

ARTICLE

Biobanking in the subcontinent: exploring concerns

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Abstract

Biobanking is an important tool for biomedical research. However, it raises a variety of ethical issues, which are compounded in the developing world. This paper is based on data from three sources on the ethical issues associated with biobanking, including a mixed method pilot study conducted with students in Karachi, Pakistan, a workshop in Karachi, and another workshop held in Bengaluru, India.

Findings from these sources reveal a unanimous lack of clarity about what constitutes a biobank. While informed consent was deemed necessary for storage of materials, participants were unsure of how this could be achieved for samples stored indefinitely for future research. Although study participants showed limited understanding of genetic research, concerns were raised in the Karachi workshop. A majority of survey participants found it acceptable to transfer biospecimens across borders, but possibility of misuse was highlighted in both workshops. This paper reveals ambiguities with respect to ethical challenges of biobanking, indicating the need for further discourse.

Introduction

Recent years have seen biobanking emerge as a new industry feeding clinical and epidemiological research (1). While its utility, economic sustainability and long-term benefits are being debated, biobanking has already been termed as one of the top ten ideas changing the world (2). However, what exactly this concept entails remains elusive even after formal biobanks have become functional across the world (3). One statement that captures the essence of biobanking describes it as:

Any depository of biological samples and related derivatives, with or without a predefined period of storage, based on prospective collection or made up of previously collected material, obtained for healthcare purposes, public health

monitoring programmes, or for research, and that includes identified, identifiable, anonymised or anonymous samples.(4).

The definition covers different aspects of biobanking including samples collected for therapy, diagnosis as well as for research (5).

While there is much literature acknowledging the potential for it to do "collective good", biobanking also raises a host of legal and ethical issues that need to be understood and negotiated (4,6). Obtaining an informed consent for indefinite storage and undetermined future use in research challenges the very foundation of classic consent. Performing genetic research, which can potentially probe into information well beyond the individual donor, years into the future, complicates biobanking further. Revelation of unexpected genomic information may lead to serious consequences, as noted in the Havasupai Tribe Diabetes Project in 2010(7). Cross-border collaborations between biobanks, especially when biomaterials are transferred from developing countries to developed nations may also raise issues such as ownership of materials and data. This becomes even more contentious when populations from developing nations become the source of biomaterials, which are flown overseas. The lack of clarity surrounding these concepts reflects the diversity of opinions (8,9).

Given the paucity of local research and literature within the context of developing countries, the authors conducted a pilot study in Pakistan to understand the perceptions on the storage and use of biological material for research purposes. This pilot focused on students of a medical college and of a non-medical university. This paper analyses the findings of the study with deliberations emerging from two other sources that addressed similar issues.

Coincidental with the pilot study, a two-day workshop was organised by the authors' institution in March 2016 at Karachi to explore the perceptions of different stakeholders on ethical issues emerging from biobanking. Additionally, the April issue of the *Indian Journal of Medical Ethics* carried a report on a two-hour long workshop with a similar agenda that was held in 2014 in Bengaluru, India during the 5th National Bioethics Conference (10). Though the Bengaluru workshop was much shorter precluding an in-depth analysis of several issues, both the Karachi workshop and the Bengaluru workshop had several significantly overlapping themes of deliberation with the findings of the pilot study.

This paper, while focusing on specific questions such as challenges to informed consent, issues related to genetic

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research and transfer of biospecimens across borders, brings together some of the major ethical themes that emerged from these three activities, and provides a rare glimpse into the perceptions of an educated yet diverse community regarding biobanking in the context of the subcontinent.

Methodology

Pilot Study

Our pilot study employed a mixed method approach at two university-level educational institutes (one medical institute and one non-medical institute) in Karachi over a period of five months beginning October 2015. Ethical Review Committee clearances and necessary permissions were obtained from relevant departments of both the institutes.

For the quantitative arm, a questionnaire was used, which contained a series of open-ended and close-ended questions. The close-ended questions were mainly categorical with "Yes," "No" or "Don't know" options whereas the open-ended questions looked into the reasoning of the options chosen. The questionnaire was randomly administered to undergraduate and graduate students at both the institutes. The students from the non-medical institute were from diverse educational backgrounds, ranging from social, media, management, and computer sciences among others. Since this was a pilot study, we restricted the number of questionnaires to 100 per institute. Seventy-six men and 124 women participated in the survey.

