The Role of Design Thinking in the Application of PPI within the ProACT Project.


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Background

At present in Europe, there are over 50 million people living with multimorbidity (PwMs). Nonetheless, research pertaining to the experience of a PwM has been scant, in particular how health researchers and policy makers can promote self-management, offsetting the EU's annual €700 billion cost of chronic disease management.

ProACT (Integrated Technology Systems for ProACTive Patient Centred Care) aims to develop and evaluate an ecosystem to integrate a wide variety of new and existing technologies to improve and advance home-based integrated care for older adults with multimorbidity.

While PPI has recently been encouraged, and supported within academic research, there has been little guidance regarding how to implement it. This poster will illustrate how PPI was achieved within ProACT by borrowing existing methodologies, successfully implemented, in the disciplines of Design and Human Computer Interaction (HCI).

Methodology

A participatory design research approach provided flexible, responsive, and practical methods to follow. A consequence of this approach, within the context of community care, was the promotion of PPI.

The following steps illustrate how this was achieved:

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

Although community care is strongly advocated for in our society, living at home does not necessarily equate to living within the community.

Thanks to a design thinking approach, participation was explored within ProACT to discover 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 will be 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 Public and Patient Involvement (PPI).

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