EPSRC-NIHR: taking a systems engineering approach to multiple long-term conditions

Workshop 1 Summary Report
Monday 11 January 2021

Introduction

On 11 January 2021 the EPSRC and the NIHR held a workshop to explore how to take a systems approach to delivering care for people with multiple long-term conditions (MLTC) research.

The purpose of this workshop was to bring together the engineering, operational research and the health and social care research communities to develop an understanding of taking a systems approach to MLTC research.

The goal of this work is to understand how to structure a health and care system to take a patient-centred, whole person approach to the treatment and care of people with MLTC.

Participants

The workshop was invite only with a selection of participants drawn from diverse multidisciplinary research communities. A full attendee list can be found in Annex 1.

On the day

The agenda was designed to introduce the topic and give attendees a chance to meet and discuss questions around the challenges in effectively treating people with MLTC in the health and care system as it is configured currently, and how taking a systems approach to MLTC research might allow us to develop new and innovative solutions. The agenda for the first workshop can be found in Annex 2.

Next steps

The initial workshop discussions identified some key challenges and priority topics, see list below, which will be explored in more detail at the second workshop on 8 February 2021.

Priority topics which could potentially benefit from taking a systems thinking approach:

- High quality care shouldn't be a task for the patient (*how do we reduce the burden of accessing the right health and care?)*
- People with MLTC have diverse needs, and a person's needs will change over time (*how do we design a system that is responsive to the changing needs of a person with MLTC?)*
- We need a cultural shift to get the system to re-orientate around patient needs (*How do we create the right incentives to drive the system change we need to see?)*
- Services need to be coordinated – both from patient perspective and in closer working between parts of the system (*how do we improve navigation of the health system – e.g. care coordinators? How we improve and facilitate working across different disciplines/specialisms/parts of the system?)*
- Workforce education (*how do we attract and train a workforce with the skills and motivation to provider better care for people with MLTC?)*
- Care needs to be driven by a better picture of patient's health and needs/preferred outcomes over time (*how do we collect, use and share the right information at the right time? How do we ensure health and care remains responsive to changing patient needs?*)
- Patients need to be empowered and supported to be active agents in health and care decisions

Health inequalities, opportunities and risks of digital and IT, integration of health and care, and efficiency and affordability of the health system were identified as cross-cutting themes which will need consideration across the specific topics outlined above.

Summary of workshop discussion

A summary of the key points from the panel and breakout discussions is presented below. Facilitators in five breakout groups asked participants the following key questions:

1. What do we want the health and care system to look like?
2. What are the challenges we need to overcome?
3. What do we need to do to get there?
4. Who needs to be involved?
5. How can we move the locus of control towards patients?

What do we want the health and care system to look like?

The needs of the patient should be paramount, with expert support and knowledge from their care team, and a focus on the best available care. Patients are often well-informed and involved in their own care and, as such, the care team should be working towards patient-led outcomes. The system should recognise that patients have a life beyond their interaction with the care system. The system needs to acknowledge not just the direct time patients spend within it but how people with MLTC and their carers might want to spend their time and the goals they'd like to achieve outside of their treatment (the system might also include education services for children and young people with MLTC or complex care needs; and informal care).

The health and social care systems should be integrated, seamless and easy to navigate; getting high quality care shouldn't be a task for the patient - it should be simple and straightforward. Groups suggested this could be facilitated by specific roles that might help patients with MLTC, including care coordinators and patient managers, who take responsibility for the management of care across specialties, services and Trusts. They should act as administrators and/or advocates for the individual and help them navigate the system. It was also suggested a tool or app might help with this.

The system needs to be adaptable and flexible to patient needs. Good communication within the system is likely to be key to success. Practitioners should be clear with patients and carers (and other professions) about what the system can and cannot do. Discussions also touched on identifying patients with MLTC and thinking about their care differently, tailoring it to needs of the person.

The health and care system should work equally well for all populations, ensuring those with the greatest burden and greatest need, including those with MLTC, aren't left behind or disadvantaged (overcoming the 'inverse care law'). It needs to be more efficient, with one group suggesting a decentralisation from hospitals to take pressure off the acute care. A further suggestion discussed in the group session was a challenge to the idea that people need to come to a health provider in order to receive care but rather elements could be provided in the home.

What are the challenges we need to overcome?