Additionally, a qualitative arm was used to gain a deeper understanding of the reasons behind the respondents' positions regarding the various questions. We undertook two focus group discussions (FGDs) (one in each institute) and six in-depth interviews (IDIs) per institute. Purposive sampling was done for IDIs and FGDs—students were asked after they had returned the filled questionnaire to participate in the IDI or FGD and those who agreed to participate were then enrolled for the qualitative arm of the study. FGDs in the medical institute had an equal participation of both men and women, whereas the one in the non-medical institute consisted entirely of women. Five out of six interviewees in both the institutes were women. The dominance of women in both the medical and non-medical groups can be explained by the fact that women are in the majority of the student population in medical colleges in Pakistan (11). The FGD in the non-medical group was held with students from social sciences backgrounds, which according to one author is dominated by women.

All the IDIs and FGDs were recorded digitally by authors of the study and later transcribed. All identifiers were removed from the transcripts. Each interview took 15 to 20 minutes whereas the FGDs lasted for 30 minutes.

The quantitative data was entered into Microsoft Excel 2007 and frequencies calculated for the responses. A thematic analysis centering on main ethical issues was conducted on the qualitative data. The findings of both qualitative and quantitative data were blended for analysis.

Workshop at the Centre of Biomedical Ethics and Culture

A two-day workshop, in collaboration with the University of Copenhagen, Denmark was held at the Centre of Biomedical Ethics and Culture (CBEC)-SIUT, Karachi, Pakistan in March 2016. This was the first workshop on this topic in Pakistan with the objective of deliberating upon ethical issues of biobanking, including biomaterials being transferred across national boundaries, for storage and research overseas. Forty stakeholders from across the country were invited to participate. Eighteen participants had a background in bioethics, eight were researchers, and two participants were managing biobanks in Karachi whereas one was a manager of a contract research organisation. There were four molecular biologists, two haematologists, two pathologists and two clinical geneticists. Additionally, there were two participants who belonged to Obstetrics and Gynaecology and were working with artificial reproductive technology.

The workshop included eight talks of 15 minutes each, followed by 90 minutes of discussion, where a panel of pre-assigned discussants raised questions for the speaker. After discussing the questions raised by the panel, the floor was opened to questions from the audience. This format gave participants an opportunity to discuss issues raised by each talk in sufficient detail.

Results and discussion

Table 1 summarises the findings from the three arms of the paper.

Definition of a biobank and biobanking

The survey participants were provided a simple working definition of a biobank as a specialised cold storage where samples are stored for subsequent use in research. However, participants' opinions on what constitutes a biobank were explored in detail through FGDs and IDIs. Participants of the pilot study, from both the medical and non-medical groups, appeared largely ignorant of what these terms meant, and had not given much thought to the concept of biobanking either.

However, during the Karachi workshop, there was much deliberation upon the definition of a biobank, and what constitutes a biobank. The scientists among the group were more focused on the technicalities, particularly with regard to the size of the storage facility, and the quality of storage facilities. This was also reflected in the workshop in India—interestingly those involved with diagnostics and other technical matters, expressed concerns regarding conditions for storage and similar quality issues. Different arguments were raised which included whether the purpose at the time of collection mattered— if the biomaterial was obtained for diagnostic purpose and leftover samples later stored for research was sufficient reason for the facility to be declared a biobank or whether it was necessary for the biospecimen to be obtained specifically for the purpose of storing it in a biobank. Debates regarding whether a patients' leftover diagnostic samples qualify to be regarded as biobanked samples are also

