1.5 The current study

The above unmet NCS objectives (i.e. relating to the identification and support of family carers in health and social care settings), coupled with the widely documented negative health consequences for carers (and the growing care needs in our society), provided the rationale and impetus for the current research. The most recent monitoring report of the NCS (2012) indicates some progress since the current research began, in relation to Objective 1.1.6 regarding the identification of carers and addressing their needs. However, this relates primarily to efforts by the Department of Education to recognise young carers, and the identification of carers (particularly in General Practice) is highlighted as an area in need of outstanding work. Similarly, some initial progress has been in relation to Objective 2.1.1., but this is based on a planned assessment tool that has not yet been implemented, and the previously mentioned GP card for carers (Family Carers Ireland, 2017). This research project sought to address how carers are supported through the CHERISH (Community Health-basEd appRoach to Improving carerS' Health and wellbeing) project.

1.5.1 Aims and objectives

The research reported here, involved three separate, but related studies designed to address how carers are supported in Ireland's healthcare services and specifically within general practice/primary care. Each of these studies (and the publications and outputs produced therein) is described briefly below. The aims of the research were to:

- Examine how carers are experiencing access to supports in community healthcare in relation to their own health and well-being, with a particular focus on psychological barriers to identification and help-seeking (***Study One***);
- Explore GPs' perceptions of carers (and their caring role) to better understand the processes by which they identify carers and the extent to which they support (or not) carer health and well-being (***Study One***);
- Collate, synthesise, and critique the international literature on guidance for GPs in supporting carers in primary care (***Study Two***); and
- Develop and pilot test two brief training workshops (with accompanying supportive materials) to (a) support GPs in progressing the NCS actions that relate specifically to carer identification, health and well-being; and (b) to help carers in their conversations with GPs (***Study Three***).

1.5.2 Study One

It was deemed important from the outset, to obtain a snapshot of how carers and GPs in Ireland experience their interactions in a clinical setting; this topic has not yet been explored in an Irish context, despite similar research having been conducted in other countries, such as the UK (Carduff et al., 2014) and Australia (Burridge et al., 2017). Study One, therefore, was designed to gain a better understanding of how carers are experiencing supports in community healthcare settings. Specifically, the objectives of this stage of the research, were to determine:

(a) if carers are ever asked about their own health and well-being; (b) the extent to which they identify as carers; (c) how they seek support (or not); and (d) to explore GPs' views regarding the identification and support of carers.

1.5.3 Study Two

Study Two consists of a scoping review of the international literature to identify and critically appraise existing guidance and recommendations designed to support GPs in their consultations with family carers in a clinical setting. The overarching aim of this study was to develop evidence-based good practice guidance for GPs, with a particular focus on the identification, assessment, and referral of family carers who present to their practice. This work was intended to bridge a significant knowledge gap with respect to guidance/resources for GPs, not only in Ireland, but across the world.

1.5.4 Study Three

Study Three was conducted in collaboration with our community partner FCI, and a panel of family carers in a public patient involvement (PPI) capacity; this was completed with the support of a small 'New Foundations' research grant from the Irish Research Council (IRC) (which was awarded to the research supervisor). The aims of this study were to: (1) develop guidelines for GPs to support them in consultations when family carers present at their practice; (2) co-design and evaluate a brief training programme for GPs to assist them in identifying, assessing and signposting family carers to community supports; and (3) to co-design, deliver and pilot test a brief workshop and resources for carers to help them navigate conversations and interactions with their GPs to enable them to better support their own health and well-being.

1.6 Thesis Outline

This thesis (by publication) includes a further six chapters. **Chapter Two** provides a methodological overview of: (1) the epistemological and ontological approach to the research;

(2) its overall design; (3) other overarching methodological issues such as ethical considerations and researcher reflexivity; and (4) details on the methods used in each of the three studies, designed to supplement the methodological information contained in each of the relevant publications included later in the thesis.

Chapter Three presents the findings of Study One, consisting of one peer-reviewed paper and one article of stakeholder interest as well as any additional findings not included in the published papers. Specifically, this chapter includes: (1) a stakeholder-focused publication entitled *'Promoting a 'Think Carer' approach in health and social care services: Identifying as a carer – Why is it important?'*, published by *Frontline Irish Voice of Intellectual Disability* (online), in February 2020, (2) a peer-reviewed publication, entitled '*Supporting family carers in Ireland – the role of the general practitioner*', published in the *Irish Journal of Medical Science* on the 15th June, 2022 and (3) additional findings not included in the published papers.

Chapter Four presents the paper that was based on the findings of Study Two. The peer-reviewed paper entitled '*Supporting family carers in General Practice: A scoping review of clinical guidelines and recommendations'* was published in November 2023 in *BMC Family Practice.*

Chapter Five presents the development of resources for GPs from Study Three, including: (a) the development of GP 'practice points'; (b) the co-design and co-delivery of a workshop for GPs entitled 'Raising awareness of family carers in general practice'; and (c) a small pilot test of the workshop. This chapter also presents the publication entitled '*Addressing the needs of family carers*' that was published in 'Forum'(the Journal of the Irish College of General Practitioners) in November, 2022. This professional journal is typically widely read and easily accessible to the 2,500 GPs in Ireland. The facilitator guide written to accompany the workshop is also presented in this chapter.

Chapter Six focuses on the development of resources for carers, outlining: (a) the development of a communications skills workshop entitled, “Communicating with Doctors – Empowerment Workshop for Family Carers”; (b) presenting the results of a pilot test of the workshop and (c) presenting the accompanying facilitators guide.

Finally, **Chapter Seven** provides a critical synthesis and discussion of the key findings emanating from all three studies, framed in the context of a review of the national and international literature pertaining to the support of family carers in community healthcare, with a specific focus on general practice. The strengths and limitations of the study will be outlined and some future research directions and practice and policy recommendations highlighted.

Chapter 2: Method

This chapter outlines the epistemological and ontological approach underpinning the research, as well as the overall study design. Given that this is a thesis by ‘publication’, the methodological details pertaining to Studies One and Two are covered in the included papers, but with additional information (i.e. not provided in the publications) outlined here. Study Three involved the development of resources so the full methodology therein is more appropriately presented in Chapters Five and Six, with the theoretical framework and funding outlined here. This chapter concludes with a description of other cross-cutting methodological issues, such as ethical considerations and researcher reflexivity.

2.1 Research Philosophy

“All knowledge is knowledge from some point of view” (Fishman, 1978, p.53)

The ways in which research is conducted in terms of its methods and research questions, is a reflection of the researcher’s epistemological stance or their understanding of the world (Feilzer Yvonne Martina, 2010). The research reported here employed a mixed methods sequential design conducted within an overall framework of ‘pragmatism’. While traditionally, research paradigms, such as positivism/post positivism and constructivism/interpretivism, were seen as the dominant (although opposing) world views, pragmatism has now become an alternative framework for research in the social sciences (Feilzer Yvonne Martina, 2010; Morgan, 2017). Historically, within the sciences, prominence was often given to the positivist approach, with an epistemological position that what “can be measured can be easily measured and what cannot be measured does not exist”, resulting in a focus on quantitative methodologies. However, the constructivist approach posited that reality is interpreted and that research should aim to discover underlying meanings, thereby resulting in an increasing emphasis on qualitative methods.

The pragmatist approach is based on the premise that the researcher should adopt the philosophical and/or methodological approach that works best for the topic being investigated (Hesse-Biber & Johnson, 2015a). It is often associated, therefore, with mixed or multiple methods of inquiry (Hesse-Biber & Johnson, 2015a). Indeed, pragmatism is often cited as the middle ground between positivism and constructivism (Morgan, 2017), with pragmatist scholars believing that reality is constantly renegotiated, thus rejecting the notion that social science enquiry can access reality by using a single scientific method (Kaushik & Walsh, 2019). As such, according to the pragmatist view, as the world is both real and socially constructed, "all knowledge is [thus] social knowledge" (Morgan, 2017). Within psychology, the term pragmatism dates back to the early psychologist, William James, who, in 1898, along with scholars from other disciplines (e.g. Charles Pierce, George Mead, and John Dewey) was the architect of the original philosophical perspective of pragmatism (Hesse-Biber & Johnson, 2015b). This perspective placed a strong emphasis on the research question and advocated for the use of a range of methods in order to best address the research problem (Hesse-Biber & Johnson, 2015b; Morgan, 2017).

2.2 Research Methodology

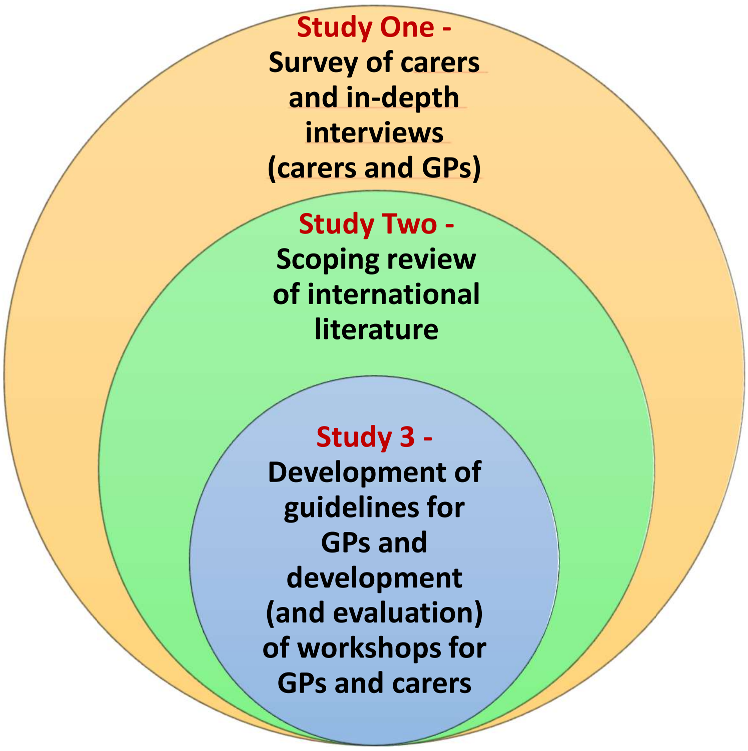
Recent decades have seen an increasing emphasis on mixed methods research (Theodorou, 2013), but with attendant debates and so-called 'paradigm wars' about whether philosophically different theoretical frameworks could be justifiably mixed (Onwuegbuzie & Leech, 2005). For example, Onwuegbuzie & Leech (2005) suggest that research based exclusively on a mono-method approach cannot be taken seriously. Indeed, to them, the mixing of methods allows for the strengths of each method to be used to better understand the social phenomena under investigation (Onwuegbuzie & Leech, 2005). Specifically, these authors argue that the use of mixed methods has been essential in understanding evidence based on the lived experience of participants, thereby allowing the researcher to investigate the research problem from both a macro and micro perspective (Onwuegbuzie & Leech, 2005).

The current research was based on a sequential mixed methods design involving three separate but inter-linked studies comprising: (1) a national survey of family carers and in-depth interviews with family carers and GPs (**Study One**); (2) a scoping review of the international literature (**Study Two);** and (3) the co-design and co-development of GP 'practice points' and workshops (plus pilot evaluations) for both GPs and family carers in collaboration with a PPI panel of carers and with the support of Family Carers Ireland (FCI), the largest carer support organisation in Ireland (**Study Three**). This design (see Figure 2.1) allowed for the "mixing" of quantitative and qualitative methods (i.e. in Stages One and Three) in order to understand the research problem more completely, and with the scoping review (Stage Two) subsequently undertaken to support the development of evidence-based resources which were identified from Stage One as being important for both GPs and carers.

This approach provided a broad perspective of the research problem (i.e. survey and scoping review), as well as more in-depth knowledge (interviews and PPI contribution), allowing for the lived experience of key stakeholders to be included and highlighted. The methodological details pertaining to each study, in turn, are described below.

Figure 2.1

Mixed method sequential design



2.3 Study One

Study One was conducted in two sequential stages which provided an initial snapshot or survey, of how carers in Ireland were experiencing health and well-being support from healthcare professionals, followed by more in-depth interviews with both GPs and carers. The two publications pertaining to this study are presented in Chapter Three. The first is a peer reviewed paper entitled 'Supporting family carers in Ireland: the role of the general practitioner' which describes the key findings from Study One and thus gives an insight into how both carers and GPs are positioned with regard to the support of carers. The second publication 'Promoting a 'Think Carer' approach in health and social care services: Identifying as a carer – Why is it important?' is a stakeholder accessible article which details some of the key findings in relation to carers' association with the term 'carer'. The following section provides some additional methodological details that are not included in either paper.

2.3.1 Rationale and theoretical framework

This was the first time (to our knowledge) that carers in Ireland had been asked about their own health in the context of their interactions with healthcare professionals. Therefore, a short survey was deemed important in the first instance, in order to provide a snapshot of the nature and extent of their experiences. As outlined earlier in Chapter One, SCT (Bandura, 1986) was used to inform the survey design and to examine, therefore, the interaction between various personal and environmental factors and behaviours associated with caring. For example, a number of measures (outlined below) were used to assess carers' self-reported health, psychological wellbeing, QoL and perceptions of stigma. Additional questions were included to assess carers' current behaviours in relation to their health and wellbeing (e.g. engagement with activities and help-seeking behaviours).

Environmental factors were examined through questions about the caring role and access to supports, while a number of Likert-style questions were also designed to understand carers' perceptions of, and engagement with, supports (e.g. 'To what extent do you feel you have the supports to adequately look after your own health and wellbeing?'). Caregiver Identity Theory (Montgomery et al., 2007) (described earlier in Chapter One) was also relevant to the design of Study One because it suggests that carers may not engage with the term 'carer' until much later in the caring journey and that this can have an impact on help-seeking behaviours and activities. Therefore, the survey also included a number of questions to explore carer identity (although it was beyond the focus of Study One to explore this in detail); for example, respondents were asked if they ever referred to themselves as a 'carer' when completing official documents.

2.3.2 Stage one - Online survey

The carer survey was administered online using Qualtrics (Qualtrics.com) (during August to September 2019), as it was felt that this offered a number of benefits over a traditional postal survey. Firstly, given the complexities of identifying as a carer, it was imperative that the survey was accessible to carers who may not currently identify with the carer role. This can be problematic as research often relies only on participant samples based on those who are receiving carer welfare payments, or who are members of carer support groups, thereby excluding those carers who are not engaged with such services or supports. Secondly, it was important that the online survey allowed for participation on a national level. Lastly, carers are often time poor due to their caring responsibilities and they may also may find it difficult to get to a post office or post box. The online survey allowed for completion at a time that was convenient to the participants and could be completed over a period of two weeks. It was hoped that this would promote greater participation. A pen-and-paper option was also offered to accommodate those who may not be comfortable with the online option.

2.3.3 Participants and settings

Prospective participants were required to be aged over 18 and to be providing care to a family member or loved one. A national convenience sample was recruited using the target audience features of social media platforms which allowed for the distribution of the survey across the country, thereby maximising reach. The use of social media in Ireland (and elsewhere) has become extremely popular in recent years, with 75% of Irish adults using Facebook on a regular basis and 30% using Twitter (McGarrity, 2019). For the purposes of this survey, therefore, a Facebook and Twitter account were set up for the CHERISH project, in order to facilitate recruitment while allowing for ease of distribution. However, it must be noted that while the use of social media offers several advantages, such as wide reach, rapid and cost-effective recruitment, and ease of access to diverse and potentially hard-to-reach audiences, there are also limitations relating to, for example, sampling bias and the generalisability of the findings. These are discussed in more detail in the concluding chapter.

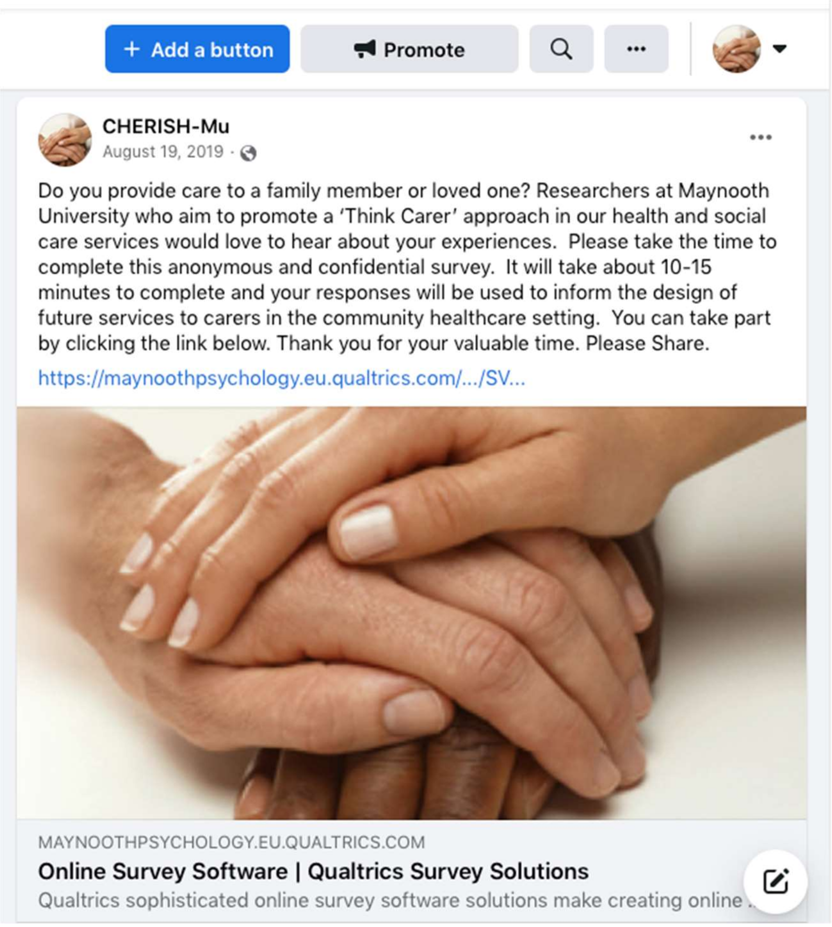
2.3.4 Procedure

The social media pages were set up several months in advance of survey distribution, to allow for the building of 'followers' and to share relevant information that would increase traffic to the page. An element of snowball sampling also occurred spontaneously by means of carers sharing and commenting on the survey.

In the case of Facebook, an invitation to take part and a link to the survey were posted (Figure 2.2). Sampling was also supported using the Facebook advertising features which allow for creating an 'audience', before distributing the survey for a small daily cost. The 'audience' group set up for the purposes of distributing the survey contained keywords of relevance, such as: 'disability rights', 'home care', 'special needs', 'Alzheimer's', 'cancer', 'Dementia', and 'Multiple Sclerosis'. These were chosen on the basis of reasons for providing care published by Care Alliance (Care Alliance Ireland, 2015). This allowed the post to appear on the pages of those who may search for information or websites related to these issues with the intent of capturing those who did not already identify as carers. Several carer organisations in Ireland also kindly agreed to share the survey invitation and link including Family Carers Ireland, Care Alliance, disability support groups, and Alzheimer's support groups.

Figure 2.2

Survey distribution on CHERISH project Facebook page



Do you provide care to a family member or loved one? Researchers at Maynooth University who aim to promote a 'Think Carer' approach in our health and social care services would love to hear about your experiences. Please take the time to complete this anonymous and confidential survey. It will take about 10-15 minutes to complete and your responses will be used to inform the design of future services to carers in the community healthcare setting. You can take part by clicking the link below. Thank you for your valuable time. Please Share.

https://maynoothpsychology.eu.qualtrics.com/.../SV...

MAYNOOTHPSYCHOLOGY.EU.QUALTRICS.COM

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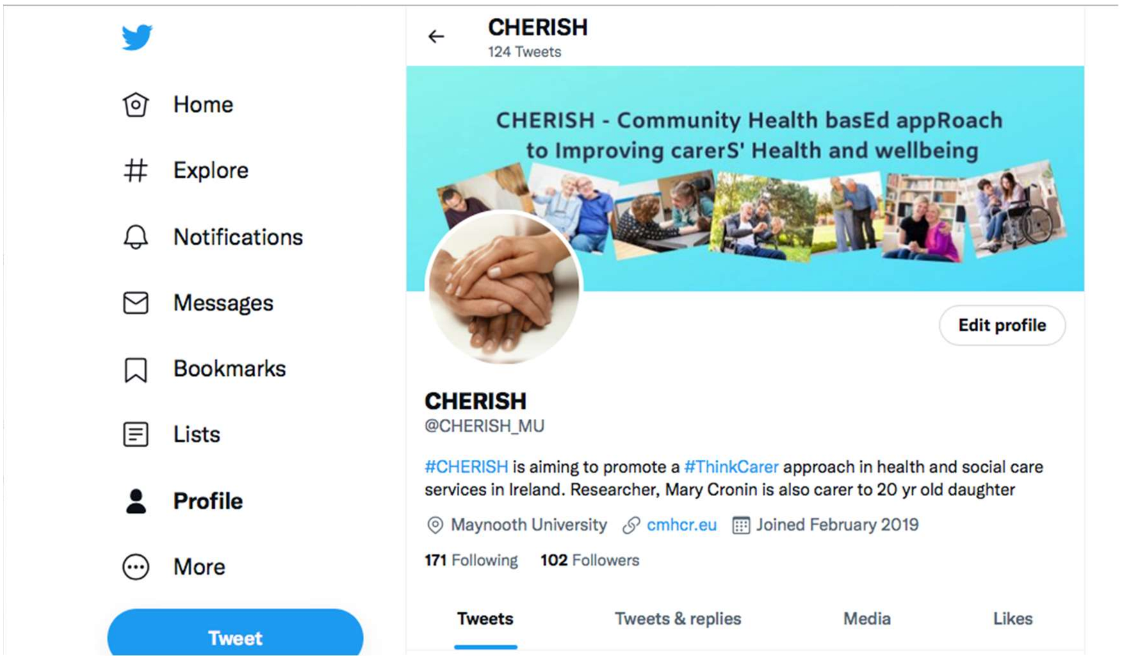
An invitation to take part in the research project, along with a link to the Qualtrics survey, was also posted on the CHERISH Twitter page (Figure 2.3). This involved the use of relevant hashtags (e.g. #carers, #dementia, #disability, #carecantwait) to ensure that the post would be seen by the relevant audience. On completion of the survey, respondents were invited to take part in an in-depth interview.

Figure 2.3

Research project twitter page



CHERISH - Community Health basEd appRoach to Improving carerS' Health and wellbeing

CHERISH
@CHERISH_MU

#CHERISH is aiming to promote a #ThinkCarer approach in health and social care services in Ireland. Researcher, Mary Cronin is also carer to 20 yr old daughter

Maynooth University cmhcr.eu Joined February 2019

171 Following 102 Followers

2.3.5 Measures

The battery of measures incorporated into the survey are briefly described in the paper included in Chapter Three, but additional information is provided here for completeness. The survey was designed following a wide-ranging review of the academic and grey literature, during which a number of possible measures for use in the study were identified and critically reviewed in collaboration with the research supervisor. The final survey included a brief Background Questionnaire (BQ) plus four psychometrically robust scales (Appendix A1.1), each of which is described below.

2.3.5.1 Background Questionnaire

The BQ included information such as age and gender, reason for providing care, duration of caring role, and caring hours. In addition, respondents were asked a number of Likert scale questions specific to identifying as a carer and their experiences with health care professionals. Several open-ended questions were also included to allow those who provide care to voice their experiences. The survey took approximately 10-15 minutes to complete.

2.3.5.2 The General Health Questionnaire-12

The 12-item version of the *General Health Questionnaire-12* (GHQ-12) was used to assess psychological distress in the sample. This was selected because it is short and easy to complete and has been validated in many countries and languages (Salama-Younes et al., 2009). It has also been widely used in research on carer health and wellbeing (Burrows & Gannon, 2013) and caring related to specific conditions such as intellectual disability (Emerson et al., 2004), cancer (Grande et al., 2017), and autism (Salomone et al., 2018).

The *GHQ-12* contains 12 items which require the respondent to indicate the degree to which they have experienced a particular feeling or behaviour during the last four weeks (e.g. "lost sleep due to worry"). The scale can be scored using either a bimodal or Likert scoring, the latter of which was used here (i.e. scoring 0-1-2-3 for the four responses) because it is considered the preferred option when assessing the severity of psychological distress (Goldberg & Hillier, 1979) and has previously been used in an Irish general practice context (Doherty & Kartalova-O'Doherty, 2010). A score of 1–10 indicates 'low psychological distress'; 11–12 is 'typical'; 13–15 is 'more than typical'; 16–20 shows 'evidence of psychological distress'; while scores over 20 indicate 'severe distress' (Goldberg et al., 1997). The robust reliability and validity of the GHQ-12 has been demonstrated in a large number of studies (Lundin et al., 2016; Picardi et al., 2001; Salama-Younes et al., 2009; Sánchez-López & Dresch, 2008). For example, two population-based studies in Spain (*N* =1001) (Sánchez-López, 2008) and Sweden (*N* = 484) (Lundin et al. 2016) reported good validity and internal consistency (Cronbach's alphas of .76 and .86 respectively).

2.3.5.3 Stigma Impact Scale (SIS)

The 24-item *Stigma Impact Scale* (SIS) was used to assess perceived stigma. The SIS comprises four subscales: ‘Social Rejection’ (9 items), ‘Financial Insecurity’ (3 items), 'Internalised Shame’ (5 items), and ‘Social Isolation’ (7 items). The Cronbach alpha coefficients for these subscales has been reported to range from .85 to .90 (Fife & Wright, 2000). Each item is scored on a four-point scale from ‘strongly agree’ to ‘strongly disagree’, with a rating of ‘4’ representing the strongest perceptions of being stigmatised. A fifth, ‘not applicable’ option has a ‘0’ value, allowing for a total scale score ranging from 0 to 96 (Burgener & Berger, 2008). Some questions were negatively worded and, therefore, scores were reversed for the relevant questions. Some of the wording of the items was adapted to improve their applicability to many diverse caring roles; For example, the item “Due to my family member’s illness, I have a sense of being unequal in my relationship with others” was re-worded to: “Due to my caring role, I have a sense of being unequal in my relationships with others”.

The SIS scale was initially developed by Fife and Wright, (2000) for use with people with HIV/AIDS and cancer and subsequently found to be reliable and valid in measuring perceived stigma for people diagnosed with progressive neurological disease (Burgener & Berger, 2008) and Lupus (Sehlo & Bahlas, 2013). The SIS has also been validated in a cross cultural study with people living with mental illness (Mileva et al., 2013). A caregiver version was adapted by Liu (Liu, 2011) to measure the stigma-related impact of caring for a person with dementia (Cronbach alpha of.92). The Cronbach alpha coefficient for the current study was .87, indicating good internal consistency.

2.3.5.4 Perceptions of Stigmatisation by Others for Seeking Help scale

The *Perceptions of Stigmatisation by Others for Seeking Help* (PSOSH) scale was used to measure perceived stigma when accessing support for psychological distress. It contains five items/statements regarding how the respondent believes others will react, should they seek counselling support. Responses are scored on a five-point scale from 1 ('not at all') to 5 ('a great deal'), to yield a total score ranging from 5 to 25, with higher scores indicating higher levels of perceived stigma from the respondent's social network (Vogel et al., 2009). The PSOSH has been shown to have good reliability and validity for those experiencing mental ill health (reliability .91 and test-retest reliability .82), (Vogel et al., 2009) and has been validated cross-culturally (Vogel et al., 2019). In the current study the PSOSH showed good internal consistency with a Cronbach alpha coefficient of .94.

2.3.5.5 Adult Carer Quality of life AC-QOL questionnaire

The *Adult Carer Quality of Life Questionnaire* (AC-QoL) was specifically developed for use with adult carers in order to measure quality of life (QoL) (Elwick et al., 2010), and to capture both the negative and positive aspects of the caregiving role. It has the added benefit of being applicable to all carers (Joseph et al., 2012) and was, therefore, ideally suited for use in the present study. It comprises forty items across eight domains of quality of life including: support for caring (including professional and social support); caring choice; caring stress; money matters; personal growth; sense of value; ability to care; and carer satisfaction (see Table 2.1 for further information). Sample items include "My needs as a carer are considered by professionals", "I am physically exhausted by caring", and "I feel valued by the person I look after". The AC-QOL measure has been found to be a valid and reliable measure of carer quality of life for carers of stroke patients, and parents caring for disabled children (Mei et al., 2017; Negri et al., 2019), with a reported Cronbach's alpha of .92 and .93 respectively.

Similarly, Joseph et al. 2012, reported good validity and strong internal consistency (Cronbach's alpha .94) in their UK study with carers ($N = 385$).

Table 2.1

The Adult Carer Quality of Life Questionnaire (AC-QoL) subscales

Subscale	Measuring
1. Support for caring	The level of emotional, practical and professional support carers perceive that they receive
2. Caring choice	The extent to which carers feel that they have control over their lives and are able to choose ventures outside caring, such as social activities.
3. Caring stress	The mental and physical stress from caring, such as exhaustion and depression.
4. Money matters	How carers feel about their financial situation.
5. Personal growth	How the carer feels they have grown and developed, and the positive experience of their caring role
6. Sense of value	The extent to which the carer feels they are valued and respected, including the relationship between the carer and the care recipient
7. Ability to care	The extent to which the carer is able to provide care for the person they care for, how they cope with the caring role, and how they feel about their competency to care
8. Carer satisfaction	The extent to which the carer is satisfied with their life and role as a carer, and how they feel about being a carer.

2.3.5.6 Measure of help-seeking activities

Respondents' engagement with activities that may help/support them in their caring role, was assessed using a scale adapted for this study. The measure of help-seeking activities is based on the work of the large (n = 4,037), US American Association of Retired Persons (AARP) Caregiver Identity Study (Kutner, 2001). The AARP scale, 'Caregiving Activities

Ever Performed', was the key measure used in the AARP study and was adapted for use in this research. The measure comprises eight statements, beginning with the primary/lead question: 'Since taking up your caring responsibilities, have you ever...', and then followed by items such as 'read brochures, leaflets or books about how to cope', and 'talked to a healthcare professional about the impact caring is having on your own health and wellbeing'. Each item is scored from one ('often') to five ('never'). in the direction of lower levels of engagement with help-seeking activities. Although no information regarding reliability was reported by the AARP, the scale has been developed for use with carers, has been used with a large sample, and the wording and items were overall well suited to this research.

2.3.6 Data Analysis

The data were exported and analysed using IBM SPSS Statistics software (ibm.com/spss). The data were initially 'screened and cleaned' before performing a number of descriptive and inferential statistics on the numerical data. Statistical tests included independent t-tests, chi squared tests, correlations, ANOVAs and multiple regression. Preliminary analyses were conducted and, where necessary, non-parametric tests were chosen. Responses to open-ended questions (four) were collated and analysed 'semi-qualitatively' using summative content analysis (Hsieh & Shannon, 2005). This approach is often used for open-ended survey questions, and involves a process through which key words are identified and quantified (McKenna et al., 2017).

2.3.7 ***Stage two: In-depth interviews***

The interview schedules used in the qualitative stage of the study, were developed, on the basis of a literature review, although the content was also informed by the stage one findings. The GP interview guide (Appendix A1.2) was reviewed by a practicing GP, who was invited to consult on the suitability of the interview content. The GP was recruited from a GP practice local to the researcher, was not a participant, and was not involved in the research thereafter. Following the consultation, some minor adjustments were made. For example, the GP suggested that interviews should be no more than approximately 30 minutes given that GPs are time poor and, therefore, less likely than most other occupational groups to take part in research. However, on reflection, after the onset of COVID-19, this was further reduced to 20 minutes to increase the likelihood of participation. The GP also suggested that the use of telephone interviews may help to increase participation. The interviews explored, among other things, GPs' awareness of, and current support strategies when they encounter family carers in their practice.

Likewise, a carer was invited to review the carer interview schedule (Appendix A1.3). The carer was caring for a parent (mother) with dementia and diabetes, and was known to the researcher. No changes were made to the questionnaire after the review and the carer who consulted did not participate in the interviews or PPI panel. The carer interviews explored associations with the term carer, the process of seeking help along with communication in healthcare settings.

The qualitative research review guidelines (RATS) were used to guide the interview process (Clark, 2003). Due to COVID-19 and the attendant restrictions and lockdowns (as well as the pressures on both carers and GPs), all interviews were conducted and recorded over the phone between March 12th and June 9th 2020, and then transcribed in full thereafter. As outlined in the publication included in Chapter Three, carer and GP interviewees were recruited respectively through the online survey and a website resource for GPs in Ireland called GPbuddy.ie. Information sheets and consent forms (Appendix A1.4) were sent to participants via email, after which they were signed, scanned and returned either via email or by post. A mutually convenient time was scheduled for the telephone interviews and, at the start of each interview, the researcher again outlined the purpose of the study and explained details around confidentiality and anonymity, as well as giving the opportunity for participants to ask any questions.

2.3.7.1 Framework Analysis

Framework Analysis, which is widely used in medical and healthcare research (Gale et al., 2013), was used to analyse the qualitative data collected. This approach to qualitative data analysis, was developed in the 1980s in response to the need for a highly structured systematic framework in social policy research and since then, the approach has become increasingly popular in medical and health research (Cameron et al., 2013; Collaço et al., 2021; Crocker et al., 2020; Gale et al., 2013) and also in psychology (Parkinson et al., 2016) due to its ability to produce credible and relevant findings that are particularly relevant to informing health service and health policy development (Gale et al., 2013). This approach was seen as more suitable, therefore, for this study than other commonly used approaches, although it sits comfortably within the wider family of analysis methods generally referred to as 'thematic analysis' (Gale et al., 2013). As with other similar analytical methods, it allows the researcher to immerse themselves in the data, allowing for an increased understanding of participant experiences (Hackett A. & Strickland, 2017). However, as outlined below, it was considered to offer several other advantages in the context of the current study,

Although not aligned with any particular epistemological or ontological approach (Hackett A. & Strickland, 2017), Framework Analysis (FWA) was considered particularly appropriate for the current research due to its highly structured format where "there is a clear audit trail from original raw data to final themes" (Gale et al., 2013).

It was felt that this was particularly important given the pragmatic underpinnings of the research and the ultimate aim of developing practical resources for GPs and carers. This structure and transparency, along with the unique feature of a data matrix that allowed for comparisons and associations within cases (Gale et al., 2013), were thought to be important features when compared to other approaches.

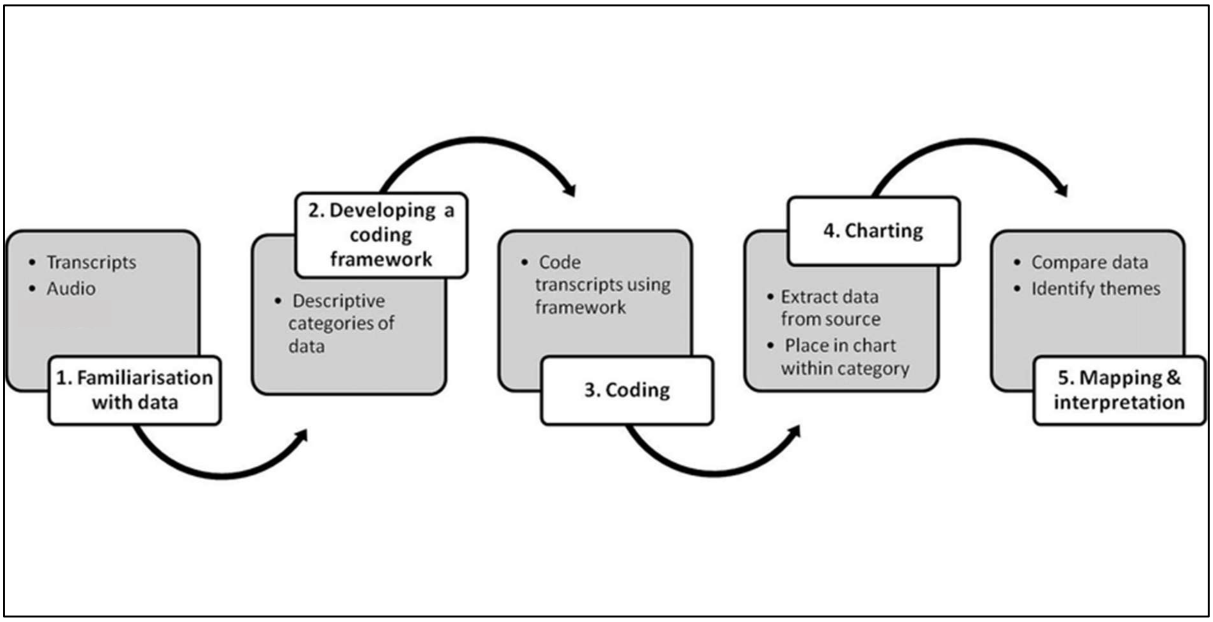
For example, Interpretative Phenomenological Analysis (IPA), which is widely used in health psychology, aims to understand the meanings of people's experience of a particular phenomenon and how they make sense of the experience (Smith & Fieldsend, 2021). However, whilst we were interested in the lived experience of the carers, we were not seeking an idiographic understanding as such (Parkinson et al., 2016); rather, we sought to explore the nature of carers' relationship with HCPs in order to inform the development of practical resources. The need for a homogenous sample for IPA (Parkinson et al., 2016) was also problematic for our design because we aimed to capture the experiences of carers, who notwithstanding the commonality of caring, were a diverse group in terms of age, years caring, caring role, and number of people for whom care was being provided.

Thematic Analysis (Braun & Clarke, 2006) – or Reflexive Thematic Analysis as it is now described (Braun & Clarke, 2019) - also offered an alternative approach. This shares some similarities with FWA, in that it is used across varied epistemological and ontological frameworks, can be applied inductively (bottom up) and deductively (top down) and follows a clear step-by-step process. However, the development of an analytical thematic framework, a unique feature of FWA, provided a good-fit with the aims of our research, as we had pre-existing themes to explore based on the stage one survey data and the relevant policy background. This framework can also incorporate both a priori and emergent data-driven themes (Parkinson et al., 2016). Furthermore, we felt that the four broad categories of research questions underpinning FWA ('Contextual', 'Diagnostic', 'Evaluative', 'Strategic') as described by Richie and Spencer (1994), were more in line with our research question and objectives. For example, 'diagnostic' questions exploring the reasons for, or causes of, what exists, fit well with our questions regarding the barriers and facilitators to carers receiving HCP support. Additionally, the question regarding how carers were experiencing supports and how these are provided by GPs, is consistent with 'evaluative' type question deemed suitable for FWA (Parkinson et al., 2016).

Specifically, FWA involves a five-stage process of: (1) initial familiarisation with the data; (2) identification of a thematic framework; (3) indexing; (4) charting; and (5) mapping and interpretation (Ritchie et al., 1994). The analytical process in the current study, was supported by the use of NVivo (NVivo release 1.3.2). The separate but highly interconnected stages of the analysis process (Figure 2.4) allowed the researcher to determine meaning, importance, and connections (Ritchie et al., 2003). Further details on each separate stage, are provided below.

Figure 2.4

Five-step process in Framework Analysis, based on Ritchie and Spencer (1994).

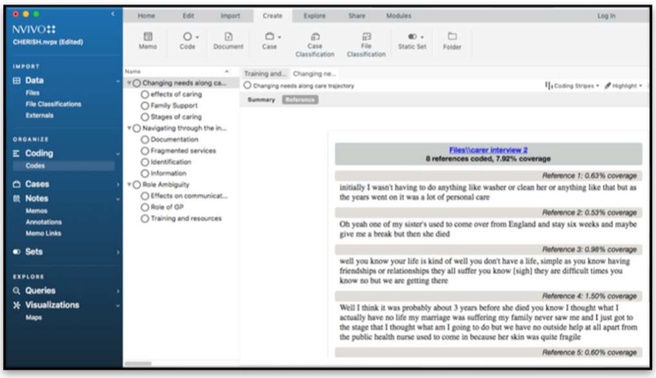


Adapted from Johnson et al. 2017

1. ***Familiarisation with the data*** involved full immersion with the data by listening and re-listening to interview audio recordings throughout the process of verbatim transcription. Following transcription, the audio recordings were again reviewed and the transcripts re-read several times. Notes were taken at this point to support the thematic framework development.
2. ***Developing a coding framework*** was done through several iterations of coding until no additional codes emerged. The development of the thematic framework, a unique feature of Framework Analysis, was informed by the earlier review of the literature as well as the stage one findings. Therefore, although deductive in its fundamental development, the thematic framework was implemented in parallel to an inductive approach to the data.
3. ***Coding*** (indexing) involved applying the analytical framework developed in step 2 to the subsequent transcripts. This involved working through the transcripts and highlighting text to be assigned to a framework category in an iterative process involving re-immersion in the transcripts, and often returning to prior transcripts for a re-read (see Figure 2.5 for an example of indexing in NVivo).

Figure 2.5

An extract from NVivo showing indexing process



Files\\carer interview 2
8 references coded, 7.92% coverage

Reference 1: 0.63% coverage

initially I wasn't having to do anything like washer or clean her or anything like that but as the years went on it was a lot of personal care

Reference 2: 0.53% coverage

Oh yeah one of my sister's used to come over from England and stay six weeks and maybe give me a break but then she died

Reference 3: 0.98% coverage

well you know your life is kind of well you don't have a life, simple as you know having friendships or relationships they all suffer you know [sigh] they are difficult times you know no but we are getting there

Reference 4: 1.50% coverage

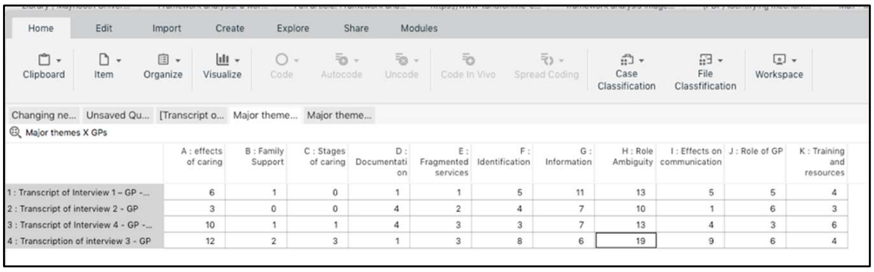
Well I think it was probably about 3 years before she died you know I thought what I actually have no life my marriage was suffering my family never saw me and I just got to the stage that I thought what am I going to do but we have no outside help at all apart from the public health nurse used to come in because her skin was quite fragile

Reference 5: 0.60% coverage

4. ***Charting*** entailed charting the data into a framework matrix that featured rows (cases) and columns (codes) of summarised data allowing for comparing across and within the data. Figure 2.6 illustrates an example of this process using NVivo software (showing a summary of the major themes in the GP interviews) and an audit trail is also provided in Appendix A1.8 based on the transcript and analysis of one full GP interview.

Figure 2.6

Extract from NVivo showing data matrix



Major themes X GPs

	A : effects of caring	B : Family Support	C : Stages of caring	D : Documentation	E : Fragmented services	F : Identification	G : Information	H : Role Ambiguity	I : Effects on communication	J : Role of GP	K : Training and resources
1 : Transcript of Interview 1 – GP -...	6	1	0	1	1	5	11	13	5	5	4
2 : Transcript of interview 2 - GP	3	0	0	4	2	4	7	10	1	6	3
3 : Transcript of Interview 4 - GP -...	10	1	1	4	3	3	7	13	4	3	6
4 : Transcription of interview 3 - GP	12	2	3	1	3	8	6	19	9	6	4

5. ***Mapping and interpretation,*** the final stage of the analysis, involved immersion in the data using the charts/matrix created, in order to find patterns, comparisons and associations and to identify major overarching themes and sub themes.

2.4 Study Two

Study Two provided a broader international perspective and sought to identify and critique guidelines or recommendations that are currently available to support GPs in their role with family carers. As mentioned earlier, this study involved a scoping review of the international literature. Scoping reviews can provide evidence synthesis “that address and inform practice in the field” (Munn et al., 2018) and in the context of the current research, this enabled us to explore or ‘scope’ the broad topic of clinical guidance in respect of family carers in both the international peer reviewed and grey literature. While less rigorous than systematic reviews, which generally address the effectiveness of interventions and often focus on high quality studies such as randomised controlled trials (RCTs) (Arksey & O'Malley, 2005), scoping reviews provide a useful systematic, transparent and rigorous approach to reviewing relevant literature (Munn et al., 2018).

Daudt et al. (2013, p 8) usefully define a scoping study as research synthesis that can "map the literature" on a particular topic or research area and provide an opportunity to identify key concepts; gaps in the research; and types and sources of evidence to inform practice, policymaking, and research*"*. These kinds of studies are considered to be particularly useful in exploring areas that have not been comprehensively reviewed, where the evidence is only emerging (Larkin et al., 2019) and where knowledge is based on a broad range of study designs and methodologies (Arksey & O'Malley, 2005). All of these apply in the context of the current study because, while there has been some work on the barriers and facilitators to supporting carers in general practice (Parmar et al., 2020), there is little published literature on guidance for GPs that has been implemented or tested and very few if any RCTs. Thus, a scoping review was considered ideal for purposes of the present study.

2.4.1 Procedure

The scoping review was conducted in line with the framework outlined by Arskey and O'Malley (2005) and involved a number of stages including: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising and reporting the results; and (6) a consultation exercise with stakeholders. A detailed account of the procedure is provided in the published paper in Chapter Four, but additional supplementary information is outlined below.

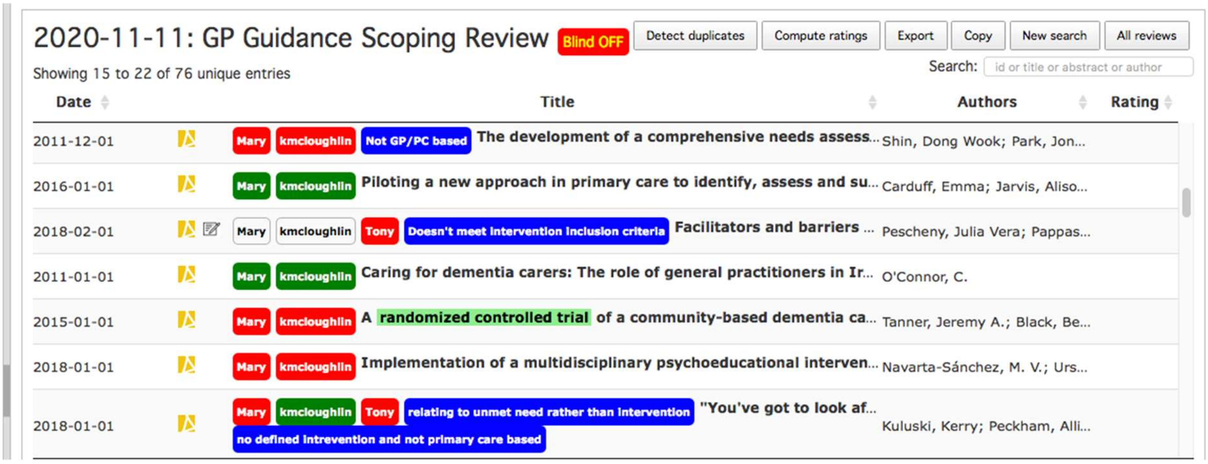
As outlined in the paper in Chapter Four, the evidence-based model for framing a research question, i.e. Population, Intervention, Comparison, Outcome, Setting (PICOS) typically used in systematic reviews, was employed to formulate the research questions and appropriate search terms (Hegarty et al., 2015). The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist was used to guide the review process (Tricco et al., 2018). Search terms were developed from an initial literature review which included previous systematic and scoping reviews related to the core PICOS elements. For example, these included the terms 'GP' (Karimi-Shahanjarini et al., 2019; Parmar et al., 2020), 'Family Carer' (Parmar et al., 2019; Burridge, 2017), 'Clinical Guidance' (Hegarty et al., 2015; Ruppar et al., 2015; Vernooij et al., 2014) and 'Intervention' (Heslin et al., 2016).

The current research also incorporated a systematic team approach as recommended by Levac et al. (2010), in order to ensure rigour. The research team consisted of members with expertise in the broad topic and evidence synthesis. The lead researcher (Mary Cronin) was first reviewer, a representative from FCI Dr. Kathy McLoughlin (former Head of Innovation & Strategic Partnerships), was second reviewer, while the third reviewer, Dr Tony Foley is a practising GP and Professor of General Practice at University College Cork (UCC) in Ireland.

The lead researcher consulted with a Maynooth University librarian, as and when needed throughout the review process. The protocol was written by the lead researcher in collaboration with the team and research questions, search terms and selection of databases were also agreed by the team. Searches were carried out during September-November 2020 on databases of peer-reviewed literature and sources of grey literature including CINAHL, Medline, PsycINFO, Lenus.ie, Google (first 200 results), OpenGrey, NICE, Cochrane, SIGN and Kingsfund (see Appendix A2.1 for search terms). Inclusion and exclusion criteria are documented in the method section of the publication, and the search process is outlined in the PRISMA flow diagram in the results section. Papers were initially imported into Mendeley software tool for data management purposes as well as for title and abstract screening (i.e. for removal of obviously irrelevant papers). Full texts for proposed included papers were retrieved by the researcher and imported into Rayyan software for full text review by both the first and second reviewer. Where there was any disagreement, the third reviewer and supervisor were consulted. The decision making process in the event of a conflict was agreed upon by the research team and PhD supervisor in advance (Table 2.2). Figure 2.7 provides an example of the review process using Rayyan software.

Figure 2.7

Extract of the team review process using Rayyan software



2020-11-11: GP Guidance Scoping Review

Showing 15 to 22 of 76 unique entries

Date	Title	Authors	Rating
2011-12-01	Mary kmcloughlin Not GP/PC based The development of a comprehensive needs assess...	Shin, Dong Wook; Park, Jon...	
2016-01-01	Mary kmcloughlin Piloting a new approach in primary care to identify, assess and su...	Carduff, Emma; Jarvis, Aliso...	
2018-02-01	Mary kmcloughlin Tony Doesn't meet intervention inclusion criteria Facilitators and barriers ...	Pescheny, Julia Vera; Pappas...	
2011-01-01	Mary kmcloughlin Caring for dementia carers: The role of general practitioners in Ir...	O'Connor, C.	
2015-01-01	Mary kmcloughlin A randomized controlled trial of a community-based dementia ca...	Tanner, Jeremy A.; Black, Be...	
2018-01-01	Mary kmcloughlin Implementation of a multidisciplinary psychoeducational interven...	Navarta-Sánchez, M. V.; Urs...	
2018-01-01	Mary kmcloughlin Tony relating to unmet need rather than intervention no defined intrevention and not primary care based "You've got to look af...	Kuluski, Kerry; Peckham, Alli...	

Table 2.2

The reviewers decision making process

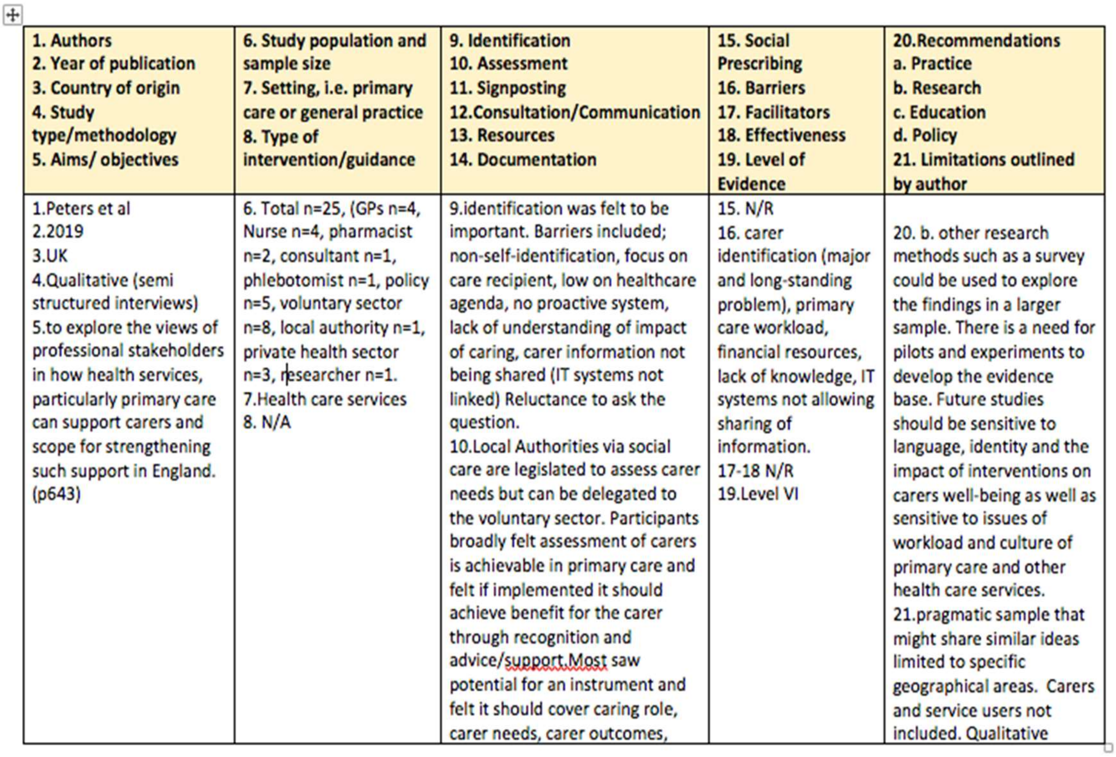
Maybe + Yes	=	Yes
Maybe + No	=	No
Maybe + Maybe	=	Maybe
		⬇
		Ask 3rd reviewer

Following the study selection procedure, the charting process involved the development by the lead researcher of an initial chart that was then piloted by both the first and second reviewers, with amendments made as necessary. Piloting resulted in the addition of a section for charting findings in relation to practice documentation, as shown in figure 2.8 (point 14).

Data extraction involved reading full texts and extracting the key characteristics of each included study, as informed by the developed chart.

Figure 2.8

Extract from charting process



1. Authors **2. Year of publication** **3. Country of origin** **4. Study type/methodology** **5. Aims/ objectives**	**6. Study population and sample size** **7. Setting, i.e. primary care or general practice** **8. Type of intervention/guidance**	**9. Identification** **10. Assessment** **11. Signposting** **12.Consultation/Communication** **13. Resources** **14. Documentation**	**15. Social Prescribing** **16. Barriers** **17. Facilitators** **18. Effectiveness** **19. Level of Evidence**	**20.Recommendations** **a. Practice** **b. Research** **c. Education** **d. Policy** **21. Limitations outlined by author**
1.Peters et al 2.2019 3.UK 4.Qualitative (semi structured interviews) 5.to explore the views of professional stakeholders in how health services, particularly primary care can support carers and scope for strengthening such support in England. (p643)	6. Total n=25, (GPs n=4, Nurse n=4, pharmacist n=2, consultant n=1, phlebotomist n=1, policy n=5, voluntary sector n=8, local authority n=1, private health sector n=3, researcher n=1. 7.Health care services 8. N/A	9.identification was felt to be important. Barriers included; non-self-identification, focus on care recipient, low on healthcare agenda, no proactive system, lack of understanding of impact of caring, carer information not being shared (IT systems not linked) Reluctance to ask the question. 10.Local Authorities via social care are legislated to assess carer needs but can be delegated to the voluntary sector. Participants broadly felt assessment of carers is achievable in primary care and felt if implemented it should achieve benefit for the carer through recognition and advice/support.Most saw potential for an instrument and felt it should cover caring role, carer needs, carer outcomes,	15. N/R 16. carer identification (major and long-standing problem), primary care workload, financial resources, lack of knowledge, IT systems not allowing sharing of information. 17-18 N/R 19.Level VI	20. b. other research methods such as a survey could be used to explore the findings in a larger sample. There is a need for pilots and experiments to develop the evidence base. Future studies should be sensitive to language, identity and the impact of interventions on carers well-being as well as sensitive to issues of workload and culture of primary care and other health care services. 21.pragmatic sample that might share similar ideas limited to specific geographical areas. Carers and service users not included. Qualitative

2.5 Study Three

The third and final study was conducted to help utilise the knowledge and findings from Studies One and Two in order to help promote a ‘Think Carer’ approach in Ireland’s primary care services by increasing awareness, promoting meaningful engagement, and translating knowledge to support family carers presenting to general practice. The study involved two separate, but related, stages that were implemented both sequentially and in parallel over the course of Study Three, culminating in a number of key outputs including: (1) practice guidelines for GPs to support them in their role with family carers (see Chapter Five); and (2) workshop resources for both GPs and carers co-designed and co-developed in collaboration with a panel of carers and with FCI. Importantly, this final stage of the project was completed with the involvement of a diverse group of five family carers who worked with the researcher in a Public Patient Involvement (PPI) capacity. All activities were underpinned by co-design and engagement principles in line with the Campus Engage Engaged Research Framework (Campus Engage, 2018). A brief note on funding and the theoretical underpinnings of Study Three are included here, but with fuller details of developing both GP and carer resources (including PPI contributions) described (more appropriately) in Chapters Five and Six.

2.5.1 New Foundations funding

During the process of development and publication of the GP practice points, an application to the Irish Research Council New Foundations grant scheme was developed and submitted by the team (led by the lead researcher) with the support of FCI. The aim of the application was to secure funding to support the completion of the subsequent development of workshop materials, delivery and pilot evaluation. The New Foundations grant scheme is designed to support the pursuit of research, networking or dissemination activities across all disciplines and in partnership with government departments and other agencies/organisations In the case of the current study, funding was successfully secured under *Strand 1a (Enhancing Civic Society)* which supports “small, discrete collaborative projects between researchers and civic society groups in the community and voluntary sector”. The award was for a 9-month period, from May 2021 to December 2021, with the researcher assuming the role of Research Assistant (with the supervisor as Principal Investigator as required under the terms of the scheme). A small panel of carers was recruited to inform the work and to participate in a public and patient involvement (PPI) capacity, in keeping with the IRC objectives regarding civic engagement.

2.5.2. The Public Patient Involvement (PPI) process

Study Three involved the inclusion and empowerment of family carers as key stakeholders of the project. This was achieved by recruiting five family carers in a Public Patient Involvement (PPI) capacity to support co-design, co-development, and co-facilitation. The recruitment of the PPI panel was co-ordinated by FCI, and all PPI participants were provided with information sheets and provided their written informed consent to be involved. (Appendix A3.1). The carers occupied a diverse range of caring roles, as shown in Table 2.3.

Table 2.3

Public and Patient Involvement (PPI) Panel

Reason for caring	**Relationship to care recipient**
Disability	Mother
Complications of diabetes	Wife
Dementia	Wife
Autism	Mother
Cancer	Son

*Each panel member received a €25 euro voucher as a token of thanks for their participation

In the first instance, the PPI panel were invited to attend an ‘induction workshop’ to explain the research and to discuss the nature and extent of their involvement. This included a number of key elements including:

- An overview of the research and findings, to date
- A discussion of GP and carer resources
- The proposed PPI panel involvement (explaining their proposed role and inviting discussion)
- Discussion of other project-related PPI opportunities, for example co-facilitating during workshop delivery.

Following induction, the PPI panel participated in two group discussions, one to review the GP practice points, GP workshop (content, and delivery) and another to review the carer workshop content and delivery. A schedule of questions was prepared prior to the group discussions in order to guide the conversation (Appendix A3.2). The consultation with the PPI panel was audio recorded with permission and again, written informed consent was obtained from all participants and the findings used (along with detailed notes) to inform the design and development of three key resources, i.e. the GP practice points, carer workshop, and GP workshop.

2.5.3 Theoretical frameworks

2.5.3.1 GP workshop

The small-scale pilot evaluation of the GP workshop was informed by the Theory of Planned Behaviour (TPB), previously used for research in general practice (Rashidian & Russell, 2012; Williams et al., 2015) and other health care settings (Kortteisto et al., 2010). Therefore, the GP workshop was designed to influence the GPs' intention to support family carers when they present in clinical practice. According to the TPB, intention is preceded by other key factors such as attitude (i.e. toward the behaviour), subjective norms (i.e. about the behaviour), perceived behavioural control (i.e. of the behaviour) and finally intention (i.e. to perform the behaviour). GP *attitudes* to supporting carers was also addressed in the workshop by including key information about the extent and impact of caring in Ireland as well as providing information on how to manage the consultation and signpost carers' to supports. The workshop also aimed to influence *subjective norms* about supporting family carers by including information on GP guidelines from other countries such as the UK, and discussing the potential role of the GP. The role of the GP was further highlighted by the presentation of a case-based example by the co-facilitating GP. In addition, international literature from GP professional bodies was included in the materials along with the finding from the CHERISH study. Lastly, *perceived behavioural control* was addressed by providing guidance on how to support carers as well as a demonstration of current supports available through the national carer NGO, Family Carers Ireland.

Following the workshop, a questionnaire was devised for use in the pilot testing of the GP workshop; this was also based on the three key elements of the TPB (Francis et al., 2004). For example, it included statements on attitudes (e.g. Supporting family carers is not part of the GP role), subjective norm (e.g. My GP colleagues view the identification and support of family carers as an important part of their day-to-day work), and perceived behavioural control (In general, I am confident I have the skills to meet the needs of family carers) (see Appendix 3.6).

2.5.3.2 Carer Empowerment Workshop

The theoretical framework employed to inform the pilot evaluation of the carer empowerment workshop, was Bandura's Self-efficacy Model (Bandura, 1997); this refers to an individual's belief in his/her capacity to manage behaviours and performance in a given situation and aims to: (1) identify a discrepancy between current and desired behaviours; (2) model the desired behaviour; (3) rehearse the desired communication behaviour; and (4) receive constructive, positive feedback. Self-efficacy is widely used as a theoretical model in healthcare settings. For example, Martin et al. (2016) developed a programme called Med Wise, to support older adults in having conversations with their pharmacist about their medications (Martin et al., 2016). The Med Wise programme was later adapted by Smith et al. (2018) to support carers to have conversations with healthcare professionals regarding the needs of the care recipient. Similarly, Moore (2008) used the theory of self-efficacy to support caregivers to speak about care recipients' health needs (Moore, 2008) while the model also been used to examine doctor-patient communication (Capone & Petrillo, 2014).

The workshop also incorporated a self-directed approach to learning as set out by Knowles' (1984, as cited in Moore, 2008) adult learning theory. Adult learning theory incorporates principles such as an individual's need to know why they are learning something, learning being approached as problem solving, adults being granted the opportunity to learn experientially, whilst also acknowledging that adults learn best when the core issue is of immediate value (Moore, 2008). Knowles et al. (1998) further propose that adult learners' previous experience needs to be respected and built upon throughout the process.

2.6 Ethical considerations

This research was conducted in line with the Psychological Society of Ireland's Code of Professional Ethics that includes four overall principles encapsulating a large number of ethical standards (Psychological Society of Ireland, 2019). These include respect for the rights and dignity of the person, competence, responsibility, and integrity. Ethical approval for this study was granted by the Maynooth University Social Research Ethics Subcommittee in 2018 (SRESC-2019-017, Appendix A1.5).

2.6.1 Informed consent

Participants in Study One who completed the online survey were given information about the research at the start of the survey and were asked to tick a box to indicate that they agreed to give consent for their participation. Those completing a paper-and-pencil version of the survey were also provided with a detailed Information Sheet (Appendix A1.4) and asked to provide their written informed consent (Appendix A1.4). Those who agreed to be interviewed were provided with a separate Information Sheet (Appendix A1.4) and consent form. In the case of Study Three, the PPI panel recruited through our charity partner FCI were issued with an Information Sheet and were asked to provide their written informed consent online (Appendix A3.5). The same procedure was adopted with the General Practitioner Registrars (GPR's) and carers who took part in the small-scale online evaluation (Appendix A3.5).

2.6.2 Confidentiality

Although no personal details were sought in the online survey, respondents were invited to state whether they would be willing to take part in the in-depth interviews and, if so, they were asked to provide their name and contact number. Participants were reminded that if they chose to participate in the interviews at a later stage and gave their contact details, then their survey responses would no longer be anonymous to the researcher. However, assurances were given that all personal details would remain confidential, with no identifying information ever included in any presentation, publication, or thesis. It was explained that all information would be held securely under lock and key and would be accessed only by the researcher and not distributed to any other unauthorised individual. Additionally, it was reiterated that if participants decided to take part in the interviews, at a later stage, it was their right to change their mind before the commencement of the interviews. Participants were also reminded of their right to withdraw their data at any point up to analysis.

Interviewees were reminded at the beginning of the interview that their participation was wholly voluntary, that they could withdraw at any point and that their data could be withdrawn up to the point of analysis. Verbal permission to record was sought at the start of the interview (although this was also included in the Information sheet and consent form), and additional assurances that recordings would only be listened to by the researcher were given. The transcription process was explained and participants were assured that all personal identifiers were removed and that no personal details would be disclosed at any point in the process of analysis and dissemination.

2.6.3 Wellbeing of participants

As outlined earlier in Chapter One, carers have been shown to experience poorer quality of life than the general population and may also experience psychological distress as a result of their caring role (O'Sullivan, 2008). Therefore, the research was approached with the knowledge that although carers are not widely acknowledged as a vulnerable group per se, the researcher may encounter some who may be vulnerable. Information was also provided to all participants on sources of support including FCI, who provide support to carers across several domains, including counselling. Considerable efforts were also invested in securing participation from those who may not have previously identified themselves as a carer. The researcher was mindful of the fact that this may, in some instances, be psychologically difficult for some carers. Therefore, care was taken with language so that those who identified as carers and those who did not, felt equally comfortable with the questions. The questionnaire was piloted with a small group of carers to ensure that there were no questions that were unduly sensitive or distressing. When the one-to-one interviews had concluded, participants were asked about their experience of taking part and were given an opportunity to discuss any issues that arose.

2.7 Reflexivity

Reflexivity, as a process of acknowledging the role of the researcher in the project, was to the forefront throughout this piece of research. Reflexivity is referred to as “a process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated” (Guillemin & Gillam, 2004). As both a researcher and a carer to my 23-year-old daughter (with an intellectual disability), I was cognisant of the influences of my own experience on all aspects of the research, including the design, methods, and findings. Although the subjectivity of the researcher and the role of reflexivity is primarily discussed with regard to qualitative research (Mortari, 2015), which in this case formed only part of the research, the potential subjective stance of my own experiences as a carer was given careful consideration throughout the project. The section below discusses how my position as carer influenced all stages of the research from its outset through to completion and dissemination.

At the pre-design stage of this project, I was, myself, an unidentified carer, despite the fact that at that point, I had over 20 years' experience dealing with HCPs in my capacity as a carer. Therefore, I was very aware from the outset, of potential researcher bias. In the initial stages, I struggled with the need for the researcher to "probe into others' lives to explore phenomena" (Davis, 2020) (p.6) and questioned whether this was a reasonable course of action for someone who was effectively an 'insider' in this group. However, this was balanced with a motivation to try to make a difference, even in some small way, by adopting a pragmatic approach to the research with the ultimate goal of achieving real world change that could potentially improve the experiences of carers. Thus, the research was approached with an awareness of the potential advantages and disadvantages of my own position as both carer and researcher.

My experiences as a carer allowed for empathy, compassion and sensitivity throughout the design; for example, this was reflected in sensitivity to the language used in the carer survey and the approach to the interviews. My background meant that I approached the design with a motivation to 'give voice' to the carers who so often report being 'invisible'. When designing and conducting the carer interviews, I had to be particularly mindful that my experiences were not necessarily mirrored by other carers. My own position as carer also meant that I had my own (sometimes negative) experiences with HCPs and I had to be prepared to approach the GP interviews with my ‘researcher hat’ firmly in place.

My professional background and training were important in supporting me as a researcher in this regard. As a qualified Adult Guidance Counsellor for many years prior to beginning this research, I felt that: (1) I had already developed an awareness regarding how a person’s own frame of reference may influence the process; (2) I had developed good listening and empathy skills; and (3) reflective practice was already an established approach I had adopted in my working life. For example, the training for guidance counsellors requires a significant amount of reflective practice that permeates both the training and the professional practice. Therefore, reflective practice, by way of note taking and journal keeping, was already an established part of how I worked.

In addition, I carefully considered decisions at the design stage of the research, to identify any potential biases in order to ensure that the validity of the research was not negatively impacted (but rather strengthened) by my own personal experiences. For example: the survey was piloted with a diverse group of carers; interview guides were developed in consultation with a carer and a GP; a team approach was taken to the scoping review; and a group of carers (n=5) were involved in a PPI capacity in the development of resources and dissemination of findings. The choice of data analysis for the interview data (i.e. Framework Analysis) was also an important part of reducing bias in that a clear audit trail was established.

Throughout the process of the qualitative interviews, I kept a reflective diary completed on the day of the interview, a process that I found to be very beneficial in uncovering any potential bias-related issues. Reflective journals have been found to be helpful in highlighting distress for either the participant or interviewee (Roberts, 2009), and to this end, I was conscious of my own self-care throughout, while I also spent time at the end of each interview to ‘check-in’ with how the carer was feeling after the interview and offered them information on relevant supports.

2.8 Conclusion

This chapter described the epistemological and ontological approach underpinning the research as well as outlining the overall study design. Methodological information that is not included in the published papers pertaining to Studies One and Two have also been presented here. As mentioned earlier, Study Three involved the development of resources (research outputs) and so the complete details are provided later in Chapters Five and Six. As both a carer and a researcher, the process of reflection was important and is included along with other additional methodological issues such as informed consent and ethical considerations. The publications pertaining to Study One are presented in the next chapter (Chapter Three).

Chapter 3: Study One

As previously outlined, and in keeping with the aims of this project, it was considered important to disseminate findings to a wide range of academic and non-academic audiences and stakeholders. Therefore, this chapter first presents a paper published in a carer-accessible platform called *Frontline: The Voice of Intellectual Disability,* aimed at those with intellectual disabilities and their carers. This paper presents the findings from the national survey in Study One with a particular focus on identifying as a carer and why it is important. The second paper presented here, was published in the *Irish Journal of Medical Science* and outlines the broader findings from Study One, including data from both the national survey of carers and the findings from interviews with a small number of both GPs and carers. An additional brief article was published in *Healthnews.ie* in February 2019 to introduce the research project and highlight the needs of family carers. As this brief paper does not contain any findings it is presented in Appendix A1.7.

Some additional findings from Study One that were not included in either of the above publications (e.g. relating to stigma and identifying as a carer), are presented in the final section of this chapter. A number of these findings were presented at the Care Alliance Third Biennial Conference (November 2019) entitled '*Toward a refreshed national carers strategy – from research to policy'*. A copy of the conference presentation is included in Appendix A1.6.

Promoting a 'Think Carer' approach in Health and Social Care services: Identifying as a carer – why is it important?

Cronin, M., McGilloway, S. Promoting a 'Think Carer' approach in health and social care services: Identifying as a carer – Why is it important? *Frontline Irish Voice of Intellectual Disability* (online), Issue 116, February 2020, available at: http://frontline-ireland.com/promoting-a-think-carer-approach-in-health-and-social-care-services-identifying-as-a-carer-why-is-it-important/

Introduction

Mary Cronin and Professor Sinead McGilloway from Maynooth University's Centre for Mental Health and Community Research, discuss the CHERISH project and, in particular, the importance of identifying as a carer.

