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Implementation of Open-Source Electronic Health Records Systems in Low and Lower-Middle Income Countries

What ideas and thoughts come to you when you hear 'open research'?

When I think of open research, I think of something that is made accessible or something that is freely available, like sharing knowledge with a wider audience. And something that is not as restrictive as closed research, for example, where you would have to pay for membership or licence fees to read an article in an academic journal. I think open research is really about collaboration and distribution of knowledge or shared learning.

In terms of my personal experience, I have not really had much exposure with open research concerning publications. I have shared some research outputs with the postgraduate community at Leeds and other UK, EU, and international higher education institutions. For example, where I have presented my research methodology and findings at certain events/ conferences - open to a wider academic audience.

Also, I have shared my research findings, methodology, and analysis approaches with the open-source software community I study. I try to be mindful of the audience I reach out to – reflecting on what kind of information would be most appropriate for the target audience.

What is your PhD research on?
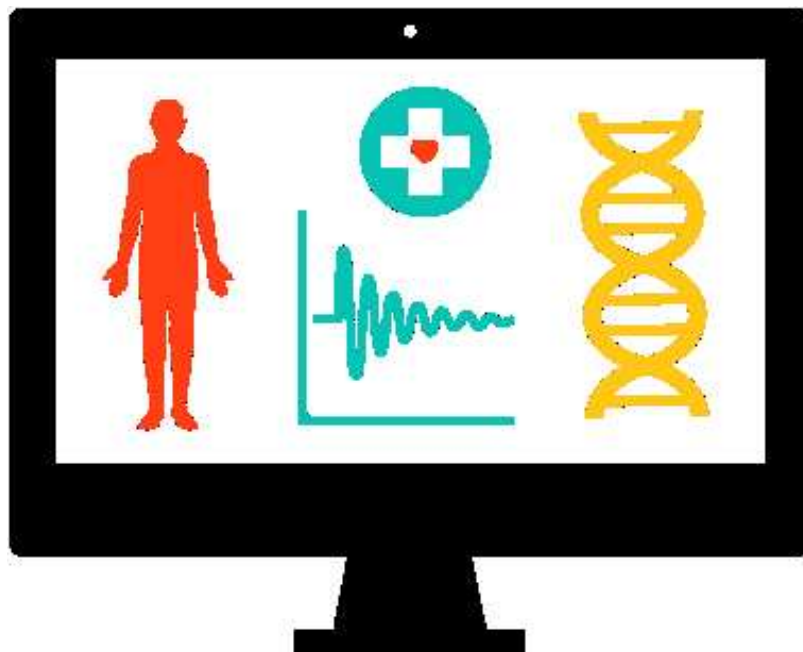
I am in my final year of undertaking an interdisciplinary PhD, so I am working closely with the School of Healthcare, School of Computing, and the Business School. My research project looks at responsible innovation in the implementation of an open-source electronic health records (EHRs) system in low and lower-middle income countries (LMICs), particularly resource-constrained settings that lack robust infrastructure, funding, technical expertise, and other key resources. Open-source EHRs can improve healthcare delivery in LMICs, address high-costs and rigidity associated with commercial EHRs to some extent.

My research explores the role of local organisations - in particular social enterprises and non-profit organisations - that support the adoption of an open-source EHR system in LMICs. These organisations adapt and implement the software to make it work in a given context. They are the ones who align the technical and the human aspects of responsible innovation. They engage with software developers and IT providers, with funders and government officials and, most importantly, end-users such as healthcare practitioners, administrators and patients. We need to better understand the role of implementers because responsible innovation is about being responsive - and about generating value. Local implementing organisations and the implementers are key to achieving both, and yet they are often overlooked.

The aim of the research has been to capture variations in implementers understandings of the work they do and then to explore how these understandings shape the way implementers approach the process of implementing open-source EHRs in LMIC settings, and what that means for what they can or cannot achieve in terms of outcomes.

How do you incorporate open research practices?

For me it was important to engage with participants throughout the research project. I have, for example, shared some preliminary findings with the participants and the open-source EHR community as I have progressed with the research project. It was important for me to provide regular updates because I want to contribute to that community. After all, they have supported this research project and are looking forward to the final outputs – research findings.

Phenomenography

I adopted phenomenography as a methodology which explores the variation in understandings of a specific phenomenon of interest. For example, you could explore health care professionals' understanding of diabetes care or examine how surgeons determine competence. I looked at understandings of what healthcare IT implementation involves, and what role local implementers have in this process.

