



Involving people with multiple long-term conditions

Changes, Benefits and Learning from Public Contributors: Public Involvement Impact Case Study

Project Team:

Stephanie Howard Wilsher - University of East Anglia

Charlotte Davies - University of East Anglia

Mike Shemko Norfolk and Norwich University Hospital

John Patman - University of East Anglia

Christopher Fox, University of Exeter

Alexander Macgregor University of East Anglia

Introduction

The UK National Standards of Public Involvement are used as a framework for the ARC EoE Public, Community, Involvement, Engagement and Participation (PCIEP) Strategy and includes 'impact'. We define 'impact' as "**the changes, benefits and learning**, gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiative's" (*NIHR Patient and Public Involvement Impact Working Group, 2019*). Through this, we seek improvement by identifying and sharing the difference that public involvement makes to our research.

The ARC EoE PCIEP Impact Case Studies are used to evaluate the impact of PCIEP on ARC EoE research and to highlight the changes, benefits and learning gained from partnership working and public involvement in ARC EoE.

Public contributors have been invited to co-produce the case studies and the perspectives of public contributors are included in the case study.



Public Involvement Impact Case Study: Involving people with multiple long-term conditions

Project Title: System mapping of care pathways for multiple long-term conditions

What problem is this research addressing?

This study examines the care pathways for people with lived experience of multiple long-term conditions (MLTC) and their care givers within local healthcare systems. Many people live with two or more conditions, such as diabetes and high blood pressure, that are treated under different care pathways. Often, there is little or no care coordination for people with several health conditions. Therefore, there is an urgent need to reform healthcare systems to improve the overall quality of care for patients with MLTC, which may involve shifting some care responsibilities from secondary to primary care services, such as GP practices.

The aim of this evaluation is to identify gaps in care, explore the challenges faced by both patients with MLTC, their carers and clinicians, and develop strategies for improving management across care pathways. By understanding the current reality of care compared to what it should be, this study aims to contribute to creating new tools that will support patients, carers and health care providers in effective management of MLTCs.

This study forms part of the InFLAIm research programme, which uses advanced computer techniques applied to large national datasets to analyse how factors such as inflammation, diet, and social factors interact over time to influence the development of MLTCs. InFLAIm is a Programme Grant for Applied Research funded by the National Institute for Health and Care Research (NIHR), led by the University of East Anglia (UEA) and in partnership with the Norfolk and Waveney Integrated Care Board. The findings from this study inform Phase 2 of the InFLAIm programme which will explore the most feasible and acceptable interventions and policies to prevent MLTC.

How were the public involved in this research?

There has been PPI involvement throughout the study process, from the generation of the research idea to the design and implementation of study material. The InFlAIm programme has a core PPIE group who are consulted on research methodologies and provide feedback on study materials. A study flyer was produced in consultation with three PPIE partners already involved in the InFlAIm programme as part of the PPIE group. We also engaged with key stakeholders and research and clinical colleagues for additional feedback.

The flyer was distributed to a variety of organisations including:

- Healthwatch Norfolk
- East of England Citizen's Senate
- Citizen's Academy, UEA
- 33 local Primary Care Networks
- Norfolk and Waveney Integrated Care Board (ICB)
- Community group meetings
- UEA newsletters
- Local libraries
- National support groups for arthritis, diabetes and heart disease
- Social media including Facebook groups
- National groups and local community groups.

Individual emails were also sent to four GP surgeries via their website to request engagement with the study.

Each workshop was attended by between 3 - 8 stakeholders and was composed of health and social care providers, people with at least two MLTC (advisors), and caregivers. Ages of stakeholders ranged from 41 to 84 years of age. Healthcare providers represented primary and secondary care, integrated Care Boards, and academia. There was a wide range of physical and mental health issues experienced by stakeholders including: diabetes, arthritis, high blood pressure, osteoporosis, asthma, allergies, colitis, depression, autism and cystic fibrosis.

Three, 2-hour workshops (face-to-face and online) with key stakeholders. The workshops adopted an informal approach to facilitate stakeholder discussion. At the beginning of each session, a brief introductory talk about the study was provided, followed by refreshments and a break halfway through. Researchers took notes throughout the discussions, which were later used to create summary points for stakeholder at the end of the session and to inform the thematic analysis. Follow-up emails were sent to all stakeholders, thanking them for their contributions and inviting any further feedback.

The aim of the workshops was to provide critical insights into the current challenges in MLTC management, how these may be addressed and how future research should be designed.

1. What are the problems people with MLTC and healthcare professionals face?
2. How could care pathways for MLTC be improved?
3. How should the research around MLTC be designed?

What were the outcomes of public involvement in this project?

The involvement of PPI in the workshops provided valuable insights into the everyday challenges faced by people with MLTCs, their carers, and healthcare professionals. It revealed the need for a

more integrated and holistic approach to care, improved communication across healthcare systems, and better coordination between services. It also highlighted the importance of mental health support for both patients and caregivers.

While the study identified several systemic challenges, such as poor communication and logistical barriers, it also offered practical solutions to streamline processes and improve the overall care experience. Future research could further explore these issues and test the effectiveness of proposed improvements, including the use of technology, interprofessional education, and the development of more flexible and patient-centred healthcare pathways.

