User Requirements for Co-Managed Digital Health and Care

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Executive Summary

This paper presents a set of recurring user requirements and themes for co-managed digital health and care services from a body of co-design projects within a digital health and care programme. The paper aims to support knowledge sharing to enable people and organisations to re-orient their health and care transformation from a system-led and condition-specific approach to a more person-centric, whole-of-life model.

The paper presents a set of 14 common user requirements resulting from a review of 52 co-design projects. The findings demonstrate overlapping and mutually reinforcing needs of citizens and care professionals relating to how data is co-managed to improve both the care experience and the care outcomes. The paper highlights requirements for personal health storytelling; for sharing data on health experiences to support personalised guidance; for visualising trends to enable decision-making; and generally, for improving the dialogue between a person and their care provider (a 'vertical' relationship). The paper also highlights a growing, unmet need for 'horizontal' co-management of care in 'many to many' circles of care, involving professionals, family and friends, and the need to work across typical domain boundaries.

The findings pose difficult questions for people developing health, social care, and broader support services, because these cross-cutting user requirements are not easily met by organisations traditionally operating in silos.

The paper proposes future recommendations for care delivery based on conceptualising the person as an active, informed and consenting partner in their own care, and on using new form of privacy-preserving digital infrastructure that puts the person in firm control. The findings can be used by those developing new digital health and care services to ensure they can start with current knowledge of the broader user requirement context.

Further work on these common requirements is needed to specify the trust framework that will be required when people are co-managing their data and care across a broad range of formal and informal actors. Consideration of how the concepts of 'authority', 'delegation', and 'trust' function between members of the public will be critical.

1. Introduction

Health and care systems worldwide face unprecedented sustainability challenges that the impacts of the Covid-19 pandemic have exacerbated. A changing political landscape and a growing recruitment crisis further impact the UK's health and care service delivery and staff wellbeing. In parallel to this, there is an increasing policy and practice imperative to shift the balance of care to communities and to enable a system that supports person-centred, integrated, preventative, co-managed and sustainable care. The Scottish Digital Health & Care Strategy recognises digital technology and partnership with citizens as critical to creating change at scale.

Digital health and care capabilities can evolve to reflect people's lived experience - and define their health beyond what a clinical record system holds - to include their broader personal, social, and environmental needs, experiences, and outcomes. Balance has to be found between a health and care system's need for controlled, governed, and secure record systems, and the person's need for agency, trust, choice, and the ability to connect their data across different agencies, care circles and communities. Broader changes to the culture and practice of care delivery can enable the shift from transactional relationships between people and systems to a more personalised and relational approach to care and support. A care system must use any assets available to sustain the engagement and enhance interactions and experiences of co-managed care.

The concept of 'co-management of health and social care' emphasises working in partnership with those who access support to curate multiple relationships and assets to achieve person-centred care. Through mutual discussion and decision-making, this approach will create more sustainable methods to meet peoples' needs and wishes for support and self-care. This method contrasts with prevalent systems focusing on organisation-centric needs, practices and efficiencies.

This paper presents the findings of a review of 52 co-design projects run over seven years. These projects involved over 3500 people with care and support needs and 1000 health and care providers across 16 health boards, 15 charities and 10 social care organisations in Scotland. The projects engaged with diverse stakeholder groups, generating insights across e.g., healthy ageing, mental health, and long-term condition management.

The insights translate into a set of common user requirements for product development and innovation to support co-managed care: "As a [person or role], I want to be able to [do something] to [achieve a goal]." The table in Section 1.1. presents the requirement, an example quote from co-design, and the number of co-design studies that evidence this requirement.

2. Common User Requirements

As a person co-managing Health and Care services, I want to be able to:

Requirement	Example Quote	Studies
Hold and share my personal health story and have services use this to personalise my care.	*"… it would be really nice if there was a little bubble with my story there without me having to say it again and again."* **(Person living with Multiple Sclerosis, Backpack)**	19

Requirement	Example Quote	Studies
Share my experience and outcomes – and for this to improve care for myself and others in the future.	*"Perhaps when I am sending notes to you, you can see, 'yes, she cycles once a week' - or 'she works seven days a week on her back-side!' I think [the consultant] needs to know that people are doing some level of exercise."* (Person living with diabetes, Digital Diabetes Dashboard)	11