Phenomenography shifts the focus of analysis from commonalities to an appreciation of diversity in understanding. Having said that, it looks for patterns in understandings. The methodology hence takes a second-order perspective focusing on the experience as described by individuals. This methodology was suitable for my research because I was looking to capture the distinct ways in which implementation was understood by a group of implementers and how such understandings informed implementer actions. I conducted 30 online in-depth semi-structured interviews with implementers from 19 organisations across LMICs. The online interviews really helped me focus on capturing such variation and how the

implementers understood the implementation process, and how such understandings translated to different aspects of implementation responsibility and accountability.

Have you encountered any challenges in your research?

Data collection and the Covid-19 pandemic

Yes, unfortunately there have been challenges, especially with how the Covid-19 pandemic limited opportunities for conducting research abroad. I had to give up my plans for conducting field research in Africa because of the lockdowns and travel bans. As a result, my research direction and approach had to change significantly. With the support from my fantastic supervisors (Dr Lena Jaspersen, Owen Johnson, Professor Rebecca Randell), I developed a new research design and methodology, where I had to think carefully about online research methods, especially interviewing online. But even then, there were challenges. For example, there were significant delays in the recruitment of participants and arranging interviews.

We have to remember that my research participants (implementers) based in LMIC settings were busy responding to the Covid-19 crisis, and it was really difficult for me to ask participants, in an ethical way, to give their time for remote interviews! The interviews were conducted late, and they took longer to complete. So, it was important for me to be patient, resilient, and adaptive throughout the global pandemic.

When I conducted the online interviews, I encountered further challenges. For example, internet connectivity; some rural settings did not have strong or stable internet connection. Sometimes the connection would cut off because of power cuts. In such instances, I had to spread out interviews across two sessions or more, which again was not logistically ideal but manageable. In the end, I achieved great progress and a quality research project!

What have been the ethical issues you had to deal with, especially around participant anonymity and data collection?

I had to be mindful, given my research project, the setting, and sensitivity of the subject, where confidentiality and anonymity were extremely important. So, I made sure participant identities were kept anonymous, pseudonyms were used, and the data was secured following the relevant protocols.

Are you planning for your research and findings to have a public engagement and/ or policymaking impact?

Definitely, there will be some kind of public engagement from my side, giving back to the participants and the wider community. I am hoping that my research will have a tangible impact. I have participated at the annual conferences and kept the community updated with my research progress. I will continue to do so – and I hope that my work helps towards building sustainable implementation practices.

In terms of policymaking impact, I think there are various aspects in this research project that can help shape effective policymaking but I will need to think more about that – in practical terms.

Because of the nature of your research has decolonisation featured as major aspect?

I think 'decolonisation' as a feature was inherently embedded in my research and what I wanted to explore. If you think back to when I said that I wanted to capture the variation of implementers' understandings, how this notion of implementation manifests - I wanted to ground it faithfully in *their* experience, voices, identities - and not mine.

As researchers, we have to be very mindful and self-reflexive in the choice of words and concepts we use, and how we define them, because we have this North/South divide.

"For me it was important to show my research participants that I am the novice; they are the ones who are the key subject experts."

Of course, there is a tension between my position as researcher in the Global North and the experiences of my research participants in the Global South. Many implementations are funded at least in part through development cooperation. This context is fraught with power asymmetries.

While I cannot be sure that these did not play a role in my research, I adopted a self-reflexive approach where I tried my best to ensure that I listened carefully when I sought to capture the experiences of the implementers as truly as possible. I do believe my research provided a safe and open platform to allow the implementers to speak and express their concerns - and to do so in a way where they felt heard. I learned a lot from the implementers, and I am grateful for it.

What are your views on open access?

I think open access is an interesting and useful concept because as a researcher, it is important to keep abreast of developments in your field. Often restrictions/ paywalls can be a major obstacle towards making research open and accessible. When you look at the costs of academic journal subscriptions, it becomes clear that the audience who can read articles published in such journals is by and large limited to fellow academics in the Global North.

Moreover, while a PhD may aim at a contribution to academic debate, we also want to achieve impact. We put so much effort into our work, we want to engage with both the academic community as well as practitioners. I hope that open access will therefore help me give back to the organisations and communities that I have worked with throughout my PhD project.

In terms of publication costs, these can be a major obstacle for PGRs who usually don't have funding allocated for publications and are given a limited training budget anyways. I think it is unfair that we are asked to rely on our own funds to make our research accessible – we already do all the hard work! So, I am a big fan of open access and platforms for openly publishing research without having to pay any publication or user access charges.