**Supporting Global Research Participation with Technology in the COM-IC Project to Develop Core Outcome Measures for Dementia Care in Australia**

Authors: Danelle Kenny1, Jack Nunn1,2, Karyn Lendich1,3, Jane Thompson3, Debbie Brittain1,3, Bronte Parkin1,3, Ruth Semler1,3, Fleur O’Keefe1,3, Benedict Davies1,3, Subin Acharaya1,3, Sonia Markoff1,3, Alyssa Welch1, Tracy Comans1.

Affiliation:

1 University of Queensland, Brisbane, Australia

2 Science for All, Melbourne, Australia

3 Member of the Public, Multiple, Australia

Introduction/Background

Realising high quality healthcare and outcomes is enabled by robust research, informed by a diversity of experiences and perspectives from the many stakeholder groups that comprise the health system. Opportunities to understand the needs of people diagnosed with neurodegenerative diseases causing dementia have been frustrated by beliefs about their capacity to inform other stakeholders. Coupled with the inherent challenges of collating multi-stakeholder input across disparate geographical areas, true co-design involving people with dementia is perceived as too difficult.

The COM-IC project challenges these beliefs through a series of co-designed, multi-stakeholder, consensus building exercises to identify outcomes of care that are relevant and important to people living with dementia and carers. The Stakeholder Reference Group (SRG) brings together an inclusive cohort of people living with dementia, formal and informal carers, aged care industry representatives, researchers, clinicians, non-clinical practitioners, and policy actors from various locations around Australia and internationally. Such collaboration and consensus building are possible through integrating a wide range of technological supports in a dynamic, adaptable, responsive system that supports inclusive approaches to meaningful stakeholder engagement.

Method

A combination of programs (Microsoft Teams, Outlook, Qualtrics, Loomio, Zoom, and Sharepoint) was used to develop a digital, multi-system framework enabling individual and group level collaboration, discussion, resource sharing, and decision-making in synchronous and asynchronous formats. Additionally, the framework provided for recording and analysis of generated data to inform dissemination of research findings.

Results/Findings

Synergistic employment of digital technologies created dynamic and robust communication pathways that supported co-designed research, and allowed for variations in collaboration preferences which met the needs of our diverse stakeholders, including people with neurodegenerative, located across large geographical distances.

Implications/Key Message

Combining multiple types of synchronous and asynchronous technological communication tools increases capability to involve multiple stakeholders with different abilities and expertise from disparate locations in research.