- Many people who provide care to their loved ones do not see themselves as 'carers'. This may prevent them from receiving the help and support they may need.
- This can also mean that they do not get a say in services and that they are not included in routinely available statistics on caring.
- The researchers were able to look at this from a personal point of view also because the lead researcher is also a carer
- It is important for health and social care professionals to recognise and understand the carer role and to be able to talk to carers about their own health and wellbeing.

Findings

Recent years have seen a significant growth in care needs within our society. For example, the Annual Report of the National Intellectual Disability Database Committee (2015) shows that the proportion of those aged 35 or more who are living with a moderate, severe or profound intellectual disability, increased from 37.9% in 1996 to 48.7% in 2015 (Doyle & Carew, 2016). While it is good to know that people with intellectual disabilities are living longer, this must also be considered in the context of care needs. While some people with a disability are in a position to live independently with minor supports, there are many who require a significant level of care. This is often provided at home by a parent or other family member. The changing demographic in Ireland means that people with intellectual disabilities are now often being cared for by ageing parents and indeed, given our ageing population, we are also seeing persons with intellectual disabilities themselves becoming carers to ageing parents (Hughes, 2016).

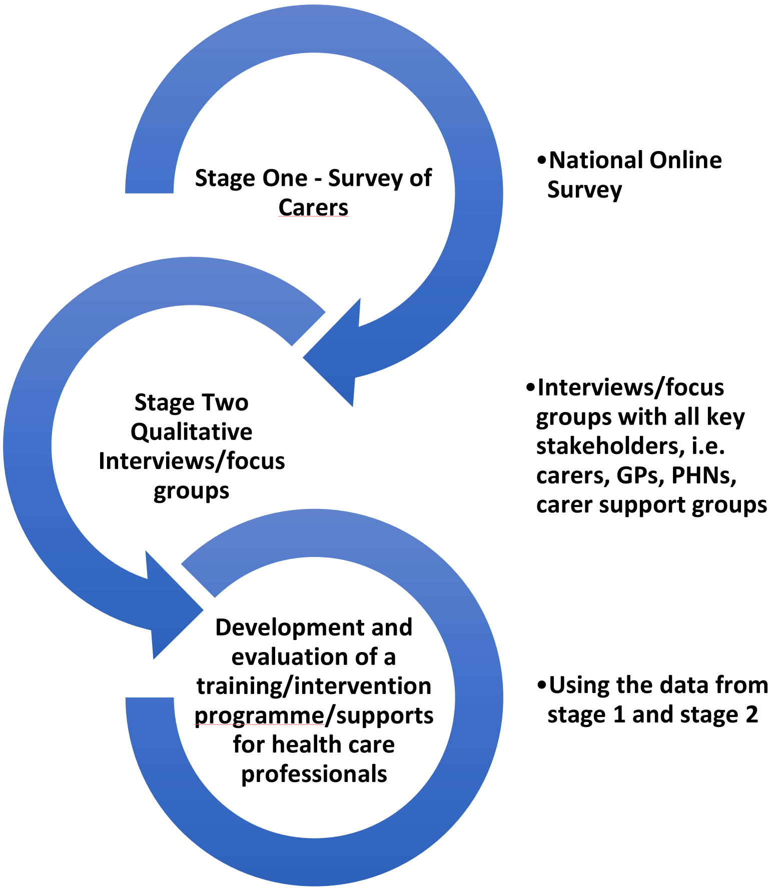
Arguably, supporting those who provide care has never been more crucial in our communities. This article focuses on the early identification of carers and how they are supported (or not) in health and social care services in Ireland. The National Carer Strategy (NCS) developed in 2012, sought to tackle both of these issues within some of its key objectives (National Carer Strategy, p.20). Crucially however, almost 8 years on since the strategy was developed, there has been little or no progress on either of these actions.

Lead author, Mary Cronin, has the unique opportunity to study this important topic from the perspective of both a carer/parent of a young person with an intellectual disability and a researcher on the CHERISH project at the Centre for Mental Health and Community Research in Maynooth University Department of Psychology and Social Sciences Institute.

The CHERISH (**C**ommunity **H**ealth-bas**E**d app**R**oach to **I**mproving carer**S** **H**ealth and wellbeing**)** project (supervised by Professor Sinéad McGilloway) aims to help promote a 'Think Carer' approach in health and social care settings in Ireland. The project involves a mixed methods sequential design and is being conducted in three stages (Figure 3.1). Some of the key findings from Stage One of the study - based on a nationwide survey of carers are outlined here.

Figure 3.1

The CHERISH project design

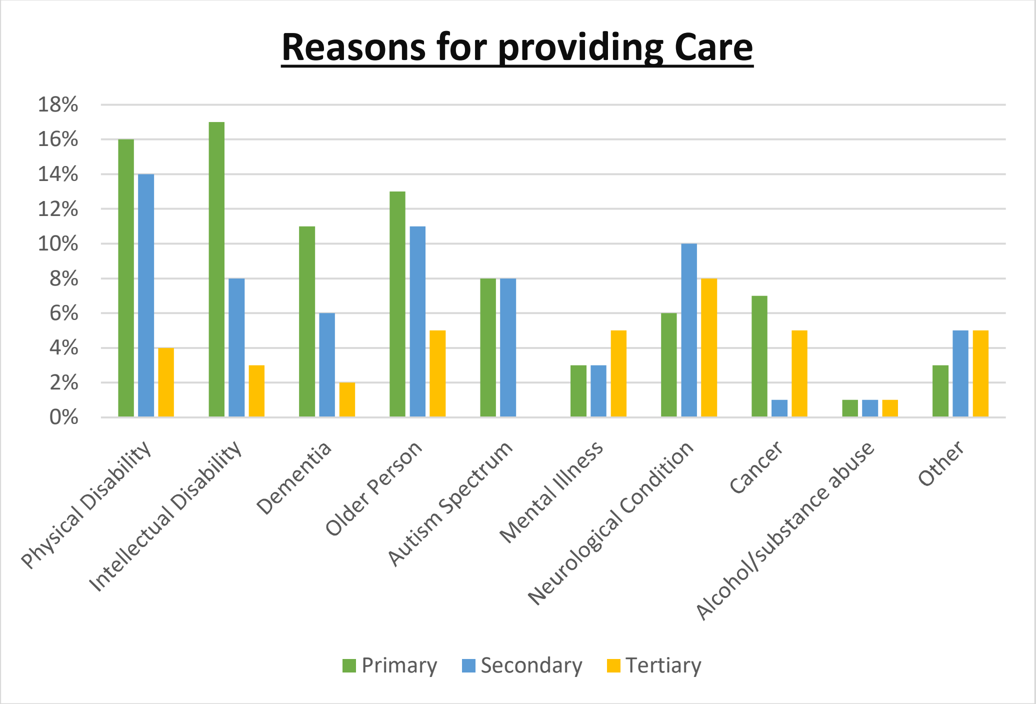


A large amount of care in Ireland is provided in the home by people who are often referred to as 'family carers' or 'informal carers'. In recent years, the term 'carer' has received some attention in the literature due to the fact that many people who provide care, do not refer to themselves as 'carers', but rather identify with the relationship they have with the person for whom they provide care (e.g., mother, father, brother, sister) (Hughes & O'Sullivan, 2017). This has important implications because many of those who provide care, either do not avail of the supports that are available to carers in the community, or do not seek such support; for this reason, they are often absent from carer research and routine statistics.

One of the challenges in developing policy and supports for carers is that there is no generic caring role. Unsurprisingly perhaps, our survey findings showed that care recipients typically have diverse and complex needs with many having more than one reason for needing care. For example, those with autism often also had an intellectual disability. Each caring role may be influenced by cultural and familial experiences (Montgomery & Kosloski, 2013), which in turn, pose a significant challenge for health care professionals in identifying carers, as well as enabling people to self-identify as carers. In a review of the literature on carer identity, Eifert *et. al.* (2015) discuss the importance of identity and its influence on behaviour (Eifert et al., 2015).

Figure 3.2

Reasons for, and complexity, of informal care provision



The failure to self-identify as a carer is one of the key reasons why carers do not request help or avail of supports. According to a Eurocarers factsheet on the physical and mental health of informal carers, ‘it is crucial that carers are identified in national health and social care systems to enable systematic data collection as well as to target carers and to inform them about the range of support available to them’. (Eurocarers, 2018, P4).

As someone who provides day-to-day care to her daughter, Niamh, who has an intellectual disability, Mary Cronin reflects here on her own experiences of identifying as a carer and how it influenced her when embarking on her PhD ‘journey.’

> *‘Even before her birth, I was her mother; it’s what we expect when we await the arrival of a newborn. We are not expecting to become a ‘carer’. The events that were to unfold following her birth - the health issues and the subsequent diagnosis of a rare syndrome - further reinforced my maternal instincts. As a mother (or parent), you cater for the needs of all your children and basically just get on with it. Niamh was raised happily in the middle of her two brothers. Her challenges were dealt with as they arose and, in many respects, we did not feel differently to any other family. We never thought much about the additional care which Niamh required - it was just part of the routine to us. It was the accumulation of a number of things that caused me to consider my role more closely and acknowledge that, although I was just a mother here, the level of care being provided was far beyond what would be considered in typical parenting.*
>
> *Prior to Niamh turning 18, in 2017 we had to face the daunting prospect of sourcing adult disability services and during this time, her older brother had just started university while her younger brother had just started secondary school. All of these*

transitions were emotional in their own way, but it was at this point when I really began to reflect on my role as a parent to Niamh.

As exhaustion set in, and anxiety arose about the future (both mine and hers), I struggled to think about or plan for it all and had no idea who to ask. Through an interest in research, I began to read and came upon the term 'family carer' and for the first time acknowledged that it applied to me. I realised that as well as being a mother, I provided additional care and that it goes above and beyond the standard parenting role and will continue to do so. At this point, I realised that I had effectively been adopting the role of 'carer' for almost 20 years and had never availed of any information, help or supports for carers other than the supports within the disability sector itself. Also, as a consequence of not identifying as a carer I had no voice in service development and research. This was the impetus for my PhD research and the CHERISH project which I see as an important vehicle to give a voice to other carers. I was expecting to become a mother, I was not expecting to become a carer as well and it took me almost 20 years to acknowledge that it had actually happened'.

Thus, the CHERISH project emerged for both personal and academic reasons. The aims of the (recently completed) national survey which was conducted during Stage One of the project were to: (1) explore carers' experiences in health and social care services; (2) ascertain the extent to which they identify as a carer; and (3) assess psychological distress, quality of life, stigma and help seeking.

The findings paint a grim picture of how carers feel they are understood in health care settings. For example:

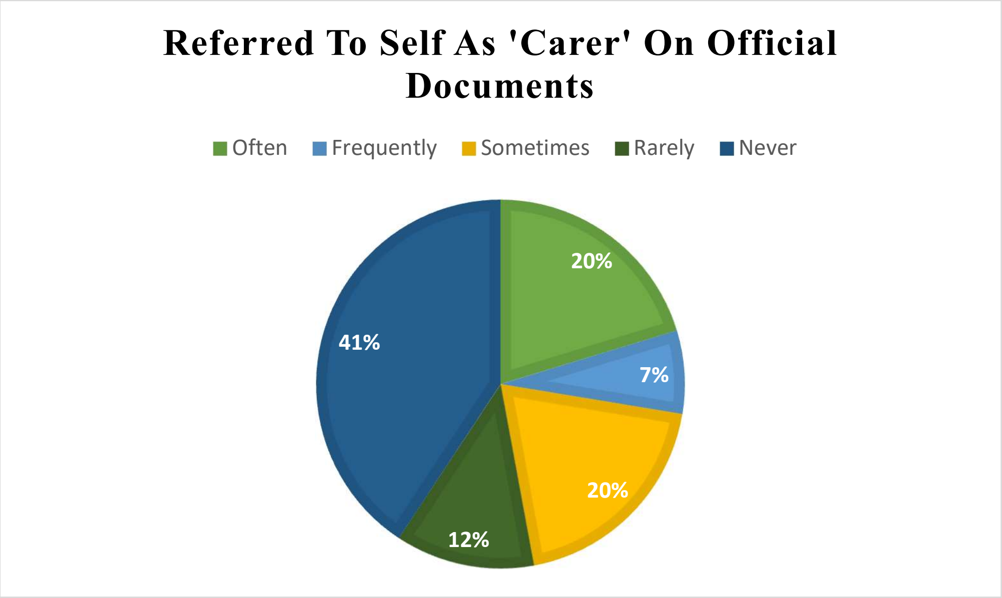
- 61% felt that Health Care Professionals (HCPs) rarely or never understand the challenges faced in caring role.
- 51% felt that HCPs are rarely or never concerned for carers' health and wellbeing.
- 77% felt that HCPs are rarely or never interested in hearing about their experiences of caring.

In addition, a number of questions were included in the survey to ascertain how those who provide care, respond to the term 'carer'. For instance, respondents were asked if they refer to, or describe, themselves as 'carers' when completing official documents, such as census forms, national health surveys etc. As outlined below, we found that the vast majority of those surveyed, did not informally or formally identify themselves as 'carers'.

Participants were also asked how they refer to themselves in terms of the person for whom they are providing care. Only 27% of those surveyed choose the word 'carer' and in all but one case, it was chosen along with another option such as brother, sister, mother, father etc. Furthermore, 53% of respondents indicated that they 'rarely or never' refer to themselves as a 'carer' when completing official documents (Figure 3.3).

Figure 3.3

Figures relating to self-identifying as a ‘carer’ on official documents



The survey responses also reflect mixed feelings about the term ‘carer’, with some seeing it as an acknowledgement and others rejecting it outright and finding it offensive. A number of selected illustrative quotations in this respect, are provided below, all of which relate to participants who are providing care to someone with an intellectual disability.

> *‘…makes me feel like less of a parent’*
>
> *‘Was weird at first because my son was young and didn’t really feel different, now with the level of extra care he needs I see how I am a carer and a parent’*
>
> *‘Offended, I am my daughters mother. A carer to me means someone hired to help her’*
>
> *‘I prefer to be referred to as his mother. If filling forms that request profession I put in carer as I had to give up my profession. I don't like the term carer it infers*

we've sorted out my sons care but the reality is family members are trying to do a job they're not trained for'

'Involuntary! Life failure'

'Fine - it's the correct term and at least is an acknowledgement of all you do.'

The above responses illustrate the complexity of feelings regarding the term 'carer'. Our findings also confirm that many of those who provide care in our communities are hidden or invisible carers and, therefore, that our statistics regarding caring are likely to be highly conservative.

These early findings from the CHERISH project will help to inform Stage Two of the study which will involve in-depth interviews with a range of stakeholders in order to identify how best we might inform and support HCPs to enable them to better identify and help those who provide care in our communities. As part of this work, we will also explore in more detail, the complexities around the use of the term 'carer' and how health care professionals might be encouraged and supported to initiate a conversation about caring in a sensitive manner; this, in turn, may enable them to provide appropriate care, whilst also acknowledging the carer role and the importance for the carer of maintaining, at the same time, their own personal identity.

Supporting family carers in Ireland: the role of the General Practitioner

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Abstract

Background

Ireland has over half a million family carers who provide care to a family member or loved one. Internationally, it is recognised that General Practitioners (GPs) have a critical role to play in the identification and support of family carers but, to date, no guidelines exist in Ireland to support GPs in this role.

Aims

The aim of this study was to examine how carers are currently supported (or not) by health care professionals in Ireland, with a particular focus on the role of the GP.

Methods

A mixed methods design was used, involving a national online survey (N=132) of family carers in Ireland and one-to-one interviews with 10 stakeholders (4 GPs; 6 carers). The quantitative data were analysed using a series of descriptive and inferential statistics; the interview data were analysed using Framework Analysis.

Results

Sixty-one per cent of the carer sample reported experiencing psychological distress, more than two-thirds of whom (69%) reported ‘rarely’ or ‘never’ being asked about their own health and wellbeing. Sixty-one per cent also felt misunderstood in terms of the challenges they face in their caring role. Three key themes were identified from the interview data including: (1) GP role ambiguity; (2) navigating informal processes; and (3) changing needs along the care trajectory.

Conclusions

The findings suggest important gaps in terms of the role of GPs vis-à-vis their support of family carers. GPs themselves indicated that they need both greater clarity regarding their role with family carers and more training and resources in this regard. A requirement for more streamlined communication and information provision was also highlighted by both GPs and carers. Carers reported a need for more information on the role of GPs in supporting carers as well as more support in addressing, in particular, the psychological complexities of carer identity and help seeking.

Keywords: Family Carer, Health & wellbeing, Ireland, General Practice, National Carer Strategy

Introduction

Care needs are increasing in our society due to improved longevity, advances in medical care and a shift away from institutional care (Spotlight, 2019). Eighty per cent of Long-Term Care (LTC) in Europe is provided by family carers (Eurocarers, 2021) while recent Central Statistics Office (CSO, 2016) 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). Although caring (Lefranc et al., 2017) has been reported to have some benefits for carers (e.g. a sense of purpose and achievement), greater caring responsibilities have been linked with progressively poorer health outcomes for carers (Thomas et al., 2015). Indeed, those providing care, often experience negative consequences to their own health and wellbeing. For example, a recent survey of family carers in Ireland (*N*=1250) found that 45% reported a long-term illness, health problem or disability while 80% of those carers felt that their caring responsibilities had contributed to their illness/disability (Family Carers Ireland, 2020). These figures are also reflected in other work undertaken internationally (Embracing Carers, 2017; OECD, 2017), thereby indicating that large numbers of family carers require more health and wellbeing support.

It has been suggested for decades that community health professionals such as General Practitioners (GPs), Public Health Nurses /Health Visitors and primary care centres are well placed to support carer identification, health and wellbeing (Chantal et al., 2002; Parmar et al., 2020). Furthermore, family carers have more contact with their GP than any other health professional (Royal College of General Practitioners, 2014). For example, a recent international scoping review of physicians' perspectives of their role in supporting family caregivers, indicates that primary care is the appropriate context for identifying and supporting carers (Parmar et al., 2020). However, barriers still exist at practice, health systems and policy level. For example, existing evidence points toward a number of factors that impact on adequate carer identification and support, including: lack of time and reimbursement; failure to self-identify as a carer; focusing on the care recipient to the exclusion of the carer (by both the carer and the health service provider); disjointed health and community systems; inadequate services; and a lack of policy and ethical guidance (Parmar et al., 2020). The importance of primary care in the identification and support of carers was also highlighted in another scoping study involving a diverse sample of professional stakeholders in the UK (Peters, et al., 2020). The findings indicate that the failure of carers to self-identify, or to recognise themselves as carers and the ambiguity within primary care services to proactively identify carers, were key obstacles to the provision of appropriate, effective and timely carer support.

An analysis of responses from carers in the 2011-12 English General Practice Survey (*N*=195,364), showed that they reported lower Health Related Quality of Life (HRQoL) when compared with non-carers, and this was especially marked amongst those providing longer periods of care (Thomas et al., 2015). Carers also reported poorer patient experience than their non-carer counterparts with regard to access, making appointments, seeing their preferred doctor, receptionist communication, doctor and nurse communication, and overall experience. HRQoL in carers, and carer burden, have also recently been explored in the context of health literacy (HL), with high levels of health literacy found to be significantly associated with lower carer burden (Häikiö et al., 2020). Other research in this regard, has highlighted the importance of improving communication between carers and healthcare professionals and recommended that, for example, a short assessment can be used to guide consultations (Burridge, et al., 2017) and/or that communication skills training for carers (Smith et al., 2018) and GPs (Riffin et al., 2020; Fisher et al., 2020) may be beneficial.

GPs in Ireland, as elsewhere, play a key role in healthcare delivery, and as is the case internationally, demand is increasing and expected to increase further, leading to workload concerns in general practice (Crosbie et al., 2020). Consequently, in order to support family carers, GPs need effective streamlined resources to support them in this task. Some guidance and training are available to support GPs in their role vis-à-vis family carers, in a number of western countries (e.g. UK, Australia and Canada) (Doctors of BC, 2016; Northern Sydney Local Health District, 2019). However, no such guidelines are as yet available in Ireland to support GPs or other health professionals despite the fact that the National Carers Strategy (Department of Health, 2012) – which represents an important first step toward recognising the contribution of family carers and supporting them in their role – calls for more effective approaches to identifying and supporting family carers in health care settings.

The current study was conducted as part of a larger project (called 'CHERISH') designed to raise awareness amongst GPs of the physical and emotional health issues experienced by carers and to identify how best to support GPs and promote more 'proactive approaches to the identification of carers' (Department of Health, 2012, p.20). The objectives of the study reported here were to: 1) examine how carers are experiencing access to supports in relation to their own health and wellbeing, with a particular focus on psychological barriers to help-seeking; and 2) assess GP perceptions of carers and their caring role in order to better understand the processes by which they identify carers and the extent to which they support (or not) carer health and wellbeing.

Methods and procedure

This study used a two-stage explanatory sequential mixed method design (Creswell, 2007). Stage One involved the design and administration of an online national survey of carers, whilst Stage Two entailed a small number of in-depth one-to-one interviews with both carers and GPs.

Participants and settings

A convenience sample of carers was recruited online through social media platforms (Twitter and Facebook), where specific pages were created for the research and a link to the online survey was provided. Participants were required to be over 18 and to be providing care to a family member or loved one. On completion of the survey, respondents were invited to express an interest in taking part in Stage Two of the study. GPs were recruited for stage two via a forum post which was placed on a website resource for GPs in Ireland called GPbuddy.ie (https://www.gpbuddy.ie).

Stage One: Online survey

The Family Carer Questionnaire (FCQ) was developed specifically for the purposes of this study and included a number of psychometrically robust measures (see below), as well as a brief Background Questionnaire comprising a number of sociodemographic and background items (e.g. age, gender, reason for providing care, duration of caring role, caring hours) combined with several Likert-style questions on identifying as a carer, experiences with health care professionals (HCPs) and engagement with activities that may help/support carers in their caring role. The last of these was adapted from the Caregiving-Related Activities Scale which was used in the large American Association of Retired Persons (AARP) caregiver identity study (*N*=4,037) in the USA (Kutner, 2001). Four open-ended questions were also added to inquire about the nature, availability and impact of health and wellbeing supports provided (or not) by GPs and other HCPs as well as respondents' feelings about being referred to as a 'carer' and their own help seeking behaviour.

The 12-item version of the General Health Questionnaire (GHQ-12) was included to assess overall psychological distress or minor psychiatric morbidity (Burrows, & Gannon, 2013). Items were scored using the Likert method 0-1-2-3 as recommended by Goldberg (1979), with total scores ranging from 0–36. The scoring thresholds are as follows: a score of 1–10 indicates 'low psychological distress'; 11–12 is 'typical'; 13–15 is 'more than typical'; 16–20 shows 'evidence of psychological distress'; and scores over 20 indicate 'severe distress' (Goldberg et al., 1979).

The 40-item Adult Carer Quality of Life Questionnaire (AC-QoL) was used to measure Quality of Life (QoL) in eight separate domains including 'caring choice', 'money matters', 'support for caring', 'caring stress', 'personal growth', 'sense of value', 'ability to care' and 'carer satisfaction'. Domain scores ranging from 0-5 indicate a low reported quality of life, 6-10 indicate a mid-range reported quality of life and 11+ indicate a high reported quality of life (Joseph et al., 2012). Total scores range from 0 to 120 with higher scores indicating better QoL and categorised as follows: low (0-40), mid-range (41-80) or high (81+).

The FCQ was piloted with five carers from different care situations (i.e. parent caring for a child, son/daughter caring for parent, spouse carer), after which some minor adjustments to layout and wording were made. The data were analysed using SPSS; all open-ended questions were analysed 'semi-qualitatively' to identify key categories/themes.

Stage Two: In-depth interviews

A series of semi structured interviews was conducted with six carers and four GPs as part of stage two. Two separate interview schedules were devised on the basis of a review of the literature, and piloted with a GP and carer respectively in order to ascertain the appropriateness of content, wording and timing. Due to COVID-19 restrictions at the time of the study (2020), it was not possible to conduct face-to-face interviews. Furthermore, the recruitment of GPs for research can be extremely challenging due to the fact that they are time poor (McKinn et al., 2015), as are many carers, and both groups had significant additional and new demands placed upon them during the restrictions and lockdowns of the COVID-19 pandemic (Family Carers Ireland, 2020a; Homeniuk & Collins, 2021). Telephone interviews were therefore considered to be a convenient and time efficient method of data collection that did not require any additional software or technological know-how. These have also been successfully used in the past as a convenient and efficient means of interviewing GPs (Poudel et al., 2020; Wichmann et al., 2018).

All interviews were audio recorded with consent, anonymised and transcribed verbatim in preparation for analysis, which was conducted using NVivo. Framework Analysis, which is widely used in medical and healthcare research, was used to analyse the data (Gale et al., 2013). This involved a five-stage process of: (1) initial familiarisation with the data; (2) identifying a thematic framework; (3) indexing; (4) charting; and (5) mapping and interpretation (Ritchie et al., 1994).

Results: Stage One

Participant profile

A total of 132 carers from 23 counties in Ireland and from an almost equal mix of urban and rural locations, participated in the survey. Respondents were predominantly female (89%) with a mean age of 50 (SD = 10.57), were caring for a family member/loved one for an average of 11 years (SD =11.62) and spent 17 hours in any typical 24- hour period in a caring role (SD = 7.40) for an average of 6.6 days per week (SD = 1.05). The mean age of the care recipient was 51 (SD = 31.64) and reasons for providing care were multiple and complex with 11% of the sample providing care for more than one person. Many carers reported that the care recipients had multiple co-morbidities, such as physical and intellectual disabilities, autism and intellectual disability and dementia often present with other complications of senior care.

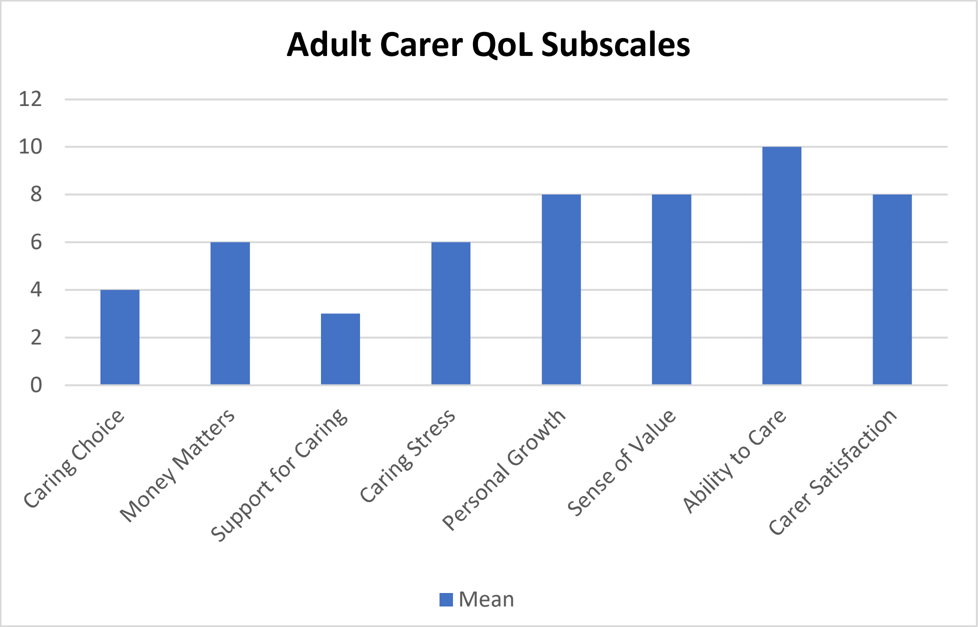
Health and wellbeing

Sixty-nine per cent of respondents were 'rarely' or 'never' asked how they were; only 3% reported that they were 'often' asked this question. The carer sample obtained a mean score of 23 (SD = 6) on the GHQ-12 (Cronbach Alpha 0.86), indicating typically severe levels of psychological distress (Goldberg et al., 1997). No significant differences were found by gender ($p = 0.72$) or community setting i.e. rural or urban ($p = 0.39$), although a correlation analysis revealed a small negative correlation between total GHQ-12 scores and age ($r = -0.207$, $n = 112$, $p < 0.05$) with younger carers reporting higher levels of psychological distress. The total mean score on the AC-QoL (Cronbach Alpha 0.78) measure was 55 (SD = 16), indicating QoL levels in the lower to mid-range (mid-range, 41 – 80). No significant differences were found by gender ($p = 0.97$), age ($p = 0.74$) or community setting, ($p = 0.18$). An analysis of the eight subscales showed that the lowest scores were reported for 'Support for Caring' (Mn=3, SD = 2) and 'Caring Choice' (Mn=4, SD = 3), suggesting that carers perceived a low level of emotional, practical and professional support and a low level of control over their own life.

Conversely, respondents reported the highest mean score on their ‘Ability to Care’ (Mn = 10, SD = 3) (Figure 3.4), indicating high levels of competency to care.

Figure 3.4

*Adult Carer Quality of Life subscale Scores**

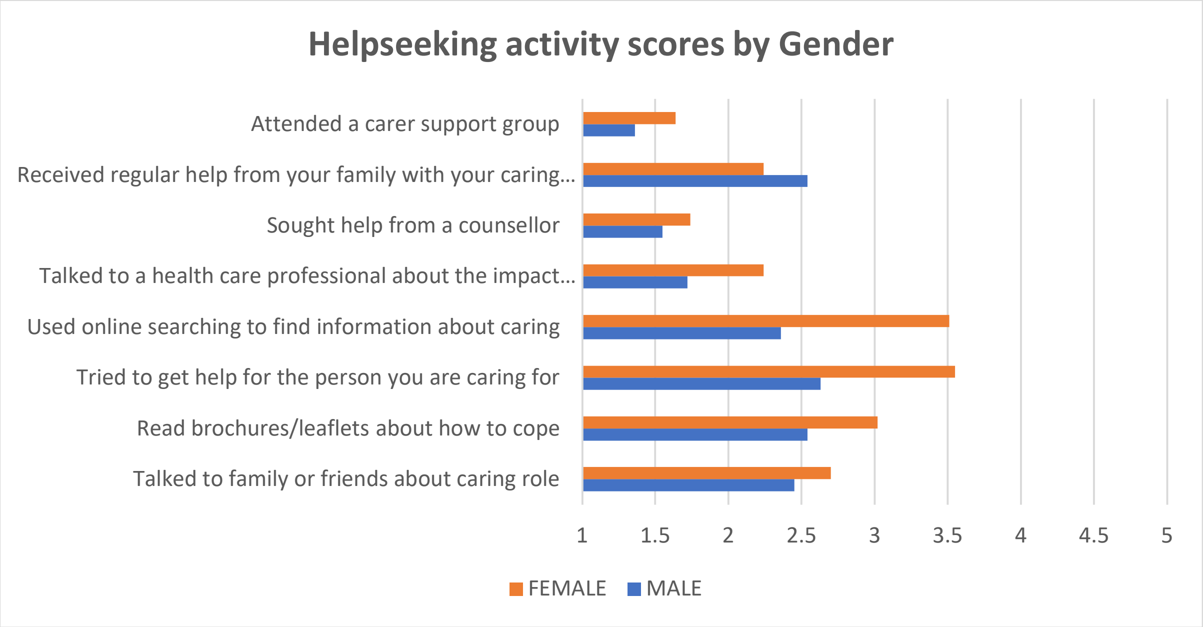


**(0-5: indicates a low reported quality of life and may suggest problems or difficulties; 6-10: indicates a mid-range reported quality of life;11+ indicates a high reported quality of life)*

More than three-quarters (79%) reported that they had little or no support to help them in looking after their own health and wellbeing, and 85% (93/110) indicated that this had a negative impact on their health and wellbeing. This was also reflected in the mean score of 20 (SD = 6) on the ‘engagement with help seeking activities’ items devised for this study (Cronbach alpha 0.65), which indicated a generally low level of engagement, but with females reporting significantly more engagement than males (p = 0.035, r = 0.2) (Figure 3.5). These findings were amplified in the responses provided by most of the sample to an open-ended question around help-seeking, which showed that only 11% (9/82) were comfortable to ask for help, whilst an identical proportion felt that help would not be forthcoming, so they decided not to ask. The remainder of respondents either had difficulty in asking for help (41%, 34/82), or stated that this was something they would never do (28%, 23/82).

Figure 3.5

*Help-seeking activities by Gender**



* *Likert scoring: 1 = 'Never'' and 5 = 'Often'*

Understanding from Healthcare professionals

Respondents (61%) felt that HCPs, including GPs, rarely if ever understand the challenges which they face in their caring role while approximately half (51%) felt the same way in relation to HCP concern for carers' own health and wellbeing. More than three-quarters (77%) felt that HCPs are 'rarely' or 'never' interested in hearing about their experiences of caring. Further analysis showed a small statistically significant positive correlation between the number of years spent caring and perceptions of understanding from healthcare professionals ($r = 0.20$, $p < 0.05$), whereby those who had been carers for longer, felt less understanding and concern from HCPs. Responses to an open-ended question which explored this further, showed that 40% of those who responded (38/95), reported that they would value practical supports such as referral to support agencies, advocacy regarding respite/home support, and information. A similar proportion (38%, 36/95) indicated they would like to be asked how they are, and to be listened to, whilst 9% (9/95) were unsure what HCPs could do for them, with 4% suggesting counselling. Only 3% were happy with the supports they were receiving.

Identifying as a Carer

Just over one quarter of the sample (27%) indicated that they would describe themselves as a 'carer' whilst over half (53%) 'rarely' or 'never' referred to themselves as a carer when completing official documents. Further responses to an open-ended question in this regard, showed that approximately one third (34%, 37/108), disliked being referred to by HCPs as a carer due to, for example, a perception that this diminished their familial role and identity. However, the largest proportion (59%) either did not mind the label (31%, 34/108), or felt it was a validation of the care they provided (28%, 30/108); 6% stated that they had never been asked about their caring role.

Results: Stage Two

Interviews with carers lasted approximately one hour and with GPs, approximately 30 minutes. Carers had a range of caring roles, (Table 3.1), and had been caring for their relative for periods ranging from 3 to 18 years.

Table 3.1

Carer participant characteristics

Relationship to Care Recipient	***Reason for Care***	***Years Caring***
Mother	Autism	18 years
Husband	Rheumatoid Arthritis	8 years
Brother	Mental health	14 years
Wife	MS	19 years
Daughter	Senior Care	13 years (recently bereaved)
Daughter	Senior Care	3 years

Care recipients had a mix of care needs and were aged 18 to 93. Sadly, one carer had suffered the loss of the person for whom they were caring, in the interval between completing the survey and being invited to the interview, but they were still keen to participate in the interview nonetheless. Three overarching themes were identified from the analysis, as outlined below; these are presented in order of their prominence within the data.

Navigating through informal processes

All four GPs reported that they were navigating an informal system of carer identification and sourcing information, a process which was compounded by issues relating to documentation and fragmentation of services. Likewise, all of the carers were navigating a system where they felt the provision of information and support was typically ad hoc, difficult to access and often covert. The findings suggest that carers are typically identified by GPs on a very informal basis and often informed by their longer experience in primary care, as well as the duration of time the care recipient has been attending their practice; longer term attendance by the care recipient, led to better (informal) identification of carers and their needs, but no formal information about carers is typically conveyed to GPs. The GP interviewees reported that they may be alerted to a particular carer need on occasion (i.e. a carer struggling, a care recipient deteriorating), but this was often communicated informally by another member of the primary care team who may have noticed something and ‘flagged’ it with the GP, or the GP heard there might be an issue through another source. This type of informal ‘grapevine’ communication system was a challenge for the GPs because, professionally, it can be difficult for them to act on informal information. The GPs were then left in a situation of trying to ‘broach’ it with the carer but doing so tentatively or waiting to see if anything else would arise to support the conversation. One GP spoke of how this can be a particular problem where there may be a safeguarding concern in the caring role:

> *“And when you are hearing it third hand and then they are presenting with the person they are caring for …. and that its quite tense….that’s when its problematic, That can be quite difficult to broach…..* “(GP2)

The lack of information and the fragmentation of services were a source of considerable frustration to both GPs and carers. The GPs indicated that they did not have any information about what was available in their community and this was a clear barrier to having discussions with carers about their needs:

> *“We have no access to what's available in the community to advise our patients… just to be able to click and go ok, we have got that or this person that we can contact. We don't have any of it….”* (GP4)

Carers reported that often, after many fruitless attempts to obtain information, they were eventually given very valid and useful information ‘unofficially’ from healthcare staff such as nurses and co-ordinators who imparted the information in an almost clandestine manner. This advice/information typically focused on how to ‘manage’ the system in order to secure the best outcome for their loved ones. While carers were very pleased to receive this information, it did leave them wondering why information had to be conveyed in this way:

> *"And I think, who knows about these things - that's what I don't understand. Only that I opened my mouth to appeal it, I wouldn't know a thing about it." (Carer 4)*

> *"I have to say in thanks to some people in the HSE who would never tell you they told you, would never write anything down, would only tell you over the phone, but it was thanks to those people who told me."* [how to access a service] *(Carer 5)*

Interactions with carers were not documented by GPs, other than if the carer was a patient and then only two of the four GPs interviewed, stated that they had documented the identity of the carer. For example, one GP reported inserting the carer's name on the patient's (care recipient's) chart with permission, for contact and communication purposes. Another GP commented that, while he did not currently record carers' names in the patient file (as he knew them all), he would likely do that in future in the event of having a locum filling in at the practice.

Role Ambiguity

Ambiguity around the role of GPs in supporting carers' health and wellbeing, was a strong and recurring theme amongst interviewees. The role of the GP was seen as being of limited value for the carer unless they had a particular 'medical problem' to discuss, or required paperwork or medication management for their relative/loved one. There was a sense that the GP could not help with many of the challenges of caring, such as accessing appropriate services. There was also an acute awareness and appreciation from the carer's perspective, of the busy primary care environment and they felt that the GP would not have the time for them to discuss their caring-related concerns. However, the carers' assessment of their own needs was mitigated somewhat by making comparisons to the difficult circumstances of other carers whom they knew and the complex medical needs of the care recipients. Therefore, they often hesitated in bringing up their own needs with their GP as they were unsure as to whether or not it was appropriate, or if they would be justified in so doing:

> *…"but you see, I don't know is the GP the way to go…but you know you don't know who to go to in a way."* (Carer 4)

> *"There's no point in seeing the GP they haven't got anything, they have nothing for you……it was all the paperwork we went in with this form or that form for whatever it was. It was very practical you know……. like it's not a medical problem".* (Carer 5)

Notably though, those who had longstanding relationships with their GPs were more comfortable with discussing their own needs, and spoke highly of the support which they received.

The caring role was typically portrayed (by both GPs and carers) as being adversely affected by decisions made within the wider health service system, often without consultation with the carer. Carers felt that while frontline staff and, in particular, home support carers, disability services staff, palliative care nurses, were often very understanding of their role and went above and beyond to support them, there was much less understanding at higher levels of the health service (e.g. policy makers, home support co-ordinators). In some instances, this was an important barrier to carers communicating their needs. For example, one carer spoke of how a GP suggested she learn how to manage and replace a catheter herself rather than calling a healthcare professional as she "would be well able for it"; likewise, another spoke of how a PHN had suggested that they were "well able" and left them to tend to wound dressing themselves. References to them as being 'able bodied' or 'capable' were used as a means to encourage them to take on extra caring responsibilities, but without any assessment of their current circumstances or capacity to care.

GPs also felt some ambiguity about their role with carers. None of the GP interviewees had any awareness of the National Carers Strategy or its objectives regarding the support of carers in health services including, general practice. Although they were sympathetic to the needs of carers, they were very much working with their own intuition regarding if and how they should support carers, with some making efforts to source supports while others did not feel this was their responsibility.

> *"So obviously I'm involved with the PHN and I'm providing medical and mental health services to the carer so after that not a lot else really, if there are support groups they will find those themselves I'm not that familiar with what's involved there."* (GP 2)

> *"I think that something is definitely lacking in primary care ... I let them call the places, and I say if you need anything from me to back this up let me know…its time limit thing really, but also from a general practice point of view, we are not aware of what's out there.*" (GP 4)

All of the GPs agreed that additional resources and/or training would be necessary in order for them to more effectively support carers. For example, they provided a number of helpful suggestions in this regard, including an up-to-date database of specific carer resources and easily accessible and short training (e.g. by means of short videos and/or through local GP group meetings).

Changing needs along the care trajectory

The caring role was identified as ever-changing and evolving over time, with numerous different challenges. Although it was not addressed explicitly in the interview schedule, all of the carers spoke about the time their loved one was first diagnosed. This clearly had a considerable emotional impact on them and was remembered as a hugely stressful time where they felt they were given little information or support; furthermore, all of those interviewed stated that it took them years to negotiate their way through the process of obtaining appropriate support for their loved one. Conversely, challenges for carers at the time of diagnosis, was not raised by any of the GP interviewees.

The GPs referred to family support as a possible source of help for carers, although the experience of the carers was mixed in this regard. Those who had strong family support greatly benefitted from it, but carers who had very difficult caring responsibilities (e.g. MS, severe autism) felt that their families did not fully understand their situation and had distanced themselves from them over time. As caring progressed, accessing informal help from family or friends often become more challenging, even if family had previously been providing help. Furthermore, when the caring circumstances progressed to a requirement for specialised care, carers reported that this could only be delivered by someone who was appropriately trained.

> *"His disability, his illness has progressed over time. It's a long term chronic illness - it's not just going to go away tomorrow…this is for the long haul…And that's the hardest part….I just find friends diminish very fast with disability, with illness"* (Carer 6).

> *"They* [adult children*] are working and everything you know, like, I mean they have things too……you don't want them to be torn between, you know looking after somebody and you know, trying to do a job themselves and look after their own families."* (Carer 4).

Key transitions on the caring 'journey', such as the care recipient moving to residential care or approaching end of life, were sources of additional stress for carers and times during which they reported a need for higher levels of support. Several of the carers spoke about how the progression of the caring role over time meant that they had to stop working or work shorter hours. Changes to services for the care recipient throughout the care trajectory also had a significant impact on carers, with several alluding to how cuts to, or withdrawal of, services, had negatively affected their own ability to work or to have any kind of social life for themselves.

Discussion

This study was conducted to investigate how carers in Ireland are supported in relation to their own health and wellbeing needs, and to explore GP perceptions of carers and the processes by which they identify carers (or not) and support their health and wellbeing. The results showed that the vast majority of family carers were rarely if ever asked how they were, despite the fact that most were clearly in need of formal mental health intervention according to their GHQ scores. The in-depth interviews helped to shed light on some of the reasons why this might be, particularly with regard to their attendance at primary care. As shown in research conducted elsewhere (Carduff et al., 2014), the GPs were ambiguous about their role vis-à-vis carers and this was particularly true if the carer was not a registered patient of the GPs practice and if the GP had only limited information about them. Furthermore, when the topic was raised in conversation, the GPs interviewees felt that they had little or no information about the services available for carers in their area, while patchy service provision was also a source of considerable frustration for them. This is in line with the findings of a recent scoping view by Parmar et al., indicating that a disjointed health and community system can impact carer identification and support (Parmar et al., 2020). The carers in the current study, likewise, were unsure about how GPs could best support them, and this perception was a key barrier to their help-seeking. Importantly, some also felt reluctant to seek help, or to communicate their concerns, as they felt this could further burden GPs or other HCPs in their role. Indeed, a recent survey of members of the Irish College of General Practitioners (ICGP), found that GPs in

Ireland carry out an average of 29 consultations a day and report higher levels of exhaustion than their counterparts in Europe and the UK (Collins & Homeniuk, 2021). Our findings suggest that these demands may influence the extent to which (and how) some carers (and possibly patients) approach concerns about their health in primary care settings.

The identification of carers in general practice is a logical first step in providing support, but this remains a complex issue, with a number of barriers from both a carer and GP perspective. Recommendations from research and guidelines internationally have aimed to address how GPs might identify carers through, for example, practice initiatives (NICE, 2020; Onwumere et al., 2016; Doctors of BC, 2016) and/or the provision of carer-focused training (Jones et al., 2012). The introduction of carer-focused initiatives in GP practices (e.g. appointing a member of staff to act as carer champion and have primary responsibility for identifying carers), has been recommended in UK by a number of organisations, including the Royal College of General Practitioners (RCGP), Carers Trust Wales and the National Institute for Health and Care Excellence (NICE) (NICE, 2020; Carers Trust Wales, 2019). Our findings suggest that GPs in Ireland (and possibly also elsewhere) would benefit from brief training and additional resources to support them in their role with carers. For example, an interesting pilot study of GP training in England, found a positive impact of training across many areas, including knowledge of carers, awareness of need and greater GP confidence in supporting carers (Jones et al., 2012). The formal assessment of carer needs in general practice has also been shown to be valuable in identifying the level of need and guiding the consultation process (Burridge, Mitchell, Jiwa, Girgis, 2017; NICE, 2020; Røen et al., 2019).

Importantly, our findings highlight the many psychological complexities for carers regarding their own needs, including carer identity, understandings and perceptions around self-care and communication with GPs (and other HCPs), all of which also need to be addressed. The nature and extent of these barriers, evident from our findings, suggest that encouraging self-identification amongst carers may not be sufficient, and that they may also benefit from psychological interventions that would help them to explore identity, self-care and communication skills specific to health care settings. Indeed, communication-enhancing interventions have been shown to be effective in healthcare settings, both when used by HCPs and patients alike (Straub, 2019), and recent work on carer burden has also highlighted health-literacy to be a factor (Häikiö et al., 2020). A communication and empowerment intervention for carers, could also be helpful in terms of helping them to explore carer identity and support them in having difficult conversations with their doctor about the impact of caring, their own health needs and concerns about the person for whom they are caring. However, previous research suggests that barriers exist, not only at individual carer level, but also within practices (Carduff et al., 2014), and therefore, any carer-focused initiatives at practice level may only can have a limited impact in the absence of individual supports for carers themselves.

The number of carers in Ireland is estimated to be in excess of half a million (Family Carers Ireland, 2020). However, our findings indicate that many carers do not refer to themselves as such when completing official documents, thereby suggesting that these figures are likely to be extremely conservative. A recent working paper on family carer enumeration (Family Carers Ireland, 2022), suggests that several issues exist in our current recording of carers in Ireland, resulting in likely under-reporting. These include challenges such as irregularities in the carer data, including the low numbers reported through the Census of Population. For example, in Census 2002 and 2016, the reported occurrence was 4.8% and 4.1% respectively. These figures are very low compared to, for example, Northern Ireland where 12% of the population in 2011 identified as carers. The Irish Health Survey, a large nationwide survey administered by the Central Statistics Office, also gathers data on carer numbers, and reported a similar figure in 2015. Such variation may be due to how the questions in surveys are worded and/or interpreted but also, as shown here, the extent to which carers identify as such.

As outlined in our previous work, reported in a carer-accessible publication (Cronin & McGilloway, 2020), identifying as a carer has clear implications for seeking help or support. Typically, however, it is not until later in the caring trajectory that those who provide care, identify with the term and seek support and often this will not occur until a point of crisis (Montgomery, 2007; Eifert et al., 2015). The results reported here, suggest that early intervention is important, as prevously pointed out by Carduff et al. in the UK (Carduff et al., 2014), while the point of diagnosis may also be an ideal time to identify who will be providing the care (Carduff et al., 2016). In Australia, the Northern Sydney Health District guidelines, *'Think Patient, Think Carer',* suggest that the carer should be identified at first appointment or at the point of diagnosis (Northern Sydney Local Health District, 2019). Caring challenges for the carers in our study, clearly emerged from the point of diagnosis of the persons for whom they were providing care, but at this very crucial stage, they they did not know where to turn for support. While carers may not be ready to accept support at an early stage, it is important, nonetheless, that they are alerted to existing supports, including those available through their GP, so that they know from whom to seek help when/if the need arises.

The GPs in the current study, reported a lack of information regarding resources for family carers in the community. This is interesting because they were recruited through 'GP buddy', an online resource for GPs and other healthcare professionals in Ireland, providing information about other medical professionals and services. Perhaps consideration could be given to the inclusion of community-based resources or social prescribing options on platforms used routinely by GPs when seeking local or national information. The results reported here, also highlight the lack of awareness amongst the GP participants, of Ireland's National Carers

Strategy (NCS) (Department of Health, 2012), thereby suggesting that perhaps greater efforts are needed to communicate policy objectives to frontline staff and key stakeholders. Indeed, this would also help with policy implementation more generally. In the UK, the RCGP include a reference in their carer guidance document ('Supporting Carers: An action guide for general practitioners and their teams') (p.15), to the UK Carer Strategy, and the key elements therein that GPs might address (Royal College of General Practitioners, The Princess Royal Trust, 2013). A recent scoping review by Parmer *et al.* (2020) further highlights reimbursement as a barrier to the identification and support of carers in General Practice. The UK Quality and Outcomes Framework (QOF), that is intended to compensate general practices for providing good quality care provides financial rewards for GPs for stipulated carer care (Parmar et al., 2020). This was not something that was raised by GPs in this study and, to date, has not been addressed at policy level in Ireland.

Worryingly, some of the carers in this study also reported that they were expected to complete 'medicalised' tasks. Concerns regarding increased medicalised tasks by family carers, have recently been raised elsewhere. For example, the American Association of Retired Persons (AARP) highlighted the increasing amount of complex care being provided in the home, in a recent 'Home Alone Revisited' study (*N*=2,089) (Reinhard, 2019). Over half of the carers in this study were engaging in medical/nursing tasks that had previously been carried out by HCPs, with 7 out of 10 of these carers dealing with pain management. Furthermore, those engaged in these tasks, reported more time spent caring and a heavier emotional responsibility. Dow *et al.* refer to the shift of complex medical care to the community as the 'invisible contract', whereby carers are expected to take a large level of responsibility for care tasks in the home that were previously the work of paid staff (Dow & McDonald, 2007). Arguably, the setting of clear parameters with regard to family caring should be carefully considered and agreed amongst all parties so that carers are not expected to provide care that should be the responsibility of medically trained professionals.

Our findings highlight further an urgent need for the assessment of carer needs, particularly around their capacity to care, and their need to avoid the, often-overwhelming, burden of shouldering additional responsibilities. Notably, White *et al.* (2021) recommend that a 'Carer Readiness Tool (CRT)' should be used before hospital discharge in order to assess carer readiness to undertake the caring role and to help HCPs assess the limits of what carers can be expected to do, as well as engaging them in discharge planning (White et al., 2021). Our findings suggest that a similar tool could be usefully employed in settings in Ireland, and with routine in-built monitoring and review. This is particularly important in view of a number of societal changes to suggest that the frequency and complexity of care offered in the community is likely to increase in the not too distant future, owing to a generally ageing population (who are living longer), the shift away from institutional forms of care and an attendant increased emphasis on home care (Spotlight, 2019). It is imperative, therefore, that family carers are not unduly burdened with a level of care that would historically be carried out by HCPs.

Strengths and Limitations

This study addressed, for the first time in Ireland, the nature and extent of support provided to family carers in healthcare settings, with a particular emphasis on general practice. The study employed a mixed method design and explored the barriers and facilitators to HCP identification and support of carers, including GPs. This is important in light of some of the objectives outlined in the National Carers Strategy in Ireland which, to date, have not been fully implemented. The one-to-one interviews, whilst based on only a small sample of carers and GPs, yielded some interesting and important insights into the complexities surrounding the challenges involved in meeting these policy goals. The online administration of the survey also circumvented the need to recruit the sample using more traditional social welfare department or support services, and this may have encouraged those who do not usually identify themselves as carers, to participate. This is an important lesson in terms of carer recruitment which is typically based on convenience sampling of those who are in receipt of carers allowance and/or who have registered with a carer organisation (Family Carers Ireland, 2020b; Lafferty et al., 2016), thereby only reaching those who explicitly identify as a carer.

The findings from this study were important in informing the research questions underpinning an international scoping review of the literature that was subsequently undertaken as part of the larger project. This was carried out to determine the nature and extent of any guidance available internationally to GPs to assist them in consultations with carers as part of their day-to-day role. The results have also been used to inform the development and pilot testing of a brief training workshop for GP registrars (with an accompanying suite of supportive materials) to help them better identify and support family carers.

At the same time, the study was limited in a number of ways. The survey sample was not large, although it comprised a very diverse group of carers drawn from 23 of the 26 counties in Ireland and across a wide range of age and care recipient needs. It is possible that only those carers who were most adversely affected by their caring role decided to participate in the survey and interviews, and indeed, the lack of information on non-respondents is a well-known drawback of the survey method (Haslam & McGarty, 2014). Male carers were underrepresented in the sample despite vigorous efforts to recruit more men through engagement with the Men’s Health Forum Ireland (who shared the survey link with members) and with Kilbeggan Mens’s Sheds in the Midlands. Unfortunately, the low participation by males is common in carer (and other) research (Archer et al., 2008; Family Carers Ireland, 2020b). Furthermore, the GPs who participated, did so because they had a particular interest in carers due to past professional or personal experiences and they may not, therefore, be representative of GPs who have not had such experiences. Additionally, they were all recruited through the same GP online forum and so it is difficult to know the extent to which they were representative of all platform users. Lastly, the onset of the COVID-19 pandemic in March 2020, meant that fewer interviews were conducted at that time than anticipated and before saturation could be reached. Attempts to contact further participants were unsuccessful and it was felt that, due to the unprecedented crisis in general practice, as well as the considerable demands on carers, it would be inappropriate and counter-productive to continue the interviews.

Lastly, the fact that the first author is also a carer, was important in informing the study design, although steps were taken to avoid any unintended researcher bias. For instance, the questionnaire was piloted with five carers from diverse caring roles. The interview questions were also reviewed by the research team and in collaboration with a carer and a GP. The framework analytical approach used in the analysis of the qualitative data, is also highly structured, with a clear audit trail (Gale et al., 2013), while the lead researcher also kept a reflective journal throughout the interview process.

Conclusion

This study has highlighted some of the possible reasons why the objectives of the NCS (Department of Health, 2012), with respect to the identification and support of carers in community healthcare settings such as general practice, have remained largely unmet. Carers in this study were experiencing high levels of psychological distress, as well as important psychological barriers to help seeking and, overall, they reported a low level of satisfaction with the supports they were receiving. GPs were unaware of the NCS, were unclear about their role vis-à-vis carers, and lacked training and resources to be able to identify, assess or support them in general practice/primary care. All of the indications are that carer numbers will continue to rise (Oireachtas Library & Research Service, 2019), so it is critical that a robust process is put in place for the identification, signposting and support of family carers in general practice and primary care settings**.** Conversely, and as outlined earlier, general practice workloads are also set to increase (Crosbie et al., 2020) so policy makers and practice initiatives need to take into account the views of all stakeholders, including carers and the challenges that they face, particularly in the context of such increasing demands.

The changing needs along the care trajectory, suggest that carer identification, assessment and supports should be offered from the point of diagnosis of the care recipient, and a regular review process implemented thereafter. Further research could explore the extent to which the overburdening of family carers with 'over medicalised' tasks is present, and how parameters may be set to help manage this issue. Interventions/initiatives that promote carer identification from the perspective of the carer also need to be further investigated, as well as ways to provide more resources and referral routes for GPs, including for example, social prescribing. Social prescribing for family carers was recently noted by NICE to be an important knowledge gap (NICE, 2020) with no data currently available on its implementation or effectiveness.

The next stage of the larger multi-stage CHERISH project, currently underway and informed by the findings reported here, involves: (a) the development, piloting and evaluation of a brief educational workshop for GPs; (b) the development of an educational webinar (and attendant 'Practice Points' guidelines) for GPs to provide guidance to assist them in identifying, assessing and supporting carers; and (c) the design and delivery of an educational resource for family carers aimed at helping them to better address their issues related to carer identity and self-care, as well as their communication with GPs and other HCPs. The GP and carer-focused initiatives/resources have been co-designed, and will be co-delivered by both GPs and carers in line with public and patient involvement (PPI) guidelines (PPI Ignite, 2022). Further information will be made available on these at a later date.

Additional findings: Study One

This section presents additional findings not included in the published papers presented earlier in this chapter. Descriptive and inferential statistics are presented for a number of dimensions including activities and supports, stigma and identifying as a carer. Methodological details such as participant recruitment, settings and questionnaire measures are described in detail earlier in Chapter Two (Method) as well as in the preceding published papers.

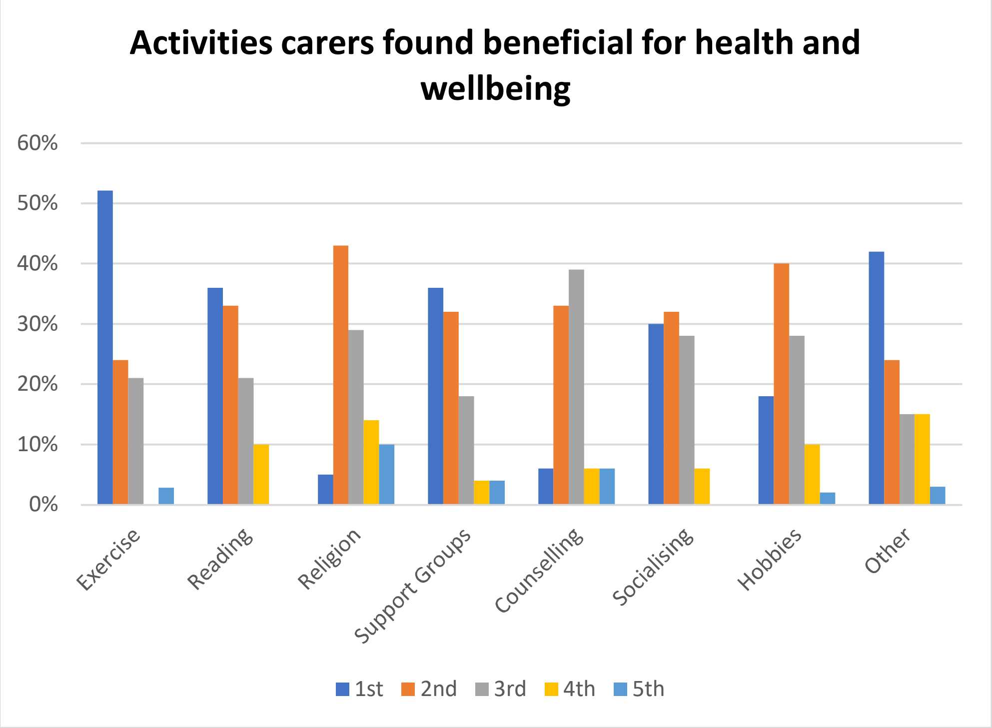
Health and well-being - activities and supports

As outlined in the paper presented earlier, the carers in this sample reported both low levels of support and low engagement in help-seeking behaviours. For example, over three-quarters (79%) reported having little or no support to assist them with their own health and well-being. A Mann-Whitney U test demonstrated no significant differences in these levels of support with regard to males versus females (males: $Md = 2$, $n = 13$; females: $Md = 2$, $n = 117$; $U = 818.5$, $z = .483$, $p = .62$, $r = .04$). Similarly, a Spearman's rho test showed no significant difference between age and perceived supports, $r(132) = -.072$, $p > .05$. No significant differences were found either for those living in in rural ($Md = 2$, $n = 62$) versus urban ($Md = 2$, $n = 70$) locations/communities, ($U = 2133$, $z = -.181$, $p = .85$, $r = .01$).

Respondents were also asked to indicate in which activities they engaged to support their health and well-being (Figure 3.6). The results showed participation in a wide range of activities (typically more than one), including exercise, reading, attending carer support groups (e.g. disability support group, FCI, Alzheimer's group), and socialising.

Figure 3.6

Activities in which carers engaged, or found beneficial in supporting their health and well-being (listed in order of preference from 1 to 5)



A one-way ANOVA was conducted to explore the impact of the perceived availability of support on levels of psychological distress (GHQ-12), Quality of Life (AC-QoL), help-seeking behaviour and perceived stigma (SIS) (see Table 3.2). Respondents were categorised into four groups according to their perceptions of the adequacy of the support they were receiving for their health and well-being (i.e. Group 1: 'Not at all', Group 2: 'A little', Group 3: 'A moderate amount', and Group 4: 'A lot'). A Levene's test for equality of variance indicated that the assumption of homogeneity was not violated (p > .05). The results demonstrated a statistically significant difference in psychological distress between groups, $F(3, 108) = 4.02$, $p = .009$, with a medium to large effect as measured by Cohen's d ($d = 0.1$). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for group 1 (M

= 25, *SD* = 6) was significantly differed from group 2 (*M* = 20, *SD* = 6); groups 3 (*M* = 22, *SD* = 5) and 4 (*M* = 24, *SD* = 3) did not differ significantly from other groups, indicating that even a small level of perceived support was better than none at all in terms of its impact on overall levels of psychological distress.

No significant between-group differences (p > 0.05) were found with regard to help-seeking or perceived stigma. However, there was a statistically significant difference in the QoL scores, with post-hoc comparisons (using the Tukey HSD) indicating that group 1 (i.e. those reporting no support (*M* = 55, *SD* = 14) reported statistically significantly lower scores than group 2 (i.e. those reporting 'a little' support (*M* = 56, *SD* = 18); those receiving 'moderate' support (*M* = 58, *SD* = 15) obtained statistically significantly higher scores than those who felt that they were receiving 'a lot' of support (*M* = 34, *SD* = 15) indicating perhaps, that those receiving a lot of support had a particularly demanding caring role.

Table 3.2

Means, Standard Deviations and ANOVA (Impact of having adequate support)

	Mean (SD)				***F***	***p***	**Cohen's *d***
IV: Level of support for own health & well-being	Group 1 Not at all	Group 2 A little	Group 3 A moderate amount	Group 4 A lot			
GHQ-12	25 (6)	20 (6)	22 (5)	24 (3)	4.09	.009*	.10
Help-seeking	20 (7)	20 (5)	20 (6)	24 (5)	1.09	.39	.00
AC-QoL	55 (14)	56 (18)	58 (15)	34 (15)	3.12	.03*	.09
SIS	51 (16)	51 (13)	54 (13)	56 (13)	.452	.71	.01

*Significant at the p<0.05 level

Identifying as a Carer

In order to understand the extent to which carers might identify with the term ‘carer’, respondents were asked if they had ever identified themselves as a carer when completing official documents, such as census forms or health surveys. More than half (53%) stated that they ‘rarely’ or ‘never’ refer to themselves as a carer when completing official documents. A chi-square test for independence indicated no significant association between formally identifying as a carer and sex, $X^2(4)$, = 6.57, $p = .160$, while no significant correlation with age was identified either, $r(123) = .076$, $p >.05$.

A number of one-way analysis of variance (ANOVA) tests were conducted to explore whether formally identifying as a carer impacted psychological health, engagement with help-seeking, QoL, or perceptions of stigma. For purposes of this analysis, the frequency with which respondents formally identified as a carer, was categorised into the following three groups: ‘often/frequently’, ‘sometimes’ and ‘rarely/never’. A Levene’s test for equality of variance indicated that the assumption of homogeneity was not violated ($p > .05$). A small significant between-group difference was found with regard to GHQ scores, and the post-hoc tests showed only a marginal difference between the groups ‘often/frequently’ and ‘sometimes’. No differences were found for help-seeking behaviours or perceived stigma (see Table 3.3).

Table 3.3

Means, Standard Deviations and ANOVA (Impact of identifying as a 'carer')

	Mean (SD)			*F*	*p*	Cohen's *d*
IV: Formally Identifying as a carer	Often/Frequently	Sometimes	Rarely/Never			
GHQ-12	22 (7)	25 (5)	22 (6)	3.12	.048	.05*
SIS	50 (14)	53 (12)	51 (16)	.272	.76	.00
Help-seeking	28 (5)	26 (5)	28 (6)	1.83	.16	.03
AC-QoL	56 (16)	50 (14)	57 (17)	1.08	.34	.02

*Significant at the $p \leq 0.05$ level

Perceived Stigma

As outlined in Chapter Two (Method), stigma was assessed using the Stigma Impact Scale (SIS). The sample obtained a mean overall score of 52 (*SD* = 14) which indicates that the respondents were experiencing some stigma. A breakdown of the subscales showed that the highest scores were obtained with regard to 'Social Rejection' (*M* = 18, *SD* = 6) and 'Social Isolation' (*M* = 18, *SD* = 4.5), followed by 'Internalised Shame' (*M* = 8, *SD* = 3) and 'Financial Insecurity' (*M* = 7, *SD* = 4).

A Mann-Whitney U test revealed no significant difference in the perceived stigma scores of males (*Md* = 60, *n* = 10) versus females (*Md* = 54, *n* = 98,), (*U* = 419.5, *z* = -.748, *p* = .45, *r* = -.07), or with regard to rural (*Md* = 55, *n* = 53) and urban (*Md* = 54, *n* =56) location , (*U* = 1428, *z* = -.337, *p* = .736, *r* = -.03). However, a Spearman's rho test showed a medium negative correlation between age and perceived stigma *r*(109) = -.305, *p* <.001, indicating lower perceived stigma scores amongst older respondents. Caring for a younger person was also associated with higher levels of perceived stigma, albeit only to a small extent, *r*(109) = -.226, *p* < .05.

A Spearman's rho test was also used to indicate if there was an association between perceived stigma, psychological distress, well-being and help-seeking. The findings demonstrate a statistically significant, moderate, positive relationship between stigma and GHQ scores, $r(109) = .39, p < .05$ and a statistically significant, moderate, negative relationship between stigma and QoL, $r(109) = -.43, p < .05$. There was no significant relationship between stigma and help-seeking. A multiple regression analysis was used to explore how much of the variance in GHQ-12 scores could be explained by aspects of stigma. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, homoscedasticity and multicollinearity. The results showed that both 'Social Isolation' and 'Financial Insecurity' were significantly related to GHQ-12 scores, $F(4,100) = 5.51$, $p = .000$, $R^2 = .18$, *Adj* $\mathrm{R}^2 = .14$, and both accounted for 14% of the variance in this sample. 'Financial Insecurity' was weighted most highly ($\beta = -.231$, $p =.000$), followed by 'Social Isolation' ($\beta = - .227$). The remaining two dimensions of stigma assessed in the study, 'Social Rejection' and 'Internalised Shame', were not identified as predictors in this model. A second multiple regression analysis undertaken to explore how much of the variance in QoL scores could be explained by stigma, found that 'Financial Insecurity' ($\beta = - .366$) was significantly related to QoL, $F(4,88) = 6,32$, $p = .001$, accounting for 18% of the variance in AC-QoL scores in this sample.

The extent to which respondents felt that they would be stigmatised by others for seeking help was also examined using the PSOSH. The analysis of scores showed that respondents did not feel stigmatised by others in this regard ($M = 9$, $SD = 5$).

Conclusion

This chapter has outlined the findings from Study One. Firstly, the paper published in *Frontline: The Voice of Intellectual Disability*, was presented. The paper published in the *Irish Journal of Medical Science* was presented next, and finally, any descriptive and inferential statistics not included in the papers, are presented in the final 'Additional Findings' section of the chapter. The implications of these additional findings are discussed later in Chapter Seven. The next chapter presents the published paper from Study Two.

Chapter 4: Study Two

This chapter presents the paper published in the peer-reviewed journal *BMC Primary Care* in November 2023. The paper outlines the key findings from the scoping review regarding the identification, assessment and signposting of family carers in general practice/primary care.

Cronin, M.[1], McLoughlin K.[2], Foley, T.[3], and McGilloway S.[1] Supporting family carers in General Practice: A scoping review of clinical guidelines and recommendations. *BMC Family Practice* (under review – submitted in Jan, 2023).

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Supporting family carers in General Practice: A scoping review of clinical guidelines and recommendations

Abstract

Background

Increasing numbers of family carers are providing informal care in community settings. This creates a number of challenges because family carers are at risk of poor physical and psychological health outcomes, with consequences both for themselves and those for whom they provide care. General Practitioners (GPs), who play a central role in community-based care, are ideally positioned to identify, assess, and signpost carers to supports. However, there is a significant gap in the literature in respect of appropriate guidance and resources to support them in this role.

Methods

A scoping review was undertaken to examine clinical guidelines and recommendations for GPs to support them in their role with family carers. This involved a multidisciplinary team, in line with Arksey & O'Malley's framework, and entailed searches of ten peer-reviewed databases and grey literature between September-November 2020.

Results

The searches yielded a total of 4,651 English language papers, 35 of which met the criteria for inclusion after removing duplicates, screening titles and abstracts, and performing full-text readings. Ten papers focused on resources/guidelines for GPs, twenty were research papers, three were review papers, one was a framework of quality markers for carer support, and one was an editorial. Data synthesis indicated that nine (90%) of the guidelines included some elements relating to the identification, assessment, and/or signposting of carers. Key strategies for identifying carers suggest that a whole practice approach is optimal, incorporating a role for the GP, practice staff, and for the use of appropriate supporting documentation. Important knowledge gaps were highlighted in respect of appropriate clinical assessment and evidence-based signposting pathways.

Conclusion

Our review addresses a significant gap in the literature by providing an important synthesis of current available evidence on clinical guidelines for GPs in supporting family carers, including strategies for identification, options for assessment and potential referral/signposting routes. However, there is a need for greater transparency of the existing evidence base as well as much more research to evaluate the effectiveness, and increase the routine utilisation, of clinical guidelines in primary care.

Keywords:

Family Carer, General Practice, GP, Clinical Guidelines, Primary Care, scoping review.

Background

The provision of care in the community has attracted increasing concern in recent years, due to the growth in ageing populations, lower birth rates (Khavinson et al., 2020), shifting societal demographics (Oireachtas Library & Research Service, 2019), and changes in healthcare delivery (Burke et al., 2018). However, care for many vulnerable citizens is provided largely by family members or loved ones, who are described as 'family carers' or 'informal carers'. For example, in Europe alone, it is estimated that 10% to 25% of care in the community is provided by family carers (Zigante, 2018) In Ireland, the support/labour provided by family carers saves the state an estimated €20 billion in care costs annually (Family Cares Ireland, 2019).

A wealth of evidence indicates that these carers report poorer physical and mental health outcomes than the general population (Eurocarers, 2018; Family Cares Ireland, 2019; OECD, 2017). For example, a recent study by Gallagher and Bennett (2021) found that carers had a 33% increased risk of future illness or disability when compared to non-carer controls. Crucially, this impact on carer health appeared to be present even beyond the end of the caring role. Furthermore, carers typically report higher levels of psychological distress (Cronin & McGilloway, 2022) than non-carers (George et al., 2020). Despite these psychological and physical impacts robust systems to support those who provide care, continue to be ad hoc, inconsistent, or absent (Parmar et al., 2020).

A growing body of evidence suggests a number of barriers to the provision of appropriate systems for supporting family carers (Parmar et al., 2020). The identification of carers, in the first instance, can be challenging, as many carers do not identify with the term 'carer' but, instead, identify with the relationship to the person for whom they are providing care (NICE, 2020). Furthermore, healthcare professionals (HCPs) are not always aware of who is providing the care and, even when they are, evidence suggests they are reluctant to raise the question, as they are unsure of their role in this regard (Carduff et al., 2014; Cronin & McGilloway, 2022). Thus, even when carers are identified, there is a lack of clear direction regarding how their needs can be best assessed and to where they can be referred or signposted for support (Cronin & McGilloway, 2022).

