



Health is Wealth Workshop:

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

Date: 28th September 2023, 5.30-7.30pm

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

Attendees

Our second workshop had attendance from 23 individuals, up by 6 from our previous event. Our group again represented diverse backgrounds, including those from Asian and African origins, as well a dentist, from an Eastern European country, working directly with asylum seekers and refugees. We also welcomed individuals representing neurodivergence, including autism and bipolar disorder. Furthermore, representatives from Plymouth Hope, an organisation dedicated to supporting asylum seekers and refugees, were present.

As per the previous workshop reflections, Nicole advertised that she would be at Jabulani between 11am and 5.30pm for those who may want to drop in and have a quieter informal conversation outside of the workshop.

Aim of the workshop

The goal of this workshop was to delve further into the details of participating in health research and to identify potential barriers. This focus applied both to community organisations that identify individuals for research and to the

participants themselves. Additionally, we aimed to deepen our understanding of trust-building and explore ways to foster mutually equitable relationships.

Format

The workshop followed a format akin to our previous one. Jabo Butera, a Rwandan refugee and founder of [The Diversity Business Incubator](#) (DBI) hosted the ComPHAD project as part of their monthly 'Health is Wealth' sessions. This time, the DBI promoted the event through their networks using an Eventbrite link, offering more details about the upcoming workshop as a continuation from the last. The Eventbrite link was also shared via the University of Plymouth events page. Once again, [Jabulani](#), an African food court located within [The Plot](#), provided both the venue and the food.

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

For this workshop, a whiteboard displaying key elements of the research process was displayed along with accompanying questions, and the [The Story of Mr O](#).



Figure 1: Display of questions and talking points which attendees could use post it notes to comments on

Jabo first reinforced the purpose of the Health is Wealth workshops and then invited Nicole to describe the aims of the workshop before everyone was invited to eat.

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

As the workshop lasted for two hours, all those who attended received a £50 shopping voucher of their choice (Tesco, Sainsbury's or One4All).



Figure 2: Nicole talking to an advocate for refugees and asylum seekers.

Contribution to ComPHAD Methodology Development

Using an informal approach was instrumental in facilitating candid discussions on sensitive topics. Feedback on 'The Story of Mr O' illuminated certain beliefs within the African culture about dementia and its related stigmas, notably the tendency to 'hide affected loved ones.'

Furthermore, attendees shed light on the profound emotional toll stemming from the paperwork and inquiries associated with refugee and asylum processes. This feedback is invaluable for understanding potential barriers in health research methodologies when collecting data.

Central to the workshop was the challenge of building trust and the subsequent hesitancy to discuss personal matters, like brain health. The complexities of maintaining contact in a 'Dispersal City' were also touched upon.

Two standout queries from these discussions, crucial for shaping the ComPHAD methodology, were the questions: "What is Trust?" and "What can we do?".

What is Trust?

Trust was a recurring theme in our discussions, emphasising its intricate relationship with symbols of authority, like uniforms. It was expressed by one individual that uniforms, whether worn by police officers or healthcare professionals, don't automatically command respect; it must be earned. An example was the differentiation made in the healthcare setting, especially regarding consultants who are often identified by the colour of their scrubs. This discussion resonated with a previous conversation from the previous workshop, where a man of African descent expressed reservations about uniforms. The similar sentiment in this workshop was voiced by a white male with a history of mental illness and bipolar disorder. He reflected the significance of recognising hierarchies, even within a research context: "Who is in charge, and what do they want?"



Figure 3: Paraphrased conversations to demonstrate salient points raised relating to trust.

This theme about hierarchies transitions into a broader conversation that was had about trust or, more precisely, the lack thereof. There was a sense of ‘suspicion’ surrounding healthcare professionals and researchers, especially when their roles involve questioning or interviewing. This was a sentiment felt both the dentist treating refugees and asylum seekers, as well as those on the receiving end of health questions. It was felt this cynicism could be attributed to the rigorous screening and interrogative processes immigrants undergo upon arrival in the UK, leading to a guarded stance when later interacting with health professionals. It was reflected how this too could impact the research data collection process.

Furthermore, the mere presence of a university badge or emblem doesn't necessarily instil trust. It was discussed by one individual, a person of Black heritage born in the UK, that it doesn't represent the institution's core values but rather stands as a testament to systemic barriers that might deter certain individuals and groups.

Our discussions concluded that setting clear expectations and embodying core values is essential. Crafting a 'brand' that genuinely mirrors these values may influence public perception and trustworthiness. This brand itself could also be co-developed with the community.

It was shared via a post-it note that those who work within community organisations typically begin with a foundational understanding and appreciation of the complexity of human experiences as they 'may be open to differences' and recognise that 'everyone comes with a background of knowledge'. Trust would be lost due to 'someone assuming they know what I know' or 'deciding what I need and want'.