A core challenge identified was the fragmentary and sometimes siloed nature of health and social care services. The way that services and organisations are structured and relate to one another may hinder more joined-up working. People with MLTC move between clinicians from multiple disciplines, who often do not communicate with one another, which can be frustrating for patients. We know that continuity of care and building relationships with healthcare professionals matters for people with MLTC.

There is currently a lack of interoperability across the system, for example in patient data not being shared due to concerns about governance or incompatible IT or database systems. In order for this to happen, IT systems need to be improved to enable data sharing across interfaces.

Another challenge is balancing the patient's needs with the system's needs. A person-centred approach allows greater choice, patient control and personalisation, but may pose a challenge to system efficiency or appetites for risk. People with MLTC have diverse needs, and a person's needs will change over time. There is a challenge inherent in finding a way to enable patients and doctors to collectively decide on which health care journey to take (of which there will be many different journeys or pathways), and to do so in a way that adapts to a person's changing needs.

Digital and IT were highlighted as an area that offered potential solutions to some of the challenges, but there was a need to be aware of the potential unintended negative impacts of assuming this is the answer. One group discussed the digital divide, asking whether digital health services were inevitable and how that might balance against personal control and choice (e.g. those who do not want to or can't use digital or IT). Any new innovations in the health care system need to address these inequalities by ensuring equitable uptake across patient groups, rather than creating a system which gives preferential treatment to patients in more affluent areas.

People with MLTC are heterogeneous in many ways; some want clinicians to take the lead in their care while others want empowerment. Several groups considered the information that patients have access to about their health, highlighting that for those who lack support or understanding to navigate this information, it may lead to anxiety and distress. In addition, a cohort of people with MLTC who cannot or do not want to engage with health systems results in unmet needs.

It was generally agreed that a lack of resource in the system is a major issue, making long-term change difficult to achieve. Participants felt there had not been enough investment in some areas, particularly primary care and mental health services, at the same time as there has been a rise in people with MLTC. There were also concerns that deprived areas may not have the system resources (e.g. primary care staff, GPs, acute care) needed given the burden of need. Healthcare systems are focused on managing supply rather than addressing need and demand, which means that there is a tendency for systems to be reactive rather than proactive.

Furthermore, there will need to be a cultural shift in order to address issues such as how to measure performance, and how to incentivise parts of the system properly for the patient benefit. Complexity and size of the task were raised as challenges to be overcome but we may be able to learn from other fields and other complex systems. There may be difficulties involving professionals across the health and social care system, including GPs, social care professionals, and other health practitioners working in the community. Professional interest groups can be detrimental to holistic care if cultural change is not part of the solution.

What do we need to do to get there?

Several groups discussed the importance of creating a more generalist workforce to support people with MLTC. One group considered a primary care led or coordinated service for people with MLTC to support patients on their journey through the system. A 'one-stop service' for patients would provide continuity for patients in the form of one specialist who cares for all a patient's needs. One example given of where this works well was in paediatric allergy care. Moving away from siloed, specialised working towards more generalist skills could provide greater support for people with MLTC.

Educating the current and future workforce is a priority. By focusing on patient-centred care and empowerment in medical training and professional development, we can train the workforce to manage the systems and culture change needed. Establishing a shared language would enable health and social care professionals to understand perspectives from outside their own disciplines and enable a more patient-centred approach.

It was acknowledged that we need to design a system that promotes personalisation, and with a focus on individuals rather than looking at patients' diseases, individually and in isolation. There is a need to create and develop a picture of a patient's health over time, and this would require the transfer and availability of patient data between disciplines and services.

We need to identify patterns in care, showing what works well and what the barriers are in the current health and social care system. Moreover, we must look for opportunities to implement and trial new approaches; generating evidence of how to do things differently will be essential in garnering greater support for change.

Finally, both the breakout groups and the panel acknowledged the importance of political support to re-design the health and social care system. It will be essential to have champions at higher levels with a will to make change.

Who needs to be involved?

To structure a health system that takes a patient-centred, whole person approach to the treatment and care of people with MLTC, it is important that those people and their carers are front and centre, as well as community organisations with expertise of MLTC.

The health and social care workforce need to be involved. This includes stakeholders within primary and secondary care, as well as medical students representing the workforce of the future. A particular emphasis was placed on the role of primary care professionals, as these individuals are essential to the provision of holistic generalist care to people with MLTC.

