
Public Involvement Workshop on Multiple Long-Term Conditions Summary

27th May 2021

On Thursday 27th May, the Cicely Saunders Institute (CSI), in collaboration with the public health and social care themes of the Applied Research Collaboration South London (ARC SL), hosted a virtual public involvement workshop on health and social care research for people with multiple long-term conditions. The workshop provided an opportunity for people with multiple long-term conditions, and their carers, to contribute to research at the ARC SL. Multiple long-term conditions can include combinations of physical and mental health issues as well as related factors such as social isolation. The workshop involved small group discussions, and a large group feedback session to enable exchange of ideas and learning opportunities. 16 people attended, and 9 members of staff across the CSI and ARC SL supported the event. One public member contributed after the event via a Zoom meeting.

Group 1: How can we work together as partners to improve our research?

Group 1 was facilitated by Peter Littlejohns and Mev Hocaoglu. In the discussion public members agreed that there is a need for researchers to be compassionate and understanding towards those who contribute to research projects. This includes acknowledging any and all levels of contribution. People reflected on the timings of meetings and interactions with researchers, and they highlighted the need for flexibility (outside of 9-5pm) to accommodate personal and health care commitments such as medical appointments. They thought engaging members of the public creatively was a good idea. They mentioned the use of open communications and creating opportunities for the public members to socialize (to ensure good ongoing support and connections between them), and expanding advertising opportunities such as on GP noticeboards. Several members also felt that creative use of simple lay language might help to better understand and clarify the many acronyms or initials used in the field of research on multiple long-term conditions.

Members discussed reaching out to local support groups. Groups such as the Diabetes Association, whilst focussed on a single disease, generally support people with multiple long-term conditions also as those affected by diabetes are commonly affected by another condition. The importance of ensuring diversity, and engaging community groups was mentioned. Patient Participation Groups (PPGs) and local voluntary support groups were given as examples to reach out to. For this to be successful, public members mentioned the need for flexible communication and allowing sufficient resources (time and money) in the project proposals.

Group 2: How can we support more people with multiple long-term conditions to participate in research projects?

Group 2 was facilitated by Jo Bayly and Marion Sumerfield. In the discussion public members commented on the need for research to address an issue which is important to those with multiple long-term conditions. Therefore, those living with multiple long-term conditions should be involved in the *beginning* of the work i.e., during the research design process. Public members emphasised that this is a way to ensure projects are more attractive to participants. They also reflected on practical issues for research participants and public involvement members such as the need for clarity on: time commitment required, reimbursement and payment, and updates on research progress. The group

also suggested rewards for participating through to completion of the research study (e.g., a badge). Like Group 1, the group stated that every person's experience must be heard and acknowledged.

The group mentioned the importance of building community as a way of encouraging research participants to stay involved in the study. One member gave an example of bringing research participants in to the research setting (i.e. clinic, centre or office) in groups so they can talk to each other and build relationships.

Public members agreed that a previous negative health or care/health services experience may deter an individual from participating in research. They felt that researchers need to create a safe and supportive environment for participants, and that trust needs to be established. Some asked specific questions about trauma and distress, and what happens to a research participant if a question is triggering this? The group felt it would be best for researchers to clarify that the interview, for example, might be upsetting and that support is available if that does happen.

Eligibility, inclusion, and exclusion criteria were also discussed. Public members highlighted that an individual may self-exclude from research opportunities if they feel that their other conditions are not relevant to the work. The concept of digital exclusion was raised by one member, and the need to be mindful of this. It is important to find other ways to reach target groups.

Group 3: How can we make sure our research improves the lives of people living with multiple long-term conditions?

Group 3 was facilitated by Jill Manthorpe and Emeka Chukwusa. In the discussion public members mentioned care homes as places where almost all residents had a long-term condition. The need for care homes to be culturally competent to meet the needs of residents from diverse ethnic groups was emphasised. The lack of multidisciplinary specialists in care homes was also raised. Public members suggested a dedicated/liason person with multidisciplinary expertise within NHS secondary care services for patients with multiple long-term conditions. The dedicated person could, for example, keep in regular contact with patients after hospital discharge. The group also discussed shortages of some health workers for those with multiple long-term conditions such as geriatricians. Public members suggested conducting research on how to incentivise individuals to become geriatricians.

A lack of compatible data and IT systems across and within the NHS was a common frustration for the members. They agreed that this caused problems with data sharing, and this impacts on the care of people like themselves with multiple long-term conditions.

A researcher in the group spoke about the absence of national surveys which could contribute to our understanding of those living with multiple long-term conditions. It was emphasised that is important to capture data at the individual level to help understand care needs. The group also discussed how carers are a repository of information about those living with multiple long-term conditions, especially when individuals find it difficult to communicate themselves. The group agreed that carers are often forgotten and can be overlooked.

Overall, the need for research for better care coordination for people with multiple long-term conditions was highlighted. The need to spread research funding beyond cancer, and to understand the types of conditions that occur together in people with multiple long-term conditions was raised. New technologies such as Artificial Intelligence might also have a lot to offer the world of information sharing.