FAMILY CARERS IRELAND

VIRTUAL AUTUMN RESEARCH CONFERENCE

Programme

10am	**Welcome** Rob Anderson (Chair of Family Carers Ireland's Research & Policy Committee)
10:05am	**Covid-19 and family carers** Prof Amanda Phelan (School of Nursing and Midwifery, TCD) *Caring Through Covid* Emilia Grycuk & Dr Yaohua Chen (Global Brain Health Institute, TCD) *Care burden, loneliness, and social isolation in informal caregivers in Ireland: before and during COVID-19* Dr Emma O'Shea (Centre for Gerontology and Rehabilitation, UCC) *Factors Influencing the Sustainability of Family Caregiving in Dementia: A Multiphase Qualitative Study*
10:50-11:05am	Dr Damien Brennan (School of Nursing and Midwifery, TCD) in conversation with Dr Nikki Dunne (Family Carers Ireland) *The Social Contract for Care Provision in Ireland*
11:05-11:45am	**Involvement of family carers in research** Mary Cronin and Prof Sinead McGilloway (Department of Psychology and Social Sciences Institute, Maynooth University) *Patient and Public Involvement (PPI) in the development of learning resources for GPs and family carers* Dr Tamasine Grimes (School of Pharmacy, TCD) *Public and Patient Involvement with a Descriptive Qualitative Study to Explore Household Medication Safety Among Carers* Dr Irene Hartigan (School of Nursing and Midwifery, UCC) *Caring Beyond COVID-19: Identifying Priorities For Family Carers Through A Participatory Process*
11.45-11.55am	**Reflections and learning** Jo Bergin (FCI PPI Network) Dr Avril Kennan (Health Research Charities Ireland) Dr Emma Dorris (UCD PPI Ignite)
11.55-12pm	**Close conference,** Rob Anderson

Abstracts

Exploring experiences of carers in the Covid 19 pandemic (*Prof. Amanda Phelan, School of Nursing & Midwifery, TCD)*

Ireland has over 500,000+ caregivers who provide a range of supports in the community. It is recognised that, while caregiving can be very rewarding, it can also result in psychological, physical, social and economic stress. Adult family carers' ages range from 18 and above and a recent study by Family Carers' Ireland (FCI) (FCI, 2020a) with 59% caring for between 5-20 years and 57% delivering 140-168 care hours per week. While there were significant challenges apparent in the pre pandemic period (such as difficulty accessing services, juggling full-time employment, financial difficulties and information poverty), a survey in May 2020 (FCI 2020b) has demonstrated the additional pressures experienced by carers during Covid 19. While the survey had provided a general picture, this study enables a depth exploration of experiences, generating additional important insights into carers' reality in Covid 19 and pointing to ways of alleviating challenges.

Two methods were used to collect data: semi-structured interviews and a photovoice methodology Fifteen participants were recruited. Data were collected via semi-structured Interviews conducted by telephone. Data is being analysed using Braun and Clarke's thematic analysis (2006;2021) approach.

Findings currently point to various challenges that carers' experienced. This included coping with the cancellation of services, managing within the public health regulations and making efforts to protect their care recipient against infection.

SustainCare: Factors Influencing the Sustainability of Family Caregiving in Dementia *(Dr Emma O'Shea, Centre for Gerontology & Rehabilitation, School of Medicine, UCC)*

<u>Background:</u> Families provide the bulk of community-based dementia care in Ireland. Evidence suggests that over 60% of people with dementia in Ireland are living in the community, supported by their families. However, the primary family carer does not exist in a vacuum; they are typically part of a wider family unit. Little research has been done from a family systems perspective, regarding dementia in Ireland, or internationally.

<u>Aim:</u> To understand the factors influencing the sustainability of supporting a family member with dementia to remain living at home in the community, from a family systems perspective.