There is also a need for scientists and researchers who can design, implement and evaluate system change, including systems engineers, data scientists, computer scientists and social science researchers. On an institutional level, there needs to be support from NHS England and commissioners, regulators such as NICE and MHRA, and Health Education England.

The panel considered who could lead the changes required within the system. There would need to be support from Chief Executives of hospital trusts, but it was noted that systems leaders do not necessarily need to be clinical leaders provided they have sufficient knowledge of the system, including where the risks and priorities are.

Several challenges were identified within the discussion. Firstly, it was noted that NHS management does not typically support iteration, a factor which may hinder development in this area. There is also a divide between the academic and clinical worlds, which would need to be bridged.

How can we move the locus of control towards patients?

In order to establish a patient-centred system, the patient needs to be positioned in the centre of the system, around which everyone else revolves. While patients should have the final say in their care, and should be given options, for example in how they want to access healthcare, they will need to be supported to take more control. For patients wanting access to digital healthcare, there will need to be professional support to enable digital access and inclusion.

It should be made as easy as possible for patients to take more control within the system, and it will be vital to appreciate and acknowledge issues of power and control between the patient, healthcare professionals, and the wider system. However, groups identified that the patient cannot be in control of every aspect of their treatment and care, and some control must be retained elsewhere within the system. Similarly, not every patient will want control, and their preferences must be accommodated and included. Feedback from patients about their experiences in the system will be useful here to establish what is wanted and needed by patients.

Shifting the locus of control towards patients requires a change in perception across the NHS. It will be essential to consider issues of equality, diversity and inclusion to ensure that all patients are represented equitably.

How can the engineering, health and social care communities work together to create integrated, whole person care systems that work for people with MLTC?

There was a vision emerging of what a health and care system that works for people with MLTC would look like, but there were also outstanding questions about overarching aims, for example:

- Is it about changing the care provided to some patients, or a fundamental redesign of the care system?
- Is the outcome to improve patient experience, or to reduce the utilisation of care?
- Should we break the system down into particular challenges or pathways/areas? This would make it more manageable for research, but risks perpetuating the challenges around siloed working.
- Should we be thinking in terms of a new system or a separate stream for people with MLTC and how would this work for others?

The following opportunities for applying systems thinking and learning from interdisciplinary teams were identified:

Systems engineers could help convene all relevant professionals and stakeholders in the conception, planning, design, construction, operation and progressive refinement of the system. The individuals involved would need to work beyond disciplinary silos in order to

understand the language and perspectives of other members. Although this approach will require time and effort, it will yield huge rewards and enable effective collaboration.

Part of a systems approach involves looking at how much redundancy is needed in a system for it to function well. Panel members discussed the role of redundancy and uncertainty within the systems approach. Working at 100% occupancy is not efficient for a health care system as it means that things are missed or overlooked.

The consequences of implementing change need to be analysed in the widest possible sense, not just considering financial implications, in order to de-risk the decision to invest in change. Business models for any new systems need to be considered as a balance of all positive and negative consequences.

We can learn from other complex systems, for example the system behind Amazon, which is built around collecting data from people and then generating and advertising products to meet individual needs and interests. There is also learning to be taken from 'hard' systems such as road networks and infrastructure.

It will be important to understand the overarching strategy behind any system changes, as well as the bottom-up context of the current health and social care system. A top-down approach would not leave room for adjustments as the system is developed, and this would need to be considered before beginning the change process.

Annex 1: Workshop Agenda

09:45 – 10:00	Meeting opens
10:00 – 10:15	Introduction
10:15 – 10:45	Keynote - 'a systems approach to MLTC research':

- Professor John Clarkson (Cambridge),
- Professor Daniel Lasserson (Birmingham)

10:45 – 11:25	Panel discussion - 'How can the Engineering, Health and Social Care communities work together to solve the challenges of MLTCs to create, integrated, whole person care systems?'

- Dr Jennifer Bostock (PPI representative)
- Professor Peter Bower (Health Services)
- Professor Frances Mair (Clinical)
- Professor Richard Kitney (Engineer)

11:25 – 11:45	Break
11:45 – 12:20	Breakout session
12:20 – 12:30	Wash-up, next steps and workshop 2