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Relating Systems Thinking and Design
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Healthcare Research through Systemic Design: Mapping entangled systems to identify leverage scenarios to enhance care coordination for people with learning disabilities

Cecilia Landa-Avila, Gyuchan Thomas Jun, Satheesh Gangadharan, Sarah Rabbitte, and Amy Wilkins

Healthcare systems worldwide are facing challenges to cope with the contemporary demands of the population. Many strategies have been implemented in an attempt to mitigate the urgent needs. In the UK, plans for Integrated Care Systems (ICS) are looking to reconcile health and social care and provide holistic care for people (NHS England, 2021).

Despite these efforts, some populations with more complex needs are not yet receiving the care they need. This is the case for People with Learning Disabilities (PLD), who often face healthcare inequalities. PLD is seen as a disadvantaged population, making up about 1% of those enrolled in the UK's National Health Service; about two-thirds of this population also have two or more long-term conditions (Tyrer et al., 2019). Moreover, PLD tends to die between 18 to 14 years younger than the rest of the population, and 38% of PLD died from an avoidable cause, compared to 9% in a comparison population of people without a learning disability (Emerson & Hatton, 2013; Heslop et al., 2014). Health disparities that this group experiences result from their inadequate participation in healthcare research, which fails to capture the complexity of care required (Mimmo et al., 2021; Raman & French, 2021).

Therefore, a joined-up model is needed to effectively coordinate care for PLDs. This model must be co-developed with PLDs, their carers, and health and social care professionals. Moreover, it could be leveraged with new technologies, such

> as Artificial Intelligence (AI), that can support sensemaking and integration of large amounts of data.

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

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

Context and Scope

This presentation aims to present the findings from the first study on the development of the joint model of care for PLD. Specifically, the findings from graphic/visual facilitated interviews conducted with multiple healthcare stakeholders to map a healthcare system model for care for PLD.

DECODE (Data-driven machine-learning aided stratification and management of multiple long-term conditions in adults with learning disabilities) is a research project funded by the UK's NIHR (National Institute for Health Research). The project aims to develop new knowledge of clusters and trajectories of Multiple Long-Term Conditions (MLTC) in PLD with AI and utilise that knowledge to develop a joint health and social care model for PLD.

DECODE includes four Work Packages (WP) and one Patient and Public Involvement and Engagement (PPIE) working group (Figure 1). WP1 and WP2 concentrate on developing the AI model of MLTC trajectories; WP3 and WP4 focus on qualitative methods to codesign data visualisation and systems scenarios. PPIE work is embedded across all the work packages. This presentation focuses on the interviews from WP4.

A previous publication (Landa-Avila et al., 2022) discussed that systemic design methods tend to exacerbate barriers to participation with certain populations due to cognitive demands. Some of these barriers are more significant within certain populations, such as PLD, which were not equally considered when such methods were developed (Brereton et al., 2015).