Table 1
Comparison of responses on the themes explored in the three events

Themes explored	Pilot study		Karachi workshop (n=40, duration=2 days)	Bengaluru workshop (n=35, duration=2 hour)
	Medical students (n=100)	Non-medical students (n=100)		
<i>Definition of a biobank</i>	Limited understanding	Limited understanding	Different opinions	Different opinions
<i>Necessity of informed consent for storage</i>	Majority considered it necessary	Majority considered it necessary	Considered absolutely necessary	Necessary but may become mere "formality"
	More concerns expressed	Fewer concerns expressed		
<i>Type of consent for research</i>	Majority opted for specific consent	Majority opted for specific consent	Blanket consent considered problematic; specific consent considered a hassle; no consensus	Not discussed
	Greater concerns raised with blanket consent	More accepting of blanket consent		
<i>Understanding about genetic research</i>	Limited understanding	Limited understanding	Greater understanding but concerns raised; not discussed in detail	Not discussed
<i>Genetic research on biobanked samples</i>	Majority found it favourable; more concerns raised	Majority found it favorable; fewer concerns raised	Emphasis on lack of oversight in Pakistan	Not discussed
<i>Transfer of biospecimens across borders</i>	Majority found it acceptable; concerns raised	Majority found it acceptable; concerns raised	Concerns expressed	Concerns expressed

evident in the current literature (12). There was also ambiguity on what is a bio repository as opposed to a biobank, and no agreement was reached on this aspect. Overall, the discussion on this subject corresponded with the published literature where there is largely no consensus among the scientific community about what constitutes a biobank (3).

It is also important to understand that despite lack of consensus about what constitutes a biobank even among the scientific community, biobanks are still operating in the developing world. This lack of clarity perhaps highlights the ambiguities surrounding the concept of biobanking, which may lead to confusion. This has important implications, since the development of guidelines and researchers' adherence to these guidelines is closely linked to how biobanks are envisioned. It therefore becomes important to arrive at a consensus regarding the nature, role and governance mechanisms regarding biobanking.

Necessity of informed consent

Informed consent was discussed, both in the Karachi workshop and the pilot study, on two aspects: consent for long-term storage of biosamples and consent concerning research on those banked samples.

Specifically for long-term storage of biosamples, among the pilot study respondents, 156 of 200 deemed informed consent necessary for their samples to be stored in a biobank. This was because they considered these samples to be part of their body and hence their property. As one respondent stated, "The fact is that you should know about it because it's your personal thing." In addition, one respondent from the medical group ascribed the importance of informed consent to potential outcomes that may arise: "Giving people the choice will alleviate any potential controversy that may arise."

Similarly, the entire group of the Karachi workshop was in agreement that permission is required before the storage of samples. Although the Bengaluru workshop brought about similar viewpoints regarding the necessity of informed consent, there were mixed opinions about whether informed consent is essential in all situations, especially within the context of a developing country like India. These opinions mirrored some of the viewpoints raised by respondents in our pilot study.

There were 37 respondents in our pilot study who deemed informed consent irrelevant prior to storage in a biobank. Respondents in this small cohort included students from both medical and non-medical institutes. One of the primary reasons for the irrelevance of consent was captured in the following statement by a medical student:

They wouldn't know what you're talking about, right. They might just end up over-thinking...someone who doesn't have the knowledge about biobanking will not understand the concept of biobanking.

Similar concerns were also raised by the participants of the Bengaluru workshop, arguing that the culture of a particular country may also influence the process of informed consent. The procedure of informed consent and the circumstances in which it is obtained may render the process a "formality", as raised in the Bengaluru workshop. This reflects a widely held perspective that participants' illiteracy may limit their ability to fully comprehend the concept, rendering this process procedural and therefore redundant. However, such assumptions are ethically problematic and expose the participant to possible exploitation. Any perceived lack of ability to adequately comprehend the issue increases the obligation on the researcher to make more effort to ensure proper understanding. This was also the conclusion that emerged from the Karachi workshop.

Non-medical respondents from our pilot study cited their trust in the medical community as the main reason for allowing their sample to be stored in a biobank without their permission. The credibility of the institution serving as a biobank also emerged as one of the reasons. The theme of having trust in the scientific community is elaborated further, while considering consent for research on these stored samples.

With respect to obtaining an informed consent for research on stored biological sample, the majority of participants were in agreement that it is an ethical requirement– a right of the participant that ought not to be violated. Both Bengaluru and Karachi workshops were in agreement on this issue.

