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SET4
Transforming transitions

Optimising care transitions for people with multiple long-term conditions: learning from a stakeholder engagement workshop

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This briefing paper reports on the findings from a stakeholder engagement workshop undertaken in collaboration with the Digital Health & Care Innovation Centre (DHI). This work is part of the Systems Engineering and Thinking to Transform Transitions (SET4) of Health and Social Care study. The stakeholder engagement workshop included a diverse group of individuals from various sectors, including those directly involved in providing health and care services, as well as representatives from universities, industry, policy-making bodies, and other representative organisations.

What is the problem?

Population ageing is a key driver in the rapid increase in the number of people living with multiple long-term conditions (MLTC or multimorbidity).[1,2,3] People with MLTC are more likely to experience frequent and complex health and social care transitions.[4] We define a health or social care transition as any change in a person's place of care (e.g., home, hospital), people involved in care (e.g., family, professional carers) or type of care (e.g., GP care, hospital outpatient team). Transitions often result from a change in health status and/or dependency, and people with MLTC are at high risk of suboptimal transitions associated with adverse events (e.g., mortality, functional decline, and hospital readmissions).[5,6,7] Approximately 20% of patients experience an adverse event following a transition from hospital to home, and it is believed that up to two-thirds of these are potentially avoidable.[5]

Navigating health and social care transitions is challenging for people with MLTC due to hospital-centric, fragmented, under-resourced, and often poorly coordinated services,[4,5,6] where teams in each part of the system of care have different priorities in the face of varying pressures.[8] We need new approaches to optimise transitions of health and social care for people with MLTC across the whole system. Care integration between hospital and community services assumes better coordination and continuity of care for people with MLTC and may be effective in improving the safety of transitions and outcomes for people with MLTC.[9,10] It is however unclear which integrated care models or components are most effective.[11]

Box 1. Key points

Living longer is a good thing, but population ageing and increasing MLTC present challenges for long-standing models of health and social care.

People with MLTC experience frequent care transitions, often lacking care coordination and continuity.

Integrating Systems Engineering and Systems Thinking approaches with stakeholders to explore systems problems and model processes and behaviours is a key step in work to redesign care systems.

Workshop participants characterise good care as person-centred, coordinated, empowering, accessible, and flexible, with patient-reported outcome measures being key to person-centred care delivery.

Workshop participants identified important interactions between physical and mental health, and practical system barriers that reduce effectiveness of current care transitions for people with MLTC.

What did we do?

Health and social care systems are complex. Complex systems consist of many dynamic interactions between people, tasks, technology, environments, organisational structures, and external factors with the potential for chaotic behaviour.[12] Systems Engineering and Systems Thinking approaches (e.g., process mapping, soft system methodologies) are useful in addressing the complexity and challenges that emerge from many interacting influences and stakeholders.[13,14] In collaboration with the DHI Design team, we co-hosted a stakeholder engagement workshop with health and social care professionals and representatives from universities, industry, policy-making bodies using system thinking and co-design approaches to better understand what constitutes good care and the challenges experienced by people with MLTC, their caregivers, and professionals at key transition points in health and social care, and identify opportunities for improvement.

We started by asking participants *'What does good care mean to you?'* and capturing their responses on an interactive board ahead of the workshop. Building on previous stakeholder engagement work with health and social care professionals in the scope of an NIHR-funded AI and Multimorbidity (AIM-CISC) project, we developed three personas with heterogenous personal characteristics (Figure 1) and two high-level system maps to represent some of the complexities of MLTC and associated care transitions. Working in four groups we asked workshop participants to discuss which person's story resonated most with their experience of supporting people with MLTC and how this person would interact with the system if their condition changed (e.g., a deterioration, new symptoms, new care needs). This was followed by an interactive game where each group was divided into *'Improvers'* and *'Disruptors'* to identify areas where the system could be strengthened, or likely to be broken, as they followed the person's journey through the system step-by-step.

