mCHW: A mobile learning intervention for community health workers

Explanatory notes for deposition of project data in an academic archive

Project outline

The mCHW project (http://www.mchw.org) – a mobile learning intervention for community health workers (CHWs) – represents an ongoing research collaboration between the Institute of Education, University of London (IoE), the University of Oxford and Amref Health Africa to advance the training and supervision of community health volunteers in Kenya, seeking improved access to primary health care for the marginalised communities of Makueni County and the Kibera informal settlement.

CHWs, often called community health volunteers in Kenya, are community members who provide basic medical services. Research consistently evidences their pivotal role in providing equitable health access in support of poverty alleviation by preventing and diagnosing diseases like malaria and HIV, treating minor ailments, referring patients and providing support and care for pregnant women and babies (see, for example, Ofosu-Amaah 1983). However, concerns remain that CHWs’ work is less effective than it could be: ‘there is no longer any question of whether CHWs can be key agents in improving health: the question is how their potential can be realized’ (Kahassy et al. 1998:2; in Oliver et al. 2015).

This research project has worked closely with CHWs and their supervisors to collaboratively design, develop implement and evaluate a mobile learning intervention that better connects CHWs and supervisors. The project’s central research question is: ‘How can the access of poor communities to health care in Kenya be improved by the participatory development of a practice-based mobile learning intervention for community health workers (CHWs) and their supervisors?’

This question has been addressing via the following six objectives:

1. Identify CHWs’ learning needs and their level of access to existing supervisory provision
2. Determine CHWs’ views on how effective existing supervisory structures are for supporting them to set and pursue their own goals
3. Develop processes and mechanisms for CHWs and their supervisors to engage in the participatory design and implementation of a mobile learning intervention to enable CHWs to deliver health services effectively
4. Detail how mobile-based supervision and training can be embedded within the existing structures of the local primary healthcare system so as they can be most effective in supporting the poverty-relevant practices of CHWs in a sustainable and equitable way
5. Determine how Sen’s Capability Approach can be effectively operationalised to study the use of a mobile learning intervention in support of addressing the informational and health access dimensions of poverty alleviation
6. Detail the main implications and lessons learnt for health policy development on the use of mobile interventions for the supervision and training of CHWs in Kenya.
Project methodology

A qualitative case study was chosen as the methodological approach because these are well suited to developing an in-depth understanding of contexts and issues, allowing for the 'social construction of meaning in-situ' (Stark et al. 2005). The emphasis here is on the identification and description of issues as identified and understood by the CHWs and other CTC actors, as a precursor to theory development, claims about prevalence or other generalisations. Such cases can also contribute to theory refinement by generating interpretations, which can be useful in limiting other generalisations or identifying areas of complexity that warrant further study (Yin 2014). Used in such ways, case studies support better informed understandings of factors influencing complex interventions (Craig et al 2008).

The study therefore explored CHWs’ roles and practices, generating an explanation of the day-to-day practices of CHWs in their own words, and allowing an investigation of how CHWs understand their roles, and the ways in which they incorporated the mobile learning intervention into their practices. Specifically, the study invited them to reflect on the challenges they face, and the forms of support that might help them with these. A case study approach was required to explore these open-ended, practitioner-focused questions.

About the data

The project data takes the form of 82 interview transcripts, conducted with community healthcare practitioners working in two research sites in Kenya. We recognise that data should be preserved as far as possible in order to maximize its usefulness to the broader research community. However, we also feel we have a safeguarding responsibility for our research participants. In order to protect the individuals who disclosed this data, and to prevent the potential misrepresentation of their views by other researchers and professionals who would be dealing with the data in a de-contextualised manner, some parts of the data have been screened prior to deposition. The remaining part of this document presents a justification for the way in which this screening has taken place under four categories:

1. A politicised, devolving healthcare system for marginalised communities
2. Safeguarding vulnerable, stigmatised groups
3. Information disclosure in participatory research
4. An on-going research collaboration with on-going ethical commitments

Official British education research guidelines (BERA 2004) suggest that in publishing such data, participants’ identity should not be revealed, unless individuals choose to be identified; that is, participants’ names should be changed, and precise details that could make a setting or participant identifiable should not be given.

