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Are Systemic Design Methods Excluding People with Learning Disabilities?

A protocol to enable the participation of people with learning disabilities to codesign artificial intelligence healthcare systems scenarios

Cecilia Landa-Avila 1, Satheesh Gangadharan 2, Sarah Rabbitte 2, Amy Wilkins 2, Michelle O'Reilly 3, Neil Sinclair 4, Chris Knifton 5, Panos Balatsoukas 1, Rohit Shankar 6, and Gyuchan Thomas Jun 1

Loughborough University 1 | Leicestershire Partnership NHS Trust 2 | | University of Leicester 3 | University of Nottingham 4 | De Montfort University 5 | University of Plymouth 6

This presentation aims to present an inclusive research protocol to enable the participation of people with learning disabilities to codesign Artificial Intelligence healthcare systems scenarios and reflect on how some groups of populations have been excluded while participatory systems thinking approaches/methods have been conceptualised and applied.

A succinct review of systems thinking methods (i.e., systems mapping, ecosystems scenarios and patients' journeys) will be presented and reflect on how inclusive they are. Next, the protocol followed in an ongoing project that explores the integration of Artificial Intelligence for codesigning a joined-up healthcare model for people with learning disabilities will be presented. This protocol describes a methodology that introduces and adjusts some systems thinking methods to meet the needs of people with learning disabilities to

become active participants in sessions with multiple stakeholders (e.g., health and social care professionals, policymakers and tech innovators, among others). The presentation will emphasise the ethical considerations for recruitment and consent, adjustments for reducing the cognitive workload of methods, environmental aspects to ensure participants' wellbeing, follow-up actions for long-term engagement and meaningful contributions and building up learnings to increase 'complexity' and independence.

The presentation will conclude with a reflection on how these adjustments and considerations could be adopted in other approaches, methods and techniques to demystify the complexity of systems thinking methods and contribute to enabling more inclusive research practices. This inclusive perspective promotes the integration of diverse actors, especially those that have remained excluded from the mainstream methodological approaches to achieve genuine participation within a systems thinking approach.

KEYWORDS: inclusive systemic design, multistakeholder participation, healthcare scenarios, artificial intelligence

RSD TOPIC(S): Health & Well-Being, Methods & Methodology

Presentation summary

Despite the growth of Systems Thinking (ST) approaches across design disciplines and domains in the last years, many challenges remain in the dissemination and application of its methods. Some of these challenges are more significant within certain populations that were not equally considered when such methods were developed (Brereton et al., 2015).

This is the case of the inclusion of People with Learning Disabilities (PLD) in participatory research (Di Lorito et al., 2018), especially in the area of healthcare. PLD are considered a disadvantaged group representing 1% of the people registered in the National Health Service of the UK; of these, approximately two-thirds have two or more long-term

conditions in addition to a learning disability (Tyrer et al., 2019). The poor engagement of this group in healthcare research fails to encapsulate the complexity of care that this population need and contributes to the health inequities experienced by this group (Mimmo et al., 2021; Raman & French, 2021). Therefore, there is a need to reflect on how ST approaches might have excluded specific populations and what can be done to mitigate and revert such phenomena.

This presentation aims to: i) present an inclusive research protocol to enable the participation of PLD to codesign Artificial Intelligence (AI) healthcare systems scenarios and ii) reflect on how the adjustments proposed could be adopted in other research approaches and methods to integrate marginalised groups. Ultimately, the presentation aims to trigger a discussion that faces researchers and practitioners with their methodological inclusion decisions and how this could perpetuate a biased construction of systems structures.

Description of the research project

DECODE (Data-driven machine-learning aided stratification and management of multiple long-term conditions in adults with learning disabilities) is a UK's NIHR (National Institute for Health Research)-funded research project with the goal of utilising the Artificial Intelligence enabled new knowledge to develop actionable insights for effective joined-up health and social care for PLD and multiple long-term conditions.

The research project will be conducted across 30 months. We are aiming to engage and retain our participants to enable genuine participation. Long-term engagement will help participants learn from previous studies, increase their understanding of the relevant concepts, and provide more meaningful feedback as they will have extended periods to reflect on the issues addressed.

An inclusive protocol for applying a systems thinking approach

Genuine and inclusive participatory research should care for several aspects. Figure 1 summarises the protocol in which different actions and methods have been integrated. We have obtained feedback from PLD representative groups about this process and the

recruitment materials. Based on the learnings from developing the protocol, there are five significant considerations that we have reflected upon.

Ethical recommendations for consent and recruitment

Ensuring that all the participants understand the purpose of the study requires that the information be shared gradually, starting with a simple, accessible summary of the whole research project and increasing the level of detail until the full explanation of the study is conveyed. PLD are encouraged to share the information with someone they trust (e.g., family, carers or friends) before deciding to participate.

During the recruitment process, it is essential to conduct a mental capacity assessment that provides evidence that the participant understands the study (e.g., activities, use of data) and their rights (e.g., withdrawing at any time, raising any concern).

