



## Patient and public involvement in the ongoing applied artificial intelligence and complex health interventions co-design work

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### AIM-CISC Briefing Paper 1

This briefing paper describes how we involved Patient and Public Involvement (PPI) methods in the ongoing applied artificial intelligence (AI) and complex interventions co-design project seeking to improve pathways of care for people with multiple long-term conditions (MLTCs) in Scotland. This project is part of the wider NIHR-funded programme called AIM-CISC ([www.aim-cisc](http://www.aim-cisc)) which aims to use AI and state-of-the-art data science, social science, genomics, and health service research methods to understand the clustering of MLTCs within individuals, communities, and in key clinical contexts.

#### Patient and Public Involvement

The term PPI is used to describe research that is being carried out in close partnership 'with' or 'by' members of the public (e.g., patients, service users, carers, potential patients or service users) rather than 'to', 'about' or 'for' them.<sup>1,2</sup> In 2018, UK National Standards for Public Involvement was launched to improve the quality and ensure the consistency of public involvement in the research process.<sup>2</sup>



PPI contributions are important in all stages of complex intervention development and implementation work; their involvement ensures that interventions are both relevant and meaningful to patients and the public.<sup>3</sup> Recent years have witnessed substantial growth in the literature describing the benefits of involving PPI contributors in the intervention development process.<sup>3,4</sup> However, the quality and depth of PPI reporting in research varies considerably, with few practical examples of how PPI contributors were involved and the impact their involvement had on shaping research.

#### Aims

We involved PPI contributors in 2-stage PPI activity to help (i) determine the health targets of future complex health interventions for people with MLTCs, and (ii) select adverse events of primary importance to people with MLTCs that the AI-applied risk prediction tools underpinning the complex interventions will predict.