<u>Methods:</u> Qualitative interviews (N=20) were conducted with 10 families supporting a person with dementia, across Ireland. All participants were ≥18 years of age and aware of the dementia diagnosis. Purposive sampling was employed. Interview duration ranged from 30–85-minutes. Thematic analysis was applied to the data. Ethical approval was obtained by the local REC.

<u>Findings</u>: Six superordinate elements influenced sustainability, relating to: The Person with Dementia; The Primary Carer(s); Family Network and Dynamics; Local Community; Formal Health and Social Care Services; and Wider Socio-cultural and political factors. From a family systems perspective, these six elements differentially impacted upon four cross-cutting conceptual themes, each of which are discussed in detail: 1) Values & Expectations; 2) Family Roles, Relationships and Dynamics; 3) Individual & Collective Capacity; and 4) Contextual Factors (including the impact COVID-19).

Discussion: This study has identified factors influencing the sustainability of caring for a family member with dementia, with a specific focus on the family system as the unit of care. Better supporting resilience at a family-level will require dedicated resources and defined actions on the part of several stakeholder groups. Implications are discussed for families, clinicians, policy- and decision-makers, and service planners/ providers.

Care burden, loneliness, and social isolation in informal caregivers in Ireland: before and during COVID-19 (*Emilia Grycuk & Dr Yaohua Chen, Global Brain Health Institute)*

Background: Public health restrictions resulting from the outbreak of COVID-19 have worsened the mental health outcomes of general population, but especially the populations at risk, such as informal caregivers. The prepared report explores the care burden, loneliness, and social isolation of informal caregivers in Ireland before and during the first and the second wave of the COVID-19 pandemic.

Methodology: The data used for the report are extracted from the Coping with Loneliness, Isolation, and COVID-19 (CLIC) Global Caregiver survey. 372 Irish informal caregivers took part in this cross-sectional, anonymous, and online questionnaire. Those informal caregivers cared for people with dementia, intellectual disability, mental health, and/or physical health challenges. Data analyses were descriptive followed by ordinal regression for factors associated with burden, loneliness, and social isolation, and by analysing the cost of loneliness.

Results: Findings revealed that, compared to pre-pandemic, Irish caregivers experienced a significant increase in care burden, overall loneliness, emotional and social loneliness, and isolation. Care burden was associated with COVID-19 impact on care delivery, loneliness was associated with COVID-19's impact on caregiver's finances, moderate and frequent social isolation prior to and during the pandemic, substantial change in social isolation during the pandemic, and a relatively poorer mental health. A significant change in social isolation was associated with heightened levels of social loneliness.

Conclusion: COVID-19 had a substantial impact on the care circumstances and mental health outcomes of informal caregivers, in Ireland. Implementation of intervention and preventative measures is of high priority, especially in the context of the potentially extended nature of the pandemic.

The Social Contract for Care Provision in Ireland (*Dr Damien Brennan, School of Nursing & Midwifery, TCD*)

This research initiative entails a collaborative research process with Family Carers Ireland with the aim of establishing conceptual clarity regarding the social contract for care giving within domestic settings in Ireland.

Care provision within family settings is a profoundly private, intimate and interpersonal process and yet it is shaped by large scale social dynamics including gender, family, housing, care system typologies and the wider political, economic and philosophical orientations of the nation state. The relationship between individuals, families and the state is thus encapsulated and embodied in the act of caregiving.

This project explores the 'social contract' or assumed responsibility for care provision in Irish society. In partnership with Family Carers Ireland, this project will provide clarity regarding social policy expectations; assumed responsibility; and the capacity of families to provide care within family homes.