The National Institute for Care Excellence (NICE) suggests that health and social care practitioners should "actively seek to identify carers" (NICE, 2020) (p.12). Furthermore, existing literature highlights, in particular, the benefits of a role for general practitioners (GPs) in identifying and supporting family carers (Parmar et al., 2020). A number of countries or regions, such as the UK and parts of Australia and Canada, have developed guidelines for GPs in their role vis-à-vis carers (Doctors of BC, 2016; Northern Sydney Local Health District, 2019; Royal College of General Practitioners & The Princess Royal Trust, 2013), whilst other studies have examined how GPs may support specific caring roles (Burridge et al., 2017). Guidelines are often used in primary care to support and improve patient care (Abdelhamid et al., 2014), and are either produced by GP professional bodies, external agencies, or adapted from national guidelines (O'Brien et al., 2021). However, no guidelines to support GPs in their role with family carers are, as yet, available in many countries across the world despite the fact that evidence-based guidelines can be an important resource for GPs in a clinical setting (O'Brien et al., 2021). The barriers and facilitators to supporting carers in general practice have been widely researched and identified (Parmar et al., 2021), but there is still little published literature regarding the provision of appropriate and effective clinical guidelines for the support of family carers.

The current study was conducted as part of a larger project that investigated how family carers in Ireland are supported in healthcare settings, with a particular focus on general practice. The aims of the sub-study reported here, were: (1) to identify and critically review the existing national and international guidelines, practice standards, procedures, and/or other literature relevant to the development, implementation, and evaluation of clinical practice guidance for GPs, in order to assist them to identify, assess, and signpost family carers in general practice; (2) identify examples of good practice that have been demonstrated to support the identification, assessment, and referral of family carers in general practice; and (3) to help inform the development of guidelines and accompanying education and audit resources for use by GPs in Ireland. The specific research questions that guided the study were:

1) What clinical guidance is available to GPs to support carer identification and assessment?
2) What guidance is available to enable GPs to signpost family carers to relevant services/supports?
3) What processes are in place (if any) to evaluate the effectiveness of the above guidance?
4) What resources are available to support GPs in the identification, assessment, and referral process of family carers?
5) What is the level of evidence available for clinical guidance on supporting family carers?

We used a scoping review methodology that allowed us to explore or 'scope' the broad topic of clinical guidelines in respect of family carers, in both peer-reviewed and grey literature. Scoping studies are particularly useful in exploring areas that have not been comprehensively reviewed and where the evidence is emerging (Larkin et al., 2019), or based on a broad range of study designs and methodologies (Arksey & O'Malley, 2005). We expected that few, if any, randomised controlled trials (RCTs) would be available and that much of the literature would be based on guidance produced by professional GP bodies and carer support agencies, as well as other sources of grey literature.

Method

The scoping review method used here was in line with the original guidelines proposed by Arksey and O'Malley (Arksey & O'Malley, 2005), whilst also incorporating more recent revisions and suggestions (Daudt et al., 2013; Levac et al., 2010). This involved a six-step process including: (1) identifying the research question; (2) identifying relevant studies; (3) selecting studies; (4) charting the data; (5) collating, summarising and reporting the results; and (6) consulting with key stakeholders. We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines in reporting the findings (Tricco et al., 2018) (See Additional File 1). We did not publish a protocol for this review.

Search terms and databases

The PICOS (Population, Intervention, Comparison, Outcome, Setting) framework was used to formulate the research question and to identify appropriate and relevant search terms (Hegarty et al., 2015). A full outline of the PICOS components is provided in Additional File 2. The search terms were formulated by the lead (MC) and second author (KMcL), and circulated to the wider team for review before being finalised. Searches were carried out between September and November, 2020. We included studies relating to general practice or primary care and any interventions/guidance that supported the identification, assessment, or signposting of family carers in these settings. We excluded studies related to paid carers such as Health Care Assistants (HCAs) and hospital or nursing home settings. The databases of peer-reviewed and grey literature searched were: CINAHL, Medline, PsycINFO, Lenus.ie, Google – first 200 results [69,70], OpenGrey, NICE, Cochrane, and Kingsfund. A search was also undertaken of GP professional bodies and government websites from countries considered by the OECD [36] to be proactive in carer assessment (e.g. UK, Sweden, and Australia), as well as those where larger numbers of research papers on the topic were generated, such as Canada and USA. The databases and other websites searched (and including GP professional bodies), were selected in consultation with the full research team. The full search strategy for Medline, including medical subject headings (MeSH), is available in Additional File 2. Papers from the previous 10 years (Jan 2010 – Oct 2020) were included in order to gain up-to-date clinical guidance. All included papers were in the English language due to time and funding constraints.

Identifying relevant studies and study selection

The first author (MC) conducted searches on databases, grey literature and professional bodies, as well as hand searching of reference lists of retrieved papers, while the second author (KMcL) searched the CINAHL database. Searches were limited to title and abstract. Papers were imported into Mendeley for initial data management purposes such as de-duplication, and titles and abstracts were screened for removal of obviously irrelevant papers. The full texts of included papers were retrieved and imported into Rayyan software for full text review by both MC and KMcL. In the event of any disagreement, another member of the multidisciplinary research team (TF) acted as a third reviewer. This team approach to data extraction was used to ensure rigor (Levac et al., 2010). Furthermore, although we were expecting a low level of evidence (LoE), we decided to rate the included studies using the seven hierarchical levels of evidence outlined by Ackley et al. (Ackley et al., 2007) (see Table 4.1).

Table 4.1

Level of evidence rating.

Level of evidence (LoE)	Description
Level I	Evidence from a systematic review or meta-analysis of all relevant RCTs (randomized controlled trial) or evidence-based clinical practice guidelines based on systematic reviews of RCTs or three or more RCTs of good quality that have similar results.
Level II	Evidence obtained from at least one well-designed RCT (e.g. large multi-site RCT).
Level III	Evidence obtained from well-designed controlled trials without randomization (i.e. quasi-experimental).
Level IV	Evidence from well-designed case-control or cohort studies.
Level V	Evidence from systematic reviews of descriptive and qualitative studies (meta-synthesis).
Level VI	Evidence from a single descriptive or qualitative study.
Level VII	Evidence from the opinion of authorities and/or reports of expert committees.

Based on: Ackley BJ, Swan BA, Ladwig G, & Tucker S. Evidence-based nursing care guidelines: Medical-surgical interventions. St. Louis, MO: Mosby Elsevier. 2008;7.

Charting and data synthesis

Data charting involves mapping out the data according to key issues and themes (Arksey & O'Malley, 2005). As recommended by Levac et al. (2010), we completed an additional step to charting which involved two reviewers (MC & KMcL) independently reviewing the first five to ten papers using the charting form and then consulting to see if our approach was consistent and in line with the core research question. This ‘trial charting exercise’ followed by consultation, was very helpful in ensuring the richness of the data (Daudt et al., 2013). The first author (MC) developed a draft form to encompass a range of items including author and publication details, as well as: 1) aims/objectives; 2) study population and sample size; 3) setting (i.e. primary care or general practice); 4) identification; 5) assessment; 6) signposting 7) consultation resources; and 8) level of evidence. The first and second authors

(MC and KMcL) then piloted the form, as recommended (Levac et al., 2010), resulting in the inclusion of one additional item (i.e. documentation).

Consultation exercise with stakeholders

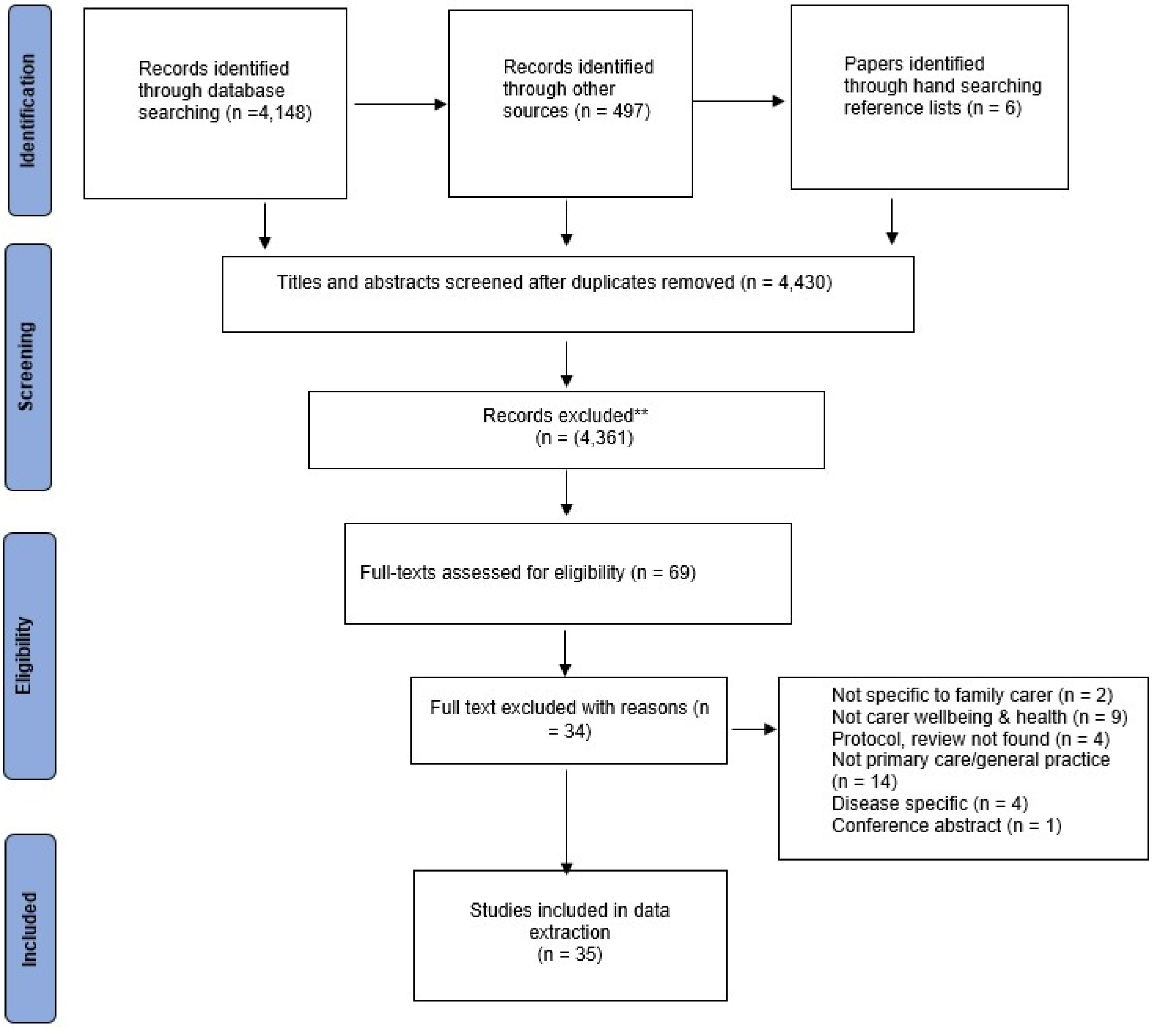
Arksey & O'Malley (Arksey & O'Malley, 2005) suggest that stakeholder consultation should be an optional step in a scoping review, while Levac et al. (2010) and Daudt et al. (2013) go farther by recommending it as a requirement; interestingly, Daudt et al. (2013) argue that several stakeholders can be included on the review team in order to enhance the consultation process. Thus, our multidisciplinary research team included a number of key stakeholders in the form of a GP (TF), and a psychologist from a national carer support organisation (KMcL) to ensure relevance of the study to clinical practice; the first author (MC) is also a carer with over 20 years' experience in that role while the last author (SMcG) is a senior academic with considerable experience in conducting reviews. However, as the results of this scoping review were intended to be applied to inform the development of clinical guidelines (also known as 'clinical practice points'), we felt it was important to include the voice of carers as primary stakeholders. Therefore, a consultation exercise was conducted with a panel of carers (N=5) from a number of diverse caring roles (e.g. a son caring for his father, wife caring for husband etc.). A draft of the 'practice points' was presented to the carers for comment during this exercise, with their input incorporated into the final set of clinical practice points.

Results

A total of 4651 papers were retrieved, 4,430 (95%) of which were included in title and abstract screening following deduplication. Sixty-nine papers met the eligibility criteria for full text review, 35 of which were selected for inclusion in the review (Figure 1). Further details relating to the numbers of papers per database and specific search dates are included in Additional File 3.

Figure 4.1

PRISMA Diagram of literature search



Characteristics of included studies

Ten papers were categorised as resources or guidelines designed for GPs to support them in their role with family carers, twenty were based on peer reviewed research (12 qualitative, 5 quantitative, 1 study protocol, 1 RCT and 1 systematic review), three were review papers (2 narrative reviews, 1 literature review), one was a quality marker indicator for carer support, and one was an editorial paper. Whilst four of the included studies focused solely on carers, 12 involved the recruitment of participants from other sources including GPs, general practice staff, other healthcare staff and policy makers (See Table 2). Sixteen of the included research studies focused on primary care/general practice settings, with carer participants providing support to family members with issues ranging from advanced cancer and palliative care to older person care, stroke and dementia. Sample sizes ranged from 19 to 40 for 12 of the included qualitative studies with the exception of one study with a sample size of 70 recruited from a diverse group of stakeholders. The largest sample size of all the included studies (N > 800) was reported for a piece of work that explored the components of the Family Strain Questionnaire with a view to developing a shorter psychometrically robust version. Most included studies were from the UK (12), with the remainder based in the USA (5), Canada (3), Australia (3), Germany (1), Norway (1), Italy (1), and Ireland (1).

Health-related risks for carers were mentioned in six of the included papers and referred to symptoms of psychological distress, such as anxiety and depression (Eurocarers, 2018), neglect of own health due to a focus on the care recipient, or difficulty in attending appointments (Royal College of General Practitioners, 2013b), as well as other ailments such as back injury/pain (Royal College of General Practitioners, 2013b), shoulder injury (Royal College of General Practitioners & The Princess Royal Trust, 2013), high blood pressure (Royal College of General Practitioners, 2013b), greater risk of stroke (Royal College of

General Practitioners, 2014), increased mortality in older carers (Royal College of General Practitioners, 2014), insomnia (American Family Physician, 2015), and sleep problems (RCGP Scotland).

Table 4.2

Characteristics of included studies

Study/Guidelines	Aim	Study Design	Country	Participants and sample size	Level of Evidence**
Burridge, Mitchell et al. (2011)	To explore the views of lay caregivers and health professionals about the way lay caregivers' health concerns are raised by their GP?	Qualitative: Semi-structured interviews	Australia	Cancer Caregivers (n = 6) Health professionals (n = 19).	VI
Burridge, Mitchell et al. (2017)	Explores carers and GPs' views regarding the acceptability and usefulness of the NAT-C for helping carers to address their own health concerns.	Qualitative: Semi-structured interviews	Australia	Cancer caregivers (n = 11) and GPs n = 5).	VI
Carduff et al. (2014)	To identify barriers to and explore strategies for identifying carers in primary care. Particularly self-identifying as a carer and identifying those caring in end of life.	Triangulated data: Lit review, workshop and focus groups	UK (Scotland)	Lit review (n = 50 papers), Researcher workshop (n = 70), Focus groups carers (n = 15), health professionals (n = 8)	VI
Carduff, Jarvis et al. (2016)	To develop, pilot, and evaluate a new model of identifying, assessing, and supporting unpaid carers of people with palliative care needs.	Feasibility study, qualitative evaluation interviews	UK (Scotland)	Carers of terminally ill in 4 GP practices. (n=81) received carer pack, (n=25) returned CSNAT form, (n=11) took part in follow up interviews.	VI
Family caregiver alliance (2012)	To provide practitioners with a wide range of measures from which they may generate assessment instruments appropriate and applicable to their practice setting, and beneficial for care planning.	Assessment measures resources inventory	USA	N/A	N/A
Fisher et al. (2020)	To identify barriers and facilitators faced by HCPs in supporting FCGs, as well as knowledge, skills and attitudes needed by HCPs, to provide comprehensive services to FCGs.	Qualitative – symposium to gather perspectives of FCG's, HCP's and stakeholders	Canada	N = 40, FCGs n = 8 (Caregivers of seniors), frontline HCPs n = 6, managers n = 3, senior services organizers n = 3, non-government organizations leaders n = 6, academics n = 11 policy makers n = 3.	VI
Greenwood et al. (2010)	Investigate GPs' attitudes to carers, awareness and knowledge of issues facing carers and perceived barriers to supporting carers.	Post-training questionnaire survey of GPs	UK	Practice managers and receptionists) n = 33	VI

Study/Guidelines	Aim	Study Design	Country	Participants and sample size	Level of Evidence**
Greenwood et al. (2011)	Explores the support stroke carers would like from general practice and reactions to a community-based support and perceptions of a general practice team on carer supports.	Qualitative study – Semi - structured interviews	UK (England)	Stroke carers (n = 13) General practice staff (n = 10) GPs from varying sized practices. N = 78	VI
Greenwood et al. (2016)	Identify, appraise, and summarize all the published evidence on general practice-based interventions to support carers of people with stroke or dementia.	Systematic Review	UK (England)	4 included studies – all dementia carers	I
Jiwa et al. (2010)	To develop an innovation to be tested in a formal clinical trial in Australian general practice (p.10). Pilot testing of NAT-C prior to RCT.	Complex intervention using actor patients	Australia	GPs (n = 6) Actor patients (n = 6), 34 recorded consultations.	VI
Jones et al. (2012)	Inform the department of health about the impact and efficacy of the pilot workshop programme in increasing the participants' knowledge and awareness about carers and how they might be assisted.	Questionnaire evaluation pre-workshop, post-workshop and 3 months post-workshop	UK	GPs (n = 95), clinical primary care workers (practice nurses, HCA's) community matrons (n = 25), non-clinical primary care workers	VI
Kingston University (2010)	Evaluate six pilot workshops across England as part of the National Education Programme for Supporting Carers in General Practice organized by the Royal College of General Practitioners and the Princess Royal Trust for Carers.	Evaluation of RCGP pilot training for GPs. Questionnaires: preworkshop, end of workshop and post three months	UK	Six pilot workshops, total participants n =192, total participants working in primary care n = 153. Workshops delivered by 2 GPs and 1 former carer	VI
Katja Krug et al. (2018)	Increase the knowledge about challenges in general practice for patients, lay carers, and professionals carers in end-of-life (EoL) care.	Qualitative – focus groups	Germany	GPs (n = 12), medical assistants (N = 7) – with a special interest in palliative care.	VI
Mitchell et al. (2010)	To assess the efficacy of the systematic utilization of a GP Toolkit in reducing caregivers' reported number and level of unmet needs AND Evaluate the acceptability of the intervention for GPs and caregivers.	Study protocol for RCT		GPs and caregivers (approx. 400 caregivers and 330 GPs to complete the study)	N/A
Mitchell et al. (2013)	To assess the hypothesis that the efficacy of a GP-based intervention incorporating a carer-reported needs checklist and a supporting GP Toolkit of resources, reduces the reported number and intensity of unmet carer needs, compared with usual care.	RCT - general practice	Australia	Carers of people with advanced cancer (N = 392)	II

Study/Guidelines	Aim	Study Design	Country	Participants and sample size	Level of Evidence**
National Health Service (NHS) England, patient experience team (2016)	Developing an integrated approach to the identification, assessment, and support of Carers and their families across health and social care.	A resource to help promote working together between Adult social care services, NHS commissioners and providers, and third sector organizations	UK	N/A	N/A
National Institute for Health and Care Excellence (NICE), (2020)	Guideline providing action-orientated recommendations for good practice, aimed at improving outcomes for adult carers.	Recommendations for health and social care practitioners in supporting Adult Carers.	UK	N/A	N/A
O'Connor C. (2011)	Assess the role of Ireland's general practitioners in caring for dementia carers.	Literature Review	Ireland	Dementia caregivers and general practitioners, general practice-based studies	N/A
Onwumere (2016)	Article in British Journal of General Practice discussing how GPs are in a unique position to support the individual with psychosis and carers in general practice.	Editorial	UK	General practice audience	VII
Parmar et al. (2020)	(1) To review stakeholder engagement process that led to the development of the competencies, (2) describe the process used to identify the competency domains, (3) report on the modified Delphi process used to validate the domain indicators, and (4) introduce the competency framework.	Multilevel interdisciplinary stakeholder codesign to develop a competency framework	Canada	Expert panel of Stakeholders (n = 50) included family caregivers health care leaders, not-for-profit social care leaders, health professionals, front line health care providers, policy makers and policy influencers, national and international researchers	VI
Peters et al. (2019)	To explore the views of professional stakeholders on how health services, particularly primary care, can support carers and scope for strengthening such support in England.	Qualitative – semi-structured interviews	UK	Total n = 25, (GPs n = 4, Nurse n = 4, pharmacist n = 2, consultant n = 1, phlebotomist n = 1, policy n = 5, voluntary sector n = 8, local authority n = 1, private health sector n = 3, researcher n = 1.	VI
Royal College of General Practitioners (RCGP) (2013) – in partnership with Princes Royal Trust for carers.	Guide to help GPs understand who carers are, why they need help, how to involve them in patient care, and how to support them AND Educational tool AND summary report.	Action guide for GPs and their teams	UK	N/A	N/A

Study/Guidelines	Aim	Study Design	Country	Participants and sample size	Level of Evidence**
Roen et al. (2019)	To explore and describe health care professionals' (HCPs) carer support within cancer palliative care within Orkdal district.	Qualitative - focus groups	Norway	HCPs n = 21	VI
Riffin et al. (2020)	To identify current approaches to identifying carer needs and risks in primary care, to understand benefits and barriers to implementing a standardized caregiver assessment in primary care, to derive recommendations for integrating assessment tools into primary care.	Qualitative – semi-structured interviews	USA	Primary care clinicians, staff and administrators (n = 30), Patient and family caregivers (n = 40)	VI
Robinson et al. (2010)	Addresses long-term care at home for people with dementia with a focus on psychosocial interventions, provision of information, caregiver support, behavioural and psychological symptom management and case management.	A narrative review	UK	N/A	N/A
Royal Australian College of General Practitioners (RACGP)(2019)	To support clinicians in supporting families and caregivers of older persons.	Part B of aged care clinical guide. – families and carers	Australia	N/A	N/A
RCGP Scotland (n.d.)	To support GPs in the identification, support, and signposting of carers and young carers.	GP Resource/Information leaflet	Scotland	N/A	N/A
Smith et al. (2018)	To develop and evaluate a series of workshops intended to increase confidence as it relates to communication between caregivers, care recipients and healthcare professionals and thereby decrease caregiver burden.	Feasibility study	USA	Caregivers (N = 16)	VI
Sunne et al. (2017)	To provide a concise review of how to care for the caregivers.	Review paper	USA	N/A	N/A
Swartz & Collins (2011, & 2019)	Summarizing caregiver care by primary care physicians and offer direction for future research – handout for carers is included.	American Family Physician article – Caregiver Care	USA	N/A	N/A
Vidotto G (2010)	To examine the properties of the Family Strain Questionnaire in the context of the Rasch model for scale construction to pave the way to develop a shortened refined version that practitioners can use routinely to screen for caregiver stress.	Development of a short form of the family strain questionnaire (FSQ). (semi structured interview	Italy	Caregivers (n = 811) completed original FSQ, caregivers (n = 40) participated in reanalyzing the revised shorter version	VI

Study/Guidelines	Aim	Study Design	Country	Participants and sample size	Level of Evidence**
Doctors of BC (British Columbia, Canada)	Tool kit for doctors - how to organize your practice to support family caregivers.	Supplementary resource part of Doctors of BC policy paper "Circle of Care: Supporting Family Caregivers in BC"	Canada	N/A	N/A
Carers Trust Wales (2019)	Designed to be used by Regional Partnership Boards, Local authorities, Local Health Boards and third sector organizations in Wales to support the identification and commissioning of good services for un-paid carers.	Good practice approaches to supporting carers in wales	UK - Wales	N/A	N/A
NHS (2019)	Quality markers for supporting carers in general practice.	Quality markers	UK	N/A	N/A
Northern Sydney Local Health District (Australia)	To provide information to GP's on the caring experience, what it means to be a carer, the impact of caring for another person, as well as how a GP can support those important partnerships in caring.	A guide for GPs and primary care teams	Australia	N/A	N/A

**Level of evidence rating assigned to studies (Ackley et al., 2007)

Guidance on the identification of Carers

The identification of carers is the first step toward offering support, and this was addressed in 19 of the papers, including 9 of the 10 resource/guidance documents. Identification also forms a key part of the quality markers paper by the NHS (NHS, 2019). Six papers reported on studies where carer identification was a component of the findings (Carduff et al., 2014; Carduff et al., 2016) (Fisher et al., 2020; Greenwood et al., 2011; Krug et al., 2018; Peters et al., 2020). Two review papers discussed the support of carers in general practice (Onwumere et al., 2016; Sunne & Huntington, 2017), while one paper identifying the core competencies in HCP education, included the identification of carers (Parmar et al., 2020). Overall, the identification of carers in general practice/primary care emerged as the responsibility of the whole practice.

A Whole-practice approach to the identification of carers

Strategies to identify carers fell into three broad categories, as outlined in Figure 4.2, including a key role for GPs, responsibilities for practice staff, and the availability and use of practice documentation. GPs may identify carers in a number of ways, including consultations with the care recipient, communication with other HCPs, pro-actively making enquiries and being alert to signs (and symptoms) of carer burden, as well as appointing a carer champion / carer lead within their practice. A number of guidelines suggest that the point of diagnosis or first appointment can be an opportunity to ascertain who will be providing most of the care or support for patients who have longer term illness/disability (Carduff et al., 2016; Northern Sydney Local Health District, 2019). Additionally, transitions such as the care recipient moving to adult services, or relocating to a nursing home or other form of residential care, were also highlighted as particularly stressful times when carers may need additional support (Cronin & McGilloway, 2022).

Figure 4.2

Whole practice approach to carer identification

GP

At diagnosis of long-term illness or disability find out who will be providing the care (Carduff et al., 2016; Northern Sydney Local Health District, 2019)

Seek out carer details through hospital admission and discharge process (NICE, 2020)

Consider the impact of the patient’s condition on the family and make enquiries about who is providing care (RCGP Scotland)

Be aware of the signs of an undisclosed caring role (e.g. back problems, stress, minimising own health, poor mental health, sleep problems) (RCGP Scotland)

Ask patients if someone helps them with care needs (NICE, 2020; RCGP Scotland)

Invite a member of staff to be carer champion/lead with key responsibility for identifying carers (Carduff et al., 2016; Carers Trust Wales, 2019; NHS England and NHS Improvement, 2019; Royal College of General Practitioners & The Princess Royal Trust, 2013)

At multi-disciplinary meetings with other HCPs seek out carer details(Royal College of General Practitioners, 2013a)

Carer Lead/Practice Staff

Encourage carers’ to self-identify by: Displaying information in reception area and website (NHS England and NHS Improvement, 2019)

Ask family members if they are the primary carer when they bring patients for flu or other vaccine (Royal College of General Practitioners & The Princess Royal Trust, 2013)

Take note of who is making appointments/ordering prescriptions and ask if they are providing the care (Doctors of BC, 2016; Embracing Carers, 2017)

Be aware of carers’ from hard to reach groups such as:
ethnic minorities, the LGBTQI+ community
carers’ of those with mental health or substance misuse
or carers’ with disabilities (Royal College of General Practitioners, 2013b)
(Links with community groups can help identify these carers’)

Practice Documentation

Have a register to identify and record carers (NHS England and NHS Improvement, 2019)

Keep register up to date, particularly in the case of the death of the care recipient (NHS England and NHS Improvement, 2019; Royal College of General Practitioners & The Princess Royal Trust, 2013)

Have a brief form to allow carers to request to be put on the carer register (Eurocarers, 2018; NHS England and NHS Improvement, 2019)

Include a question on the new patient registration form (Doctors of BC, 2016; Northern Sydney Local Health District, 2019) such as:
Do you rely on someone for your care? OR Does someone rely on you for their care?

When forms are received for disability or related allowances, enquire who the carer is (Royal College of General Practitioners, 2013a)

Note any carer details on communication from consultants/specialists (Royal College of General Practitioners & The Princess Royal Trust, 2013)

Review other practice registers, for example, disease specific registers, long term illness register (Carduff et al., 2016)

Carer Champion

The appointment of a carer champion by the GP was a recurring finding in this review (Carduff et al., 2016; Carers Trust Wales, 2019; NHS, 2019; Royal College of General Practitioners, 2013a), defined by NICE as a "…designated member of staff who is tasked with supporting and speaking up for carers". Carer champions can act as a key contact for carer information and advice, providing knowledgeable expert advice, as well as training other practitioners working within the service" (NICE, 2020) (p.32). They could have responsibility for promoting self-identification, liaising with family members, being alert to who accompanies care recipients, and being proactive about identifying carers from 'harder- to-reach' groups. A carer champion may be one of the clinical or administrative staff and play a significant role in carer identification (Royal College of General Practitioners, 2013a). One of the included papers, an RCGP educational resource for GPs and primary care teams, provides useful, more detailed guidance on the responsibilities of a carer champion, for example, maintaining the carers register, being in-practice point of contact for carers and sourcing information for carers (Royal College of General Practitioners, 2014) (p.32).

Documentation and record keeping are also important in supporting the identification of carers by, for example: providing a carers' register (i.e. a list of carers in the practice that can be used to provide targeted supports such as invitations to vaccine clinics or health checks) (NHS, 2019), and pro-actively seeking information about carers through current practices, such as new patient registration, completion of welfare applications, communications with other HCPs, linking with in-house databases (i.e. illness specific registers), and providing routes for self-registration. The importance of keeping the carer register up-to-date was highlighted by the RCGP summary report (Royal College of General Practitioners, 2013a) which emphasised, in particular, the need to remove carers when a care recipient dies or moves to residential care.

This report also usefully highlights systems that may be used to record carers in a number of exemplar practices, including coding carer status as ‘has a carer’ or ‘is a carer’ (Royal College of General Practitioners, 2013a).

Guidance on the Assessment of Carers

Twenty-two studies discussed the assessment of carers’ needs in general practice. However, just two of the ten guidelines for GPs referred to the type of assessment that may be useful. For example, the American Family Physicians resource (Collins & Swartz, 2011), entitled ‘Caregiver Care’, refers to both the Adapted Zarit Burden Interview and the Modified Caregiver Strain Index, while ‘Doctors of British Colombia’ in their resource (Doctors of BC, 2016), ‘Organising your practice to support family caregivers: A toolkit for doctors”, also refer to the Adapted Zarit Burden Interview. An additional five assessment tools were indicated throughout the review including: (1) the Needs Assessment Tool – Caregivers (NAT-C) (Burridge et al., 2017; Burridge et al., 2011; Jiwa et al., 2010; Mitchell et al., 2010; Mitchell et al., 2013); (2) The Carer Support Needs Assessment Tool (CSNAT) (Carduff et al., 2016; Røen et al., 2019); (3) The Adult Social Care Outcome Tool - Carer (ASCOT – Carer) (Peters et al., 2020); (4) The Carers Star (Carers Star™)The Outcomes Star for people caring for others (Peters et al., 2020) and (5) the Family Strain Questionnaire (FSQ) (Vidotto et al., 2010). Notably, the Family Caregiver Alliance in the USA (Family Caregiver Alliance, 2012) provides a comprehensive range of measures that may be used in health and social services to assess carers across a range of domains that include physical and mental health (section 4).

Although just seven assessment tools were mentioned specifically, several of the included papers discussed assessment in terms of its therapeutic and preventative effect (Fisher et al., 2020; NICE, 2020) and the usefulness of an assessment to facilitate communication

(Burridge et al., 2017; Riffin et al., 2020; Røen et al., 2019) during a GP consultation. Other studies highlighted a need for carers to be systematically (Robinson et al., 2010) and periodically (Collins & Swartz, 2011) assessed, with interventions designed to meet their needs (Robinson et al., 2010). The structure and wording of assessments was mentioned in several papers, with suggestions that they should be brief and linked to patient outcomes, and with wording that is free from judgement about carers' performance or any assumption that all carers need (or want) help (Riffin et al., 2020).

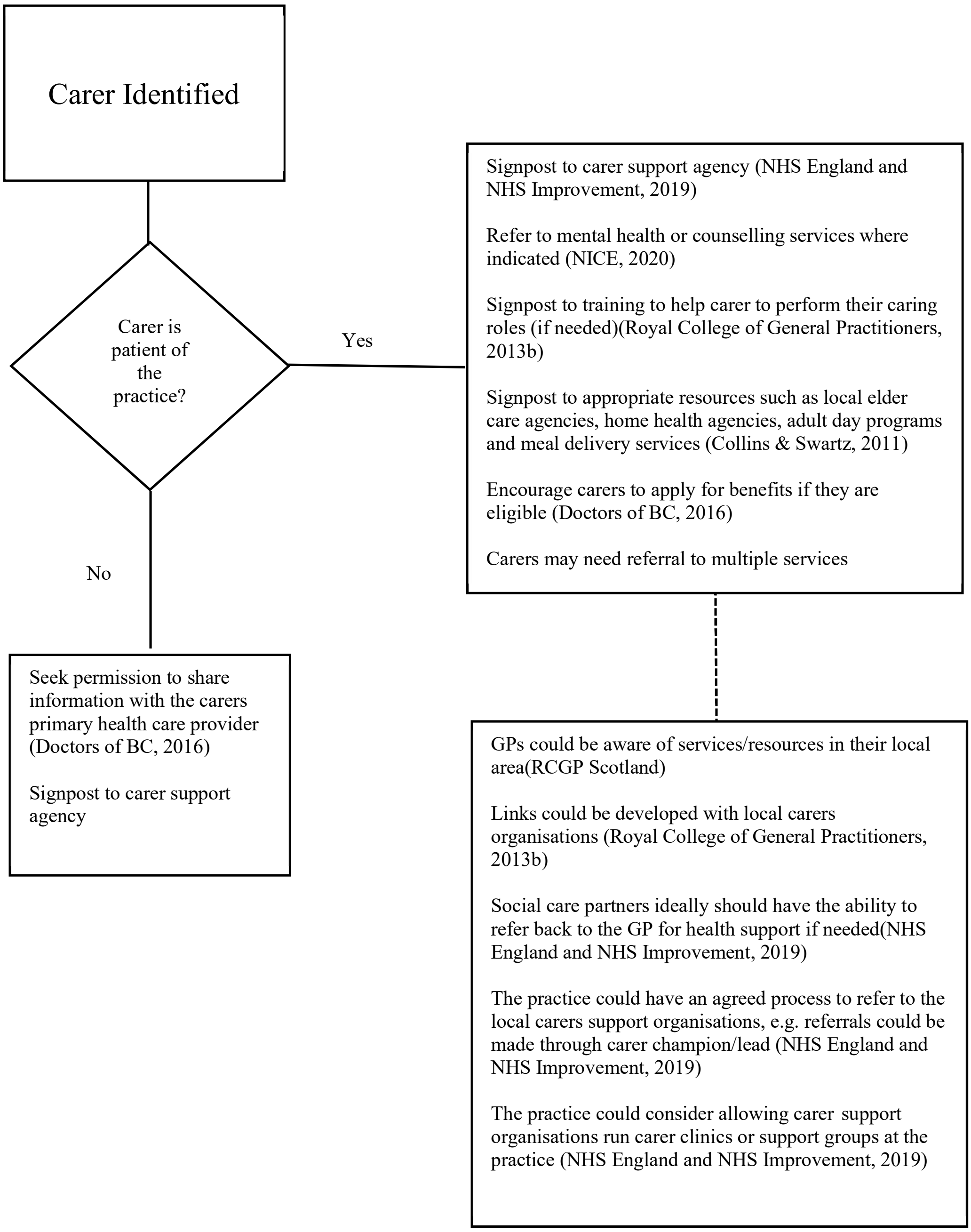
According to NICE guidelines, assessment can be performed by the family doctor or other health or social care team member (NICE, 2020). For example, in the UK, Local Authorities (local county councils via social care) are legislated to assess carer needs, but this can also be delegated to the voluntary sector (Peters et al., 2020). In Wales, the North East Wales Carer Information Service offers an assessment of carers who receive support through social services. In this case, Wellbeing Officers are trained to deliver the 'what matters' carer needs assessments, which can take up to 8 hours to complete (we unsuccessfully attempted to obtain a copy of this assessment (via email) on several occasions). As part of their Quality Markers for supporting carers (NHS, 2019), the National Health Service (NHS) recommend that carers have their support needs assessed and receive an integrated package of support (Peters et al., 2020). The RCGP Scotland also affirms that carers have a legal right to an assessment of needs through social work and should be encouraged to request an assessment (RCGP Scotland). NICE guidelines (NICE, 2020) indicate further that practitioners carrying out or contributing to carer assessments should ensure that: a) the assessment covers all aspects of health wellbeing and social care needs; b) details are shared with other practitioners who are involved in the assessment; and c) those who are carrying out assessments are trained to do so.

Guidance on Signposting of Carers

Seventeen of the included studies/guidelines mentioned referral or signposting of carers to supports. Nine guidelines/best practice papers offer recommendations on referral/signposting (Carers Trust Wales, 2019; Collins & Swartz, 2011; Doctors of BC, 2016; NHS, 2019; NICE, 2020; Northern Sydney Local Health District, 2019; RCGP Scotland; Royal Australian College of General Practitioners, 2019; Royal College of General Practitioners, 2013b) (see Figure 4.3). For example, these suggest referral to community resources, counselling, and training. NHS England, in outlining an integrated approach to identifying and supporting carers (principle 3, p.16), indicate that carers should be encouraged to access appropriate services, with referral to carer support services as possibly the best way by which this may be achieved (NHS, 2016). According to Sunne (2017), referral to supports, such as carer support agencies, may be achieved through an appointed team member who is the primary contact for patients and families. These agencies or social care partners, in turn, should have the ability to refer back to the GP for health support, if needed (NHS, 2016). However, a key barrier to meaningful consultation and referral for support, exists when a carer is not a patient of the practice, even if the care recipient is already registered there (Riffin et al., 2020). In this instance, it has been suggested, in a guideline for doctors in British Columbia, that the GP could consider offering to write to the carer's GP regarding their caring role (Doctors of BC, 2016). The RCGP, in their action guide for GPs, provide useful details of national carer charities, government websites (e.g. NHS Carers Direct, Directgov), helplines and carer support projects (Royal College of General Practitioners & The Princess Royal Trust, 2013) to which GPs can refer carers.

Figure 4.3

Summary of signposting/referral route



Signpost to carer support agency (NHS England and NHS Improvement, 2019)

Refer to mental health or counselling services where indicated (NICE, 2020)

Signpost to training to help carer to perform their caring roles (if needed)(Royal College of General Practitioners, 2013b)

Signpost to appropriate resources such as local elder care agencies, home health agencies, adult day programs and meal delivery services (Collins & Swartz, 2011)

Encourage carers to apply for benefits if they are eligible (Doctors of BC, 2016)

Carers may need referral to multiple services

Seek permission to share information with the carers primary health care provider (Doctors of BC, 2016)

Signpost to carer support agency

GPs could be aware of services/resources in their local area(RCGP Scotland)

Links could be developed with local carers organisations (Royal College of General Practitioners, 2013b)

Social care partners ideally should have the ability to refer back to the GP for health support if needed(NHS England and NHS Improvement, 2019)

The practice could have an agreed process to refer to the local carers support organisations, e.g. referrals could be made through carer champion/lead (NHS England and NHS Improvement, 2019)

The practice could consider allowing carer support organisations run carer clinics or support groups at the practice (NHS England and NHS Improvement, 2019)

In a follow-up summary report (Royal College of General Practitioners, 2013a), they describe exemplar practices where staff had developed good relationships with their local carer support organisations. There were some differences in these exemplar practices with regard to the ways in which carers were signposted to supports; for example, some were referred through their own carer registration form, while others used a referral form provided by the local carer support organisations. Two guideline documents included a specific focus on mental health referrals (Northern Sydney Local Health District, 2019; Royal Australian College of General Practitioners, 2019), particularly with regard to bereavement (Royal Australian College of General Practitioners, 2019), and although NICE guidelines acknowledge that no evidence regarding referral pathways is currently available, they recommend that a referral should be made to appropriate services in the case of an identified mental health problem (NICE, 2020) (p.27).

Several guidelines provided links to services and resources. For example, “Carers and Young Carers: A GP Resource”, published by RCGP Scotland, provides a comprehensive list of carer support services (RCGP Scotland). Likewise, “Caregiver Care”, an ‘American Family Physician’ publication, provides a list of caregiver resources, including tools such as the AARPs (formerly the American Association of Retired Persons) ‘Prepare to Care’ guide for carers that can be accessed online and provided to a carer during the consultation (Collins & Swartz, 2011). They also include online resources, websites, and apps that may be of use to GPs. In British Columbia, a community resource for family caregivers is available, including links to support agencies, as well as details of financial benefits for family caregivers (Doctors of BC, 2016). Robust systems for referring carers, are also part of the NHS quality markers for supporting carers in general practice which refer specifically to, for example, the ability of the practice to refer to local carer support organisations, whether there is an agreed process in place for this referral, and if the practice allows carer support organisations to run carer clinics or support groups at the practice (NHS, 2016).

Parmer et al. (2021) developed a helpful set of 6 health workforce training competencies for HCPs encountering family carers (Parmar et al., 2021). One of these, entitled

‘Competency E’, refers to “navigating the health and social systems and accessing resources” (p.5) and recommends that referrals to other providers, in line with the family carer preferences, should be part of healthcare workforce training. Although referral to other agencies was more common, ten of the included studies also mentioned, or contained, resources for GPs to assist them in their consultations with family carers. A summary of resources identified from this review is provided in Table 4.3.

Table 4.3

Resources to support GPs and carers

Resources to support GPs in their role with carers
Carer Assessment tool (s)
URL Links to online resources (Collins & Swartz, 2011)
Information on resources related to caregiver support agencies, education resources, online resources, bereavement helplines, community-based health services, condition specific supports and hospice. (Doctors of BC, 2016)
Information sheet on financial benefits for family caregivers as part of toolkit/GP Resource (Doctors of BC, 2016)
Links to examples of where practices had implemented carer support (Royal College of General Practitioners, 2013a)
Information on technology or Apps that can support carers in their role (Collins & Swartz, 2011)
Link to carer resource page available on GP professional institute (RCGP Scotland)
Resources to support practices to implement recommendations (Royal College of General Practitioners, 2013a): A step by step guide to developing a practice action plan A self-assessment checklist for auditing how a practice supports carers.
Resources to support Carers (to be given by GP or practice)
Carer Information pack (Royal College of General Practitioners, 2013a)
Handout/pamphlet/leaflet for carers covering(Collins & Swartz, 2011): Who is considered a caregiver? What the benefits and challenges to caregiving are What the doctor can do to help How carers can help themselves Where more information can be found
A letter explaining how the practice can support them (Carduff et al., 2014)
‘Who to call’ fridge magnet with useful numbers (Carduff et al., 2014) (for those approaching end of life)

Level of evidence

The level of evidence for the included research studies was low, overall (Table 2), with 89% of the studies rated falling in level VI category, and only one study each at level I and level II. No evaluation of the guidelines was reported. The NICE paper “Supporting Adult

Carers", included details on the evidence that was reviewed in the development of their guideline (NICE, 2020). Other guidelines, for example, 'Think Patient, Think Carer', from the Northern Sydney Health District, report that they drew on evidence from the UK paper, 'Supporting carers, an action guide for GPs and their teams'. 'Carers Trust Wales' report that academic and other sources of information were consulted in the development of their guide. Formal audit tools to evaluate the guidelines provided to GPs, were not evident in the review, apart from the Royal College of General Practitioners (RCGP); its action guide for GPs, produced in partnership with the Prince's Trust for Carers, includes an audit tool called the 'RCGP Self-Assessment Checklist', that can be used to determine if a practice is adequately supporting carers (Royal College of General Practitioners & The Princess Royal Trust, 2013)(p.35). Additionally, the National Health Service (NHS) provides a set of quality markers to determine if best practice indicators are being met (NHS, 2019).

Discussion

This scoping review synthesised the available national and international literature on the broad topic of guidelines and good practice standards for GPs, to support them in consultations with family carers. Specifically, the review focused on carer identification, assessment, and signposting to supports.

Carer identification and assessment

The guidelines and research included in the review, suggest that carer identification, widely acknowledged to be a complex process (Carduff et al., 2016; NICE, 2020), is best achieved as a 'whole practice' approach led by the GP and involving other practice staff and appropriate supporting documentation. This finding is in line with previous research by Carduff et al. who piloted an intervention for carers in general practice and found that its success was dependent on whole practice involvement (Carduff et al., 2016). Our review also identified a range of actions that can be taken by both GPs and practice staff, to encourage carers to self-identify. For example, a key finding in this regard, was the appointment of a carer champion or carer lead within a practice. Although our findings outline many of the proposed responsibilities of a carer champion, there is a clear unmet need for more comprehensive information with respect to this role, including selection guidelines, specific role description, accountability, and remuneration (or compensation).

The point of diagnosis was also highlighted as an opportune time to identify carers and has previously been shown to be a time when carers need support (Cronin & McGilloway, 2022). Our review suggests that carer needs should be integrated into care plans developed at the point of diagnosis. Previous literature has indicated there are many barriers to identifying and supporting carers in general practice at policy, practice and health systems level (Parmar et al., 2020); for example, the carer may not be a patient of the practice (Riffin et al., 2020). However, a simple solution is highlighted in a guideline produced in British Columbia, which suggests that primary care doctors could offer to write to or refer back to the carer’s own health care provider to inform them of their caring role (Doctors of BC, 2016). However, it is not known how well this would work at a practical level and a need for further research is indicated.

The content of the guidelines was variable, but most offered some recommendations regarding the identification, assessment, and referral of family carers. Notably, most of the included guidelines originated from GP professional bodies. Previous research suggests that GPs are likely to use guidelines more often when they have been developed in collaboration with other GPs and where they have particular relevance to general practice (O'Brien et al., 2021). However, it has also been suggested that GPs are more likely to use guidelines where the content is evidence-based, ideally based on systematic reviews, and where there is transparency regarding the sources of the evidence (Abdelhamid et al., 2014). The level of evidence for the included research studies was low, overall, and no evaluations of the guidelines were identified. Moreover, only one set of guidelines – the NICE- produced 'Supporting Adult Carers' document – was fully transparent, with regard to evidence that was reviewed in its development (NICE, 2020).

The evidence presented here, suggests that consideration should be given to future guideline development, but with a particular focus on transparency and clear and accurate reporting of the existing evidence. Future research might also focus on formally assessing the quality of practice guidelines using an appraisal instrument, such as the Appraisal of Guidelines for Research & Evaluation (AGREE II); this tool has previously been used to assess the quality of guidelines in primary care settings in for example, diabetes management (Radwan et al., 2017) and postpartum care of women and infants (Haran et al., 2014). The AGREE II evaluates the quality of guidelines across several domains, including scope, stakeholder involvement, developmental rigor, clarity of presentation, applicability, and editorial independence (Hoffmann-Eßer et al., 2017). However, it should be noted that this tool is not designed to evaluate the uptake or impact of the guidelines in practice or, indeed, the outcomes for family carers. No studies accessing the utility of guidelines in practice and the resultant outcomes for the target population (i.e. family carers), were identified from this review, highlighting an important evidence gap relating to existing guidelines for GPs and the development of audit tools for future guidelines. Furthermore, according to the World Organisation of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (WONCA), any future guideline development should ideally incorporate patient and public involvement to ensure that the needs of patients are accurately identified (Ronen Bareket, 2018).

This review suggests that the assessment of family carers, while recommended, remains an area in need of considerable research and policy development/support. The assessments highlighted in this review were largely relevant to carers from specific caring roles, such as cancer care, end of life, and care of the older person. Conversely, in a recent survey of carers in Ireland (N=1,484), Family Carers Ireland (FCI) report that the average age of care recipients, was 37 years and that 44% of those surveyed, were caring for a child with additional needs under the age of 18 (Family Carers Ireland, 2022b). Thus, a significant gap exists with regard to a generic assessment that applies across caring roles and that may be effectively used in a general practice setting.

However, the development of a universal carer assessment tool may be challenging due to the different health systems and social policies that exist internationally. For example, in the UK, carers are legally entitled to a carer assessment via their local authority (i.e. the local county council responsible for local health and social care priorities) or voluntary (i.e. not-for-profit) agency (Peters et al., 2020), a strong policy commitment that does not appear to be replicated in many other countries. It is worth noting that most of the included papers (n = 12) in this review were produced by UK researchers, thereby reflecting a stronger policy imperative in this jurisdiction than elsewhere. Despite this, however, it has been suggested that only one per cent of family carers in the UK are identified through general practice and that, overall, the support of carers is still viewed as secondary within health services (Peters et al., 2020). Furthermore, according to a number of UK studies, even when carers do receive an assessment, it often does not lead to any meaningful changes in the support they receive (Marczak et al., 2022; Seddon & Robinson, 2015). It is also interesting to note that, further afield, the Australian government has just launched an inquiry into the impact of its Carer Recognition Act on carer outcomes (Department of Social Services, 2023). Thus, current evidence points toward a significant policy-practice gap internationally (to which we have also alluded in our earlier work) (Cronin & McGilloway, 2022), which raises questions about the utility of guidelines, albeit these are still needed and an important step in the right direction.

Signposting and resources

Our previous research suggests that GPs did not have adequate information regarding resources for carers and that this can be a barrier to offering support (Cronin & McGilloway, 2022). This finding has been noted elsewhere; for example, in Australia, a study (N=66) examining GPs' awareness of the emotional needs of family carers, highlighted the under-utilisation of community resources within the primary care system mainly because GPs reported difficulties in accessing the required services (Bulsara & Fynn, 2006). The lack of information regarding community resources may be problematic as previous research has highlighted that those carrying out assessments for carers need to have the necessary information regarding where the carer may be signposted for support (Peters et al., 2020; Riffin et al., 2020). Our review has outlined some interesting resources available to GPs, including practical information the GP can offer to carers such as financial support information, details of carer support agencies or online resources. Arguably, a robust system that allows GPs to access resources in the community requires an approach that involves community support services, such as carer support agencies, reaching out to local primary care/general practices to raise awareness of their services. Equally, an appointed staff member, such as the previously mentioned carer champion, could actively seek out what resources are available in the community.

Study Strengths and Limitations

This is the first review, to our knowledge, to scope and synthesise guidelines and recommendations for GPs, with a specific focus on the identification, assessment, and signposting of carers. Whilst previous research examined support for carers in particular settings, such as, cancer care (Burridge et al., 2017), terminal illness (Parmar et al., 2020), and end of life (EoL) care (Røen et al., 2019), this review has identified a comprehensive list of strategies for identifying, assessing and signposting family carers, that can be incorporated into practice and which may be applicable to a diversity of caring roles. This is important, given the increasing and complex care that is provided by both family carers (Barrett et al., 2014) and GPs (Irish College of General Practitioners, 2022).

We also applied a systematic, transparent, and rigorous methodology (Munn et al., 2018) coupled with a multidisciplinary team approach (Daudt et al., 2013; Levac et al., 2010). Importantly, whilst the assessment of the quality of individual studies does not normally form part of scoping studies (Arksey & O'Malley, 2005), in clinical settings, we rated the level of evidence for each study in order to increase the transparency around the level of evidence. However, this exercise demonstrated a typically low level of evidence, highlighting an overall lack of transparency in the field, and furthermore, we were unable to rate the evidence underpinning the guidelines.

Although our review did not seek to identifying or synthesising the health risks for carers, the findings provide a selective, albeit not exhaustive, reference list to which GPs may be alerted when a family carer presents at their practice. Information regarding the health risks for carers is also useful in terms of identifying an undisclosed caring role. For example, if a patient presents with these symptoms, the GP may enquire as to whether they are providing care (RCGP Scotland). Importantly, a previously mentioned study by Gallagher and Bennett (2021), indicates that the health risks for carers can persist beyond the cessation of the caring role, yet the mechanisms for supporting former carers did not arise in this review, aside from a recommendation to refer for counselling in the case of bereavement (Royal Australian College of General Practitioners, 2019). Future research is needed to determine the requirement for, and parameters of, support for former carers. We consulted with carers in a PPI capacity, to enhance the development of practice guidelines, as recommended by WONCA. Consultation exercises with stakeholders are included in less than 40% of scoping reviews that follow the Arksey and O'Malley framework (Buus et al., 2022). However, the current study incorporated both a multidisciplinary team approach to the review and a consultation exercise with carers as primary stakeholders, thereby enhancing the applicability of the findings in clinical practice. The detailed findings from the stakeholder consultation will be reported elsewhere.

Although we conducted a comprehensive search of both peer-reviewed and grey literature, we were limited to papers in the English language due to funding and time constraints. Therefore, some important studies may have been missed. Additionally, in an international context, countries may have differing policy backgrounds in respect of support for carers, particularly in general practice. Therefore, the strategies and approaches identified within this review, may be more challenging to implement in certain settings.

Conclusion

As care needs in our communities continue to increase due to medical advancements, societal and health systems changes, it is becoming increasingly important to put procedures in place to support family carers. Despite considerable evidence indicating that the carer population typically experiences poor physical and mental health due to their caring role, many family carers report that they are rarely, or never, asked about their own wellbeing (Cronin & McGilloway, 2022). GPs, due to their pivotal role in healthcare (Crosbie et al., 2020; Loeb et al., 2016), are well positioned to support the needs of family carers. Despite this, very little guidance has been made available to GPs to support them in identifying carers, assessing their needs, and signposting them to appropriate supports. This is problematic because without appropriate guidance and resources, GPs may find it challenging to support family carers, particularly in the context of ever-increasing demands on general practice, such as staff shortages and increasing workload (Irish College of General Practitioners, 2022). The findings of the study reported here, add considerable value by identifying models of best practice that may be used to produce high quality clinical guidelines for GPs. We have synthesised data pertaining to health risks, identification, assessment, and signposting of carers to supports, whilst also highlighting a need for health systems and social policies to better support both GPs and family carers in their respective roles.

Chapter 5: Study Three (Resources for GPs)

5.1 Introduction

This chapter describes the development of resources for GPs, based on the combined findings from Studies One and Two. The development of resources for GPs was a central aim of the current research and was identified as a clear gap in the provision of support for family carers in general practice. The process involved in the development of GP 'practice points' will be outlined first, followed by a paper on the same topic that was published in the *Journal of the Irish College of General Practitioners (Forum*).

The co-design of the GP workshop (entitled 'Raising Awareness of Family Carers in General Practice') and development of the attendant materials are described next, followed by the results of a small pilot evaluation. The contribution and impact of the PPI panel in informing resource development, is also documented here, and the overarching impact of PPI is further outlined using the GRIPP2-SF (See Chapter Two) (Appendix A3.7). The facilitator guide that accompanies the workshop is presented at the end of this chapter.

5.2 Method

5.2.1. Developing 'Practice Points' for GPs

Engagement with GPs throughout this research was difficult due to the challenges in general practice and especially with the onset of the COVID-19 pandemic, which placed significant pressures on the entire healthcare system in Ireland, including general practice. The 'practice points' produced as part of Study Three were developed from the key findings of the international scoping review. The team submitted, in the first instance, a detailed proposal to the Irish College of General Practitioners (ICGP) for the development of a Quick Reference

Guide (a detailed topic-specific reference guide for GPs) pertaining to the support of family carers in general practice. The review of the proposal by the Quality in Practice Committee (ICGP-QIP) was a lengthy process, and the outcome was mixed. For example, while the ICGP were interested in the topic, they felt it was more suited to a 'practice points' document, which is essentially a shorter bullet-pointed guide. This was subsequently developed by the researcher and reviewed by both the scoping review team and the PPI panel prior to re-submission to the ICGP-QIP. This document went through several iterations and received favourable feedback overall. The team also addressed the minor comments of the ICGP-QIP efficiently and effectively, including the provision of a one page infographic that was requested during this process (Appendix A3.3).

Disappointingly however, and despite another lengthy review and commendations from the committee, there appeared to be continuing hesitancy about the topic, which led to a third suggestion to develop a webinar instead, as it was felt this would be more suited to the topic area. The lead researcher followed this up but was informed that the webinars for the year (2022) were already planned and that perhaps an article for the ICGP publication, *Forum*, would be more appropriate. *Forum* is the Journal of the ICGP and is circulated to all GPs in active practice in Ireland (approximately 2,500), as well as being available to GPs through the ICGP website. The journal, which has been published monthly since 1991, features articles of interest to GPs in a clinical setting. Our paper, '*Addressing the needs of family carers',* was written by the lead researcher and reviewed by members of the team before being finally published in November 2022 (the published paper is presented later in this chapter). The final published paper is based on the original practice points; therefore, the content was reviewed, and comments and edits suggested by the multi-disciplinary team (which included the supervisor), the PPI panel, and the ICGP-QIP were included. The paper is also publicly available through the Centre for Mental Health and Community Research webpage (cmhcr.ac.eu). This entire process, illustrated in Box 5.1, took over two years.

Box 5.1

Process of development and publication: Practice Points for GPs

July 2020, submission to ICGP to prepare Quick Reference Guide

February 2021, ICGP requested practice points document rather than QRG

Practice points written by lead researcher from findings of scoping review

- Reviewed by scoping review team (K McL, TF, SMcG)

Consultation with PPI panel

Review by scoping review team following PPI panel input

Submitted to ICGP-QIP committee (Nov 2021)

ICGP-QIP feedback:

- Documents should be shorter
- Carer register and assessment not practical
- Links to resources were useful
- Questioned evidence for health check

Resubmitted to ICGP-QIP (Jan 2021)

- Assessments reduced to two
- Would like register retained due to evidence but would change the wording to 'recommended'
- Annual health check removed

ICGP-QIP feedback (Feb 2022)

- Requested carer register be removed
- A one page infographic would be useful
- Possibility of a webinar

Resubmitted to ICGP-QIP (March, 2022)

- Carer register removed
- One page info graphic provided
- Informed that GP workshop in development

ICGP-QIP feedback (June 2022)

- Decision not to publish best practice points
- Information best disseminated via a webinar

Contact with ICGP regarding webinar (June 2022)

Feedback from webinar committee (June 2022)

- Webinars for year already decided
- Reducing slots
- Recommended ICGP Forum journal article

ICGP Forum article published November 2022.

5.3 Addressing the needs of family carers

This section contains the accepted version of the paper, which was published in November 2022.

Cronin, M. [1], Foley T. [2] and McGilloway, S. [1] Addressing the needs of family carers. *Forum, Journal of the Irish College of General Practitioners, Vol 39, No.9* (2022)

[1]Centre for Mental Health and Community Research, Department of Psychology and Social Sciences Institute, Maynooth University

[2]Department of General Practice, University College Cork and Kinsale Medical

GPs in Ireland lack standardised guidance or resources on their role with family carers, and ambiguity exists regarding what role the GP has to play

Introduction

GPs play a pivotal role in family and community healthcare and are uniquely placed, therefore, to recognise the needs of family carers, many of whom they will have established a positive rapport with over a long period of continuing family care. But how can GPs in Ireland address the needs of this cohort in a clinical setting?

Why is this of concern for GPs?

The National Institute for Health and Care Excellence (NICE, 2020) suggests a key role for social care and health service professionals (including GPs) in the identification and support of family carers (i.e. adults who provide "unpaid care and support to a family member, partner or friend because of a disability, health condition, frailty, mental health problem, addiction or other health or social care need" (NICE, 2020). GPs often find themselves in contact with family carers, either because they are a patient of the practice or the person they care for is a patient. They are in the unique position, therefore, of having knowledge of the family/family context, as well as the medical needs of the patient (Burridge et al., 2011), allowing for the establishment of a positive and trusting relationship with the patient, carer and their families. This type of supportive relationship is highly valued by carers and allows them to disclose the impact of caring on their own health and well-being (Cronin and McGilloway, 2022).

The well-being of the family carer is important for both carer and care recipient, and not least because a carer's failing health can result in the care recipient having to transition to hospital or residential care. Unlike GP colleagues internationally (e.g. UK, Canada, Australia), GPs in Ireland lack standardised guidance or resources in relation to their role with family carers, and a considerable amount of ambiguity exists regarding what (if any) role the GP has to play (Cronin and McGilloway, 2022). A GP may be reluctant to initiate the conversation if they are not aware of the supports that can be offered to carers. Furthermore, family carers, because of their close relationship to the care recipient, are often slow to ask for help and, indeed, are often reluctant to view themselves as 'carers' (NICE, 2020). Therefore, an important first step for a GP is to identify carers in their practice and prompt a conversation regarding their caring role.

Care needs in Ireland have increased and are set to rise further in the coming years. Changes in the provision of healthcare in recent decades has seen a large proportion of care move away from institutional settings and long-term hospital stays, resulting in increasingly complex care being provided in the community. The provision of day-to-day care in the community has largely become the responsibility of family members, and there are currently an estimated half a million family carers in Ireland.

What are the health and well-being risks for carers?

While many family carers report a sense of satisfaction and purpose in caring for their loved one, their caring role can take a significant toll on their own health and well-being. Thus, they may experience a wide range of physical and mental health problems, including:

- Psychological distress symptoms, such as anxiety and depression (Eurocarers, 2018)
- Neglect of their own health due to a focus on care recipient or difficulty getting to appointments (Northern Sydney Local Health District, 2019).
- Back injury or back pain (Northern Sydney Local Health District, 2019) and shoulder injury (Royal College of General Practitioners, 2013)
- High blood pressure (Northern Sydney Local Health District, 2019)

- Higher risk of stroke (Royal College of General Practitioners, 2014).
- Increased mortality in older carers (Royal College of General Practitioners, 2014).
- Insomnia (American Family Physician, 2015) and sleep problems (RCGP Scotland).

Transitions in the caring role can be particularly stressful for carers. For example, these might include the point at which the care recipient receives a diagnosis or has to be relocated to nursing home or other residential care.

What role can the GP play?

Ultimately, all practice staff can have a role in identifying and signposting family carers in General Practice. However, the GP can be the key driver of carer identification by encouraging a 'carer friendly' environment. One of the ways in which GPs might help to increase awareness, and improve support of family carers, is to invite a member of staff (where applicable) to be carer champion/lead with responsibility for carers (Royal College of General Practitioners, 2013; (Carduff et al., 2016; Carers Trust Wales, 2019; NHS, 2019; Royal College of General Practitioners & The Princess Royal Trust, 2013) Conversely, there are particular times when the GP themselves can be proactive regarding the needs of the carer, at, for example, the point of diagnosis of the care recipient. This has been identified as a very challenging time for carers and is the ideal juncture at which to begin a conversation regarding who will be providing the care. When that person(s) has been identified, the GP can let them know that supports and signposting will be available to them throughout their caring journey if so required.

Information regarding who is providing care can be exchanged through the hospital admission and discharge process. In the case of existing patients who have care needs, the GP could consider the impact of the patient's condition on the family and make enquiries about who is providing the care (RCGP Scotland). A common challenge for GPs is that often the care recipient may not be a patient of the practice and, therefore, the GP will have no awareness of their patient's caring role. It is prudent, therefore, to look out for signs of a possible undisclosed caring role (e.g. back problems, stress, minimising own health, poor mental health, sleep problems) (RCGP Scotland) and to ask the patient if they are providing care when they present with these symptoms. GPs may also consider asking their patients with care needs whether someone supports them with those needs (NICE, 2020; RCGP Scotland).

What role can practice staff play?

As a GP, you may consider appointing a Carer Lead/Carer Champion to be the point of contact for carers and have responsibility for identifying those on the practice list who are providing care. The carer champion can also create and maintain a *carer register*, advocate for carer needs, provide information and importantly, stay informed regarding carer support organisations in the community. The carer register can be used for other purposes, such as reminders for flu or other vaccines, but it is important that it is kept up to date, particularly in the event of a carer bereavement.

The carer champion and/or other practice staff can support identification by:

- Displaying information in reception area/website to encourage carers to self-disclose their caring role (NHS, 2019).
- Asking family members if they are the primary carer when they bring a patient for flu (or other regular) vaccines (Royal College of General Practitioners, 2013)
- Taking note of who is making appointments/ ordering prescriptions and ask if they are providing care (Doctors of BC, 2016).

- When registering new patients, including a question on the registration form, such as, for example, ‘do you rely on someone for your care?’ OR ‘does someone rely on you for their care?’ ((Doctors of BC, 2016; Northern Sydney Local Health District, 2019)Doctors of BC, 2016).
- On completing forms for disability or related allowances, gently enquire regarding who will be providing the care;
- Reviewing existing practice registers, such as those which are disease specific, or relate to long-term illness (Carduff et al., 2016);
- When completing forms for disability or related allowances, enquire as to who is providing the care.

Particular attention may need to be given to carers from hard-to-reach groups such as, ethnic minorities, the LGBTQI+ community, carers of those with mental health illness or substance misuse and carers with disabilities (Royal College of General Practitioners, 2013). Establishing links with community groups can assist with the identification and support of these carers.

Assessing carers needs

The assessment of carers’ individual needs is useful in terms of offering them adequate supports and informing the appropriate referral route. A number of validated tools are available to assist with assessing the needs of carers, including those outlined below

- The ABCEDS Caregiver report is a brief five-item tool (developed by Professor William Molloy at University College Cork) which can be used to effectively and speedily assess carer burden.[*]

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[*] This assessment was not part of the scoping review findings but included through charity partner Family Carers Ireland

- The Modified Caregiver Strain Index is a brief 13-item tool that measures strain related to care provision. https://www.sralab.org/sites/default/files/2017-07/issue-14.pdf

How can the GP signpost carers to supports?

Carers may be signposted to Family Carers Ireland (FCI), the national carer support agency that offers a wide range of supports including: full assessment (Carer star that covers health, well-being, home life, work life and finances); free counselling service; support groups; and a range of education and carer well-being supports. Referrals can be made through their website https://familycarers.ie or on careline number: 1800 240724

Any carer who is not a patient of your practice can be signposted to FCI and/or permission can be sought to share information about their caring role with their own GP. Other referrals for family carers may include:

- Mental health supports or counselling
- Training for caring role where applicable
- Community resources such as local elder care agencies, home help agencies, adult day programs and meal delivery services

Caring can also result in significant financial burden, and a number of government supports are available to provide financial support, including those outlined below.

Carers Allowance
https://www.gov.ie/en/service/2432ba-carers-allowance/
Half rate carers allowance
https://www.gov.ie/en/publication/e7b36c-half-rate-carers-allowance/
Carers' Benefit
https://www.gov.ie/en/service/455c16-carers-benefit/
Domiciliary Care Allowance
https://www.gov.ie/en/service/30fac9-domiciliary-care-allowance/
Carer Support Grant
https://www.gov.ie/en/service/16220307-carers-support-grant/

Conclusion

The provision of support for family carers is crucial in influencing the well-being of both the care recipient and the carer, as well as having an impact on the wider health service. Initiatives to identify and signpost carers outlined here are evidence-based and can be incorporated into existing clinical practice, both in Ireland and elsewhere. Although social prescribing for this cohort has not been established to date (NICE, 2020), the appointment of a carer champion and signposting to national carer support agencies (e.g. FCI) is strongly recommended. Caring for a loved one can be a challenging role, and many carers may find it difficult to acknowledge and/or discuss the impact on their overall health and well-being. Therefore, conveying empathy, listening actively and offering emotional support can help in establishing a good rapport with the carer and, in turn, identifying, recognising and responding appropriately to their health and well-being needs.

The authors would like to acknowledge the contribution to the larger CHERISH project, of Family Carers Ireland and the carers who kindly participated in a Public Patient Involvement (PPI) capacity: Maire Killowry, Siobhan Hanley, Jo Bergin, Paraic McGahey and Johanna Powell (all gave permission to be named).

5.4 GP Workshop

A comprehensive online workshop and accompanying facilitator guide was developed in the first instance by the lead researcher and subsequently reviewed by the PPI panel, who provided important insights in terms of both content and delivery (see Table 5.2). This co-designed input, combined with the findings from the international scoping review and the practice point guidelines described earlier, were used to inform programme development and delivery, both of which are described in more detail below. Continuing professional development (CPD) accreditation was also sought in parallel, and approved by the ICGP, in order that participating GPs could avail of CPD points. However, due to prolonged delays and recurring cancellations in scheduling the GP training throughout the COVID-19 pandemic (and the vaccination schedule), we were advised to pilot this training, in the first instance, with GP Registrars (GPRs); GPRs are qualified doctors who are completing their general practice specialisation.

5.4.1 Workshop development and co-design

The structure of the new programme was designed to encompass four broad domains, including: (1) family caring in Ireland; (2) key recommendations for GPs (based on the guidance published in *Forum*); (3) a case-based example from practice; and (4) assessments and resources. Four learning objectives/outcomes were agreed by the course facilitators (Mary Cronin and Dr. Tony Foley) for each of these domains, relating to, for example, increased awareness of potential health challenges for carers and improved knowledge of strategies to identify carers in a clinical setting (Table 5.1). A number of supportive materials were also developed as part of the programme including:

- A one-page infographic summarising the main points of the GP guide, including, for example, simple strategies for identifying carers, potential health risks for carers, and signposting to supports (Appendix A3.3),
- A facilitators' guide for delivery of the workshop (presented later in the chapter),
- A corresponding workshop manual for GPR attendees.

Table 5.1

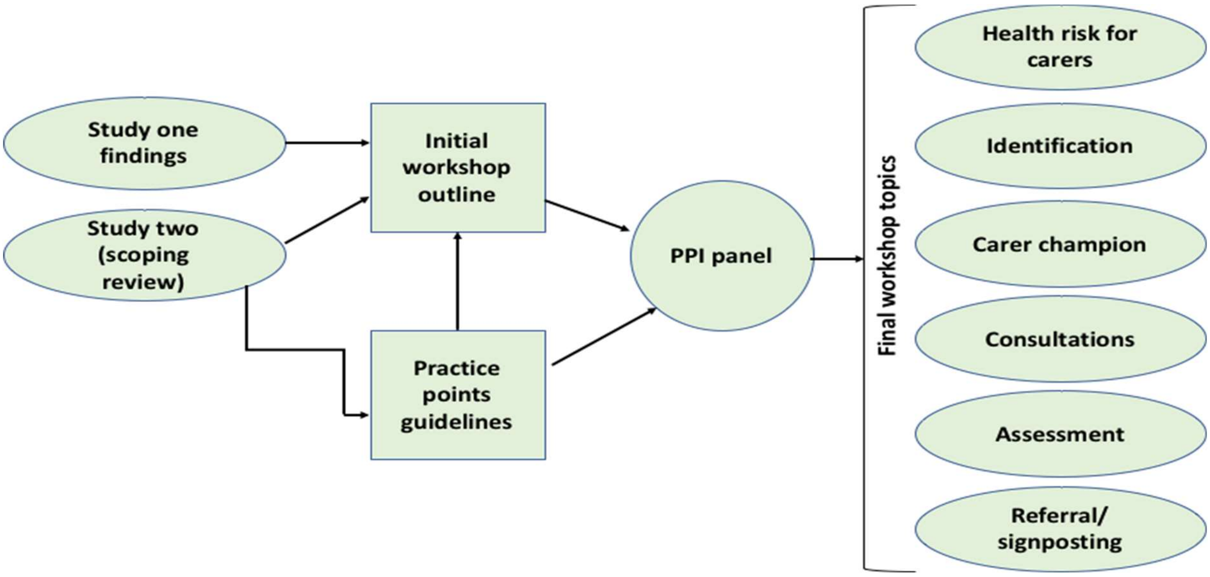
GP Workshop - learning objectives

Topic	**Learning Objective**
Introduction (summary of family caring in Ireland)	Improved knowledge of the increase in family caring in our communities and the challenges posed for those providing care.
Guidance for supporting carers	Increased understanding and awareness of the health and well-being risks for family carers and how to identify, assess and signpost them as needed.
Case-based discussion	Improved knowledge of how the process of identifying, through to possible referral, works in practice.
Demonstration of assessments and Family Carers Ireland website	Enhanced knowledge and awareness of carer needs assessments and the supports available to them.