Moving on to the role of informed consent for research on stored samples, a major debate regarding samples from biobanks is whether consent should be taken only once at the time of storage to cover all subsequent usage of the sample (blanket consent), or specific consent be required each time the sample is being used for a new research. The former option, a one-time blanket consent, involves much less hassle, making the job of the researcher easy as compared to approaching the donor each time his or her samples are involved in any new research, which in addition to being cumbersome, may not even be practical. The pros and cons of blanket consent have been discussed extensively in the literature(13,14). Other forms of consent pertaining specifically to biobanking, such as limited consent and tiered consent, have also been discussed in the literature, but were not explored during our pilot study, which focused only on blanket consent and specific consent for the sake of simplicity. The Bengaluru workshop did not delve into the specifics of informed consent whereas the Karachi workshop discussed different forms of consent.

In the pilot study, 109 of the 200 respondents wanted to be asked their consent each and every time their sample was used. This reflects a greater awareness among the medical group as compared to the non-medical group. Regarding ethical issues in research, a student from the medical group said:

I may be morally and ethically opposed to the purpose of research. Or I might be opposed to someone who is using the sample, for example, a pharmaceutical company might be using it, then I may be against it.” Another respondent said: *“My blood is my property. It can only be used for the purpose for which it was intended.”*

They also alluded to some of the concerns regarding misuse of biospecimens. This mirrors the findings of some previous studies conducted in other countries (8). This difference in opinion has an important ethical implication– individuals unfamiliar with scientific research (as the non-medical scientific population in our pilot study) may not fully understand what it means to participate in a research. In such populations, the researcher will need to perhaps apply more innovative and easier-to-comprehend approaches for raising awareness among the potential study participants.

The participants in the Karachi workshop displayed mixed opinions with respect to blanket consent, with most participants expressing their discomfort with this type of consent where information was limited or non-existent. One of the Karachi conference speakers during his formal talk on this issue however supported the concept of blanket consent, opining that the idea was not morally problematic and that scientists may actually be acting paternalistically if they assume that the general population will not prefer blanket consent. However, keeping Pakistan’s situation into consideration, the consensus that emerged from the workshop was that the country may not yet be ready for blanket consent as it might engender a feeling of mistrust and expose vulnerable populations to exploitation. This finding is particularly relevant to those drawing up guidelines and regulations governing biobanks in countries like Pakistan. Blanket consent may be more appealing to researchers but greater caution needs to be exercised since it is open to misuse and may erode the trust of the participants in the scientific community.

Interestingly, while the majority of the pilot study respondents did not support the notion of blanket consent, 76 of the 200 respondents did express their comfort with this notion. One respondent from the group captured the sentiments of others by commenting: “I am all for research, [since] the sample is of no use to me.” Respondents believed that blanket consent was acceptable because they regarded the sample useless and a “waste”. A similar point was raised in the Bengaluru workshop during the discussion against informed consent– the material may be considered a waste, and thus would hold no utility for the donor. These opinions represent a general lack of information regarding biological materials and the potential uses to which such discarded materials may be put to. This finding would not come as a surprise but nevertheless underlies the vulnerability of the general population for exploitation, which must be paid due consideration.

Others said that they would not seek re-consent for their samples because they had trust in medical professionals: “Physicians, scientists, and researchers know better.” This cohort of participants believed that since a credible organisation was obtaining their samples, they trusted their decisions regarding the future use of their samples, thus requiring no re-consent. This underlines the importance of the credibility of an organisation in the eyes of the public. This opinion was particularly dominant in the non-medical student population as opposed to the medical population, who seemed more skeptical perhaps because of their greater awareness about the norms of the scientific community.

The notion of trust was also discussed in the Karachi workshop. It was speculated that perhaps scientists working in communities for prolonged periods, by virtue of their interaction with community members, engender trust for themselves and for the scientific community. This was also raised briefly in the Bengaluru workshop, when on the issue of consent, it was stated that the physician-researcher

may be considered “demigod”, illustrating the extent and nature of trust imposed on them. This trust in the scientific community however may leave communities open to exploitation, as raised in the Pakistani workshop. Other studies, both from developing and industrialised countries have reported trust in the scientific community as one of the reasons for blanket consent (13,15).

