



## Health is Wealth Workshop:

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

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**Date:** 31<sup>st</sup> August 2023

**Location:** Jabulani, 80-84 Union Street, Plymouth, PL1 3EZ

### Attendees

Around 17 people attended the workshop, encompassing a wide range of backgrounds and experiences. Among the attendees were individuals representing various regions of Africa, a spokesperson for Romanian voices, a member of the Police Diversity and Inclusion team, a spokesperson for those with lived experience of homelessness, an individual living with dementia and their caregiver, a retired academic with lived experience of dementia, and local faith leaders.

### 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. Our mission is to create culturally and socially appropriate ways of understanding brain health and memory problems by actively involving the community in every step of the process. This workshop was to build relationships within the community and to get feedback on what we have learned so far from our literature searches to iteratively inform our methodology development.

## Format

Jabo Butera, a Rwandan refugee who founded [The Diversity Business Incubator](#) (DBI) and who is now Director at Devon and Plymouth Chamber of Commerce, hosted the ComPHAD project during their monthly 'Health is Wealth' workshops. The DBI advertised the workshop through their networks and recommended that the first workshop to take the format of introducing the project, sharing food and then having informal conversations. This was so community champions and faith leaders can reach out to their communities with a better understanding of the project for the more formal workshops should they be deemed acceptable to the community.

Nicole Thomas (University of Cambridge) and John Downey (University of Plymouth) represented the ComPHAD project.

In order to facilitate the conversations, we created a vignette from peer reviewed literature, grey literature and informal conversations with academics and experts. This told the story of "Mr O", an Eritrean refugee who had settled in Plymouth, who has started to experience issues with his mood, memory and information processing.



Jabo first reinforced the purpose of the Health is Wealth workshops and then went around the room for everyone to introduce themselves. Jabo then invited Nicole to describe the ComPHAD project before we were invited to eat. Props were used in the form of infographics printed onto A3 card (Figure 1) to provide a background to ComPHAD and an outline of the aims.

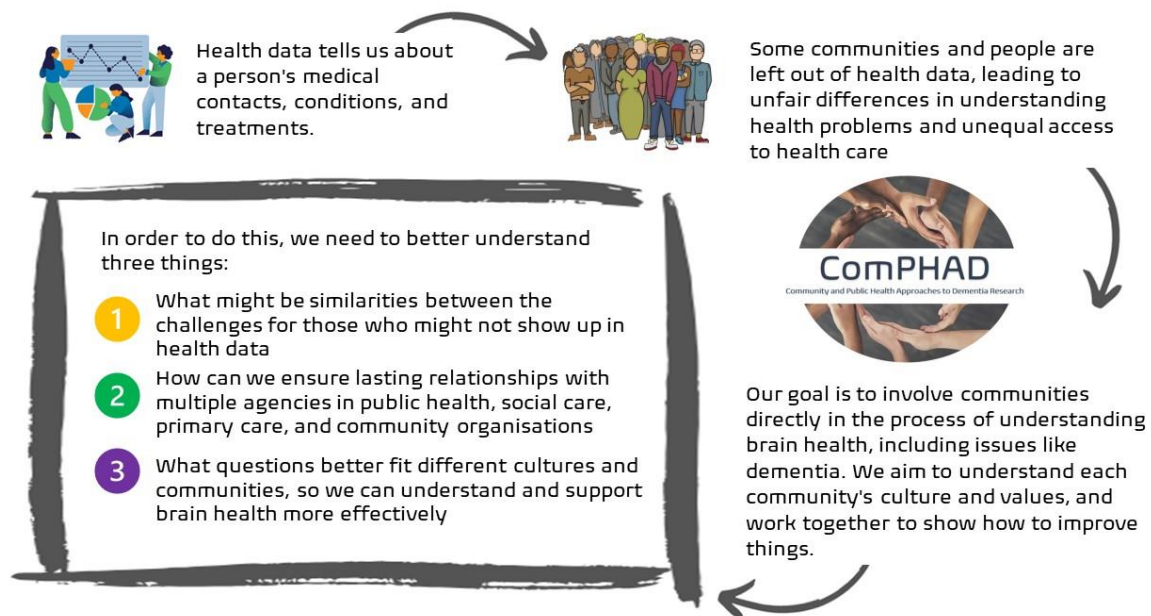


Figure 1: Infographic used to help describe the ComPHAD project

During the conversations, both Nicole and John made notes. Others were invited to make their own notes on the paper or post-it notes provided and place on the relevant discussion points on the posters.