Ultimately, the findings emphasise the importance of PPI in shaping healthcare interventions, ensuring that both the needs of patients and the perspectives of healthcare providers are addressed in any redesign of healthcare services for individuals with MLTCs. The findings are being used to support an application for a NIHR Programme Development Grant (PDG).

How did public involvement influence the project overall?

The participation of PPI in the workshops offered critical insights into the experiences and challenges faced by individuals living with MLTCs, as well as the wider impact these challenges have on their carers and healthcare professionals. It underscored the need for more integrated and holistic approaches to care, stronger communication across healthcare systems, and improved coordination between services. Additionally, the importance of mental health support for both patients and caregivers was emphasised.

Positive outcomes of PPI involvement included the identification of practical solutions to streamline processes and improve care experiences, such as the use of technology, interprofessional education, and the development of more flexible, patient-centred healthcare pathways. Ultimately, the findings emphasise the importance of PPI in shaping healthcare interventions, it has provided valuable insights into the real-life challenges faced by patients and caregivers, deepening our understanding of the issues at hand, and helping shape the direction of the research grant which will be developed from this study.

The study faced logistical and recruitment challenges, especially in engaging diverse or lesser-heard groups, which may have limited the range of perspectives included. Both the geographic limitations of the study and the difficulty in engaging with primary care clinicians further constrained the representation of healthcare providers' views. However, it has provided us with useful lessons to learn from going forwards and given us new directions in terms of engaging with primary care physicians.

What was the feedback from public contributors involved in this project?

The study had very good levels of engagement from our patient partners both in terms of recruitment but also with levels of engagement within the workshops. All voices were heard with minimal facilitation from workshop leaders and the overall the feedback was very positive.

A female advisor and their carer both living with MLTC gave the following feedback:

“We thought that the meeting was conducted in a friendly way. It was a pity that the participants were seated in a line - an oval or circular arrangement would have been better. In addition, we both

agreed that the clinician's idea of having a QR code on a "credit card" containing all an individual's medical history would be of great benefit to all. On reflection we failed to emphasise the mental health problems associated with MLTC. As a carer this is the most difficult area to cope with. Most physical problems have some solutions, but severe continuing pain and frustration leads sometimes to irrational thoughts and muddled thinking. Almost all unpaid carers have no training or experience to deal with spiralling depression, anxiety, panic attacks and low esteem. They themselves feel inadequate. Clearly in my view this is so important that another session dealing with mental health issues would be well worthwhile".

A male advisor living with MLTC said:

'It made me feel valued to be part of a group that looked into the difficulties faced by people living with multiple long-term conditions and how to make processes easier for us. It was great to hear the perspectives of others in the group who are in healthcare or looking after those with multiple conditions. It was clear that there were many different aspects that, when combined, formed considerable barriers and how different people's experiences were'.

A female advisor living with MLTCs said:

'Whilst the group was a small group, it was a valuable learning experience. It was useful to hear the experiences of other people with MLTC, particularly those who were older than me and with different conditions - there were lots of similarities in our experiences. It was really interesting to hear the views of healthcare practitioners, and to know that they are also as frustrated about communication systems as we are. I hope that feedback from the groups has some degree of influence over decisions about healthcare systems. It is really needed. It was an enjoyable experience, and the facilitators were thoughtful and empathic towards our experiences'.

A healthcare professional provided detailed feedback:

'Engaging in the multiple long-term conditions workshop deepened my understanding of the challenges and priorities within the project. It broadened my awareness of the complexities involved and allowed me to see firsthand how different perspectives contribute to shaping discussions and solutions. More importantly, it instilled a strong sense of empowerment, not only for me but also for others involved by providing a platform where our contributions were valued in shaping decisions, policies, and strategies. This, in turn, fostered greater engagement and investment in the subject matter.

Participation in initiatives like this brings numerous benefits for both public contributors and hosting organisations. For individuals, it offers the opportunity to develop new skills, build confidence, and gain valuable experience in professional collaboration. It also facilitates networking by connecting people with shared interests whether members of the public, researchers, or policymakers enabling more meaningful partnerships that contribute to improved services and research outcomes for communities.

A key learning from this experience was the importance of articulating ideas effectively within a group setting, particularly in complex discussions where diverse perspectives must be considered. I also gained valuable insight into decision-making processes, research frameworks, and the broader impact of public engagement on shaping policies and services. Additionally, I developed a deeper appreciation for the role of varied viewpoints and the importance of advocating for meaningful change.

However, one aspect that often feels lacking in such engagements is the follow-up process. While the workshops create a space for open dialogue and idea-sharing, there is often little communication afterward regarding how, or if, contributions have influenced tangible improvements. Providing clear updates on whether the discussions have led to changes in processes, services, or policies would not only enhance transparency but also reinforces the value of public participation, encouraging greater long-term engagement’.

What are the reflections and learning from public involvement in this research?

