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Theory of Change: Use of Data to Enhance Care of People Living with Frailty

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Date: January 2023

1 Background and context

The theory of change focuses on better use of available data to inform care provision for people living with frailty. It has been developed following discussions with stakeholders from the Portsmouth and Southeast Hampshire (PSEH) locality and stakeholders from Hampshire County Council and Hampshire and Isle of Wight (HIOW) Integrated Care Board.

This work forms part of the NHS Insights Prioritisation Programme (NIPP) project in Wessex which focuses on digital remote monitoring and frailty. The work therefore initially set out to consider use of digital remote monitoring data to inform care provision for people living with frailty. However, on discussion with stakeholders it was clear that digital remote monitoring was only in the initial stages of development. It was also apparent from clinical stakeholders, in particular, that routinely collected health and social care data was not easily available and accessible to inform decision-making across organisations and settings in relation to care of people living with frailty. Better sharing of data was considered a potential tool to improve clinical decision making and enable earlier detection of deterioration.

The Theory of Change approach is a method to hypothesise a causal pathway through which an initiative achieves impact. This is visualised in a Theory of Change map, which provides a comprehensive illustration of how long-term outcomes can be achieved in a specific context and under particular circumstances (De Silva et al., 2014). In this project, this approach was used to improve understanding of how and why cross-organisational sharing of data would work to enhance care of people living with frailty in HIOW. The development of the Theory of Change occurred alongside development of a Population Health Management approach to frailty care and also a review of the HIOW data sharing service, Care and Health Information Exchange (CHIE), and can be used to inform further developments in this area.

2 Methods

A pragmatic approach to this work was taken, as initial communication with stakeholders indicated that a series of 2 or 3 stakeholder workshops to discuss and agree the Theory of Change was unrealistic. The development and refinement of the map therefore drew on individual discussions and email communication with stakeholders, a workshop involving Wessex Academic Health Science Network (WAHSN) colleagues and a public contributor to draft an initial map and one virtual stakeholder workshop. The steps taken to develop the Theory of Change map, detailing the aim, methods and outputs of each step are provided in the Table 1 below. Stakeholder involvement is outlined in Table 2.

Table 1: Steps take to develop the Theory of Change Map

Step	Aim	Methods	Output
1.	Scoping and review of available evidence	Online searches were completed of the following organisations webpages: NHSX, NHS Digital, NHSE, NHSEI – South East Region and NHSEI – South West Region in October 2021.	Details of a project undertaken in Luton relating to the electronic frailty index (eFI) and social care data. Further information was sought but no responses received.

Step	Aim	Methods	Output
2.	To understand the local landscape in terms of digital remote monitoring and data sharing arrangements.	Individual meetings with stakeholders with two objectives: 1) To explore what remote monitoring tools were currently in use that were used or potentially used by people categorised as having frailty and how these are accessed within PSEH. 2) To investigate how data routinely collected from remote monitoring (either business as usual or pilot schemes) was used to inform care and support of people living with frailty.	Collated information on current remote monitoring provisions and data sharing arrangements, analysed to identify key themes and individual relevant points raised.
3.	To draft an initial Theory of Change map using collated data.	Two-hour workshop involving three WAHSN Healthy Ageing Programme and Digital Programme colleagues and one public contributor, alongside the researcher.	Draft Theory of Change map.
4.	To discuss, further develop and agree an updated version Theory of Change map.	Two-hour stakeholder workshop involving six stakeholders. (Three stakeholders only attended part of the workshop.)	Updated draft of Theory of Change, subdivided into two distinct maps: 1) relating to use of data to inform the eFI and 2) relating to use of data to enable timely identification of deterioration.
5.	To refine and finalise the Theory of Change map.	All stakeholders were emailed an updated version of the Theory of Change map following the workshop for further refinement and agreement. Specific questions were asked of frailty practitioners (as they were not represented at the workshop) relating to data they would consider useful to their decision-making.	Final version of Theory of Change map.
6.	To understand the local Population Health Management approach to frailty and potential overlap with the Theory of Change (as identified at the stakeholder workshop).	Meeting with Population Health Management Implementation Manager.	The planned use case for frailty within the population health management record includes calculating the eFI using data from multiple sources, which in time will also include social care, so this means the first part of the Theory of Change will not be required in HIOW.

Table 2: Stakeholder involvement in development of Theory of Change map

Stakeholder job role	Individual meeting	Email communication	Stakeholder workshop	Email review of one or more draft maps
Transformation Managers x 2	Yes x 1		Yes x 1	
Commissioning Project Manager	Yes		Yes	
Telecare and Home Safety Manager	Yes			
Consultant Frailty Practitioner	Yes			Yes
Associate Director of IM&T		Yes	Yes	
Digital Programme Manager	Yes		Yes	
Head of Technology Enabled Care and Digital	Yes		Yes	
Heads of Nursing and AHPs x 2	Yes x 2			
Consultant Nurse – Frailty	Yes			
Operations Director	Yes			Yes
Consultant Geriatrician	Yes			Yes
Operations Manager for Intermediate Care	Yes		Yes	
Population Health Management Implementation Manager	Yes			

3 Results

As suggested in the Checklist for Reporting Theory of Change (Breuer et al., 2016), the Theory of Change is depicted in diagrammatic form in Figure 1. This includes the 1) impact, 2) long-term outcomes 3) ceiling of accountability, 4) preconditions, 5) interventions and 6) assumptions, with more detail on each of these also provided below.