The process of developing the training programme is outlined in Figure 5.1, which shows that a total of six key topics were identified, informed by the findings of Study One and Study Two, along with the contribution of the PPI panel (Figure 5.1). An initial workshop outline was developed by the lead researcher based on the previously developed GP practice points. The proposed outline was reviewed by the PPI panel before finalising the key topics.

Figure 5.1

Development and co-design of the GP workshop



In addition to the key topics outlined in Figure 5.1, a summary of family caring in Ireland was also included. This incorporated the NICE definition (NICE, 2020) of an adult carer, facts about the number of carers in Ireland, the reasons they are caring, and why the increase in carer numbers demonstrates the importance of carer support. Information was also included to acknowledge the challenges in general practice with regard to supporting carers. The findings of the international scoping review (Study Two) were also incorporated throughout the programme by, for example, outlining the guidance/recommendations that emerged across the areas relevant to clinical practice, such as the identification of carers, the role of the carer champion, assessment of needs, and referral to supports and documentation.

5.4.2 Workshop delivery

The programme was delivered using a group-based workshop format and co-facilitated by Dr. Tony Foley (UCC Department of General Practice), a GP who is experienced in delivering training to both practicing GPs and GPRs and a member of the scoping review team. Previous research has been shown that having a practicing GP deliver training is more acceptable to GPs (Jennings et al., 2017). During the workshop, the lead researcher (Mary Cronin) discussed the research background and findings, while Dr. Foley discussed its implementation in a clinical setting and presented a case-based discussion drawn from GP practice, which outlined the challenges for a single middle-aged woman caring for a parent with dementia. This case also drew attention to carers from hard-to-reach backgrounds, with the case scenario based on a carer from the immigrant community. The final programme component was dedicated to outlining the services of FCI and how GPs can signpost carers to these and other supports, for example, financial supports. The training workshop ran well despite some technical difficulties at the beginning due to the new building to which the GPRs had just moved.

5.5 PPI Input

5.5.1. Embedding of PPI consultation

At the workshop pre-design stage, a panel of carers were consulted in a PPI capacity, as outlined previously in this chapter. The PPI panel reviewed the GP practice points and the content of the GP workshop. The contribution from the PPI panel influenced the practice points content as well as the design and delivery of the workshop. The Guidance for Reporting Involvement of Patients and the Public (GRIPP) 2-SF (Staniszewska et al., 2017) reporting checklist was used to provide a transparent outline of the overall PPI contribution to Study Three and is provided in Appendix A3.7.

Table 5.2 (below) indicates key areas where the PPI panel input was embedded into the practice points and workshop design. PPI input informed important strategies around the identification of carers, for example, the appointment of a regional carer champion. Potential barriers and facilitators for assessment tools were highlighted, such as time constraints for some assessment tools as well as the potential for the assessment to guide the conversation. Importantly, some additional resources, such as links to financial benefits, were also advocated by the panel.

As part of the process, the panel also reviewed the carer needs assessments that were part of the findings from Study Two. An additional assessment called the ABCEDS Caregiver Report (a brief five-item tool), developed by Professor William Molloy at University College Cork, was included by our collaborating partner FCI. FCI have previously used this tool to triage carers presenting to a clinic for care of the older person in St. Finbarrs Hospital, Cork. The PPI panel made many valid comments regarding the various assessment tools (Table 5.2), for example, highlighting potential issues such as the length of time taken to complete it and the language. This is further discussed in Chapter Seven.

Overall, the carers felt that GPs would benefit from the workshops and suggested that the information (both workshop and practice points) be made available to all GPRs as part of their GP training.

Table 5.2

Contribution of PPI panel to GP practice points and workshop

Topic	**PPI panel comments**	**How was this input embedded in resources?**
1. Defining carers	1) The panel felt it was important to stress the differentiation between carers in a paid capacity and unpaid family carers.	The NICE definition of carers was included in both the practice points and the workshop materials.
	2) It was noted that young carers were not addressed specifically within the workshop.	It was mentioned in the workshop that FCI also provide services to young carers.
2.Carer identification	1) A carer champion/carer lead would be very beneficial for carers, though it might not be possible for small practices; in this case, would it be possible to have a regional carer champion shared by a number of practices?	This was incorporated within the workshop and Facilitator Guide.
	2) Carer identification could be incorporated into existing practice documentation. Carers felt they would not object to their details being recorded in this way.	Small changes to existing practices to facilitate identification were included in the workshop content.
	3) With regard to identifying carers through disability forms, it was pointed out that not all those on Disability Allowance have (or need) a carer.	Potential barriers from points 3) & 4) were included in the Facilitator Guide and highlighted by the facilitator during workshop delivery.
	4) A potential barrier to carer identification relates to the fact that not all of those who require care/support acknowledge this need.	
3. Assessment	1) Assessments would be a good prompt for carers to express how they are feeling and guide the conversation for GPs.	Assessment tools were included in the practice points and workshop facilitators manual.

Topic	PPI panel comments	How was this input embedded in resources?
	2) The assessment tools considered were thought to be more relevant for caring for older people and, therefore, – not inclusive of all caring roles. 3) It would be positive if an assessment asks about physical strain and asks about work. 4) The Outcome Star assessment was deemed not suitable due to time constraints as it cannot be completed in 10 minutes. The GP could focus on the Health section. Star could be done first by FCI and referred to GP regarding health section. 5) What can the GP do after the assessment? This was indicated as a barrier to all assessments.	Points 2-4) The two brief assessment tools deemed most suitable by the PPI group were included in both the practice points and the workshop. *Note:* One of these assessments (the ABCEDS caregiver report) was introduced by FCI and was not part of the scoping review. The Facilitator Guide includes referral to FCI for initial assessment. Point 5) Referral routes were included in practice points publication and facilitator guide.
4. Signposting	1) Some GPs are not aware of the supports that are available. 2) Greater awareness of Family Carers Ireland is needed. 3) Connection to Healthy Ireland through county council.	Points 1) & 2) included in practice points and GP workshop. Point 3) not included for now due to Healthy Ireland not being fully operational in all counties and not having a specific remit regarding family carers.
5.Consultation process	1) Annual health check from GP should be standard and should focus on the impact of the caring role and encourage carers to	Point 1) was included in initial draft of practice points, but ICGP requested it be removed, citing

Topic	PPI panel comments	How was this input embedded in resources?
	discuss. Carers on allowances receive a carer GP visit card that would cover the cost. 2) Carers are sometimes afraid to admit they are struggling. 3) Carers need time to become comfortable and be honest. 4) It is important to recognise primary carer, secondary carers, and young carers (can be 2 or more people). 5) Carers need to be recognised for the work they do.	lack of evidence. It was included in GP workshop to 'encourage health check'. Points 2) – 5) covered in practice points and workshop.
6.Resources for GPs	In addition to introducing the FCI services, it was suggested that GPs would benefit from some knowledge regarding the financial benefits available to eligible carers.	This point is also supported by evidence from Study Two and was, therefore, included in the GP practice points and the GP workshop.

5.6 Pilot testing

5.6.1. Participants and settings

Initial plans to pilot the GP workshop through three previously identified pilot sites (one in Cork and two in Dublin) proved to be unachievable following the pressure on GP practices during both the initial stages of the COVID-19 pandemic and the vaccination clinics that followed. After several attempts to recruit further GPs to participate through online invitations, it was agreed to pilot the workshop with GP Registrars in the first instance. Participating GPRs (n=5) were in their final year of training and attended the workshop online.

The GPRs were recruited through the GP training scheme (Sligo division) to evaluate the GP workshop. Recruitment was through the Director of the GP training scheme, to whom we had submitted a proposal to pilot the workshop. The participating GPRs were all in their final year of general practice training. The one-hour workshop was delivered online by the lead researcher and Dr. Tony Foley.

5.6.2. Measures

As indicated earlier in Chapter Two, pre and post-workshop questionnaires (Appendix A3.6) were devised to evaluate the workshop based on TPB principles (See Chapter Two). The pre-workshop questionnaire was used to elicit background and demographic information (e.g. how long the GPR had been in the practice and how many patients were registered) and included a number of Likert scale statements to assess the relevant constructs. The pre-workshop questionnaire was administered via email, with a link to the online questionnaire provided several days prior to the training. The post-workshop questionnaire was administered via link provided at the end of the online workshop and also via email. An additional three-month post-workshop questionnaire was also administered, but unfortunately, it was not completed by any of the workshop attendees because, at that point, they had transitioned from their training into their work as GPs and did not respond despite several follow-up requests. The research team made further contact with the GP training scheme coordinator to see if a focus group evaluation would be possible, but unfortunately the GPRs were not available to participate.

5.6.3. Analysis

Data analysis was conducted using SPSS version 25. The sample was too small to permit any kind of meaningful statistical analysis, so descriptive statistics were used instead to examine pre- and post-workshop responses.

5.6.4. Findings

Whilst the participants attended the full workshop and were interactive throughout, engagement with the evaluation process was, unfortunately, poor. Despite being sent out in advance of the workshop (and time being allocated at the start of the workshop), the pre-workshop questionnaire was fully completed by only three GPRs. Likewise, the post-workshop questionnaire was only completed by three GPR participants, and the three-month follow-up received no response (despite several attempts via email). The three participants who completed both questionnaires (two were female, and one preferred not to say) were working as GPRs in general practice and had been in their current practice for a total of 5 to 10 months. Their practices were serving catchment populations of 2,000 to 8,000 patients.

Nine of the 14 items on the TPB variables showed no pre-post workshop changes in mean scores, while no changes were seen either in attitude or subjective norms. However, five of the fourteen items did show some increase in mean scores associated with perceived behavioural control and intention (see Table 5.3). The perceived behavioural control item that showed the largest increase in mean was related to confidence in having the skills to support family carers (pre-workshop M = 2.00, SD = 1.0 and post-workshop M = 3.33, SD = .57), followed by incorporating carer awareness into current practice (pre-workshop *M* = 3.00, *SD* = .00 and post-workshop *M* = 3.67, *SD* = .57). In the negatively worded item regarding not being confident of having resources to support carers, the mean decreased from *M* = 4.33, *SD* = 1.1 pre-work, to *M* = 3.67, *SD* = .57 post-workshop. The GPRs' intention to support carers also showed post-workshop increases regarding their perception of how proactive they had been in identifying and supporting carers. Intentions to be more pro-active following the workshop also increased.

Table 5.3

Means (SD), pre and post-workshop data

Theory of Planned Behaviour variables	**Pre-workshop Mean (SD)**	**Post-workshop Mean (SD)**
Attitude (4 items):		
The negative impacts of caring on carers' health and well-being can be reduced if I offer support to carers in my practice.	3.67(.57)	3.67(.57)
There may be family carers in my practice of whom I am unaware.	4.00(1.0)	4.00(1.0)
Supporting family carers is not part of the GP role.	2.33(.57)	2.33(.57)
Family carers make an important contribution to the overall health service.	4.00 (1.0)	4.00 (1.0)
Subjective norm (3 items):		
My GP colleagues view the identification and support of family carers as an important part of their day-to-day work.	2.67(.57)	2.67(.57)
Government guidelines suggest that carers should be supported in General Practice.	3.67(.57)	3.67(.57)
Family carers would not value support from their GP.	2.33(.57)	2.33(.57)
Perceived Behavioural control (5 items):		
In general, I am confident I have the skills to meet the needs of family carers.	2.00 (1.0)	3.33 (.57)

Theory of Planned Behaviour variables	**Pre-workshop Mean (SD)**	**Post-workshop Mean (SD)**
Incorporating carer awareness into my current practice would be relatively easy.	3.00 (.00)	3.67 (.57)
I am not confident that I have the necessary resources to meet the needs of family carers.	4.33(1.1)	3.67 (.57)
Having a Practice Points reference guide would increase my confidence in identifying and signposting carers.	3.67(.57)	3.67(.57)
Completing a brief assessment with family carers would help me in signposting them to appropriate supports.	3.67(.57)	3.67(.57)
Intention (2 items):		
In the past three months, I have been proactive in identifying and supporting carers.	2.33 (.57)	2.67 (.57)
Following the workshop, I intend to be more proactive in identifying and supporting carers.	3.00 (1.0)	3.67(.57)

The overall satisfaction with the workshop was good, with two of the three reporting that they found the workshop ‘moderately/very useful’. The quality of the workshop was also reported as ‘good/excellent’ by two of GPRs, and they also agreed or strongly agreed that they would recommend it to other GPs.

Participants were asked to indicate what aspects of the workshop they found most useful. Information regarding the signposting of carers to supports was thought to be most useful, followed by identification of carers and health risks for carers. Respondents were also invited to make further comments via an open-ended question at the end of the post-workshop questionnaire (see Table 5.4). These responses, as outlined below, showed that the GPRs were ambiguous regarding the value of this type of workshop for their clinical practice, indicating perhaps an element of frustration regarding time and workload, as well as a sense that other healthcare professionals might be better placed for this role. The link to FCI, however, was seen as a useful resource. A fuller discussion of these findings is included in Chapter Seven.

Table 5.4

Responses to open-ended questions - GP workshop

Link to family carers Ireland was useful. *If we are truly to address people's unmet health needs, what I need is more time and fewer patients. More well-intentioned workshops won't help.* *Just to discuss the role of PHN [Public Health Nurse] here also, I feel they are better placed to address this issue*

Conclusion

This chapter has outlined the process involved in the development and co-design of two key resources for GPs, namely the practice points and the training programme which was delivered in an online workshop format. The significant PPI contribution to the development of these resources was also described in detail. The small pilot evaluation of the GP training had a disappointingly poor participation/response rate, but nonetheless, the findings show some initial promise in terms of raising awareness of the needs of family carers in general practice. These findings are discussed further in Chapter Seven. Importantly, both the facilitator guide and one page infographic (Appendix A3.3) will be made available to GPs in Ireland via the ICGP website, representing an important step forward in meeting the needs of family carers in Ireland through general practice. The facilitator guide for the workshop is presented next.

5.7 Raising awareness of family carers in general practice/primary care – facilitator guide.

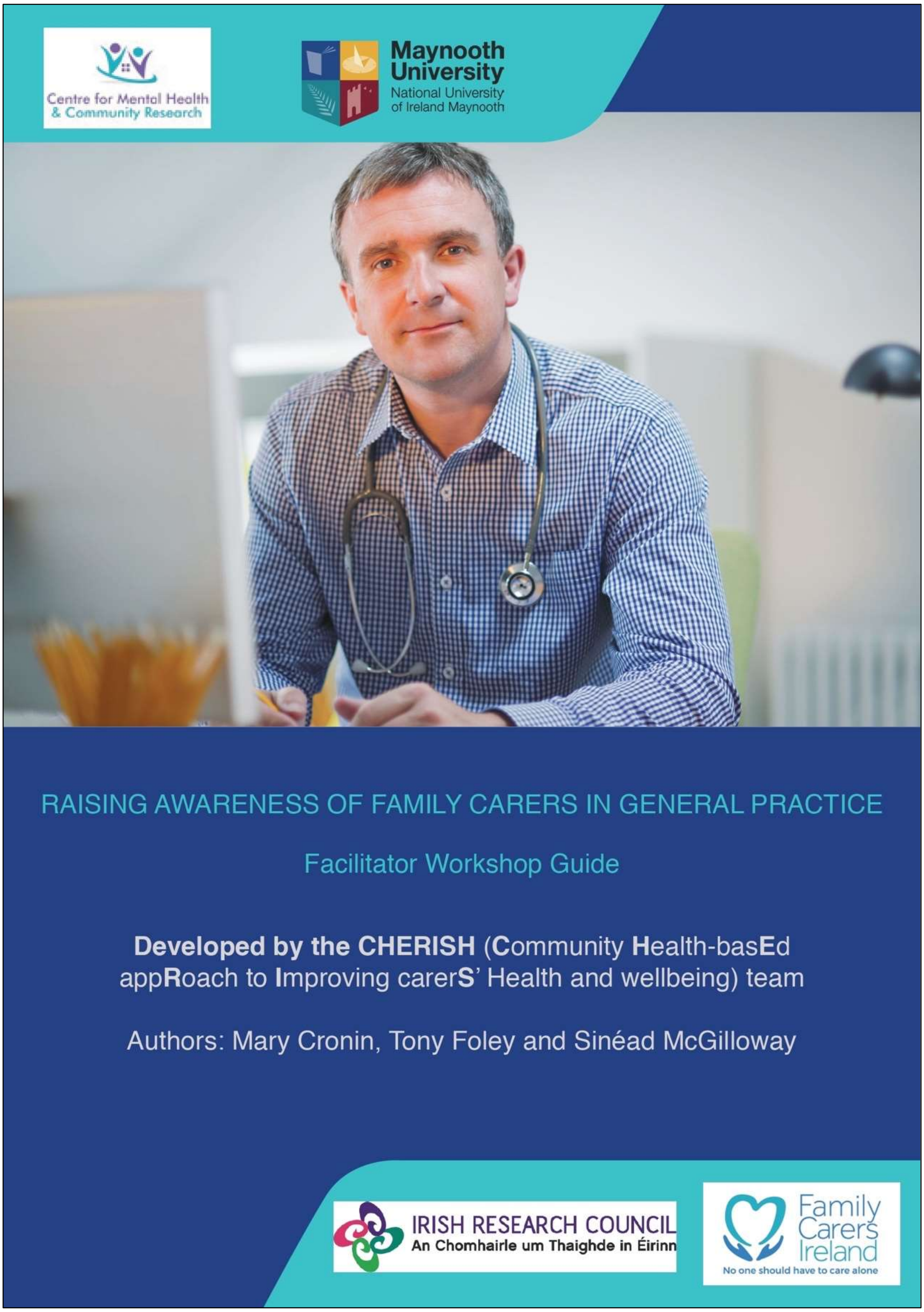
This section presents the facilitator guide that will be made available to GPs in Ireland through the ICGP website.

Suggested citation:

Cronin, M[1], Foley, T[2], McGilloway, S[1]. (2022) Raising awareness of family carers in General Practice: Facilitator's Workshop Guide. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

[1]Centre for Mental Health and Community Research, Department of Psychology and Social Sciences Institute, Maynooth University

[2]Department of General Practice, University College Cork and Kinsale Medical



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RAISING AWARENESS OF FAMILY CARERS IN GENERAL PRACTICE

Facilitator Workshop Guide

Developed by the CHERISH (**C**ommunity **H**ealth-bas**E**d app**R**oach to **I**mproving carer**S**' Health and wellbeing) team

Authors: Mary Cronin, Tony Foley and Sinéad McGilloway

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Family Carers Ireland
No one should have to care alone

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Acknowledgements

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Suggested Citation: Cronin, M, Foley, T, McGilloway, S. (2022) Raising awareness of family carers in General Practice: Facilitator's Workshop Guide. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

Background

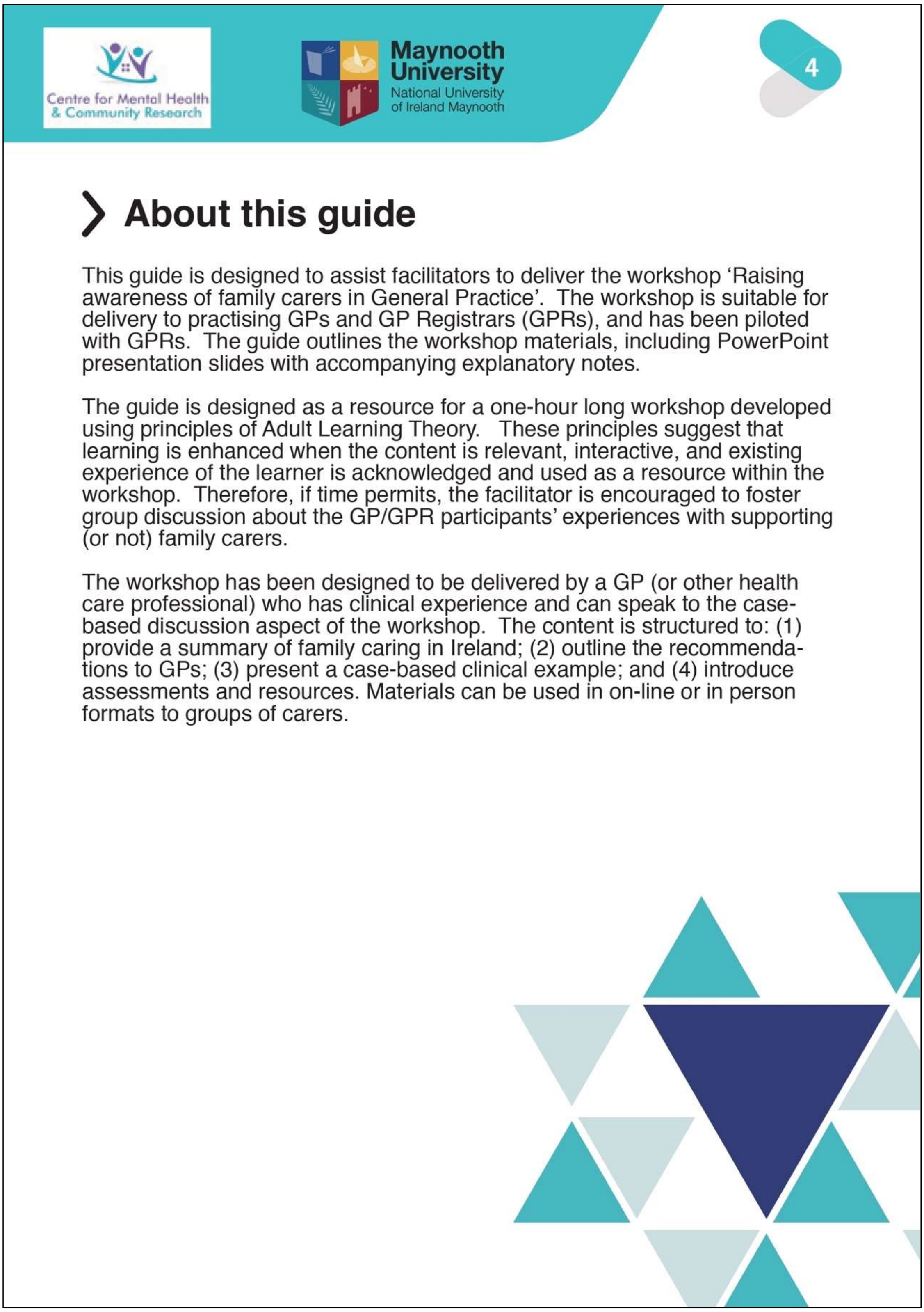
Caring needs are increasing globally, resulting in many more people taking up the role of 'informal' or 'family' carer. This is due to ageing populations, improved medical care and a shift away from long-term hospital stays and institutional care. Existing evidence suggests that, although caring is often very rewarding, the health and wellbeing of family carers across the world, is considerably poorer than that of the general population. Despite this, many carers report difficulty in asking for help and often view their own health and wellbeing needs as secondary to the person for whom they provide care. Indeed, many of those providing care do not identify with the term 'carer' per se, which can, in turn, impact negatively on their access to services and supports.

There have been efforts in an Irish context, to recognise the role and contribution of family carers, particularly through the development of a National Carers' Strategy (NCS) in 2012. A number of specific objectives therein aim to address how carers are identified and supported in healthcare services, including general practice.

General Practitioners (GPs) can play an important role in supporting family carers due to their central role in community health care. However, no resources are currently available to healthcare professionals or carers to support the achievement of these goals.

Evidence suggests that GPs are unclear regarding their role with family carers and do not feel they have the resources and information necessary to adequately support them. This was addressed as part of a research project called 'CHERISH', led by the Centre for Mental Health and Community Research, Maynooth University (https://cmhcr.eu). This project aimed to address knowledge gaps in relation to the health and wellbeing of family carers in Ireland, with a specific focus on how they can be better supported by community health professionals. CHERISH sought input from stakeholders by surveying carers and interviewing both carers and GPs. A scoping review of international literature was also conducted to inform guidelines for GPs (published in ICGP publication 'Forum' in November, 2022). This accompanying workshop for GPs, is based on the evidence from the scoping review and, therefore, contains best practice recommendations for supporting family carers internationally.

The workshop was co-designed with a panel of carers in a public and patient involvement (PPI) capacity, and developed in collaboration with Family Carers Ireland (FCI). This element of the CHERISH project was funded by a New Foundations grant from the Irish Research Council (IRC) in April, 2021. The project also involved the development of resources for carers including, for example, a workshop to enhance communication skills in conversations with GPs and other healthcare professionals.

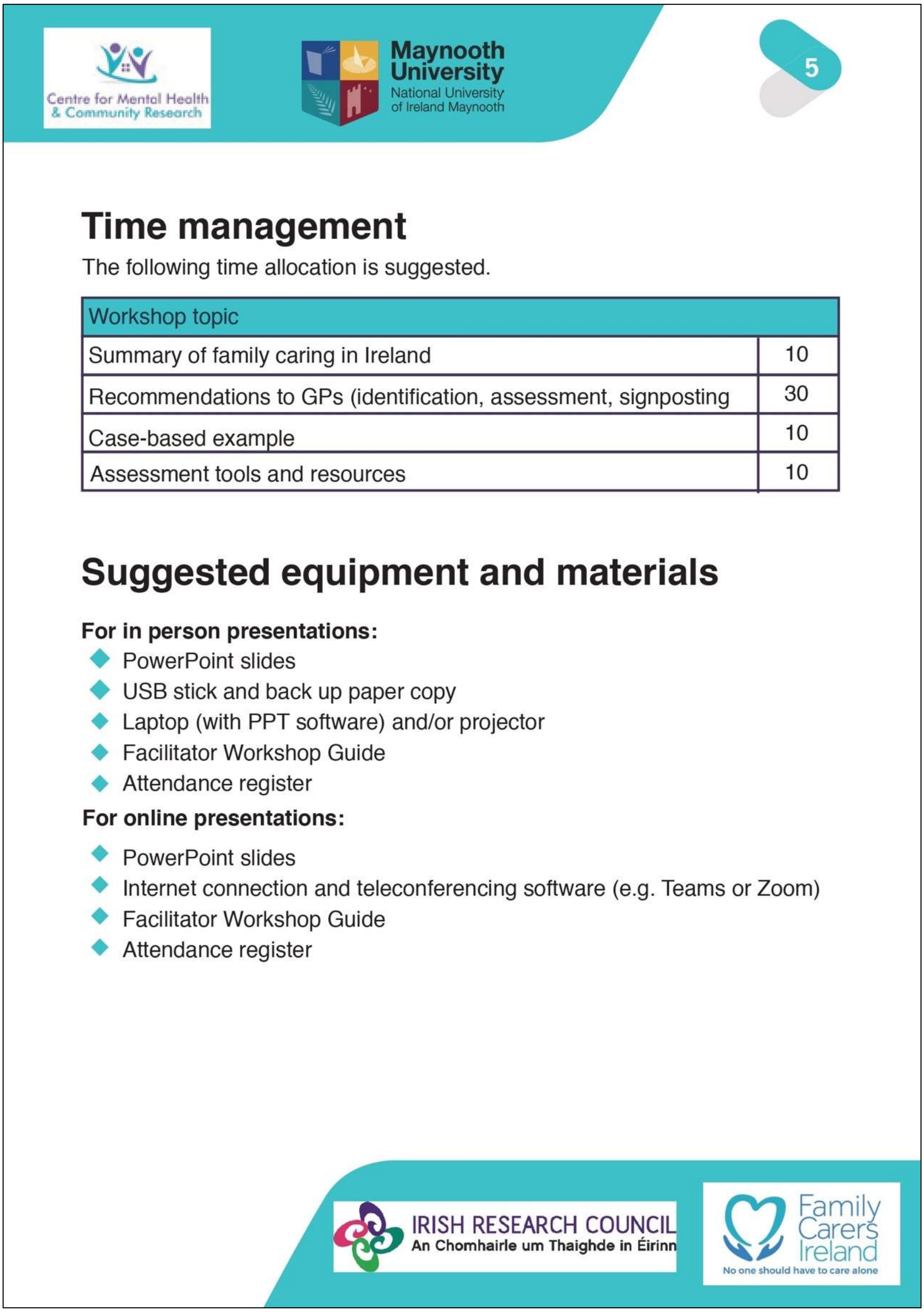


About this guide

This guide is designed to assist facilitators to deliver the workshop ‘Raising awareness of family carers in General Practice’. The workshop is suitable for delivery to practising GPs and GP Registrars (GPRs), and has been piloted with GPRs. The guide outlines the workshop materials, including PowerPoint presentation slides with accompanying explanatory notes.

The guide is designed as a resource for a one-hour long workshop developed using principles of Adult Learning Theory. These principles suggest that learning is enhanced when the content is relevant, interactive, and existing experience of the learner is acknowledged and used as a resource within the workshop. Therefore, if time permits, the facilitator is encouraged to foster group discussion about the GP/GPR participants’ experiences with supporting (or not) family carers.

The workshop has been designed to be delivered by a GP (or other health care professional) who has clinical experience and can speak to the case-based discussion aspect of the workshop. The content is structured to: (1) provide a summary of family caring in Ireland; (2) outline the recommendations to GPs; (3) present a case-based clinical example; and (4) introduce assessments and resources. Materials can be used in on-line or in person formats to groups of carers.



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Time management

The following time allocation is suggested.

Workshop topic	
Summary of family caring in Ireland	10
Recommendations to GPs (identification, assessment, signposting	30
Case-based example	10
Assessment tools and resources	10

Suggested equipment and materials

For in person presentations:

- PowerPoint slides
- USB stick and back up paper copy
- Laptop (with PPT software) and/or projector
- Facilitator Workshop Guide
- Attendance register

For online presentations:

- PowerPoint slides
- Internet connection and teleconferencing software (e.g. Teams or Zoom)
- Facilitator Workshop Guide
- Attendance register

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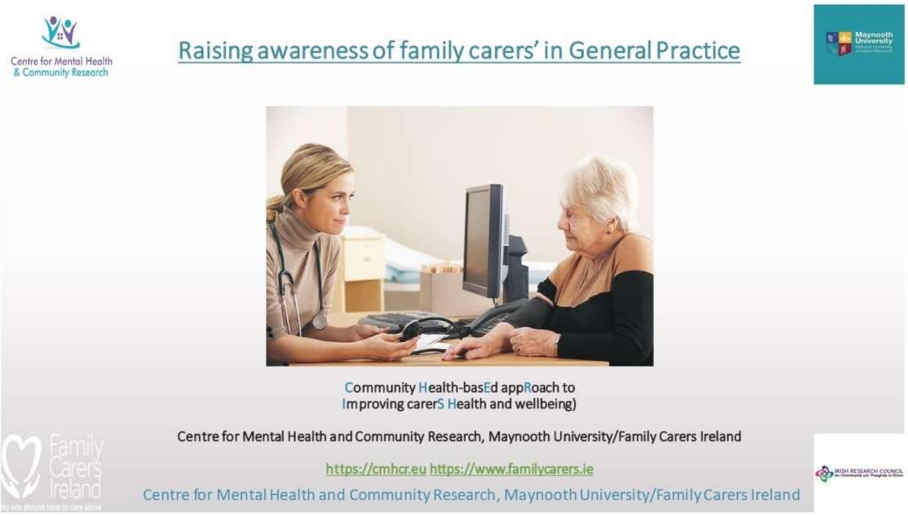

Raising awareness of family carers' in General Practice

Community Health-basEd appRoach to
Improving carerS Health and wellbeing)

Centre for Mental Health and Community Research, Maynooth University/Family Carers Ireland

https://cmhcr.eu https://www.familycarers.ie

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Slide 1:
Introductions and thanks to attendees.

Background:

- Care needs are increasing in our society due to improved longevity, advances in medical care and a move away from institutional care.[1]
- Ireland has over half a million family carers who provide care to a family member or loved one.[2]
- The Central Statistics Office has estimated that family carers provide 16.7 million hours of voluntary care each week (excluding any care by young carers).
- Estimated savings to the Exchequer are at least €20 billion.
- Internationally it is recognised that general practice has a critical role to play in the identification and support of family carers[3]. However, to date, no guidelines exist in Ireland to support GPs in this role.

Key points:

- Highlight importance of supporting family carers – increasing prevalence of care needs, societal impact and cost.
  General Practice due to its accessibility by all carers, has a central role to play – hence the need to support GPs.

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Today’s discussion

- ➢ Family caring in Ireland
- ➢ Risk to carers health and wellbeing
- ➢ Challenges for General Practice
- ➢ Case based discussion
- ➢ Barriers and facilitators to identification
- ➢ Introduce assessment tools
- ➢ Resources

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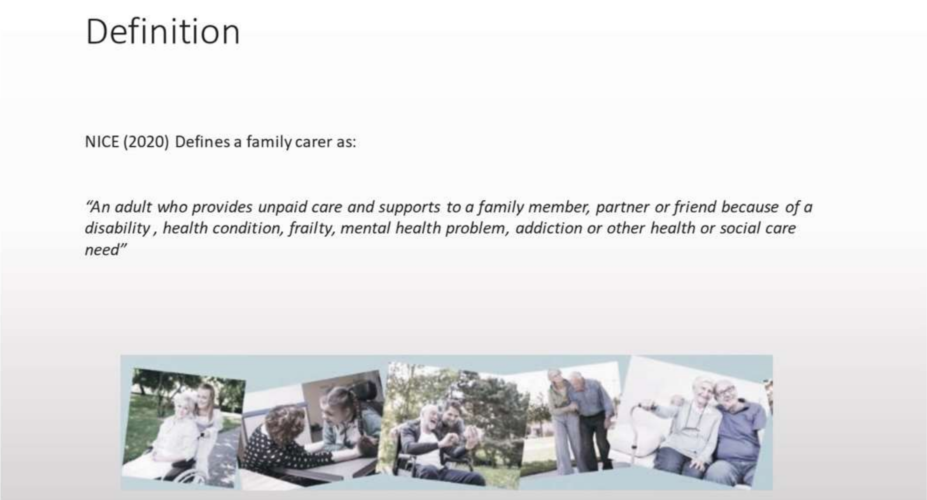
Slide 2:
Introduction to workshop topics

Family caring in Ireland

- A look at carer numbers and the types of carer roles that are common in our communities.
- Risks to carers health and wellbeing.
- An overview of some of the documented potential health risks for carers.
- Challenges for general practice.
- It is important to discuss the challenges that may exist in general practice, for example, workload, limited information.
- Barriers and facilitators to identification.
- Many of those who provide care do not identify themselves as carers – we will discuss this complex process.
- Introduce brief assessment tools.
- A few short assessment tools will be introduced that may support consultations with carers.
- A case-based discussion will allow us to explore a case example of a family carer.
- Resources that GPs may use to support family carers will be introduced including, for example, an introduction to the national carer charity, Family Carers Ireland.
- Resources – Family Carers Ireland Website. Family Carers Ireland (FCI) are a not-for-profit organisation supporting carers and have centres in more than 22 counties.



Definition

NICE (2020) Defines a family carer as:

"An adult who provides unpaid care and supports to a family member, partner or friend because of a disability , health condition, frailty, mental health problem, addiction or other health or social care need"

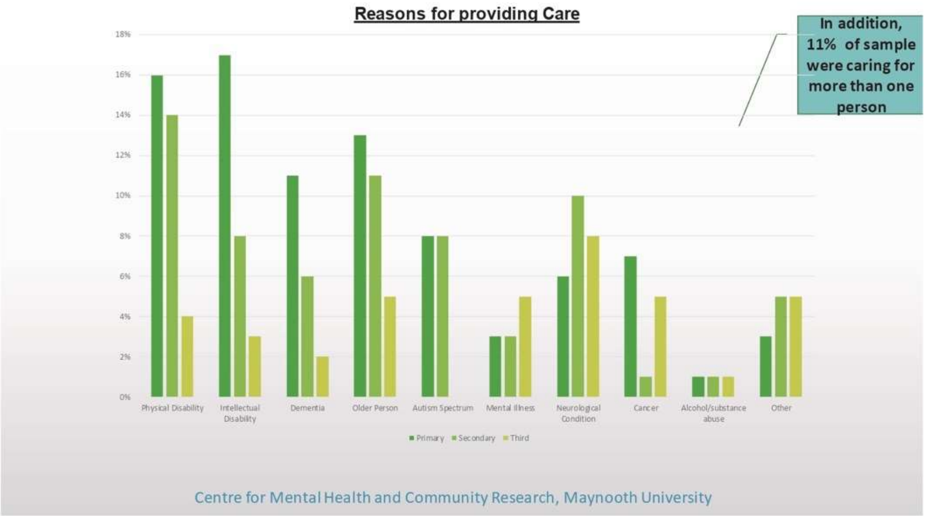
Slide 3:

Background:

A number of definitions of family or 'informal' carer exist. For example, the Irish National Carers Strategy uses the definition *'those who provide regular unpaid personal help for a friend or a family member with a long-term illness, health problem or a disability'*[4]. The National Institute of Care Excellence (NICE) definition is provided here due to its relevance in healthcare settings[5].

Key point:

- It is important to make the distinction between family carers and 'paid carers' such as Health Care Assistants (HCAs), who work in community, nursing home and hospital settings.



Reasons for providing Care

In addition, 11% of sample were caring for more than one person

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Slide 4

Background:

Care needs can be diverse and complex with a wide range of care being provided by family members. Data from the CHERISH national survey of carers in Ireland, provides some insight into the type of care being provided in the community. The graph highlights that many of those receiving care may have multiple reasons for needing care. Those who provide care may also be caring for more than one person, such as caring for a child/young adult with a disability as well as an ageing parent/spouse.[6]

Key points:

- Many care recipients may have complex care needs and co-morbidity.
- Carers are often caring for more than one person.

Why is supporting carers important?

- Ireland has upwards of half a million family carers
- Save the state approx. 20 Billion euros a year
- 45% of carers report a long-term illness, health problem or disability
- Number of family carers set to rise
  - Aging population
  - Advances in medical care
  - Shift away from institutional and prolonged hospital care
- Family carers are providing increasingly complex care in the community
- Contribution to health system

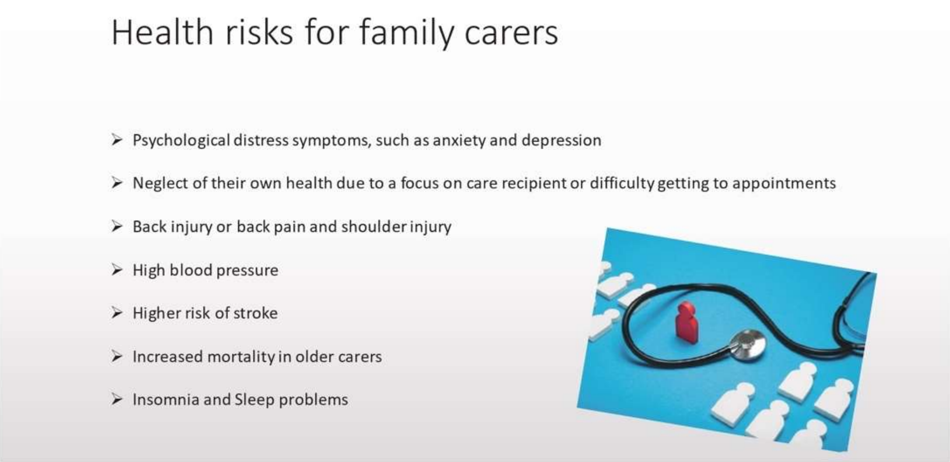
Slide 5

Background:

The adequate support of people who provide care, has implications for the carer themselves, the person for whom they provide care, and the wider health service. Carer numbers are on the increase and with our ageing population, this is set to continue.

Key points:

- Numbers are rising due to a move away from institutional care, rise in incidences of dementia and other conditions.[1]
- People with very complex medical needs are now living in the community.[7]
- Carers often neglect their own health as they become engulfed in the caring role.
- The caring provided in the community has an impact on length of hospital stay, hospital and nursing home admissions, medication compliance, attendance at appointments/clinics.
- There are implications for the care recipient when the carer is no longer able to care.



Health risks for family carers

- Psychological distress symptoms, such as anxiety and depression
- Neglect of their own health due to a focus on care recipient or difficulty getting to appointments
- Back injury or back pain and shoulder injury
- High blood pressure
- Higher risk of stroke
- Increased mortality in older carers
- Insomnia and Sleep problems

Slide 6

Background:

As previously mentioned, although many carers feel a sense of satisfaction and purpose in caring for their loved one(s), there are also associated risks to their own health and wellbeing. Carers report lower overall health status when compared to the general population. Throughout this module, we will be looking at identification and referral, but at this point, it is important to note that due to the focus on the care recipient, many carers will not be aware of the risks to their own health and will not proactively seek help. [8]

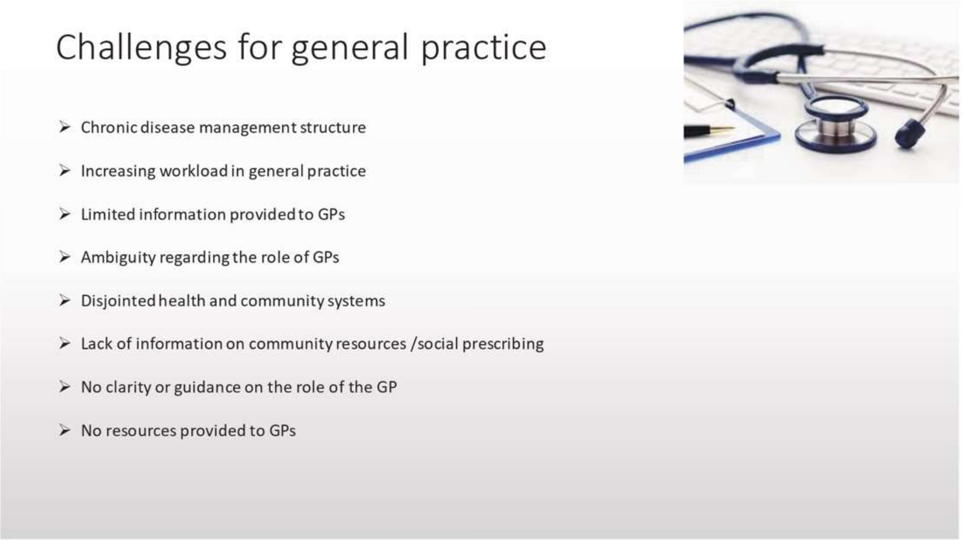
Key points:

Psychological distress symptoms such as anxiety and depression can occur and may be linked to:

- The demands of the caring role.[9]
- The emotional impact of the changing relationship (with the care recipient).[10]
- The loss of own identity (isolation).[10]
- Lack of support.[11]

Physical impacts of caring may include but not be limited to:

- Back[8] or shoulder injury or pain.[12]
- High blood pressure.[8]
- Higher risk of stroke.[13]
- Increased mortality in older carers.[13]
- Insomnia [14]and sleep problems.[15]



Challenges for general practice

- ➢ Chronic disease management structure
- ➢ Increasing workload in general practice
- ➢ Limited information provided to GPs
- ➢ Ambiguity regarding the role of GPs
- ➢ Disjointed health and community systems
- ➢ Lack of information on community resources /social prescribing
- ➢ No clarity or guidance on the role of the GP
- ➢ No resources provided to GPs

Slide 7

Background:

The international literature suggests a role for general practice in supporting family carers due to the centrality of the GP to the healthcare system, and the fact that they are very often the first point of contact[3]. However, obstacles exist at practice, health systems and policy level.

Key points:

- ◆ GPs are often not given information following diagnosis and /or hospital discharge.
- ◆ There are already significant demands on general practice.
- ◆ Disjointed communication systems exist within the health service.
- ◆ GPs are typically unaware of relevant resources in the community.
- ◆ No guidance or resources are available to the GP.
- ◆ The aim of this workshop is to provide information and brief resources to GPs.

Barriers to identifying carers

- Dislike of the term as they may feel it detracts from their identity as a parent, spouse, child etc.
- Identifying as a carer can be a gradual process
- They can become engulfed in the competing demands of the role
- The care recipient may not accept that they have care needs
- They may not live with the care recipient
- Focus on care recipient – by health system and carer

Slide 8

Background:

The identification of carers requires a proactive approach, as many carers will not associate themselves with the term ‘carer’ and may be in crisis or failing health before they seek help [16]. In addition, caring is often a progressive role with increasing demands as the needs of the cared for family member increase. [5, 8]

Key points:

- Caring can be all consuming and overwhelming, taking up the majority of the carers time.
- Not all people who have a carer will admit to this or be open to engaging with support external to the family.
- We will be looking next, at ways in which carers can be identified – many small changes to existing practice can have significant impact.

Facilitating identification

(1) Role of the GP	(2) Practice Staff/ Carer Lead	(3) Through Practice documentation/ Record keeping
At diagnosis, find out who will be providing care	Encourage carers to self-identify by: Displaying information in reception area & website	Have a register to identify and record carers Keep register up-to- date, particularly in the case of the death of a care recipient
Seek out carer details through hospital admission and discharge process	Ask family members if they are the primary carer when they bring a patient for flu vaccine	Have a form to allow carers to request to be put on the carers register
Consider impact of patient's condition on family and make enquiries about who is providing the care	Notice who is making appointments/ ordering prescriptions and ask if they are providing care	Include a question on new patient registration form e.g. Do you rely on someone for your care?/ Does someone rely on you for their care?
Be aware of the signs of an undisclosed caring role e.g. back problems, stress, minimising own health, poor mental health, sleep problems	Be aware of carers from hard to reach groups • Ethnic minorities • LGBT community • Carers of those with mental illness or substance misuse, • Carers with disabilities Links with community groups can help identify these carers	Review other practice registers such as; disease specific registers, long term illness registers, at risk registers
Ask patients if someone helps them with care needs		When forms are received for disability or related allowances enquire who is carer is
Appoint a member of staff to be carer champion/lead with key responsibility for identifying carers		

Slide 9

Background:

Identification is best achieved as a 'whole practice' approach with the appointment of a designated 'Carer Champion'. Many ways to identify carers can be incorporated into existing practices. Practice staff can support the identification of carers, but this is best achieved if the GP is leading the initiative.

Key points:

- Actively seek out carer details through admissions/discharge process.[5]
- When a patient is diagnosed with a condition that requires care, ask who will be providing that care[8, 17]
- Be aware of the signs of an undisclosed caring role such as those outlined in health risks for carers. [15]
- Ask patients if someone helps them with their care needs.[15]
- Appoint a member of staff to be carer champion/lead.[18]

PRACTICE STAFF:

Many staff in the practice can support the identification of carers through small changes to their current practices. For rexample, new patient registration could include an additional question such as 'do you provide care?' or 'does someone rely on you for care?'[19]

A carer champion/carer lead

- ➢ Member of practice staff - appointed by GP
- ➢ Point of contact for carers in the practice
- ➢ Develop links between the practice and local carer support services
- ➢ Identifying carers, provide information and signpost to supports
- ➢ Setup and maintain the carer register, notice board area, website
- ➢ Keep colleagues up to date with developments at a local and national level
- ➢ Produce a carer support policy

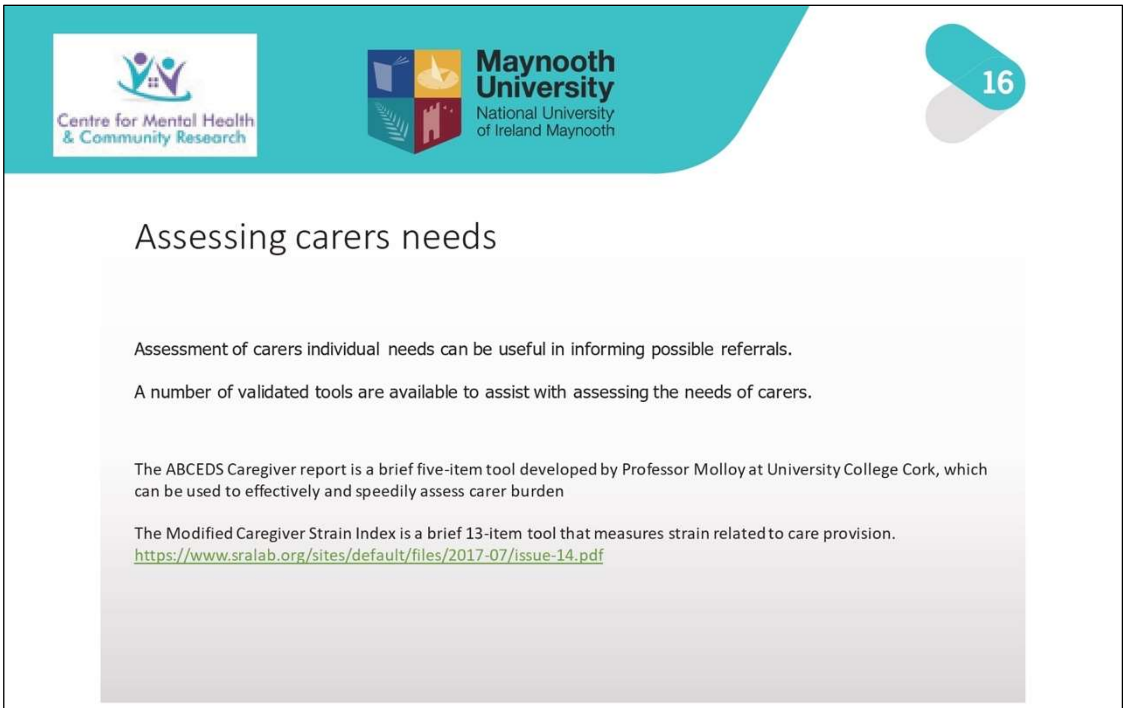
Slide 10

Background:

A carer champion is *"a designated member of staff who is given the task of supporting and speaking up for carers. They can act as a key contact for carer information and advice, providing knowledgeable, expert advice as well as training others in the practice"*. This role is recommended by several organisations, such as NICE, Royal College of General Practitioners (RCGP) and the National Health Service (UK). [12, 17, 18, 20]

Key points:

- ◆ A carer champion/lead in the practice could help to streamline the process of carer identification and signposting.
- ◆ Small practices could work together to elect a carer champion or regional carer champion to support the identification of carers.
- ◆ The carer champion can oversee many of the suggestions in columns 2 and 3 of the previous slide.



Assessing carers needs

Assessment of carers individual needs can be useful in informing possible referrals.

A number of validated tools are available to assist with assessing the needs of carers.

The ABCEDS Caregiver report is a brief five-item tool developed by Professor Molloy at University College Cork, which can be used to effectively and speedily assess carer burden

The Modified Caregiver Strain Index is a brief 13-item tool that measures strain related to care provision.
https://www.sralab.org/sites/default/files/2017-07/issue-14.pdf

Slide 11

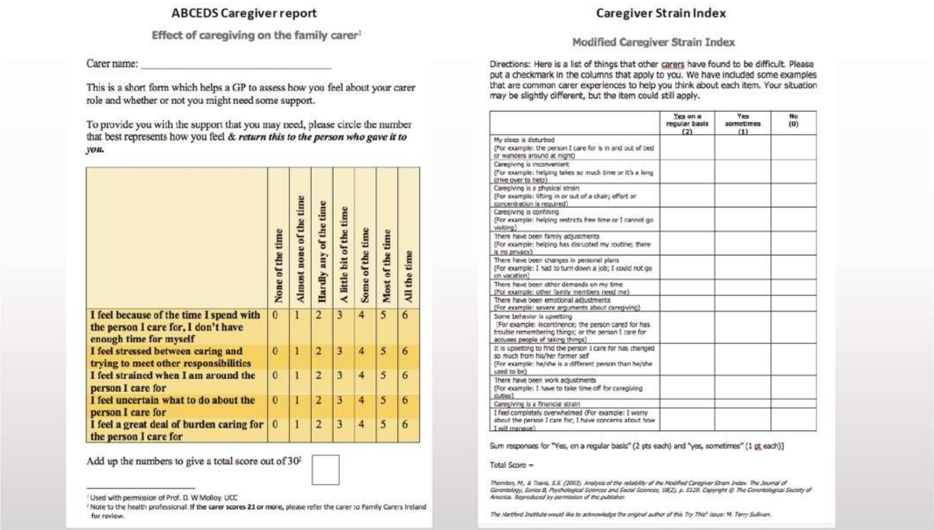
Background:

Research has suggested that a short assessment can help to guide the consultation and inform the referral process.

Key points:

Two tools will be introduced in the next slide. These are suitable for all carers and indicated for use in general practice.

- The ABCEDS Caregiver report (Appendix 1)
- The Modified Caregiver Strain Index (Appendix 2)[21]



ABCEDS Caregiver report

Effect of caregiving on the family carer[1]

Carer name: ______________________

This is a short form which helps a GP to assess how you feel about your carer role and whether or not you might need some support.

To provide you with the support that you may need, please circle the number that best represents how you feel & ***return this to the person who gave it to you.***

	None of the time	Almost none of the time	Hardly any of the time	A little bit of the time	Some of the time	Most of the time	All the time
I feel because of the time I spend with the person I care for, I don't have enough time for myself	0	1	2	3	4	5	6
I feel stressed between caring and trying to meet other responsibilities	0	1	2	3	4	5	6
I feel strained when I am around the person I care for	0	1	2	3	4	5	6
I feel uncertain what to do about the person I care for	0	1	2	3	4	5	6
I feel a great deal of burden caring for the person I care for	0	1	2	3	4	5	6

Add up the numbers to give a total score out of 30[2] ☐

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[1] Used with permission of Prof. D. W Molloy. UCC

[2] Note to the health professional: **If the carer scores 21 or more,** please refer the carer to Family Carers Ireland for review.

Caregiver Strain Index

Modified Caregiver Strain Index

Directions: Here is a list of things that other carers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common carer experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes on a regular basis (2)	Yes sometimes (1)	No (0)
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

Total Score =

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

The Hartford Institute would like to acknowledge the original author of this Try This® issue: M. Terry Sullivan.

Slide 12

Background:

Whilst there are many different instruments available to support the assessment of carer needs, these two have been selected (in consultation with PPI panel) for inclusion in the workshop. Both are short assessments that are relevant across different caring scenarios.

Key points:

- The ABCEDS Caregiver report is a brief five-item tool developed by Professor Molloy at University College Cork, which can be used to effectively and speedily assess carer burden (Appendix 1).
- The Modified Caregiver Strain Index [21] is a brief 13-item tool that measures strain related to care provision https://www.sralab.org/sites/default/files/2017-07/issue-14.pdf (Appendix 2).

Centre for Mental Health & Community Research

Maynooth University
National University of Ireland Maynooth

The consultation process

- Carers may worry about appointment time constraints and may not come forth with their own concerns unless prompted
- An annual health check specific to the caring role can be beneficial for carers to discuss their needs
- A carer assessment tool can be used to guide the consultation process
- Convey empathy, active listening and offer emotional support
- Open communication can be both preventative and helpful and it can help to manage expectations.

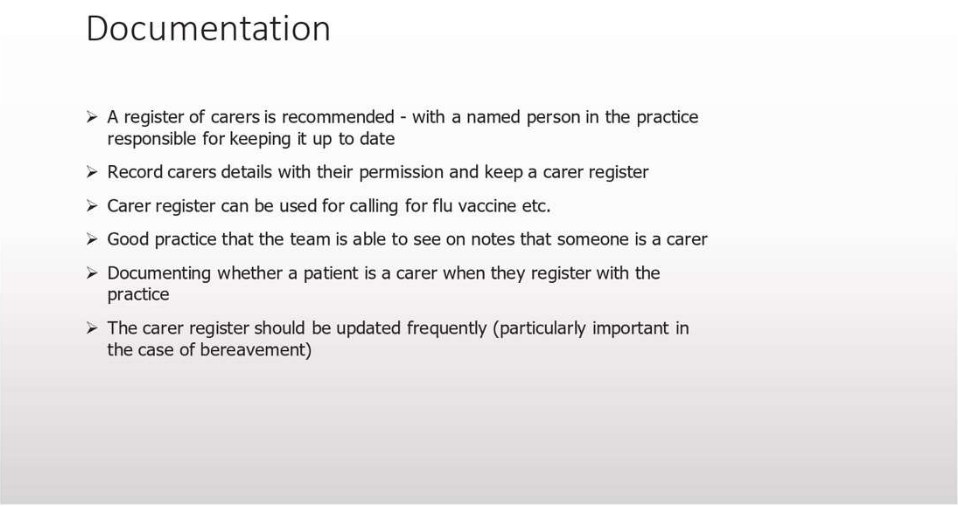
Slide 13

Background:

Carers may be resistant to the term ‘carer’ and the impact of the carer role, so starting the conversation may sometimes be challenging. Research shows they do not seek help until crisis point and by then, often do not know to whom they should speak.

Key points:

- Carers may respond to a communication style such as using the ‘permission question’ – ‘Would it be alright to discuss for a moment, the impact caring for [care recipient name] might be having on your own health and wellbeing?
- If the impact on their health and wellbeing is raised once, even if they do not engage, it may encourage them to come forward at a later date if the need arises.
- The point of diagnosis can be a good time to initially raise the possibly detrimental effect of the caring role on a carer’s own health over time - and let them know you are there to talk when needed. [17]



Documentation

- A register of carers is recommended - with a named person in the practice responsible for keeping it up to date
- Record carers details with their permission and keep a carer register
- Carer register can be used for calling for flu vaccine etc.
- Good practice that the team is able to see on notes that someone is a carer
- Documenting whether a patient is a carer when they register with the practice
- The carer register should be updated frequently (particularly important in the case of bereavement)

Slide 14

Background:

Practice documentation, including existing documentation systems, can play an important role in supporting family carers. Keeping a register of carers is highly recommended and is best designated to a particular staff member within the practice. [17]

Key points:

- A carer register can be incorporated into current practice record systems.
- It can be beneficial to contact carers with regard to their own health or that of the care recipient.
- It is very important that someone is removed from the register in the event of the care recipient passing away.

Case-based discussion

- 55 yr woman
- Patient of practice 5 years
- Rare attender
- Symptoms of depression
- Former nurse
- Caring for 85 yr old mother with advancing dementia - with insomnia and wandering

Slide 15

Background:

The following is included as a case example. GPs delivering the workshop may wish to substitute with their own example as appropriate.

Key points:

◆ This 55-year-old female is a rare presenter at the GP. She is a former nurse and is showing signs of depression. She is currently caring for a parent with advanced dementia with symptoms of insomnia and wandering.

Case based discussion

- Sibling living abroad
- Limited social network
- Culture against nursing home care
- Feelings of guilt
- Home visit

Slide 16

Background:

The extent of the burden of care for this individual, only became apparent after a home visit. She is a non-national whose siblings live abroad and has a very limited social network. Culturally, she is unaccustomed to the notion of nursing home care and, therefore, she has been shouldering the responsibility alone, leading to significant isolation. The home environment is a safety concern with very steep stairs which need to be navigated by the care recipient, with the support of the carer.

Key points:

- The facilitator may use this case discussion to highlight the often 'invisible' nature of caring – it was only through a home visit that the extent of the caring role became evident.

- The case also highlights some potential hard-to-reach groups, such as those from minority and immigrant populations.

Case based discussion

- Primary Care Team
- Occupational Therapist
- Family Carers' Ireland
- Counselling
- Lessons Learned
- Identify Carer
- Assess Needs
- Social & Primary Care Supports

Slide 17

Background:

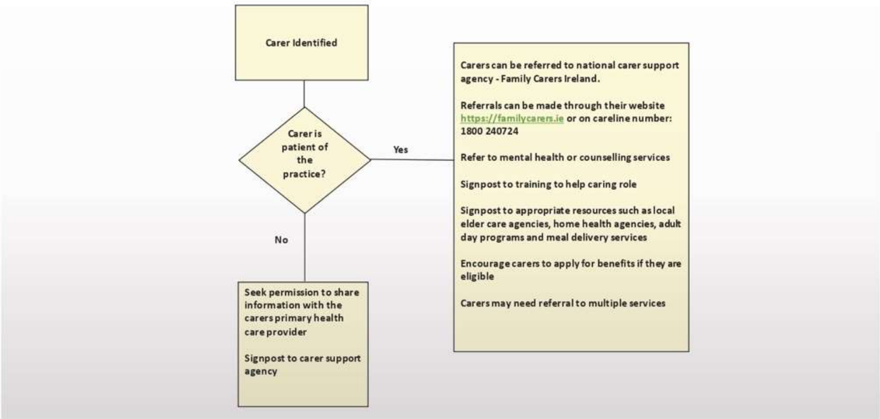
This slide discusses the intervention for the carer. The carer was referred to wider primary care team (e.g. the Public Health Nurse and Occupational Therapist). Referrals were also made to Family Carers Ireland and for counselling.

Key points:

Some valuable lessons were learned through this case presentation:

- The carer was only identified through home visit to the care recipient.
- The assessment of need, including the home environment, proved valuable.
- The carer can now be considered for more substantial social and primary care supports.

Signposting to supports



Carer Identified

Carer is patient of the practice?

Yes

Carers can be referred to national carer support agency - Family Carers Ireland.

Referrals can be made through their website https://familycarers.ie or on careline number: 1800 240724

Refer to mental health or counselling services

Signpost to training to help caring role

Signpost to appropriate resources such as local elder care agencies, home health agencies, adult day programs and meal delivery services

Encourage carers to apply for benefits if they are eligible

Carers may need referral to multiple services

No

Seek permission to share information with the carers primary health care provider

Signpost to carer support agency

Slide 18

Background:

GPs are often reluctant to enquire about the wellbeing of the carer as they are not informed about possible resources or supports. This flow diagram outlines some potential signposting pathways for family carers. Carers can be referred to Family Carers Ireland (FCI) for a detailed assessment.

Key points:

Sometimes the carer is not a patient of your practice.

- With their permission, you could offer to write to the carer's own GP to highlight any needs arising from their caring role, or they can be informed about FCI.[19]

Training for caring role

- Carers often value training on aspects of their caring role. However, it is important that their capacity to provide that care is determined first by discussing their role with them as some carers become over burdened.[22]

Counselling

- Carers may benefit from counselling and this can be particularly important in the case of bereavement. Many GPs report a lack of awareness of services in their community. In the meantime, a member of practice staff (carer lead) could research what supports are available in the local community.

Resources for GPs

- Family Carers Ireland : https://familycarers.ie
  - National charity providing support to carers
    - Free counselling
    - Education programs
    - Full assessment
    - Free careline

- Government financial supports – gov.ie
  - Carers Allowance
  - Half rate carers allowance
  - Carers benefit
  - Domiciliary care allowance
  - Carer support grant

https://www.gov.ie/en/service/2432ba-carers-allowance/
https://www.gov.ie/en/publication/e7b36c-half-rate-carers-allowance/
https://www.gov.ie/en/service/455c16-carers-benefit/
https://www.gov.ie/en/service/30fac9-domiciliary-care-allowance/
https://www.gov.ie/en/service/16220307-carers-support-grant/

Slide 19

Background:

Family Carers Ireland are a good option for referring family carers for a range of supports. Through the consultation with family carers, it may emerge that they are struggling financially due to the increasing demands of the caring role. It is useful for GPs to be aware of the financial supports that are available or to be able to direct the carer to someone who would have access to this information.

Key points:

Carer's Allowance

- A means tested payment to people on low incomes who are looking after a person who needs support because of age, disability or illness (including mental illness).

Half-rate Carer's Allowance

- For those who are getting another social welfare allowance and also providing care.

Carer's Benefit

- A payment made to PRSI insured people who leave the workforce to care for a person(s) in need of full-time care.

Domiciliary Care Allowance

- Monthly allowance for those raising a child with a disability.

Carer Support Grant

- The Carer's Support Grant is automatically paid to people who receive the Carer's Allowance (in June of each year), but those who do not qualify for Carer's Allowance may also apply for it.

Care at Home - Costs of Care Arising from Disability

New report published

Caring by Numbers

500K

€20BN

19M

https://www.familycarers.ie

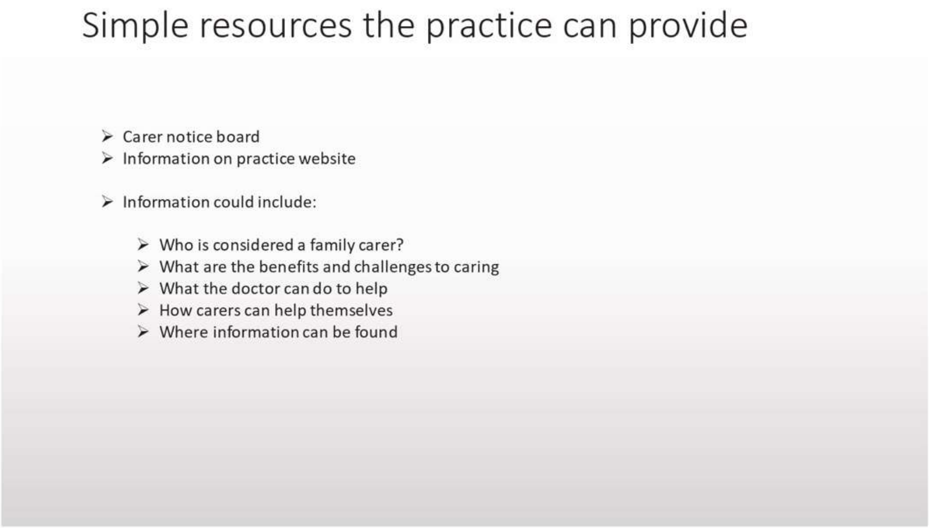
Slide 20

Background:

A short demonstration of the Family Carers Ireland website can be helpful to attending GPs/GPRs. The ‘Carer Support’ menu therein, includes details of FCI offices around the country.

Services include:

- Helpline number.
- Full assessment (Carer star assessment covering: health, wellbeing, home life, work life and finances).
- Free counselling service.
- Education supports such as: mental health and caring, caring with confidence, and a Level 6 certificate in family caring.



Simple resources the practice can provide

- Carer notice board
- Information on practice website

- Information could include:

  - Who is considered a family carer?
  - What are the benefits and challenges to caring
  - What the doctor can do to help
  - How carers can help themselves
  - Where information can be found

Slide 21

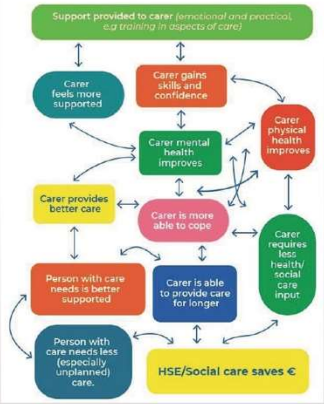
Background:

There are some resources for carers that the practice can provide in order to make the environment ‘carer friendly’ and encourage carers to self-identify.

Services include:

- The carer champion, if appointed, can take charge of these resources.
- Having visible resources can encourage carers to self-identify and seek help before a crisis.

Why carer support is important


Support provided to carer *(emotional and practical, e.g training in aspects of care)*

Carer feels more supported

Carer gains skills and confidence

Carer physical health improves

Carer mental health improves

Carer provides better care

Carer is more able to cope

Carer requires less health/ social care input

Person with care needs is better supported

Carer is able to provide care for longer

Person with care needs less (especially unplanned) care.

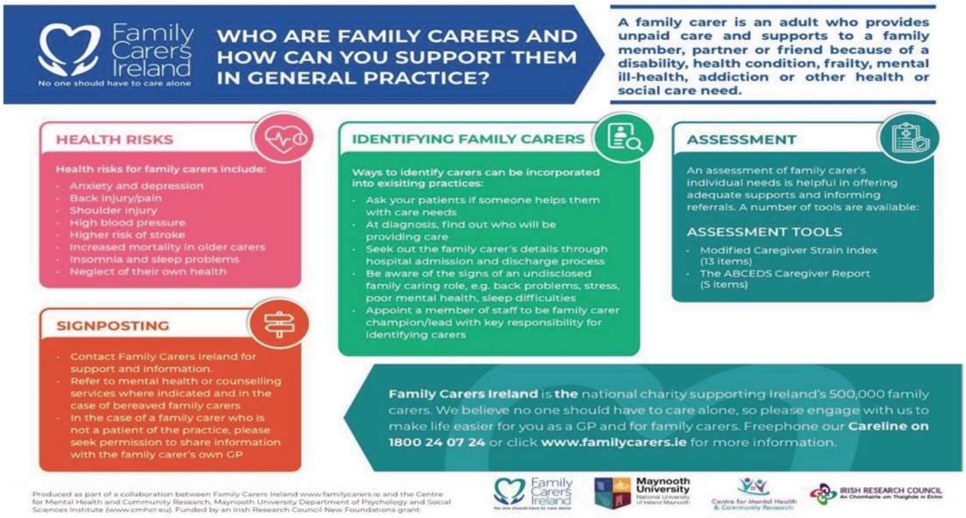
HSE/Social care saves €

Centre for Mental Health and Community Research, Maynooth University/Family Carers Ireland

Slide 22

In summary, supporting carers is associated with improved outcomes for carer, carer recipient and the health service. These include:

- Better ability to cope with demands of caring role
- Increased support for care recipient
- Ability to care longer
- Saving to overall healthcare system



WHO ARE FAMILY CARERS AND HOW CAN YOU SUPPORT THEM IN GENERAL PRACTICE?

Family Carers Ireland
No one should have to care alone

A family carer is an adult who provides unpaid care and supports to a family member, partner or friend because of a disability, health condition, frailty, mental ill-health, addiction or other health or social care need.