Patient and Public Involvement (PPI) in the development of learning resources for GPs and family carers *(Mary Cronin and Prof. Sinéad McGilloway, Department of Psychology, Maynooth University)*

The National Carers Strategy (2012) was an important step toward the recognition and support of family carers in Ireland. However, many of the objectives regarding the identification and support of family carers in healthcare settings have remained unmet. The CHERISH Project aims to address how carers can be best identified and supported in community health services, with a particular focus on general practice. To date, the CHERISH project has involved the completion of: (1) a national survey of family carers and in-depth interviews with family carers and GPs; and (2) a scoping review of the international literature to inform the development of Practice Point Guidelines for GPs. The third and final strand of the project, currently underway, involves the development of: (a) a distance learning education programme for GPs, with accompanying Good Practice Points; and (b) an empowerment and communication skills workshop for family carers to support them in having productive conversations with their GP.

Both programmes have been developed with a strong focus on the involvement of carers in a public patient involvement (PPI) capacity in order to ensure that their needs and outcomes remain central. Five family carers with varying experiences of caring and across a range of backgrounds, were recruited for the PPI panel and have been involved in the co-design of the GP training and the development of an educational video for GPs as well as co-design and co-facilitation of carer workshops. The PPI panel, in their capacity as experts by experience, have made invaluable contributions to co-producing programme design, content and delivery.

Public and Patient Involvement with a Descriptive Qualitative Study to Explore Household Medication Safety Among Carers (*Dr Tamasine Grimes, School of Pharmacy, TCD)*

The COVID-19 pandemic caused disruption to people's household routines, wellbeing and social networks and had the potential to affect how people manage their medication in heir homes, especially for people who were cocooning or caring for someone who was cocooning. We undertook a descriptive qualitative study, using interviews by phone or video call, with people who were cocooning, or their carers, to understand how the pandemic had affected their medication management during this time. We involved patients and the public in validating our interview topic guide and we partnered with Family Carers Ireland to secure Irish Research Council funding to engage with family carers to analyse, interpret, disseminate and maximise the impact of our research findings on everyday medication management practice and policy. The project with our PPI panellists is ongoing. This presentation will provide an overview of the practical, logistical and governance steps involved in partnering with family carers in research. It will provide insights into considerations for the recruitment of PPI panellists, provision of training to support research tasks, engagement with research ethics committees and research offices to ensure research governance, and some practicalities around project management.

IdeNtifying the top 10 priotiTiEs foR Family CarErs: The INTERFACE project (*Dr Irene Hartigan, School of Nursing & Midwifery, UCC)*

Background: Family carers play a vital, yet often invisible role in our society and healthcare system. In Ireland, there are 499,904 carers - around 12.5% of the population. The pandemic has led to new and intensified existing pressures for carers underscoring the necessity to collaboratively identify research priorities. The interface project established research priorities for carers, in partnership with families and key stakeholders.

Method: A priority setting partnership methodology was engaged and through collaboration with carers, healthcare professionals and researchers, a participatory process was conducted to identify gaps in the current literature and prioritise research questions and uncertainties. Several sources of data were used to inform the development of a long list of questions or unmet needs of family carers. Focus group discussions was one source if data that were conducted with family carers (n=5) and key stakeholders (n=3) to identify and understand carers uncertainties. An iterative process of data analysis was undertaken a Multi Stakeholder Advisory Committee to identify the research priorities for Family Carers Ireland.

Results: The top 10 researchable questions were distilled from a list of 16 and fit into 7 broad categories. 1) economic impact and financial strain 2) Systemic issues, education, resources and policy 3) technology 4) support services and infrastructure 5) mental health and wellbeing of the carer 6) carers in society 7) Recognition and acknowledgment of the family carer.

Conclusion: The partnership approach of this project allowed the ‘ground-up’ development of research priorities for carers by carers. The COVID-19 pandemic served to magnify systemic issues already present in society, as well as highlight new burdens. The identification of 10 researchable questions will guide further investigation to improve the support and wellbeing of family carers. Research priorities can help shape reform and create awareness in the community regarding the role of family carers.

