



Pioneering AI in MLTC: Bridging Research and Practice

9 & 10 September 2024 | Manchester

Focussing on the future:

How do we ensure impact through translation of your research to improve health & social care for MLTC patients, in the next 5 years?

The workshop logistics

The workshop was designed to provide members of the AIM community with an opportunity to discuss key topics shaping the future of AI and MLTC research, aiming to improve lives for those living with or caring for people with Multiple Long-Term Conditions. In collaboration with NIHR, six discussion topics with guiding questions were prepared to explore challenges and potential solutions.

The event welcomed 80-100 registered attendees, with 12-16 participants engaging in discussions on each topic and eight joining online. A one-hour session included 50 minutes for discussion, focusing on capturing attendees' insights and identifying three key takeaways for feedback.

There were 7 topics discussed in the workshop, this summary includes the discussion and takeaway from the 7th topic.

- **Topic 1: How can we mobilise knowledge that has been generated by AIM?**
- **Topic 2: What are the strategies & good practices for engaging and sustaining patient communities?**
- **Topic 3: How can we champion early career researchers in MLTC research?**
- **Topic 4: What technical support is needed for the next stage of translation/impact?**
- **Topic 5: Who do we need to engage to ensure broad collaboration for translating research?**
- **Topic 6: How would we move towards system thinking and transdisciplinary research in MLTC?**
- **Topic 7: What are the strategies & good practices for engaging and sustaining patient communities?**

Topic 7: What are the strategies & good practices for engaging and sustaining patient communities? (ONLINE GROUP)

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The key takeaways

- Still a lot of barriers to diverse participation - mapping these out and coming up with proactive strategies to address them (and supporting this with time and resources is important)
 - Funders and policymakers need to support community outreach efforts to improve education and connection with under served groups
- Opportunity to make the most of existing PPIE groups and participants to ensure that future projects aren't "starting from scratch"
- Providing pathways for researchers with lived experience of MLTCs through flexible training opportunities and improvements in work culture
- There are a lot of existing resources and training to improve researchers skills in PPIE throughout their career - how do we help people not to re-invent the wheel?

Recommendations for MLTC funders

1. Create sustainable PPIE infrastructure:
 - Establish a central PPIE registry to maintain connections beyond individual projects
 - Fund long-term community outreach programmes in underserved communities
 - Support hybrid engagement models combining online and in-person participation
 - Resource practical support (childcare, transport, digital devices) for participation
 - Create tiered involvement options to suit different capacity levels
 - Fund PPIE steering groups for project accountability
 - Develop standardised evaluation tools for PPIE impact
 - Support regular cross-project communications (e.g., newsletters)
2. Support the change in research culture and access:
 - Fund part-time fellowships specifically for researchers with MLTCs
 - Create flexible training pathways for patient contributors

- Support researcher training in engagement and facilitation
- Resource community-based health events and outreach
- Fund translation and language support services
- Create safeguarding systems for PPIE involvement
- Support innovative engagement methods (e.g., virtual platforms with avatars)
- Require reporting on team diversity alongside participant diversity

Summary of all the discussion

- **What support is needed to deliver this in the next stage?**
 - Scoping future work - uneven extensions, how to make sure people are signposted to other groups that exist
 - Engagement skews older - how do we address the barriers to including younger people and those with caring responsibilities? Haven't cracked it yet!
 - Agreement - involving patient and the public is important but need to educate people raise awareness of AI and gain trust
 - Engaging and listening are important, working collaboratively
 - Raising awareness, educating people and building trust but need to have effective approaches to this
 - Having researchers with MLTC's is also important...I know that there are some on the projects that I'm involved in, but there are bound to be more
 - Collaboration needs to be genuine and meaningful, not tokenism or a tick-box exercise
 - Jargon and acronyms are further barriers
 - EA NIHR - disparate sectors and groups rather than cohesive - tend to work in quite a siloed way so how can we look at other funders and other groups in existence and pull in the different facets and funders - want a joined-up approach
 - I think that getting the data right is a massive issue...we don't have accurate, complete patient records to work with so we don't have generalisability from our work and accurate representation
 - This is the multiple long-term condition collaboration that I mentioned, the NIHR MLTC CNC
<https://www.nihr.ac.uk/news/195-million-for-new-nihr-collaboration-to-tackle-multiple-long-term-conditions/32211>
 - Changing the definition of PPIE - including researchers with MLTCs etc to tackle things together