HEALTH RISKS

Health risks for family carers include:

- Anxiety and depression
- Back injury/pain
- Shoulder injury
- High blood pressure
- Higher risk of stroke
- Increased mortality in older carers
- Insomnia and sleep problems
- Neglect of their own health

IDENTIFYING FAMILY CARERS

Ways to identify carers can be incorporated into exisiting practices:

- Ask your patients if someone helps them with care needs
- At diagnosis, find out who will be providing care
- Seek out the family carer's details through hospital admission and discharge process
- Be aware of the signs of an undisclosed family caring role, e.g. back problems, stress, poor mental health, sleep difficulties
- Appoint a member of staff to be family carer champion/lead with key responsibility for identifying carers

ASSESSMENT

An assessment of family carer's individual needs is helpful in offering adequate supports and informing referrals. A number of tools are available:

ASSESSMENT TOOLS

- Modified Caregiver Strain Index (13 items)
- The ABCEDS Caregiver Report (5 items)

SIGNPOSTING

- Contact Family Carers Ireland for support and information.
- Refer to mental health or counselling services where indicated and in the case of bereaved family carers
- In the case of a family carer who is not a patient of the practice, please seek permission to share information with the family carer's own GP

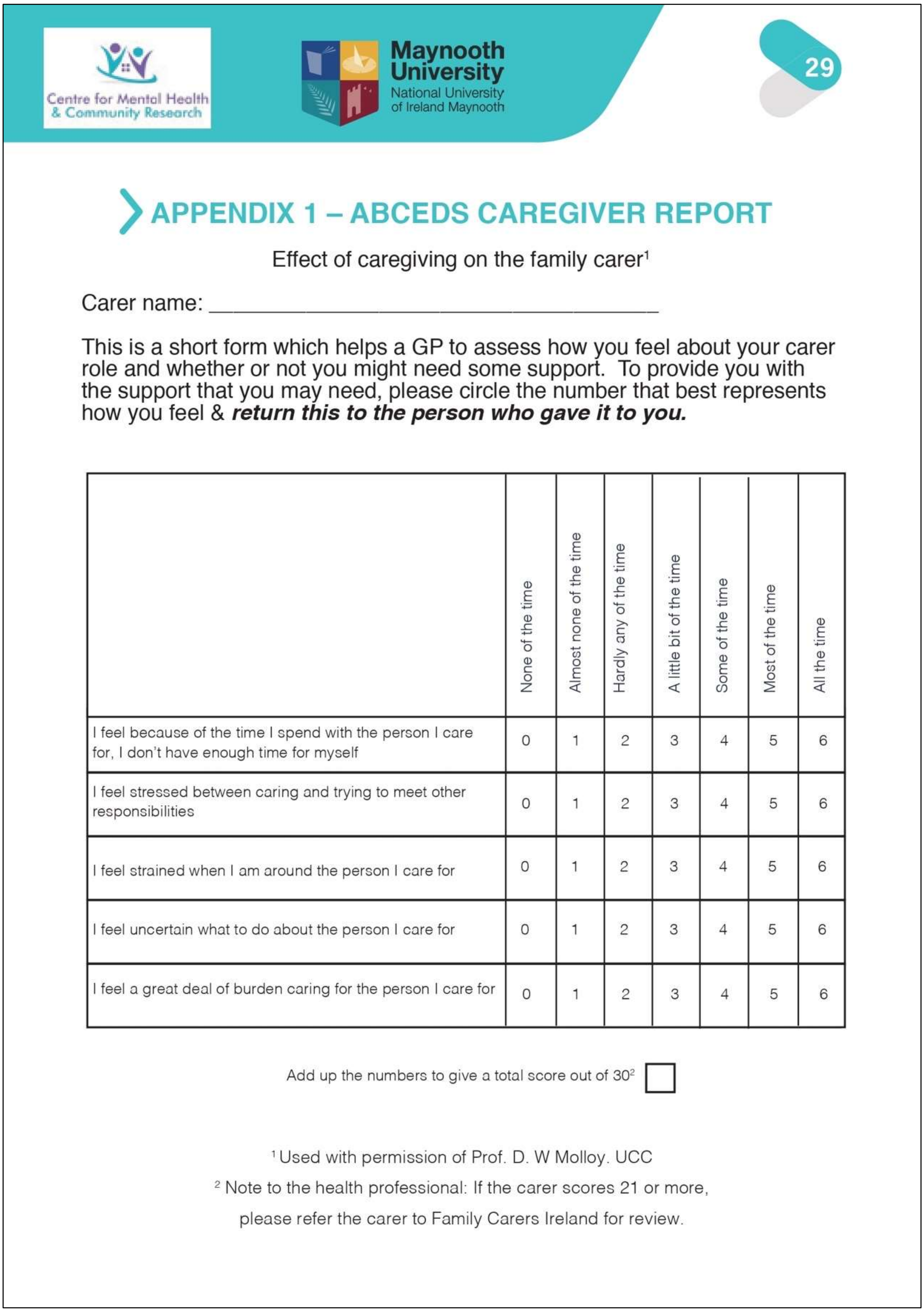
Family Carers Ireland is **the** national charity supporting Ireland's 500,000 family carers. We believe no one should have to care alone, so please engage with us to make life easier for you as a GP and for family carers. Freephone our **Careline on 1800 24 07 24** or click **www.familycarers.ie** for more information.

Produced as part of a collaboration between Family Carers Ireland www.familycarers.ie and the Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute (www.cmhcr.eu). Funded by an Irish Research Council New Foundations grant.

Family Carers Ireland
Maynooth University National University of Ireland Maynooth
Centre for Mental Health & Community Research
IRISH RESEARCH COUNCIL An Chomhairle um Thaighde in Éirinn

Slide 23

This infographic/poster will be made available along with the workshop manual after the workshop. The infographic provides a quick at-a-glance reference that may be used during consultations.



APPENDIX 1 – ABCEDS CAREGIVER REPORT

Effect of caregiving on the family carer[1]

Carer name: ___________________________________

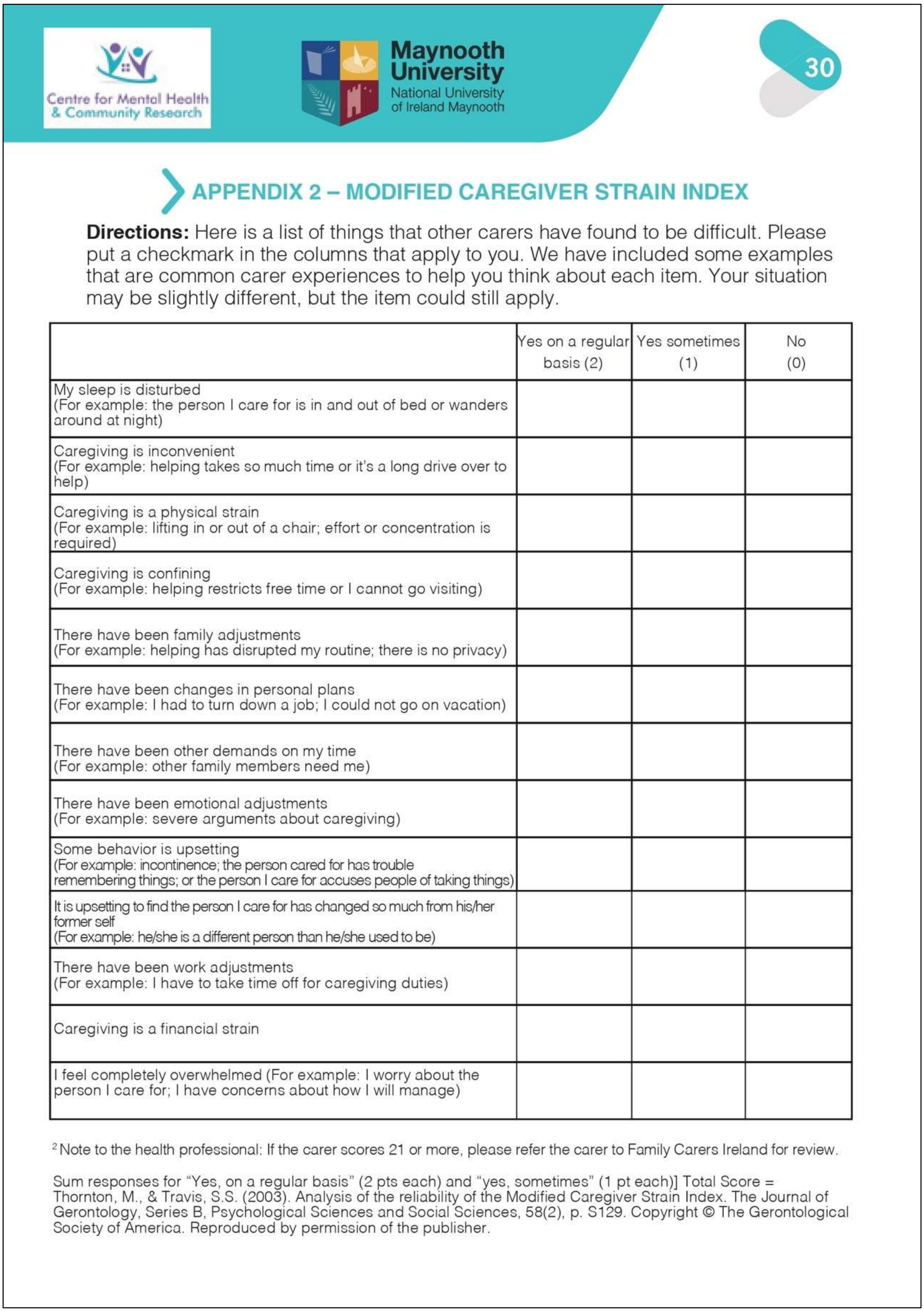
This is a short form which helps a GP to assess how you feel about your carer role and whether or not you might need some support. To provide you with the support that you may need, please circle the number that best represents how you feel & ***return this to the person who gave it to you.***

	None of the time	Almost none of the time	Hardly any of the time	A little bit of the time	Some of the time	Most of the time	All the time
I feel because of the time I spend with the person I care for, I don't have enough time for myself	0	1	2	3	4	5	6
I feel stressed between caring and trying to meet other responsibilities	0	1	2	3	4	5	6
I feel strained when I am around the person I care for	0	1	2	3	4	5	6
I feel uncertain what to do about the person I care for	0	1	2	3	4	5	6
I feel a great deal of burden caring for the person I care for	0	1	2	3	4	5	6

Add up the numbers to give a total score out of 30[2] ☐

[1] Used with permission of Prof. D. W Molloy. UCC

[2] Note to the health professional: If the carer scores 21 or more, please refer the carer to Family Carers Ireland for review.



APPENDIX 2 – MODIFIED CAREGIVER STRAIN INDEX

Directions: Here is a list of things that other carers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common carer experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes on a regular basis (2)	Yes sometimes (1)	No (0)
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

[2] Note to the health professional: If the carer scores 21 or more, please refer the carer to Family Carers Ireland for review.

Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)] Total Score =
Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

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Chapter 6: Study 3 (Resources for Carers)

6.1 Introduction

This chapter outlines the development of resources for carers from the findings of Study One and Study Two. The development of the carer workshop ‘Communicating with doctors, empowerment workshop for family carers is described, followed by the details of a small-scale pilot evaluation of the workshop. The contribution of the PPI panel and how it was embedded in the workshop development is outlined. As mentioned in the previous chapter (Chapter Five), the overarching impact of PPI is further outlined using the GRIPP2-SF (Appendix A3.7). The facilitator guide that accompanies the workshop is presented at the end of this chapter.

6.2 Method

6.2.1 Carer Empowerment workshop

Findings from Study One suggested that carers view their own health as secondary and are often slow to ask for help or engage in help-seeking activities. Carers also reported that conversations with their doctor can be challenging, highlighting that they may struggle to communicate their needs effectively and assertively in a clinical setting. Communication in healthcare settings is often impeded by hierarchical structures and power differentials (Leonard et al., 2004), and findings from Study Two suggest that family carers can experience this as an obstacle to being assertive in conversations with their doctor. The ‘carer empowerment’ training was co-designed with carers from the PPI panel to address this. The training took the form of an online workshop that was co-facilitated by a carer who was also a member of the PPI panel (The opportunity to co-facilitate was offered to the full PPI panel, and one carer agreed to participate in this capacity). The comprehensive online workshop was developed based on the findings of the project to date, as well as existing literature regarding communication tools in healthcare settings (Figure 6.1). The aim of the workshop was to support carers in having conversations with their GP about their own health and well-being, along with discussing concerns about the person for whom they provide care.

6.2.1.1 Workshop development and co-design

The workshop was designed around evidence-based communication tools widely used to enhance communication in healthcare settings (Battles & King, 2015). A number of specially designed supplementary materials were also developed (e.g. a template entitled ‘planning your doctor visit’, as well as templates for each communication tool), and these are presented in the facilitator guide. The workshop was designed to last approximately two hours. It focused on: 1) Stages of carer identity; 2) health risks and help seeking; 3) the role of the GP; 4) preparing for doctor’s visit; and 5) communication skills.

The workshop was designed to be interactive throughout, with the section ‘preparing for the doctors’ visit, including a demonstration of the accompanying handout. In addition to the practical preparation suggested by the PPI panel (see Table 6.1), preparation for the visit included specifics of the consultation, such as prioritising things to discuss, details of symptoms (both old and new), and being assertive. Four learning objectives/outcomes were agreed by the course facilitator and co-facilitator for each of these domains, relating to, for example, increased awareness of the importance of identifying as a carer, knowledge regarding the potential health risks and increased confidence in communicating in health care settings.

Table 6.1

Communicating with doctors: Empowerment workshop for family carers - learning objectives

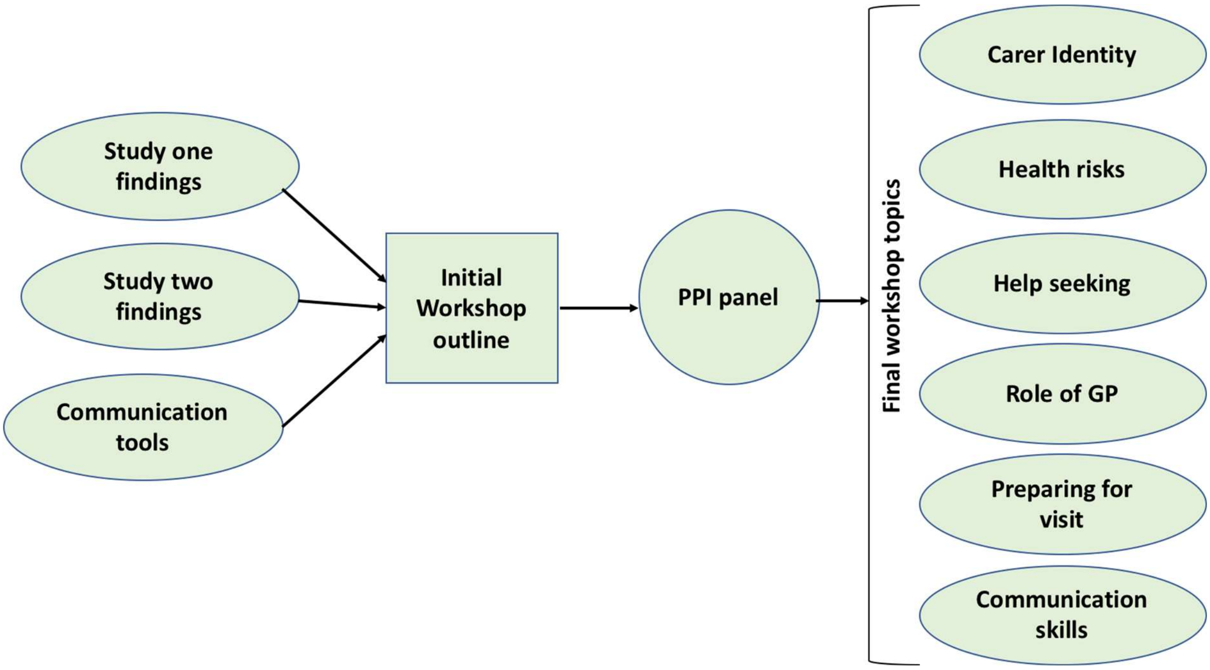
Topic	**Learning Objective**
Stages of carer identity	Increased understanding of how the carer identity emerges and how association with the term carer can be ambiguous but that recognition of the role is important in terms of help-seeking.
Health risks and help seeking	Raising awareness of the 'potential' health risks associated with providing care. Encouraging engagement with help-seeking activities.
The role of the GP and preparing for the visit	Improved knowledge of how the GP may be able to support carers and encouragement of practical tools to support planning for visits in advance to maximise the outcome for the carer.
Communication tools	Increased confidence about communicating with GPs (and other health care professionals).

Attendant workshop materials included:

- A facilitators' guide (presented later in the chapter) for delivery of the workshop that includes:
    - A handout for preparing for a visit to the doctor or other healthcare professional.
    - A handout for the CUS communication tool.
    - A handout for the SBAR communication tool.
- A corresponding workshop manual for carer attendees.

Figure 6.1

Process of carer workshop development



The section on carer identity looked at how the caring role emerges and evolves and was adapted from the model of caregiver identity available in gerontology literature (Montgomery et al., 2007). This theory is outlined in detail in Chapter One (Introduction). The theory was included in the workshop to provide a platform to discuss the potential progressive and engulfment nature of the caring role, as highlighted in the findings from Study One. A discussion on potential health risks for carers that emerged from Study Two followed, and this led seamlessly to the topic of help-seeking, where relevant findings from study one were presented to illustrate how carers often see their own needs as secondary (but are also reluctant to seek help). The role of the GP was included to address the ambiguity about the role of the GP that emerged in Study One.

The workshop was developed using the Self-Efficacy Framework (outlined in Chapter Two); therefore, the largest portion of time (1hr) was allocated to presenting the communication tools, CUS and SBAR (see below). The presentation of communication tools, in each case, included a practical example, followed by role-play opportunities, where the carers worked together in breakout rooms to use the communication tools and feedback their experience to the larger group. The content of the workshop is fully outlined in the facilitator's guide presented at the end of the chapter.

6.2.1.2 Communication tools

The communication tools adapted for use in the carer empowerment workshop included the CUS tool and the SBAR tool (detailed below). Both communication tools are evidence-based and developed by the USA Agency for Healthcare Research and Quality (AHRQ, 2019) as part of the Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS) programme. TeamSTEPPS is designed to improve communication between healthcare professionals when patient safety is of concern. Although the TeamSTEPPS programme has several other tools available, these two were deemed most suitable for adaptation for use with family carers. For example, other tools include 'check-back', used to clarify information such as medication dose, or 'hand-off', used primarily in healthcare staff shift change over. Effective communication tools for carers needed to provide assertive language and be flexible enough to be used both when discussing their own needs (i.e., impact of caring, concerns about completing care tasks) and also facilitating communication about the care recipient when necessary. The lead researcher reviewed the tools and selected those deemed most appropriate for adaptation in a carer/doctor scenario. The selected tools were then presented to the PPI panel of carers before being included in the workshop content, as outlined in Figure 6.1.

6.2.1.3 CUS

The CUS communication tool facilitates communication and supports assertiveness using language such as, “I am Concerned, I am Uncomfortable, and This is a Safety Issue”. Often known as CUS words, this tool is primarily used in professional healthcare settings such as hospitals and clinics (for example, The American Hospital Association (AHA) makes the tool available to medical staff on their website). The CUS tool is designed to support the individual to feel empowered to speak assertively about their concerns without causing conflict or challenge to authority.

The tool is intended to be used as an escalation, i.e. if stating their *concern* is not effective, the carer moves on expressing how they are *uncomfortable* and finally refer to *safety* (Figure 6.2). A fourth escalation (Stop) is sometimes included in certain hospital settings, such as operating theatres (Doyen et al., 2018). A further strength of the CUS tool for use by family carers is its use of “I” language, which has been shown to be important in healthcare settings to support doctor and patient communication (Rosen, 2014).

Figure 6.2

CUS Communication Tool

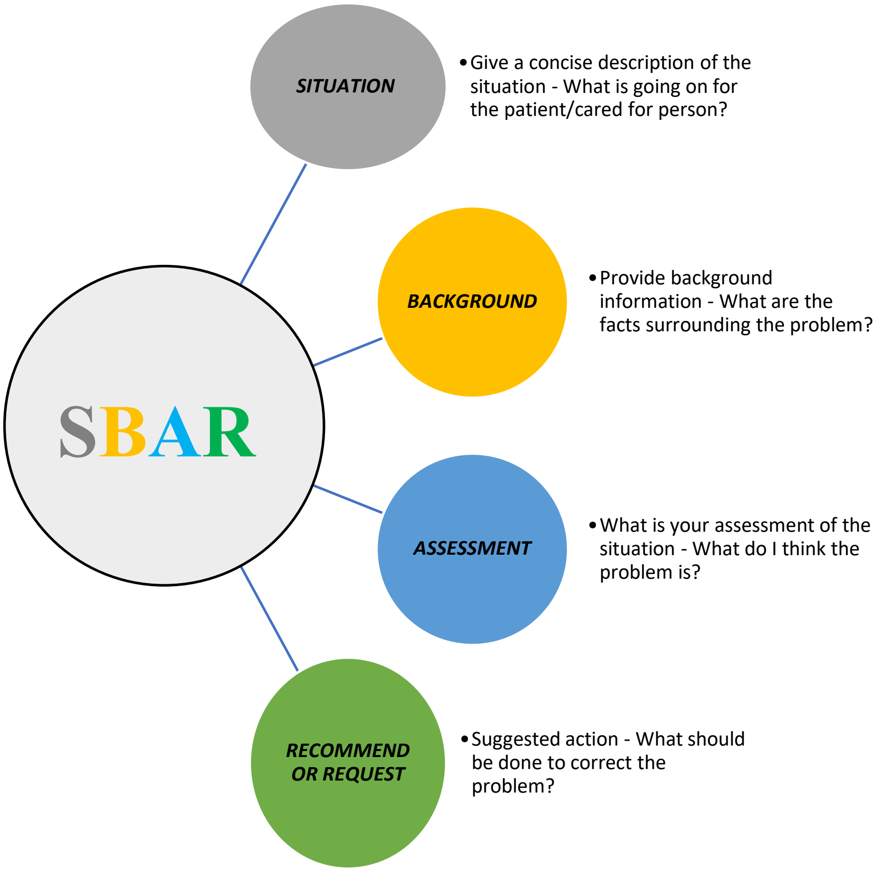
Source: American Hospital Association (aha.org)

6.2.1.4 SBAR

The SBAR communication tool is also used for communicating vital information in an easily understood and clear manner and includes language that: describes the **S**ituation, includes important **B**ackground, gives an **A**ssessment, and concludes with a **R**ecommendation or request (Figure 6.3). SBAR is a widely used communication tool in healthcare settings and has been shown to be particularly useful when 'bridging the gap' between the different communication styles of nurses and doctors (Leonard et al., 2004). Improvements in communication between healthcare professional teams in nursing home and hospital settings using the SBAR tools have been reported (Bai et al., 2020; Renz et al., 2013). The tool is designed to give a structured comprehensive account of the concern (Figure 6.3), thereby encouraging critical thinking of the issue before communication (Leonard et al., 2004). It was included primarily to assist carers with conversations about the care recipient, though it can also be used to discuss challenges/concerns related to the impact of caring regarding the carers own health and well-being.

Figure 6.3

SBAR communication tool



6.2.2. Embedding of PPI contribution

As previously mentioned, the workshop was co-designed with a panel of carers. The PPI contribution was incorporated into both the design and delivery of the carer workshop. Specific details on how these contributions were embedded in the final workshop design and delivery are presented in Table 6.2

As previously mentioned in Chapter Two, the panel took part in an induction process to fully brief them on the initial design and the relevant findings from studies One and Two.

The PPI panel reviewed the full content of the workshop. The contribution from the PPI panel influenced the design and delivery of the workshop; for example, the panel came up with the workshop title, and the proposed delivery time was extended from 1 ½ hours to 2 hours to allow for adequate peer interaction as well as practise of the communication tools. The PPI panel added value to the overall design through their practical contributions, such as, for example, the inclusion of handouts to support preparing for a visit to the doctor. The panel felt very strongly that the peer support aspect of this type of workshop was crucial, and this worked well with the theoretical framework of Self-Efficacy (See Chapter One and Chapter Two).

Overall, the PPI panel felt that this workshop addressed a very important need for family carers and strongly recommended that it be rolled out to interested family carers.

Table 6.2

Embedding of PPI panel contribution – Carer Workshop

Workshop topic	**PPI panel comments**	**How was this input embedded in resources?**
Carer Identity	1) The panel agreed that carers do not always self-identify, particularly in a GP setting. They highlighted the (often) progressive nature of the role. 2) The group work in the 'Carer workshop' can be hugely beneficial, as the peer interaction can support carers to acknowledge the role and seek help.	The workshop content included the progressive nature of the caring role. The workshop was extended to a 2-hour session to allow adequate time for peer interaction, as well as the required role play.
Health risks and help-seeking	1) Carer health needs and advocating for the health needs of care recipient are both part of communication with GPs, therefore both need to be given equal consideration in the workshop. Carers see themselves and the person they care for as a 'unit'. 2) Carers may think they are the 'only ones' finding communication with doctors difficult as it is not often discussed.	An example of both carer health needs and care recipient needs are included in the communication tools examples in the workshop. A carer will be invited to co-facilitate and share their own experience of help seeking during the workshop.
Role of GP	1) When the GP is supportive, it is very reassuring for the carer.	The role of the GP and the potential power differential was discussed as part of the slide "Role of the GP".

Workshop topic	PPI panel comments	How was this input embedded in resources?
	2) Many carers are nervous/anxious regarding interactions with the GP; they are not familiar with being assertive in this scenario. 3) Carers are not always sure if it is ok to challenge the GP, and there might be an underlying concern about upsetting the GP because the care recipient is reliant on the GP care.	Communication tools provided relevant examples to support assertiveness. Use of 'I' language is included in both communication tools. The benefits of cultivating a good rapport with the GP are included in the workshop.
Preparing for doctors visit	1) Medical appointments can be stressful, and carers may forget what they need to ask, thus, preparation and handouts were thought to be very useful. 2) Handout regarding preparation for doctor visit needs to include practical issues such as timing, parking etc., in order to reduce carer stress before arriving at appointment 3) Organising replacement care should be referred to as 'care cover.	1) & 2) The handout 'preparing for the doctor visit' was revised to include both questions and notes to allow for practical planning for the appointment. Point 3) The wording was changed in the slides and handouts to reflect this.
Communication skills tools	1) Carers might like to hear some examples of the experiences of other carers in communicating with their doctor. 2) The panel felt different examples for each communication tool are needed to include the diversity of caring. 3) Carers are often in a crisis when having difficult conversations with the doctor; therefore, the opportunity to practise the tools in the workshop setting was thought to be hugely beneficial.	A carer (PPI panel member) will be invited to co-facilitate at the workshop and share their own experiences, provide encouragement and encourage discussion. 2&3) Different scenarios were used for each communication tool. Examples were also included in the handout.

Workshop topic	PPI panel comments	How was this input embedded in resources?
	4) Look at language as well, and perhaps even provide phrases.	Time will be allocated for adequate role play of communication tools – including feedback. 'I' language is included in content, and phrases are included through the CUS communication tool.

6.2.3 Workshop delivery

The workshop was delivered online via Zoom and co-facilitated by a carer from the PPI panel who had volunteered to take part. The two-hour workshop used the ‘break-out’ room feature in order to facilitate role-play activities. A member of FCI (collaborating partner) was also present to answer any questions regarding the services of FCI. During the workshop, the lead researcher discussed the six topics presented in Figure 6.1, while the co-facilitating carer gave examples from her own lived experience to support the introduction of the communication tools. The contribution of lived experience from the co-facilitating carer was a valuable aspect of the workshop delivery. It provided an example of a challenging conversation with a GP and encouraged robust discussion around this particular topic and how the communication tools can support such conversations. In line with the theoretical framework of self-efficacy, the communication tools were demonstrated (with an example), the carers were given the opportunity to role-play (in pairs) a real or hypothetical example and provide feedback to one another. Following role-play, the carers were encouraged to discuss the process in the larger group setting.

6.3. Pilot testing

6.3.1. Participants and settings

The workshop was piloted online with a number of carers (*n* = 7) in March 2022. The diverse group of family carers was recruited through our charity partner, FCI. Recruitment was enabled by a workshop poster (Appendix A3.4) that was circulated online through the FCI social media outlets. Participating carers were issued with an information sheet and informed consent (Appendix A3.5).

6.3.2. Measures

Pre and post-workshop questionnaires (Appendix A3.6) were devised based on Self Efficacy Theory (See Chapter One and Two). Questionnaires asked for demographic information, for example, how long the carer had been providing care and to whom, as well as a number of statements using Likert scales to assess the relevant constructs. The pre-workshop questionnaire was administered via email through a link to the online questionnaire several days prior to the workshops. The post-workshop questionnaire was administered via a link provided at the end of the online workshop and also via email.

6.3.3. Analysis

Data management and analysis was conducted using SPSS version 25. Descriptive statistics were used to analyse responses for each participant pre-workshop and post-workshop, as appropriate. Due to the small sample size, conducting inferential statistics was not appropriate.

6.3.4. Findings

All participants were female, with the majority aged between 55 and 64. The participants had been caring for several years, with the least amount of time caring being 2 years and the highest number of years caring was 35 years. Table 6.3 shows the demographic characteristics of the sample, including the reasons they provided care.

Table 6.3

Demographic characteristics of the sample (n=7)

Reason for providing care	Age Range	Years Caring
No other care provision available	55-64	19 years
Dementia	55-64	3 years
Old age	55-64	2 years
Stroke and Dementia	45-54	6 years
Stroke and Huntingtons's Disease	65-74	14 years
Child with additional needs	65-74	35 years
Frail elderly and parkinsons	45-54	3 years

Overall, the carers who participated in the workshop experienced an increase in confidence scores in all items (see Table 6.4). The ability to be assertive with the doctor about care tasks the carers found difficult showed the highest increase, followed by getting the GP to answer questions, discussing own health needs and preparing for doctor visit.

Workshop satisfaction was high overall, with six of the seven strongly agreeing that the workshop was useful to them. They stated they intended to use the handout provided and that they would recommend the workshop to other carers.

Table 6.4

Descriptive statistics of small-scale evaluation data

Item	Pre-workshop Mean (SD)	Post Workshop Mean (SD)
Make the most of your visit to the GP	2.71 (.75)	3.43 (.53)
Prepare for your visit to the GP	2.34 (.97)	3.71 (.48)
Discuss the impact of your caring role with GP	2.00 (1.0)	3.14 (.69)
Communicate with your GP about concerns for person you care for	2.43 (.97)	3.29 (.75)
Get the GP to answer all of your questions	1.57 (.78)	3.14 (.69)
Be assertive regarding care tasks you are finding difficult	1.29 (.49)	3.29 (.75)
Discuss your own health needs with GP	2.00 (.57)	3.43 (.78)

Six of the participants gave further feedback through the open-ended question at the end of the questionnaire. These responses showed an overall positive reaction to the workshop and its delivery; though one carer felt it was more weighted toward those caring for elderly parents. Full responses are provided in Table 6.5.

Table 6.5

Responses to open-ended questions, Communicating with Doctors -Empowerment workshop for family carers

Really hope this will be rolled out to all carers/differently abled patients. Excellent focused, useful training. Many thanks.
A very useful workshop, especially talking to other carers in our varied family situations.
Maybe shorter and more concise, but overall really good. `THANK YOU
I found the workshop and the resources and handouts very clear, informative and useful. Many thanks to the excellent presenters.
More aimed at people who are caring for an elderly parent as opposed to a child with special needs

Very well run and presented. The facilitators made interaction very comfortable

6.4 Conclusion

This chapter has outlined the process involved in the development of a workshop and accompanying materials for family carers, including the significant contribution of PPI. The pilot testing of ‘Communication with Doctors – Empowerment workshop for family carers’, has provided some evidence for its effectiveness in increasing carers’ confidence in communication with their GP. These findings are discussed further in the next chapter (Chapter Seven). The facilitator guide for the workshop is presented next.

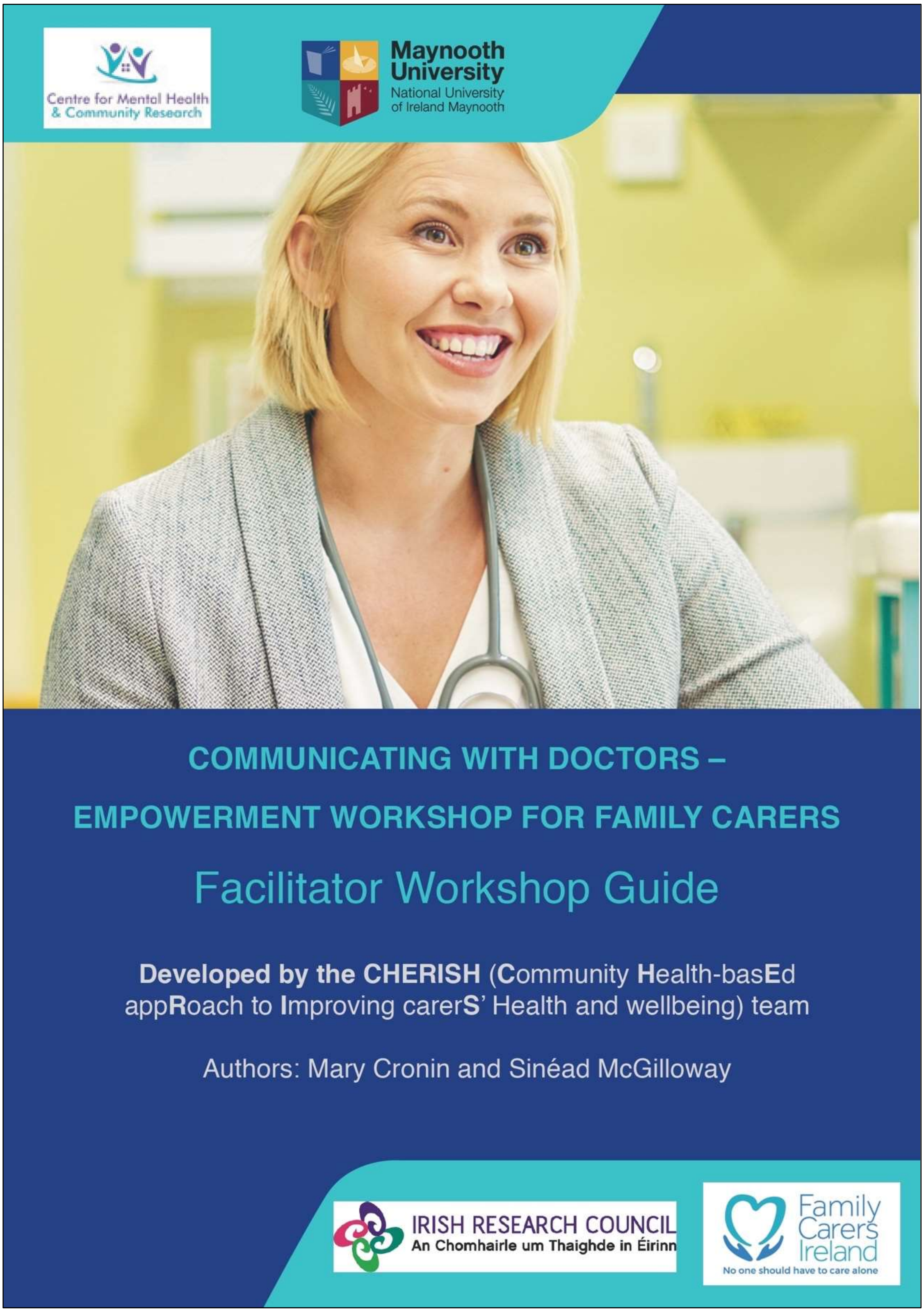
6.5 Communicating with Doctors: Empowerment Workshop for Family Carers – Facilitator Guide

This section presents the facilitator guide that will be made available to FCI for delivery of the workshop nationally.

Suggested citation:

Cronin, M[1]., McGilloway, S[1]. (2022) Communicating with doctors – empowerment workshop for family carers. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

[1]Centre for Mental Health and Community Research, Department of Psychology and Social Sciences Institute, Maynooth University



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COMMUNICATING WITH DOCTORS –
EMPOWERMENT WORKSHOP FOR FAMILY CARERS

Facilitator Workshop Guide

Developed by the CHERISH (**C**ommunity **H**ealth-bas**E**d app**R**oach to **I**mproving carer**S**' Health and wellbeing) team

Authors: Mary Cronin and Sinéad McGilloway

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Family
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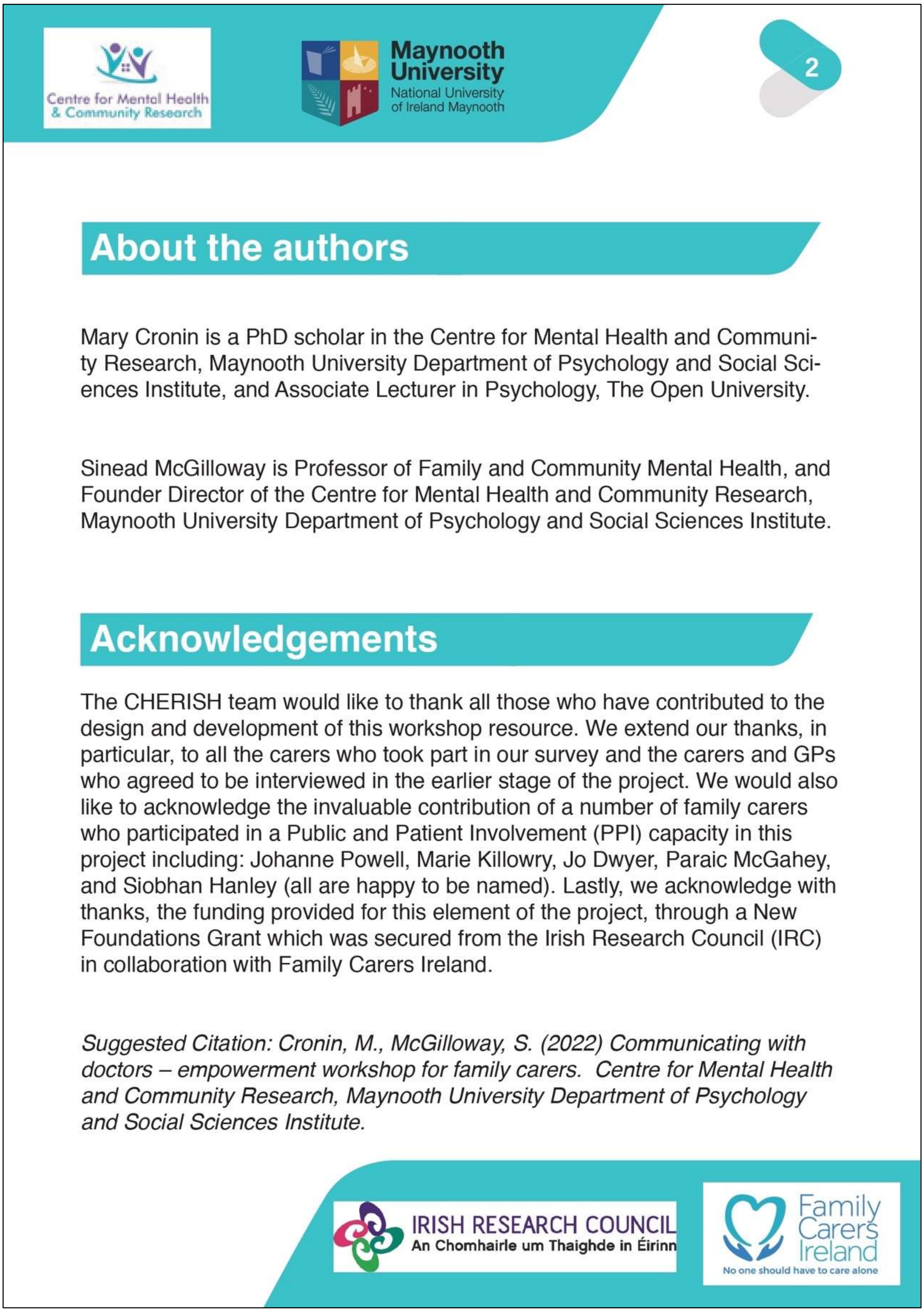
Ireland
No one should have to care alone



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Suggested Citation: Cronin, M., McGilloway, S. (2022) Communicating with doctors – empowerment workshop for family carers. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

Background

Ireland has over half a million family carers who care for some of our most vulnerable citizens. Evidence suggests that, although caring is often very rewarding, the health and well-being of family carers across the world is considerably poorer than that of the general population. Despite this, many carers report that they find it hard to ask for help and often view their own health and wellbeing needs as secondary to the person for whom they provide care. Indeed, many of those providing care do not identify with the term ‘carer’ per se, which can, in turn, impact on the extent to which they seek support for their own health and well-being.

General Practitioners (GPs) can play an important role in supporting family carers in the community and indeed, carers see their GP more than any other healthcare professional. However, evidence suggests that GPs are unclear regarding their role vis-a-vis family carers, and do not feel they have the resources and information necessary to signpost them to appropriate supports. Carers also report ambiguity about the part the GP can play, and they often find communication with doctors (including GPs) challenging.

Some of the above issues were addressed by a research project called ‘CHERISH’, led by the Centre for Mental Health and Community Research, Maynooth University (https://cmhcr.eu).

This project aimed to address knowledge gaps concerning the health and wellbeing of family carers in Ireland, with a specific focus on how they can be better supported by community health professionals, such as GPs. The CHERISH team sought input from stakeholders by surveying carers across Ireland and interviewing both carers and GPs. A scoping review of international literature was also conducted to synthesise the international evidence on guidance and recommendations for GPs.

In addition, a core element of the CHERISH project has involved the development of a workshop for family carers to empower them in their conversations with doctors. This workshop has been developed from the findings of the CHERISH project and draws on theories of adult learning and self- efficacy (i.e. an individual’s belief in their ability to competently complete a task). The workshop was co-designed with a panel of carers in a public and patient involvement (PPI) capacity, and developed in collaboration with Family Carers Ireland. This element of the CHERISH project was funded by a New Foundations grant from the Irish Research Council (IRC).

The CHERISH project team have also developed practice guidelines for GPs and an accompanying workshop to support GPs in their role with family carers.

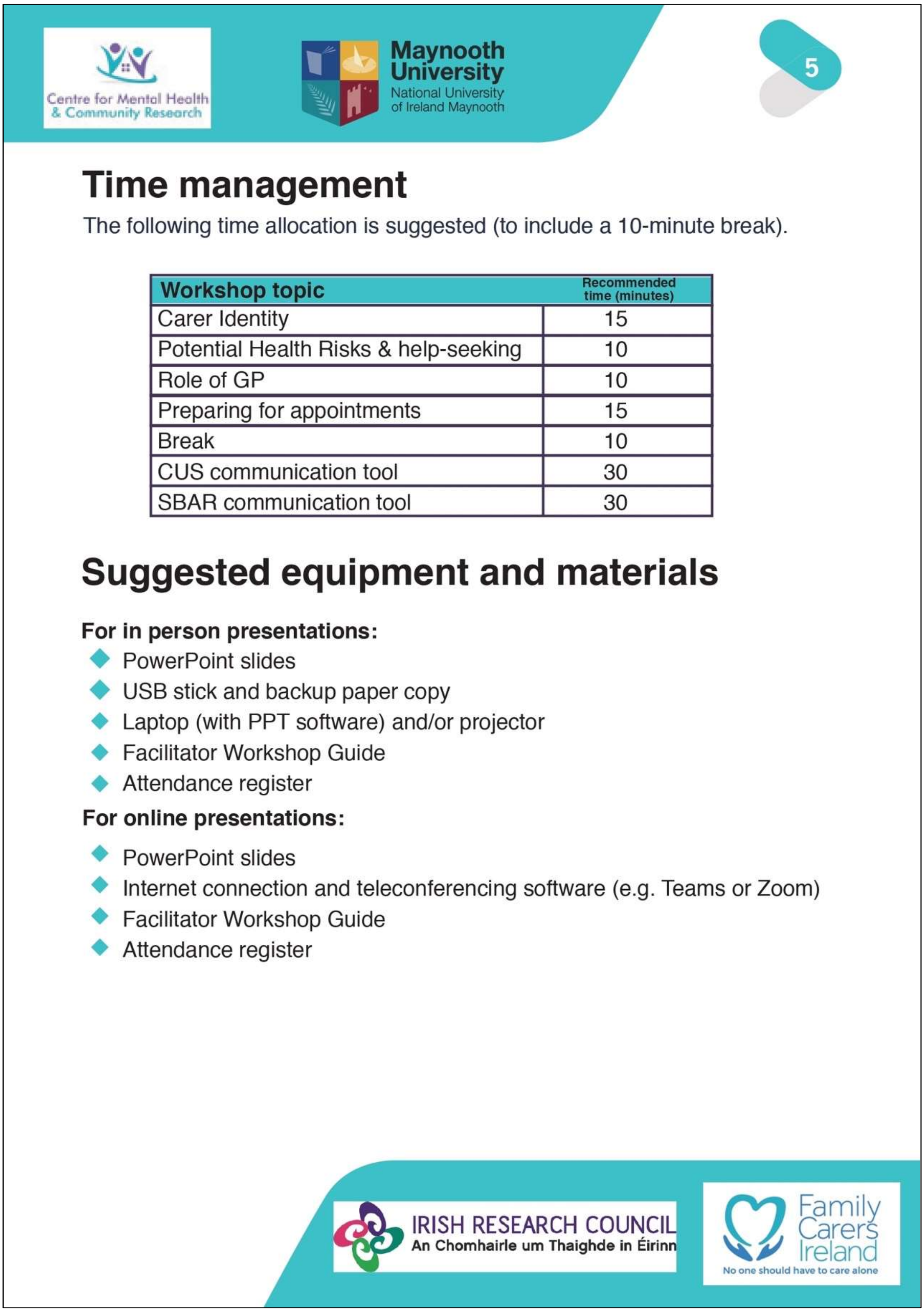
About this guide

This guide is designed to assist facilitators to deliver the workshop to family carers and comprises the workshop materials, including PowerPoint presentation slides and associated advisory notes.

The workshop aims to explore carer identity, health risks for family carers, the role of the GP and preparing for a doctor's visit, while also introducing two communication tools that have been adapted from other healthcare settings. Accompanying handouts are included for carers to use to help them prepare for a visit to their doctor and to support the use of the included communication tools.

The guide is designed to be used as part of a two-hour workshop that incorporates peer interaction and role play. The core principles of self-efficacy suggest that enhancement relies on a discrepancy between current and desired behaviours, modelling and rehearsal of the desired communication behaviour and the provision of constructive, positive feedback[1]. Therefore, carers need to be given ample time to 'practise' the communication skills introduced in the workshop and participate in a group discussion afterwards.

It is recommended that at least one hour be allocated to demonstrating and role-playing communication tools. The principles of adult learning suggest that learning is enhanced when the content is relevant, interactive and the existing experience of the learner is acknowledged and used as a resource within the workshop. Therefore, the facilitator is encouraged to foster group discussion about carers' lived experiences regarding communication with GPs and other healthcare professionals. Materials can be used in on-site or on-line delivery to groups of carers. The pilot workshop was co-facilitated by a carer and this can add value by encouraging honest and open conversations about lived experience.



Time management

The following time allocation is suggested (to include a 10-minute break).

Workshop topic	Recommended time (minutes)
Carer Identity	15
Potential Health Risks & help-seeking	10
Role of GP	10
Preparing for appointments	15
Break	10
CUS communication tool	30
SBAR communication tool	30

Suggested equipment and materials

For in person presentations:

- PowerPoint slides
- USB stick and backup paper copy
- Laptop (with PPT software) and/or projector
- Facilitator Workshop Guide
- Attendance register

For online presentations:

- PowerPoint slides
- Internet connection and teleconferencing software (e.g. Teams or Zoom)
- Facilitator Workshop Guide
- Attendance register

THE CHERISH PROJECT

Community Health-basEd appRoach to
Improving carerS Health and wellbeing)

Centre for Mental Health and Community Research, Maynooth University/Family Carers Ireland

https://cmhcr.eu

Centre for Mental Health and Community Research, Maynooth University/Family Carers Ireland

Slide 1:
Introductions and thanks to attendees for coming along.

Background:

Highlight the increasing prevalence of caring and introduce the fact that there may be potential health and well-being consequences for carers.

The CHERISH project to date has comprised: (1) a national survey of family carers and in- depth interviews with family carers and GPs; (2) a scoping review of the international literature to inform the development of practice point guidelines for GPs; and (3) development and evaluation of training and resources for GPs and carers.

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Empowerment workshop

Two purposes (1) Carers own health and wellbeing, (2) dealing with doctors on behalf of the person you are caring for

- **Focus on peer interaction and opportunity to 'practice' the communication skills covered**
- **To increase confidence in discussing the impact of caring on own health and wellbeing**
- **To encourage proactive approach to own health and wellbeing**
- **To increase confidence in discussing concerns about care recipient**
- **To support carers towards assertiveness in conversations regarding care tasks that may further increase the impact of their caring role**

Family Carers Ireland
No one should have to care alone

Centre for Mental Health and Community Research, Maynooth University/Family Carers Ireland

Maynooth University

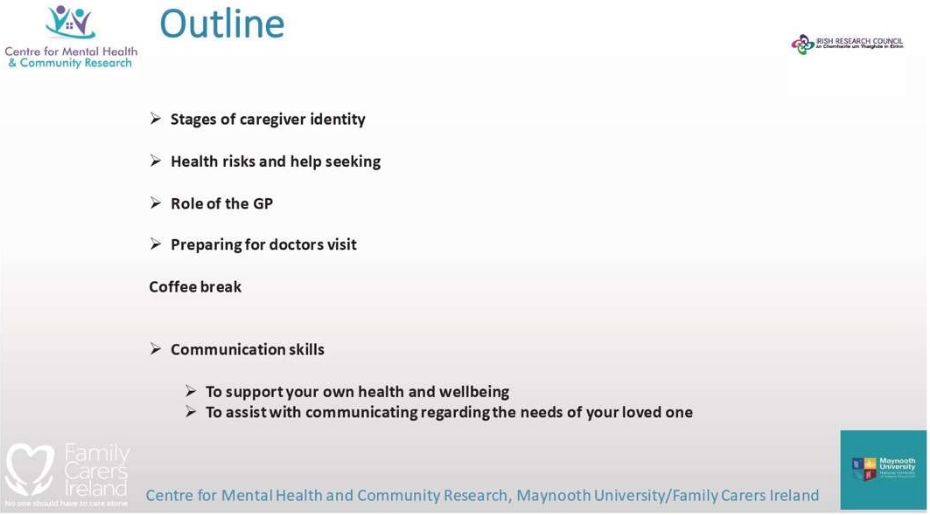
Slide 2:
Introduce today's workshop including the key aims and format.

This empowerment workshop provides tools to assist carers:

- In conversations with doctors about their own health
- In conversations with doctors about the well-being of the person for whom they provide care.

The workshop is designed to be interactive throughout, with lots of opportunities for examples and role play.

Early findings of the CHERISH project suggest that carers can often be asked to complete tasks with which they are uncomfortable or in which they have received no training[2]. This workshop aims to address this by looking at assertive communication when discussing these issues with the doctor.



Outline

- Stages of caregiver identity
- Health risks and help seeking
- Role of the GP
- Preparing for doctors visit

Coffee break

- Communication skills
  - To support your own health and wellbeing
  - To assist with communicating regarding the needs of your loved one

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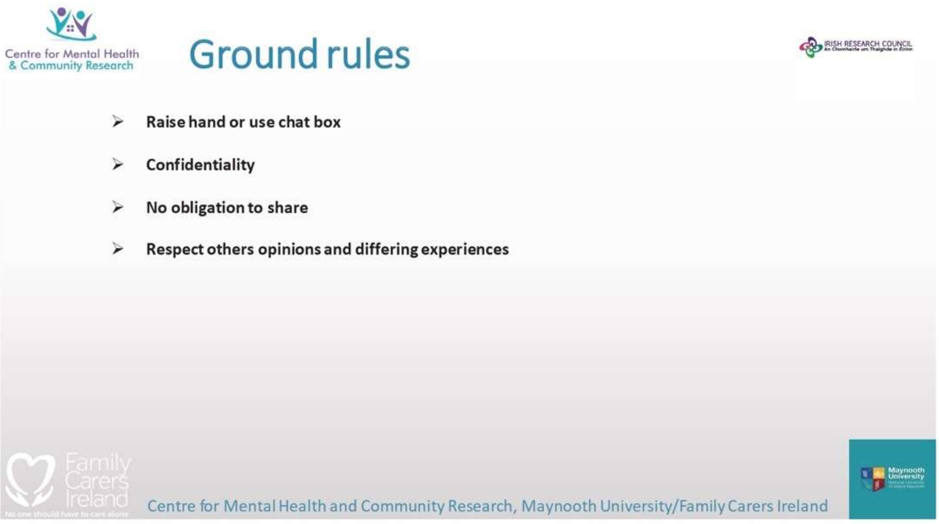
Slide 3:

Workshop Outline:

- The workshop will look firstly at the stages of carer identity to highlight how the role evolves. A carer may not recognise themselves as a carer until the later stages (or time of crisis). Carers are typically more comfortable with the identity associated with their relationship to the person for whom they are providing care (e.g. mother, father, son, daughter, etc.).[3]
- Health risks for carers and typical help-seeking patterns will be explored.
- We will also discuss the role of the GP and look at the typical doctor/patient relationship.
- We will examine ways to prepare for a visit to the doctor, from practical arrangements to the content of the conversation.
- Communication tools (adapted from other healthcare settings)[4] will be introduced to support the conversation between doctors and carers.



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Ground rules

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- Raise hand or use chat box
- Confidentiality
- No obligation to share
- Respect others opinions and differing experiences

Family Carers Ireland
No one should have to care alone

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Slide 4

Background:

Introduce ground rules and invite the group to comment and add what they feel is important. This is important to create a safe space for carers as some may share difficult information regarding their caring role, or may wish to share an emotional example regarding help-seeking or communicating with health-care professionals.

Key points:

- All participants need to respect confidentiality of others (and the person for whom they provide care).
- Stress no obligation to share – hypothetical examples can be used in place of personal experience.
- There is no generic caring role; each person will have a very different experience and therefore may have differing opinions (although there may also be many commonalities).

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Stages of Carer Identity

Family Carers Ireland

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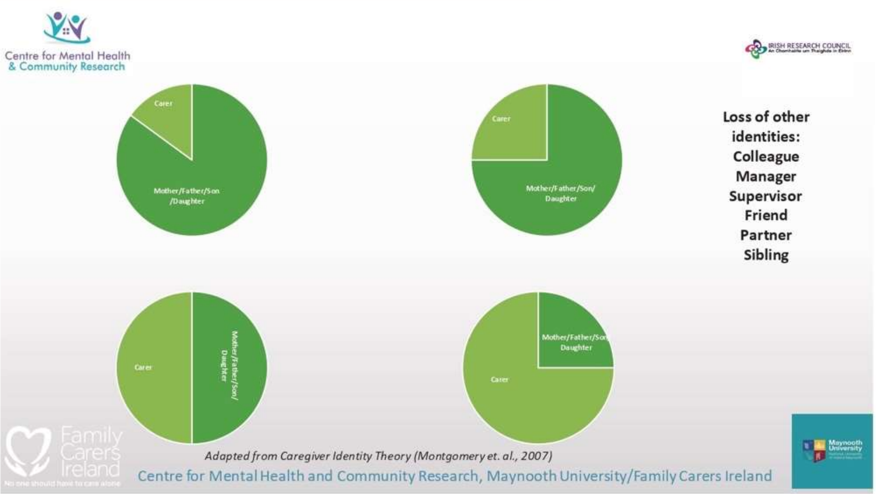
Slide 5

Background:

The following discussion on carer identity has been informed by research with those caring for their spouse, and highlights the often evolving and progressive nature of the role.[5]

Key points:

- Slide 6 (next) explores how the caring role emerges and sets the scene for discussing the possible health risks later on slide 7.



Loss of other identities:
Colleague
Manager
Supervisor
Friend
Partner
Sibling

Adapted from Caregiver Identity Theory (Montgomery et. al., 2007)

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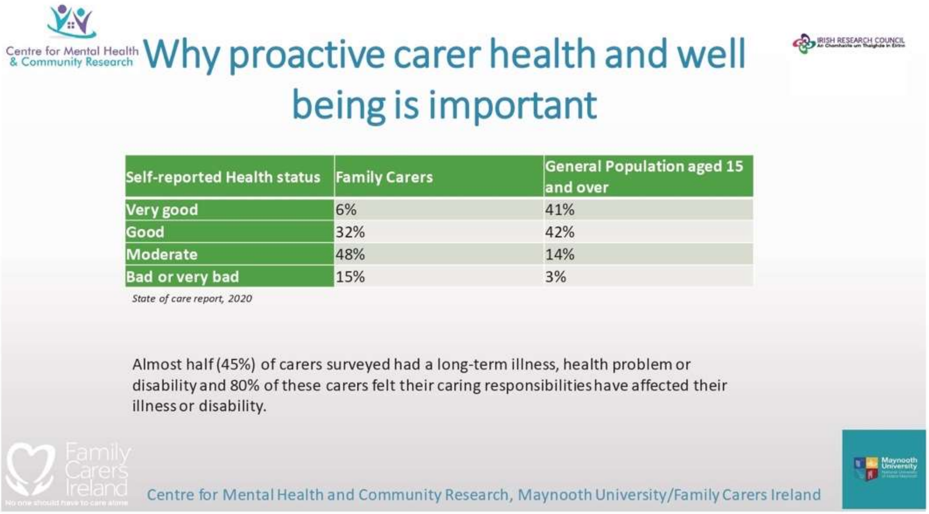
Slide 6

Background:

This slide draws attention to how the caring role evolves over time and the extent to which a carer can feel a sense of being engulfed by the role. It is also important to understand how self-identifying as a carer can take some time and often does not happen until a time of crisis, or until the role is taking up a very significant part of the carer's identity.

Key points:

- For many, the caring role emerges over time.
- At the time the care recipient is diagnosed with an illness or disability, there may be small changes to the relationship and the carer will begin to provide support. Over time, particularly if the care recipient has a progressive condition, the role may gradually require more and more time and space in the carer's life, often up to a point where other identities have been lost or become secondary.
- It is important to note that in some instances, such as an accident, stroke, or the birth of a child with additional needs the caring role can begin overnight, but is often still progressive which means that the carer identity can take time to emerge[6].



Why proactive carer health and well being is important

Self-reported Health status	Family Carers	General Population aged 15 and over
Very good	6%	41%
Good	32%	42%
Moderate	48%	14%
Bad or very bad	15%	3%

State of care report, 2020

Almost half (45%) of carers surveyed had a long-term illness, health problem or disability and 80% of these carers felt their caring responsibilities have affected their illness or disability.

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Slide 7

Background:

Many carers find their carer role rewarding and get a real sense of purpose from caring for their loved ones. Although many carers report satisfaction in the caring role due to their relationship with the care recipient, it is not without its challenges and carers are often not aware of how it may impact their own health and well-being. This slide draws attention to some of the research on carer health and sets the scene for the specific health risks covered in the next slide[7].

Key points:

- Although many carers feel a sense of purpose and personal reward in caring for their loved one, they need to be mindful of potential risks to their own health.
- Carers report lower overall health status compared to the general population.
- This slide presents the results of a Family Carers Ireland ‘state of care’ survey conducted in 2022 . The findings demonstrate how the self-reported health status of carers can differ from that of the general population.
- Early findings of the CHERISH project (based on a survey of 132 carers) found that 61% reported psychological distress[2]. Consider asking attendees for their views on this.

Specific health risks for carers’

Family carers can be at higher risk for a number of health related challenges

- **Psychological distress symptoms, such as anxiety and depression**
- **Neglect of their own health due to a focus on care recipient or difficulty getting to appointments**
- **Back injury, back pain, shoulder injury**
- **High blood pressure**
- **Higher risk of stroke**
- **Increased mortality in older carers**
- **Insomnia and Sleep problems**

Slide 8

Background:

Research evidence internationally suggests that there are many health risks associated with caring. This slide introduces both the psychological and physical risks and creates a platform to discuss help-seeking – covered in the following slides.

Key points:

There are many documented health risks associated with caring.

Psychological distress symptoms such as anxiety and depression can occur

- The demands of the caring role[8]
- The emotional impact of the changing relationship (with the care recipient)[5]
- The loss of own identity (isolation) [5]
- Lack of support [2]

Physical impacts of caring include:

- Back[9] or shoulder injury or pain [10]
- High blood pressure[9]
- Higher risk of stroke[11]
- Increased mortality in older carers[11]
- Insomnia[12] and sleep problems[13]

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Typical help seeking behaviours of carers

Family Carers Ireland

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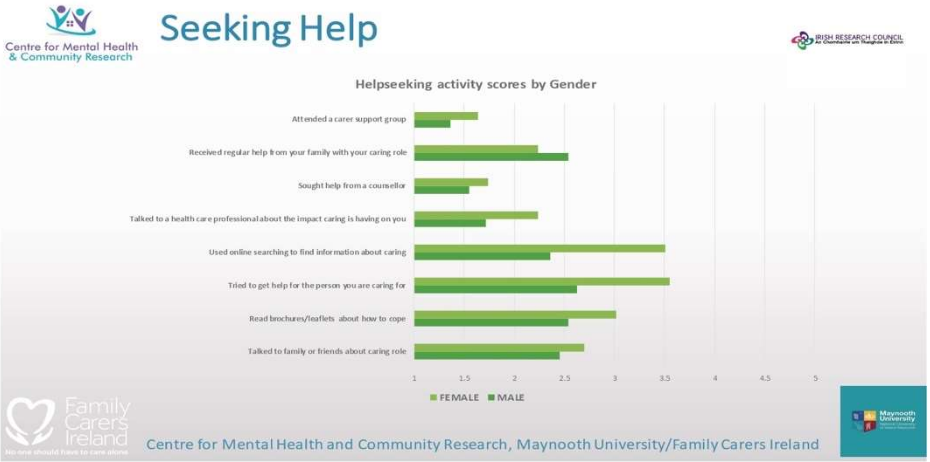
Slide 9

Background:

Previous slides looked at carer identity and health risks; the following slides focus on help- seeking by again drawing on evidence from the CHERISH project.

Key points:

Slides 10 & 11 provide data from a CHERISH survey of carers and includes some responses to open-ended questions, thereby allowing for the carer's voice in describing the experience of asking for help for themselves.



Seeking Help

Helpseeking activity scores by Gender

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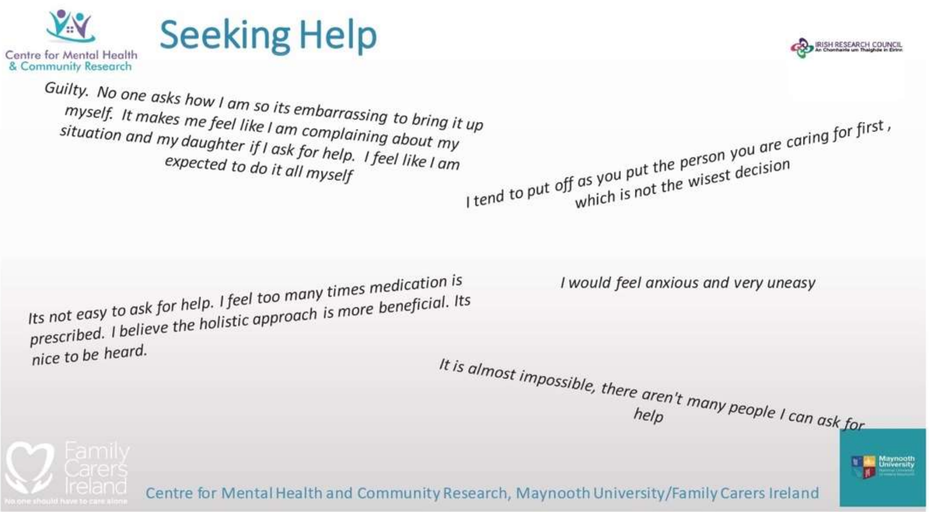
Slide 10

Background:

Despite the potential risks to carers' health and well-being, they are often slow to ask for help. Asking for help can be difficult and they often see their own needs as secondary to the care recipient.

Key points:

- Findings from the CHERISH project[2] showed engagement with help-seeking activities was generally low, but females reported significantly more engagement with help-seeking than males.
- The use of online searching to obtain information about caring and trying to get help for the person for whom they provide care, were the most common help-seeking activities.
- Attending support groups, counselling, or talking to a healthcare professional about the impact of caring, were the least reported activities.



Seeking Help

Guilty. No one asks how I am so its embarrassing to bring it up myself. It makes me feel like I am complaining about my situation and my daughter if I ask for help. I feel like I am expected to do it all myself

I tend to put off as you put the person you are caring for first , which is not the wisest decision

Its not easy to ask for help. I feel too many times medication is prescribed. I believe the holistic approach is more beneficial. Its nice to be heard.

I would feel anxious and very uneasy

It is almost impossible, there aren't many people I can ask for help

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Slide 11

Background:

This slide presents some of the answers to the question 'How does it feel to ask for help for yourself?' from the CHERISH carer survey[6]. These responses to the open-ended questions provide some interesting examples of the reasons why carers found it difficult to ask for help.

Key points:

- A sense of guilt – feel it is complaining about a loved one.
- Feeling that medication may be the suggested pathway.
- Putting the carer's needs second.
- Asking for help may make carers uneasy and anxious.
- Uncertainty about who they can ask.
- Participants may wish to discuss their own experiences in this regard.

Obstacles to conversations with GP about own health and wellbeing

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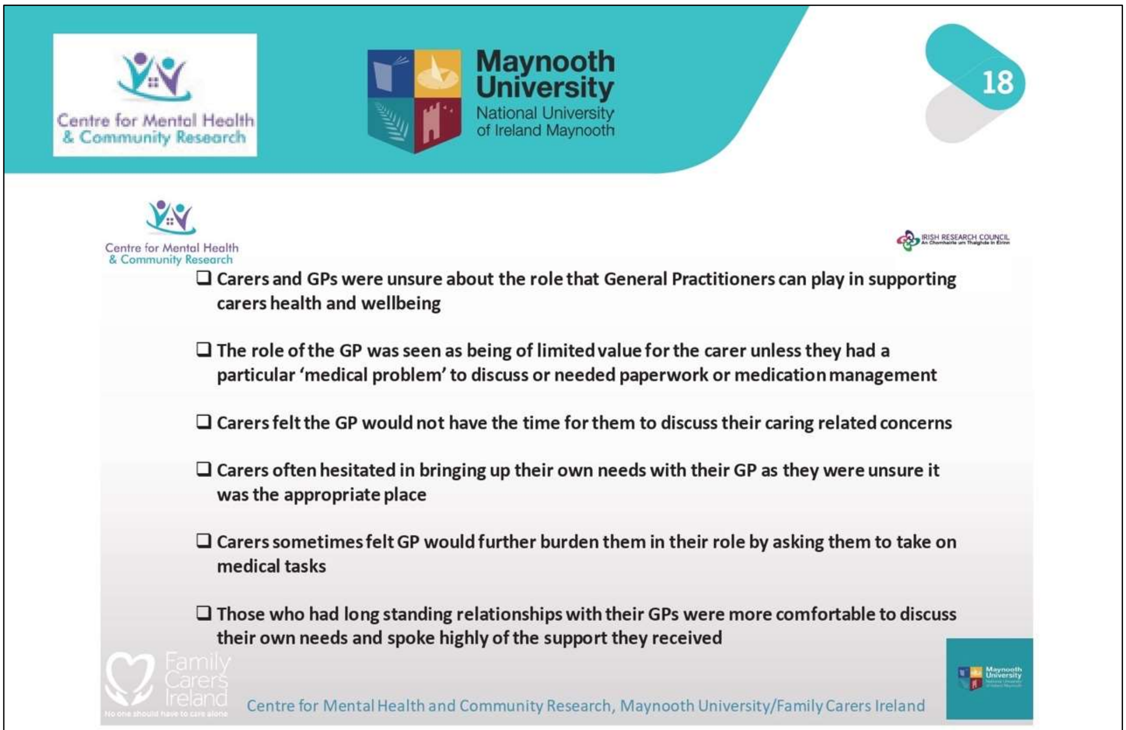
Slide 12

Background:

GPs are the healthcare professional whom carers encounter most often and are central to community healthcare. However, many carers do not discuss their own health needs with their GP while GPs often do not ask the carer about the impact the role may have on their own health.

Key points:

Slide 13 looks at some of the obstacles that carers and GPs have highlighted in the CHERISH research survey and interviews[6].
Slide 14 examines the role of the GP.



18

☐ Carers and GPs were unsure about the role that General Practitioners can play in supporting carers health and wellbeing

☐ The role of the GP was seen as being of limited value for the carer unless they had a particular 'medical problem' to discuss or needed paperwork or medication management

☐ Carers felt the GP would not have the time for them to discuss their caring related concerns

☐ Carers often hesitated in bringing up their own needs with their GP as they were unsure it was the appropriate place

☐ Carers sometimes felt GP would further burden them in their role by asking them to take on medical tasks

☐ Those who had long standing relationships with their GPs were more comfortable to discuss their own needs and spoke highly of the support they received

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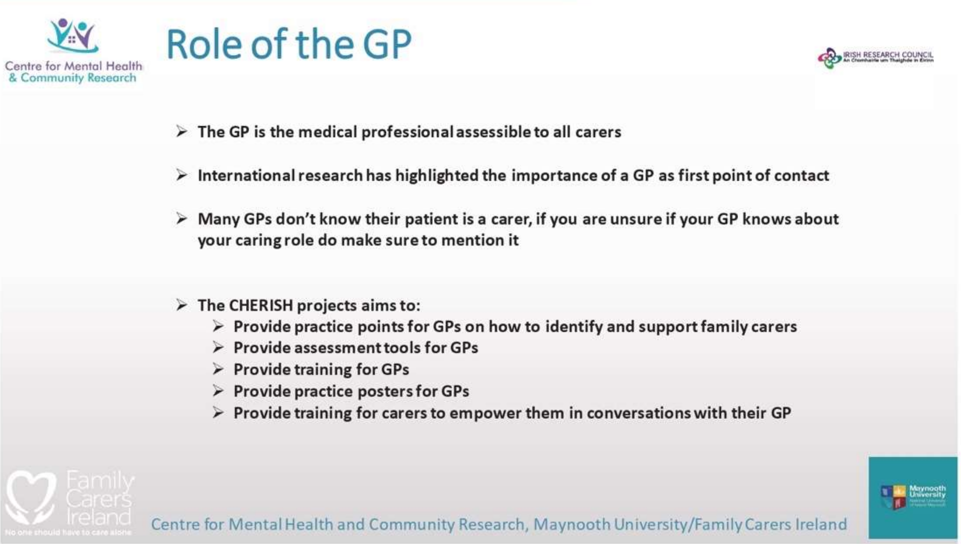
Slide 13

Background:

Although carers see the GP often, important conversations about health and psychological well-being are not generally taking place. The international literature suggests an important role for GPs, as is also suggested in Ireland's National Carer Strategy (2012).[14]

Key points:

- Both carers and GPs were unsure as to the role of the GP.
- GPs are sometimes seen as someone to talk to only in the case of specific medical need.
- Barriers exist with regard to time and also GPs often do not receive information from other professionals at, for example, the time of hospital discharge.
- Cares sometimes experience scenarios where they are expected to take on extra care tasks with which they were uncomfortable, but find it difficult to be assertive in this regard.
- If a good rapport is established, the relationship with the GP can be an important source of support.