All those who attended received a £50 Sainsburys shopping voucher. Some of those have chosen to use the voucher to buy food for their local food bank.





## **Contribution to ComPHAD Methodology Development**

Despite being an informal introduction to the ComPHAD project, the workshop provided an invaluable platform for diverse perspectives to converge and explore access challenges experienced by underrepresented groups. Feedback on the 'The Story of Mr O' provided insights that inform the three main three aims of ComPHAD (See Figure 1).

At the core of these discussions was the central theme of addressing emotional vulnerability and cultivating trust in the context of healthcare and research interactions. While many of these insights are well-documented in existing literature, the workshop also unveiled novel perspectives that were previously unsurfaced by ComPHAD. Notably, the workshop shed light on the influence of African matriarchal systems on shaping perceptions of stigma, access to healthcare, and participation in research. It also strengthened a preliminary theory about the importance of emotional safety which may be used to frame the ComPHAD methodology.

There were three main themes elicited from the discussions that will inform the development of the ComPHAD methodology. These were, "Communication and Language", "Cultural Sensitivity and Dignity" and "Overcoming Vulnerability and Building Trust".

### **Communication and Language**

One of the core elements that was present during the workshop discussions was the indispensable role of empathy and effective communication skills in establishing and nurturing trust. Although it was discussed in the context of healthcare providers and patients, it is also important for the researcher-participant relationship and therefore the principles can be translated as such.

It was felt that many of those in healthcare roles need to have conversational skills and empathy training. One attendee reflected on how her father, a GP from African descent, is very well respected by everyone in his community. It was thought that this was because of his character built by his own generational history as he was able to empathise and build trusting relationships with all of his patients. This was further reinforced when reviewing the memory screening questions which have been developed to be more culturally and educationally sensitive (RUDAS and CSI'D). It was suggested that it doesn't really matter what the questions are if someone takes the time to put people at ease by showing respect. However, for these

questions in particular, and the responses from “Mr O’s” experience was that screening questions would understandably feel like a test and therefore impact accessibility – not everyone copes well under ‘exam’ conditions.

It was discussed how dignity and respect may help with potential anxiety about attending a GP or healthcare appointment, Respect can be given by employing appropriate titles, such as Uncle or Aunty, for an elder from an African or South Asian background. By merely acknowledging the importance of cultural elder titles, it can uphold the person’s dignity and strengthen the trust in the relationship.

A male perspective was shared about feeling vulnerable in the hierarchy of the medical system – consultants can feel disempowering to a man. Clothing can dehumanise someone, including uniforms and set up a power dynamic that is difficult to overcome. In addition, not having any prior knowledge of what is going to be discussed or how the information will be used, further exacerbates the pre-emptive anxiety that accompanies a visit to a GP, or healthcare setting. Stepping into ‘another world’ such as a GP surgery can be disabling for someone who hasn’t grown up embodying the healthcare system.

There is a sense that you need to know the healthcare professional ‘has your back’ in the same way that a family member would – there is accountability in family systems and community, which cannot be trusted in healthcare. This was thought to be due to the emphasis on the individual across the NHS. There is a community approach to all aspect of care in African communities, whereas the healthcare system in the UK feels like individuals are treated and somewhat separated from the community.

In addition to male perspectives being discussed, it was also reflected how women from a heavily matriarchal system (The Congo was given as the location of this experience, although this is not reflected as being a matriarchal system within the published literature) are far less likely to discuss what is considered as a health issue which represents weakness. There is shame in sending the message home about ill health or ‘weakness’ when they have come here for a better life. The UK is supposed to be seen as an “Eldorado”, “a better world”.

Ultimately, it was discussed how culture, beliefs and backgrounds inform our sense of self. *“The word dementia is ‘cancelled’ in some communities because of its association with weakness and loss of dignity.”*

Language was discussed in terms not only of being able to speak a country's language, but also understand the language of its many systems. For a migrant, this may be learning the language of housing, benefits, healthcare and law enforcement. Each has their own language and culture, each of which is difficult to navigate unless there is existing intricate knowledge and understanding – even sometimes for those working within the system. An example given was 'what is it to be British' which is an exam immigrants are expected to take.