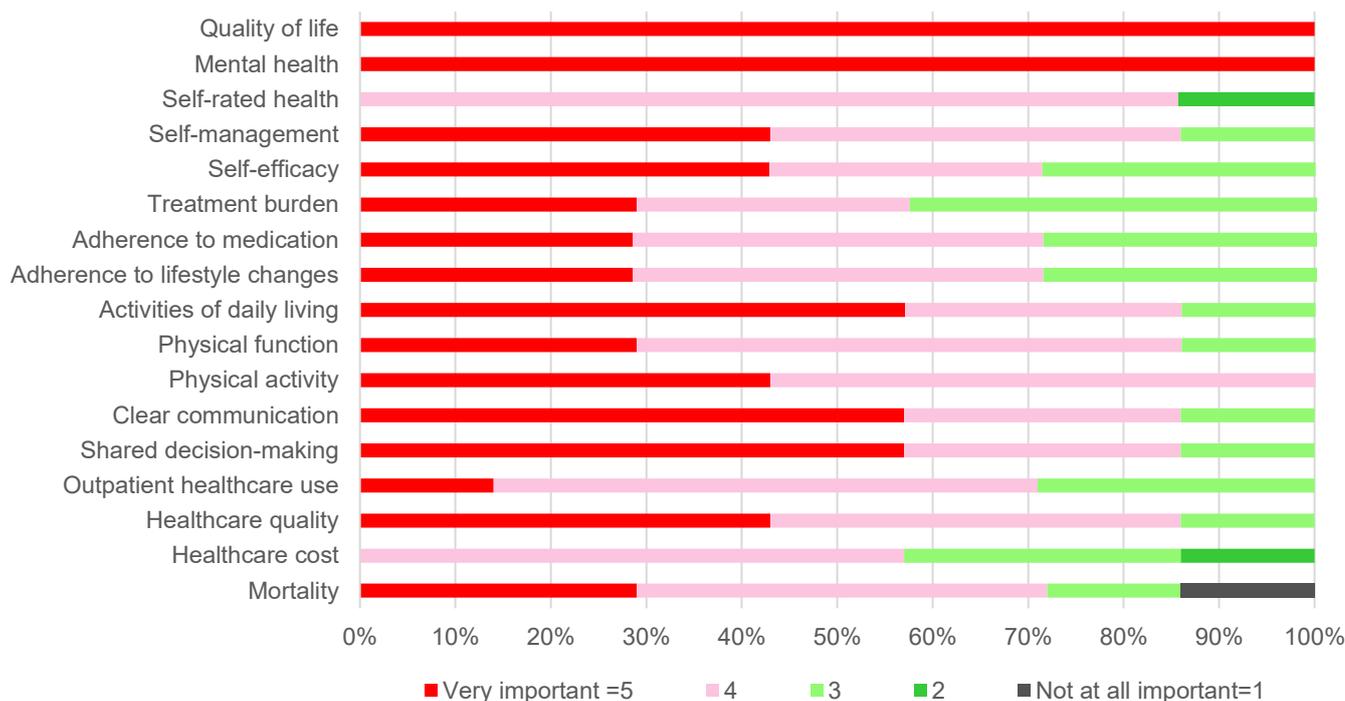
#### What we did

We conducted an online survey with seven PPI contributors with personal experience of living with a variety of MLTCs or caring for someone with MLTCs, asking them to rate the relative importance of 17 health outcomes and 15 adverse events for people with MLTCs. The proposed outcomes and adverse events were informed by an international consensus-based set of core outcomes for multimorbidity research (COSmm)<sup>5</sup> and a targeted literature search.<sup>6</sup> The rating scale was a 5-point Likert, ranging from 'Not at all important'=1 to 'Very important'=5. A glossary was provided alongside the online survey to explain the terms and ensure consistent interpretation across the group. The survey findings were analysed descriptively to present to the group during the follow-up online workshop.

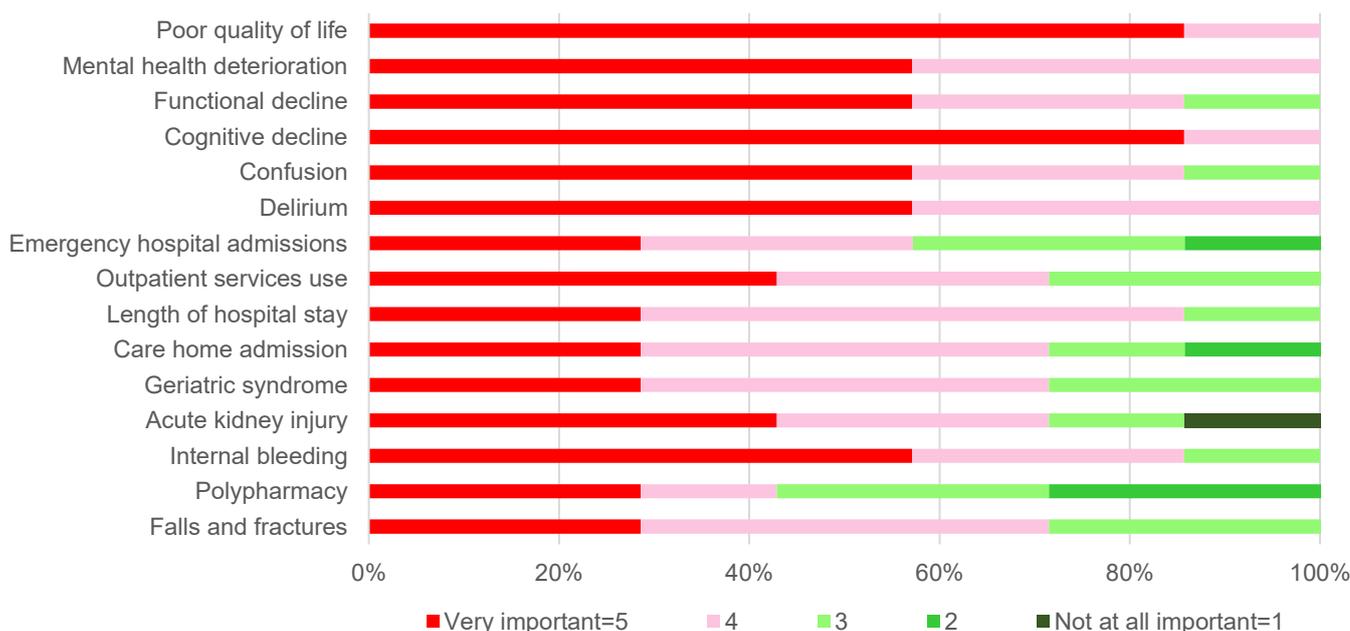
Four PPI contributors participated in the online workshop (60 min); the aim was to discuss the survey responses and develop an in-depth understanding of the PPI contributors' views. Through rich discussions, we also wanted to determine the factors impacting the scoring of outcomes and agree on the top five health outcomes and adverse events that should be prioritised in our intervention development work.

