

“It’s all about trust”

Qualitative Research at the SJCH: Understand community perceptions on the storage of biological samples for biomedical research in Liberia:

For decades, research has flourished in Africa and large volumes of biological samples and data have been transferred to developed countries for storage in biobanks and uncertain secondary use.

Biological sample and data transfer within and out of Africa is still steeped in controversy in Liberia with the H3Africa project now aiming to establish biobanks in Africa. It is essential that there are ethical and legal governance structures in place to oversee the operation of these biobanks.

In early 2016, the Barcelona Institute for Global Health (ISGlobal) established a research collaboration in Liberia with the Saint Joseph’s Catholic Hospital (SJCH) and the Liberia Medicines and Health Products Regulatory Authority (LMHRA). With funding from the European and Developing Countries Clinical Trials Partnership, two ISGlobal-led projects started^{1,2}. Both aiming at building hospital and regulatory authority staff capacities to conduct research on infectious diseases. During the 2014-16 Ebola outbreak, many patients with infectious diseases other than Ebola (i.e. malaria) saw neglected their healthcare needs. Capitalizing on ISGlobal expertise on basic and applied research for the development of new diagnostic and preventive tools for malaria prevention and elimination, special emphasis has been placed in the frame of these two projects in building local capacities to support malaria research in Liberia.

In this context, the IGORCADIA team has engaged to design and conduct a qualitative research in the SJCH in order to to understand community perceptions, contextual barriers and opportunities on the storage of biological samples for biomedical research in Liberia. This component of the project has been achieved through the conduct of semi-structured interview and focus group discussions conducted among individuals with fever (temperature $\geq 37.5^{\circ}\text{C}$) or history of fever during the last week, pregnant women at their first antenatal visit, LMHRA stakeholders, Community Advisory Board, Medical, Nursing and Laboratory staff from the Saint Joseph Catholic Hospital and hemo biobanking group.

The ethics issues below have been drawn from the qualitative inquiry findings:

- Culturally, any activity involving blood is of a sensitive nature. Liberians are used to giving blood in clinical settings only. Exposure to Ebola vaccine trials in Monrovia made some people believe that specimens were being collected from trial subjects with illicit purposes. How the population

will interpret that blood samples are requested for unspecified research is something that deserves thorough exploration prior to setting a Biobank at the SJCH.

- The communities are aware that, during the Ebola epidemics, there were various initiatives that involved collection of specimens that were shipped abroad for research or public health purposes (i.e. Ebola vaccine trials, Ebola Treatment Centres, Plasmapheresis Unit). Unless governance and communication is improved, communities invited to assent to Biobanking in Liberia may perceive that the destination and usage of exported samples cannot be controlled by local research staff and, hence, that fair conditions for storage, retrieval, tracking and disposal of specimens cannot be guaranteed to the study participants.
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- Due to difficulties to access free-of-charge healthcare services, there is a risk that therapeutic misconception may motivate some people consent partake in Biobanking research. If the Biobank is located in a hospital, clear information on risks, benefits and compensation needs be provided during the consent process to all approached individuals to avoid undue inducement to participate.
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- There is widespread fear that samples collected in clinical and research settings may be tested for stigmatizing diseases (i.e. HIV) against the person's will. This fear may make broad consent inappropriate as people may want to know the exact intended use of their samples and may want be reassured that research staff will not perform certain diagnostics tests.
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- There is a generalized lack of trust in the healthcare and research establishment. Lack of trust will compromise autonomous informed decisions to participate in biobanking research. Methods to increase community members' trustworthiness need be thoroughly discussed with the C.A.B. However, some individuals may have also stopped trusting their traditional authorities because some traditional leaders are –allegedly– collaborating with the Ministry of Internal Affairs. Innovative individual-targeted approaches to improve trustworthiness need be created and implemented ahead of the creation of a biobank at the SJCH.
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- In relation with the export of specimens, a widespread rumour is that researchers monetize them abroad and manage to raise revenue that is never shared with the researched communities. Sustainability of a biobank in Liberia could largely depend on cost recovery of its running costs. A pay-per-service system may accentuate this rumour. Seemingly, as per out study participants' narratives, some community members may not oppose to the commercialization of their samples should a benefit sharing plan engaging them and their communities be in place.



BIOBANKING IN HEALTH RESEARCH



It's all about trust!

1. What are BioBanks?

Biological sample storage or biobanks are **repositories that accept, process, store and distribute bio specimens** and associated data for use in research and sometimes clinical care.

(De Souza, 2013)



2. Why is Biobanking important for future researches?

Biobanking has the potential to support scientists, increase scientific efficiency, and **improve the quality and value of research, particularly in low-income countries such as Liberia.**

*** Epidemic diseases remain a serious threat to the world and the timely sharing of data and biobank specimens is likely to be an essential part of outbreak responses.**



3. What are the ethical challenges?

Cultural and religious beliefs



Corruption/ Commercialization of specimens



Custodianship. Ownership



Trust



Rumors and fears



Attitudes of researchers



Privacy and confidentiality

5. Role of EDCTP-funded IGORCADIA* project:

Building capacities and promoting **long-term sustainable research and collaborations** to generate, share and analyse high-quality data-sets in Liberia settings.



4. Key actions to promote biobanking in Liberia:

- ⚙️ **Respect individual participants**
- ⚙️ **Build and maintain public trust**
- ⚙️ **Engage communities**
- ⚙️ **Ensure privacy and confidentiality**
- ⚙️ **Identify discrimination and marginalisation risks**
- ⚙️ **Ensure that sharing of data and samples benefit all - participants, communities, researchers.**
- ⚙️ **Advance good governance**



6. Importance of a harmonised biobanking:



Better control



Increased quality and cost efficiency



Enhanced credibility



Support to underdeveloped countries

ARE YOU READY TO GET INVOLVED?

Find more information online at:

WWW.IGORCADIA.ORG

Ask at your local clinic how you can participate