Importantly, the fragile and politicised context in which the research has been conducted, and the often vulnerable and marginalised position of the healthcare worker participants and the community members they support, mean that some of the data collected as part of this project is both sensitive and personal. According to the UK’s Data Protection Act (1998), ‘sensitive personal data’ includes personal data relating to the data subject's racial or ethnic origin; political opinions; religious beliefs or other beliefs of a similar nature; or physical or mental health or condition.
1. *A politicised, devolving healthcare system for marginalised communities*

Two regions in Kenya constitute the sites for this study. The first is a semi-arid rural county in Eastern Kenya which experiences long droughts, resulting in high poverty levels. The second site is an informal urban settlement in Nairobi, also characterised by high levels of poverty, insecurity and inadequate access to basic social services. In both regions, healthcare provision is extremely limited, poorly resourced and difficult to access, with deteriorating maternal and infant mortality rates, making the extended reach of CHWs critically important (see Oliver et al. 2015).

Prompted by the challenges of health service delivery across Kenya, and in specific response to deteriorating maternal and infant mortality rates, in 2006, the Ministry of Health introduced a radical policy of health service decentralisation and devised a new health strategy, the *Kenyan Community Health Strategy* (ibid.), which placed emphasis on the role of close-to-community (CTC) providers of primary healthcare.

This research study was conducted with CTC providers working directly under the community health strategy: The voluntary CHWs, the community health extension workers (CHEWs), who serve as supervisors to the CHWs, and the community health committees who manage them.

The research participants have thus been working in the context of a politicised, devolving healthcare system amongst poorly resourced, marginalized and close-knit communities. Given that scholars have identified a history of censorship and a lack of freedom of expression in Kenya (see for example Uganga 2011), political opinions, linked to individuals and/or organisations could be perceived to place a research participant or partner organisation at risk. Individuals who agreed to participate in the research did so in the understanding that the research team would be able to assure anonymity. However, because the broad locations for the research have been revealed, and there are a limited number of individuals carrying out the denoted roles in these areas, it might still be possible to identify individual responses from the data after a process of straightforward anonymisation. We thus err on the side of caution.

We also recognise that potential sources of bias in the data render some parts less useful to broader research audiences. For example, qualitative descriptions of bad experiences of the Kenyan health system might have validity within the context of this research project but would represent biased and partial accounts for those with an alternative research focus. Thus, it is important that expressions of political opinion within the data, particularly related to broader socio-economic issues of funding and resourcing of the healthcare system have been removed from the shared project data.

2. *Safeguarding vulnerable, stigmatised groups*

Vulnerable groups have often been defined in research as groups of people presumed to be more likely than others to be misled, mistreated, or otherwise taken advantage of as participants (Levine *et al.* 2004). There is, therefore, an assumed duty for researchers, review committees, and regulators to provide special protections for them (ibid.). In the context of this study, the work of CHWs and their colleagues necessarily involves engagement with some of the most vulnerable community members, including those experiencing sexual assault and domestic violence, those with HIV and other serious health conditions, and those with disabilities. Indeed, researchers have identified underlying ethnic and religious beliefs and superstitions, particularly surrounding the issue of disability that can
serve to exacerbate the stigmatisation of these vulnerable groups (see, for example, Ingstad and Grut 2007).

This project has identified children with disabilities and their parents as a group in need of continuing support, and has developed specific interventions that seek to improve their health and participation in society. This work is on-going. There is thus a particular imperative to protect the identity of such vulnerable families, including their critiques of care; and details of their circumstances, and the healthcare workers who are supporting them.