Role of the GP

- The GP is the medical professional assessible to all carers
- International research has highlighted the importance of a GP as first point of contact
- Many GPs don't know their patient is a carer, if you are unsure if your GP knows about your caring role do make sure to mention it
- The CHERISH projects aims to:
  - Provide practice points for GPs on how to identify and support family carers
  - Provide assessment tools for GPs
  - Provide training for GPs
  - Provide practice posters for GPs
  - Provide training for carers to empower them in conversations with their GP

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Slide 14

Background:

GPs do not always know that someone is providing informal care, particularly if the cared-for person is not in the same GP practice. GPs play an important role in the community and may be able to help.

Key points:

- It is important to let your GP know about your caring role if you feel they may not know.
- A workshop has also been developed by the CHERISH team aimed at GPs and designed to support them in their role vis-à-vis carers.
- Family Carers Ireland and the CHERISH project team are committed to promoting better support for carers through general practice/primary care.

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Preparing for Doctors Visit

Family Carers Ireland
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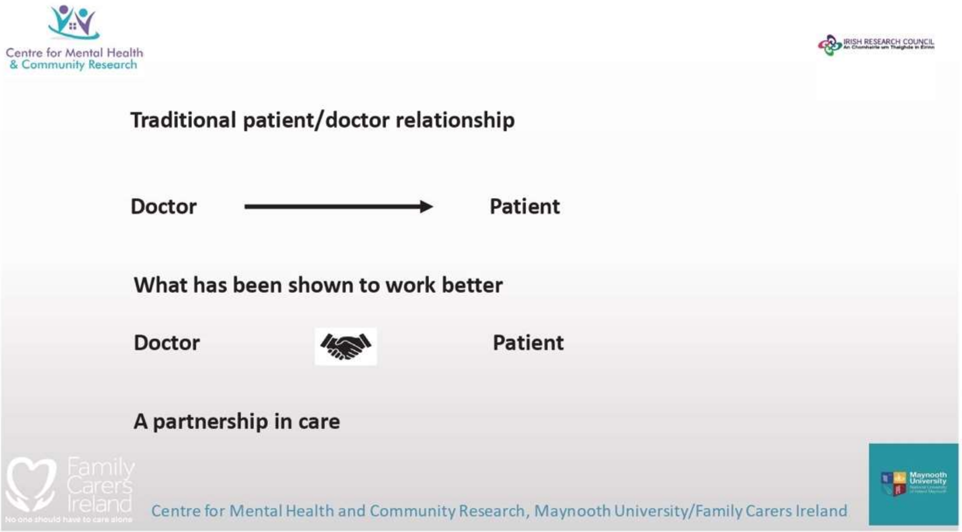
Slide 15

Background:

Communication with GPs is often complicated by traditional ideas of doctor-patient relationships, where the doctor is seen as directing the communication and there is a perceived hierarchy. What has been shown to work better, is the relationship being viewed as a partnership.

Key points:

- A supportive relationship with your GP is worth cultivating, and preparing for the visit and the use of communication tools, can be helpful.



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Traditional patient/doctor relationship

Doctor → **Patient**

What has been shown to work better

Doctor 🤝 **Patient**

A partnership in care

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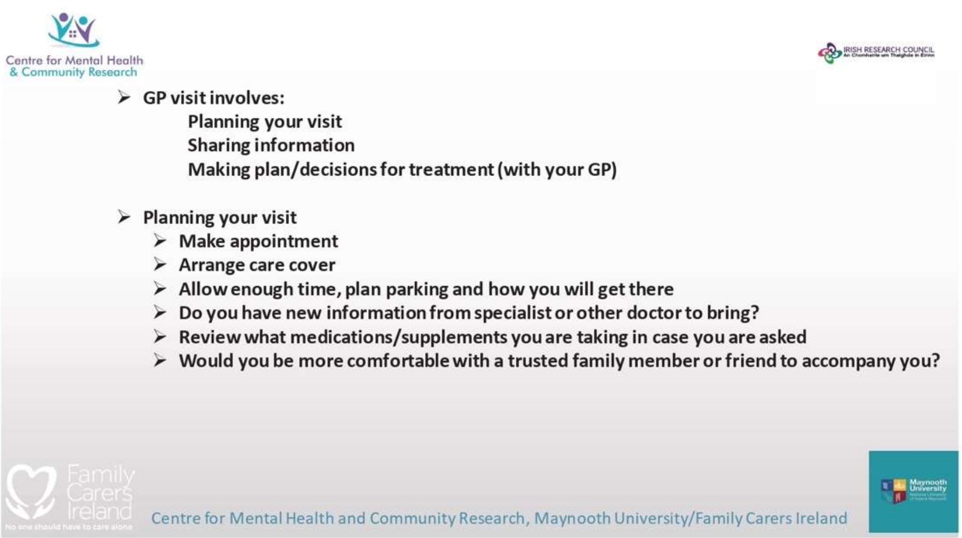
Slide 16

Background:

Time can be a challenge in doctor appointments and we may often leave without asking key questions or having all of our concerns addressed. Prior planning can help with this.

Key points:

- Slides 17, 18, and 19 will discuss preparing for a visit with the doctor.



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- GP visit involves:
    Planning your visit
    Sharing information
    Making plan/decisions for treatment (with your GP)

- Planning your visit
  - Make appointment
  - Arrange care cover
  - Allow enough time, plan parking and how you will get there
  - Do you have new information from specialist or other doctor to bring?
  - Review what medications/supplements you are taking in case you are asked
  - Would you be more comfortable with a trusted family member or friend to accompany you?

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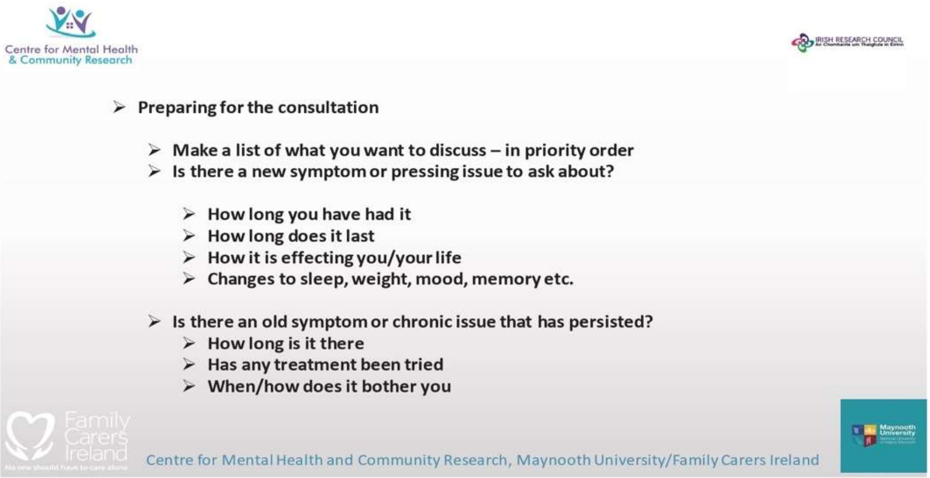
Slide 17

Background:

Planning the visit to the GP can reduce some of the stress and make sure you get the most from the visit.

Key points:

- Think in advance about practical things like travel time, parking, someone to care while you are attending an appointment, and whether there is information or medications you need to bring with you. Some people like to have a supportive friend or family member to accompany them, so think about this and ask them in advance.



- Preparing for the consultation
    - Make a list of what you want to discuss – in priority order
    - Is there a new symptom or pressing issue to ask about?
        - How long you have had it
        - How long does it last
        - How it is effecting you/your life
        - Changes to sleep, weight, mood, memory etc.
    - Is there an old symptom or chronic issue that has persisted?
        - How long is it there
        - Has any treatment been tried
        - When/how does it bother you

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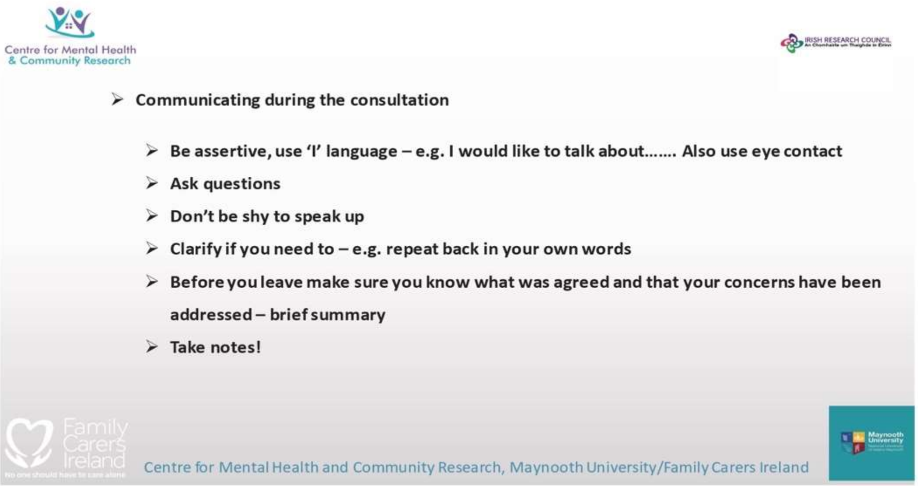
Slide 18

Background:

Once the practical details are covered, it is time to think about what you want to get from the appointment. It can be useful to break these down into new and old symptoms so that nothing is forgotten.

Key points:

- Prioritise what you would like to discuss and think about it in terms of the information that might be useful for the GP to know.



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- Communicating during the consultation
  - Be assertive, use ‘I’ language – e.g. I would like to talk about……. Also use eye contact
  - Ask questions
  - Don’t be shy to speak up
  - Clarify if you need to – e.g. repeat back in your own words
  - Before you leave make sure you know what was agreed and that your concerns have been addressed – brief summary
  - Take notes!

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Slide 19

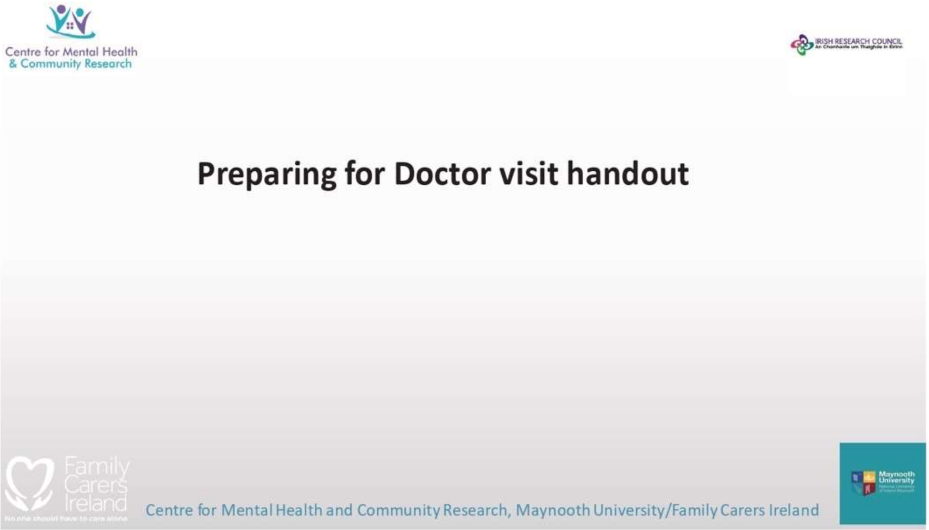
Background:

Communication style is important as well as preparation. Specific communication tools for healthcare settings will be introduced later in the workshop, but the tips below can also help with the communication process.

Key points:

- Using the word ‘I’ can help with assertiveness and eye contact can help to keep the doctor’s attention. [15]
- Don’t be shy to ask questions, this time is for you to get what you need from the consultation.
- If you don’t understand something it is best (and perfectly acceptable) to say so and ask for further explanation.
- Take notes to review later if needed.

*The handout ‘Preparing for the doctor visit’ is introduced next to support the points made here.



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Preparing for Doctor visit handout

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Slide 20

Background:

'Preparing for the doctor visit' handout is introduced and demonstrated. (See Appendix 1)

Key points:

- In a face-to-face setting, hard copies can be distributed with additional copies emailed to participants. The handout is to support preparation for the visit. The second page provides a template for making notes during the consultation.

Communication Skills

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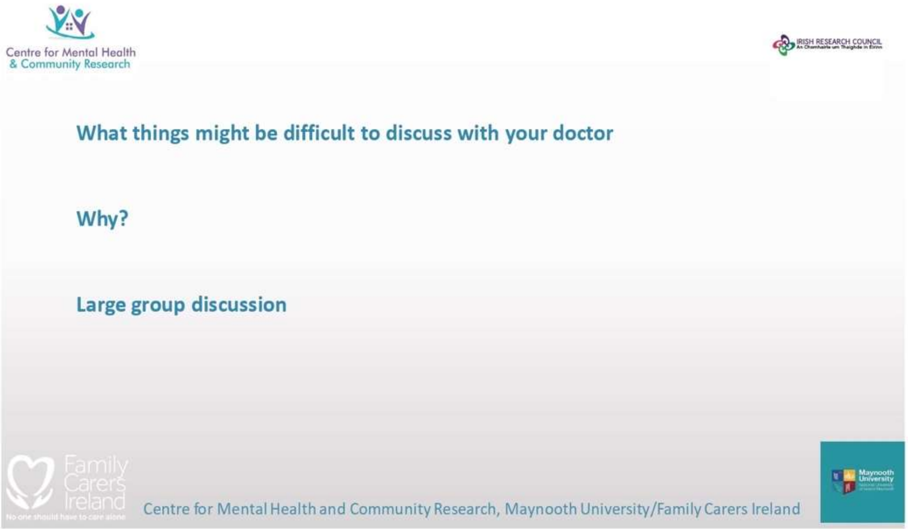
Slide 21

Background:

Consultations with doctors can be an anxious time, particularly when there are difficult things to discuss. The patient/carer is often aware of the hierarchy that exists in medical settings and can be more familiar with the traditional doctor-patient interaction, i.e. fully directed by the doctor.

Key points:

- Having the right language and communication tools can support raising your concerns and initiating a more productive conversation with your doctor.
- We are going to look at two different communication tools that will support discussions about your own health as well as the person for whom you are caring.
- The tools will be presented with case examples – one from the carer's own health perspective and one regarding concerns for the care recipient.



What things might be difficult to discuss with your doctor

Why?

Large group discussion

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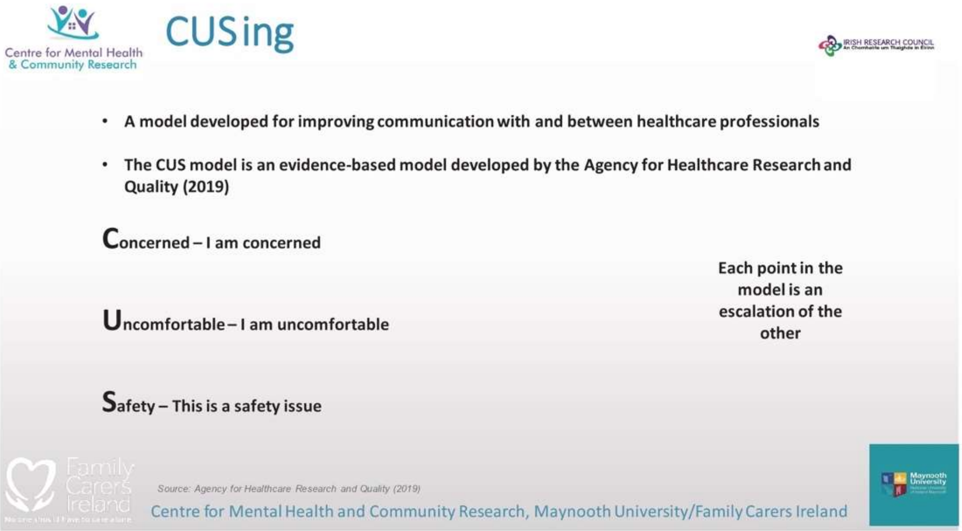
Slide 22

Background

Before introducing the tools allow the participants (if they wish) to discuss some examples (real or hypothetical) of what might be difficult to discuss. This can be done by breaking into small groups or large groups depending on numbers.

Key points:

- This is an important time to refer back to ground rules regarding confidentiality and respect for different circumstances/experiences of caring.
- Examples discussed by the group can be referred to when discussing the upcoming communication tools.
- Piloting of the workshop showed that peer interaction was beneficial for the carers.



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CUSing

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- A model developed for improving communication with and between healthcare professionals
- The CUS model is an evidence-based model developed by the Agency for Healthcare Research and Quality (2019)

Concerned – I am concerned

Uncomfortable – I am uncomfortable

Safety – This is a safety issue

Each point in the model is an escalation of the other

Family Carers Ireland

Source: Agency for Healthcare Research and Quality (2019)

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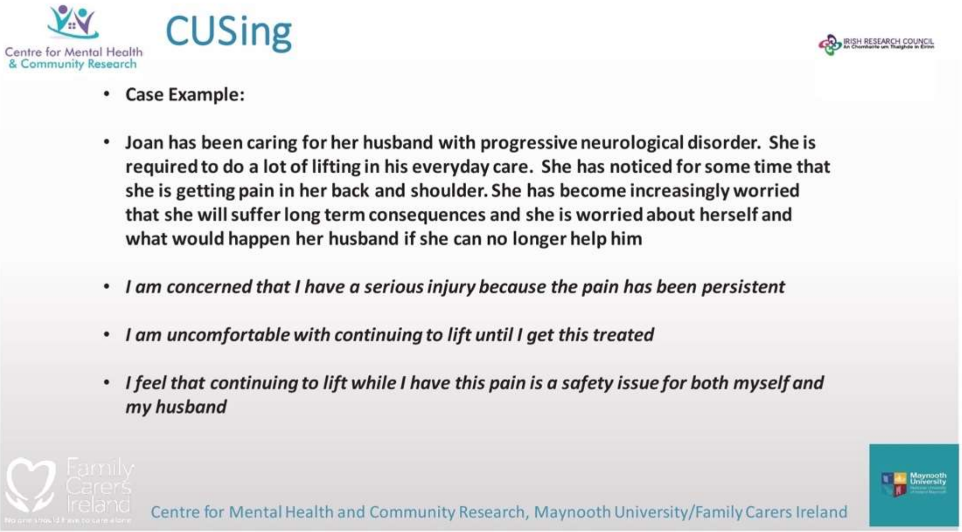
Slide 23

Background

The CUS model of communication[4] is widely used in healthcare settings to, for example, support nurses in consultation with senior hospital doctors. We have adapted it for use to support family carers in similar conversations and it can be used across all caring roles.

Key points:

◆ The CUS acronym makes it easy to remember.
◆ This tool does not require a long consultation time.
◆ The tool uses ‘I’ language (referred to earlier) so promotes assertiveness.
◆ The CUS model is designed to be an escalation of raising concern. If, as a carer, you are not getting a response by stating you are ‘concerned’, you can move to ‘uncomfortable’ and finally ‘safety’.



CUSing

- **Case Example:**
- **Joan has been caring for her husband with progressive neurological disorder. She is required to do a lot of lifting in his everyday care. She has noticed for some time that she is getting pain in her back and shoulder. She has become increasingly worried that she will suffer long term consequences and she is worried about herself and what would happen her husband if she can no longer help him**
- ***I am concerned that I have a serious injury because the pain has been persistent***
- ***I am uncomfortable with continuing to lift until I get this treated***
- ***I feel that continuing to lift while I have this pain is a safety issue for both myself and my husband***

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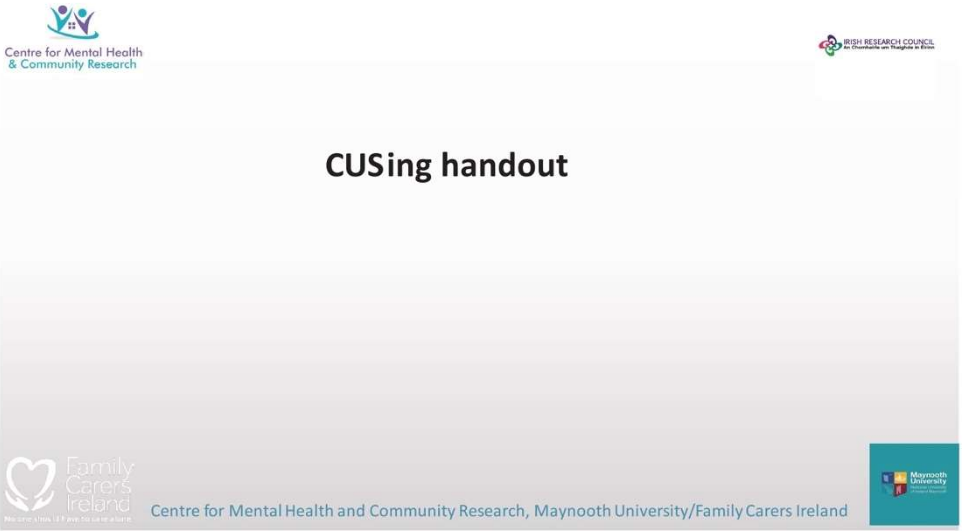
Slide 24

Background

Working through an example, demonstrates the use of the communication tool from a carer perspective. In this example, the carer is concerned about the impact on their own physical health – which could also result in an impact on the person for whom they provide care.

Key points:

- Throughout this example, Joan is using 'I' language.
- The CUS model supports the escalation of the statement up to the point of safety.



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CUSing handout

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Slide 25

At this point, the CUSing template can be introduced. It is designed to allow for planning of the conversation in advance of the appointment with the doctor. As with the previous handout, this can be made available in hard copy in face-to-face settings and also emailed to participants.

(See Appendix 2)

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Applying CUSing to personal scenario

5 mins prep time

10 mins in small group

10 mins in large group

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Slide 26

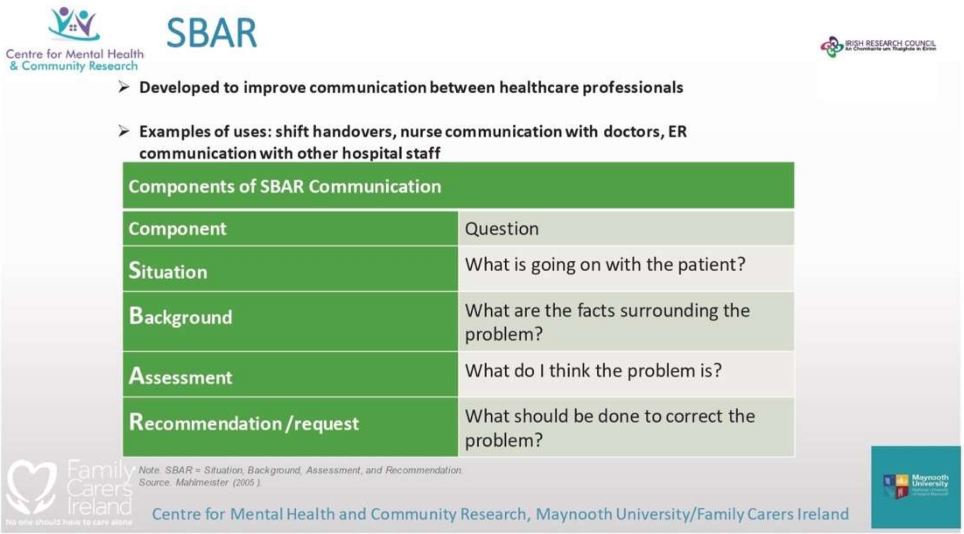
Background

Having the opportunity to practise using the communication tools, is an important part of the workshop. This should be done ideally in pairs, with each carer having the opportunity to practise using the tool.

A few minutes should be allocated to allow each carer to think about a scenario (real or hypothetical).

Key points:

- Carers are encouraged to give feedback to one another following practise of the communication tool.
- The facilitator can support small group conversations as necessary.
- Carers are invited to discuss their ‘practise’ of the communication tool in the larger group.



SBAR

- Developed to improve communication between healthcare professionals
- Examples of uses: shift handovers, nurse communication with doctors, ER communication with other hospital staff

Components of SBAR Communication	
Component	Question
Situation	What is going on with the patient?
Background	What are the facts surrounding the problem?
Assessment	What do I think the problem is?
Recommendation /request	What should be done to correct the problem?

Note. SBAR = Situation, Background, Assessment, and Recommendation.
Source. Mahlmeister (2005).

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Slide 27

Background

The SBAR tool[4] is also used in professional healthcare settings in, for example, emergency rooms and for nurse shift handover. This model allows for more detailed information about the concern being communicated. It offers the carer a way to discuss concerns about the person they are caring for, and can be adapted for use when more detailed background information about their own health concerns may be required.

Key points:

- The components of the tool allow for a detailed, but concise account of the scenario.
- As with the previous tool, the conversation can be planned in advance.
- The handout is available on the next slide.

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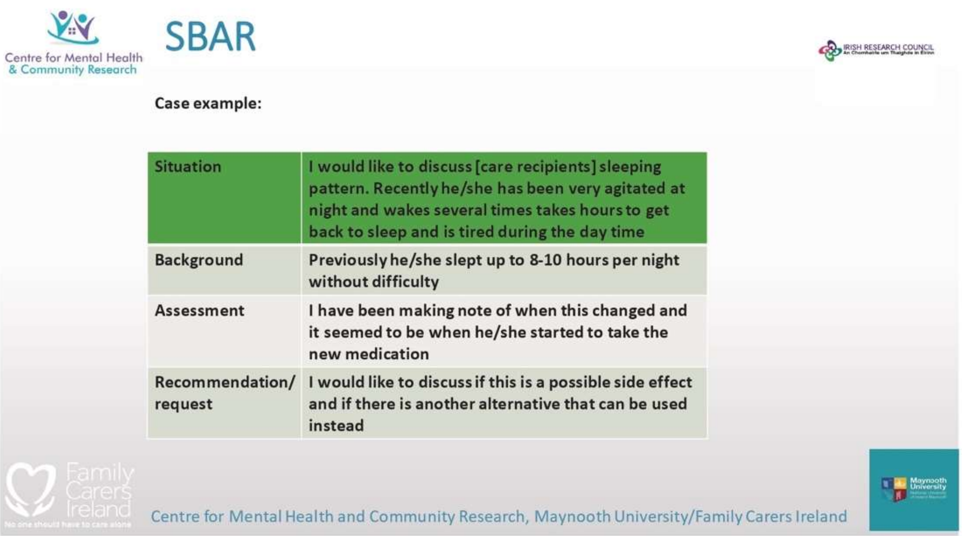

SBAR

Case example:

Situation	I would like to discuss [care recipients] sleeping pattern. Recently he/she has been very agitated at night and wakes several times takes hours to get back to sleep and is tired during the day time
Background	Previously he/she slept up to 8-10 hours per night without difficulty
Assessment	I have been making note of when this changed and it seemed to be when he/she started to take the new medication
Recommendation/ request	I would like to discuss if this is a possible side effect and if there is another alternative that can be used instead

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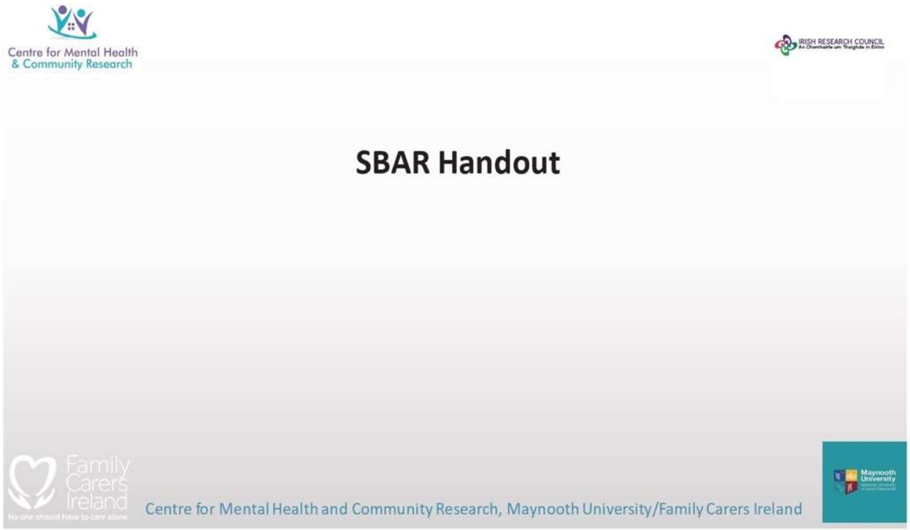
Slide 28

Background

A case example from a caring role is provided to illustrate the value of providing the key background information before making a request in a clinical setting. In this example, the carer has noticed changes in sleep patterns and would like to discuss their assessment of the situation and what they feel might help. Carers must be heard by healthcare professionals regarding their concerns and this tool structures the information in a way that is acceptable and easily understood in that setting.

Key points:

- Provides a detailed yet concise account of the concern/problem.
- As with the previous tool, ‘I’ language is used.
- Can be adapted to discuss own health needs.



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SBAR Handout

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Slide 29

The SBAR handout is introduced next (see Appendix 3).
This includes a blank template on the second page to allow carers to use the handout to prepare in advance for a conversation with the doctor.

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Applying SBAR to personal scenario

5 mins prep time

10 mins in small group

10 mins in large group

Family Carers Ireland
No one should have to care alone

Centre for Mental Health and Community Research, Maynooth University/Family Carers Ireland

Maynooth University

Slide 30

Background

As with the CUS tool, having the opportunity to practise the communication tool is an important part of the workshop. Again, this should be done ideally in pairs with each carer having the opportunity to practise using the tool.
A few minutes should be allocated to allow each carer to allow them time to think about a scenario (real or hypothetical) before beginning the group work.

Key points:

- Carers are encouraged to give feedback to one another following practice of the communication tool.
- The facilitator can support small group conversations as necessary.
- Carers are invited to discuss their ‘practise’ of the communication tool in the larger group.

Applying SBAR to personal scenario

5 mins prep time

10 mins in small group

10 mins in large group

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Slide 31

Final Slide

Summarise briefly what was covered in the workshop as outlined below:

- Stages of caregiver identity.
- Potential health risks and the importance of help-seeking.
- Role of the GP and the optimal doctor-patient/carer relationship (i.e. a partnership).
- Preparing for a doctor visit (discussed and handouts provided).

Communication skills:

- Two (easy to remember and use) communication tools presented – CUS and SBAR to support communication.
- Can be used to discuss your own health and well-being concerns.
- Can assist with communicating regarding the needs of the person you care for.
- Handouts are available for planning of conversation if needed.

Q&A – and closing.

APPENDIX 1 – PLANNING YOUR GP VISIT

Appointment date: ____/_____/_____ time: ______________

I scheduled this appointment because (e.g. I am concerned about...):

____
____
____
____

Points I want to discuss (in priority order):
E.g. New/old symptoms, impact on your health/life, changes to sleep, weight, mood, memory, etc.

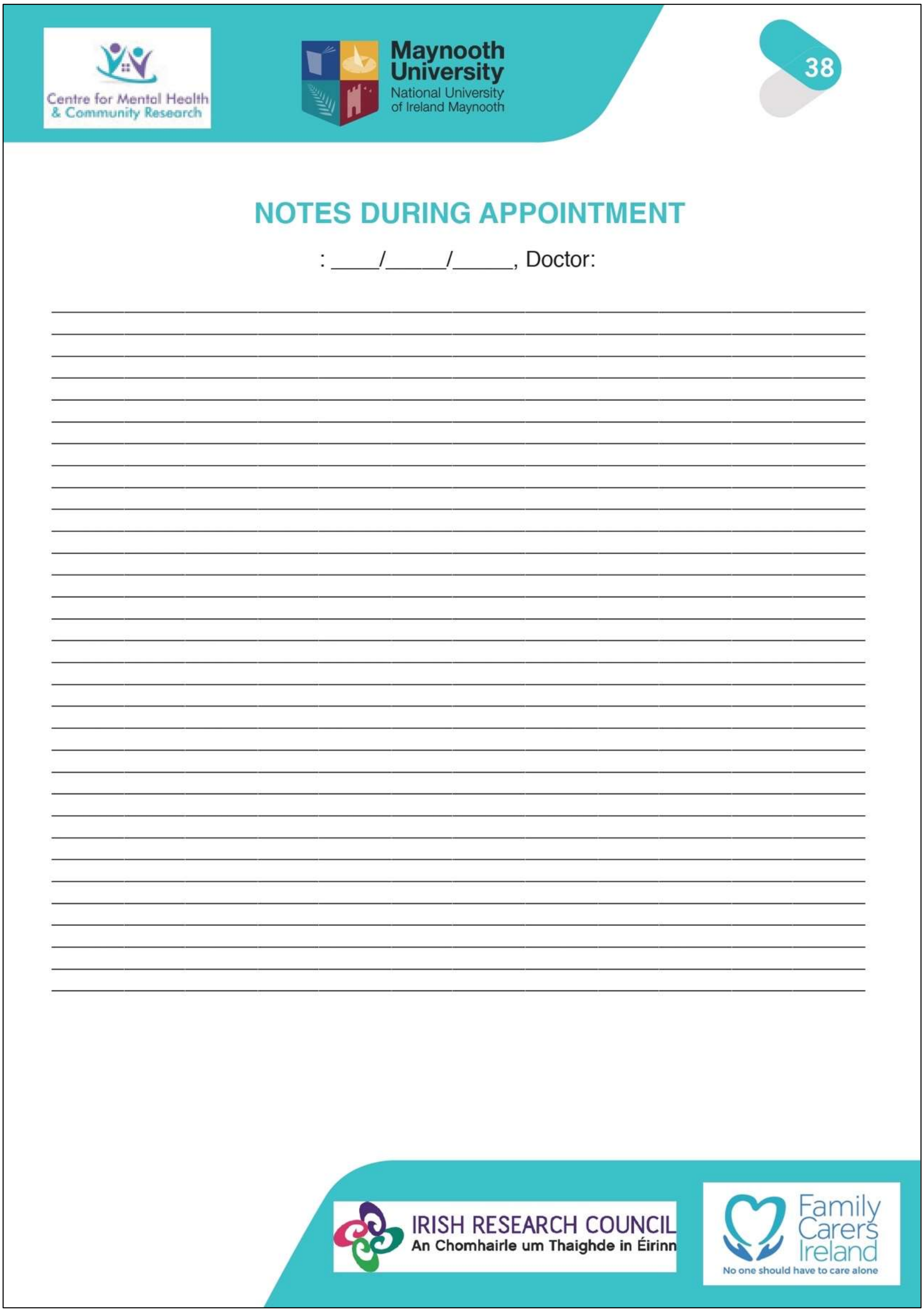
1. ____
____
2. ____
____
3. ____
____

Questions for GP (e.g. What is the diagnosis, Why did it occur, When can treatment start, How long does it last)

1. ____
____
2. ____
____
3. ____
____

Checklist before seeing GP

- ☐ Make appointment
- ☐ Completed plan
- ☐ List of current medications/ supplements
- ☐ Any relevant letters/ information from specialists or other professionals



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NOTES DURING APPOINTMENT

: ____/_____/_____, Doctor:

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

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APPENDIX 2 – CUS MODEL OF COMMUNICATION

To support family carers' communication with healthcare professionals

Concerned – I am concerned

Example: I am concerned that my health is suffering; for example, I ....

Uncomfortable – I am uncomfortable

Example: I am uncomfortable with not addressing this because...........

Safety – This is a safety issue

Example: I feel this is a safety issue for myself (or the person for whom I provide care)

Please list your own concerns below, remove,
and bring with you to your doctor's appointment

....

I am concerned that

____

____

I am uncomfortable because

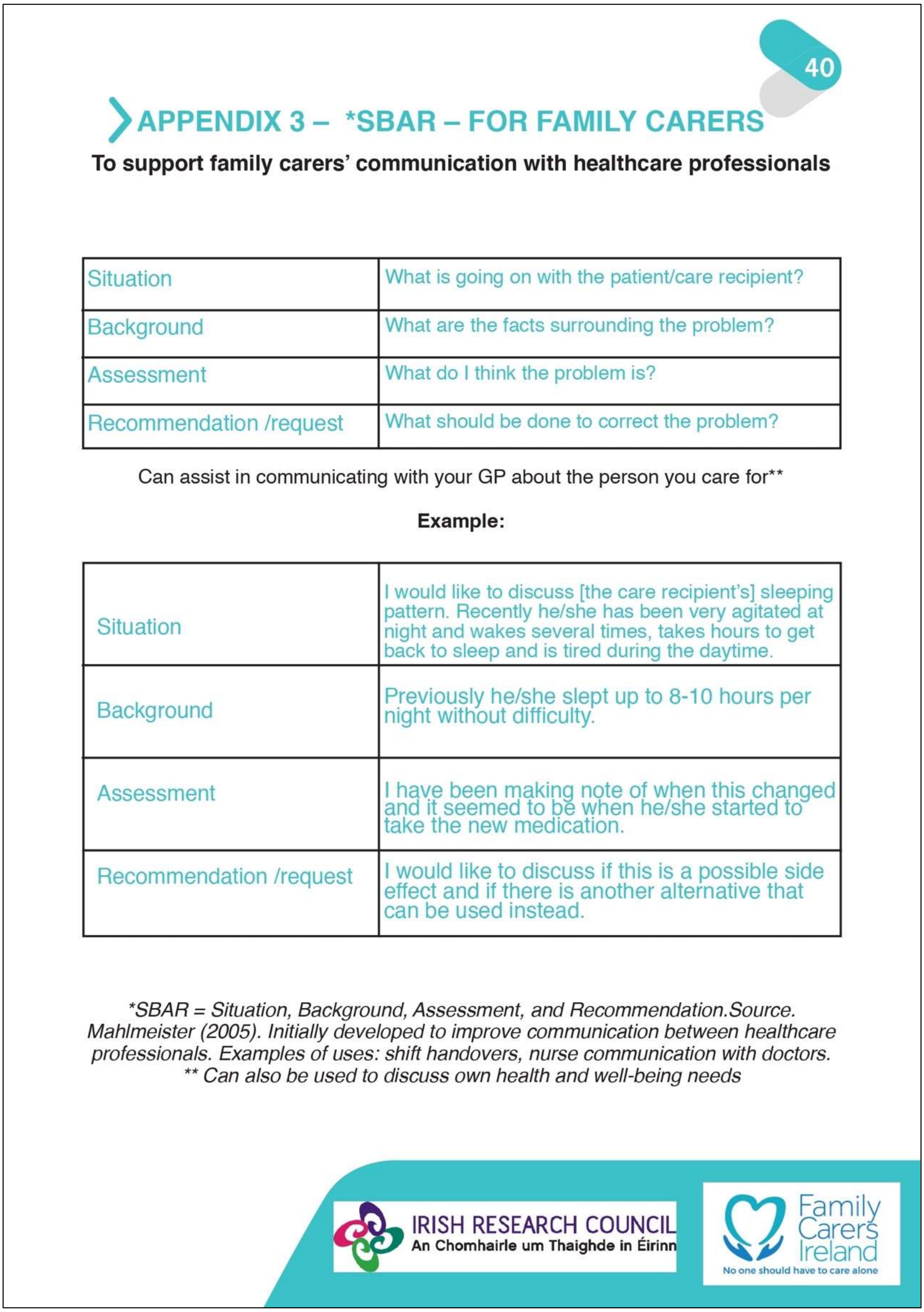
____

____

I feel this is a safety issue because

____

____



APPENDIX 3 – *SBAR – FOR FAMILY CARERS

To support family carers' communication with healthcare professionals

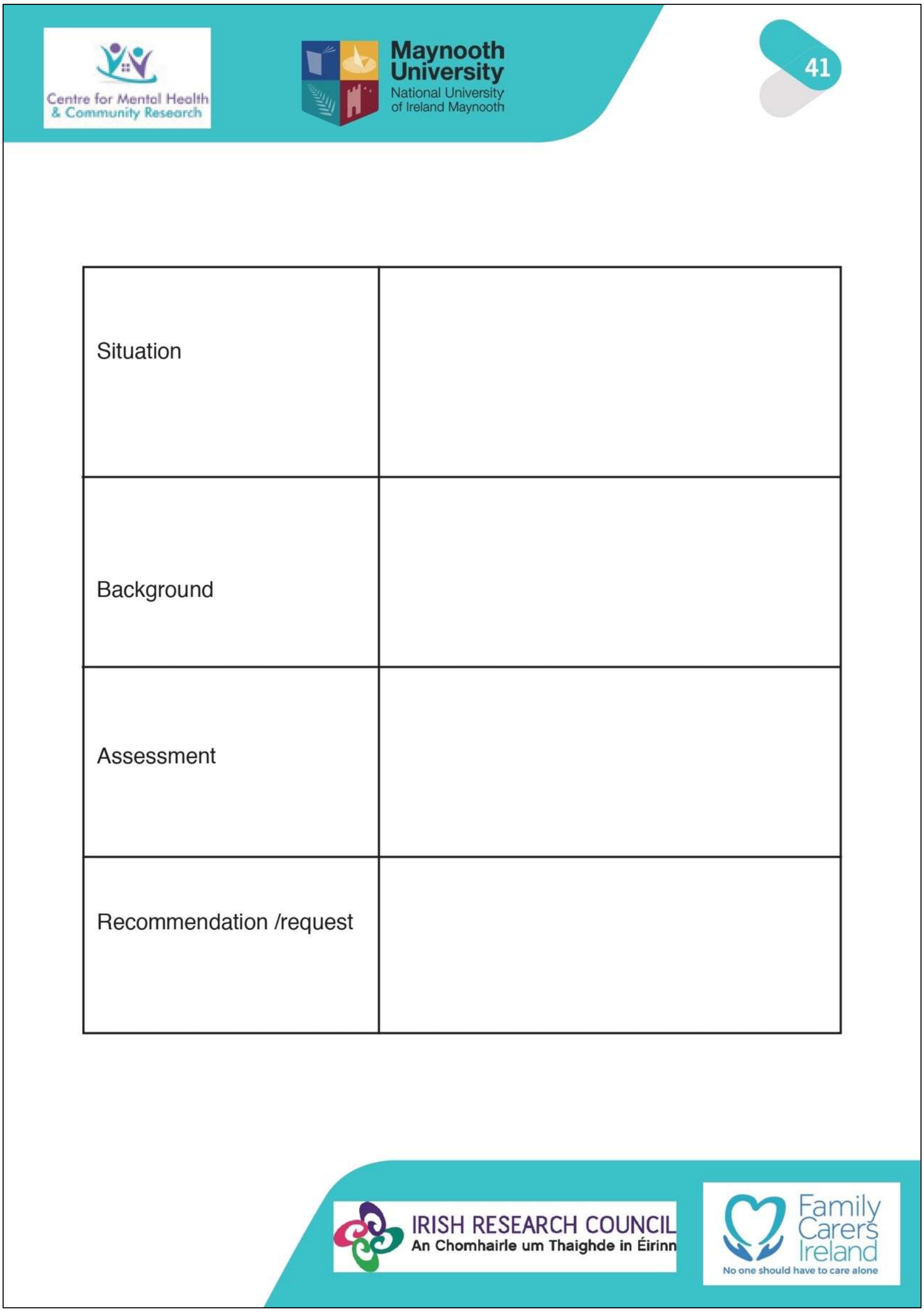
Situation	What is going on with the patient/care recipient?
Background	What are the facts surrounding the problem?
Assessment	What do I think the problem is?
Recommendation /request	What should be done to correct the problem?

Can assist in communicating with your GP about the person you care for**

Example:

Situation	I would like to discuss [the care recipient's] sleeping pattern. Recently he/she has been very agitated at night and wakes several times, takes hours to get back to sleep and is tired during the daytime.
Background	Previously he/she slept up to 8-10 hours per night without difficulty.
Assessment	I have been making note of when this changed and it seemed to be when he/she started to take the new medication.
Recommendation /request	I would like to discuss if this is a possible side effect and if there is another alternative that can be used instead.

**SBAR = Situation, Background, Assessment, and Recommendation.Source. Mahlmeister (2005). Initially developed to improve communication between healthcare professionals. Examples of uses: shift handovers, nurse communication with doctors.*
*** Can also be used to discuss own health and well-being needs*



Situation	
Background	
Assessment	
Recommendation /request	

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Chapter 7: Discussion

7.1 Introduction

The research reported here aimed to address, in three sequential stages, the extent to which family carers are, and can be, supported by health professionals, with a particular focus on GPs. Firstly, the project examined how psychological barriers to identification and help-seeking influenced how carers experienced access to support in community healthcare settings (Study One). This first study also examined the processes by which GPs currently identify carers and the extent to which they support family carer health and well-being. Secondly, Study Two explored the nature and extent of available guidance/recommendations for GPs by scoping, synthesising, and critiquing the international literature on their role in supporting family carers in primary care. Lastly, Study Three used the findings from Studies One and Two to help progress the NCS objectives by providing GP 'practice points' and the development and pilot testing of an accompanying workshop. Study Three also involved developing and pilot-testing a complementary communications skills workshop for carers to assist them in conversations with their GP and other healthcare professionals.

This chapter reviews and critically appraises the collective findings from the three studies. Firstly, a commentary is provided on the complexity of caring and challenges in communication that emerged throughout the project. Secondly, the results are discussed in the context of the critical components of support in a clinical setting, namely the identification of carers in the first instance, followed by an assessment of their needs and subsequent signposting to support. Thirdly, the potential role of GPs in supporting carers is critically evaluated in light of the findings and the international literature. Finally, an evaluation of the research is presented, including the implications of the results (and attendant resources) for national and international policy and practice. A summary of the findings in relation to the key research questions underpinning each of the three studies is provided in Table 7.1 below.

Table 7.1

Summary of key findings in relation to each of the key research questions across studies

Study	Key research questions	Key Findings
Study One (Survey and interviews)	1. Are carers ever asked about their health and well-being?	1. Carers were rarely/never asked about their health and well-being despite experiencing psychological distress.
	2. To what extent do they identify as carers?	2. Carers frequently did not formally identify as 'carers'. Most carers indicated that they are more likely to associate with the familial relationship to the care recipient than with the term 'carer'.
	3. Do they seek support?	3. Carers perceived their needs as secondary and rarely sought or received support.
	4. What are GPs' views regarding the identification and support of carers?	4. GPs were ambiguous about their role with family carers and lacked appropriate information and resources.
Study Two (Scoping Review)	1. What clinical guidance is available to GPs to support carer identification and assessment?	1. A whole-practice approach that includes a 'carer champion' is optimal for the identification of carers. Assessments were shown to have a preventative effect and can be used to guide the consultation. A total of seven assessments were outlined in the review.
	2. What guidance is available to enable GPs to signpost family carers to relevant services/supports?	2. The available guidance suggests that carers can be referred to carer support agencies, community services and, where necessary, mental health services.

Study	Key research questions	Key Findings
	3. What resources are available to support GPs in the identification, assessment, and referral process, of family carers? 4. What is the level of evidence available for clinical guidance on supporting family carers?	3. Key resources include links to services and support, such as carer support agencies, online resources and education. Resources such as financial support information were also considered to be important. In addition, GPs were encouraged to provide carers with a carer information pack that outlines how the practice may support them. 4. The level of evidence for the included studies was low overall, and no evaluation of the guidance was reported.
Study Three (Development and pilot testing of resources). *Note: Study Three involved the development of resources for stakeholders. The questions and findings presented here relate to the pilot testing of these resources.*	1. Can a short training workshop (co-designed with PPI) support carers in difficult conversations with healthcare professionals, such as GPs? 2. Can a short training workshop for GPs support them in having conversations with family carers who present in clinical practice?	1. Despite the poor response rate, the findings show some initial promise in raising awareness of the needs of family carers in general practice. For example, increased post-training mean scores were reported for intention to support family carers and perceived behavioural control. However, these findings should be interpreted with caution in view of the small sample size. 2. Overall, the carers who participated in the workshop, reported increased confidence in conversing with their GP, particularly with regard to their ability to be assertive about care tasks which they found difficult, receiving answers to questions, discussing their health needs and preparing more effectively for GP visits.

The findings from this project indicate that despite the complex care being increasingly provided in our communities, carers are not routinely asked about the impact of caring on their health and well-being. Study One shed some light on the possible barriers to implementing the strategy objectives, particularly in general practice, including the carers' often complex associations with the term ‘carer’, as well as GPs' and carers' ambiguity regarding what (if any) role the GP should have, and the typically ad hoc and informal communication processes in community healthcare settings. Study Two provides some important information and standardised approaches/strategies that may be used by GPs and other healthcare staff to better support their interactions and conversations with family carers. The international literature, in particular, yielded new information that can be incorporated into existing practices, nationally and internationally, in terms of how best to identify carers, assess their needs, and signpost them to appropriate supports and services. Study Three, with a PPI panel of family carers, involved the co-design, co-development and pilot testing of resources for GPs and carers, respectively; in the case of GPs, the resources consist of practice points and a workshop, while a workshop and accompanying supporting materials were developed specifically for carers.

7.2 Complexity of family caring and carer-doctor communication

A finding of some concern from Study One was the complexity of care being carried out in our communities by family members. The carers often supported loved ones with multiple comorbidities and frequently cared for more than one person. Indeed, this is also evident in the literature (Family Carers Ireland, 2020b; Glasson et al., 2014; Ploeg et al., 2020; Polenick et al., 2017). Worryingly, no limits regarding the type and level of care provided were considered. As a result, as care needs escalated, carers reported becoming increasingly burdened without any acknowledgement or support.

Additionally, respondents in Study One reported that they were often providing care over many years, and perhaps unsurprisingly, those caring for the longest periods of time were less satisfied with the (perceived) health professionals’ understanding of their caring role.

Notably, evidence suggests that the number of hours caring and the level of care being provided negatively impact carer health and well-being outcomes (Schulz et al., 2016). Furthermore, the carer participants in Study One indicated that informal help from family and friends declined as the needs of the care recipient increased. Very little research has looked at how support from healthcare professionals and family members may diminish over the course of enduring caring roles, such as caring for a child with a disability into adulthood (Brennan et al., 2022). While many carers may choose the role, even over a lifetime, inadequate services in areas such as disability mean that care is often provided by ageing parents struggling to cope (Quin et al., 2005). Conversely, many carers of older persons with dementia are spousal carers and, therefore, may have their own health challenges (O'Shea et al., 2017). Thus, the findings in this project and existing literature point to a need for more discussion and research regarding the provision of additional support and/or an alternative means of care when caring continues over a prolonged period of time.

The results reported here also suggest that there are no limits regarding the care tasks that family carers may be asked to undertake. While we need to interpret this finding with caution due to small sample size, it is interesting nonetheless, to note that it has been reported elsewhere. As mentioned in Chapter Three, this finding is in line with results from a recent large US study, 'Home Alone Revisited' (*N* = 2,089), which found that family carers were increasingly carrying out complex medical tasks alongside assistance with daily living (Reinhard, 2019). This is perhaps not surprising due to increases in care needs arising from advances in medical care, with people living with complex medical conditions now enjoying longer life (Barrett et al., 2014). While such progress in medical care has led to positive policy and health system shifts toward community-based care (Barrett et al., 2014), the consequences for the provision of informal care in the future, as highlighted in the literature (Oireachtas

Library & Research Service, 2019) and the subsequent impact on family carers specifically, has not been considered by policymakers.

Given that both of the above trends are predicted to continue (Oireachtas Library & Research Service, 2019), it is timely that future research considers the true extent of care tasks undertaken by family carers and the attendant impact on the provision of informal or broader family support. In addition, it is important to understand the mechanisms that can be put in place to set parameters around medical care provided in the home. This is important, especially because the findings from Study One also suggest that communication between family carers and doctors can be challenging, and carers can struggle to raise their own health needs/issues with healthcare professionals.

The findings from the current research suggest that GPs can be reluctant to 'broach' the health impact of caring with family carers, while carers themselves are often hesitant in conversations with the GP. Communication appeared to be particularly difficult when discussing concerns about care tasks with which they may feel uncomfortable. Carers in this research reported that being assertive about their needs and the needs of the person for whom they provide care can be challenging. They felt on the periphery of conversations in clinical settings. Similar communication barriers in healthcare settings have been noted elsewhere. For example, patients can often feel a sense of relinquished autonomy due to their ill health while also being aware of a power imbalance in the relationship that is heavily skewed toward the doctor (Rosen, 2014). Conversely, communication is reportedly also challenging between health professionals in clinical settings where a medical hierarchy can exist between, for example, nurses and consultants (Leonard et al., 2004). Our findings add considerably to the discourse regarding consultations with doctors by highlighting that family carers are in the unique position of needing to communicate with doctors both as patients, in addressing their own health needs, and as carers, seeking to address the needs of the person for whom they provide care (and setting boundaries regarding their caring role).

Despite this, communication skills for carers have received very little attention in the literature, and only two small studies were identified from the review of the literature conducted as part of this study. The first of these, in the US (*n* = 16), involved an evaluation of the effectiveness of an intervention to improve communication between carers of older relatives and healthcare professionals. Although some evidence for effectiveness was reported, the intervention focused primarily on communication regarding the care recipient's needs (P. D. Smith et al., 2018). Likewise, Moore et al. (2008), in a larger study (N = 51), investigated the effectiveness of communication skills training for carers, but focused on the care recipient's outcomes rather than the carers themselves. Thus, a significant gap exists concerning the unique needs of family carers with respect to communicating with their GP and other healthcare professionals.

The research reported here addressed this gap in Study Three. The workshop developed as a central element of this study and described earlier in Chapter Six is, to our knowledge, the first time that communication tools used routinely in healthcare settings, such as hospitals and clinics, have been adapted for use by family carers to help them when discussing both their own health needs and those of the person for whom they provide care. Such tools are commonly used in healthcare training to facilitate, for example, communication between nursing staff in a hospital setting (Battles & King, 2015). The Study Three workshop represents a significant development as carers often report that they are not viewed as partners in healthcare and, thereby, cannot avail of the same skills training afforded to those working in a paid capacity in this environment (Family Carers Ireland, 2020a).

The pilot testing of the workshop with a small but diverse group of carers showed promising preliminary findings. Importantly, the workshop will be integrated into the services provided by FCI and will be delivered nationally to family carers in Ireland commencing in January 2024. Specifically, the workshop will be delivered by regional Carer Support Managers (CSMs), who will attend facilitator training prior to delivery. A family carer will co-facilitate each workshop as in the current study. These are very positive developments in terms of the study outputs being used more widely (and with the agreement of the research team) to support family carers.

7.3 Critical components of family carer support in general practice/primary care

7.3.1 Carer Identification

The identification of carers is challenging globally (Parmar et al., 2020). Carers' frequent non-association with the term 'carer' is well documented and widely cited as a critical barrier to self-identifying and subsequently accessing support (Collins & Swartz, 2011; Doctors of BC, 2016; NICE, 2020; Royal College of General Practitioners & The Princess Royal Trust, 2013). The findings from Study One indicate that many carers did not associate with the term 'carer' and this was shown to have a small influence on psychological distress, although no association was found with regard to QoL or help-seeking behaviour. The findings highlight the ambivalent relationship that many carers have with the term. Whilst some felt it was, in part, an acknowledgement of their essential role, the majority felt that it detracted from, or minimised, their familial relationship with the person for whom they provide care. This is consistent with the international literature (Carers Trust Wales, 2019; Doctors of BC, 2016; Northern Sydney Local Health District, 2019), as well as research that was conducted in Ireland to better understand associations with the term ‘carer’. For example, Hughes & O'Sullivan (2017) indicate that support services may need to find ways to address these differing views and perspectives in order to adequately identify and support those providing care.

However, despite the considerable evidence to show that many carers do not identify with their caring role, the proactive identification of carers by professionals in healthcare settings is sadly lacking (Carduff et al., 2014; Peters et al., 2020). Worryingly, this is also evident in countries which have more robust policy and legislative requirements regarding the identification and support of family carers. For example, in the UK, where an estimated 10% of the population is providing care, it is suggested that a mere 1% of family carers are identified through general practice (Peters et al., 2020). The current research adds significant value by investigating the mechanisms by which carers can be first identified and, subsequently, supported in general practice.

The findings from this current research also emphasise the potential broader consequences of not identifying as carers and raise questions about the mechanisms that are currently used for recording carers. Study One provides some evidence that reluctance to identify as a carer impacts not only on availing of support, but also on the broader issue of estimating current and future carer numbers. For example, many carers in our survey indicated that they would 'rarely or never' identify themselves as a carer on an official document such as a census form or health survey. This is problematic, as these mechanisms for recording carers are widely used internationally (International Carers, 2021), as well as in Ireland (Family Carers Ireland, 2022a), and could indicate that the current and future numbers of carers are significantly underestimated, with resultant implications for funding and resource provision.

The international scoping review that was conducted during Study Two yielded many recommendations that can be incorporated into existing practice (e.g. by means of a new patient registration system or vaccine programme) to support the identification of carers despite wide differences in health systems and structures in general practice internationally (Irving et al., 2017). Indeed, these recommendations were used to inform the development of the resources for GPs conducted as part of Study Three and reported earlier in Chapter Five. Notably, many suggestions for identifying carers in general practice/primary care are best implemented on a ‘whole practice’ basis led by the GP but with a broad role for other practice staff. The appointment of a carer champion in particular (i.e. a staff member that 'champions' the needs of carers and coordinates their identification and support) was a recurring finding from the scoping review reported earlier in Chapter Four. Many of the papers recommending a carer champion emerged from the UK and included large healthcare organisations such as NICE, RCGP, NHS, and Carers Trust Wales (Carers Trust Wales, 2019; NHS, 2019; NICE, 2020; Royal College of General Practitioners & The Princess Royal Trust, 2013). However, it is important to note that the recommendation of a carer champion is not new and was first suggested over two decades ago by Greenwood et al. (2010) as a way to incorporate meaningful carer support into general practice. However, the authors indicated that no formal evaluation had occurred at that time.

Indeed, a robust evaluation of the benefits of a carer champion is still lacking today, although a recent study in Scotland included a carer 'liaison' as part of an intervention designed to support family carers in four general practices (Carduff et al., 2016). The findings suggest that having a single point of contact was helpful, but the carer liaison worked best if the assigned liaison was a clinical staff member. Still, over a decade since it first appeared in the literature, and despite the fact that it is widely recommended, there appears to be very little peer-reviewed literature available to determine the effectiveness of the role of carer champions, thereby presenting a significant gap in our knowledge and understanding. It is interesting to note, in the context of the present research, that the PPI panel suggested the notion of a regional carer champion to accommodate GP practices of different sizes. For example, group practices of GPs are not always the norm internationally, and many GPs work alone or in very small practices. In Germany, GPs predominately work solo (O'Dowd et al., 2017) while in Denmark, small practices of two or fewer are common (Pedersen et al., 2012). In Ireland, general practice has been moving toward larger primary care facilities, though there are still many small rural practices (Irish College of General Practitioners, 2022) that may, with more robust evidence, benefit from a regional carer champion.

The results from Study One highlight the significance of the time of diagnosis, although this was not deliberatively explored as a question in the carer survey or as part of the interviews. The findings suggest that, psychologically, carers can struggle with the diagnosis received by their loved one, and as they come to terms with that, they are often only beginning their caring journey and considering the subsequent changes to their lives. This is also consistent with the findings of the scoping review (Study Two), where it was noted that the point of diagnosis is also important for HCPs who are planning long-term care and, therefore, is an opportune time for early intervention with the carer. The Study Two findings also point to times in the caring journey when identification may be embedded into existing practice. The time of diagnosis for the care recipient emerged as a critical point in the caring journey for both carers and HCPs and is perhaps the optimal time, therefore, to identify carers, record their details (with permission), assess their needs, and signpost them to support as (and if) required (Carduff et al., 2016; Northern Sydney Local Health District, 2019).

Further research could establish ways in which the needs of the carer can be integrated into care plans from the time of diagnosis onward, with ongoing reviews through the caring journey. Clearly, a sensitive approach to early intervention is required, given the previously mentioned associations with the term ‘carer’. Establishing a strong rapport with healthcare professionals, such as the family GP, from the outset of the caring role may mean that challenging caring milestones can be navigated more easily with support. Moreover, it may mean that the GP is alert to the possible health risks for the carer and is more comfortable initiating a conversation in this regard. This is particularly important when a standardised approach to assessing carers' needs is typically not implemented.

7.3.2 Carer Assessment

The assessment of carer needs has been explored in previous research and has been found to be beneficial in supporting the consultation process and encouraging carers to consider their own health and well-being needs (Burridge et al., 2017). However, the research reported here indicates that time pressure and the lack of a simplified generic assessment tool remain significant barriers to assessing carer needs, particularly in a general practice setting. For example, a number of tools that have been used to assess the needs of family carers were identified in the scoping review (Study Two), although many of these were developed for specific caring roles, such as cancer, palliative care, and care of the older person (Burridge et al., 2017; Carduff et al., 2016; Collins & Swartz, 2011).

The PPI panel of carers in the current study, and in line with the findings from elsewhere (Burridge et al., 2017; Peters et al., 2020), were open to the idea of a short assessment. The panel appraised the full range of assessment tools identified as part of the review (along with a short FCI assessment, outlined in Chapter Five) because it was intended that one or more of these would be incorporated into the practical resources for GPs and carers that were developed as part of Study Three. Crucially, the panel felt that many of the tools were not appropriate due to their specific focus on particular caring situations (e.g. cancer) or because they were considered too lengthy to complete in a general practice setting. For example, the Carer Star assessment can take up to 40 minutes to complete, although this is used by carer support agencies such as FCI (familycarers.ie). Time pressure has been noted elsewhere and is often cited as a significant and widely reported barrier to conducting an assessment in general practice (Collins & Swartz, 2011; Riffin et al., 2020; Røen et al., 2019).

The PPI panel also felt that, whilst each assessment tool had some value, a new, more generic assessment was needed. Indeed, this is consistent with findings from another recent scoping study by Peters and colleagues (2020), who likewise found that healthcare stakeholders expressed a preference for a more generic assessment tool suitable for all carers. However, in developing a generic assessment, consideration needs to be given to the appropriateness for general practice and the likelihood that it will be widely used. For example, in the UK, NICE guidelines for physical activity promotion (NICE, 2019) recommend an assessment for use in general practice. The General Practice Physical Activity Questionnaire (GPPAQ) was designed to be completed by the patient before the visit or with the GP during the consultation and alerts the GP to the need for intervention. The assessment takes less than one minute to complete, yet a large study of over 1000 GPs (*N*=1,103) found that, although 70% were aware of the assessment, only 39% had used it in practice (Chatterjee et al., 2017). Similarly, in a study in Irish general practice (N=213) investigating the use of risk assessment tools for cardiovascular disease, only around one-third of GPs (32%) reported using the tool frequently despite very high levels of awareness of its existence (92.5%) (Byrne et al., 2015).

Importantly, the findings from the scoping review also highlight an ambiguity in relation to *who* should conduct carer assessments. For example, in the UK, where carers have a statutory entitlement to an assessment, the NICE (2020) guidelines suggest that the assessment can be administered by 'local authorities or practitioners from health and social care' (p. 15). However, Peters et al. (2020) suggest that the assessment could also be delegated to the voluntary sector. This lack of consensus is potentially problematic, particularly in view of the Study One findings that highlighted GPs' general ambiguity regarding their role with family carers. Previous research has also considered self-report measures for carers as an alternative to the GP completing the assessment during the consultation. However, Carduff et al. (2016), in a pilot study of a Carer Needs Assessment Tool (CSNAT), found that fewer than one-third of the sample (25/81) completed and returned the assessment, with the volume of paperwork already completed by carers cited as the reason for poor engagement.

In Ireland, a promising collaboration between the Health Service Executive (HSE) single assessment tool (SAT) project and national not-for-profit organisations (i.e. Family Carers Ireland and Care Alliance), along with international organisation interRAI, hoped to develop a Carer Needs Assessment (O'Sullivan et al., 2017). However, at the time of writing, an assessment tool for use in healthcare settings had not been introduced, and carers in Ireland had no formal entitlement to an assessment (International Carers, 2021). However, it should be noted that a comprehensive review of needs is provided by Family Carers Ireland when carers present to them for support (familycarers.ie).

Ideally, there needs to be a consensus regarding who carries out the carer assessment and where it is carried out to ensure maximum benefits for carers. Without this understanding, there is a risk that the assessments will not happen or as Bandura (1990) would say, "what is everyone's responsibility often ends up being no one's responsibility" (Bandura, 1990)(p.37). The findings reported here raise some critical questions regarding the type, content and frequency of assessment. For instance, Study One indicates the need, as a priority, for an assessment of capacity to care in the first instance, ideally at the point of diagnosis, with regular reviews as the caring journey progresses. This corresponds with the NICE (2020) guidelines for supporting adult carers, that recommend those carrying out carer assessments should "not make assumptions about the willingness and the ability of carers to carry out caring tasks" (p.8). Additionally, our findings regarding the lack of resources for GPs point to the fact that those who complete assessments should have the necessary information regarding where the carer may be signposted for support (Peters et al., 2020; Riffin et al., 2020). This is discussed in more detail below.

7.3.3 Signposting

Several of the guidelines identified in the scoping review indicated the need for the GP to refer family carers to community support and training. The findings of the GP interviews in Study One indicate that a lack of information and resources was a barrier to signposting carers to support. The albeit small number of GPs interviewed as part of Study One suggested that they had minimal knowledge regarding what support is available in their communities. This finding has been noted elsewhere; for example, in Australia, a study (N=66) examining GPs' awareness of the emotional needs of family carers highlighted the under-utilisation of community resources within the primary care system mainly because GPs reported difficulties in accessing the required services (Bulsara & Fynn, 2006).

More recently, a scoping study with professional stakeholders in the UK, including GPs, found that pathways for referral to community organisations are not well established and community healthcare services appear to 'operate in silos' (p.14), resulting in frustration for HCPs attempting to access services (Peters et al., 2020). This is problematic in a healthcare environment where time constraints are often cited as a significant barrier to optimal care. Arguably, this points to the need for community support services, such as carer support agencies, to reach out to local primary care/general practices to raise awareness of their services. Equally, an appointed staff member, such as the previously mentioned carer champion, could actively seek out what resources are available in the community.

The need to alert carers to financial benefits and entitlements (if appropriate) was one of the findings to emerge from the scoping review (Study Two). Study One also indicated that carers can experience stigma in terms of ‘financial insecurity’ and that this can be predictive of poorer psychological health and QoL. These findings were presented to the PPI panel in Study Three, who recommended that links be provided for the social welfare payments available to carers. The ICGP, when reviewing the initial practice points, also commented on the utility of this suggestion, indicating a case perhaps, for including this type of information in GP guidelines going forward. This finding is also important within the context of the recommendations of the EquiFrame Manual (Mannan et al., 2011) which outlines a framework for improving human rights and enhancing equality in healthcare. One of the core concepts enshrined in this document is the right for people to know which benefits are available to them and how they might access them. In addition, the Study Two findings highlighted the important role of mental health and bereavement support, with counselling specifically recommended for carers. However, according to both GPs and carers, the counselling waiting lists in general practice can be long and carer support agencies may be able to circumvent this if GPs are aware of their service. For example, in the UK, the Carers Trust (Carers.org) indicates that counselling may be available at some of its centres, and likewise, in Australia, counselling is available through Carer Gateway (carergateway.gov.eu) and in Ireland through Family Carers Ireland (familycarers.ie).

Carer support agencies, such as FCI, provide numerous services to carers, including training, respite, support groups and counselling (see familycarersireland.ie). The Study One findings suggest that most carers felt they had little or no support and that attending support groups or engaging in counselling were the least likely help-seeking activities they engaged with. This is a source of some concern as social support has been found to mediate some of the health risks for carers mentioned earlier. For example, an interesting study by Gallagher and Whiteley (2012) suggests that higher blood pressure in parents caring for a child with a disability, when compared to a control group, was mediated by the level of social support, with those indicating higher social support showing lower blood pressure readings (Gallagher & Whiteley, 2012).

At the same time, clear referral pathways are needed so that signposting to carer support agencies can work in practice. The findings of the scoping review indicate that referral pathways in the UK were mixed, with some GPs referring through the general practice directly when requested by the carer and others completing a referral form provided by a carer support agency (Royal College of General Practitioners, 2013a). Arguably, a number of factors should be in place to facilitate a more streamlined referral process (e.g. to carer support agencies), including agreements amongst all parties on the most effective pathway and the availability of an appropriate member of staff tasked with making the referrals.

7.4 The role of general practice/primary care

All the indicators are that successful mechanisms for identifying carers in general practice require a proactive approach on the part of the GP by, for example, following up with regard to who is providing care when a patient receives a diagnosis or enquiring whether a patient provides care when they present with symptoms associated with an undisclosed caring role, such as back pain or depression (Carduff et al., 2016; Doctors of BC, 2016; Northern Sydney Local Health District, 2019). The collective findings of the current research broaden our understanding of the practice and systems-level barriers (Parmar et al., 2020) that have been previously mentioned about supporting family carers in general practice. The findings from both Study One and Study Two highlight gaps in the information provided to GPs with respect to family carers. GPs are not routinely provided with formal information about carers and have little knowledge, therefore, of the resources available to support their role with family carers. Although a role for GPs and other healthcare professionals is highlighted in the NCS, GPs have no official remit with respect to carers. Therefore, considerable ambiguity exists about what (if any) role they play in carer support. Our findings suggest that both carers and GPs are aware of this gap, and it presents a substantial barrier that can prevent either party from initiating a conversation about the impact of the caring role.

Demands in primary care/general practice are increasing globally (Irving et al., 2017) and GPs report workload increases and burnout (Collins & Homeniuk, 2021). In an Irish context, Slainté Care initiatives, such as free GP care for children and older adults, have increased GP workloads by 29%, and this is due to grow further, with the longer-term plan to eventually extend free GP care to all (Irish College of General Practitioners, 2022). Our findings suggest that carers are cognisant of and sympathetic to the demands and attendant time pressures on GPs, but this would also appear to reduce their willingness to discuss the impact of their caring role, a conversation that can be difficult to have, regardless of time. In a relatively recent systematic review that incorporated studies/evidence from 67 different countries, Irving et al. (2017) reported that time barriers can impact patient health outcomes, particularly regarding health promotion and record keeping. In addition, the carer sample in Study One presented here, similar to those elsewhere (Family Carers Ireland, 2022b), report high levels of psychological distress. Worryingly, evidence suggests that time constraints in general practice can be a significant barrier to correctly identifying depression and other psychological problems/symptoms (Hutton & Gunn, 2007). Encouragingly, however, the average GP consultation time in Ireland is estimated to be 13.7 minutes (Irish College of General Practitioners, 2022), a figure that compares favourably internationally; for example, Irving et al.'s (2017) systematic review suggests that up to half of populations globally spend less than five minutes at a GP appointment.

A lack of resources and guidelines for GPs was identified in the current research as a key barrier to carer support. As previously mentioned in Chapter Four, it has been suggested in the literature that GPs are more likely to use guidelines that apply to their clinical setting and are based on evidence. However, Study Two indicated that evidence in this sphere is, overall, low, and transparency regarding the evidence used in the development of guidelines is lacking, pointing to a need for evaluation of guidelines and a more robust evidence base. Nonetheless, the development of guidelines in this project was challenging due to the disappointingly low engagement from GPs.