**What we found**

Findings of the online ranking exercise are presented in Figure 1 and Figure 2. Quality of life (QoL), mental health, activities of daily living, provider clear communication and shared decision-making were the highest-scoring health outcomes. Adverse events of high importance were poor QoL, cognitive decline, functional decline, mental health deterioration, confusion, delirium and internal bleeding.



**Figure 1. Rating and ranking of health outcomes based on importance**



**Figure 2. Rating and ranking of adverse events based on importance**

To get the most out of the group discussion, we asked PPI contributors' permission to auto-record the discussion and took extensive notes. As discussion moderators (SA and JR), we prepared a list of questions for PPI contributors to discuss and encouraged them to bring examples from their personal experience, provided they were happy to share those.

The group consensus-based top three health outcomes of importance were QoL, mental health and functional status. PPI contributors talked at length about the importance of having an optimal quality of life and how this concept is closely linked to mental and physical functioning:

*"Quite a lot of what ..... said, I agree. I mean, quality of life and mental health is very important. I mean that it is a no brainer really, isn't it?"*

*"It is important that somebody's quality of life is maintained and good mental health and independence is really key to ensuring this".*

*"...Life expectancy for people in some care homes is pretty abysmal because they don't really have any quality of life. So I think the quality of life and shared decision-making in care would certainly be ranked as being in the top..."*

PPI contributors further agreed on the critical importance of quality of care with respect to provider communication skills, information and knowledge translation skills and shared decision-making. One PPI contributor talked about their encounter with a health provider, which affected their willingness to seek care in the future. They described the language used by the provider to describe their health conditions as inappropriate and stigmatising. Another PPI contributor expressed worries in relation to variability in individualised care provision based on the consultant or GP seen:

*"I had very different experiences with consultants. When I was exploring the types of treatments that would maximise the benefits for me, it was very much left to me to make the decision. ....I met different consultants in that process, and there was a very big difference in their attitude towards me and the amount of time that they gave to explain what the issues were for me."*

*".....the level of importance that the health service puts on care seems to be variable. I have talked to people from outside of my area that don't get the sort of service as I get for the same health conditions. It makes me feel a little anxious really ... you know it's like a postcode lottery".*

During discussions, we also sought PPI contributors' reflections on the variability in scorings for a commonly selected outcome of health interventions – *mortality*. PPI contributors shared a sentiment that mortality might be more of a concern from the carer's standpoint rather than the patient perspective, and that in prolonging years to life quantity vs quality matters:

*"I think mortality would only be important to me, if I'm thinking from a carer's point of view."*

*".....And interestingly mortality is highly variable which indicates to me that most of us would rather be dead than having a significant disability to enjoy life."*

*"As you get nearer to mortality, you start to wonder how much influence you can have on the overall outcome in terms of years left with a good quality of life."*

*"..... I think I might have been one of the ones who didn't rank it [mortality] at all actually but ranked quality of life really very highly. I don't know whether that's a sort of wrapped up a little bit with your own personality as well in terms of how you view things, but for me my quality of life is central to my wellbeing....."*

When it comes to adverse events, poor QoL, general health and loss of independence emerged as key adverse events warranting risk prediction. This was then followed by mental health deterioration and length of hospital stay as the latter could lead to poor health, functional decline and care home admissions. Interestingly, the high rate of outpatient service use was not perceived as a suboptimal outcome at all but rather as something that helps patients stay in the community for longer.