The use of Interpreters was not seen ideal as the message being communicated by the key person is lost, people can't explain themselves fully, and the healthcare professionals lack patience/time. The issue of privacy and confidentiality of discussing issues via a stranger was also a concern.

### **Cultural Sensitivity and Dignity**

Medical environments were seen with engrained power dynamics, and people were not comfortable with how they may be viewed in this context. The process of diagnosis was seen as stigmatising due to the tests and questions that need to be answered.

Conversations centred around the meaning of community, and how it impacts individuals. It was felt that there is no 'community' within the Southwest. There is no dedicated physical space that could be used for community endeavours. Because diaspora are scattered there is currently no way to understand what any particular community *is*. It was reflected as a regional issue - urban areas quickly build diverse communities – but there is less opportunity for this across large rural geographies in Devon and Cornwall so people remain disconnected and dispersed.

This dispersion impacted how they were able to support one another. An example was given where an elderly African woman was experiencing memory problems. She did not have any family or next of kin. Those who knew her did their best to facilitate her care - the African community gathered around her, helped her dress, and helped her cook. However, *"GPs won't talk to you unless you are next of kin"* or power of attorney and once healthcare professionals became involved, they moved the individual away from the area, further isolating her from people she knew as it was too far for them to visit and stay involved in her care.



Talking about illness was discussed as taboo, due to it being seen as weakness, and showing failings in strength. Both men and women talked about preferring to hide signs of illness as the norm in order to preserve their dignity.

### **Overcoming Vulnerability and Building Trust**

This theme was closely interconnected with both the previous themes. However, there were some unique insights given which build upon overcoming vulnerability and building trust.

Where there is a safe space that is not medical, people will come and share their story if there is trust. *"With the right approach, no one is hard to reach."* An example of GPs going on walks with people with complex lives being supported by a community organisation in Plymouth demonstrated how individuals with avoidance of healthcare professionals can learn to trust through engagement in non-threatening environments.

For those who are living in a constant state of low-level fear, there is no emotional safety and fatalism gains traction. For those in these fear-states, the thought of losing their memory is a terrifying concept as it is sometimes all they have to rely on to survive.

In addition, people are told to 'take it easy' and are encouraged to be less mobile but then it becomes harder to self-advocate and motivate action for change which can exacerbate the risk and issues associated with dementia. *"It is really difficult to track memory problems in those who keep themselves perpetually self-isolated due to their fear-states."*

Story telling was suggested as a way to help overcome vulnerability and encourage opening. *"Everybody wants to tell their story. Stories are identities. There is dignity in telling your story."* It was thought that engaging communities and healthcare professionals in creative storytelling, the audience becomes equals – it doesn't matter who they are (professionals or patients), they are all united by the story.

### **Informing the methodology:**

Enhancing the preparation process for healthcare and research appointments can reduce anxiety among patients and participants. Providing individuals with clear expectations regarding the information they need to share and offering preliminary emotional support, along with a feedback mechanism after appointments, may be beneficial. As it's often the case that crucial details are

forgotten once you leave the doctor's office, these measures ensure a more productive and less stressful experience.

The physical environment of research activities needs careful consideration to ensure the emotional safety of the individual.

To foster a mutually beneficial relationship, it's crucial to not only have community ambassadors who facilitate health-related discussions but also introduce the concept of 'research ambassadors.' Research ambassadors could play a pivotal role in real-time evidence gathering, which helps underscore the needs of communities to their local decision-makers. Moreover, they could act as interpreters of the complex systems landscape, making it more accessible to the community. This could be a role played by an Early Career Research network who are engaged with deep community work as part of their field of work.

This concept could also be seamlessly integrated into other Patient and Public Involvement and Engagement (PPIE) activities, empowering communities to become an integral part of shaping research questions that directly impact them.

## **Conclusion**

The conversations from the ComPHAD workshop held in Plymouth provided an invaluable platform for diverse perspectives to converge and explore various facets of healthcare and research challenges. Central to these discussions was the overarching theme of overcoming vulnerability and nurturing trust in healthcare and research interactions. The deliberations underscored the pressing need for compassionate and inclusive practices. Moreover, the workshop illuminated the potential for researchers to play a pivotal role in bridging gaps, deciphering complex healthcare jargon, and advocating for equitable healthcare experiences. This would be through accessing evidence which is largely behind a paywall and specialist sources to help build their arguments for change within their communities.