David is a 78-year-old man who lives with his wife. David was diagnosed with multiple sclerosis (MS), chronic pain, chronic fatigue syndrome, and hypertension 20 years ago. David has been taking 8 medications 3 times a day to slow down the progression of his MS and cope with pain, fatigue, and control his BP. His wife has been his primary informal caregiver, with limited support from their wider family. In recent years his MS affected his mobility, cognition, and mental health and an additional 5 medications were added to ease the symptoms, maintain brain function, and reduce anxiety and depression. During the last 6 months, David has experienced multiple falls and has been in and out of the hospital 6 times linked to sepsis, delirium, and acute kidney injury. He is currently receiving informal care from his wife 24/7 and formal care four times per day.

Kate is a 66-year-old woman living alone, with no extended family. Kate has diabetes, hypertension, arrhythmia, arthritis, depression, and hypercholesterolemia. Kate takes 10 medications three times per day for these conditions and often sees her GP for uncontrolled high BP and arrhythmia. She sees specialists at the metabolic clinic and rheumatology every three months and struggles with prescribed lifestyle changes such as diet and physical activity. Recently she has been admitted to the hospital twice because of diabetic ketoacidosis and acute pancreatitis. Currently, she struggles to manage her multiple conditions, forgets to take her medication on time, and becomes more isolated and depressed.

Norman is 90 years old. He is a widower living alone. He has diabetes, hypertension, Parkinson's disease and chronic obstructive pulmonary disease. Norman takes 13 tablets and uses 2 inhalers each day. He admits that he sometimes gets these tablets mixed up even with a pre-filled dosing box made up by his local pharmacy. He was 'just managing', living alone without formal care but with a caring daughter attending daily to help with his meals and managing the house. Three weeks ago, he fell walking without his Zimmer frame, which he sometimes forgets to use. He was admitted to hospital following a fall and hip fracture. Norman is now waiting for a package of care to be allocated and is getting increasingly frustrated waiting in hospital.

Figure 1. Three personas with heterogenous characteristics and complexity of MLTC (Illustration credit: Tessa Mackenzie)

What did we find?

What makes 'good care'

Workshop participants characterised good care as person-centred, coordinated, empowering, accessible, and flexible (Figure 2). From a service delivery perspective, they viewed good care as involving comprehensive and holistic assessment of the person's needs, care plan development tailored to complexity, care coordination across organisations, and integration of services to meet the person's health and care needs and goals. Participants argued that good care should maintain continuity of care relationships and avoid transactional 'hand-offs'. Taking a person-centred perspective, professionals described good care as accessible and flexible, leaving the person with the feeling of being heard, empowered, and supported to self-manage their conditions and take greater shared responsibility for their health. They indicated that measures that capture people's views on their functioning, experienced symptoms, quality of life, and experience with care should be used to monitor service performance, inform policy, and guide quality improvement initiatives.