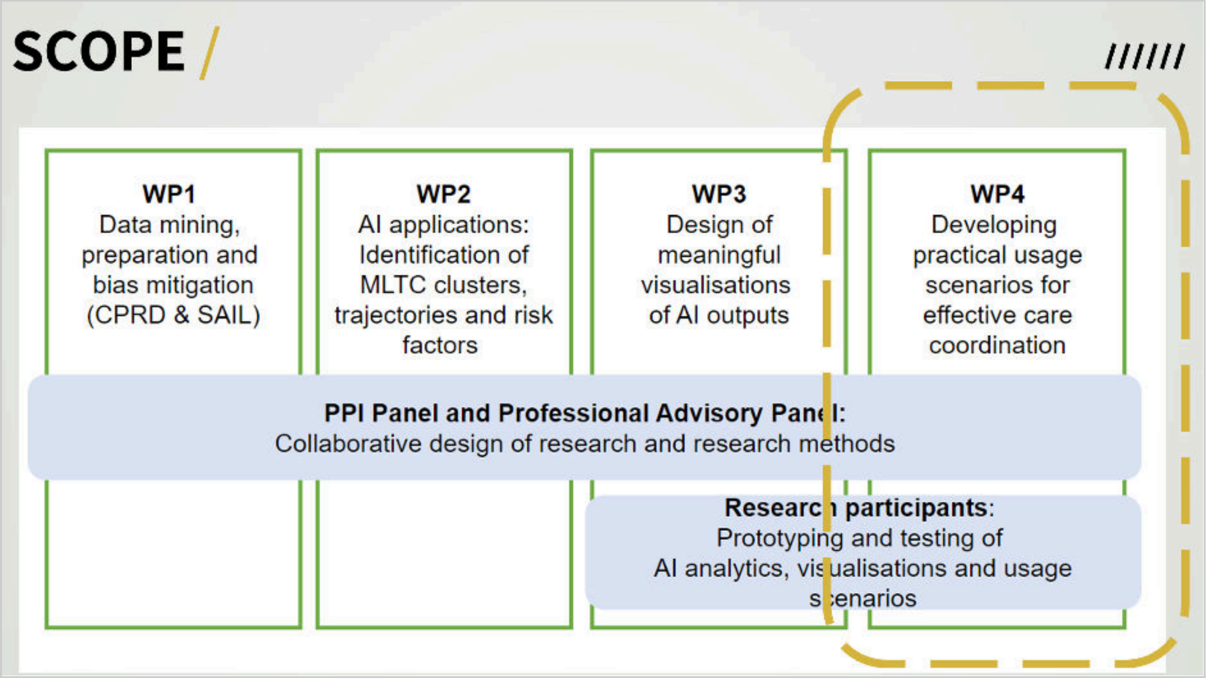

Figure 1. Summary of the work packages across the DECODE research project.

Hence, the DECODE research protocol development focused on adjusting each method and technique to mitigate these barriers. Graphic/visual facilitated interviews were the first data collection method (Figure 2), as it was defined that the complexity of the methods needs to be gradually increased.

Methodology of the graphic/visual facilitated Interviews

The graphic/visual facilitated interviews were conducted with four groups of stakeholders. Thirty-five interviews have been conducted until August 2023. It is expected to complete 60 interviews from the four types of participants, and there is an expectation to achieve an equivalent sampling among the groups. The type and number of participants completed so far are described in Table 1.

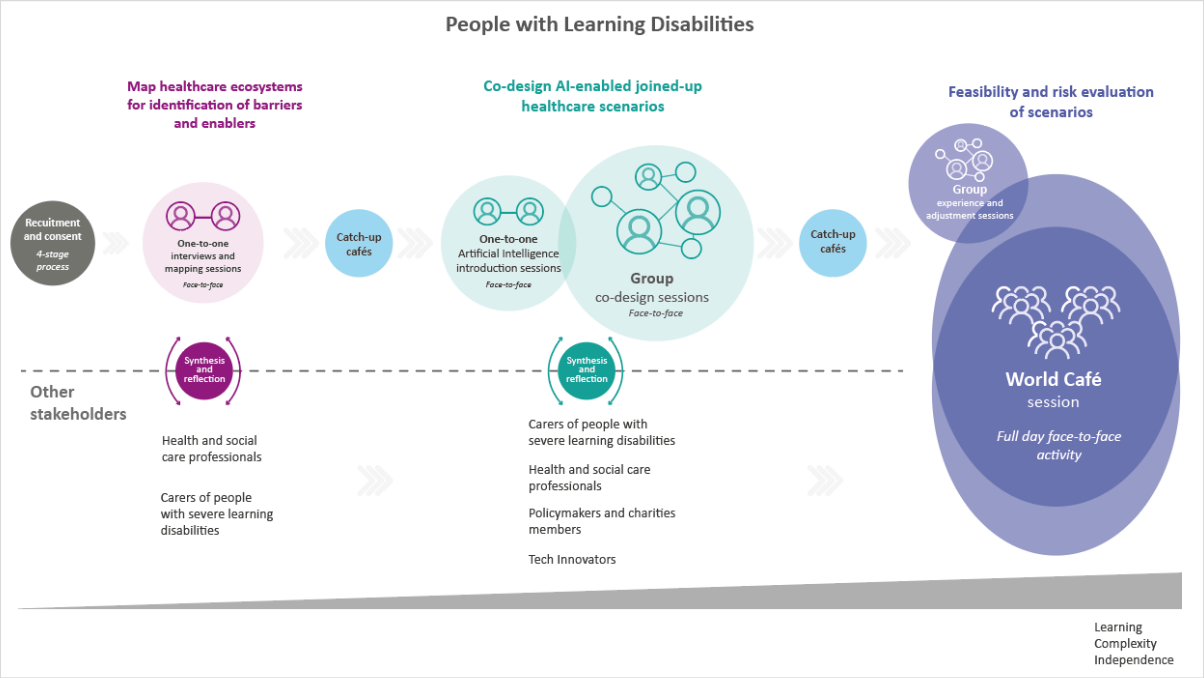

Figure 2. Summary of the methodology and activities across the DECODE research project.

