IDENTIFYING THE TOP 10 RESEARCH PRIORITIES FOR FAMILY CARERS: THE INTERFACE PROJECT

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Background: In assessing the global impact of the COVID-19 pandemic on society, it is important to understand the communities most affected and develop methods of support. Family carers provide a vital, yet often invisible role in our society and healthcare system. Identifying research priorities for carers helps establish overall gaps in the research agenda and increases awareness of the role of carers in the community.

Methods: 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. Focus group discussions followed, the first consisted of family carers (n = 5). The second (n = 3) interviewed stakeholders namely healthcare professionals, researchers and policy makers. After collating the data, researchable questions were developed through an iterative process with a Multi Stakeholder Advisory Committee to identify the top 10 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 focus of this project allowed the ‘ground-up’ development of research priorities for carers by carers. The COVID-19 pandemic served to magnify systemic issues already present in society, as well as highlight new burdens. As a result, the subsequent development of 10 researchable questions will guide further investigation to improve the support and wellbeing of family carers.