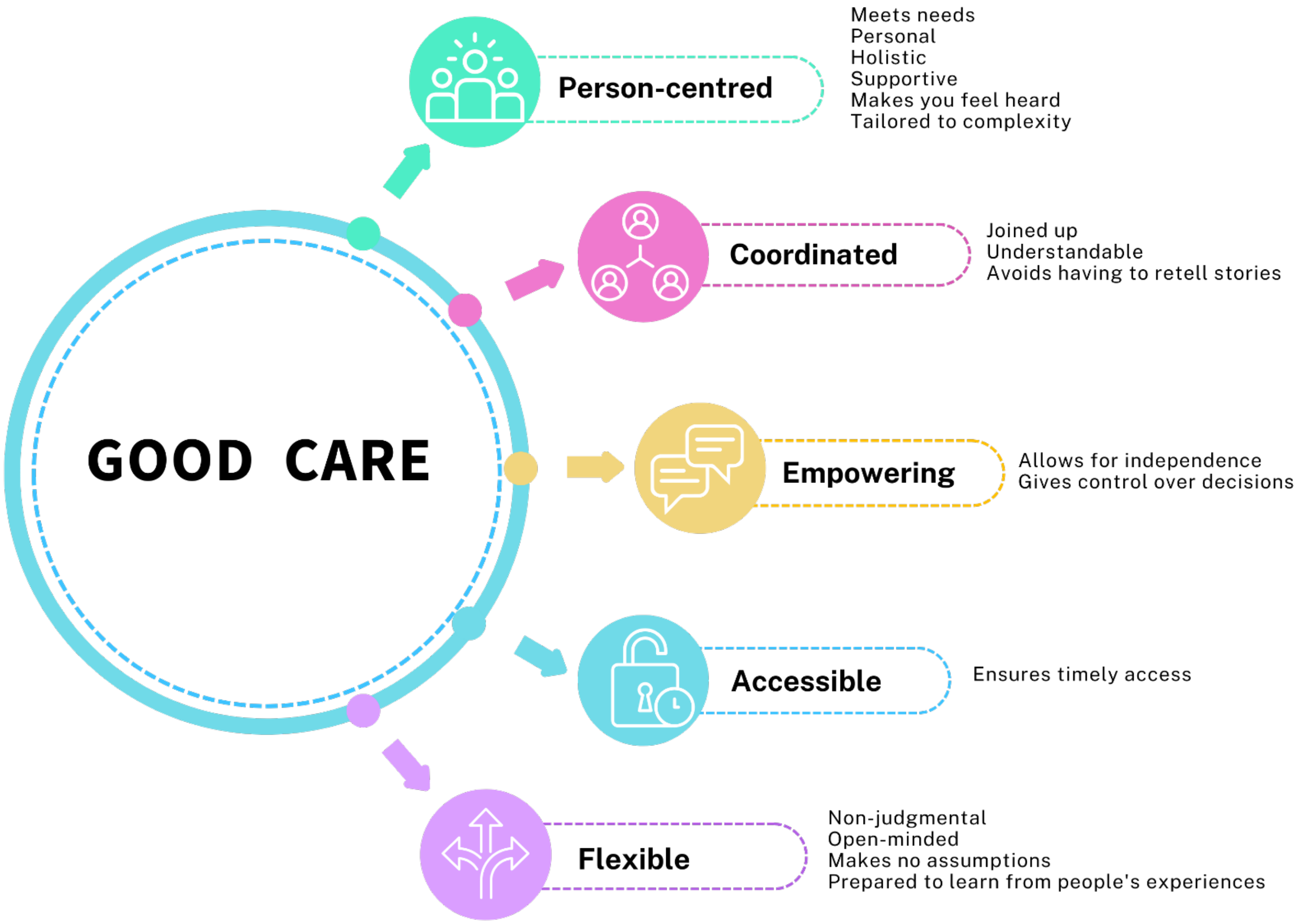

Figure 2. What 'good care' means to health and social care professionals

Person's journey through the care pathway

All four groups of participants chose to focus on a persona with MLTC experiencing mental health issues and loneliness (Kate) and a system map focusing on community care pathways. Mental health issues commonly exacerbate long-term physical conditions, leading to poorer health outcomes and reduced quality of life, and participants felt that issues of physical and mental health overlap received the least attention for improvement work. This was highlighted as a primary reason for focusing on Kate's experiences and journey through the community care and support pathways.

Participants talked about stigma and marginalisation of people with mental health issues. They identified potential challenges with mental health referrals and the under-recognition of mental health conditions due to fragmented care pathways, highlighting the importance of holistic needs assessment and more efficient and streamlined referral pathways. Kate's family circumstances (Figure 1) sparked discussions around practical concerns (e.g., hospital transport, costs, and physical accessibility) and potential barriers and logistical challenges to accessing care. Various alternate pathways to access specialist services (e.g., direct calls bypassing GP systems) and self-referral to services for 'non-acute' issues were discussed, highlighting a need for novel approaches to accessing care and managing service flow.