However, this is not unusual, as researchers often consider GPs a 'hard-to-reach' group. For example, the findings of an interesting study in Germany (*N*=96) suggest that GPs are particularly resistant where patient records are involved but that, overall, they have negative attitudes toward research and do not believe in its relevance in clinical practice (Hummers-Pradier et al., 2008). Notably, however, the GPs in this study also indicated they might be more willing to participate in research if they were involved in the design (and ownership) of the research, which speaks to the increasing importance placed on PPI and engagement in health and social care (and other) research in Ireland and elsewhere (e.g. Campus Engage, 2018). A more recent study, also from Germany, found that time and remuneration were key barriers to GP participation in research, with GPs (*N* = 336) reporting that they would be willing to give twice as much time if payment was offered and they perceived low-time effort research as optimal (Virnau et al., 2022). The researcher's status was also reported by the same authors to be a possible facilitator, with GPs reporting a preference for a 'reliable counterpart within the leading institution' (Virnau et al., 2022, p 237). Although the current research was conducted during a global pandemic, with unprecedented demands on general practice, the poor engagement from GPs was, nonetheless, disappointing.

To facilitate the greater participation of GPs, we attempted to evaluate the workshop in the shortest possible time (one hour), and the GP who co-facilitated is also a trainer on the GPR training scheme. Unfortunately, we were unable, due to funding constraints, to offer the GPs or GPRs remuneration, but perhaps future research and funding applications could consider incorporating this as part of the research process, in line with the findings of Virnau et al. (2022). As mentioned above, and as also documented in Study Three (Chapter Five), engagement with the ICGP was also challenging, and although all efforts were made to meet their requirements, the overall response was somewhat disappointing. This may be due, at least in part, to the fact that from a health systems and policy perspective in Ireland, GPs do not have a definitive role regarding family carers and, in an increasingly pressurised work climate, they may be unwilling to engage with consultations that they see as ambiguous. This is evidenced, albeit in only a small way, by the limited responses returned from the GP workshop evaluation, where the potential role of the PHN was mentioned, as well as an apparent frustration with patient numbers and available time. A need for further work in this regard is indicated.

Interestingly, although there would appear to be a consensus in the literature that general practice/primary care is ideally placed in terms of providing services/support to carers (Chantal et al., 2002; Parmar et al., 2020), the debate regarding which healthcare professional should be primarily responsible for supporting carers, has been rumbling for decades. For example, in an early study of PHN (referred to as District Nurses in the UK) attitudes to carer support, it was suggested that carer support should be the responsibility of the GP (Chantal et al., 2002). Notably, in a much more recent scoping study in the UK, where policy initiatives are more robust, there is still a lack of leadership regarding the support of family carers in primary care (Peters et al., 2020). Despite this, many countries are moving toward a primary care-led approach to healthcare, which may mean perhaps that the overall commitment to carers in these settings will improve over time. For example, although the COVID-19 pandemic had many negative consequences in healthcare, it also led to new practices in, for example, digital health, that could be considered for future initiatives in carer support. For instance, further research could explore how these newly established initiatives in general practice, such as video consultations (Alsaffar et al., 2021), might be harnessed and utilised to support family carers.

Although specific health risks for carers are widely documented (American Family Physician, 2015; Eurocarers, 2018; Gallagher & Bennett, 2021; Northern Sydney Local Health District, 2019), the list of health risks for carers collated as part of Study Two, while not exhaustive, provides valuable information for GPs about the possible symptoms of an undisclosed caring role. This is important in light of the wealth of evidence indicating that carers are more likely to experience ill health than the general population and, worryingly, are also more likely to experience illness/disability in the future (Gallagher & Bennett, 2021). For example, in a recent large survey in Ireland (N=1,250), only 6% of family carers reported their health status to be 'very good' compared to 41% of the general population (Family Carers Ireland, 2020b). More recently, Gallagher and Bennett (2021) measured physiological markers in carers across metabolic, endocrine and immune systems and found that carers were more likely (23%) to have future illness than non-carers (17%). These important studies indicate that providing a comprehensive reference list of health risks for carers is both timely and necessary. This reference list can be of value to both carers and GPs and for that reason, it formed part of the 'practice points' for GPs and was included in the carer workshop. The latter was considered important because it has been suggested by previous research that carers subordinate their health concerns unless they are validated by a healthcare professional (Burridge et al., 2017). Arguably, therefore, it is important to highlight potential health risks to the carers themselves in order to raise awareness and encourage them to initiate conversations with and actively seek help from, their GP.

7.5 Policy context and implications

This research sought, from the outset, to shed some light on why some of the objectives of Ireland's NCS (Department of Health, 2012) concerning the identification and support of family carers in health and social care settings, remain largely unmet. Study One revealed some of the barriers from both a GP and carer perspective, while Study Two identified many practical approaches and strategies that may be of help in this regard. The findings from Study One and Two were then used in Study Three to inform the development and pilot testing of brief training workshops and attendant resources for both GPs and carers. Although the NCS was published over a decade ago, the GPs in Study One were unaware of its existence. Despite the fact that the sample size was not large, this does (potentially) point to a lack of communication of policy objectives to relevant stakeholders. Since the development of the NCS, other policy measures, such as Slainté Care, mentioned earlier, have been launched to address Ireland's two-tier healthcare system (Burke et al., 2018). Slainté Care aims to eventually provide free GP care for all cohorts in our communities, commencing with children and also aims to move much of previously hospital-based care to community settings. Although progressive in its intention, this is likely to increase the burden of care being provided by family carers and also has implications for healthcare professionals working in the community. As previously mentioned, the ICGP has already highlighted the impact of Slainté Care on GPs' workloads (Irish College of General Practitioners, 2022) and this suggests an increased urgency in finalising the revised NCS to which the then-incoming government indicated its commitment in 2020 (Draft Programme for Government, 2020).

However, it is notable that the previous iteration of the NCS was developed on a cost-neutral basis, possibly reducing its impact. The UK Government have led the field in terms of strategy and policy to support family carers, yet a defined role or focus for primary care is still lacking in the UK, while only a fraction of the health budget is spent on carers (Peters et al., 2020). It is possible that this lack of leadership, even in countries with a strong policy imperative, is due to the ambiguity whereby the responsibility for providing carer support is not formally assigned to any particular healthcare professional but instead shared amongst many practitioners within the extensive health and social care system. Thus, no member of the healthcare profession currently has an official remit in terms of supporting family carers. Furthermore, recent policy advancements in an Irish context have been somewhat contradictory because, on the one hand, they encourage home-based care, but on the other, they undermine home-based care by failing to provide any support for those who provide that care (Hanly & Sheerin, 2017).

The PPI panel in this research suggested a role for the recently launched Healthy Ireland initiative (part of Slainté Care) in supporting family carers. This initiative (Government of Ireland, 2021) has four main goals including: (1) to increase the proportion of people who are healthy at all stages of life; (2) reduce health inequalities; (3) protect the public from threats to health and well-being; and (4) create an environment where every individual and sector of society can play their part in achieving a healthy Ireland (p.10). Healthy Ireland Co-ordinators are currently being appointed, but no specific function regarding family carers is defined within this new community role, which is perhaps a missed opportunity. Therefore, as elsewhere in the world, carers are not the remit of any healthcare professionals and are largely invisible in what are considered progressive policy and service advancements. The 'invisible contract' (Dow & McDonald, 2007) referred to in Chapter Three, appears to be fulfilled by an equally invisible workforce. The voluntary sector, via organisations such as Care Alliance and FCI, is currently the primary source of support for family carers in Ireland.

7.6 Theoretical relevance

As outlined in Chapter One, two theories provided the theoretical context for this research. The work presented here indicates that SCT can be usefully applied to enhance our understanding of carer health and well-being by considering how individuals' beliefs, self-perceptions, and social interactions influence their caring experience, engagement with help-seeking, and overall well-being. In addition, the self-efficacy construct of this theory was used to inform the co-design and pilot testing of a communication skills workshop for family carers. Furthermore, the TPB was usefully employed to guide the qualitative research with the GPs and the co-design and piloting of the GP workshop, thereby demonstrating its applicability in terms of advancing our understanding of GPs' attitudes, beliefs and perceptions about the importance of supporting family carers. This, in turn, facilitated a more strategic approach to co-designing the GP workshop and its evaluation.

7.7 Strengths and limitations of the research

The research reported here, has a number of strengths and limitations. Uniquely, in an Irish context, the CHERISH project has provided information specifically about carer communication with healthcare professionals concerning their health and well-being needs. The project explored the nature and extent of support provided to family carers in healthcare settings, with a particular emphasis on general practice. The mixed method design explored the barriers and facilitators to HCP identification and support of carers, including GPs. This was important in view of the need to fulfil the NCS objectives regarding the identification and support of family carers in healthcare settings. During the initial online survey conducted as part of Study One, we also sought to actively include carers who may have been previously unrepresented. For example, they may not have engaged with social welfare or support agencies (which are typically widely used to recruit samples for this type of research). The sequential design employed in the research also ensured that the findings from Study One were used to inform the research questions underpinning the international scoping review of the literature (Study Two).

The scoping review of the international literature with respect to guidelines and recommendations to GPs to support a role with family carers is, to our knowledge, the first review to focus on this topic. Findings from the international scoping review provide strategies for identifying and supporting carers that can primarily be absorbed into existing practice and may be applicable across diverse, caring roles. This is important, as many studies and recommendations previously focused on specific caring roles, such as cancer or end-of-life care.

Furthermore, the guidelines for GPs were made available through GP Forum, a bi-monthly publication for GPs to keep them informed of advancements and issues in clinical settings. This is the first time in Ireland that GPs have been provided with resources to identify and support family carers and represents an important first step in terms of better supporting family carers which can hopefully be built upon further through continuous engagement with the ICGP. This element of the research also yielded important information that was subsequently incorporated into the development and evaluation of resources for both carers and GPs in Study Three.

As previously mentioned, only a small number of studies, to date, have focused on communication skills for carers, but these focus largely on communicating about the needs of the care recipient. Importantly, our research involved the development of a practical resource for carers to support them in conversations about their caring role and how it might impact their health and well-being. The workshop described earlier in Chapter Six was designed to support carers to reflect on their caring role and its impact on their health and well-being. The workshop also provides useful tools to enable carers to be more assertive in their conversations with healthcare professionals, where there are often power imbalances due to hierarchical structures. The pilot testing of the carer workshop demonstrates that existing resources in healthcare settings, such as the previously described communication tools, can be successfully adapted for use by family carers who are, arguably (informally), part of the broader health service and deserving, therefore, of much more support. As outlined earlier, this workshop will be delivered to family carers nationally as part of an education and training programme being implemented by FCI in 2024 as part of a collaboration with SETU. This is a key output and impact of the research and a good example of how research can inform practice and how even a small amount of public funding, such as the IRC New Foundations grant awarded to support this element of the research, can have ‘real-world’ impact. Crucially, FCI is also planning to secure funding to evaluate and develop the workshop through this programme by collecting data from a much larger sample (approx. 180 carers) and in an in-person setting. It will be interesting to see how the results of this work (if funded) will build on the research reported here.

The involvement of carers in a PPI capacity in the co-design of the resources in Study Three was another key strength of this research. The contributions of the PPI panel, particularly concerning the practical application, add considerable value to the international discourse regarding the support of family carers in general practice. For example, in Study Two, the appointment of a carer champion emerged as a key recommendation as part of a whole practice approach that can support the identification of carers. This was further explored by the PPI panel in Study Three, who helpfully suggested small or sole practices could consider appointing a regional or shared carer champion.

One of the central aims of this research was to practically influence the identification and support of carers in Ireland and internationally, particularly in general practice, and to add to the existing peer-reviewed literature. To that end, the research findings were published in stakeholder-accessible platforms as well as peer-reviewed journal articles. Overall, the CHERISH research project makes a considerable academic and practical contribution in terms of building on the existing literature and developing useful stakeholder resources. Overall, the project has led to the production of a number of publications and outputs that fill important gaps in knowledge relating to the support of family carers, particularly in general practice. (see Appendix A3.9).

Despite the many strengths of the project, there were also some limitations that need to be considered. Although it was outside the researcher's control, the project was impacted by the global COVID-19 pandemic, which became a crisis in the second year of the research. However, the pragmatic framework within which the research was conducted, lent itself well to navigating this unprecedented obstacle, and the project proceeded with some modifications to the original design. Nonetheless, there were a number of limitations to each of the three studies, as outlined below.

As mentioned in Chapter Three, although the survey sample was diverse and drawn from 23 counties, the sample size was not large and male carers were under-represented. This may impact the generalisability of the findings as results may not truly reflect the experiences of carers within the wider population in Ireland. Furthermore, the online administration of the survey, while it may have facilitated the inclusion of those not currently availing of carer support, may have also biased the findings in a number of ways. For example, only carers familiar with the online platforms of Facebook and Twitter took part, and this may have skewed the sample toward younger carers. Although a pen-and-paper option was offered for those who were not comfortable with the online environment (see Chapter Two), only a small number of questionnaires were completed in this way. The online social media algorithms may also have resulted in the inclusion of only those carers who had searched for information, thereby potentially leading to another source of sampling bias. In addition, the online environment is not accessible to all; for example, people from lower socioeconomic backgrounds may not have access to technology, or those living in areas with poor connections may not be able to participate.

Furthermore, it was only possible to conduct a small number of semi-structured interviews due to the COVID-19 pandemic, which began in March 2020. Although smaller sample sizes in qualitative research are often typical and acceptable due to the emphasis on obtaining detailed insights into the topic (Boddy, 2016; Theodorou, 2013) the GP interviews may not be conceptually representative of GPs nationally because they were recruited through the same online platform (as described in Chapter Two). Moreover, the interviews only focused on GPs rather than a broader sample of healthcare professionals (e.g. practice nurses, PHNs) due to the emphasis in the literature on the role of the GP. It is possible, therefore, that this limited our findings in terms of the relevance to a whole-practice approach that was later identified as important in Study Two. We did not include any young carers either due to their particular requirements and the complexities around the age of medical consent in general practice. Arguably, however, many of our findings also apply to this carer cohort.

Study Two, as outlined in Chapter Four, was constrained by funding (and time) and did not include papers in other languages. We may, therefore, have missed some relevant studies. Furthermore, as indicated by Arksey and O'Malley, 2005 a scoping review does not require an assessment of study quality but focuses instead on the broad scope of the research topic. Nonetheless, we did chart the level of evidence for the included studies. Lastly, while Study Three involved the design, development and co-delivery of resources for both GPs and carers, the engagement from GPs was poor overall, despite the best efforts of the research team and this limited, therefore, the generalisability of the findings from the, albeit, preliminary evaluations. Due to the ongoing pandemic, it was also necessary to deliver the workshops online, which may have impacted the results and participant engagement with the evaluation process. Some of these limitations may be addressed through future research, as outlined below.

7.8 Directions for future research

Several directions for future research have already been highlighted in this chapter as well as in the included papers. More specific information relating to these and additional research is summarised here by way of highlighting a number of ways in which family carers may be better supported in the future in general practice/primary care.

- While this research provided some important insights from key stakeholders, the potential for general practice/primary care to take a key role in carer support warrants further investigation. For example, a larger sample that includes GPs and other practice staff and which involves the use of a range of qualitative methods could be used to obtain a clearer picture of the willingness to support carers and the practical aspects of implementing the many recommendations outlined in Study Two.
- The evidence presented in this thesis, suggests that appointing a carer champion in general practice/primary care would be a positive step forward, but this currently lacks empirical evidence. Future research could look at the effectiveness of such an approach while also considering the possibility of a regional carer champion to support a number of smaller practices within a particular geographical region.

- The point of diagnosis was highlighted as a critical opportunity for the identification of carers, but this needs to be validated in practice to determine carers' acceptance of the conversation at this sensitive time in the caring journey. Arguably, healthcare professionals, such as GPs, would also require guidance on approaching this conversation, and practical mechanisms for including carers in care plans need to be examined.

- Concerns regarding family carers completing medicalised tasks that are typically the responsibility of trained medical professionals should be explored to understand the nature and extent of these experiences, and if, and how, it may be causing an increased burden on family carers or indeed posing a safety issue to either carer or care recipient.

- The carer workshop that was developed here showed some promise in terms of its overall effectiveness, but this could be evaluated using a much larger sample and a longitudinal design including focus groups to assess its effectiveness in the short and longer term, including any tangible changes over time in GP attitudes and practices toward supporting family carers as well as improvements in carer experiences.

- GPs are a hard-to-reach group within research, and for this reason, researchers could consider engaging GPs as part of the research team from the outset, thereby including them in design, analysis and dissemination. In addition, funding applications could consider how they might be reimbursed or recognised for their time and input.

- A formal assessment of the quality of guidelines for use in general practice (e.g. using tools such as the AGREE II outlined in Chapter Four) would also be important in terms of promoting the wider use of tools within these settings.

- The potential use of new practices in general practice, such as video calls, could be explored as a possible avenue for carer support.

7.9 Conclusion

Caring is challenging; it is not generic, linear or time-limited and can have a significant impact on the health and psychological well-being of family carers. It would be expected that all carers have a GP, and this research, which addressed a number of hitherto largely unexplored areas, provides important insights into the many ways in which the therapeutic relationship between carer and GP can be managed more effectively in a clinical setting. The findings presented here suggest that while a pivotal role for GPs in identifying and supporting family carers is suggested in the literature, there are a number of factors that need to be considered for this to work effectively and efficiently in practice. This research has provided important insights regarding the potential obstacles, particularly at practice, individual and policy levels. Furthermore, it has highlighted that each of these obstacles is being negotiated against a backdrop of complex caring roles which are often progressive and involve many adjustments or transitions for the carer (e.g. deterioration in care recipients' health, changes in services, or moving to residential care). The collective evidence from this research and elsewhere suggests that family carers are an important resource to their families and communities and should be prioritised and supported accordingly within policy and in our wider healthcare system, both in Ireland and across the developed world.

Appendices

Appendix A1.1 CHERISH Project Survey

Are you male or female, please tick?

- ○ Male
- ○ Female

What is your age (in years)?

____

What county do you live in?

____

How would you describe your community, please tick?

- ○ Urban
- ○ Rural

Who do you provide care for?

- ○ Husband
- ○ Wife
- ○ Father
- ○ Mother
- ○ Son
- ○ Daughter
- ○ Brother
- ○ Sister
- ○ Other, please specify

____

____

People often have a number of reasons why they need care. Please indicate the three main reasons your loved one needs care by numbering in order with 1 being the primary reason. For example, *1 Dementia, 2 Elderly, 3 Cancer*

Physical Disability
Intellectual Disability
Dementia
Elderly
Autism Spectrum disorder
Mental illness, please specify
Neurological Condition, please specify
Cancer
Alcohol/substance abuse
Other, please specify

How old (in years) is the person you are caring for?

How long (in years) have you been caring for this person?

What is the approximate time you spend caring in any typical 24-hour period (number of hours)?

How many days per week do you provide care?

How would you usually describe yourself in relation to the person you are caring for? Please read all options before indicating your choice. You may tick more than one.

○ Mother
○ Neighbour
○ Brother
○ Father
○ Son
○ Friend
○ Carer
○ Sister
○ Daughter
○ Grandparent
○ Partner
○ Other, please specify

Providing care to a loved one can impact on your own health and wellbeing. To what extent do you feel you have the supports to adequately look after your own health and wellbeing?

Not at all	A little	A moderate amount	A lot
○	○	○	○

Please tell us more about how supports or lack of supports has impacted your own health and well-being.

As someone who provides care you may often be asked about the person you are caring for. Have you ever been asked how *you* are?

Often	Frequently	Sometimes	Rarely	Never
○	○	○	○	○

Please tell us about some of the things that help you to look after your own health and wellbeing. Please number in order of preference the supports you find most beneficial to you with 1 being the activity or support used most often. *For example, 1 Exercise, 2 Counselling, 3 Hobbies etc.*

Exercise
Reading
Religion/spirituality
Support groups, please specify
Counselling
Socialising
Hobbies
Other, please specify ___________________________

Since taking up the responsibility of caring for your loved one have you:

	Often	**Sometimes**	**Frequently**	**Rarely**	**Never**
Talked to friends or family about how caring makes you feel?	○	○	○	○	○
Read brochures, leaflets or books about how to cope?	○	○	○	○	○
Used online searching to find information about caring?	○	○	○	○	○
Tried to get help from community health organisations for the person you are caring for?	○	○	○	○	○
Talked to healthcare professionals about the impact caring is having on your own health and wellbeing	○	○	○	○	○

	Often	**Sometimes**	**Frequently**	**Rarely**	**Never**
Sought help from a counsellor	○	○	○	○	○
Received regular help from your family to cope with your caring role	○	○	○	○	○
Attended a carer support group	○	○	○	○	○

Have you ever referred to yourself as a 'carer' when completing official documents, e.g. Census Form, Health Surveys etc.?

Often	Frequently	Sometimes	Rarely	Never
○	○	○	○	○

If someone else (such as a health care professional) refers to you as a 'carer' how does this make you feel?

____

____

____

____

To what extent do you feel healthcare professionals you meet:

	Often	Frequently	Sometimes	Rarely	Never
Understand the challenges you face in your caring role	○	○	○	○	○
Are concerned for your health and wellbeing	○	○	○	○	○
Are interested in hearing about your experiences of caring	○	○	○	○	○

What do you think community healthcare professionals such as GP's, primary care nurses, public health nurses etc. could do to support you? Remember, this question is about your own health and wellbeing rather than that of the person you care for.

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We would like to know how you have been feeling in general, over the past few weeks. Please answer ALL the questions simply by clicking the answer which you think most applies to you. Remember that we want to know about how you are feeling today and how you've been feeling recently, not about how you have been feeling in the past. It is important that you try to answer ALL the questions. Thank you very much for your co-operation.

	More than usual	**Same as usual**	**Less than usual**	**Much less than usual**
Been able to concentrate on whatever you're doing?	○	○	○	○
Lost much sleep over worry?	○	○	○	○
Felt that you were playing a useful part in things?	○	○	○	○
Felt capable of making decisions about things?	○	○	○	○
Felt constantly under strain?	○	○	○	○
Felt you couldn't overcome your difficulties?	○	○	○	○
Been able to enjoy your normal day-to-day activities?	○	○	○	○
Been able to face up to your problems?	○	○	○	○
Been feeling unhappy and depressed?	○	○	○	○
Been losing confidence in yourself?	○	○	○	○
Been thinking of yourself as a worthless person?	○	○	○	○
Been feeling reasonably happy, all things considered?	○	○	○	○

Providing care can affect many areas of a person’s life. Please read the statements below and choose the option that best describes your agreement with each statement based on your experiences as someone who provides care.

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Not Applicable**
I have experienced financial hardship that has affected how I feel about myself	○	○	○	○	○
My job security has been affected by the care I provide to my family member	○	○	○	○	○
My employer/co-workers have discriminated against me	○	○	○	○	○
I have experienced financial hardship that has affected my relationships with others	○	○	○	○	○
I feel like I have been treated with less respect that usual by others	○	○	○	○	○
I feel set apart from others whose family members are well	○	○	○	○	○
I feel others are concerned they could 'catch' my family members illness/condition through contact like a handshake or eating food I prepare	○	○	○	○	○
I feel others avoid me because of my family members illness/condition	○	○	○	○	○
Some family members have rejected me because of my contact with my family members illness/condition	○	○	○	○	○
I feel others think I am to blame for my family member's illness/condition	○	○	○	○	○
I do not feel I can be open with others about my family members illness/condition	○	○	○	○	○
I fear someone telling others about my family member's illness/condition without my permission	○	○	○	○	○

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**	**Not Applicable**
I feel a need to keep my family member's illness/condition a secret	○	○	○	○	○
I feel some friends have rejected me because of my family members illness/condition	○	○	○	○	○
I have a greater need than usual for reassurance that others care about me	○	○	○	○	○
I feel lonely more often than usual	○	○	○	○	○
Due to my family members illness/condition, I have a sense of being unequal in my relationship with others	○	○	○	○	○
I feel I am at least partially to blame for my family member's illness/condition	○	○	○	○	○
I feel less competent than I did before my family members illness/condition	○	○	○	○	○
I encounter embarrassing situations as a result of my family member's illness/condition	○	○	○	○	○
Due to my family member's illness/condition others seem to feel awkward and tense when they are around me	○	○	○	○	○
Some people act as though I am less competent than usual	○	○	○	○	○
Due to the illness/condition of my family member, sometimes I feel useless	○	○	○	○	○
Changes in the appearance of my family member have affected my social relationships	○	○	○	○	○

Imagine your caring role meant you had an emotional or personal issue, that you could not solve on your own. If you sought counselling services for this issue to what degree do you think that others would:

	Not at all	A little	Some	A Lot	A great deal
React negatively to you	○	○	○	○	○
Think bad things of you	○	○	○	○	○
See you as disturbed	○	○	○	○	○
Think of you in a less favourable way	○	○	○	○	○
Think you pose a risk to others	○	○	○	○	○

As someone who provides care you may frequently have to ask for help for the person you care for. Please comment about how it feels to ask for help for *yourself* if you experience a mental or physical health issue.

____

____

____

____

This section asks you about different aspects of your life as someone who provides care, therefore the term carer is used throughout. Please think about your experience within the last two weeks and click the box that best applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as someone who provides care.

	Never	**Some of the time**	**A lot of the time**	**Always**
I have a good level of emotional support	○	○	○	○
My needs as a carer are considered by professionals	○	○	○	○
I am happy with the professional support that is provided to me	○	○	○	○
I feel able to get the help and information I need	○	○	○	○
I have all the practical support I need	○	○	○	○
I feel that my life is on hold because of caring	○	○	○	○
My social life has suffered because of caring	○	○	○	○
I feel I have less choice about my future due to caring	○	○	○	○
I feel I have no control over my own life	○	○	○	○
Caring stops me doing what I want to do	○	○	○	○
I feel depressed due to caring	○	○	○	○

	Never	Some of the time	A lot of the time	Always
I feel worn out as a result of caring	○	○	○	○
I am mentally exhausted by caring	○	○	○	○
I am physically exhausted by caring	○	○	○	○
I feel stressed as a result of caring	○	○	○	○
I worry about going into debt	○	○	○	○
I feel satisfied with my financial situation	○	○	○	○
I am able to save for a rainy day	○	○	○	○
I worry about money	○	○	○	○
There is enough money in our house to pay for the things we need	○	○	○	○
I have become a more tolerant person through my caring role	○	○	○	○
Because of caring, I have learnt a lot about myself	○	○	○	○
Because of caring, I feel that I have grown as a person	○	○	○	○
I have experienced many positive things through caring	○	○	○	○
I feel that I have become a better person by caring	○	○	○	○
I feel valued by the person I am looking after	○	○	○	○
The person I look after respects me for what I do	○	○	○	○
The person I look after makes me feel good about myself	○	○	○	○
I get a lot from the person I am looking after	○	○	○	○
I have a good relationship with the person I am caring for	○	○	○	○
I am satisfied with my performance as a carer	○	○	○	○

	Never	Some of the time	A lot of the time	Always
I can take care of the needs of the person I am caring for	○	○	○	○
I feel I am able to make the life of the person I am looking after better	○	○	○	○
I can manage most situations with the person I care for	○	○	○	○
I am able to deal with a difficult situation	○	○	○	○
Caring is important to me	○	○	○	○
I resent having to be a carer	○	○	○	○
I feel frustrated with the person I am caring for	○	○	○	○
I enjoy being a carer	○	○	○	○
I am satisfied with my life as a carer	○	○	○	○

You have now completed all questions, thank you for your time and participation. The results of this survey will be made available to respondents on request.

Thank You.

If you would like to speak to someone about the impact of your caring role Family Carers Ireland can be contacted on 1800 240724.

Appendix A1.2 Interview guide – GP

Tell me a little bit about the practice you work in?

When you have chronically ill patients who are living in the community do you usually know who their primary carer is?

So for people being cared for in the home by a family member, what is your understanding of the role of those family carers/caregivers?

Do you feel they are well equipped to perform the role they have found themselves in?

How do you feel their own health and mental health can be impacted by their caring role?

Do you feel they (carers) get adequate supports? Which supports are you aware of?

Have you been approached by a carer to help them? Tell me about that (or tell me how you might react if you had)

Is your interaction with carers ever charted or documented?

Do you sometimes notice a carers distress and feel it necessary to start a conversation with them about their own health and wellbeing?

What do you feel is the role of the GP (if any) with caregivers?

What would be helpful to you in supporting you to support carers?

For GP's who are less informed about carers what would be useful for them?

Have you experienced a scenario where you feel the patient might not be getting good care from the person who is their carer?

Are you aware of the NCS objectives that suggest that HCP's have a role in identifying carers and should be more aware of their needs? What is your view on this? Do you feel equipped to support carers?

Are there benefits to your practice in supporting family carers

If you had a structure in place to identify and support family carers what might it look like?

What problems (if any) do you foresee in such a structure?

If you had electronic resources or online support would this encourage you to identify or support carers

Is there anything you would like to add?

Appendix A1.3 Interview guide – Carers

Could we start by you telling me about your caring role? - (who cared for, how long, average time)

Can you describe what it is like for you in this role?

Do you feel it’s a valued role in health services?

Do you see yourself as a carer or as a daughter (son… father…etc.)

Do you think there was a particular point when that relationship/identity changed?

How would you describe the process of taking your [care recipient] for medical appointments

Can you describe how you are generally communicated with at these appointments

Which healthcare professionals do you encounter on a regular basis?

Can you tell me about the support you get from your GP?

Can you tell me about the support you get from your Public health nurse?

If you were to think of a support that is there for you what would come to mind? How does this support you?

Have you had to ask for help for yourself, can you describe what that was like

Would you do it again?

What do you think would support them (HCP's) to do better?

How are you coping in the current crisis?

Do you have any comments to add about how you are supported in Community Health Care settings?

Appendix A1.4 Information Sheets and Informed Consent

Carer Survey Information Sheet

Research Project: A health-based approach to supporting informal carers/caregivers in the community

We would like to invite you to take part in a research study. This research is being carried out by Mary Cronin, as part of a PhD project. The research is being supervised by Professor Sinead McGilloway. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please contact us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

The purpose of this study is to understand how people who provide care, are currently supported by community health professionals. It is hoped that the findings will be used to develop a programme or intervention to improve how community health professionals support those who provide care for family members or loved ones.

Why have I been asked to take part?

You are being invited to complete this survey because you are currently providing care for a family member or loved one.

Who has approved this study?

The research proposal has been reviewed by Maynooth University Social Research Ethics Subcommittee (SRESC).

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give us some time to complete the survey that will provide valuable information regarding how people who provide care are experiencing supports in their community. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, please read this Information Sheet and indicate your consent by signing below. If you decide to take part, you may later withdraw from the research if you wish.

You are being invited to take part in the first part of this research which involves a short survey. At the end of the survey, you will be invited to take part in the second stage of the study at a later date; this will involve either a one-to-one interview with the researcher (of approx. 30-45 minutes) or a group discussion in order to gain further knowledge on the research topic. If you consent to take part in the interviews or focus groups, you will be asked to provide your name and an email address or contact number. You will then be contacted to check that you are still willing to participate. If so, an appropriate time will be arranged and consent will be sought separately for any interviews/group discussions in which you agree to take part.

What will happen to me if I take part?
You will be asked to complete a number of short questionnaires as part of the survey. The first one is a brief background questionnaire which will ask you a few basic questions about yourself. The others include a number of brief and easy-to-complete questionnaires relating to how you look after your own health and wellbeing, how your caring role impacts your life and the ways in which you currently receive support. If you have any questions/concerns, please contact the researcher or their supervisor using the details provided at the end of this form.

How long will the whole process take?
The maximum length of the time you will spend completing the survey is approx. 10-15 minutes, although it may be shorter than this depending on how you get on.

Will my taking part in this research be kept confidential?
All information which is collected about you during the course of the research will be kept **strictly confidential**. No names or email addresses are recorded in the case of online surveys. However, if you choose to participate in the interviews or focus group at a later stage and give your contact details, then your survey responses will no longer be anonymous to the researcher. However, all details will remain confidential and no identifying information will ever be included in any presentation, publication or thesis. It is also important to note that you can stop and withdraw at any point in the process. Therefore, if you decide today to consent to taking part in the second stage of the study, you may change your mind at any time before or during Study 2.

What will happen to the results of the research?
The research will be written up in report format and may be published in a journal and/or presented at one or more conferences. A summary of the research findings will be available in late 2019, should you require a copy.

Who do I contact if I have a question?
Please feel free to address any questions firstly to Mary Cronin, mary.cronin.2014@mumail.ie, 01 708 6311
Alternatively, you may contact Professor Sinéad McGilloway, Centre for Mental Health and Community Research, Maynooth University, Department of Psychology, John Hume Building, Maynooth, Co. Kildare, Ireland (Tel: (01) 708 4765 or Sinead.McGilloway@mu.ie.

Thank you for taking the time to read this

Carer Survey Informed Consent Form

Research Project: A health-based approach to supporting informal carers/caregivers in the community.

Please read and sign this form if you would like to participate in this study

Consent Form

I……………………………… agree to participate in the research study entitled "A health-based approach to supporting informal carers/caregivers in the community".

Signing below indicates that:

The purpose and nature of the study has been explained to you in writing.

You are participating voluntarily.

You understand the limits of confidentiality as described in the information sheet

You are 18 years of age or older

Signed……………………………………. Date………………

Participant Name in block capitals ……………………………………………...

Consent to take part in Stage 2

I am also interested in taking part in the follow up (stage 2) of this research and provide my details here to be contacted for this purpose.

Contact Details:

Phone number: ________________________ Email: ___________________

Consent to data being used for other research purposes:

Please check to confirm your consent for:

Re-using of and/or sharing of anonymous data at the beginning of the project ☐

Re-use and/or sharing of the un-identifiable data for any purpose other than the current research project ☐

Depositing in an Archive such as the Irish Qualitative Data Archive or the Irish Social Science Data Archive ? ☐

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Information Sheet – Interviews: Health Care Professionals (GP's)

We would like to invite you to take part in a research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please contact or ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

The purpose of this study is to understand how people who provide care are currently supported by community health professionals and also aims to use the data collected to develop a programme or intervention to improve how community health professions support those who provide care.

Why have I been asked to take part?

You are being invited to take part in this research because you work as a GP in the community setting.

Who has approved this study?

The research proposal has been reviewed by Maynooth University Social Research Ethics Subcommittee (SRESC) and ethical approval has been granted.

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give us some time to discuss your encounters with carers in your daily work. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, please read this Information Sheet and indicate your consent by signing the consent form provided by the researcher. If you decide to take part, you are still free to withdraw at any time without giving a reason (or withdraw your information up until the point of anonymisation).

What will happen to me if I take part?

You will take part in a recorded telephone interview with the researcher where you will be asked a few basic questions about yourself at the start and then you will be asked a number of questions regarding your experiences of carers in your daily work. If you have any questions/concerns, please contact the researcher or their supervisor using the details provided at the end of this form.

How long will the whole process take?

Due to time constraints on GP's we are suggesting an approximate time of 20 minutes for the interviews.

Will my taking part in this research be kept confidential?

All information that is collected about you during the course of the research will be kept

strictly confidential. All names will be erased from the transcripts and recorded data will be stored separately from the consent forms. All information will be held under lock and key and will be accessed only by the Researcher (MC) and will not be distributed to any other unauthorised individual.

What will happen to the results of the research?
The research will be written up in report format and may be published in a journal and/or presented at one or more conferences. A summary of the research findings will be available in late 2020, should you require a copy.

Who do I contact if I have a question?
Please feel free to address any questions firstly to Mary Cronin, mary.cronin.2014@mumail.ie, 01 708 6311
Alternatively, you may contact Professor Sinéad McGilloway, Maynooth University Department of Psychology, John Hume Building, Maynooth, Co. Kildare, Ireland (Tel: (01) 708 4765 or Sinead.McGilloway@nuim.ie.

THANK YOU FOR TAKING THE TIME TO READ THIS

Informed Consent Form – GP Interviews

Research Project: A community health-based approach to supporting informal carers/caregivers in the community

Please read and sign this form if you would like to participate in this study

Consent Form

I………………………………… agree to participate in Mary Cronin's research study titled "A community health-based approach to supporting informal carers/caregivers in the community".

Signing below indicates that:

The purpose and nature of the study has been explained to you in writing.

You are participating voluntarily.

You understand the limits of confidentiality as described in the information sheet

You are 18 years of age or older

Signed……………………………………. Date………………

Participant Name in block capitals ……………………………………………...

<u>Consent to data being used for other research purposes:</u>

Please check to confirm your consent for:

Re-using of and/or sharing of anonymous data at the beginning of the project ☐

Re-use and/or sharing of the identifiable data for any purpose other than the current research project ☐

Depositing in an Archive such as the Irish Qualitative Data Archive or the Irish Social Science Data Archive ? ☐

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

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Information Sheet – Interviews: Carers

We would like to invite you to take part in an important research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please contact or ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

The purpose of this study is to understand how people who provide care are currently supported by community health professionals and also aims to use the data collected to develop a programme or intervention to improve how community health professions support those who provide care.

Why have I been asked to take part?

You are being asked to take part because you are currently providing care for a family member or loved one.

Who has approved this study?

The research proposal has been reviewed by Maynooth University Social Research Ethics Subcommittee (SRESC).

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give us some time to discuss how people who provide care are experiencing supports in their community. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, please read this Information Sheet and indicate your consent by signing the consent form provided by the researcher. If you decide to take part, you are still free to withdraw at any time without giving a reason (or withdraw your information up until the point of anonymisation).

What will happen to me if I take part?

You will take part in a recorded telephone interview with the researcher where you will be asked a few basic questions about yourself at the start and then you will be asked a number of questions regarding your experiences of caring, your encounters with health care professionals in your community and your views on what you feel would be helpful to you. This research focuses on your own health and wellbeing rather than that of your loved one. If you have any questions/concerns, please contact the researcher or their supervisor using the details provided at the end of this form.

How long will the whole process take?

The maximum length of the interview will be 45 minutes although it may be shorter than this depending on how you get on.

Will my taking part in this research be kept confidential?
All information that is collected about you during the course of the research will be kept **strictly confidential**. All names will be erased from the transcripts' and recorded data will be stored separately from the consent forms. All information will be held under lock and key and will be accessed only by the Researcher (MC) and will not be distributed to any other unauthorised individual.

What will happen to the results of the research?
The research will be written up in report format and may be published in a journal and/or presented at one or more conferences. A summary of the research findings will be available in late 2020, should you require a copy.

Who do I contact if I have a question?
Please feel free to address any questions firstly to Mary Cronin, mary.cronin.2014@mumail.ie, 01 708 6311

Alternatively, you may contact Professor Sinéad McGilloway, Maynooth University Department of Psychology, John Hume Building, Maynooth, Co. Kildare, Ireland (Tel: (01) 708 4765 or Sinead.McGilloway@mu.ie.

THANK YOU FOR TAKING THE TIME TO READ THIS

Informed Consent Form – Carer Interviews

Research Project: A community health-based approach to supporting informal carers/caregivers in the community

Please read and sign this form if you would like to participate in this study

Consent Form

I……………………………… agree to participate in Mary Cronin's research study titled "A community health-based approach to supporting informal carers/caregivers in the community".

Signing below indicates that:

The purpose and nature of the study has been explained to you in writing.

You are participating voluntarily.

You understand the limits of confidentiality as described in the information sheet

You are 18 years of age or older

Signed……………………………………. Date………………

Participant Name in block capitals ……………………………………………...

<u>Consent to data being used for other research purposes:</u>

Please check to confirm your consent for:

Re-using of and/or sharing of anonymous data at the beginning of the project ☐

Re-use and/or sharing of the identifiable data for any purpose other than the current research project ☐

Depositing in an Archive such as the Irish Qualitative Data Archive or the Irish Social Science Data Archive ? ☐

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

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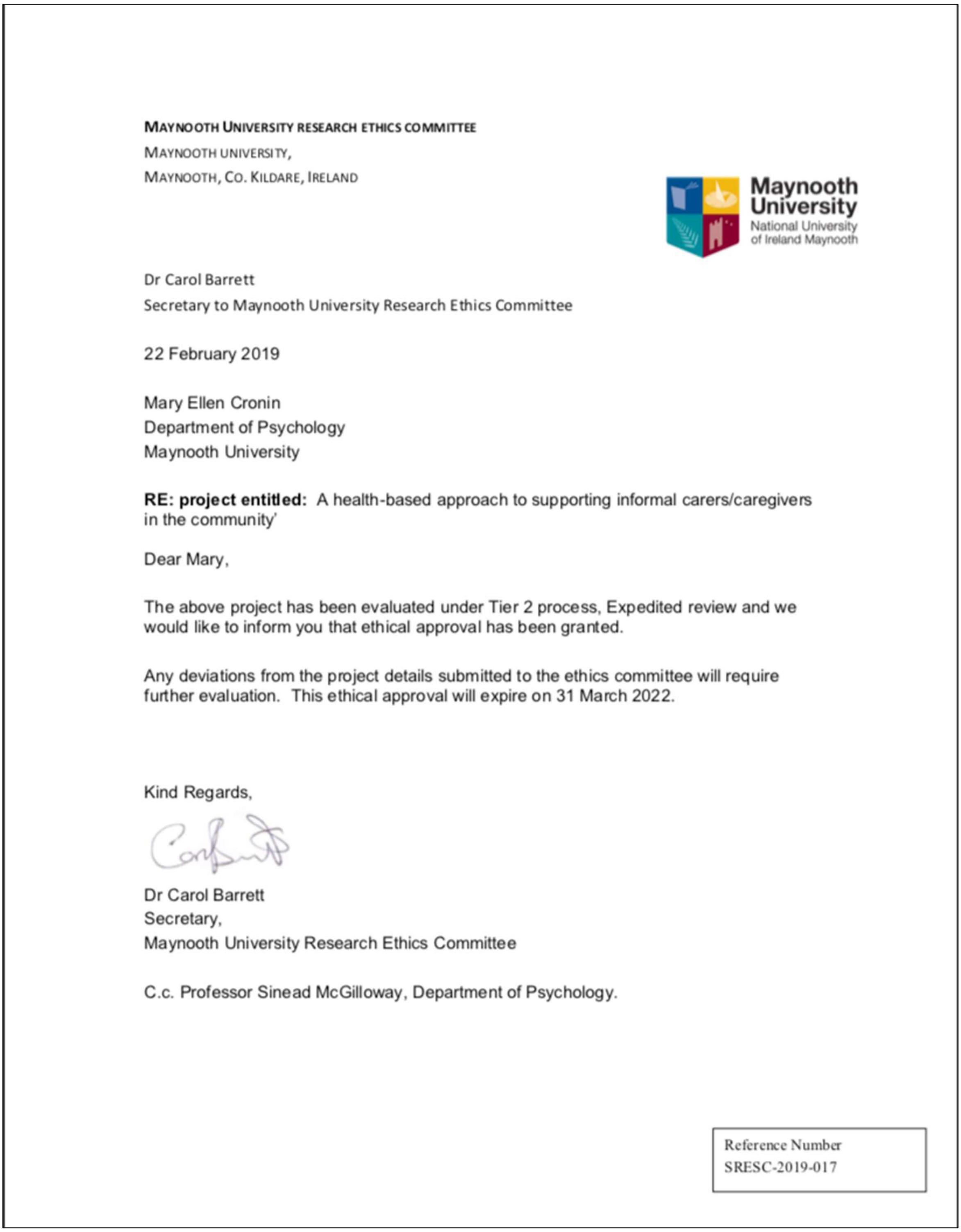
Appendix A1.5 Ethics approval – SRESC-2019-017



MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University Research Ethics Committee

22 February 2019

Mary Ellen Cronin
Department of Psychology
Maynooth University

RE: project entitled: A health-based approach to supporting informal carers/caregivers in the community'

Dear Mary,

The above project has been evaluated under Tier 2 process, Expedited review and we would like to inform you that ethical approval has been granted.

Any deviations from the project details submitted to the ethics committee will require further evaluation. This ethical approval will expire on 31 March 2022.

Kind Regards,

Dr Carol Barrett
Secretary,
Maynooth University Research Ethics Committee

C.c. Professor Sinead McGilloway, Department of Psychology.

Reference Number
SRESC-2019-017

Appendix A1.6 Conference presentation slides – Study One

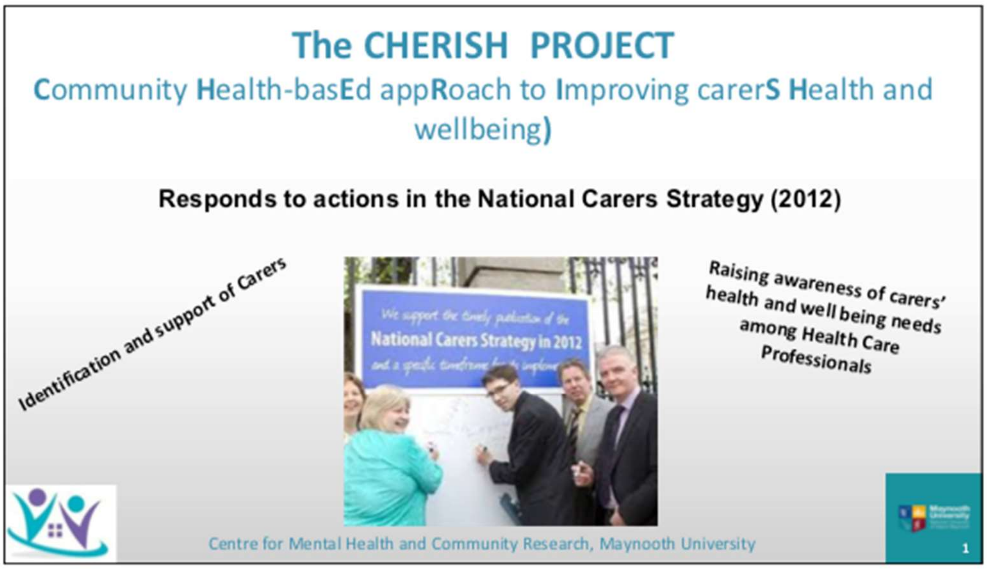
Promoting a '*Think Carer*' approach in Ireland's health and social care services: First steps

THE CHERISH PROJECT

Mary Cronin and Sinead McGilloway

Centre for Mental Health and Community Research
Maynooth University Department of Psychology

Centre for Mental Health and Community Research, Maynooth University



The CHERISH PROJECT

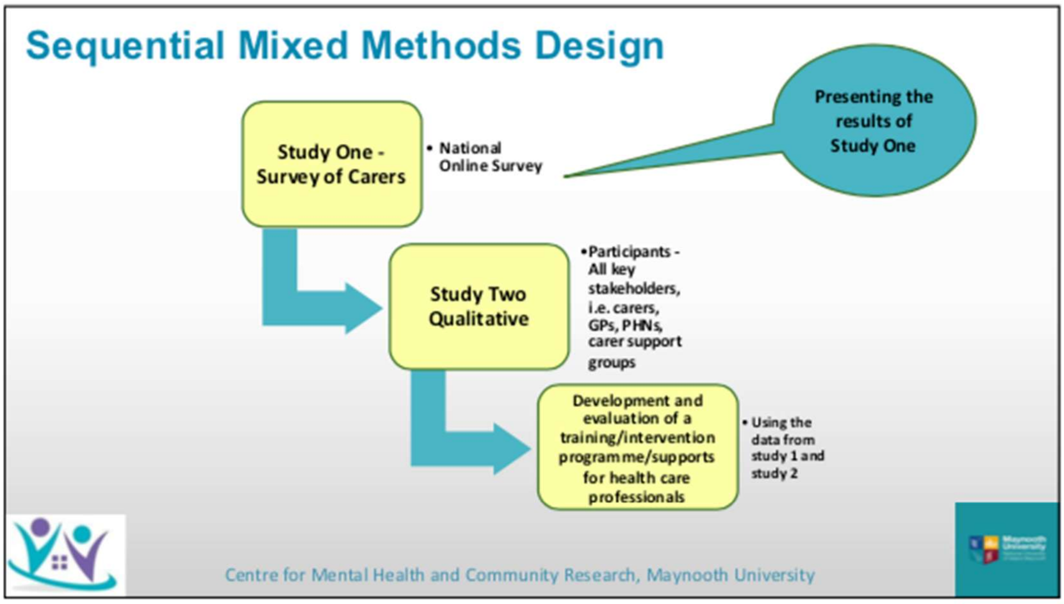
Community **H**ealth-bas**E**d app**R**oach to **I**mproving carer**S** **H**ealth and wellbeing**)**

Responds to actions in the National Carers Strategy (2012)

Identification and support of Carers

Raising awareness of carers' health and well being needs among Health Care Professionals

Centre for Mental Health and Community Research, Maynooth University



Sequential Mixed Methods Design

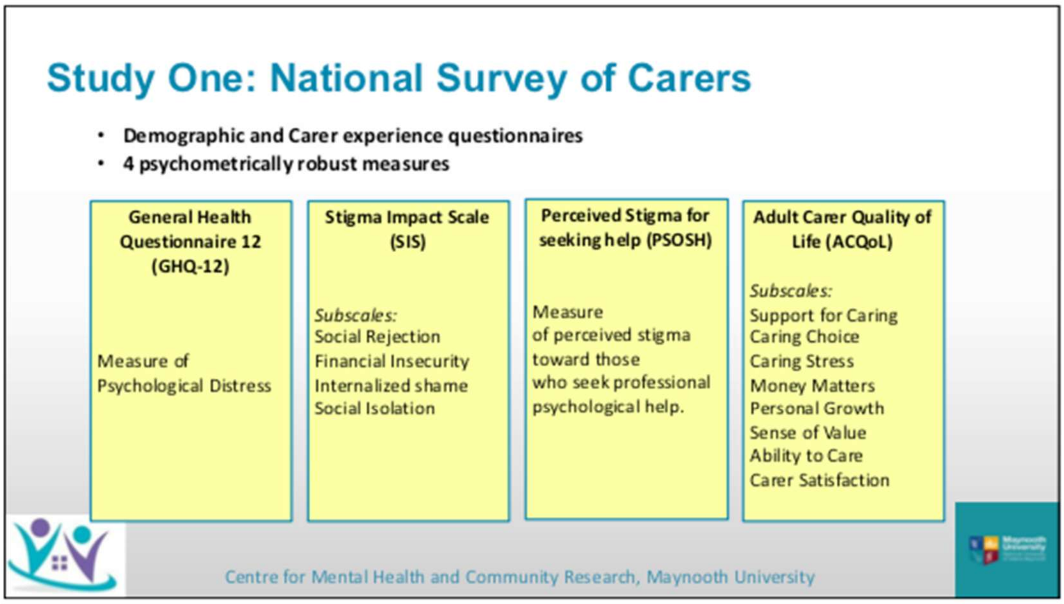
Study One - Survey of Carers
- National Online Survey

Presenting the results of Study One

Study Two Qualitative
- Participants - All key stakeholders, i.e. carers, GPs, PHNs, carer support groups

Development and evaluation of a training/intervention programme/supports for health care professionals
- Using the data from study 1 and study 2

Centre for Mental Health and Community Research, Maynooth University



Study One: National Survey of Carers

- **Demographic and Carer experience questionnaires**
- **4 psychometrically robust measures**

General Health Questionnaire 12 (GHQ-12)	**Stigma Impact Scale (SIS)**	**Perceived Stigma for seeking help (PSOSH)**	**Adult Carer Quality of Life (ACQoL)**
Measure of Psychological Distress	*Subscales:* Social Rejection Financial Insecurity Internalized shame Social Isolation	Measure of perceived stigma toward those who seek professional psychological help.	*Subscales:* Support for Caring Caring Choice Caring Stress Money Matters Personal Growth Sense of Value Ability to Care Carer Satisfaction

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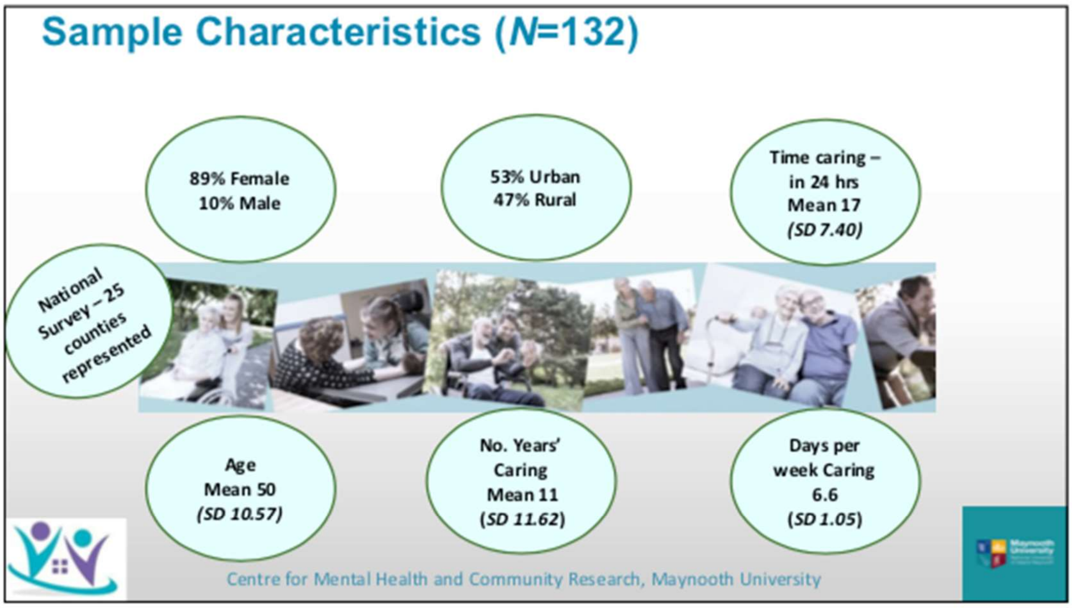

Sample Characteristics (*N*=132)

89% Female
10% Male

53% Urban
47% Rural

Time caring – in 24 hrs
Mean 17
(SD 7.40)

National Survey – 25 counties represented

Age
Mean 50
(SD 10.57)

No. Years' Caring
Mean 11
(*SD 11.62*)

Days per week Caring
6.6
(*SD 1.05*)

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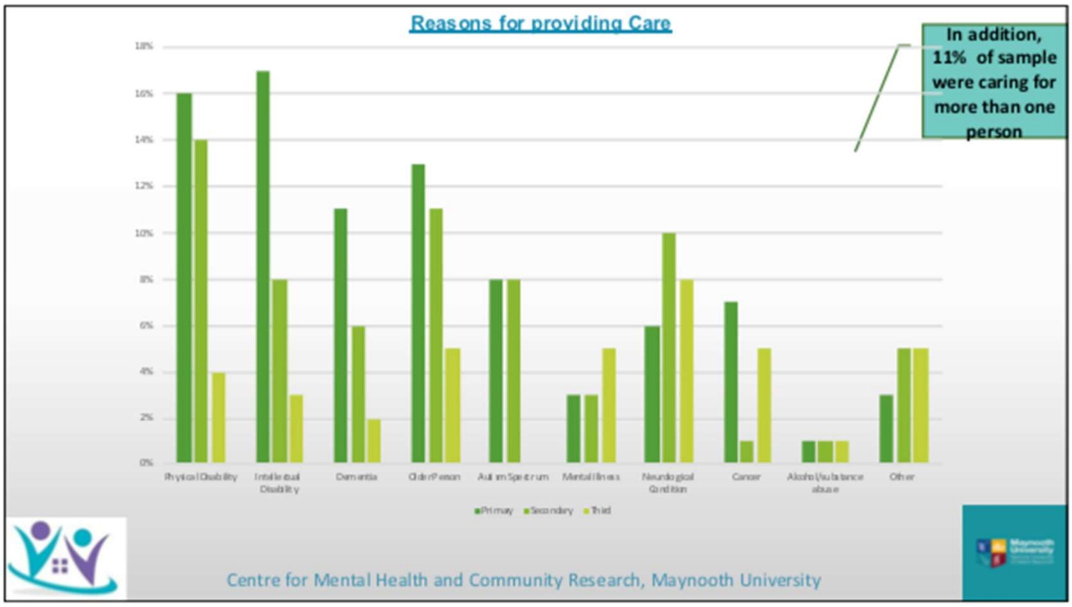

Reasons for providing Care

In addition, 11% of sample were caring for more than one person

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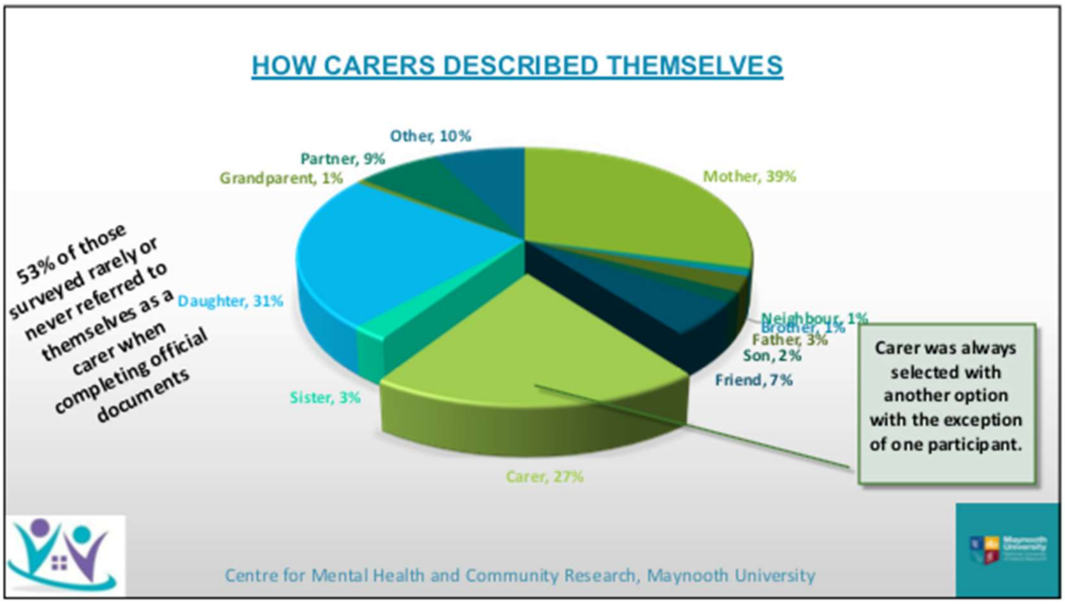

HOW CARERS DESCRIBED THEMSELVES

53% of those surveyed rarely or never referred to themselves as a carer when completing official documents

Carer was always selected with another option with the exception of one participant.

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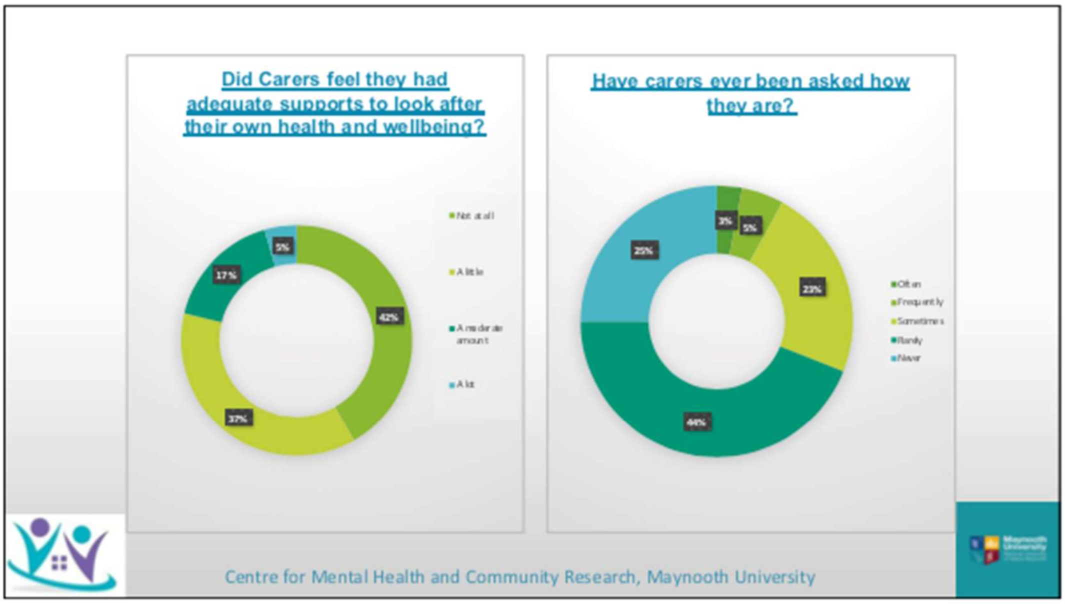

Did Carers feel they had adequate supports to look after their own health and wellbeing?

Have carers ever been asked how they are?

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Perception of Healthcare Professionals

- ☐ 61% felt that Health Care Professionals *rarely or never* understand the challenges faced in caring role
- ☐ 51% felt that HCPs are *rarely or never* concerned for carers' health and wellbeing
- ☐ 77% felt that HCPs are *rarely or never* interested in hearing about their experiences of caring

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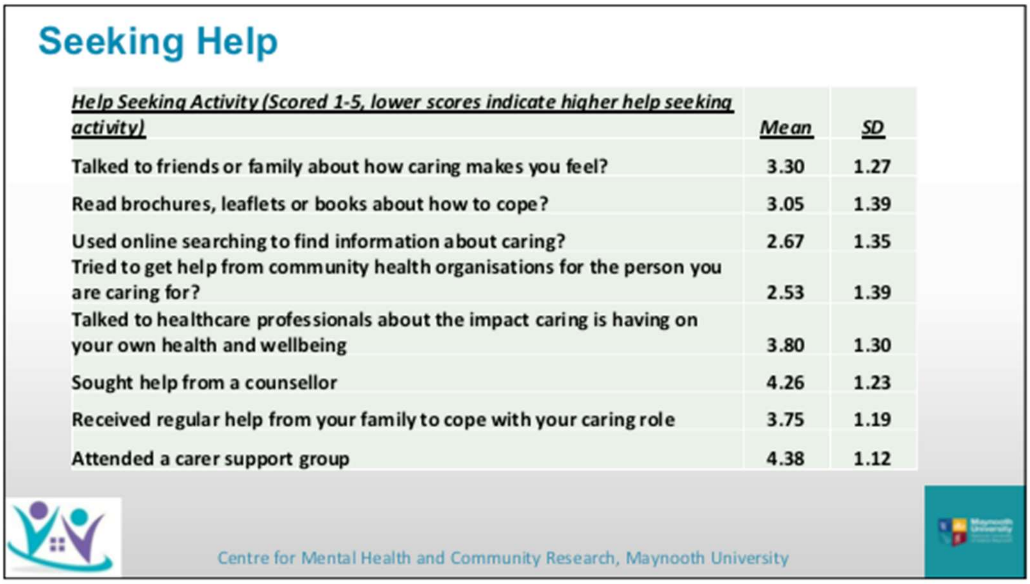

Seeking Help

Help Seeking Activity (Scored 1-5, lower scores indicate higher help seeking activity)	*Mean*	*SD*
Talked to friends or family about how caring makes you feel?	3.30	1.27
Read brochures, leaflets or books about how to cope?	3.05	1.39
Used online searching to find information about caring?	2.67	1.35
Tried to get help from community health organisations for the person you are caring for?	2.53	1.39
Talked to healthcare professionals about the impact caring is having on your own health and wellbeing	3.80	1.30
Sought help from a counsellor	4.26	1.23
Received regular help from your family to cope with your caring role	3.75	1.19
Attended a carer support group	4.38	1.12

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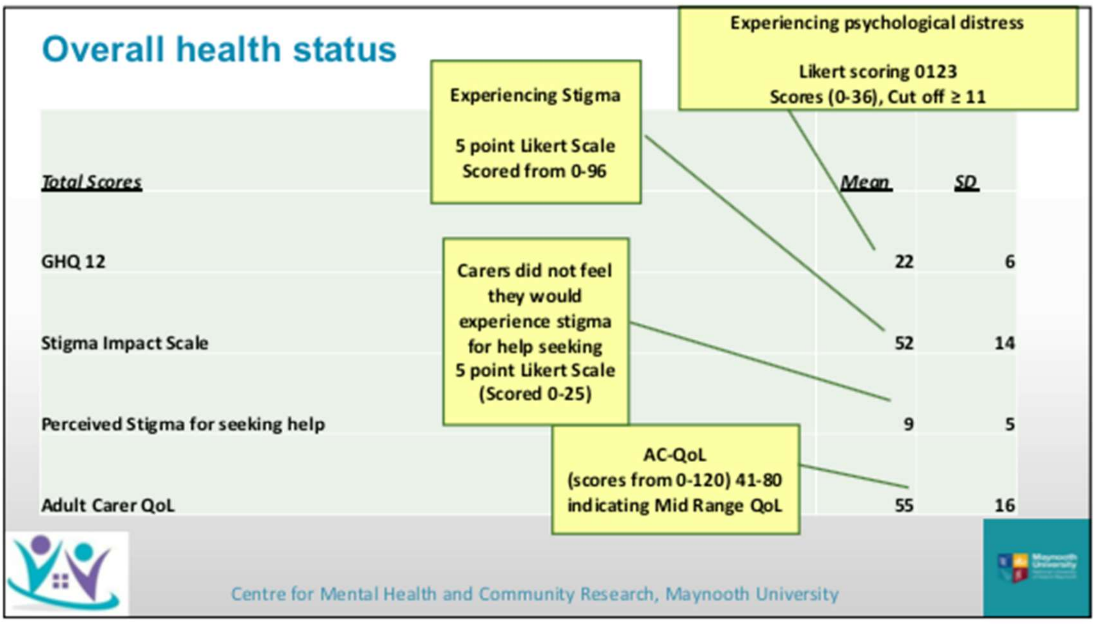

Overall health status

Total Scores	*Mean*	*SD*
GHQ 12	22	6
Stigma Impact Scale	52	14
Perceived Stigma for seeking help	9	5
Adult Carer QoL	55	16

Experiencing psychological distress

Likert scoring 0123
Scores (0-36), Cut off ≥ 11

Experiencing Stigma

5 point Likert Scale
Scored from 0-96

Carers did not feel they would experience stigma for help seeking
5 point Likert Scale
(Scored 0-25)

AC-QoL
(scores from 0-120) 41-80 indicating Mid Range QoL

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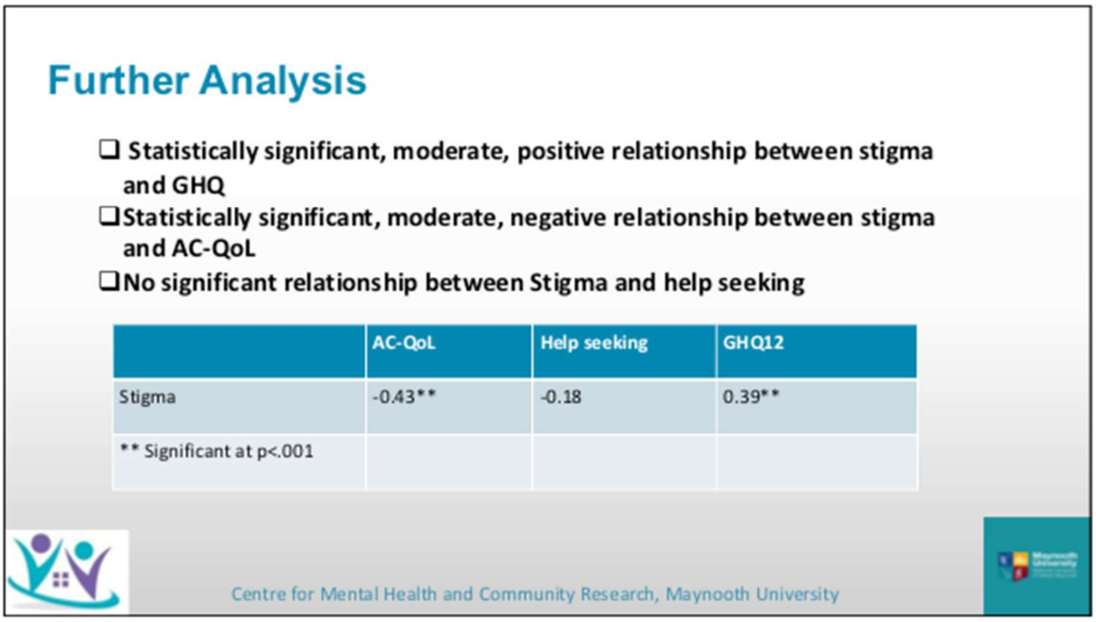

Further Analysis

- ❑ Statistically significant, moderate, positive relationship between stigma and GHQ
- ❑ Statistically significant, moderate, negative relationship between stigma and AC-QoL
- ❑ No significant relationship between Stigma and help seeking

	AC-QoL	Help seeking	GHQ12
Stigma	-0.43**	-0.18	0.39**
** Significant at p<.001			

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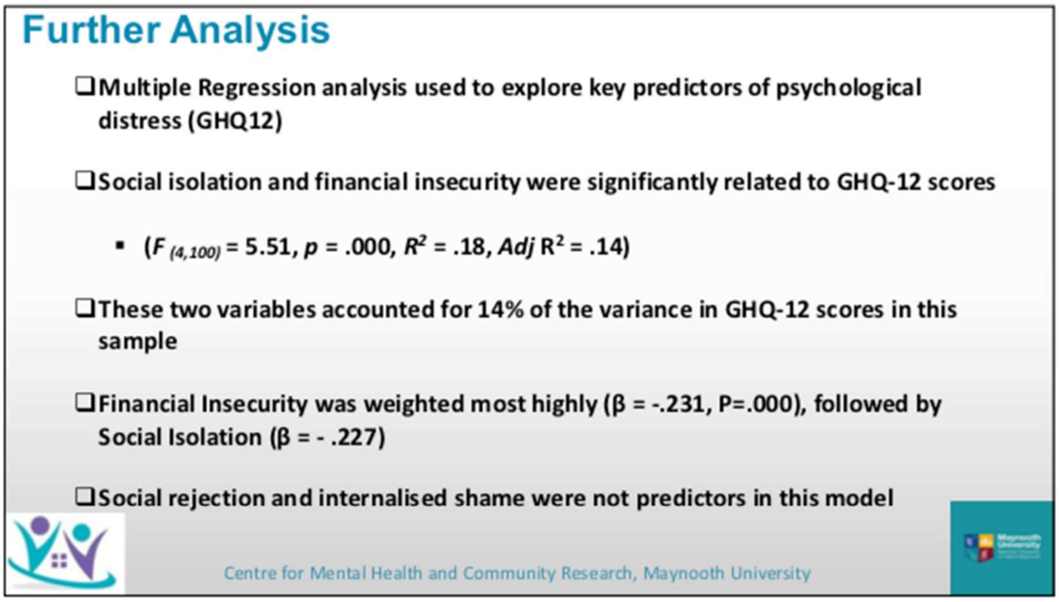

Further Analysis

- ❑ Multiple Regression analysis used to explore key predictors of psychological distress (GHQ12)
- ❑ Social isolation and financial insecurity were significantly related to GHQ-12 scores
  - ($F_{(4,100)} = 5.51$, $p = .000$, $R^2 = .18$, $Adj\ R^2 = .14$)
- ❑ These two variables accounted for 14% of the variance in GHQ-12 scores in this sample
- ❑ Financial Insecurity was weighted most highly ($\beta = -.231$, $P=.000$), followed by Social Isolation ($\beta = -.227$)
- ❑ Social rejection and internalised shame were not predictors in this model

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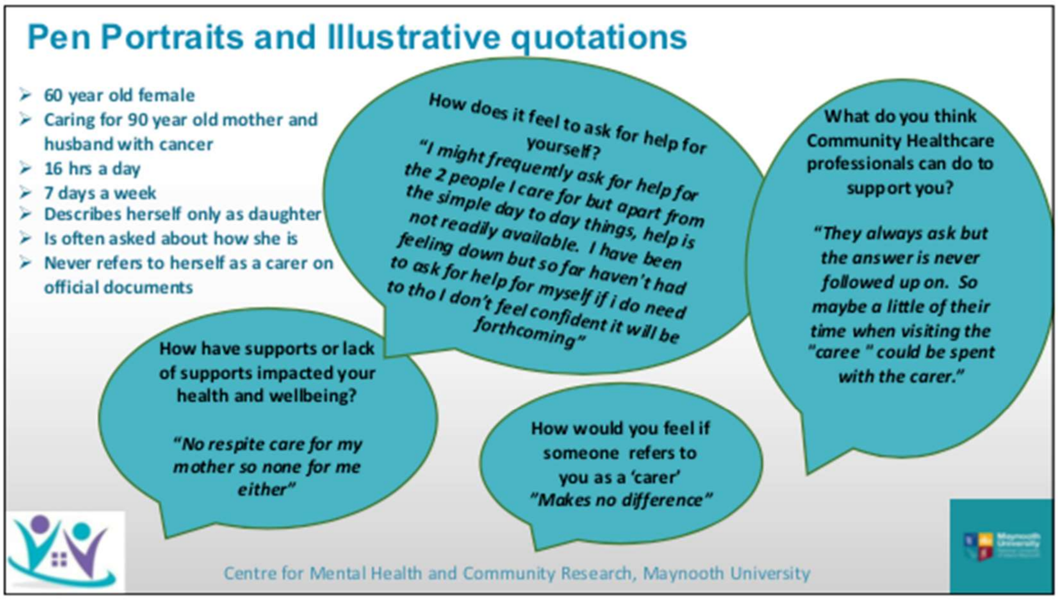

Pen Portraits and Illustrative quotations

- ➢ 60 year old female
- ➢ Caring for 90 year old mother and husband with cancer
- ➢ 16 hrs a day
- ➢ 7 days a week
- ➢ Describes herself only as daughter
- ➢ Is often asked about how she is
- ➢ Never refers to herself as a carer on official documents

How does it feel to ask for help for yourself?