Requirement	Example Quote	Studies
Have conversations with professionals that focus on my priorities.	*"It's just trying to balance up what the patient's needs are versus your own agenda with them."* Care Professional, Supporting Behaviour Change)	12
Have conversations with professionals that have the necessary information or test results available and gathered ahead of time.	*"... before I come in you would be reading [my] notes, and I'll have a wee drop-down box with the questions I would like to ask you about my blood sugar levels, so you have [time] to think ', oh that is what she wants to discuss today'"* (Person living with diabetes, Digital Diabetes Dashboard)	11
Have an ongoing dialogue with professionals outside of formal appointments, allowing me to ask questions on my own terms.	*"...you always forget everything. The number of times I go to a clinic appointment, and I think 'oh, I must ask them this', and then afterwards you go out and my mum's like, 'did you ask about...?'"* (Person with asthma, Next Gen Asthma Care)	6

Requirement	Example Quote	Studies
Access personalised guidance, signposting and navigation support based on my personal health story.	*"That's one of the challenges for patients, if clinical staff potentially aren't aware of the service, it could take somebody a long time to then get engaged"* (Care Professional, Future of Cancer Care)	11
Have joint visualisations of clinical and personal data available to help me and others to see patterns and trends over time.	*"It's all about constant monitoring and recording and using previous experience."* (Person living with diabetes, IDDEAS and GDS) [41]	12
See a timeline or route map of my care interactions and understand their content and purpose.	*"I wouldn't know who to contact or even if you phone the MS nurse, you leave a message, and they'll get back to you but even that gets lost in translation… bits of paper just go missing, I know it's my biggest problem."* (Person living with MS, Backpack)	7

Requirement	Example Quote	Studies
Use my technology to access services and monitor myself to support my care.	*"[anon] is wearing something here… she walks about with a bottle of Lucozade and sweeties so something else would drive her nuts, she just wants to fit in and be normal. A Fitbit is a good example because everybody wears one now…"* **(Carer of a person living with diabetes, IDDEAS and GDS)**	13
Manage my circle of care, communicating and sharing data with my peers, family, friends, care professionals and community organisations.	*"I quite like to get advice from other mums as professionals so it's like real-life experiences, even if those professionals have fed themselves, it's nice to have some mums that are going through it at that particular point"* **(Mother, Breastfeeding)**	15
Jointly manage personal, 'whole of life' care plans with my circle of care, agreeing actions / rights / triggers in advance.	*"So there's a team of support, but I needed to hold in my head... but I'm quite motivated and articulate so I have pieced together the system that works for me, and the journey has meant that different people have taken centre-stage at different times."* **(Person living with MS, Backpack)**	10

Requirement	Example Quote	Studies
Trust in how others use my personal information.	*"The client needs to be able to trust us to be able to get the info from them"* **(Professional, Future of Cancer Care)**	7
Share relevant, trusted data with people who can help me.	*"So to be able to have a once and for all, okay, it's not going to be once and for all because it's changing all the time, but a template for my story of MS with all the awful bits remembered but without having to keep on doing it with each agency you engage with, having to prove yourself."* **(Person living with MS, Backpack)**	7
Have the authority to activate services that I am entitled to myself.	*"Although there might be things there, there was no trigger mechanism to trigger services happening"* **(Older adult, Digital Brokering)**	10

3. Common Professional/ Provider Needs

The co-design process often included people who access support, members of the public, carers and health and care providers. While not the focus of this paper, this section outlines the most common requirements of care providers. This high-level summary shows that in most cases, carers and providers want the same data sharing and navigation tools to help the person and the care team better coordinate care.

As a care provider co-managing health and care services, I want to be able to:

- Access and contribute to an individual's personal health story to deliver more personalised care, enhancing dialogue and joint decision making.

- Share and visualise where the individual is on their current care pathways, personalised to their story to help us both manage and prepare.

- Help me and the individual understand their condition better through joint recording of, and access to, personal symptoms, triggers, medications, and test results.

- Empower the individual with relevant knowledge and assets to either self-manage their condition or escalate their case to other people or services.

Further review is underway to explore provider co-management needs in more detail.

4. Additional Recurring Themes

In addition to the user requirements discussed in this paper, shared themes relating to emerging principles and visions for future health and care emerged during the review of the co-design work carried out by the design research team who led the 52 projects. These include:

- Enabling a person-centred focus to understand the whole person rather than their health condition only, with systems built around their holistic needs and what matters to them.

- Trust across all levels of the health and care system, with a critical focus on interpersonal and professional relationships.

- Equity of access to information, services, and systems, revealing a tension between the need for standardisation vs. tailoring of care.