Recruiting via social media was surprisingly successful, using just two local community groups on Facebook. It provided a forum for presenting information to a relevant audience in a quick and efficient manner – it also allowed for peer dissemination via the ‘sharing’ option on Facebook. The adverts resulted in 16 email responses.

We had very little engagement from clinicians, particularly those in primary care. Those clinicians who expressed an interest or were involved in the workshops generally had a role within research. Ideally, we would have liked to engage with local GPs, nurse practitioners and community pharmacists. Discussions with colleagues arising during these workshops and in the networking process have provided useful insights into why we may have experienced a lack of engagement and also avenues for future engagement.

The study was short in time period and limited in its scope which meant that we had inevitable restrictions on geographical spread across the region. In future, we would like to reach out to the rural and coastal communities and engage with more diverse ethnic groups via faith community networks, local libraries and support groups.

We have also extended our network by reaching out to research colleagues working in the same research area but in different geographical locations and with different patient populations. This will provide an exciting opportunity for co-development of future research areas and themes and shared learning from each other’s experiences and findings.

Further resources:

System map of healthcare for multiple long-term conditions developed from workshops 2025

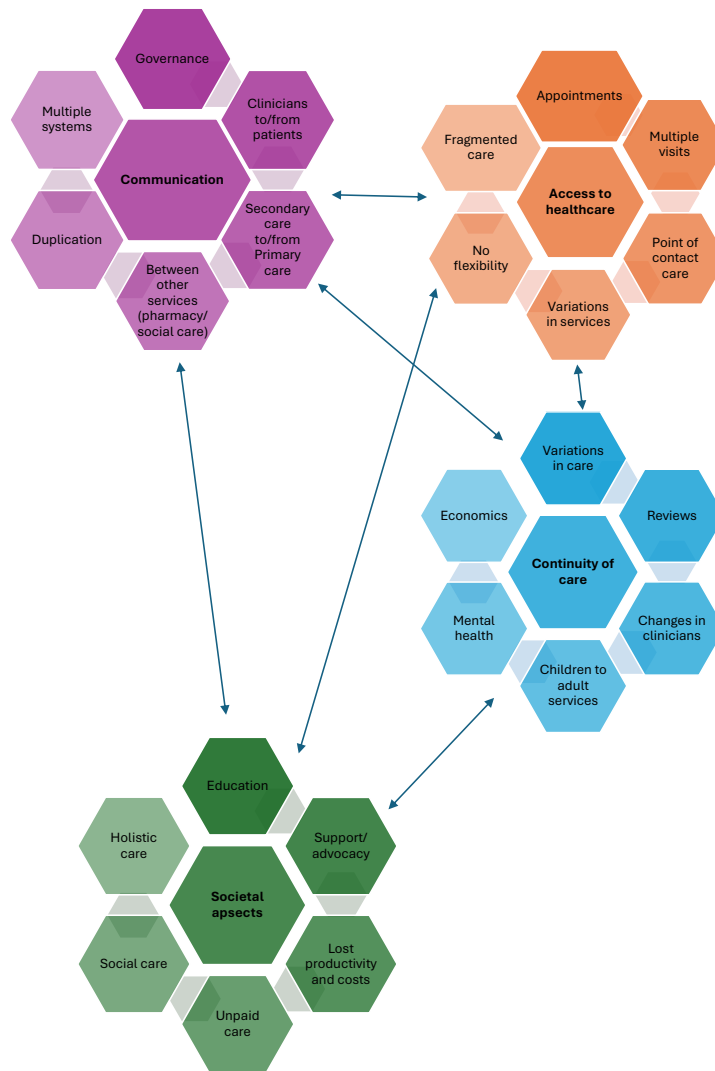


Figure 1 System Map of Healthcare for Multiple Long-Term Conditions Developed from Workshops 2025

Do you live with more than one long term condition?

Do you care for someone that lives with more than one long term condition?

Are you a health care professional?

YES?

Then we would love to hear your views on how health care can be improved

Who are we?

We are researchers from the University of East Anglia and participants from HealthWatch Norfolk.

What do you want me to do

We would like you to take part in a discussion about your healthcare experiences and views on the management of multiple long term conditions and how these could be improved. Your views are very important. Community participants and University researchers will lead a discussion at a local venue or online. This would be in small groups of around 10 people for a maximum of 2 hours. There will be refreshments and a 'thank you' shopping voucher for your time.

Please contact:

Stephanie Howard
stephanie.howard@uea.ac.uk or
Charlotte Davies:
charlotte.davies@uea.ac.uk

Why are we doing this?

Many people live with 2 or more health conditions, such as diabetes and heart disease that are treated under different care pathways. Often, there are numerous problems that reduce good care coordination for people with several health conditions. We want to find out about the gaps in care and the problems that people with multiple long term conditions and clinicians face.

Your views will help us to:

- Develop further research
- Find ways to provide better co-ordinated care
- Inform policy makers

healthwatch
Norfolk

UEA
University of East Anglia

NHS
Norfolk and Waveney
Integrated Care Board

Figure 2 Study flyer

For more information, visit the [project webpage](#)

Visit our website: arc-eoe.ninhr.ac.uk

Contact: ARCOffice@cpft.nhs.uk