- Projects struggle with recruiting and training PPIE members (120 PPIE members across the consortia?) - don't want to waste this resource!
 - Can NIHR pull those groups together to outlast the individual programmes, would be an amazing resource
 - Some people are concerned about "too experienced" PPIE participants but not everyone shares this view
 - Agreed. Some PPIE members may be interested in other opportunities whether research projects or training opportunities
- Having accountability for the delivery of PPIE is also important as you have to put it in funding applications but there is little to no support/review/accountability for delivering fully embedded PPIE within a project. I think a steering group for PPIE would be massively beneficial for the lifetime of all projects.
- Don't want to start again from scratch for more MTLC projects
- What is NIHR's role in ensuring longevity of PPIE groups?
- If we could get funders and universities to decide on design, delivery and evaluation tools from the 537 available then we could get better quality PPIE reporting that can be used as guidelines for funding applications and support a more academic/impact-driven PPIE going forward
- Big generation gap because of barriers for in-work people, who have family commitments, need time off from work, people feel they don't know enough
- Regular AIM-wide newsletter keeping everyone up to date and offering new opportunities to get involved
- AI-Multiply are planning on writing a PPIE evaluation paper and we are going to explain our multi-methods evaluation process that we've used (4 different tools/frameworks) to get a broad evaluation of the impact from PPIE on the project, we're also wanting to create some advice for designing and delivering PPIE within AI and big data projects as this doesn't currently exist
- I have certainly appreciated the hybrid approach of this conference. Due to mobility and health issues, I struggle to travel, I'm mostly housebound
- **How can we increase the diversity of patients involved in research?**
 - There are community groups out there, but outreach is hard and takes time and resources
 - Language may be a barrier for some, and financial barriers and health barriers, eg mobility may also be barriers; Not everyone has the digital skills to participate online

- Also, some PPIE members may feel overwhelmed or out of their depth, especially when lots of jargon, acronyms and they can't keep up with the conversation
- Committing to 4-5 years of study is hard
- BME community and South Asian community often have language and digital skill barriers (and digital resource issues)
- Providing training to help increase skills and confidence can help reduce barriers
- Reaching out to seldom-heard communities - e.g. people who struggle with mental health
- Lots of people have confidence issues/ power dynamics with academics, clinicians and the public and don't know what to expect when getting involved in research. Building confidence to share and discuss personal experiences is a huge barrier...there isn't an ethical/safeguarding system for PPIE involvement...some topics can be triggering and cause unintentional harm to people
 - Lots of options for involvement as we are all different
- Accessing through GP services, health events in communities, engaging community leaders
- purchase devices for those who need them to get involved
- Childcare support for meeting/study participation
- Offer different tiers of involvement, some people may have time to be fully involved, others may wish to receive regular updates and participate offline, eg surveys
- Having more diverse researchers might help with some of the confidence/power dynamic issues. I find a lot of my colleagues have very similar backgrounds.
- In our Team Science project we intend to host our PPIE meetings on a virtual platform which uses 3D avatars who interact with one another in real time, aiming to remove hierarchal structures found in traditional communications.
- **How can funders and policymakers ensure translation doesn't exacerbate health inequalities?**
 - Correct, high quality data! AI models and risk tools are designed using unrepresentative, incomplete datasets
 - Allowing patients to input into a record of outcomes - patient-generated data

