

Co-producing socio-technical solutions for people living with complex multi-morbidity: developing methodology and assessing pros and cons of a RCT

<https://www.neurodegenerationresearch.eu/survey/co-producing-socio-technical-solutions-for-people-living-with-complex-multi-morbidity-developing-methodology-and-assessing-pros-and-cons-of-a-rct/>

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United Kingdom

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Co-producing socio-technical solutions for people living with complex multi-morbidity: developing methodology and assessing pros and cons of a RCT

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€ 121,977

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1.5

Keywords

Research Abstract

The key outputs will be:

1. Preliminary field work in Site 1
2. Establish absorptive capacity for co-production at research sites
3. Develop training programme and curriculum
4. Pilot co-production in practice
5. Optimise the logistics for the project

Further develop research network

Establish second case site. Output 1: Preliminary field work in Site 1. We will conduct ethnographic fieldwork with 5 cases, and the ethnographic study of a call centre to gain a better understanding of the types of conditions and problems that people with complex multi-morbidity, and their carers, face day-to-day and the challenges in providing ALTs to support them. This research will be based in Newham, and participants will be recruited via the community care teams at East London NHS Foundation Trust (ELFT). ELFT provides services for older people with memory and mental health issues which are focused on supporting individuals to stay independent in their own home. The services are provided through the Community Mental Health Team for Older People, Community Dementia Care Team, Diagnostic Memory Clinic, Intermediate Care for Older People and a range of In-Patient mental health services. Sample strategy. The research will include five older people (index case) and their carers, with different levels of severity in cognitive impairment (including sub-clinical memory loss, mild cognitive impairment and mild, moderate and severe dementia) and a physical or chronic illness. Participants will be purposefully selected to present different health conditions, family settings and ethnic and social backgrounds. As in our previously successful ATHENE study, we will pay meticulous attention to the ethics of informed consent and assent, and follow published guidance for working with people with reduced capacity in this regard. The cases will include people with mild dementia who will give consent or assent directly, as well as those with more severe dementia for whom proxy consent will be sought from the primary carer following standard COREC guidance, according to a protocol previously approved by Harrow Research Ethics Committee for the ATHENE study.

Design

Qualitative data will be collected longitudinally for each case using ethnographic methods (including semi-structured and narrative interviews, observations, 'home tours' and cultural probes). Each participant will be visited on up to six occasions over a 6 month period.

During the first home visit, the purpose of the project will be explained to participants and they will be asked to consider taking part. During the second home visit, semi-structured and narrative interviews will be conducted, used adaptively between participants and carer(s) depending on the index individual's capacity and preferences, and focusing on routines, health, social support networks, technology and problems they experience. At

the end of the interview, participants will be provided with cultural probe tools. On the third visit (approximately one week later) the cultural probe materials will be reviewed as part of a longer interview (e.g. we will look at any photographs with the participants and invite them to tell us why they took the pictures). Following the interview, a 'home tour' will be conducted, in which the participants show the researcher different areas of their home to prompt further discussion about what they do and problems they face.

Up to three subsequent home visits will take place over a 6 month period (which will be agreed between the volunteer participants and researcher). We will pilot the use of cultural probe materials to capture ethnographic data between these visits.

Analysis

Interviews and field notes will be analysed qualitatively and reported in the form of a case study to identify interactions between physical, psychological and social needs, and the roles of social and technological supports oriented to how the wider socio-technical environment helps or hinders the participant from achieving what matters to them. The case studies will also document the use of ethnographic methods, and any adaptations that need to be made to the design and methodology.

Output 2-3 Capacity building

There are powerful arguments for shifting from a top-down 'cathedral' model (in which expensive pieces of kit are produced by manufacturers and then installed in people's homes with little or no customisation) to a 'bazaar' model (in which a broad menu of affordable and interoperable components are available to be combined creatively to produce customised, personalised solutions that can be adapted to a person's changing needs).

The development work will explore the absorptive capacity of the partner organisations to embrace new ways of working and the motivation among the care teams to engage in this activity, establish what training is required for different staff groups, and develop a curriculum and resources for them to implement the co-production methodology.