Personal experiences, observations made as an informal carer of a person with MLTCs and discussions in peer support groups were the factors driving priority setting in the rating exercise.

## PPI contributor reflections

What follows are the reflections from one of the PPI contributors who took part in both stages of our PPI activity on how they found the process.

*'The ranking exercise we held with the AIM-CISC team was thought-provoking. From the list of health outcomes, QoL was an obvious very important outcome for me; the rating of other outcomes however I found trickier. For instance, mental health - at the moment, I would rate it as very important, but having seen a lot of people in dementia wards and looking at things objectively, it may be not so important. This is because based on my observations, there is frequently little self-awareness when one's mental faculties decline. In a similar vein, mortality is important to me now, but if my health declines significantly, impacting consequently on my QoL, would I feel differently? In any event, my scoring was based on 'here and now'.*

*My self-questioning however came more to the forefront with the adverse events rating exercise. I felt there were too many options for adverse events which to me were saying pretty much the same thing. For instance, cognitive decline, confusion and mental health deterioration - whilst not exactly synonymous concepts, these adverse events are very similar to me. Some of the adverse events listed had never occurred to me, e.g., acute kidney injury or internal bleeding, therefore, I scored them as not at all important.*

*In relation to the process itself, having worked in the NHS, albeit in a non-clinical capacity, for over 30 years, I didn't look at the glossary provided to support the rating exercise. Although if I had come across an unfamiliar term, I would have checked to see whether it was there and how it should be understood.*

*The group discussion that followed the online exercise was extremely interesting and made me think about how I had scored and why. It would have been easier if I had retained a copy of my scoresheet, particularly as it was difficult to remember the nuanced scores with a choice of 5 options. It might have been better to have fewer options, e.g., not at all important, very important and some sort of middle ground. Hearing other members' rationales for scoring, we agreed as a group on how certain outcomes were linked and prioritising the top five outcomes/adverse events based on importance was difficult.*

*I would support that similar exercises should be carried out in two stages as I found it helpful. The response scales should probably have simpler choices and a copy of each member's original online scoring should be made available for discussion.*

*For me, it was gratifying to get real time feedback in the discussion from the AIM-CISC researcher who really seemed to be listening to what we were saying and to be prepared to make changes as a result of our input'.*

## What we learned

- (i) Hosting the PPI activity ensured that the views and suggestions of people with MLTCs and informal carers are represented in the development phase of our work.
- (ii) The 2-stage process – an online survey followed by a group discussion – was a useful approach for 'co-prioritising' the key outcomes and adverse events for our complex interventions to target. The survey helped visualise rank order distribution for outcomes of interest, but it is through the group discussion that PPI contributors were able to highlight what really mattered to them. Our learning is that ranking response scales could be simplified for clarity, and a copy of individual responses could be shared with survey participants, with a reminder to bring those to a group discussion.
- (iii) We find that the provision of a glossary written with the reader in mind and with the right tone of voice is important as it ensures consistent understanding and interpretations within the group around key terms of interest.
- (iv) Enhancing QoL and mental health and promoting physical function and independence of people with MLTCs through better person-centred and coordinated services has been identified as one of the priority areas for the National Health Service and social care.<sup>7</sup> Insights gained from PPI contributors strongly resonate with this aspiration and our determination to make a sustainable contribution in this space.
- (v) Mortality is a common outcome in complex health interventions targeted at patients with complex health and social care issues. If complex interventions are effective in reducing mortality rates, it is likely that some aspects of QoL will also be improved. However, the benefits of interventions for QoL and mortality should be weighted carefully when considering their efficacy. Our learning from the PPI event is that prolonging life while also maintaining functional independence and QoL is critical, in other words - *'Strive for quality before quantity'*.

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