"I might frequently ask for help for the 2 people I care for but apart from the simple day to day things, help is not readily available. I have been feeling down but so far haven't had to ask for help for myself if i do need to tho I don't feel confident it will be forthcoming"

What do you think Community Healthcare professionals can do to support you?

"They always ask but the answer is never followed up on. So maybe a little of their time when visiting the "caree " could be spent with the carer."

How have supports or lack of supports impacted your health and wellbeing?

"No respite care for my mother so none for me either"

How would you feel if someone refers to you as a 'carer'

"Makes no difference"

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- 43 year-old female
- Caring for 3 year old with complex needs
- 24hrs a day
- 7 days a week
- Describes herself only as a mother
- Is rarely asked about how she is
- Has never referred to herself as a carer on official documents

What do you think Community Healthcare professionals can do to support you?

"Stop telling you how you are, such as you are great and strong and so on.. Stop ticking boxes and actually act like they are interested and not in a rush to get you out the door. Take the time to help you find info. This role is overwhelming in and of itself and I find it really hard to begin to know where to look for options for support"

How have supports or lack of supports impacted your health and wellbeing?

"Having a sick child is life altering. Everyone I know works whereas I had to give up for the time being. My finances are low. People are afraid to mind my son so the whole experience is isolating. I cannot remember the last time I felt relaxed. I don't sleep great and cry a lot"

How would you feel if someone refers to you as a 'carer'

"No one ever has so not sure. I am a mother"

How does it feel to ask for help for yourself?

"I find it hard. I don't think people want to hear it. Think others will feel I'm using the role for sympathy"

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- 47year old male
- Caring for 6 year old with ID and ASD
- 14hrs a day
- 7 days a week
- Describes himself only as a father
- Is never asked about how he is
- Has never referred to himself as a carer on official documents

How would you feel if someone refers to you as a 'carer'

"Like less of a parent"

How have supports or lack of supports impacted your health and wellbeing?

"Anxiety and depression"

What do you think Community Healthcare professionals can do to support you?

"Ask about my health and wellbeing. Let them start the conversation. Offer support rather than waiting to be asked."

How does it feel to ask for help for yourself?

"I don't ask for help for myself"

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Conclusion:

❑Carer sample experienced moderate psychological distress and stigma

❑Stigma was positively related to psychological distress

❑Stigma was negatively related to quality of life

❑Social isolation and financial insecurity were found to be predictors of psychological distress

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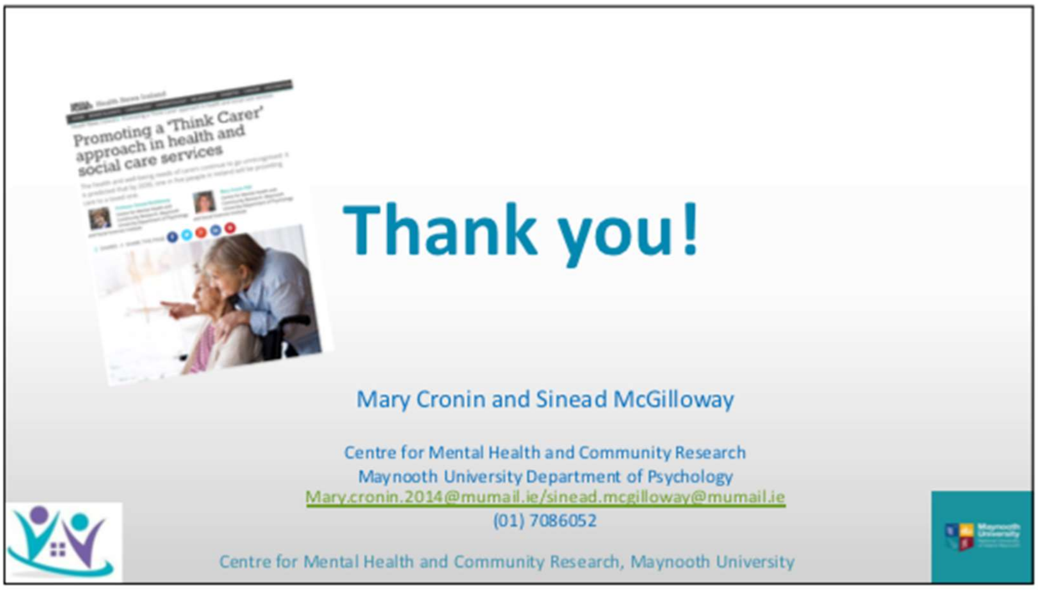
Conclusion:

❑Carers do not feel supported or understood by many HCPs

❑Most participants did not formally or informally identify as a 'carer'

❑Findings support the incorporation of a role for HCPs in supporting carers and inclusion of same in National Carers Strategy

❑There is an important need for education/training/information for HCPs and for research to inform the development of intervention/materials/supports



Promoting a 'Think Carer' approach in health and social care services

Thank you!

Mary Cronin and Sinead McGilloway

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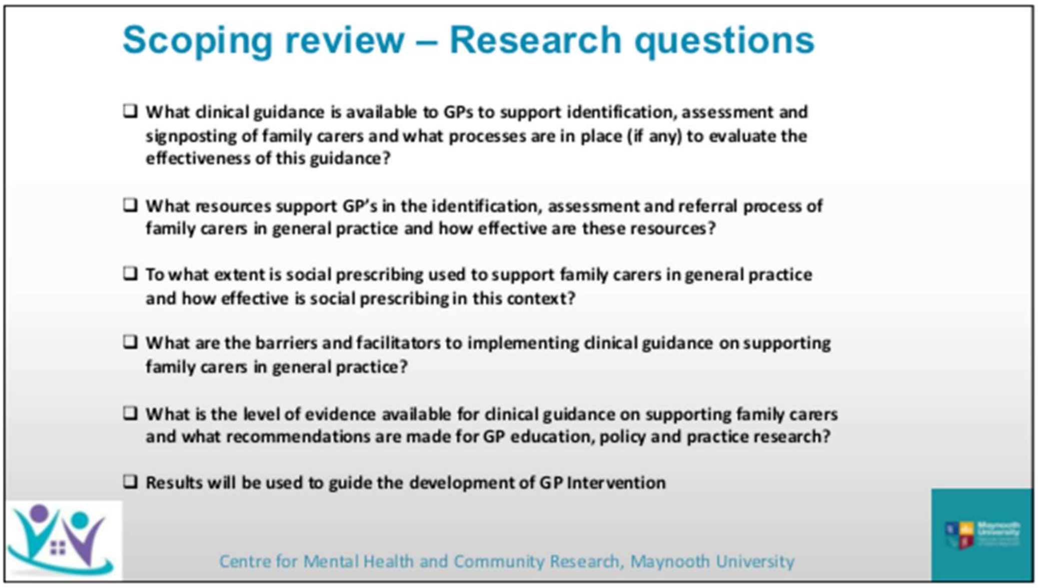


Scoping review – Research questions

- ☐ What clinical guidance is available to GPs to support identification, assessment and signposting of family carers and what processes are in place (if any) to evaluate the effectiveness of this guidance?
- ☐ What resources support GP's in the identification, assessment and referral process of family carers in general practice and how effective are these resources?
- ☐ To what extent is social prescribing used to support family carers in general practice and how effective is social prescribing in this context?
- ☐ What are the barriers and facilitators to implementing clinical guidance on supporting family carers in general practice?
- ☐ What is the level of evidence available for clinical guidance on supporting family carers and what recommendations are made for GP education, policy and practice research?
- ☐ Results will be used to guide the development of GP Intervention

Appendix A1.7 Healthnews publication

This paper was published in Healthnews.ie in February 2019.

Cronin, M. & McGilloway, S. (2019) Promoting a 'Think Carer' approach in health and social care services. *Healthnews* (Online), https://www.healthnews.ie/neurology/promoting-a-think-carer-approach-in-health-and-social-care-services/

Promoting a 'Think Carer' approach in health and social care services.

The well-being needs of carers health continue to go unrecognised. One in five people in Ireland will be providing care to a loved one by 2030.

Ireland's population is ageing, which means that a growing number of people are living with dementia and other chronic conditions. People with disabilities are also living longer.

Thus, many of our most vulnerable citizens depend heavily on the unpaid work of family carers. Through their selfless and often unrecognised work, they save the state billions of euro annually. According to the CSO Irish Health Survey, 10% of the population over 16 are carers.

The caring experience

Providing care to a loved one can be rewarding for family members, but it is not without its challenges. However, family-member carers are often not equipped to meet all of their needs (see Figure 1). Furthermore, the demands of the caring role mean that carers often have little time to look after their own health.

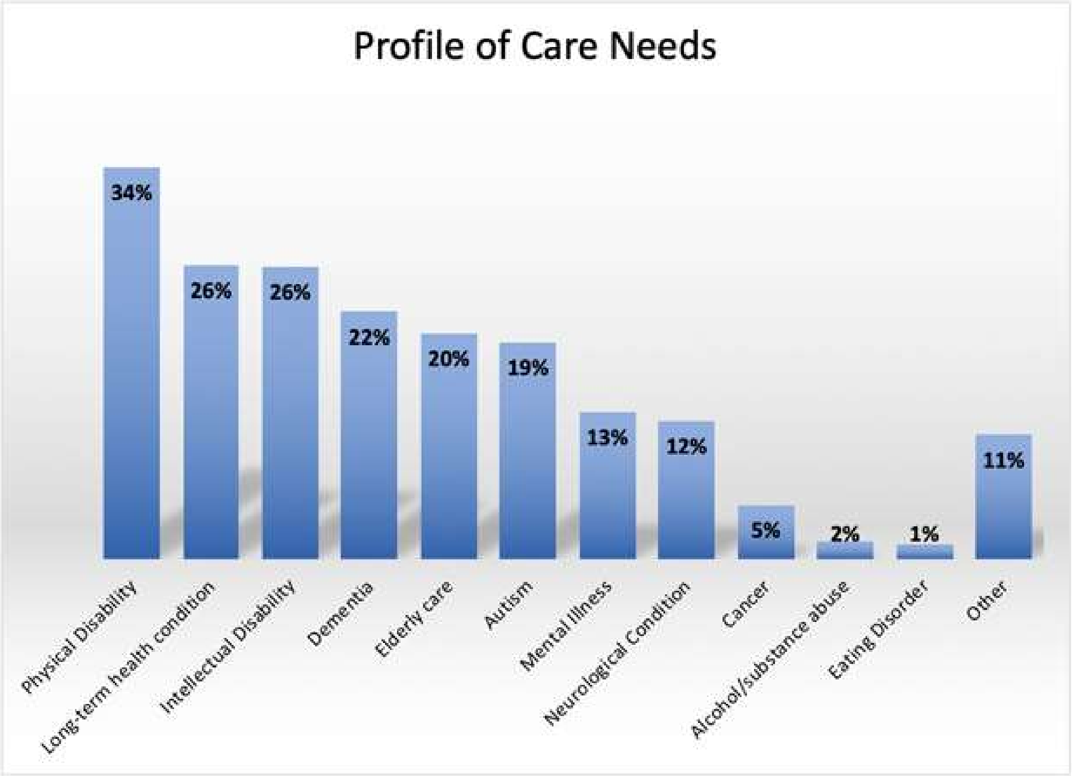


Figure 1: The diversity of care needs in Ireland, (Care Alliance Ireland, 2015)

Carers experience poorer physical and mental health than the general population; the demands of the caring role can leave them physically exhausted and emotionally isolated.

Carers' wellbeing is often misunderstood

The public regard carers highly (as exemplified by the recent 'Carer of the Year' awards). However, many report that their communities do not typically understand, the challenges of caring and its impact on the carer. Carers are asked frequently about their loved one, but are rarely asked about their own health and wellbeing.

Feeling invisible as a carer

On a related point, despite the carer advocacy work of organisations such as Family Carers Ireland and Care Alliance Ireland, many carers report feeling undervalued, overworked and under-supported. Indeed 'invisible' is often a word they use to describe themselves and the challenging work they do. This invisibility of carers is likely to continue if we do not initiate a conversation about caring with all relevant stakeholders. These include health and social care professionals.

Changing our policy on carers

Recent years have seen an increasing focus on community healthcare. These have been through the development of primary care centres in many areas around the country. Thus, health services may now be better placed to support vulnerable groups in the community such as carers. However, healthcare professionals must understand carers needs, and help them with support and consultation.

Thinking of the patient and the carer

One possible solution to this challenge would be to provide awareness-raising events and training for health care professionals regarding the needs of carers. For example, in Australia, a programme called ‘Think Patient, Think Carer’ encourages primary care services to consider the needs of carers who may be supporting a person with a chronic condition.

Likewise, in England, the Royal College of General Practitioners has developed a toolkit and ‘Action Guide’ to help GPs better support carers. To date, no such community health initiatives exist in Ireland to support the health and wellbeing of carers at a national level, thereby indicating a yawning gap in current provision.

The team at the Centre for Mental Health and Community Research, Maynooth University Department of Psychology, aims to address this gap in an Irish context by identifying the facilitators and barriers to the implementation of a community healthcare approach, whilst also investigating perceived carer stigma and training of health care professionals.

The development of, for example, practice guidelines and training will be informed by these findings. Carers will get support in appropriate, timely and effective ways by implementing this at a national level. The early findings of this research will be available in late 2019.

Appendix A1.8 Transcript and audit trail of analysis - GP interview 1

Interviewer (INT): Mary Cronin
Interviewee: GP_1
Date of interview: 11/3/20
Length of Interview: 21 mins

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
INT	Hello, Dr., Mary Cronin here from Maynooth University, ringing you as agreed. Is it still ok for you to speak now?			
GP_1	Yea, yea that's perfect			
INT	So we'll have about 20 minutes to talk if that's OK. Can I start by asking you a little about your practice			
GP_1	Yes, well, I work 3 ½ days per week, and the other doctor works, eh, about three days a week			
INT	Right, ok			
GP_1	We have about 1,500 eh medical card patients, and probably am, close on that private patients as well			
INT	Right, ok, ok, so it's am quite a number there that your dealing with			
GP_1	It is. It is			
INT	Yeah, yeah			
	Yeah			
INT	And, for your patients who perhaps are chronically ill or have disabilities and who are living in your community, would you usually be aware of who their primary carer is?			
GP_1	Am, for the most part, no, I'm only in the practice about a year at this stage, am the previous GP is retiring, he is			

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
	nearly finished, he will be finishing in the next while so he would be obviously be up to date on that, he's am, he's been there for 40 years so he would be the real touchstone for that kind of thing.	*(Established relationship with GP is important – carers are identified through long standing relationship)*	Identification	
		Identifying carer through informal ways		
	Yeah, so if there are concerns or questions, you know, I'd always kind of run them by him, but generally getting to know them am, as the time goes on.	*(Establishing the relationship takes time)*	Identification	**Navigating through informal processes**
INT	Yes, ok, so it's through, kind of, interaction with the patients? And if their caregiver is with them			
GP_1	Yeah, or occasionally actually through contact with the public health nurse; that's probably the way that most information comes through to us most often am, the carer will am, will come into the appointment with them or be the person touching base for the prescription of whateve,r you know, they are looking for	*(No clear path for information?)* *(Role for PHN?)* Informal Identification through care recipient	Identification	
INT	Right, ok, ok, so the interaction with the carer would be very much in the context of the patient?			
GP_1	Yes			
INT	Am. And do you feel that the carers are equipped to deal with the situations they find themselves in?			

	Transcript of GP Interview 1	**Initial Codes** ***(Researcher comments)***	**Thematic Framework**	**Final Themes**
	I think it depends; it very much depends, it's very much on a case-by-case basis. I think, I've a few patients, or a few carers that come to mind that are very much struggling with their situation that, you know, the supports aren't there to help support them, that's kind of my biggest frustration with it.	Awareness of carer struggle (*Coming to mind easily*) Lack of supports *(An impact on GP here, frustration with lack of support)*	Fragmented services Information Role of GP	**Role Ambiguity**
INT	Right um And then there is others that say that for them, between family and other organisations, they do have other support. You know.	Supports *(is this family support usual?)*	Family Support	
INT	Yeah. Ok, yeah, so you mentioned there that it is frustrating for you as a GP - is there anything you feel that can be offered or how do you approach it?			**Changing needs along care trajectory**
GP_1	I've actually, a number of patients who are carers so both themselves and whoever they are caring for are patients, so you know, there is two responsibilities there for that. So the patient, the people who are with us. the person who is requiring care is often getting great care from the family and or from outside, sort of, it's the carers themselves that I feel are really struggling with the burden of, of this unpaid, unsupported, care…	Identifying carer *(multiple carers)* Separate patients- Carer and care recipient *(Impact on the GP – both carer and care recipient?)* *(Carers needs are secondary?)* Value of caring Lack of supports	Effects of caring	

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
INT	Yea yea , So you feel like it's affecting their health and mental health as well?			
GP_1	Oh, big time. I can think of three patients off the top of my head that I was only ruminating about in the past week or two, going, God, you know, trying to figure out, you know, what extra things could we put in the community for them, to try and help them, spread the load a little bit for them.	Understanding Lack of supports *(Impact on the GP here – lack of resources – "trying to figure out")*	Effects of caring Role of GP	**Role Ambiguity**
INT	Yeah, and in terms of supports that are there in the community, are ye as GPs given any information, you know, regarding what's out there?			
GP_1	Not as, not as I mean we are trying to give whatever information we have, I think, I mean I am quite interested in the area of social prescribing and that kind of thing. I worked in psychiatry of later life, in Galway when I was training and that team actually is probably what sparked my interest in this whole thing because we had a really good setup with social worker, occupational therapist, psychologist and while so much of it was to help manage patients with dementia or you know, psychiatric issues over the age of 65, an awful lot of the time the patients came in when the carers just couldn't manage any more.	Information is limited (*sense of a struggle with information*) *(Social prescribing important?)* *(Interest is coming from prior experience)* *(Seeking help when unable to cope)*	Effects of caring Role of GP Information Effects of caring	**Changing needs along care trajectory** **Navigating through informal processes**
INT	Yes			
GP_1	Once supports were put in place like day services or, you know, links with the Alzheimer's society, you know, that kind of thing that that made huge differences for the carer and subsequently for the patient themselves.	Importance of supports *(Impact of supports on carer evident here)*	Information	

	Transcript of GP Interview 1	Initial Codes*(Researcher comments)*	Thematic Framework	Final Themes
INT	Yes			
GP_1	Am so I would try to link in with that kind of thing and recommend the carers association, and you know, depending on whatever the condition is that the person requiring care has to try and give information like that but actually beyond, say going to the website it can sometimes be difficult to get specific local information for them.	Supports *(individualised depending on the condition of the person?)* Resources Limited information *(Attempts to source help by the GP – time consuming? Will all GPs so this?)*	Information Role of GP	**Role Ambiguity**
INT	So it sounds like you've had conversations with carers about their own health and their well-being?			
GP_1	Yes			
INT	And you've gone, and you've tried to source things for them, would that have generally been a conversation that you initiated, or do you find it was the carer that asked for the support?			
GP_1	A bit of both, am I would try and address it, if you know, a few people who come in with mom or dad who has dementia and their able to converse in the conversation and all the rest of it, but they're not following the whole thread and I would generally touch base with that carer in an informal way in that conversation and see how things are and it would need to be explored a bit more in that moment otherwise we might need to ask them to come	Communication Hesitation/informal *(Unsure how to proceed?)*	Identification Effects on communication Role of GP	**Navigating through informal processes**

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
	back and have a proper chat about it. But it's something that I'm quite aware of, and I do try to bring it up if I can.	*(communication sometimes needs to be 'in the moment')* Informal process		**Role Ambiguity**
INT	Right, Ok, and those interactions then, are they ever charted or documented?			
GP_1	Generally, yes, if the patient is, if the carer is our patient, then yes, it would be. Definitely recorded. If it's not, if the consultation is for the person requiring care.	*(Carer and carer recipient as separate)*	Documentation	
INT	Right ok, ok, so it's when it is known that they are in a caring role?			
GP_1	Yeah, yeah			
INT	Ok			
GP_1	Yeah, that we would try ta, because it's important to, you can bring it up next time, like, how are thing going now, has anything changed blah blah. And I mean, I find so many people don't want to relinquish the caring role, they don't want to hand over, am they feel they can't hand over responsibility, that they are leaving the person down by reaching out for help but I'm afraid I'm constantly saying that if we can't mind you, you can't mind anybody else.	Communication Informal Understanding of caring *(does this align with how the carers feel about asking for help?)*	Effects on communication Effects on communication	
INT	Yes, so you are having those conversations with people			

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
GP_1	Yeah I am			**Role Ambiguity**
INT	The National Carers Strategy suggests a role for GPs in identifying and supporting carers. I don't know if the NCS - whether it filtered down into GP practices?			
GP_1	Not that I have seen it, to be honest	*(No awareness of NCS?)*	Information Training and Resources	
INT	Right, Ok, Yeah, yes, Do you feel it [identification and support of carers] has a place in GP practice?			**Navigating through informal processes**
GP_1	Oh definitely, I mean, carers provide such an invaluable role for free to government and society and are taking up such a huge amount of slack that if they're not supported, you know, the whole thing would literally just fall apart, you know, you wouldn't be able to look after these vulnerable people and its often, I find, these vulnerable groups you know like people with intellectual disabilities or the elderly because you know it can be so labour intensive and time intensive for their carer as time goes on, it's so hard for them to advocate then for themselves as well as the people they are caring for.	Value of caring *(awareness of the value of caring to the overall health service)* Understanding *(effects of caring on carer own health & WB)* Impact of caring	Effects of caring Stages of caring	**Changing needs along care trajectory**
INT	So really, what you are saying, what I am hearing, is that really you feel there is a benefit to your practice and …			
GP_1	Yeah			
INT	To the health service in general?			

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
GP_1	Yeah, hugely, I mean, hugely so, otherwise the, I mean there is three or four people I can think of, off the top of my head, that if the families weren't providing the supports that are being provided, the patients would end up in nursing homes and wouldn't have as good a quality of care as they do.	Value of caring Understanding *(interesting comment about quality of care: home or family carer – and nursing home)*	Effects of caring Stages of caring	**Changing needs along care trajectory**
INT	And one of the things that came up there as we were talking was you were mentioned that sometimes it's difficult for you as a GP to try and source information, if there was some structure that would support GP's in their role with family carers what do you think that might look like based on your experience?			
GP_1	I'd love, I'd love a database that was regionalised, you know, that place by place you could see what was available and the different, you know, the voluntary groups play a huge part and can really do so much better but if we don't know about it then, and because GPs move, so like I'm only out of training so like I'm from (Van Schalkwyk et al.), but I'm settled here, but like a lot of my colleagues would be travelling around the country moving from region to region so you know if you go in somewhere you don't know, if there was a national database that…	Information Supports *(Information can be a source of support)* *(GPs move around a lot?)* Supports as local *(Local information coming across as important here)*	Information Information	**Navigating through informal processes**
INT	Yes			
GP_1	You know all the information was there, and you could have links to outside societies or whoever and then you could link it through to their website or whatever because	Lack of information Impact on GP	Information	

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
	sometimes it's trying to think of who, who would be the best person for this, for this kind of role can be a challenging thing in a 15-minute conversation you know.	Communication *(would many GPs even consider this in a short consultation? Time is limited)*		
INT	Absolutely, and I suppose what you are suggesting there is that, at the moment, a lot of it is dependent on local knowledge?			
GP_1	Yes, exactly, and you know, small groups and that sort of thing they might advertise locally, but if a GP doesn't live in the area, they mightn't know about it, so if there was some sort of a forum where they could, you know, post information about what's available you know coffee mornings or an hour here or there you know that kind of thing, you know I think that could make a big difference.	Resources for GP Information *(Importance of local again here – easy access to information)*	Information	**Navigating through informal processes**
INT	Ok, ok, and you've mentioned there as well that you've come out into the workforce in the last year as a GP, do you feel there was anything that would have benefited you in your training, perhaps? Before?			
GP_1	I think that job that I did, like, well as a student I would have worked as a care assistant myself but that job that I did in psychiatry later REALLY opened my eyes to the carers role more so than other jobs would have, you know, so like if you were working in A&E you would obviously meet the carers in acute situations but you know it was a through put thing, but there was time in that job to develop a relationship and we followed that patient through time and that kind of thing and that	*(Prior professional experience is important- it has informed knowledge during training - and interest?)* Understanding of caring	Training and resources Training and Resources	**Role Ambiguity**

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
	probably opened my eyes probably more so than any other job in my training, and it's not a job that everybody does you know, it's a lottery type of thing, not everyone does psychiatry of later life, and not all the services are as well supported as the one I worked in so I just think I was lucky to get that one.	Time to build relationship *(knowledge and approach to carers coming from prior experience - that other GP not likely to have?)*		
INT	Right Ok, so it was through your various experiences rather being exposed to particular?			
GP_1	Yea, yea I don't remember anything, well that's not true, I think when I was in med school, we probably would have had some interaction with parents and carers of kids with disabilities and that kind of thing, but that's kind of lost, to be honest at this stage, (Brazil et al.) you know in my brain but I think I was very lucky to have had that experience in psychiatry of later life that has informed by views.	*(Nothing formal in training regarding family carers)* Training *(interacting with carers through work/training is important)*	Training and resources	**Role Ambiguity**
INT	Yes, and do you feel it would be beneficial to have electronic resources, maybe electronic training perhaps for GPs, you know, to support them in having the conversations with carers and being able to perhaps source information for them?			
GP_1	Yea, I think it probably would be yea, we've an awful lot of, we are bombarded with electronic training and that kind of thing, I do think the access to, a centralised place for access to resources for help and support would really make a difference just because depending on your	Resources *(easy to access is important!)*	Information Training and Resources	**Navigating through informal processes**

	Transcript of GP Interview 1	**Initial Codes\(*Researcher comments)***	**Thematic Framework**	**Final Themes**
	surgery things can be a bit hectic and there might have been three other things that the person actually came in for to flag it but definitely an awareness campaign or something like that would be useful you know.	Communication Challenges in General Practice/impact on GP		
INT	Great thank you, and do have anything to add yourself cause obviously, I am coming to this with the information we have from carers and the literature that is out there.			
GP_1	Am, no I suppose, just that it's such an undervalued part of our society, and they need to be looked after because without them, the whole thing would fall apart, and we would end up seeing these vulnerable patients so much more because they wouldn't have the same level of care essentially that they get at home and I really think that we don't support the carers well enough and we need to try and push that agenda a bit more like I mean the patients can't advocate and with politicians and stuff there is little interest in looking after the carers which is disappointing.	Value of Caring *(recognition of the contribution)* Understanding *(Sympathetic to needs of carers and how they are supported)*	Effects of caring	**Changing needs along care trajectory**
INT	Yes, it is, and in terms of the other people in your practice. So like practice nurses, you mentioned public health nurses as well a little while ago do you feel there is a role for any of those people?			
GP-1	I think our practice nurses do a great job; they'd often flag, you know, if a patient was in for bloods or anything like that, they mightn't necessarily flag who the carer is but they might notice that the person themselves has deteriorated, a little bit and might flag with us to bring that person in to touch base with them and that kind of	Informal information *(Is information passed informally within the health system?)* Communication	Information	

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
	thing so there is definitely a role for practice nurses to take in it.	*(Covert approach to communication?)*		**Navigating through informal processes**
INT	And in terms of when a practice nurse flags it, perhaps the approaching of the carer is another point of interest, in the sense that do you find they are all open to discussing their caring role or?			
GP_1	Not. Everybody. Is. It sometimes it takes two or three conversations to have it mentioned. I can think of one woman that you know I touch base with as in "how are things"?, and if she doesn't want to go into it, she doesn't want to go into it then, and you can't force it, and three of four conversations then and you find it all comes out and you realise she is really struggling and all the rest and that's kind of the art of general practice to let them know that you are there if there is an issue but not to force it if they are not in the headspace to deal with in that time.	Communication *(carers can be reluctant – GP persevering here to create the space?)* Process of communication *(Threading carefully until the carer is ready)*	Identification Effects on communication	
INT	Ok, so you feel that the approach of maybe gently prompting it and that over time, the person comes to..			**Role Ambiguity**
GP_1	Ye, am unburden on you or reach out or whatever. I think if they are aware that you are aware that things are difficult, it makes it that bit easier for them.	Communication	Effects on communication	
INT	So bringing it up earlier makes it easier for them to come and talk about their own particular situation?			
GP_1	Yes for sure.			
INT				

	Transcript of GP Interview 1	**Initial Codes*(Researcher comments)***	**Thematic Framework**	**Final Themes**
	That is great. Well, thank you so much - it's been so informative having the conversation with you.			
GP_1	No problem at all.			
INT	Is there anything else you want to add before we finish or do you have any questions for me?			
GP_1	No, no I don't; well how long have you to do or how many are you hoping to get?			
INT	Well we are hoping to take the data saturation lead on that in the sense that we would continue to interview until no new information is emerging am			
GP_1	Ok yea yea.			
INT	And to interview all stakeholders as well, obviously we see the GP as being quite central in that a lot of people report through the GP or refer through the GP, so I suppose that is why I am looking to get the GP's perspective in the first instance.			
GP_1	Well, best of luck with it; qualitative research is not the easiest to get through.			
GP_1	Thank you, and thank you for your participation.			

Appendix A2.1 Search strategy – Scoping Review

Database search strategy.

OVID MedLine: Searched 9th November, 2020

(general pract* or GP or GPs or family pract* or primary care physician or family physician or family doctor or Medical Home or community care or Family Medicine or Primary Health Care or ambulatory care or Community Care).tw.
*General Practitioners/
*Primary Health Care/
(((carer* or caregiver*) adj3 (spouse or son or daughter or unpaid or informal or lay)) or carer* or caregiver* or care-giver*).tw.
*Caregivers/
*Needs Assessment/
*social support/
exp *Burnout, Psychological/
exp Psychosocial Support Systems/
(best practice* or guid* or polic* or procedure* or algorithm* or protocol* or position paper* or standard* or white paper* or consensus statement or toolkit or consensus or practice recommendation* or pathway* or model or bundle or checklist* or recogni$* or refer* or assess* or screen* or signpost* or health impact assessment* or need* assessment* or social prescri* or community prescri* or community refer* or social refer* or social intervention or intervention or scheme*).tw.
*practice guideline/
(Policy and procedure manuals).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
*Health Policy/
(referral and consultation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
*"Referral and Consultation"/
*Patient Identification Systems/
Decision Trees/

Appendix A3.1 PPI panel information sheet and informed consent

PARTICIPANT INFORMATION SHEET: PPI PANEL

Study Title: CHERISH' (**C**ommunity **H**ealth-bas**E**d app**R**oach to **I**mproving carer**S**' **H**ealth and wellbeing)
Investigators: Mary Cronin, Professor Sinead McGilloway, Maynooth University Department of Psychology
Collaborating partners: Niamh Finucane, Dr. Kathy McLoughin, Family Carers Ireland

Introduction

We would like to invite you to take part in a Public and Patient Involvement (PPI) element of an ongoing research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please contact or ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

The purpose of this study is to strengthen awareness of the role/contribution of family carers and to improve how their health and wellbeing needs can be met in General Practice/Primary Care. During the earlier stages of the research, we consulted with family carers and GPs through a survey and interviews. The findings will now be used to design an online, mixed media, distance learning education programme for GPs to convey the importance of, and approaches to, identifying family carers and where to signpost/refer them for further support. In addition, we hope to deliver a workshop for family carers to empower them in their consultations with GPs.

Why have I been asked to take part?

You are being asked to take part because you are currently providing care for a family member or loved one. The research team at Maynooth University and Family Carers Ireland would like to invite you to participate in a focus group with a small number of other family carers in order to help design the proposed training for GPs and the 'empowerment workshop' for carers.

Who has approved this study?

The research has been reviewed and approved by Maynooth University Social Research Ethics Subcommittee (SRESC).

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give some of your time to help us in this work. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, please read this Information Sheet and indicate your consent by ticking the consent box below. If you decide to participate, you are still free to withdraw at any time without giving a reason (or withdraw your information up until the point of anonymisation).

What will happen to me if I take part?

Firstly, you will be invited to meet with the researchers for an information session, where you will be given further details of the research to date and what will be involved in the focus group. During the focus group, you will be with one or two other carers and a researcher and you will be invited to comment on draft practice points (short reference guides made available through the Irish College of General Practitioners) for GPs and GP training. For example, you will be asked to comment on the proposed approaches which GPs currently use to identify carers in their practice and how they refer carers to supports. The date for the focus group will be set well in advance. The focus group will be audio recorded to allow the researchers to review the information. No video recording will be made and no names will be revealed at any time.

How long will the whole process take?

The initial information session will take no more than about 45 minutes and the focus group will take an additional hour and will be scheduled about two weeks later.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

There are no anticipated disadvantages, side effects, risks, and/or discomforts of taking part in this study as the focus group will only ask you to comment on the proposed practice points and training. We will ask you and others in the group not to talk to people outside the group about what was said during the discussion. However, we need you to be aware that we cannot stop or prevent participants who were in the group from sharing information that should be confidential.

What are the possible benefits of taking part in this study?

Your views will contribute to the development of more effective approaches to strengthen awareness of the role/contribution of family carers and how they are supported by their GP.

Expenses and payments

There will be no expenses or payments available for participating in the focus groups, but we would like to provide you with a €25 gift voucher as a small ‘thank you’ for your participation.

Will my taking part be kept confidential?

All information that is collected about you during the course of the research will be kept ***strictly confidential***. All recorded data will be stored separately from the consent forms. All information will be held under lock and key and will be accessed only by the Researcher (MC) and a representative from family carers Ireland (NF) and will not be distributed to any other unauthorised individual. Your email address will be held for the purposes of communication before and during the focus group, but this will not be passed on to any third parties. It will be encrypted (see below) and kept securely in a password-protected folder and will only be accessible to the researchers. We will not report your name or anything that would make you personally identifiable in any outputs. Contact details will be encrypted and will not be stored in the same file as your data from the focus group. Family Carers Ireland and Maynooth University and their data storage procedures are fully compliant with GDPR.

What will happen to the results of the study?

The results of the focus groups will be used to inform the development of Practice Points for the Irish College of General Practitioners and to inform the content of the GP training and carer workshops. The findings of the focus groups will also be included in written academic articles and other documents that report on the development and evaluation of the GP training. Findings will be made available in early 2022.

The recording of the focus group will be stored securely at Maynooth University Department of Psychology and destroyed (by overwriting) after completion of the study by the Lead

Researcher (Mary Cronin). Your encrypted contact details will also be destroyed securely after the end of the project.

What will happen if I don't want to be part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. Your participation or non-participation in this study will in no way impact on your relationship with Family Carers Ireland. If you agree to participate, you may withdraw from the study at any time without affecting you in any way. You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw. However, if the focus group has already commenced, we will be unable to remove your pseudonymised responses from the recording.

Who is organising and funding the study?

The Irish Research Council is funding this aspect of the study, which will be carried out by Family Carers Ireland and Maynooth University.

Who do I contact if I have a question?

Please feel free to address any questions regarding the research firstly to the lead researcher, Mary Cronin, mary.cronin.2014@mumail.ie, 01 708 6311, or Niamh Finucane, nfinucane@familycarers.ie.

Alternatively, you may contact Professor Sinéad McGilloway, the Research Supervisor, Centre for Mental Health and Community Research, Maynooth University Department of Psychology, John Hume Building, Maynooth, Co. Kildare (Tel: (01) 708 4765 or Sinead.McGilloway@mu.ie).

Informed Consent Form – PPI Focus Group

Research Project: A community health-based approach to supporting informal carers/caregivers in the community

Please read below and click to confirm your consent to participate in this study

Consent Form

I agree to participate in research study titled "A community health-based approach to supporting informal carers/caregivers in the community" as part of public patient involvement.

Clicking below indicates that:

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I understand the limits of confidentiality as described in the information sheet.

I am 18 years of age or older.

I am happy for the focus group to be audio recorded.

Consent Yes No

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix A3.2 PPI panel information sheet and informed consent

PPI Focus Group schedule

Practice points and training for GPs.

Purpose: to comment on the Practice points as they will be made available to GPs as a guide for supporting family carers and will form the basis of the training for GPs. We will discuss each section of the practice points and the proposed outline for the GP training.

What were your initial thoughts on the proposed practice points (PPs) for GPs?

Do you have any comments on the health risks for carers included in the PPs?

What is your view on a member of practice staff being the liaison person (carer champion), is this something you would like to see in GP practices? What would it mean for carers?

Strategies for identifying carers are included here.   Are there any you would object to? Are there any you feel are missing?

How do you feel about having your needs as a carer assessed by your GP?

What are your comments on assessments provided (covering each assessment in turn) Would you be happy to fill them out in advance of meeting GP or do you feel it better to fill it out with the GP?

If you are not a patient of the practice how would you feel about the care recipients GP writing to your own GP to highlight any concerns?

Do you have any comments on the signposting/referral options given in the PPs?

Beginning the conversation with the GP about their own health can be difficult for many carers, do you have any thoughts on what helps with this?

What are your comments about the resources listed in the PPs?

Would you value the resources for carers suggested in the PPs?

Do you have any comments/objections to the documentation process suggested in the PPs?

Proposed Lesson Plan for GP Training:

Topic	Learning Objective
Introduction (summary of family caring in Ireland)	Improved knowledge of the increased prevalence of family caring in our communities and the challenges posed for those providing care.
Practice Points	Increased understanding of the health and wellbeing risks for family carers and how to identify, assess and signpost them in general practice
Case-based discussion	Improved knowledge of how the process of identifying through to referral in practice works
Demonstration of assessments and FCI website	Enhanced knowledge of carers needs assessments and the supports available to them.

What points do you feel should be specifically emphasised during the GP training?

How do you think GPs should begin the conversation with carers?

Case-based discussion is a common part of GP training. What do you think would be important to include in the case-based discussion?

PPI Focus Group schedule

Empowerment workshop for carers

Purpose: participation in the design of an empowerment workshop for family carers to support them in being more proactive about self-care and having conversations with their GP about their own health and wellbeing needs.

Carer workshop will be based on adult learning theory principles (Knowles, 1984) and Self-efficacy (Bandura, 1997). Adapted from training for caregivers on how to have conversations with doctors and other healthcare professionals about their care recipient and/or medications. *(short presentation on adult learning principles and self-efficacy as a framework for the workshop)*

<u>Proposed empowerment workshop outline:</u>

- Stages of caregiver identity
- Health risks and importance of self-care
- Discussion of current behaviours regarding own health and wellbeing and obstacles to discussing impact of caring with GP
- Communication skills:
  - Establishing a rapport with GP
  - Assertiveness and "I" language
  - Possible Tools: Communication planner, Tips for Doctors Visit, assessment
- Modelling or case study of a communication with GP
- Rehearsing in small groups
- Receiving constructive positive feedback

Proposed Lesson Plan for Carer empowerment workshop

Topic	Learning Objective
Introduction (carer identity, health risk and self-care)	Greater awareness of importance of own self-care and being proactive in seeking help
Communication skills	Increased understanding and enhanced skills in planning and managing the consultation with GP
Introduction of tools	Enhanced knowledge of tools that can support consultation with GP
Small group role play	Enhanced skills and confidence in conducting conversations with GP

Do you feel the type of workshop outlined here would be useful for family carers?

What do you feel are the obstacles for carers in discussing the impact on their caring role with their GP?

Do you feel the peer environment of the workshop would support family carers to develop their confidence in having conversations with their GP?

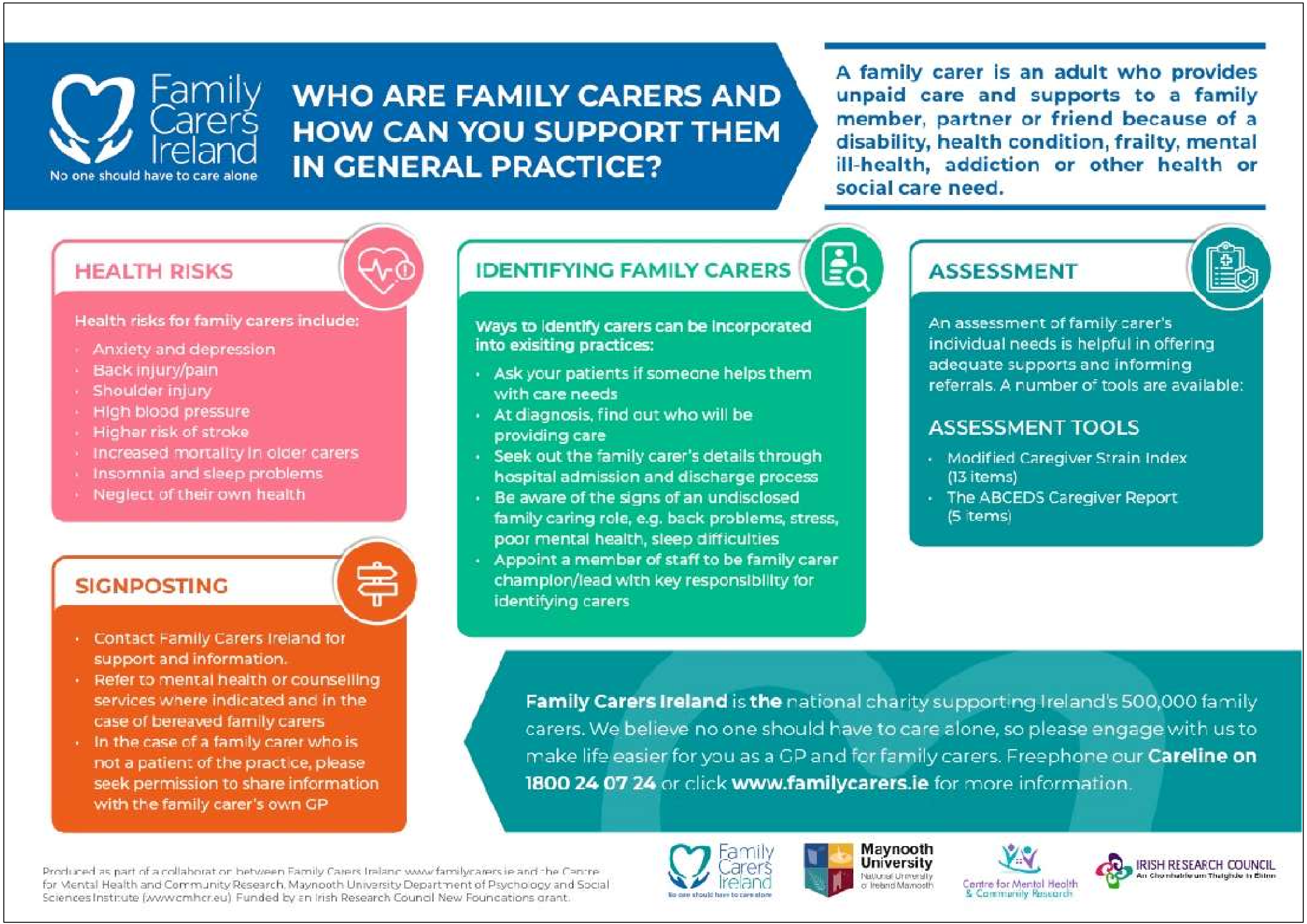
With regard to assertiveness and saying no to additional responsibilities – will this program help?

Do you feel tools to support the consultation would be useful for family carers?

Is there other content you would add to this workshop?

What do you think this empowerment workshop should be called?

Appendix A3.3 Infographic summary of GP ‘Practice Points’



Family Carers Ireland
No one should have to care alone

WHO ARE FAMILY CARERS AND HOW CAN YOU SUPPORT THEM IN GENERAL PRACTICE?

A family carer is an adult who provides unpaid care and supports to a family member, partner or friend because of a disability, health condition, frailty, mental ill-health, addiction or other health or social care need.

HEALTH RISKS

Health risks for family carers include:

- Anxiety and depression
- Back injury/pain
- Shoulder injury
- High blood pressure
- Higher risk of stroke
- Increased mortality in older carers
- Insomnia and sleep problems
- Neglect of their own health

IDENTIFYING FAMILY CARERS

Ways to identify carers can be incorporated into exisiting practices:

- Ask your patients if someone helps them with care needs
- At diagnosis, find out who will be providing care
- Seek out the family carer's details through hospital admission and discharge process
- Be aware of the signs of an undisclosed family caring role, e.g. back problems, stress, poor mental health, sleep difficulties
- Appoint a member of staff to be family carer champion/lead with key responsibility for identifying carers

ASSESSMENT

An assessment of family carer's individual needs is helpful in offering adequate supports and informing referrals. A number of tools are available:

ASSESSMENT TOOLS

- Modified Caregiver Strain Index (13 items)
- The ABCEDS Caregiver Report (5 items)

SIGNPOSTING

- Contact Family Carers Ireland for support and information.
- Refer to mental health or counselling services where indicated and in the case of bereaved family carers
- In the case of a family carer who is not a patient of the practice, please seek permission to share information with the family carer's own GP

Family Carers Ireland is **the** national charity supporting Ireland's 500,000 family carers. We believe no one should have to care alone, so please engage with us to make life easier for you as a GP and for family carers. Freephone our **Careline on 1800 24 07 24** or click **www.familycarers.ie** for more information.

Produced as part of a collaboration between Family Carers Ireland www.familycarers.ie and the Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute (www.cmhcr.eu). Funded by an Irish Research Council New Foundations grant.

Appendix A3.4 Carer workshop pilot – recruitment poster

ARE YOU A FAMILY CARER?

...caring for a loved one, relative, friend or neighbour with additional needs?

Join us for a FREE "**Communication with your GP - empowering family carers**" workshop aimed at supporting YOU, the family carer

THIS WORKSHOP WILL COVER:

- The impact of your caring role on your own health and wellbeing
- Discuss any health concerns you may have personally with your doctor
- Increase your confidence in discussing concerns about the person you care for
- Increase your confidence/assertiveness in discussing aspects of your caring role that you are concerned about

Date: Tuesday 29th March 2022

Time: 10.30am - 12.30pm **Location:** Online via Zoom

Eventbrite link to register:
https://www.eventbrite.ie/e/communication-with-your-gp-tickets-276666285307
or email Bernadette at **boconnor@familycarers.ie**

Family Carers Ireland
No one should have to care alone

Maynooth University
National University of Ireland Maynooth

Centre for Mental Health & Community Research

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Appendix A3.5 Information sheets and Informed consent – Pilot Workshops

PARTICIPANT INFORMATION SHEET: GP registrar workshop and evaluation

Study Title: CHERISH' (**C**ommunity **H**ealth-bas**E**d app**R**oach to **I**mproving carer**S**' **H**ealth and wellbeing)
Investigators: Mary Cronin, Professor Sinead McGilloway, Maynooth University Department of Psychology
Collaborating partners: Family Carers Ireland

Introduction

We would like to invite you to take part in the GP registrar workshop and evaluation element of an ongoing research study. Before you decide whether or not you would like to take part, it is important for you to understand why the workshop is being delivered and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please contact or ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

The purpose of this study is to strengthen awareness of the role/contribution of family carers and to improve how their health and wellbeing needs can be met in General Practice/Primary Care. During the earlier stages of the research, we consulted with family carers and GPs through a survey and interviews. The findings will now be used to design an online, mixed media, distance learning education programme for GPs/GP registrars to convey the importance of, and approaches to, identifying family carers and where to signpost/refer them for further support. In addition, we hope to deliver a workshop for family carers to empower them in their consultations with GPs.

Why have I been asked to take part?

You are being asked to take part because some of your patients may be providing or receiving care from a family member or loved one. Participating in this pilot workshop will support you to identify family carers and signpost them to supports.

Who has approved this study?

The research has been reviewed and approved by Maynooth University Social Research Ethics Subcommittee (SRESC).

Do I have to take part?

No, you are under no obligation whatsoever to take part in the workshop. However, we hope that you will agree to take part and give some of your time to help us in this work. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, please read this Information Sheet and indicate your consent by ticking the consent box below. If you decide to participate, you are still free to withdraw at any time without giving a reason (or withdraw your information up until the point of anonymisation).

What will happen to me if I take part?

You will be invited to attend an online workshop session with a group of GP registrars. This workshop will be delivered by a GP and will be approximately one hour duration. To evaluate the workshop you will be asked to complete a short questionnaire before workshop delivery, post workshop and again three months later.

How long will the whole process take?

The online workshop will be one hour. In addition to this, the survey will take approximately 5 minutes before the workshop, after the workshop and again in 3 months-time.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?
There are no anticipated disadvantages, side effects, risks, and/or discomforts of taking part in this study.
What are the possible benefits of taking part in this study?
Your attendance at this workshop will contribute to the findings of this research to shape more effective ways of supporting family carers. Also, by attending this workshop you can apply the content to your practice and potentially reach and improve the wellbeing of more family carers in your practice.
Expenses and payments
There will be no expenses or payments available for participating in the workshop.

Will my taking part be kept confidential?
All information that is collected about you during the course of the research will be kept ***strictly confidential***. All information will be held under lock and key and will be accessed only by the Researcher (MC). Maynooth University and their data storage procedures are fully compliant with GDPR. We will have no access to contact details as all contact will be via the Sligo GP workshop scheme.
What will happen to the results of the study?
The findings from the questionnaires will be used to evaluate the workshop impact. The findings will also be included in academic articles and other documents that report on the development and evaluation of the GP workshop. Findings will be made available in late 2022. The questionnaires will be destroyed after completion of the study by the Lead Researcher (Mary Cronin).

What will happen if I don’t want to be part of the study?
Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you agree to participate, you may withdraw from the study at any time without affecting you in any way. You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

Who is organising and funding the study?
The Irish Research Council is funding this aspect of the project through its new foundations grant.

Who do I contact if I have a question?
Please feel free to address any questions regarding the research firstly to the lead researcher, Mary Cronin, mary.cronin.2014@mumail.ie, 01 708 6311

Alternatively, you may contact Professor Sinéad McGilloway, the Research Supervisor, Centre for Mental Health and Community Research, Maynooth University Department of Psychology, John Hume Building, Maynooth, Co. Kildare (Tel: (01) 708 4765 or Sinead.McGilloway@mu.ie).

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Informed Consent Form – General Practitioner Registrar Workshop

Research Project: A community health-based approach to supporting informal carers/caregivers in the community

Please read below and click to confirm your consent to participate in this training

Consent Form

I agree to participate in research study titled "A community health-based approach to supporting informal carers/caregivers in the community".

Clicking below indicates that:

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I understand the limits of confidentiality as described in the information sheet.

I am 18 years of age or older.

Click here to submit your consent

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

PARTICIPANT INFORMATION SHEET: Carer Workshop Pilot

Study Title: CHERISH' (Community Health-basEd appRoach to Improving carerS' Health and wellbeing)
Investigators: Mary Cronin, Professor Sinead McGilloway, Maynooth University Department of Psychology
Collaborating partners: Niamh Finucane, Dr. Kathy McLoughin, Family Carers Ireland

Introduction

We would like to invite you to take part in the workshop 'communicating with your doctor, carer empowerment' element of an ongoing research study.

Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please contact or ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

The purpose of this study is to strengthen awareness of the role/contribution of family carers and to improve how their health and wellbeing needs can be met in General Practice/Primary Care. During the earlier stages of the research, we consulted with family carers and GPs through a survey and interviews. The findings have been used to design the workshop "communicating with your doctor – empowerment workshop for family carers' as well as an education programme for GPs to convey the importance of, and approaches to, identifying family carers and where to signpost/refer them for further support.

Why have I been asked to take part?

You are being asked to take part because you are a family carer. The research team at Maynooth University and Family Carers Ireland would like to invite you to participate in a workshop about communication with your GP and submit an evaluation of this workshop. Your contribution to this research will measure how effective this workshop is and what improvements can be made for further.

Who has approved this study?

The research has been reviewed and approved by Maynooth University Social Research Ethics Subcommittee (SRESC).

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research, you are welcome to attend the workshop without filling out the evaluation. However, we hope that you will agree to take part and give some of your time to help us in this work. If you decide to do so, please read this Information Sheet and click where asked to consent at the bottom of the page. If you decide to participate, you are still free to withdraw at any time without giving a reason.

What will happen to me if I take part?

You will be invited to attend a two hour online workshop with a group of family carers. You will be asked to complete a short questionnaire prior to the workshop and immediately afterwards and you will also be sent another short questionnaire three months later so that we can measure the effectiveness of the workshop content.

How long will the whole process take?

The online workshop will be two hours. In addition to this, the survey swill take approximately 5-10 to complete.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

There are no anticipated disadvantages, side effects, risks, and/or discomforts of taking part in this study. We will ask you and others in the group not to talk to people outside the group about what was said during the training session. However, we need you to be aware that we cannot stop or prevent participants who were in the training from sharing information that should be confidential.

What are the possible benefits of taking part in this study?

Your attendance and evaluation of this workshop will contribute to the findings of this research to shape more effective ways of supporting family carers.

Expenses and payments

There is no cost for attending this workshop.

There will be no expenses or payments available for participating in the training.

Will my taking part be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential. The contact information you provided when signing up for the workshop, will not be part of this workshop evaluation. All data in the evaluation will be held and accessed only by researcher Mary Cronin. We will not report your name or anything that would make you personally identifiable in any outputs.

Family Carers Ireland and Maynooth University and their data storage procedures are fully compliant with GDPR.

What will happen to the results of the study?

The results of the surveys will be used to evaluate the workshop impact. The findings from the surveys will also be included in academic articles and other documents that report on the development and evaluation of the carer workshop. Findings will be made available in early 2022. The surveys will be destroyed after completion of the study by the lead Researcher, Mary Cronin.

What will happen if I don't want to be part of the study?

Participation in this study is entirely voluntary and refusal to participate will not affect you in any way. You can attend the carer workshop but not submit your evaluation. If you agree to participate, you may withdraw from the study at any time before the results are published.

Who is organising and funding the study?

The Irish Research Council is funding this aspect of the study, which will be carried out by Family Carers Ireland and Maynooth University.

Who do I contact if I have a question?

Please feel free to address any questions regarding the research firstly to the lead researcher, Mary Cronin, mary.cronin.2014@mumail.ie, 01 708 6311.

Alternatively, you may contact Professor Sinéad McGilloway, the Research Supervisor, Centre for Mental Health and Community Research, Maynooth University Department of Psychology, John Hume Building, Maynooth, Co. Kildare (Tel: (01) 708 4765 or Sinead.McGilloway@mu.ie).

Informed Consent Form- Carer Workshop

Research Project: A community health-based approach to supporting informal carers/caregivers in the community
Please read below and click to confirm your consent to participate in this study

Consent Form

I agree to participate in research study titled “A community health-based approach to supporting informal carers/caregivers in the community”
Clicking ‘yes’ below indicates that:
The purpose and nature of the study has been explained to me in writing.
I am participating voluntarily.
I understand the limits of confidentiality as described in the information sheet.
I am 18 years of age or older.
Click here to submit your consent

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@mu.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.
For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at ann.mckeon@mu.ie. Maynooth University Data Privacy policies can be found at https://www.maynoothuniversity.ie/data-protection.

Appendix A3.6 Pilot workshops – evaluation questionnaires

Carer Pre-Workshop Questionnaire

Note that this questionnaire has TWO sections. SECTION 1 asks about you and your caring role; SECTION 2 asks about your visits with your GP.

Please enter the last 3 digits of your phone number. This will be your unique identifier number so that we can link responses from pre-workshop and post-workshop questionnaires.

____

SECTION 1

About your BACKGROUND

How long have you been caring for your loved one (years)? ____________________

What is the main reason you are caring for this person?____________________

Are you Male or Female? ____________________

SECTION 2

About your visits with your doctor

Please tick to indicate how confident are you in your ability to:

	Not confident at all	**A little confident**	**Moderately Confident**	**Very Confident**
Make the most of your visit to the GP				
Prepare for your visit to the GP				
Discuss the impact of your caring role with your GP				
Communicate with your GP about your concerns for the person you care for				
Get the GP to answer all of your questions				

	Not confident at all	**A little confident**	**Moderately Confident**	**Very Confident**
Be assertive with the GP/Doctor regarding care tasks you are finding difficult				
Discuss your own health needs with your GP				

Carer Post -Workshop Questionnaire

Thank you for completing this training evaluation form. It will help us in the development of this training for other carers.

Note that this questionnaire has TWO sections. SECTION 1 asks about your experience of the workshop; SECTION 2 asks about your visits with your GP.

Please enter the last 3 digits of your phone number. This will be your unique identifier number so that we can link responses from pre-workshop and post-workshop questionnaires.

SECTION 1

Please tick to indicate your agreement (or not) with the following statements

	Strongly Agree	Agree	Disagree	Strongly Disagree
Overall, the workshop content was useful to me				
I would recommend this workshop to other carers				
I intend to use some of the handouts provided				

SECTION 2

About your visits with your doctor

Please use the appropriate number to indicate how confident are you in your ability to:

	Not confident at all	A little confident	Moderately Confident	Very Confident
Make the most of your visit to the GP				
Prepare for your visit to the GP				
Discuss the impact of your caring role with your GP				
Communicate with your GP about your concerns for the person you care for				
Get the GP to answer all of your questions				
Be assertive with the GP/Doctor regarding care tasks you are finding difficult				
Discuss your own health needs with your GP				

We would love to hear any further comments you have about the workshop:

GP Registrar Pre-workshop questionnaire

Please enter the last 3 digits of your phone number. This will be your unique identifier number so that we can link responses from pre-workshop and post-workshop questionnaires.

____

How many GPs work at the practice where you are training?

____

How long have you been at this practice?

____

What is the practice list size (Approx)?

____

Are you

- ○ Male
- ○ Female
- ○ Non-binary / third gender
- ○ Prefer not to say

The negative impacts of caring on carers' health and wellbeing can be reduced if I offer support to carers in my practice

- ○ Strongly Agree
- ○ Agree
- ○ Neither Agree nor Disagree
- ○ Disagree
- ○ Strongly Disagree

There may be family carers in my practice of whom I am unaware.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Supporting family carers is not part of the GP role.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Family carers make an important contribution to the overall health service.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

My GP colleagues view the identification and support of family carers as an important part of their day-to-day work.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Government guidelines suggest that carers should be supported in General Practice.

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Family carers would not value support from their GP.

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

In general, I am confident I have the skills to meet the needs of family carers

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Incorporating carer awareness into my current practice would be relatively easy

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Having a Practice Points reference guide would increase my confidence in identifying and signposting carers

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Completing a brief assessment with family carers would help me in signposting them to appropriate supports

○ Strongly Agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

I am not confident that I have the necessary resources to meet the needs of family carers

○ Strongly Agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

In the past three months, I have been proactive in identifying and supporting carers

○ Strongly agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

Following the workshop, I intend to be more proactive in identifying and supporting carers

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Please let us know if you have any comments regarding family carers that you would like to add

____

GP Registrar Post-workshop questionnaire

Please enter below the last three digits of your phone number. This will be your unique identifier number so that we can link responses from the pre-and post-workshop questionnaires:

____

Overall, I found this workshop

- ○ Extremely useful
- ○ Very useful
- ○ Moderately useful
- ○ Slightly useful
- ○ Not useful at all

The quality of the content in this workshop was:

- ○ Excellent
- ○ Good
- ○ Average
- ○ Poor
- ○ V Poor

I would recommend this workshop to other GP registrars.

☐ Strongly Agree

☐ Agree

☐ Neither agree nor disagree

☐ Disagree

☐ Strongly disagree

The aspects of the workshop I found most useful were:

	0 10 20 30 40 50 60 70 80 90 100
Health risks to family carers	
How to identify family carers	
Assessment of family carers	
Signposting family carers	
Other (please specify)	

I would recommend this workshop to practicing GPs

○ Strongly Agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

Overall, I would rate this workshop as:

- ○ Excellent
- ○ Good
- ○ Average
- ○ Poor
- ○ Very Poor

The negative impacts of caring on carers' health and wellbeing can be reduced if I offer support to carers in my practice

- ○ Strongly Agree
- ○ Agree
- ○ Neither Agree nor Disagree
- ○ Disagree
- ○ Strongly Disagree

There may be family carers in my practice of whom I am unaware.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Supporting family carers is not part of the GP role.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Family carers make an important contribution to the overall health service.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

My GP colleagues view the identification and support of family carers as an important part of their day-to-day work.

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Government guidelines suggest that carers should be supported in General Practice.

○ Strongly agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

Family carers would not value support from their GP.

○ Strongly agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

In general, I am confident I have the skills to meet the needs of family carers

○ Strongly agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

Incorporating carer awareness into my current practice would be relatively easy

○ Strongly agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

Having a Practice Points reference guide would increase my confidence in identifying and signposting carers

○ Strongly Agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

Completing a brief assessment with family carers would help me in signposting them to appropriate supports

○ Strongly Agree

○ Agree

○ Neither agree nor disagree

○ Disagree

○ Strongly disagree

I am not confident that I have the necessary resources to meet the needs of family carers

- ○ Strongly Agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

In the past three months, I have been proactive in identifying and supporting carers

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Following the workshop, I intend to be more proactive in identifying and supporting carers

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

Please indicate below any recommendations you might have on how we can improve the content or delivery of this workshop and/or if you would like to comment on anything else

Appendix A3.7 Outline of PPI panel contribution using Guidance for Reporting Involvement of Patients and the Public (GRIPP2-SF)

The PPI panel consulted on the GP guidelines and contributed to the design and development of the workshops for both GPs and carers. Specific embedding of PPI contributions into the resources has been provided in Chapters Five and Six. The Guidance for Reporting Involvement of Patients and the Public (GRIPP2-SF) (Staniszewska et al., 2017) reporting checklist (Table 1) was used to provide a transparent outline of the overall PPI contribution to study 3. The recommended format for GRIPP2-SF includes (1) The aims of the study; (2) the method (description of the methods used for PPI in the study); (3) the results (including both positive and negative outcomes); (4) discussion (the extent to which PPI influenced the study overall, both positive and negative); and (5) critical reflections (reflecting on the things that went well and those that did not). Below, the aim and method are 'briefly' summarised to background the full recommended GRIPP2-SF report.

Table 1

PPI contribution to CHERISH project (GRIPP2-SF)

GRIPP2-SF Section and topic Item
1: Aim
Develop and pilot test workshops that can 1) Support GPs to identify, assess, and signpost carers to supports; 2) support carers in having conversations with GPs about the impact of the caring role, their own health and well-being, and their concerns about the person for whom they provide care; 3) develop guidelines for GPs to assist them in addressing the needs of carers. All resources will be developed with involvement of carers as key stakeholder and in collaboration with FCI.

2: Methods

Five carers were recruited to form a PPI panel to assist with the development of GP practice points and the design of workshops for both carers and GPs. The panel took part in an initial induction and were involved in refining the detail of the GP guidelines. This involved reviewing the guidelines developed from the findings of study two in a group session facilitated by the researcher and a member of FCI (collaborating partner). In a separate workshop the PPI panel again worked with the lead researcher and a member of FCI to refine the design of the workshops for both carers and GPs, including reviewing the aims and objectives, content and delivery. These group sessions were recorded so that no details would be missed throughout the development process.

3: Results

PPI contributed to the development of GP practice points and both workshops. For example:

<u>Raising awareness of family carers in general practice</u>

- Advised on practice points content (e.g. additional links in resources section),
- Highlighted aspects/scenarios where carers may be resistant (e.g. negative language),
- Provided carer views on specific aspects such as carer champion/liaison,
- Reviewed the carer assessments, including those from scoping review and one additional assessment suggested by FCI.

<u>Communication with your doctor, empowerment workshop for family carers</u>

- Valuable input regarding the separation of own health and advocating for care recipient,
- Highlighted gaps (e.g. GP visit preparation),
- Suggested templates/handouts for participants,

- Carer participated as co-facilitator.

4: Discussion

Patient and public involvement in this study influenced important aspects of the research outputs, namely, resources for both GPs and carers. The PPI panel provided the carer's voice in the development of practice points and workshops. The input of the panel allowed for alternative perspectives to that of the research team and brought new insights and innovative ideas to the project. The panel also spotted potential barriers or concerns that were then addressed in the workshop outline (see Tables 5.2 and 6.2). The fact that the PPI panel were from diverse caring roles allowed for input from many experiences of caring.

The panel were not involved in Study One or Study Two, therefore time had to be allocated to present the design and findings from these preceding stages before the PPI panel could consult on Study Three. Funding from the IRC new foundations project meant that the carers could avail of a token voucher to thank them for their time (€25). They were appreciative of this but stressed that the real reward for them was in creating change in how carers were supported in general practice. The panel of carers were particularly invested in the carer workshop and were keen that it would be made available to other carers. Having the national carer support organisation (FCI) as collaborating partners supported the recruitment of the panel and the scheduling of the online consultations. There were some suggestions from the panel that the researcher was ultimately unable to implement. For example, they felt an annual health check that focused on the caring role would be beneficial. An annual health check was included in the initial draft of the practice points (guidelines) but the ICGP requested that it be removed due to lack of clinical evidence. The panel also suggested a role for 'Healthy Ireland' who have plans to recruit co-ordinators nationwide (https://www.gov.ie/en/campaigns/healthy-ireland/#); however, on discussion with the research team, it was felt that this could not be

included at this time, as co-ordinators are not available in all regions and their role, in respect of family carers, is unclear.
5: Reflections
The PPI in the study was embedded as far as possible into the development and delivery of the workshops and the content of GP guidelines. There were challenges such as the non-acceptance of the recommendation for an annual check-up in the guidelines. However, as outlined in Table 5.2, earlier in this thesis, it was included as a 'suggestion' in the GP workshop. Additionally, the suggestion to include information on 'Healthy Ireland' was valid but could not be included, as it is still in the service development stage. These incidents highlighted the fine balance for researchers in embedding PPI input in healthcare services. Within the healthcare services, a strong evidence base is essential; therefore, although very valid inputs are made by those participating in a PPI capacity they may not always be included due to lack of empirical evidence. The inability to 'run with' all the suggestions of the panel was particularly challenging for the lead researcher. As a carer the researcher could see the PPI panel perspective and, on the other hand, as a researcher could only work within that remit.

Appendix A3.8 List of outputs

Publications:

1.Cronin, M., McLoughlin K., Foley, T., and McGilloway S. Supporting family carers in General Practice: A scoping review of clinical guidelines and recommendations. *BMC Family Practice* (under review – submitted in Jan, 2023).

2. Cronin, M. & McGilloway, S. (2022) Supporting family carers in Ireland: the role of the general practitioner. *Irish Journal of Medical Science*. https://doi-org.may.idm.oclc.org/10.1007/s11845-022-03031-9.

3.Cronin, M., Foley T. & McGilloway, S. (2022) Addressing the needs of family carers. *Forum, Journal of the Irish College of General Practitioners, Vol 39, No.9*.

4. Cronin, M. & McGilloway, S. (2020) Promoting a 'Think Carer' approach in health and social care services: Identifying as a carer – Why is it important? *Frontline Irish Voice of Intellectual Disability* (online), Issue 116, http://frontline-ireland.com/promoting-a-think-carer-approach-in-health-and-social-care-services-identifying-as-a-carer-why-is-it-important/.

5.Cronin, M. & McGilloway, S. (2019) Promoting a 'Think Carer' approach in health and social care services. *Healthnews* (Online), https://www.healthnews.ie/neurology/promoting-a-think-carer-approach-in-health-and-social-care-services/

Other outputs:

6.Cronin, M. & McGilloway, S. (2022) 'Communication with doctors - Empowerment workshop for family carers: Facilitator Workshop Guide'. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

7. Cronin, M., Foley, T. & McGilloway, S. (2022) 'Raising awareness of family carers in General Practice: Facilitator Workshop Guide'. Centre for Mental Health and Community Research, Maynooth University Department of Psychology and Social Sciences Institute.

Conference Presentations:

8. Cronin, M. & McGilloway, S. (2021). Patient and Public Involvement (PPI) in the development of learning resources for GPs and carers. Carers in Research: Family Carers Ireland Autumn Research Conference, Online, October, 2021

9. Cronin, M. & McGilloway, S. (2020). Promoting a ‘Think Carer’ approach in Ireland’s health and social care services: First steps., Presented at Care Alliance/UCD conference - Toward a refreshed national carers strategy – from research to policy, UCD, Nov 19

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