



Teamwork for Health Workshop:

Exploring a Collaborative Approach to Tackle Brain Health Inequality in Aging Underrepresented Communities

Date: 4th October 2023

Location: St Paul's Church, Hills Road, Cambridge

Attendees

There were 14 people who attended the workshop, encompassing a range of lived experience from multiple levels of disadvantage.

Aim of the workshop

The overarching aim of ComPHAD is to change how we work with communities to understand brain health with ageing, including dementia, that is not captured by routine health data. The aim of this workshop was to explore:

- 1) Barriers to inclusion in brain health research
- 2) Solutions to these barriers
- 3) Building trust in brain health research

Format

People dealing with many hard situations often find themselves without a home, struggling with addiction, getting into trouble with the law, and managing mental health issues. One council initiative addressing these issues is Counting Every Adult, a part of the broader Making Every Adult Matter coalition. This initiative already has a co-development group in place, led by Tom Tallon. Tom's

team works closely with those who have first-hand experience of facing multiple levels of disadvantages, ensuring that these community members have a say in who interacts with them.

For the ComPHAD initiative, Tom acted as a liaison, sharing ComPHAD materials with the group. After reviewing the materials, the group agreed to invite a representative from ComPHAD to one of their monthly co-development sessions. Nicole Thomas from the University of Cambridge represented ComPHAD for this discussion.

Before delving into the main agenda, the group shared a lunch courtesy of the Counting Every Adult team. As Nicole couldn't be present physically, she joined the session remotely via a laptop provided by Tom. The group dedicated an hour for Nicole to pose her questions related to the ComPHAD project.

All attendees were compensated for their time with a £25 shopping voucher, with options including Tesco, Sainsbury's, or One4All.

Nicole started the session by giving an overview of the ComPHAD initiative. To ensure clarity, Tom facilitated a Q&A, allowing group members to seek clarifications about the project. As the session progressed, both Nicole and Tom took notes on the discussions and feedback.

Contribution to ComPHAD Methodology Development

Though there were hurdles due to the absence of an in-person representative, the co-development workshop members offered crucial insights. They shared their personal experiences of facing various challenges and discussed how these might affect their interest or ability to participate in brain health research.

Some members, especially those with personal or family histories of brain-related issues like trauma injuries or dementia, showed a heightened interest in the brain health project. However, some were hesitant, concerned about the long-term commitment that the study demands.

By listening to the feedback about potential research methods, we've identified four key themes that highlight their concerns and preferences:

- 1) Personalisation and Engagement
- 2) Trust, Transparency, and Communication
- 3) Community Integration and Social Value
- 4) Incentives, Relevance, and Skill Development

These themes give us a clearer idea of how to potentially make our methodology more inclusive. They emphasise the importance of understanding and adapting to individual needs, building trust, supporting the community, and providing relevant incentives.

Personalisation and Engagement

One individual shared her motivation to participate in another health-related study, emphasising how she felt valued as an "unconventional" research participant. She appreciated that someone was "interested in someone like me."

There was consensus that research should cater more to those navigating complicated and unpredictable lives. A tailored, personal approach - understanding and adapting to an individual's current situation - could significantly enhance research engagement. The suggestion was to make research activities more engaging and interactive instead of having participants play passive roles in extended interviews. Continuity is essential, as expressed in "I'm not going to want to keep talking to lots of different people." Regular check-ins, being aware of participants' 'friendly places', and adapting to changing circumstances were all vital. It was suggested that regularly reviewing a person's 'friendly places' would be a useful way to being able to keep in touch with those who are less able to update the research team on their changes in circumstance.

To maintain involvement, commitments could be segmented into manageable parts with flexibility in participation. For instance, the group questioned the necessity of completing all research activities simultaneously.

It was also emphasised that those not participating in mainstream societal activities are equally occupied. The daily struggle of some, like finding ways to cope using drugs or alcohol, was equated to the demands of a full-time job.

Trust, Transparency and Communication

Building and maintaining trust was expressed as foundational to successful research or community involvement. Trust for this group hinged on consistent communication, demonstrating honesty, and maintaining transparency. Moreover, it was felt crucial to approach individuals with compassion, recognising the unique challenges and adversities they face. Being sensitive to their circumstances and demonstrating a genuine understanding could break

down initial barriers. However, it needs to be authentic and from a place of genuine motivation for improving the lives of those currently under-represented in health data.

There was a consensus about the importance of individuals understanding the study's goals, benefits, and implications which interlinked with the research authentic motivations. Some posed questions like, "What exactly does a 'study' mean?" or "What is the end game? What is it all for?" These questions highlight the need for researchers and community organisers to communicate clearly and compassionately about the project's objectives, ensuring individuals understand why their involvement is important for their own wellbeing more than the project's success.

Understandably, many individuals expressed suspicion or wariness of the project. It was expressed by one individual how this suspicion will be commonplace amongst those who have been consistently marginalised. It is therefore imperative for researcher teams to acknowledge this suspicion and work proactively to address concerns, providing reassurance and emphasising mutual respect.

Creating a supportive research environment, rather than one that feels interrogative, can further enhance trust and participation. Emphasising co-creation with individuals with lived experience was seen as a way to make them feel valued, acknowledged, and understood, thus fostering a deeper sense of trust.

