

Joint EPSRC and NIHR Workshop on Multiple Long- Term Conditions (2)



Virtual Workshop
Monday 8 February 2021

Introduction

On 8 February 2021 the EPSRC and the NIHR held a joint workshop to investigate how to take a systems approach to multiple long-term conditions research.

This was the second workshop in a series and the purpose of this workshop was to initiate research ideas for potential collaborative projects and to provide advice to the funders about the focus for a potential call.

Participants

The workshop was invite only in the first instance with a selection of participants drawn from the engineering, operational research and the health and social care research communities.

A full attendee list, and contact details can be found in Annex 1.

On the day

The agenda for the day is in Annex 2. The agenda was designed to recap on the first workshop and give attendees a chance to meet and discuss, through a facilitated session, focussed questions around specific challenges in this area. The write up of these discussions is shown in Annex 3.

Next steps

The information from both workshops will be used by EPSRC and NIHR to identify potential funding opportunities for research in this area.

The organising team would like to thank all participants for their time, enthusiasm and input.

Summary of workshop discussions

A summary of the key points from the panel and breakout discussions is presented below. The first breakout session focused on identifying and developing research ideas. Seven breakout groups each discussed a different theme identified in workshop 1.

Themes:

- 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 do 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 provide 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

The second breakout session sought to identify barriers and opportunities to conducting research in this space. To avoid repeating points that came up in both sessions this report summarises the key themes across both breakout sessions.

Participants recapped what success would look like:

- a health and care system that facilitates joined up, personalised care with patients at the centre;
- a system to collect and use information and data in a connected and interoperable way;
- a change from siloed working, to bring together different specialisms and care pathways to provide holistic care;
- a system that works to reduce health inequalities, ensuring any changes in service design or delivery works for the diverse people with MLTC, including underserved communities.

Data and digital

The role of data and technology as a facilitator for change came up across the different break out rooms. One group suggested a digital twin model of both the system and the patient population could be built to look digitally at possible outcomes and solutions. There was discussion about how patient records could include a wider range of data e.g. from

wearables, sensors, and devices and be configured in a way so that control of the record sits with the patient. It was also flagged that technology could be a way to capture diverse patient experiences and the outcomes that matter to patients. In developing technology and data solutions or collecting patient data consideration is needed of the balance between integration versus interoperability, with interoperability offering greater flexibility. To realise the benefit of this opportunity would require work around feasibility and acceptability. Participants raised concerns that increased use of data and technology could risk increasing health inequalities.

Participants also flagged that technology could not be a replacement for the interpersonal aspects of good care. A systems engineering approach needs to find ways to understand the way in which technology operates in a complex system and which parts of the system it could influence.

Patient and carer voice

People with MLTC need to be at the centre of any approach. Across the different themes discussed, participants highlighted the need to structure the problem differently – putting patients and people with MLTC at the forefront. Co-production, both in research and service design, was seen as a way to put patients on an equal footing with clinicians and lead to patient centred care that responds to what patients and carers want. We will need to develop methods to capture the outcomes that are meaningful to people with MLTCs (PROMS). These need to be measures that can be used in research and in monitoring services on an ongoing basis. However, participants also acknowledged that not all outcomes that matter to patients can be easily quantified and the importance of patient narratives should not be disregarded. They also highlighted that the MLTC population is highly heterogeneous and sections of that community will be less often heard and this could play into the Inverse Care Law if not sufficiently incorporated in planning. This means meeting people where they are and developing new ways of communicating, changing methodologies and ensuring that research gives something back – getting it right means people with MLTC and carers understand what's in it for them.

New methodology and approaches

Structuring the problem differently may require some new methodological approaches. Participants discussed the need to use the right research and implementation methodologies to deliver system change. This should include qualitative methods and not rely purely on traditional RCTs. Participants also noted that work to understand how the system currently works – or not – for people and to the system and interdependencies is often not seen as important and so it can be difficult to get funding for this. This was considered important underpinning work and could lead to better understanding of the pathway or roadmap to success (see section below).

Systems engineering offers a different approach which starts from the final goal – as defined with and by patients – and works backwards. Those familiar with science and engineering techniques felt that there were opportunities to better use modelling to ensure the best chance of success before real world implementation. There were also opportunities to use systems engineering to map patient journeys and pathways and better understand and articulate the factors and relationships that underpin the systems. This approach, drawing on interdisciplinary working, could also look at the interactions and consider the whole systems picture. However, participants warned that the health and care system is large and there would be a need to set boundaries to ensure this is a manageable task.

Multidisciplinary teams and stakeholders

Participants discussed who needed to be in the room to progress research in this area. As reflected in the report already, interdisciplinary working was seen as key, as was the inclusion of patients and people with MLTC throughout the process. Meetings need to be convened in a way that enables shared learning. Participants listed a wide range of skills and people who need to work together on this, including: researchers from different backgrounds (data scientists, mathematicians, operational researchers, health system researchers), clinical specialists, administrations and support staff in the NHS, outpatient and community care services, community pharmacists, nursing and social care staff, charities, commissioners and decisions makers, GPs and primary as well as local health leaders and of course a diverse range of patient voices.