Relational continuity with a healthcare provider (GP or other professional) who knows Kate's history and complexity of needs was emphasised, pointing to the value of continuous and trusting care relationships in the context of MLTC. Building on this, the concept of a "named advocate" or a care coordinator was introduced to provide Kate with dedicated support in navigating complex healthcare systems. Signposting Kate to community-based, not-for-profit voluntary services (including befriending) and for-profit services was suggested, along with the need for better integration and communication between these different care sectors. Issues and potential improvements to Kate's healthcare journey are presented in Figure 3.

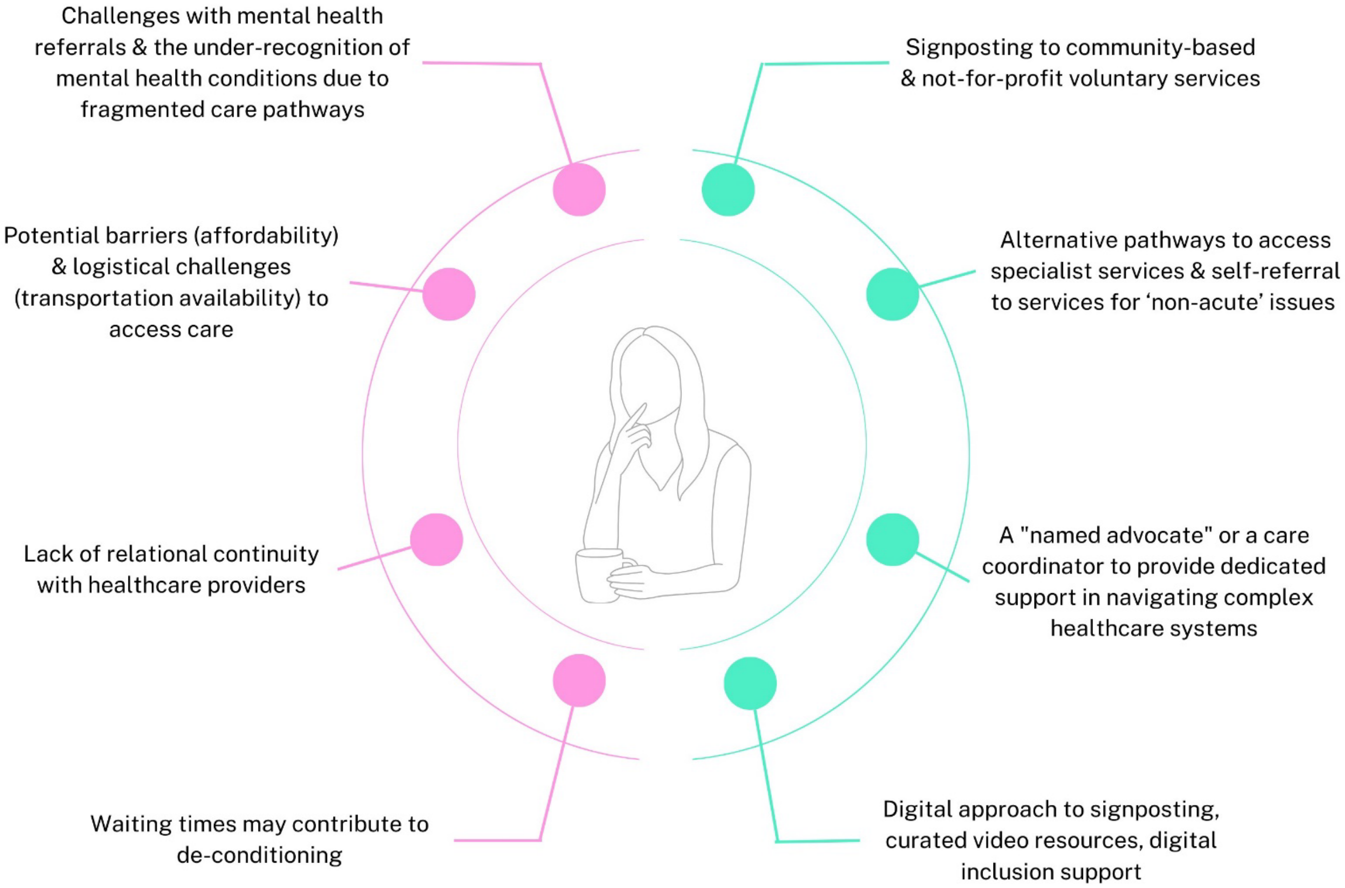

Figure 3. Issues (pink) and potential improvements (green) to Kate's healthcare journey