Community Integration and Social Value

The concept of community holds profound significance for many of the individuals, especially when navigating challenging life situations. Whether within traditional settings or in the more unpredictable environment of the streets, the bonds and shared experiences that constitute a community offer solace, understanding, and mutual support. There is a moral code which gets adhered to despite the chaotic appearance of street life. This sense of community can be lost when those experiencing homelessness become housed. Recognising and understanding the core values of these communities may be essential for those aiming to engage these communities in research or development projects.

Ideas such as establishing a brain health hub to serve as focal point where individuals come together, learn new skills delivered by researchers and health

students, access essential resources, and foster mutual support where food is shared, community ideas are listened to. Furthermore, the integration of local help groups and the active participation of primary healthcare providers, such as General Practitioners, can amplify the impact by bringing services to them.

Incentives, Relevance and Skill Development

The group discussed how in order to maximise engagement, it is crucial for projects and research initiatives to deliver discernible benefits. But these benefits shouldn't just be immediate advantages such as vouchers, but also long-term incentives as well. This was discussed as providing training or mentorship in brain health within the community brain health hub, facilitating ways to invest in their health by paying for gym memberships or other similar initiatives.

In essence, it was suggested that projects can empower individuals by giving them tools and skills that extend benefits beyond the immediate scope of the research or initiative. Such training not only addresses immediate gaps but can pave the way for future opportunities, be it in employment, education, or personal growth. By framing discussions or training in contexts that hold immediate relevance to individuals' current lives, it could build in the direct link between their involvement in the research and tangible benefits in the longer term.

The longer-term commitments could then act as evidence of the project's investment in the betterment to them as individuals but also their community and helps with the motivation for individuals to invest their time and trust.

Informing the methodology:

Firstly, the 'friendly places' concept offers an innovative solution to maintain contact without overburdening participants. Those living chaotic lives often face challenges in maintaining consistent communication due to frequent location changes or evolving circumstances. By mapping out these 'friendly places', the research team can ease the onus of updating contact details from the participants themselves. Instead, with their prior consent, these designated places or trusted contacts can help relay their whereabouts.

Co-development of data collection methods is a second fundamental aspect. Understanding what participants mean by 'interactive' is essential to ensure their active engagement. While interactive methods, such as discussions or

hands-on activities, can boost participation, they must be executed without compromising the scientific rigor necessary for large-scale studies. This challenge requires collaboration between researchers and participants to develop adaptable yet standardised data collection tools. For instance, if exercises need multiple modes of delivery due to varying participant preferences or abilities, these must be carefully calibrated to ensure that data remains consistent across the different formats.

Furthermore, recognising the core values of the community can guide the core values of the research itself. Just as the community values trust, transparency, and mutual support, these principles should be mirrored in the research approach. This alignment will enhance the authenticity of the research and foster a deeper sense of trust and commitment from participants.

Lastly, the potential for a brain health hub stands out as a promising strategy. This hub could serve as a focal point for the community, where learning, support, and research converge. It could house regular workshops or training sessions, ensuring ongoing community engagement, and offering participants tools and skills for their immediate needs and future aspirations. Through the hub, researchers can stay attuned to the evolving needs of the community, further informing the methodology and ensuring its relevance and impact.

In conclusion, a methodology that integrates the above facets—maintaining contact through "friendly places," co-developing interactive yet rigorous data collection tools, aligning research values with community values, and harnessing the potential of a brain health hub—promises a comprehensive, compassionate, and impactful approach to dementia prevalence research.

Conclusion

In conclusion, the workshop with the co-development group offered rich insights that could potentially guide the ComPHAD methodology exploration. The shared experiences and feedback from those navigating multiple levels of disadvantage highlighted the opportunity to reconsider research approaches, ensuring they are better attuned to their distinct circumstances and concerns.

An avenue to explore is the "friendly places" concept, which might offer a solution for maintaining communication with participants, thereby alleviating the challenges of frequent updates. The idea of co-developing interactive, yet rigorous, data collection tools emerges as a promising approach that could

align with participants' wishes for more engaged roles, while still respecting the demands of scientific rigour.

Emphasising the recognition of community values and potentially incorporating them into the research ethos could lay the foundation for a more genuine connection, fostering trust and deeper commitment from participants. Furthermore, the suggestion of a community-focused brain health hub stands out as an intriguing proposition. Such a hub could become a central point for collaborative learning, support, and research, ensuring that the researchers remain connected with the evolving needs and aspirations of the community. There are many community hubs already in existence, usually located in areas of increased deprivation. Exploring how we can integrate a sustainable research presence within these hubs will be important.

As the ComPHAD initiative progresses, exploring these elements - consistent communication, engaging research methods, value-centric approaches, and the possibility of a brain health hub - may offer a path towards a comprehensive, compassionate, and contextually relevant approach to understanding brain health and ageing in underserved populations.

Acknowledgments

We extend our heartfelt gratitude to all attendees for their invaluable insights and contributions during the workshop. Special thanks go to Tom Tallon for cultivating an environment conducive to meaningful discussions. His efforts will undoubtedly enrich the ComPHAD methodology.