Underpinning work is required to further understand how the system currently considers services and care for people with MLTC

Workshop participants discussed the need to map the way the system currently delivers health and care for people with MLTC in order to better understand the problems the research is trying to solve; and develop a systems map and approach to transform services and improve ways of working between different parts of the system. There is some existing work with people with lived experience who are clear what challenges they would like to see addressed but it will be important to expand this further in order to ensure the full heterogeneity of the MLTC population has a voice so the system is designed not to leave vulnerable, more seldom heard groups behind. Research to map the system, including understanding the inherent complexities between and within moving parts, might help get buy-in from system leaders to support transformation through a systems engineering approach. Acknowledging complexity and communicating this to stakeholders will be instrumental to achieving credibility and thus in the success of future programmes of work.

Learning from system changes that took place as a result of the pandemic was identified as an opportunity to understand whether for example there was a shift to the shared ownership of care management between clinicians and patients; how barriers to system change were mitigated and overcome; and what facilitated change (necessity being the mother of invention) and what the impact of these changes were, both positive and negative. It was also suggested that case studies of good practice could be carried out to see where the system is working well for people with MLTC, what underpins this and how the elements of the system have come together that could be shared and built upon.

How should we think differently about funding research?

The NIHR and EPSRC asked participants how we as funders might think differently if we moved forward to configure a call in this area:

Consider underpinning work (set out in the section above), and connect and facilitate conversations among a wide range of disciplines about coming together as a research community to be able to deliver collaborative multi-disciplinary programmes of work.

Consider system complexity. There will be diversity in language and understanding of different stakeholders and how to balance the fact that groups may value different outcomes in success criteria. Participants also highlighted that this programme will take place within a system that is constantly changing and evolving but simultaneously requires services and care to keep running during any transformation; leadership buy-in will be crucial.

Start conversations with the system leaders in the health and care system to ensure that we help to start to close the gap between possible blue skies thinking and move towards

scoping which is grounded in the realities of the system; ensuring we don't stifle innovative thinking. Facilitate buy-in to develop possible solutions which work for both people with MLTC and carers and services.

Build in appropriate resource and timelines for a programme of work in this area as suitable resource will be required for multidisciplinary evaluation with embedded iterative change. It is recognised that interventions such as RCTs are costly, but it isn't always well understood at panels that other research needs to be appropriately funded. Given we need to take a collaborative approach and there will be multiple perspectives involved, this will necessitate a high level of financial resource for salary costs. Funding for people and services that we are seeking to pilot will need to be considered, akin to excess treatment costs. Timelines for the change need to be reasonable given this is a significant task, for example time will be needed to build in amendments to ethics applications as 'interventions' change shape through learning.

Ensure that if the call went ahead, we would configure bespoke multidisciplinary panels with a mix of expertise to assess applications, including systems thinkers. Panel members would need to understand how this differs from business as usual funding, including the intrinsic complexities and associated risks, and embrace this. Clear criteria for success will be critical to funding the right research and impact measures will need to be suitably broad to speak to the wide range of stakeholders involved.

Funders will need to appreciate that the measures of success for this type of research will be different and they will need to articulate the outcomes they are interested in. Outcomes will need to be fit for purpose. Outcomes and concomitant criteria for success might be more at the process level rather than traditional outcomes. The programmes may also need to develop approaches to overcoming the challenges set out by people with MLTC which can then be applied across different contexts rather than testing simple area-specific solutions alone. Evaluations will also need to look for and learn lessons from proposals that don't work as well as from successes. All stakeholders, including funders and systems leaders will need to view 'failure' differently, as an integral part of learning. Simultaneously, all involved will need to recognise and accept the point at which an intervention or proposed solution has been shown not to work and where further iteration will not help, and be confident to stop.

Summary

Participants at the workshops agreed there would be huge value in taking a systems approach to thinking through how the health and care system might be transformed to work better for people with MLTC and carers, and how this could create an efficient and effective service which benefitted all stakeholders. It was accepted that this would take time and resource, but that research could drive a positive vision for future care for the next generation of patients. In taking the opportunity to do things differently, all parties involved would need to define and reach a consensus on the core principles for what should be achieved – and lived experience from all sections of the MLTC population should be at the heart of this. As one participant pointed out, no-one would want this research to succeed more than people living with MLTC.

There was a consensus among workshop participants that a longer-term funding model would be required to make this work and there will a concerted effort required from funders, health and care system leaders and workforce and the research community, across disciplinary boundaries, to improve services and systems for people who use, manage and work in the health and care system.

Annex 1: Workshop Agenda

The future of health & care; taking a systems engineering approach to multiple long-term conditions

8 February 2021

Agenda

09:45 – 10:00	Meeting opens Participants are encouraged to join early to mitigate for any technical issues before the workshop commences.
10:00 – 10:15	Introduction and Reflections from Workshop One
10:20 – 11:40	Breakout Session- Identifying a research idea
11:40 – 12:00	Break
12:00 – 12:30	Breakout session- Identifying barriers and opportunities
12:30 – 13:00	Next Steps