Barriers to good care delivery across care pathways

Workshop participants identified systemic barriers (Figure 4) that reduce effectiveness of current care transitions for people with MLTC who have mental health support needs. These challenges, categorised based on health system building blocks (Table 1), affect care delivery and people's experience of accessing care, underscoring the need for service improvement work.

Participants noted barriers to accessing primary care services and making appointments with GPs. They described the appointment system as "arduous," with patients often facing long waiting times and gatekeeping by receptionists. Further, insufficient staffing levels and pressures on primary care services were noted as key barriers undermining GPs' ability to comprehensively or holistically assess people's needs and health goals. In this context, urgent issues could be missed, and inaccurate assumptions could be made about the person's care plan.

Care fragmentation was identified as a driver for poor communication and lack of coordination across services. Participants noted that minimal data sharing and poor collaboration between primary care, secondary care, and social services often resulted in a lack of continuity, compromising quality care delivery. Referral pathways were described as unclear and inconsistent, with people experiencing long waiting times and a lack of follow-up after referrals were made.

Workforce challenges, such as inadequate staffing levels and interprofessional conflicts, were also identified as significant barriers to delivering effective primary care services. Participants felt that understaffing and high workloads disrupted services and affected staff's ability to provide person-centred care and self-management support. Interprofessional conflicts (e.g., between GPs and nurses) could adversely affect team dynamics and, therefore, the delivery of health services and holistic person-centred care.

Participants perceived current care models as outdated and unsuitable to meet the evolving needs of people with MLTC. They advocated for a *"paradigm shift"* and fundamental change in the way healthcare is delivered, focusing more on shared health and care responsibility, better prevention, and comprehensive care services. This shift requires a move away from the traditional biomedical model, which focuses on disease management, toward a biopsychosocial model that addresses the complex interplay of biological, psychological, and social factors influencing health and care. To achieve this, health and care systems need to invest in primary care redesign, incorporating person-centred care, shared decision-making, and self-management support.

Figure 4. Challenges and opportunities for good care delivery across care pathways identified by *'Improvers'* and *'Disruptors'*

Table 1. Barriers to good care delivery across care pathways

SERVICE DELIVERY	WORKFORCE	TECHNOLOGY, PRODUCTS & INFORMATION	LEADERSHIP & GOVERNANCE	FINANCING
Access to care Disruptive duty appointments Inadequate prioritisation of at-risk patients Misdiagnosis & polypharmacy issues Multiple referrals Narrow scope of services Lack of self-management support Long waiting lists Lack of comprehensive assessments Multiple unmet needs Lack of care coordination Treatment burden Unclear care pathways	Staff shortages Poor person-provider relationship Unsustainable workloads Limited authority & capability to address systemic issues Interprofessional conflicts Lack of relational continuity Assumptions about ‘normal’ life diverge from a person’s reality Providers missing the bigger life picture No follow-up on referrals Focus on statutory vs voluntary services	Lack of data integration & coordination Lack of centralised data Lack of information on prescriptions & diagnoses Difficulties navigating ‘Near Me’ services Limited or delayed feedback to patients after interactions with services	Need for a *“paradigm shift”* to personal health responsibility & education Challenges integrating NHS, third sector, local authorities Communication & integration barriers across health boards Mental health crisis is not prioritised Housing support not integrated into care Lack of self-referral options Health is viewed from a medical vs holistic perspective Delays in social care access Outdated care model	Inadequate funding for human resources Lack of funding for data management Underfunded healthcare system

Opportunities for good care delivery across care pathways

Workshop participants highlighted several key areas for improving integrated and person-centred care (Figure 4, Table 2). Expanding workforce capacity and promoting multidisciplinary teamwork were viewed as key to sustaining NHS and social care services. To achieve this, participants suggested implementing better recruitment and retention strategies for GPs and social care workers and creating new roles such as care navigators or care coordinators. They felt that care coordinators could take responsibility for liaising between various healthcare providers and ensuring that people receive timely and appropriate care.