The graphic/visual facilitated interviews aimed to collect data on how the care is coordinated for PLD. It was decided that an open-mapping technique would allow participants to express their more meaningful aspects freely. The interview lasted 90 minutes with PLD and 60 minutes with the rest of the stakeholders.

The process for conducting the graphic/visual interviews was as follows:

1. Introduce the topic and ask about their understanding of care coordination.
2. Open mapping. Participants were asked to create a map to explain how they provide/enable care coordination for PLD. The mapping started with two actors, they and the PLD. As an open mapping technique, participants were free to follow the direction they preferred when they added other system elements. Usually, they include other actors or processes they do. The interviewer asked questions to clarify the connections between elements and trigger the identification of more elements and connections. The mapping was conducted until no new elements were mentioned or time was consumed (up to 30 minutes).

3. Identify barriers and enablers. Once the mapping concluded, participants were asked to identify the top three barriers and enablers for care coordination. Those could be something already on the map or something not yet on the map if they decide.

A speech and language therapist and a learning disability nurse assisted the PLD during the graphic/visual facilitated interviews. PLD decided if a carer of someone they trust was there as a companion during the interview. The process with PLD was adjusted as follows:

1. Digital storytelling to introduce the topic. A three-minute presentation was used to introduce the concept of care coordination, barriers and enablers. During this presentation, a wooden block tower was built to create physical (and metaphorical) representation of care coordination.
2. Open mapping with stakeholders and action cards. Cards representing a broad range of stakeholders (e.g., family, GP, nurse, social worker, etc.) were included to help participants identify key actors. Activities cards were generated based on four areas (i.e., healthcare, social care, everyday activities and hobbies). Participants were free to include only those meaningful cards to them and include new stakeholders and activities that were part of the initial card deck.
3. Identify barriers and enablers. Participants were encouraged to identify barriers and enablers during the mapping process. There was also a final time to reflect and select the top ones.

All the interviews were audio-recorded for further analysis.

Table 1. Summary of participants.

Number	Type	Description
9	People with learning disabilities	People with mild/moderate LD took part. All participants undertook a capacity assessment to ensure they understood the research aim and could decide on their participation.
7	Carers	This group include family carers and also those who receive a payment.
12	Healthcare professionals	This group includes psychiatrists, general practitioners, LD community nurses, acute LD nurses, speech and language therapists and other medical and allied professionals.
7	Social care professionals	This group includes social workers, team managers, personal assistants and local authorities.

Maps from people with Learning Disabilities

Maps from other participants

Figure 3. Example of raw maps from the graphic facilitated interviews.

Analysis

The plan to analyse the maps is a two-step process.

1. To reconstruct the raw maps (Figure 3) to complete the missing data that participants expressed orally but were not included in the map due to time constraints. The maps will then be synthesised; one per type of participant and one group map. Tensions and disagreements will be highlighted in the final map.
2. The transcripts for the interviews will be analysed by conducting a thematic analysis. This process will identify the main areas of concern, barriers, and enablers for care coordination.

Preliminary results

A total of 35 graphic/visual facilitated interviews have been conducted so far. The preliminary results are summarised in four points.

- *Everybody is a care coordinator*. All the participants, apart from PLD, expressed that they perceived themselves as the coordinator of care. Different explanations have been drawn. First, as the care for PLD entails many sectors of the system, everybody recognises they play a key role. Second, as the system is fragmented, they have a huge commitment to their responsibilities and poor communication with other actors; therefore, there is poor recognition of how others are contributing to the care of PLD.

- *A healthcare system that reacts*. Existing collaborative models of care tend to require that a PLD be having a crisis in order to respond and adjust their care plans. Less attention is paid to monitoring and adjusting the provision of support considering a positive health status.
- *Communication issues exacerbate barriers at all levels*. Communication plays a key role at different levels and among different actors. For example, many healthcare professionals (e.g., GP, physio) do not have appropriate training on how to communicate with PLD, which makes it difficult to have an assertive consultation. Other cases also include the lack of sharing (electronic) systems between health and social care, which makes it challenging to comprehend what is happening with a patient holistically.
- *Tensions between health and social care remain*. Despite efforts that the new Integrated Care System to reconcile health and social care, professionals still experience barriers linked to medical power dynamics. For example, social care workers feel they are not heard when they raise concerns or make referrals to a health professional.

For the RSD12 presentation, all the data analysis of the 35 graphic/visual facilitated interviews is expected to be completed. Hence, new insights are likely to emerge and be presented.

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