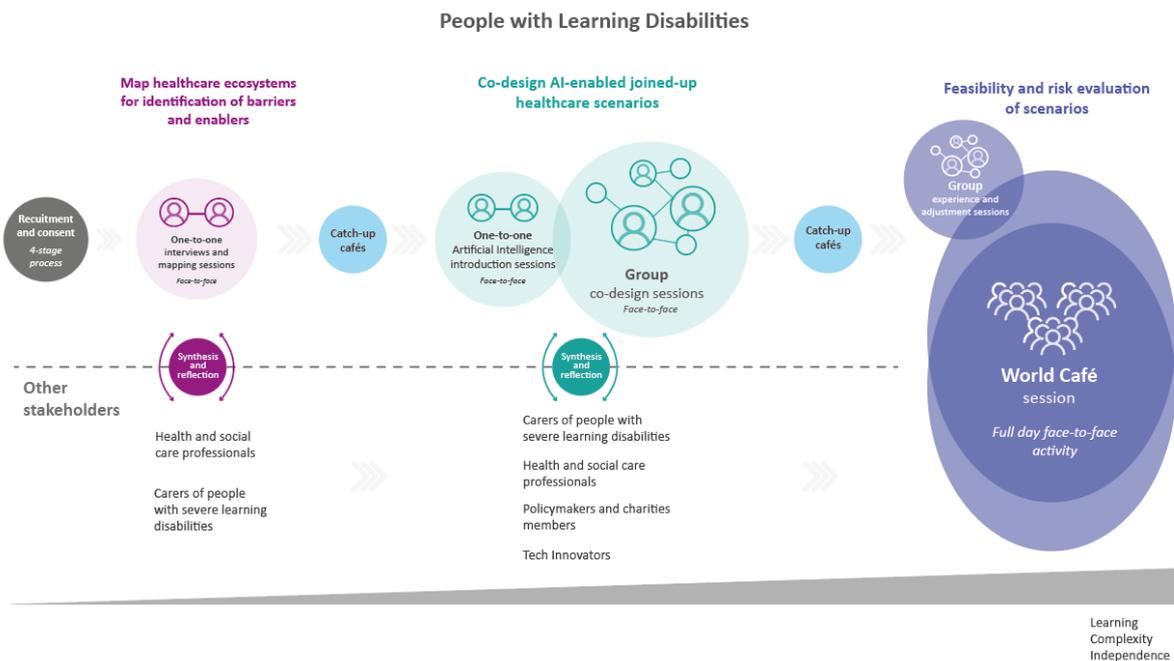


Figure 1. Summary of the methods and activities across the DECODE research project.

The cognitive workload of systems thinking methods

One of the primary concerns was the usability of the systems thinking methods (e.g., systems mapping, ecosystems scenarios and patients' journeys), which are commonly considered hard to understand and apply. Therefore, several adjustments and strategies are integrated to mitigate the cognitive load. Some of these include

- Translate complex topics (i.e., Artificial Intelligence) into tangible artefacts with personal and context-dependent meanings.
- Include physical representation of real-life systems elements (boundary objects (Star, 2010)) to map systems. Collect details of noteworthy people, places and activities and personalise the materials (e.g., vignettes) so that participants can relate to their experiences.
- Start with the simplest/individual activities to provide individual support. Use simulation sessions with PLD to introduce complex topics and activities.
- Allocate considerable/flexible time to conduct the individual mapping activities at the participant's pace. This will help to have a more accurate time estimation for group sessions.
- Provide different communication channels (e.g., easy access documents, sign language), offer support for moving objects and drawing, and respect participants' preferences to express their opinion.
- Use storytelling to communicate systems scenarios.
- Facilitators should use verbal clues that respond to participants' experiences.

Environmental aspects to ensure participant well-being.

A suitable environment is critical so participants can take part freely and safely. It is recommended to conduct the first sessions in familiar places to the participant, including their home and public places they usually visit. As the research progress, other settings could be introduced, as long as they fulfil requirements such as good accessibility in all the areas (entrances, corridors, toilets), private and quiet spaces for breaks/time-off and low-sensory rooms and presentations. Provide photos of settings, agenda and facilitators in advance. For example, in preparation for the final study, participants will be shown videos of a World Café. They will also participate in a smaller

experience session that simulates some activities. This experience will help them decide whether to participate and provide the research team with more adjustments to include in the session.

Follow-up actions for long-term engagement and meaningful contributions

There are divided positions regarding what could be called genuine participatory research. Some criticisms emerge when participation is reduced to a couple of hours to conduct a group method (Gilbert, 2004). The DECODE's protocol wants to minimise the risk of conducting tokenistic research by implementing three strategies. First, invite/include the same participants in all the studies. Second, to communicate preliminary results and updates in accessible channels. Third, to offer casual catch-up spaces/channels for exchanging ideas and reflection between the formal studies.

Building up learnings to increase 'complexity' and independence

The duration of the DECODE research project allows us to increase the complexity of the concepts and activities gradually. Participants are expected to feel more comfortable and have more holistic discussions as the research progresses. However, not all the participants will remain for the whole duration, and each study should be prepared considering participants without previous experiences. Storytelling will be a valuable strategy to communicate previous findings to new participants, individual introductory sessions will be conducted to update new members, and catch-up cafes could support informal familiarisation with the topic, participants and approach.

Concluding remarks

This presentation aims to provide high-level considerations and practical details of adjustments to engage with people with learning disabilities and conduct different study formats (individual, group and large studies) of systems thinking methods. We also expect that this protocol triggers a greater reflection among systems thinking researchers and practitioners on how inclusive their practice is and how some methods and tools are conceptualised based on a mainstream mindset that perpetuates a biased construction of systems structures. Ultimately, we hope this presentation contributes to demystifying the complexity of conducting participatory research with a diversity of

populations, especially those that have remained excluded from the mainstream methodological approaches to achieve genuine participation within a systems thinking approach.

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