Data will be collected through interviews and focus groups with the care teams at the research sites as well as ethnography, and analysis of documents (such as the organisation's strategic plan, job descriptions, business plans and project initiation documents for previous ALT development projects, and correspondence). The interviews

and focus groups will focus on issues such as their views on how ALTs could be better customised to user needs, the skills and knowledge required to adopt the co-production methodology and the organisation and technical sub-systems that would need to be adapted to embed the co-production approach within the existing work practices.

Through discussions with service teams, we will gain a better understanding of how to implement the changes and who to involve in this process (e.g. team managers, service commissioners, IT departments). The analysis will draw closely on Greenhalgh et al.'s (2004) model for diffusion of innovations in service organisations. The development work will focus on the input from, and coordination between, different people and organisations to introduce and adapt the ALT services at the case sites.

Output 4-5 Pilot co-production in practice

Co-production refers to sustained collaboration between users and stakeholders to develop, adapt and improve technological innovations and services in use. The pilot will provide proof-of-concept for the co-production methodology and feasibility to implement this approach in practice. The researchers will work alongside the service staff to co-produce ALT solutions with each case (and their carers) alongside the service microsystems in which they are embedded.

Sample

Up to 5 cases will take part in the co-production pilot. The ELFT care team will identify the case on the basis that they [a] present an assisted living need that could potentially be supported through an ALT solution, [b] able and willing to take part in the co-production process, and [c] have no over-riding practical or ethical barriers to their involvement. As we have described above, we will follow published guidance for working with people with reduced capacity in this regard, and follow standard COREC guidance.

Design

We will work with each case for up to 8 months. The co-production methodology will be adaptive to the individual case, but broadly consist of three steps:

- *Step.1: Grounding requirements through ethnography*

Each case participant will be visited at home on 3 separate occasions to build a rich picture of their lives and care needs and how the ALT could support them. The visit will be carried out by one service staff member and one academic researcher. Ethnographic techniques (developed as part of the successful ATHENE project) will be used to draw preliminary conclusions about how the technology and service should be designed to fit

within their homes, routines, lifestyles and care networks.

– *Step 2: Co-design with participants, service providers and technology suppliers*

The ethnographic case narratives will be taken forward to communicate the needs of the case participant to the service providers and technology suppliers. Participatory design methods will be used to engage the case participants, service providers and technology suppliers in the development of ALT solutions. Where possible, this will involve direct collaboration across the user and stakeholder groups (e.g. co-design workshops).

– *Step 3: Implement, adapt and evaluate the technology and service*

The ALT will be provided to the case participant, with ongoing support and review to monitor how the ALT and service should be adapted to better fit within their lives, and in response to changing needs or requirements.

Analysis

Ethnographic data will be analysed narratively and reported in the form of a case study, which will document the use of the co-production methodology. Ethnographic and interview data will be collected to explore facilitators and barriers to the adoption of the co-production methodology, and adaptations to service microsystems to accommodate and support the personalisation and adaptation to ALT solutions over time. These pilots will provide a better understanding of the feasibility implementing and evaluating co-production in practice.

Output 6-7: Establish second research site and further development of research network

The programme will include a comparative case study analysis. The first research site has been identified (ELFT). The second research site, hopefully in Oxford where Prof Greenhalgh is now based, will be established through the development work. We plan to compare the research findings from two diverse settings, and so will meet with a range of care teams to gain insight into the ALT services and organisational structure. It is important that the research sites present diverse organisational characteristics (e.g. services available, integration and interactions with other services, care pathway) so that we can draw conclusions about the wider applicability of the co-production model

During the development phase, we will further develop links with multidisciplinary research groups in the field and relevant lay and service representatives through regular meetings, e-mail, Skype and telephone contact. This will include building on existing UK programmes that are currently ongoing. In particular, we will maintain discussion with the NIHR funded ATTILA RCT trial team to identify emerging questions on ALT service development that could be answered through this programme. We will also build the partnerships required to support the development and implementation of a 'collaboration

space' (WP4), particularly with regard the design of a technical infrastructure to support co-production.

Finally, we will take detailed advice from the RDS and other methodological experts on the pros and cons of using a RCT design in the definitive programme.

Further information available at:

Types:

Investments < €500k

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United Kingdom

Diseases:

N/A

Years:

2016

Database Categories:

N/A

Database Tags:

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