When it comes to aiding recruiting for research, the same person shared that research should prioritise cultural awareness and understanding. This not only involves hiring individuals who are well-versed in various cultures but also ensuring that the workforce genuinely represents the diversity of the communities they serve.

In summary, these discussions highlighted that true engagement requires recognition of individual experiences, shedding preconceived notions, and understanding that each person brings a wealth of unique insights to the table. Only by embracing this ethos can research cultivate safe environments where everyone feels seen, understood, and valued.

What Can We Do?

Plymouth's status as a dispersal city for refugees and asylum seekers was described as carrying implications for long-term residency. It was highlighted that for many who arrive here, Plymouth isn't their final destination. While some find a sense of belonging through religious institutions, whether Christian or Islamic, and choose to remain in Plymouth, and others decide to stay due to family connections, a significant number often relocate to cities like London or Manchester once their permanent residency is finalised. It was reflected that individuals are drawn to these larger cities, seeing them as hubs of greater opportunity and community, which is their motivation for reaching the UK in the first place.

This transient nature of Plymouth's refugee and asylum-seeking population presents challenges for local organisations, such as Plymouth Hope. This in turn means maintaining consistent communication becomes especially difficult for research partners aiming to track participants over extended periods.

However, this challenge was discussed as a way for potential innovative solutions and dialogues to help develop equitable relationships between community organisations and research. During our discussions, the idea of aiding community partners in establishing efficient communication and data

pathways emerged. This has the potential to enable organisations to sustain contact with individuals even after they've relocated, which, if consented to, can help research maintain contact.

One suggestion was to take inspiration from larger community entities, who use a triaging or referral system. Such a system wouldn't track individuals but would foster an interconnected approach to ensure that even as people move and their circumstances change, they remain within a supportive network where information can be shared in a way that respects their journey and privacy.

Informing the methodology:

Using the insights from both workshops, the following steps could be taken:

1. **Development of a Co-Created Brand:** Initiate a project where the brand's identity is co-created, tapping into the wisdom and experiences of people with lived experiences. This approach not only fosters ownership but ensures that the brand is sensitive, inclusive, and genuinely resonates with the community it represents.
2. **Diversifying the Research Team:** Ensuring the research team is diverse is paramount. Actively recruiting and employing individuals who mirror the cultural and ethnic diversity of the communities we are reaching out to can offer invaluable expertise and build trust within communities. These could include community members as research champions.
3. **Strengthening Communication Pathways for Grassroots Organisations:** One of the emergent needs is to support grassroots organisations in establishing robust communication pathways. This needs to be explored further, especially how research projects may be able to build this into their funding.
4. **Re-imagining Data Collection Methods:** The traditional 'interview' process for collecting health data may feel invasive or triggering, especially to communities that already are suspicious of these techniques due to prior experiences. We need to collaboratively co-develop innovative methods to collect this data, ensuring the process is non-threatening, respectful, and mindful of the traumas or sensitivities individuals may carry. This might involve using more visual tools,

narrative methods, or even technology-assisted solutions that allow for self-reporting in a non-linear, natural way.

Researcher Reflections (Nicole Thomas)

Although there were suggestions that concealing loved ones with dementia may be prevalent within certain African cultures, I feel it is crucial to recognise that similar sentiments are observed across various ethnic groups, including white populations. This emphasises that such viewpoints are not confined to a single culture, but rather suggest a more widespread societal issue in comprehending dementia.

A chance discussion I had with a GP who supports refugees and asylum seekers was had whilst I was hosting the 'drop in' session. This centred on a previously unsuccessful community hub pilot that had NHS funding retracted due to governmental cuts. However, Jabo's persistent efforts to establish a community space in Plymouth's Stonehouse region, an area with one of the highest needs, has opened doors to a potential funding avenue that might benefit both the community and the ComPHAD project.

This initiative involved five other pilot sites across the UK. Investigating how the other sites might be progressing could be a valuable direction for further inquiry.

Workshop Improvements

Due to time constraints, some of the previously suggested recommendations for future workshops were not implemented, but they will be carried forward. This includes the incorporation of quotes to capture personal experiences, with a gradual expansion of these quotes over subsequent sessions, as well as the utilisation of the transcribing app, Otter.ai, compatible with an iPad.

Although there was low uptake of those coming to the 'drop-in' session, it was still a valuable exercise. This approach will be continued at upcoming workshops.

Beginning with shared meals and fostering open discussions has proven to be an effective approach, and this format will be maintained in the forthcoming workshops.

While only four individuals registered via Eventbrite, actual attendance was higher. While pre-event registration helps in planning for vouchers and food, it appears that individuals from these communities didn't utilise this platform.

Moving forward, we may need to explore alternative methods for registration. Facilitating voucher distribution through community organisations directly might ensure attendees receive their appreciation vouchers without delay.

Acknowledgments

Again, 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 and the wonderful ladies at Jabulani for their unwavering commitment to create an environment which allows important discussions and collaborative engagements.