Another major reason for not desiring re-consent was the hassle factor among the respondents. When asked whether she would wish to be approached each time her stored biosample was used in a new research, she responded: “Oh God no! That would be annoying. I don’t want 15 phone calls. This is an inconvenience and a hassle!” In addition, the medical group in our pilot study pointed towards another challenge: “Re-consent may cause apprehensions among lay people... ‘why is he asking now, what is it that he can find in my sample?’...”

Participants in the Karachi workshop also deliberated upon the practicality and feasibility of re-consent. However, different individuals provided varying viewpoints, posing arguments similar to those provided by pilot study participants. In fact, these views are in harmony with the previous literature on the subject, which emphasizes that re-consent is time-consuming and anxiety-inducing for research participants, as covered by a systematic review analysing 154 studies on the topic until 2010(16).

Another aspect of consent with regard to biobanked samples is that of tiered consent, which was discussed extensively in the Karachi workshop, which may perhaps serve as a middle ground between specific and blanket consent. This type of consent may provide some control to research participants to their banked samples (13). The pilot study did not seek opinions into this type of consent and the Bengaluru workshop also did not report this aspect of consent.

Genetic research on biobanked samples

Genetic research on biobanked samples is an important area that was explored in both the pilot study and the Karachi workshop.

In our pilot, 117 respondents checked the box asking them whether they understood what was meant by genetic research, but when asked to explain their reasoning during the FGDs and IDIs, it was apparent that even this well-educated cohort included in the study did not fully understand the implications of genetic versus non genetic research. Only a minority of the respondents understood the implications. For instance, a few participants in the pilot study expressed unguarded optimism regarding the potential of genetic research and its benefits. One respondent stated: “It would be helpful for future generations” and “It would end up benefiting more people.” There were only a few, mainly from the medical student population, who understood that genetic information may lead to privacy issues: “It can identify and can’t lie. It may disturb people’s lives.” The difference in opinions among the medical and the non-medical student population could potentially be as a result of the former group’s intimate

exposure to the inner workings of the scientific community and the scandals that often emerge. It is apparent that the general population may not possess such information and therefore may not have a heightened level of caution.

Stigmatisation of certain communities was also presented as one of the concerns towards genetic research, and largely came from an FGD with social science students. In addition, while individuals claimed to know about genetic research (as indicated by their agreement on the survey form), they were unable to answer the open-ended question which probed into the reasoning of their response. Nevertheless, the non-medical community in the pilot study showed faith in scientific community as exemplified by the following statement: “The people in this field know better. They would hopefully do no harm.” This is worrisome because of lack of regulatory oversight in Pakistan. Genetic research was also identified as a complicated issue in the Pakistani workshop. The Bengaluru workshop did not pick up this issue.

Transfer of biospecimens across borders

In Pakistan, as across the developing world, biomaterials are being routinely transferred from local labs to labs in the developed world so that research opportunities available there can be applied on local samples. Such transfers occur on a regular basis and are deemed necessary for many aspects of research (17).

Our pilot study also enquired into this aspect since it is important to understand perceptions of the public. More than 50% of our respondents found it acceptable for materials to be transferred abroad for research purposes. The presence of better technology abroad was provided as one of the important reasons, along with the idea that research would eventually benefit the Pakistani population. However, at least 45 respondents were not comfortable with the transfer of their material. Expressing apprehension for potential misuse, one said, “Third World countries are always being used for research and we are just a target population again.” Country ownership was also provided as one of the reasons: “Pakistani blood should stay in Pakistan.” This has been raised in other literature on the subject from developing countries, such as a study in South Africa, where the participants expressed their fears about possible transfer to other African countries and also to developed countries like the USA, UK and Europe(8).