According to UK guidance (see Working together to Safeguard Children 2013), personal information about children and families held by professionals is subject to a duty of confidence. Whilst the law permits the disclosure of confidential information between professionals in order to safeguard a child, such information should normally not be disclosed without the consent of the subject and should not be disclosed to third parties. As part of the data collection process in the project, and in the context of using the mobile intervention in their practice, community healthcare workers discuss specific case details of vulnerable and stigmatised community members and express opinions about the broader social, political and economic circumstances in which they operate. However, such details place vulnerable families and their support workers, who live and work in small and close-knit communities, at risk of being identified even after names and other identification have been removed. It is for these reasons that the research team has an ethical imperative to exclude all explicit references to vulnerable groups, and particularly to children with disabilities, referred to in project data placed in the academic archive. Furthermore, we argue that such references should also be removed to avoid any form of future controversial representation, albeit unintentional within academic literature, due to the detrimental impact this could have at both local and ministerial level.

3. Information disclosure in participatory research

This study followed the ethical guidelines of the British Educational Research Association and of Amref Health Africa, both of which required informed consent, guarantees of confidentiality and anonymity for participants, and the right of participants to withdraw and have their data removed (Oliver et al. 2015). Indeed, in participatory and exploratory research, such as this, the notion of ‘informed consent’ can be problematic, as the precise course to be taken by the research is unpredictable (see Flewitt 2005). In particular, the trusting relationships built up during a longitudinal and collaborative project can result in the researcher being privy to details of issues that should not be disclosed (ibid.). In some cases, qualitative interview data that has been recorded in this study is beyond the focus of the study’s research questions, and references unrelated initiatives or unconnected organisations. The research team has an ethical responsibility to remove such references in order to protect the research participants and the initiatives and organisations to which they refer.

4. An ongoing research collaboration with ongoing ethical commitments

It is also important to emphasise that this research data has been collected as part of an ongoing collaboration between a number of partner organizations. This partnership includes Amref Health Africa, Africa’s largest International Health NGO. Amref Health Africa is an African-based organisation that aims to strengthen the capacity and capability of health and health-related professionals and institutions in
Africa through training, research, health care provision and advocacy. It relies on an extended network of relations with governments, international donors and the private sector to conduct its work. The research team thus has an ongoing ethical commitment to partner organisations, and these partnerships should not be put at risk by the disclosure of sensitive project data, because of concerns about the way in which data might be interpreted.

The above discussion has set out what we understand to be a knowingly cautious approach, in order to protect the security and integrity of research participants, to ensure risk of harmful disclosure, and to make sure the data is not misinterpreted within the academic literature. Taking this into accounts, the data have thus been screened prior to deposition into the academic data archive according to the following criteria.

**Criteria for exclusion of sensitive personal data in the academic data archive**

a. All names of individuals and other stated identifiers have been removed.

b. All references to specific organisations and their practices will be removed. Only the following organisations will be named in project data:
   - Amref Health Africa
   - Ministry of Health

c. While the general regions in which research has been conducted (i.e. Kibera; Makueni) are named, data that refers to more specific places or locations has been removed.

d. All data in which individuals express opinions about sensitive issues related to the broader social, economic or political context, including the national and local health system will be removed. While names and identifies of individuals have already been removed in (a), data covered by (d) are subjective perspectives on the system as a whole that could be linked back to a community of individuals.

e. Data referring to, or collected from, mothers of children with disabilities, and other vulnerable groups, has been excluded.

f. Data referring to other projects or initiatives which are not directly relevant to the project’s research questions will be removed.

In order to make decisions on data exclusions as transparent as possible, each piece of excluded data in an interview transcript (delineated by blanked out text) is accompanied by the associated exclusion criteria (i.e. a, b, c…etc.).

The data that remain thus primarily focus on the following:

- Participants’ engagement with and discussion of the mobile application, and they way it has been employed in and has impacted on their practice, in particular (in line with the core objectives of the project) data on supervision and training practices
- The nature of the design of the mobile application
- The use of Whatsapp as a tool to support the use of the application
We believe that this set of criteria and accompanying rationale presents a framework to select ethically appropriate data that is of most use to the wider research community.
References


OLIVER, Martin et al. (2015) What do community health workers have to say about their work, and how can this inform improved programme design? A case study with CHWs within Kenya. Global Health Action, [S.I.], v. 8, may. 2015.


UK Government (1998) Data Protection Act