- Not always straightforward to use digital tools but could address missing data
 - Was available up to 2013 - removed access to summary care records for patients
 - Report published this week to set the record straight?
- Yes outcomes that are relevant to us...symptom impact, functionality, mobility, frailty...all not recorded...along with lifestyle and social factors that are hugely impactful to our health e.g. housing, finances, education level, social network, support etc etc etc
- Patient access and prompting to provide information
 - E.g. e-consult or clinic access to report to GP surgeries which is then put into a PDF file and not captured in the health record even as free text
 - Data shouldn't be wasted!
- NHS infrastructure has gaps and is not joined up - piecemeal
- Need full transparency on data provenance, spread of new presentation in the data - needs to feed all the way through to the end user
 - Policy makers and funders need to enforce this
- Explainability is important (and thorny!) - tools need to be understood by the people who use them and are affected by them
- There are the same issues in the North East. I live in one trust, my GP is in another and my consultants are in the same as my GP but for A&E I have to go to the trust that I live in and the systems aren't integrated...Primary, secondary and social care should all be recorded in one system and in one way so that data is accessible to all health care workers to support patient treatment
- Accurate and positive media coverage of AI could support public trust and help people to feel confident in sharing data
- Get the basics right - how are other industries tackling this? E.g. auto industry - no need to reinvent the wheel
- They need to look at the current procedure for accessing GP appointments. The difficulty of even obtaining the basic first step in primary care means many could be falling through the gaps
 - Dental appointments as well as this have a large impact on overall health
- I think one of the biggest problems is the way that "AI" is used to mean everything ranging from a simple statistical model that classifies pictures

of animals into 'cat' or 'dog', all the way up to portrayals of human-like robots and androids in science fiction films.

- **How can we make MLTC research more inclusive?**

- Researchers with lived experience of MLTC would go a long way to making research more inclusive
 - NIHR requiring reporting on diversity of team as well as diversity of participants - could this be expanded?
- Fellowships or funding to support people with MLTCs getting into research
- If participants require carers to support their involvement this needs to be accommodated
- There are so many barriers to education as well as to involvement in research...
 - Lots of courses such as PhDs or Masters are full-time - not possible to fit in around life
 - More opportunities for people with lived experience to get involved and learn the research techniques means tailoring to people's lives
- Everyone including project admins etc is involved in the project so how do we support them in an inclusive environment
- Disclosing disabilities - respecting people's experiences when they choose to share them
- It's hard being a researcher while disabled, the culture is not inclusive, very few people work part-time, schedules and work patterns can be very inflexible and difficult to manage around hospital appointments and other health needs
 - But fixing this to support inclusion would be a huge improvement to research!
 - The disconnect between the patient community and researchers
 - Targeted fellowships and researcher-ships to support part-time working
- A reference at the end of each project with a summary of involvement, skills, and experience would help participants access other opportunities whether that's PPIE, education, work, etc
- Many transferable skills are learned through different opportunities
- I was wondering if NIHR could maintain a registry of patients who have been involved in projects and want to continue their involvement in new projects

- That's a good idea, and definitely something we can feedback to the NIHR PPIE team to get their input as they offer support to researchers throughout projects
- For some opportunities, it is a type of recruitment process PPIE contributors need to go through
- Discussions are easier with a shared frame of reference with lived experiences
- Some attitudes make this engagement harder not easier!
- We're trying to do something like this in the North East and it's proving very difficult due to data laws... The NIHR website Be part of research is great for PPIE opportunities and have started keeping people "on the books" to try and link to relevant projects, but it's in very early stages and lots of researchers don't know that this resource is available
- Inclusivity for disability feels far behind other minorities
 - It's not always appreciated that disabled people's needs vary significantly
- **What are the challenges & barriers to reaching broader communities and establishing collaborative and productive ways of working together with researchers?**
 - Training for researchers in engagement and facilitation skills to help them find and engage with patients and public - learning about best practices and having ongoing support
 - This cohort has that support and it's been helpful
 - Data researchers specifically have narrow academic progression focus - how do you explain the colour blue fr people who can't see?
 - Both early-career and more senior researchers
 - Someone in the chat doesn't really think there are barriers as such - how do you go about how you get people involved - people already know who they want involved, and opportunities need to be opened up more
 - NIHR there are resources and support available but researchers and the public don't know about them
 - Research support service runs pre to post-application to help access training, resources etc to help with PPIE
 - Lots of groups that I'm involved with are working on training for researchers and contributors regarding PPIE when there are already loads available
 - Overarching networks to surface resources might help