The workshop, combined with the existing literature review, has led to the initial development of a model that outlines the interplay between individual, family, and community-level influences. This model will serve as a foundation

and will undergo iterative refinement throughout the ComPHAD project (see Figure 2).

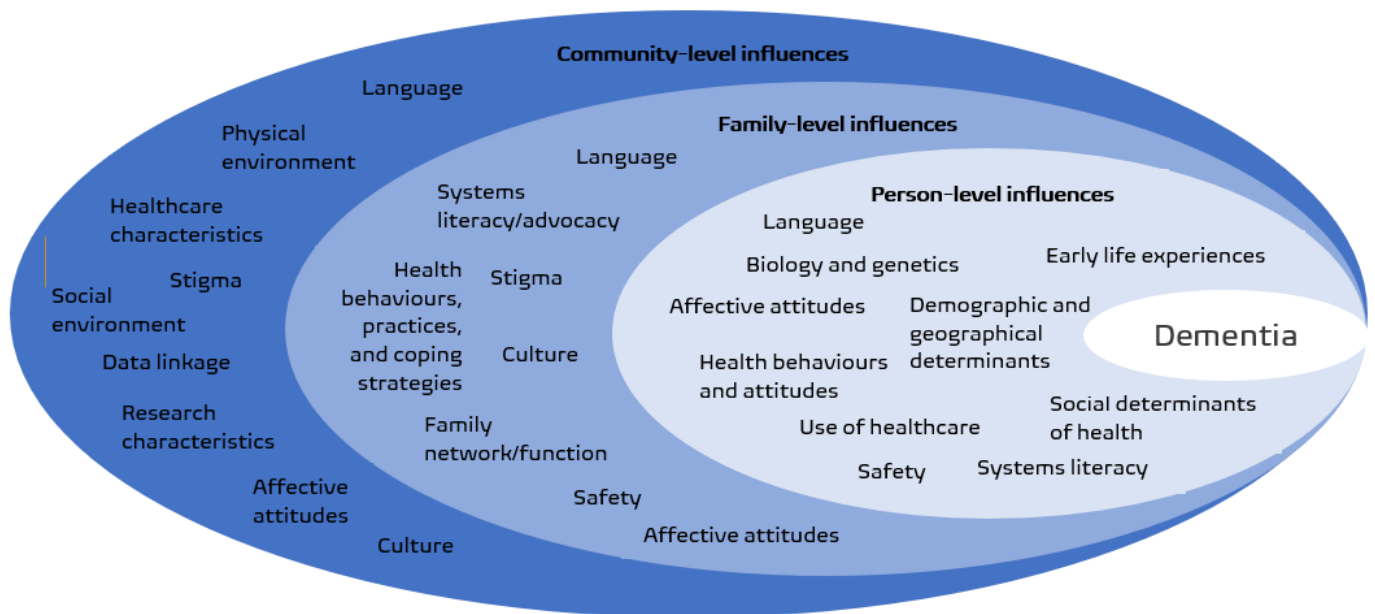


Figure 2: An early dementia model showing the interplay between three influential levels.

## Workshop Improvements

Recommendations for future workshops included the integration of authentic quotes to encapsulate personal experiences, the gradual expansion of these quotes over time, the inclusion of personal storytellers to enrich discussions, and the cultivation of equal partnerships between researchers and attendees.

In the upcoming workshops, we will introduce 'drop-in' sessions available throughout the day, alongside scheduled workshop sessions. This approach aims to accommodate individuals who may feel less at ease in group settings, encouraging their active participation.

Furthermore, as a pilot initiative, we will provide access to a transcribing app called Otter.ai, which can be used on an iPad. This tool enables individuals to express their ideas and opinions in their preferred language, enhancing inclusivity.

## **Acknowledgments**

We extend our heartfelt gratitude to all attendees for their invaluable insights and contributions during the workshop. Special appreciation is extended to Jabo Butera, Azza Gasim, Tania Nana, Ela Roszkowska and Liliane Uwimana for their unwavering commitment to create an environment which allows important discussions and collaborative engagements.