During the Karachi workshop, there was some discussion on the technical and legal aspects of such movement with a view to preserving the quality of the material. The issue of the importance of a Material Transfer Agreement (MTA) was also discussed, underlining the importance of such an instrument in ensuring that all aspects of the agreement are mutually agreed upon prior to any transfer, and that all transfers are documented and recorded by a central agency. It was opined that an MTA ought to address a range of issues including ownership of materials, and the ways to deal with the information that emerges from the research. Another aspect highlighted was that MTAs may not prove sufficient in contemporary world, where much of the data is stored on

cloud. Participants in the Bengaluru workshop discussed the complexity of this issue by pointing out that digital data often has “no borders,” making such regulations ineffectual. Among the issues that were discussed included whether the research participants were aware of such international collaborations, and even whether it was important for them to be aware at all or not, once they had consented to have their biomaterials stored in a biobank. The consensus that emerged was that if the proposed research involved material transfer from the primary lab to any other lab, it was obligatory to include this in the informed consent document. There was concern that such specimens, even if delinked and anonymised, may still be identifiable due to the presence of DNA.

Limitations

To the best of the authors’ knowledge, this is the first formal attempt to investigate the ethical challenges associated with biobanking in this region. The deliberations of the Karachi workshop and the Bengaluru workshop were combined with the findings from the pilot study from Karachi to provide a wider perspective and more depth to this emerging discourse.

The three sources of data used for this study were disconnected, which is why there is lack of synchrony of discussion on various points.

The pilot study was conducted in Karachi— a large, mostly educated urban city of Pakistan. The participants of the workshop were largely members of the scientific community and the pilot study respondents also belonged to an educated group, who possessed at least 12 years of education. This introduces a bias into the results of this paper, since the sample does not represent the general Pakistani population, thus limiting the generalisability of the results. In addition, there is a domination of women in both the medical and non-medical groups, which may also have coloured the findings. However, the population of women outnumbers men (60:40 ratio) in medical colleges. Moreover, the cohort in the pilot study was restricted to the student population, whereas other age groups may have varying viewpoints.

The Bengaluru workshop was a short two-hour parallel session in a bioethics conference. This paper relied on the reported findings of the workshop and therefore used a secondary source of data, which limited our analysis to that of the published report.

Conclusion

The outcomes of the Karachi workshop and findings of our pilot study indicated ambiguities with respect to ethical challenges associated with biobanking. These findings resonated well with the deliberations of the Bengaluru workshop, indicating a similarity of thinking among the two cohorts. Even in the educated cohort whose opinions have been captured in this paper, including participants from the Karachi workshop drawing exclusively from scientific backgrounds, it was evident that participants were largely unclear of what constitutes a biobank. It can safely be assumed

that the general population, who are potential donors to biobank facilities, may actually possess no knowledge or understanding of biobanks.

Our findings revealed that there is a general willingness to donate biosamples for future research purposes. One major contributing factor for this was the trust that the participants placed on the researchers and the research organisations. This aspect of trust was more common among non-medical student population than the medical student population. This may be due to the former’s limited understanding, and possibly also a lack of reflection, thinking and discussion on this issue. Medical students may also be potentially more aware of the norms of the scientific community, thus exhibiting some skepticism.

Whereas the scientific community represented in the Karachi workshop cohort was clear that consent was essential for storing samples in biobanks and also for research, the students in both groups were less sure about this. There was even more ambiguity regarding one-time blanket consent versus specific consent each time research is performed on the stored samples, indicating that respondents and discussants were unclear.

Although the majority of participants exhibited willingness for participation in genetic research, the interviews revealed that they had a limited understanding of what genetic research on stored samples entailed. This lack of understanding even among the educated class indicates the vast potential for exploitation. This is compounded by the lack of regulatory oversight in Pakistan, a concern raised in the Karachi workshop.

The transfer of biospecimens across borders is extremely important, especially in the context of Pakistan, which can be a rich source for biological materials from vulnerable populations, and often with limited technological opportunities. Our pilot study revealed varied opinions regarding this transfer, emphasizing the need for more investigation into this matter. In addition, it became clear through the Karachi workshop that regulation is important through the use of MTAs, but these may not be sufficient, given the diverse ways in which data can be stored and exchanged.

The Bengaluru and the Karachi workshops highlight the interest in understanding the ethical challenges to biobanking, and the importance of contextualising it to local concerns. Our pilot study was an attempt to understand perspectives from a certain segment of the society.

However, for an in-depth and more representative analysis, we plan a follow-up study, exploring specific dimensions that emerge through collating all the information sources used in this paper.

Conflict of interest: None declared.

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