3.1 Impact

Discussions with stakeholders identified two specific areas where care of people living with frailty could be enhanced through better use of data:

- Increasing proactive management of frailty. It was identified by stakeholders that care provision is often reactive. Preventative and proactive approaches to the provision of frailty care are promoted as best practice (NHS England, 2019).
- Reducing health and care crises. Emergency department attendances and hospital admission often lead to poor outcomes and have an adverse impact on level of functioning (Ellis et al., 2014, Keeble et al., 2019). Decision-making in a crisis, made at pace with little time for exploration of alternative solutions, can lead to admission to long-term care that is often not aligned with the preferences of the older person (Bowers et al., 2009).

3.2 Long-term outcomes

Key areas identified from stakeholder discussions where better use of data could help assist achievement of these impacts were early identification of both frailty risk and changes in frailty status, and appropriate and timely recognition of acute deterioration. These are supported by best practice guidance (British Geriatrics Society, 2014, NHS England, 2019).

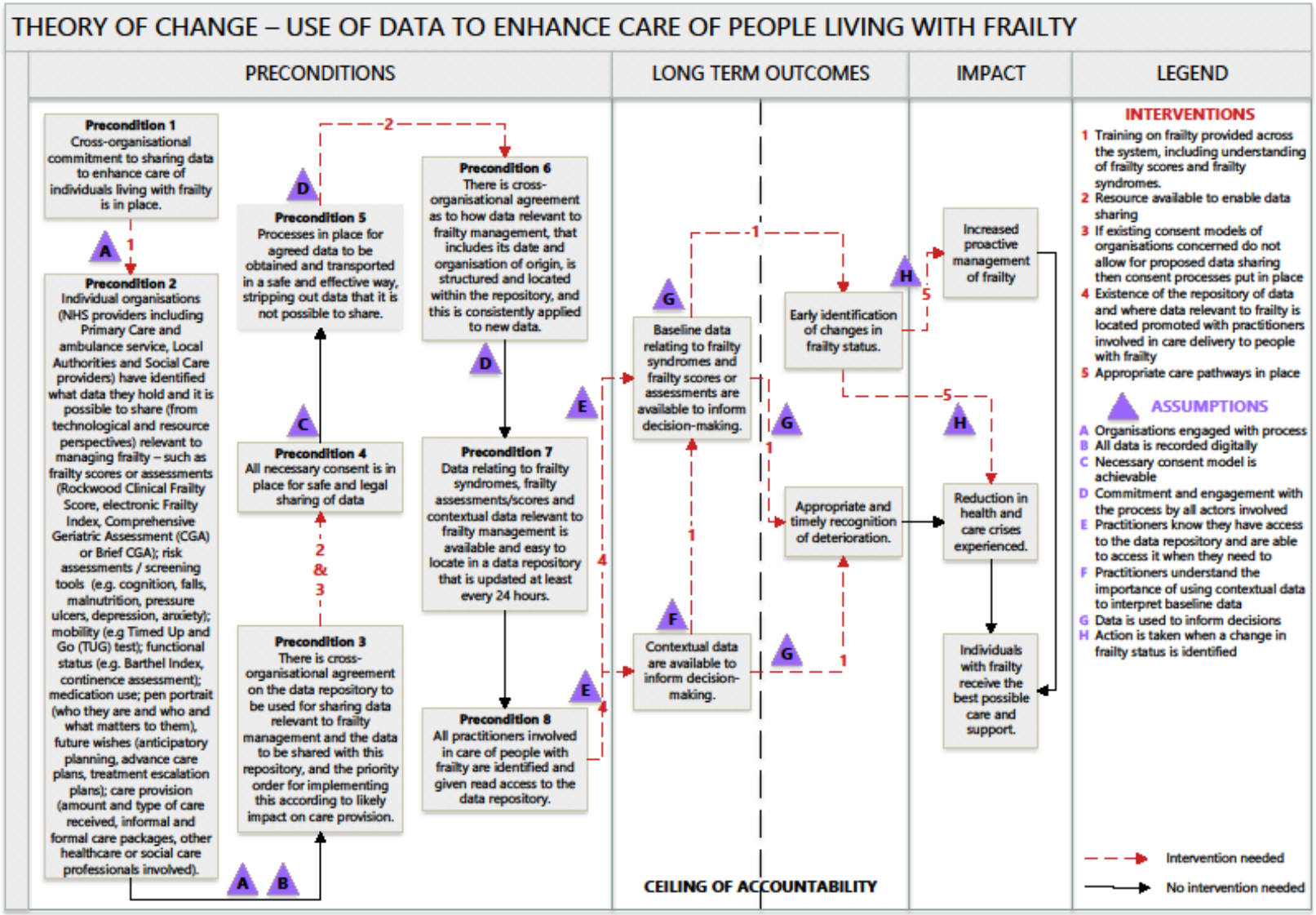

Figure 1: Theory of Change Map

Early identification of frailty risk will be enhanced through the eFI being calculated using all relevant and available data as part of the Population Health Management approach, so is not included in the Theory of Change. The long-term goals solely relating to better sharing of data that will contribute to achieving the other two long-term outcomes are:

- Baseline data should be available to inform decision-making. This should include frailty scores and frailty assessments (such as eFI or clinical frailty score and comprehensive geriatric assessment) plus risk assessment and screening tool outcomes and medication use that will help identify the frailty syndromes (falls, mobility, delirium, incontinence, susceptibility to medication side-effects) and other changes in frailty status. Knowing what is normal for an individual will assist recognition of deterioration.
- Contextual data should be available to inform decision-making and interpretation of baseline data, for example a pen portrait, information about available social support and care packages (including family and home environment), and wishes for future care and treatment (such as advance care plans and treatment escalation plans). This will assist person-centred decision-making.

3.3 Ceiling of accountability

The threshold at which the intervention to improve data use is no longer directly accountable for the desired impact is shown by the 'ceiling of accountability' line. This separates the long-term outcomes into those that are and are not directly attributable to data sharing. Early identification of changes in frailty status and appropriate and timely recognition of acute deterioration cannot be achieved with better data alone and therefore sit above the ceiling of accountability. Achieving these outcomes will also require other resources such as available care pathways and services.

3.4 Preconditions

The eight preconditions are the necessary precursors or requirements that need to be achieved for the long-term outcomes to be realised. Having a data repository was identified as solution to both ensuring baseline and contextual data is available to professionals. CHIE was suggested as a repository that could be developed to achieve this. It was agreed that accessibility of data needed to be assured, in particular ensuring consistency of recording, with data reported as currently not always in the same place on CHIE for each patient. CHIE updates data every 24 hours, which was considered timely enough by clinical stakeholders. Ensuring entries in the repository are dated was also highlighted as important, so that the date when the data was collected is known to those subsequently using this data to inform their decisions. Having the necessary data sharing agreements in place was a critical pre-condition to enabling additional data to be shared in CHIE, to ensure adherence to information governance legislation and guidance.

3.5 Interventions

The interventions are marked in Figure 1 with a dashed red line, arrows and numbers. Four interventions are required to fulfil the preconditions:

- Training on frailty provided across the system, including understanding of frailty scores and frailty syndromes. A need for education to better understand frailty by practitioners who are working with people with frailty but not within a frailty or Medicine for Older People is highlighted by research which identified that GPs felt they lacked knowledge about frailty (Mulla et al., 2021).
- Resource is required to enable data sharing. Stakeholders highlighted that without adequate resourcing prioritising this initiative over others would be difficult given the significant pressures on staff and organisations. Resources including funding, time and human capacity were highlighted.
- Consent processes need to be put in place if they do not already exist, to allow data sharing and ensure adherence to legislation.

- There needs to be promotion of the data available in the repository and where data relevant to frailty, which could be combined with the training intervention. Without this knowledge the data repository will not be used effectively by practitioners.

As identified in section 3.3, additional interventions are required alongside the long-term data outcomes to achieve the impacts of increased proactive management of frailty and reduction in health and care crises, with existence of appropriate care pathways identified by stakeholders and therefore indicated on the map.

3.6 Assumptions

Assumptions are the contextual conditions for the data sharing initiative to be successfully implemented. These are shown in Figure 1 by the purple triangles. Based on stakeholders' views a need for the following were identified:

- Active engagement with and commitment to implementation of the data sharing initiative by all involved, at both organisational and individual level.
- All data required recorded digitally. It is acknowledged that individual patient/client records are not yet all held electronically but there is a national plan to achieve this for both health and social care by 2025 (Department of Health and Social Care, 2022).
- The necessary consent model for each organisation to be achievable, so that data sharing can take place.
- Practitioners to have awareness of the data held in the repository, know how to access it, are able to easily access it when needed and understand the importance of using contextual data to interpret other data and inform decision-making. This will ensure the data repository is used as intended.

As with the interventions (section 3.5), assumptions were identified that apply to translating the long-term data outcomes into the broader long-term goals and impact. These are a need for the data to be used to inform decisions and that action is taken when a change in frailty status is identified.

4 Summary

Using the Theory of Change approach, a framework for implementing enhanced cross-organisational sharing of data relating to care of people living with frailty has been developed. This outlines how the long-term outcomes of having baseline and contextual data to inform clinical decision-making can be achieved and under what circumstances, as well as identifying additional pathways that could combine with enhanced data sharing to improve care of people living with frailty. This is presented in a structured and logical Theory of Change map. This has been developed specifically within the HIOW locality and can inform future development of CHIE.

5 References

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