- Ensuring that both people who access and people who provide care and support have time to care for themselves and others.

5. Discussion

The common user requirements for co-management of care enabled by digital provide a starting point for people and organisations looking to re-orient their approach to health and care data sharing from an organisation-centric to a person-centric model.

This work complements the broader peer-reviewed literature outlined in the [full academic publication](). Where most other publications focus on one product, service or domain of care, this review outlines an initial frame of reference for 'whole system' service and system design underpinned by insights generated through co-design with a wide range of user groups across multiple domains. Through the active participation of both people and providers in the underlying design research, the findings also demonstrate overlapping and mutually reinforcing sets of needs from both groups relating to how data is co-managed to improve care and outcomes.

Overall, the requirements align with previous research, with agreement on the need for personal health storytelling and sharing data on health experiences. These elements will support personalised guidance, visualisation of trends to support decision-making, and general improvement in the dialogue between a person and their care provider (a 'vertical' relationship). However, there are notable differences where this paper makes key contributions. The first one is the curation of new knowledge presented in this paper, with common requirements which extend to cover more 'horizontal' relationships and the more holistic needs beyond dialogue with any one care provider, such as the need to create care plans and manage care circles involving multiple providers, informal carers, agencies, and technologies. The second one is the co-management of data, with personally held data being trusted by providers and systems and, in turn, the providers and systems being trusted by members of the public to use this appropriately.

6. Implications for Practice

The requirements summarised in this paper pose difficult questions for people designing health, social care, and broader support services, which are traditionally not easily met by organisations operating in silos. For example, the most universal requirement of all was people wanting to 'tell their story once' and not repeat themselves across different parts of the system. Although numerous initiatives exist to create a joined-up approach, these have rarely looked across domain boundaries. This problem is best illustrated by the ongoing pursuit for the single clinical record, and the domain-specific goal of aggregating all clinical data to drive improved care and outcomes. This single medical record would undoubtedly help the health services and individual patients to have more joined-up medical care. However, it would not meaningfully change the way people interact with social security, housing, etc., to support their non-medical needs. Nor would a record dictated by a medical model and associated standards and governance likely tolerate new forms of data generated by people, broader organisations, and other sources. Without this, it won't be easy to develop more context-rich, whole-of-life outcomes to be pursued through greater personalisation and prevention.

However, a co-managed, holistic story will heavily depend on the quality of the organisational systems and data. A pre-requisite for more personal control and reuse of medical records requires that those records adhere to a common data model. Further, there is a need to evolve the culture, commissioning, and supplier practices to adhere to standards and separate the data from software products to enable its reuse.

The routes available to meet the user requirements outlined in this paper will almost certainly do so, with the person as an active, informed, and consenting partner in their own care, who uses new forms of privacy-preserving digital infrastructure that puts the person in firm control. Co-

management of care that respects 'whole of life' needs and satisfies whole system governance and trust can only be achieved through this kind of co-management of data.

The findings in this paper can be used by people developing new digital health and care services to ensure they can start with knowledge of the broader user requirement context. These should inform the domain-specific research and development questions and processes.

Future co-design of care and research eliciting requirements could build on this foundation and address several gaps. For example, while the 'circle of care' and 'joint care planning' were common requirements, they are both concepts that span many people and organisations. Therefore, more work is required to harmonise requirements and data sets across multiple actors. It is also unclear where peer networks (e.g. diabetes management community networks) end, circles of care (e.g. friends, family, carers) begin, and what level of data sharing and privacy relates to these different types of relationships. Lastly, the delegation of authority has started to emerge as health and care systems become more digitally enabled. To support equity of access and to maintain interpersonal care relationships, some groups will need to name and delegate authority to trusted people, who can then act on their behalf with digital services.

7. Conclusion

The paper has demonstrated common user requirements relating to co-management of care between people who access support and their circles of care. The common requirements relating to 'vertical' relationships between a person and a provider are corroborated by comparator literature. The common requirements cover 'horizontal' relationships between people and their broader support networks across services and agencies and their informal circles of care. Further work is needed to extend these common requirements to more explicitly consider the trust framework required when a person is co-managing their data and care across a broad range of actors. Consideration of how authority, delegation, and trust function between members of the public will be critical. The authors propose that these user requirements can inform service design and data sharing infrastructure across organisations that provide health, social care, and wellbeing support. We welcome further dialogue on how these requirements can drive forward a person-centred integration agenda that brings value to people and the system.