

Community engagement for biobanking research: perspectives from Africa

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Introduction

Recent trends in research governance have seen a review of the role that communities should play, particularly in emerging and innovative research. International guidelines from the Council for International Organisation of Medical Science, the Declaration of Helsinki, the Nuffield Council on Bioethics and the National Institute of Allergy and Infectious Diseases all stress the importance of early community engagement to ascertain their views on the research and to develop culturally appropriate policies related to the study. Although there are few medical risks associated with biobanking research, a fresh wave of ethical dilemmas related to psycho-social risks must be addressed. Issues surrounding consent, storage of samples for future use, exportation of samples as well as the risk of individual and community genetic discrimination and stigmatisation are real concerns that must be assessed. Within Africa, due to the cultural significance of samples, the collection, storage and reuse of samples raise unique concerns for many communities. In some African countries, hair is a symbol of strength and maturity and the cutting of hair is associated with a significant event. However there is evidence that if participants are given enough information about what their sample will be used for, they might be more willing to donate hair samples. There is a real need to determine the impact that these cultural beliefs may have on biobanking research in Africa. Community engagement (CE), a process that involves the researchers working with local groups or communities to achieve a shared goal, can achieve this. Through discussions with the community, researchers can ascertain the local cultures and beliefs that may influence their perception of biobanking research. Drawing on experiences from Africa, this paper will discuss the importance of community engagement for biobanking research and its challenges.

An understanding of community engagement

Good CE can reap benefits at the individual, community and national level. Without adequate exploration of local views on the research, governance policies and frameworks will not be informed by the community. CE has its origins in Paulo Freire's work that encourages the education of communities to empower them to act as agents of change. For the individual, it will likely lead to a more informed population as any engagement with the community is likely to require a discussion and explanation of the research. It is an opportunity for potential participants to be informed and educated about the research as well as raise questions or concerns that they may have.

In medical research, CE emerged with the advent of HIV research, particularly during the activism around access to HIV treatment in the 1980s. The importance of CE was starkly visible during the Tenofovir trials that tested the safety and efficacy of oral pre-exposure prophylaxis to prevent HIV transmission. Trials were stopped in Cambodia, Cameroon, Nigeria and Thailand due in part to inadequate CE that led to miscommunication and misunderstanding. Consequently, it was recommended that communities must be engaged with to ensure basic scientific literacy, representatives must be involved in the research and the engagement must be early and sustained.

The emergence of biobanking research in Africa is occurring after a history of parachute research whereby biological samples were regularly exported from Africa for use in other countries without any regard for developing local capacity. The recent announcement by the South African Health insurer Discovery Health that it will offer genetic testing at a reduced rate in partnership with the US firm Human Longevity Inc (HLI) and in return the samples and data will be exported to HLI in the US, demonstrates that this era of parachute research is not confined to the past. It is thus unsurprising that the use, reuse and exportation of biological samples elicit strong views from the community, with many participants having clear preferences on future use.

The importance of the community structure permeates traditional African life and is best conceptualised by the principle of *ubuntu* that sees the community as one entity in which the value and dignity of a person is manifested through their interactions with others. Similar to the communitarian view of bioethics, the individual is embedded in the social structure of the community where peace, harmony and mutual respect are the social values and the focus is on the promotion of the common good. Biobanking research can be seen as complementary to *ubuntu* as the public donate samples for research that will benefit the wider population.

However the community structure must be respected and it may be necessary to first discuss the research with community leaders, such as in Nigeria where genetic research cannot be done without first approaching the chief, his council and community leaders. Failure to engage and respect these community structures would be seen as a sign of disrespect and may discourage the community from taking part. Early engagement with these communities can help identify the cultural specific concerns that the community will have with the research. This can enable the community and its leaders to feed into the research design to ensure that the genomic research is sensitive to the cultural values and beliefs of the community.

Challenges with community engagement

Although important, CE is challenging. Discussions on CE often lack a definition of the community creating uncertainty as to who the researchers should be engaging with. Different groups have offered differing definitions. The HIV Prevention Trials Network (HPTN) defines a community as a “group of people who will participate in, or are likely to be affected by or have an influence on the conduct of the research” and the Good Participatory Practice (GPP) Guidelines for HIV prevention research define community as “separate and overlapping groups of people who are infected and affected by HIV in various ways suggesting a shared identity for members”. The definition will vary according to the type and structure of the study, but it is an issue that should be determined in advance of the commencement of the research and procurement of samples.

Once the community is identified, they must be educated to develop a basic understanding of key concepts and terms. Due to the technical nature of the research, complicated by the fact that many terms such as gene do not have a translation in many African languages, this may be challenging but not impossible. By framing the topic in a way that the community will understand, such as by focusing on the inheritability of diseases rather than discussing the molecular biology of genes, the community can understand the concept of genomic and biobanking research.

Equally important is that the research team understands the community and its culture. However, despite the acceptance of CE as an ethical best practice in medical research, there is very little

empirical research on CE in Africa. Not only does this represent a lack of understanding of the community's views on biobanking research on the many pertinent issues such as broad consent, storage of samples for future reuse, exportation of samples as well as benefit sharing and return of results, but a lack of empirical research has also led to a dearth in evidence of the processes of CE that work in practice. Allied to this is the lack of CE guidance on genomic research for Africa, with the recent H3Africa policy document on CE one notable exception.

Community Advisory Boards (CABs) are one mechanism for CE that became popular during HIV research. They are generally composed of community leaders and other members of the community who advise on the informed consent process, the research protocol and any particular concerns of the community. However the CAB can become politicised and often do not represent those they are intended to serve. Other more informal processes such as town hall meetings or community forums can be effective as they are directed at the community rather than representatives. The exact process will vary according to the targeted community, but once the community is identified, the process or approach to CE that will best engage with them must be adopted.

Conclusion

As demonstrated by the Tenofovir trials, a failure to adequately engage with the community may come at considerable scientific cost. Early and sustained CE can prevent this. Perceptions about biobanking research need to be understood and the cultural context in which the biobank is set must be known. Cultural beliefs can challenge the development of biobanking research, but should not be seen to be a barrier. Through understanding and educating the community about the research in a manner that respects these beliefs, good relationships can be established between the biobank and the community. There is no one size fits all and the structure and process will depend upon the individual community in which the biobank is based. However as the success of a biobank will often depend upon the support of the community, it is an important and necessary step in biobanking research.

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