

# ProACT: Fostering patient and public involvement within the design of digital health solutions for multimorbidity.



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## Background

At present in Europe there are 50 million people living at any one time with multimorbidity. However, our healthcare systems have not been designed to effectively support these people in their daily care needs.

ProACT (Integrated Technology Systems for ProACTIVE Patient Centred Care) is a digital health research programme funded under the European Union Horizon 2020 framework that seeks to address this problem by developing and evaluating a digital integrated care system to support older adults (65 years and over) living with multimorbidity.

This poster will illustrate how Patient Public Involvement (PPI) was achieved within ProACT by borrowing existing methodologies, successfully implemented, in the disciplines of Design and Human Computer Interaction (HCI). It offers an example of how the design of digital health interventions can ensure that participants become co-design partners of the final system.

## Methodology

A vital part of ProACT is eliciting the voices of people living with multimorbidity, including patients, formal and informal caregivers, and health care practitioners. Therefore, a co-design methodology was adopted. The data gathered from these research activities was analysed using Thematic Analysis (Braun and Clarke, 2006).

**1. A research panel consisting of participants for the duration of the project's design process, including co-design and usability testing.**

**2. To explore and understand the experience of PwM: Interviews & Focus Group**

We could not attempt to design for the experiences of PwMs until we identified all the stakeholders in their daily care: 166 stakeholders including PwMs, informal and formal carers, GPs, consultants, nurses, pharmacists.

**3. Response to the experience of PwM: Design workshops**

Participants were encouraged to be active stakeholders in not just the data collection but also the design process. This ensured co-design was at the core of ProACT.



**4. Evaluation of design decisions: Usability Testing**

The consequent design decisions from the design workshops were returned to the participants for further feedback. Participants were encouraged not to become passive agents in the research process and instead to voice their opinions.

**5. Evaluation of the technology: Trial across EU Health systems**

Living Lab facilities in Ireland and Belgium: 120 patients and their formal and informal care networks. A European feasibility study in Italy will also assess the cultural and political determinants for adoption ProACT.

**6. Promoting local involvement: Dissemination**

Non-traditional dissemination is promoted so that ProACT can be shared with the public, the *actual* community of users that it is designed *for*: For example, Information evenings, information stands at caregiver events.

## Findings

The main themes from the analysis included: impact of multimorbidity; self-management; medication; knowledge, information and education; sources of support; communication; training; and technology (Doyle, Hoogerwerf, Kuiper, et al., 2017)

By adopting a co-design methodology, PPI was achieved and participation was explored within ProACT, discovering the stakeholders involved in the community care of PwMs and equally as important, how best to respond to this experience **to enable PwMs to live within their own homes for as long as possible.**

PPI is a deliberate inclusion of patients and the public as stakeholders and not just participants of research. Design thinking allowed us to combine traditional qualitative research with a proactive, iterative approach, which fostered dialogue between researchers and participants. Hence, **ProACT ensured that design happened *with* and not *for* participants.**

The resulting digital design that is being deployed across the EU trial sites includes: a suite of supportive ICT-AT, a data aggregation platform and training tools, an innovative data analytics framework, and a behavioural change tool kit and framework.

Together, these aim to ensure a promotion of **technology as a way to empower patients to proactively manage their conditions, promoting a sense of ownership over their health and care, within their own homes.**

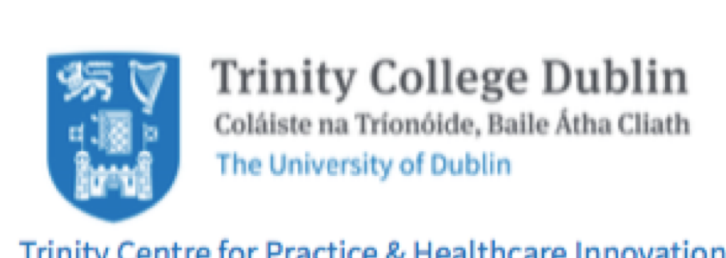


## Conclusions

The context of care is a relational one, with current models of care focusing on person-centred and relationship-centred approaches, both of which hold a dialogical viewpoint at their core. The dialogical approach advocated by these models is also advocated by design thinking and its associated methodologies.

In designing a digital integrated care ecosystem, our design thinking approach allowed us to put each member of the community care of PwMs in dialogue with each other, ensuring their full participation in the design process.

A person-centred rather than disease specific approach to design is at the core of ProACT and therefore it was imperative to identify and include all stakeholders in the community care of PwMs. A design thinking approach fostered such inclusion but also a way to push traditional participation in research to go further in considering the role of PPI.



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