Enhancing access to services was seen as critical for improving care delivery and people's satisfaction. Participants proposed several strategies to achieve this, including providing *"VIP or prioritised access"* for people with highly complex needs and those who need mental health support. Implementing flexible appointment booking options, such as online or phone triage and bookable duty doctor visits, could also help to streamline accessibility for care. Furthermore, establishing self-referral pathways through community hubs can ensure access to community support services and reduce pressure on primary care providers, especially GPs.

To deliver holistic and proactive care, health and social care professionals recommended adopting service delivery models that focus on *"what matters"* to the person. This approach would involve conducting comprehensive assessments, engaging in future care planning, and coordinating care across services. Community health workers and care navigators could help connect individuals to local resources, promoting social engagement and well-being. Further, regular medication reviews and home health monitoring could enable early identification of issues that might put people at an increased risk for adverse events.

Integrating records across services was seen as essential for delivering seamless and coordinated care. Participants further suggested that people should own their data, enabling them to take an active role in the management of their health information. Digital tools, such as mobile apps, video resources, and mental health screeners, could promote self-management and empower people to make informed decisions about their health. Additionally, using data from non-medical sectors (e.g., HM Revenue and Customs) could help identify people living in social isolation and inform targeted interventions.

Participants emphasised the need for a shift from a medical to a holistic care approach. This involved moving away from reactive *"fix-it"* models and adopting proactive approaches that consider people's circumstances, personal responsibilities, and how *"they fit"* with proposed care plans. To effectively implement whole-person integrated care models and meet needs identified by the person, health and care service and funding reforms were noted as essential.

Table 2. Opportunities for good care delivery across care pathways

SERVICE DELIVERY	WORKFORCE	TECHNOLOGY, PRODUCTS & INFORMATION	LEADERSHIP & GOVERNANCE	FINANCING
Continuity of care Longer GP appointments *“VIP access”* for complex physical-mental issues Immediate access to mental health practitioners Bookable appointments for duty doctors Triage workflow & care bundles based on records Joined up discharge planning Medication review	Workforce planning (more GPs, social care workers, mental health professionals) Create new roles (care technologists, community connectors) Direct patients to community services instead of multiple referrals Interdisciplinary teams Clinical pharmacist involvement	Summary of health & social history "My data follows me" across services New community decision support tools Market/app store for 3rd sector services Digital signposting on ‘what matters’ Curated video resources Mental health assessment digital tools	Activate student populations for intergenerational support & befriending Improve patient access to their data Digital inclusion support Realistic medicine Self-referral support Use HMRC data to locate lonely patients	Better pay for social care workers Better funding for services and the whole system

What will the SET4 do next?

The SET4 project team has ongoing work in both Scotland and England to better understand the challenges of transitions in health and social care for people with MLTC through deliberative workshops. These include further work with health and social care professionals but also with people living with MLTC and their carers as well as specific work with care homes.

A further key element of the SET4 project is building a data-driven understanding of transitions. We are using routine linked healthcare data within the DataLoch Trusted Research Environment in Edinburgh to better understand the impact of MLTC on health contacts and transitions when people are admitted to hospital with common conditions such as strokes, heart attacks, and falls with fractures. This will also use data-driven Systems Engineering approaches to better understand patterns as people move through the complex health system.

The SET4 team is building relationships with partners across health and social care to use our learning to implement changes in how transitions are managed for people with MLTC in the future. Co-design is a critical aspect of the Systems Thinking and Systems Engineering approaches to these important challenges. The DHI Healthy Ageing Innovation Cluster (HAIC) is an important delivery partner for the SET4 project. More information on HAIC can be found at Healthy Ageing Innovation Cluster (HAIC) | Digital Health & Care Innovation Centre (dhi-scotland.com).

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