Speaker Biographies

Rob Anderson

Rob Anderson is recently retired Head of the Social Policies unit at Eurofound, where he has worked as research manager since 1988 on a range of topics relating to living conditions and quality of life, including several international research projects exploring aspects of family care across Europe. Prior to joining Eurofound, Rob worked as Programme Manager at the WHO European Office in Copenhagen, with responsibility for the European Regional Programme in Health Promotion. He studied human sciences at Oxford University, and sociology as applied to medicine at Bedford College, London. Rob served as President of Eurocarers from 2009 to 2012. Rob has been appointed chairperson of Family Carers Ireland's Research & Policy Committee.

Jo Bergin

Jo Bergin is a family carer and mother to three children, aged 11, 13 and 29, all of whom have special needs. She has a background in nursing for over 20 years and also has experience as a care assistant. Jo has an interest in research that makes a difference to the lives of people with special needs and their carers and is passionate about having the carers' voice included in research in a meaningful. Jo has first-hand knowledge of the difference early diagnosis and treatment can have on children and is eager to share her experience of caring without proper supports in place.

Dr Damien Brennan

Dr Damien Brennan is an Associate Professor at the School of Nursing and Midwifery, Trinity College Dublin, where his teaching and research are focused on the sociology of health and illness. His agenda of research examines 'Contexts of Care Provision in Ireland' which seeks to understanding Ireland's problematic institutional past, while also examining the capacity for care provision within communities and families within contemporary 'post-institutional' Irish society, with particular reference to intellectual disability and mental illness. This research agenda has been supported with funding from bodies such as the Irish Research Council, the National Disability Authority, and the Irish Penal Reform Trust. Dr Brennan has disseminated research through Books, Journal Articles, TV Documentaries, Radio, Print Media, Key Note Addresses and Public Lectures.

Dr Yaohua Chen

Dr Yaohua Chen is an Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute (GBHI). Yaohua received her medical school training from the University of Lyon, France, followed by residency training in neurology at the University of Lille, France. She also earned master degrees in biology and health and completed a fellowship in the memory clinic of Lille. She simultaneously obtained a PhD position in a translational work of a murine model and a cohort of patients with Alzheimer's disease in a laboratory of vascular and neurodegenerative diseases. She continues to work in the memory clinic as a neurogeriatrician.

Mary Cronin

Mary Cronin is a PhD Scholar working on the CHERISH (**C**ommunity **H**ealth-Bas**E**d App**R**oach to **I**mproving Carer**S’ H**ealth and Wellbeing) project at the Centre for Mental Health and Community Research, Department of Psychology and Social Sciences Institute at Maynooth University (www.cmhcr.eu). She is also an Associate Lecturer in the school of Psychology and Counselling at the Open University and a graduate member of the Psychological Society of Ireland (PSI). Mary is also carer to her 22 year old daughter.

Dr Emma Dorris

Dr. Emma Dorris is the programme manager for PPI Ignite Network @ UCD. Emma is a biomedical researcher by training. She established The Patient Voice in Arthritis Research in 2017, which aimed to develop patient and researcher partnerships with the goal of reframing research to focus on the patient rather than the disease. Emma is an advocate for responsible research and innovation, and collaborates internationally to help scientists involve the public in research that is not naturally public-facing (such as preclinical and laboratory research). She has a passion for improving research culture across all disciplines. She has a particular interest in policy and practices related to PPI and in developing ways to embed PPI as part of the research culture towards more relevant and impactful research.

Dr Nikki Dunne

Dr Nikki Dunne joined Family Carers Ireland in March 2019. As the organisation’s Research Officer, Nikki leads Family Carers Ireland’s programme of research and manages a diverse range of qualitative and quantitative projects relating to family carers. She is particularly focusing on building and coordinating research involvement and engagement among family carers, researchers and other stakeholders.

Dr Tamasine Grimes

Dr Tamasine Grimes is Associate Professor of Practice of Pharmacy at the School of Pharmacy and Pharmaceutical Sciences, Trinity College Dublin. Tamasine is a pharmacist by background and worked for twenty years in the hospital and community pharmacy settings. The focus of her research is medication safety and she leads a programme of work to explore strategies to make medication use safer for the patients, carers and professional who contribute to the process and who use medications. Tamasine’s research seeks to involve patients and carers as partners in the research team and to be patient- and carer-centred.

Emilia Grycuk

Emilia Grycuk is a Clinical Research Assistant and Study Coordinator at Trinity College Dublin, St. James’s Hospital, and Mercer’s Institute for Successful Ageing (MISA) clinic. She works as an investigator and co-investigator on dementia-related projects, specifically exploring psychological and biological risk factors of dementia development and developing Delphi procedure of the Core Outcome Set (COS) for Lewy body dementia. Recently, she has been involved in research exploring care burden of informal caregivers within *Coping with Loneliness, Isolation, and COVID-19 (CLIC)* study, where she led the manuscript preparation based on the data from the English-speaking countries. She also led the preparation of the report about caregiver burden during COVID-19, in Ireland.

Emilia obtained her Bachelor’s degree in Psychology from Hunter College, City University of New York, and her Master’s degree in Clinical Psychology from Utrecht University, in the Netherlands. Previously, she has worked with multicultural aspects of psychotrauma.

Dr Irene Hartigan

Irene is a lecturer in the School of Nursing and Midwifery, at University College Cork (UCC). Within this role, Irene has academic, research and teaching commitments. Irene is a registered general nurse (R.G.N) and nurse tutor with the Nursing and Midwifery Board of Ireland (NMBI). As a researcher of international standing, Irene is currently CO-PI on an EU JPND funded project. Irene leads knowledge, translation and exchange (KTE) champions across 6 partner countries to support the integration of project activities and connect networks. Irene has several funded research projects which has entailed innovate design and management of teams and engagement of individuals across sites. The interface project engaged a PPI approach, and this was instrumental to ensure relevancy and applicability in the delivery of the research questions and findings of the project which Irene will speak about today.

Dr Avril Kennan

Dr Avril Kennan is CEO of Health Research Charities Ireland (HRCI), an organisation that supports a community of 40 charities to engage in all aspects of health research. Under her leadership, HRCI runs the Irish Health Research Forum (IHRF), manages a funding scheme for patient-focused research projects in partnership with the Health Research Board and hosts a patient and public involvement (PPI) 'Shared Learning Group' for over 30 charities. HRCI is also a national partner on the National PPI Ignite Network.

Avril's PhD and subsequent lab experience are in the field of molecular genetics. In previous roles in DEBRA Ireland and DEBRA International, she drove a range of international initiatives, including the management of a network of over 200 clinicians and patients to develop evidence-based clinical guidelines and the establishment of an international patient registry. She's passionate about improving lives through research.

Professor Sinéad McGilloway

Professor Sinéad McGilloway is Professor of Family and Community Mental Health and founder Director of the *Centre for Mental Health and Community Research* in the Department of Psychology and Social Sciences Institute at Maynooth University. (www.cmhcr.eu). She is a Chartered Psychologist and Chartered Scientist with the British Psychological Society (BPS) and an Associate Fellow of the BPS. She is also a recent recipient of the MU Faculty of Social Science Research Achievement award 2021.

Dr Emma O'Shea

Dr Emma O'Shea's background is in applied psychology and health services research. She completed her PhD through the prestigious SPHeRE programme, at DCU, and has been involved in multiple national/international research projects, yielding 40+ publications to date. Her work focuses on improving patient care, family carer support, and dyad care outcomes, in the context of neurodegenerative conditions.

Professor Amanda Phelan

Professor Amanda Phelan commenced her career as a general nurse and has worked with older people in both long-term care and community settings. Currently, she is Professor in Ageing & Community Nursing, School of Nursing & Midwifery at Trinity College Dublin. Her primary area of research is focused on safeguarding older people and older person care. She has also undertaken work related to child welfare and protection and domestic violence and is involved in research groups related to missed care, community nursing and person-centred care.