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ORIGINAL ARTICLE

Barriers and Opportunities in Consent and Access Procedures in Low- and Middle-Income Country Biobanks: Meeting Notes from the BCNet Training and General Assembly

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As biobanking research in low- and middle-income countries (LMICs) continues to grow, novel legal and policy considerations have arisen. Also, while an expansive literature has developed around these issues, the views and concerns of individual researchers in these contexts have been less actively studied. These meeting notes aim to contribute to the growing literature on biobanking in LMICs by communicating a number of challenges and opportunities identified by biobank researchers themselves. Specifically, we describe concerns that emerge in consent and access policy domains. First, we present a review of the literature on distinct policy and legal concerns faced in LMICs, giving special attention to the general absence of practitioner perspectives. From there, we outline and discuss considerations that were raised by meeting participants at a Biobank and Cohort Building Network (BCNet) Ethical, Legal, and Social Issues training program. We conclude by proposing that the unique perspectives of biobank researchers in LMICs should be given serious attention and further research on these perspectives should be conducted.

Keywords: biobank, policy, consent, access, LMIC

Introduction

Biobanking in low- and middle-income countries (LMICs) has become increasingly commonplace. While much has been written on the unique legal and policy considerations raised by that trend, somewhat lesser attention has been given to the voices and concerns of researchers working in these contexts. Mindful of that gap, this meeting report aims to communicate some of the barriers and opportunities, specifically with respect to consent and access policies expressed by biobank researchers who work in LMICs. These concerns were raised by biobank researchers who work in LMICs at a Biobank and Cohort Building Network (BCNet) Ethical, Legal, and Social Issues (ELSI) training program that took place in Lyon, France, in November 2015. The issues discussed were primarily informed consent to participate in biobank research and the conditions under which contributed data and samples may be shared with other researchers.

We begin this meeting report by outlining our reasons for being concerned with the perspectives of LMIC biobanking professionals on consent and access. We do this by broadly describing some of the existing literature on biobanking in LMICs, including empirical work on the perspectives of biobank researchers. From there, we will describe the concerns communicated by practitioners at the 2015 BCNet Training Session, highlighting areas for consideration in future consent and access policy development. The practitioners who took part in the BCNet training included researchers, pathologists, and laboratory scientists who work in a range of settings, including research institutions, public health universities, and hospitals. The purpose of these notes is narrow, but consequential. These meeting notes are situated within a growing literature on challenges and opportunities for LMIC biobanking. Our aim is to expand on some of what has been expressed elsewhere and to focus precisely on issues of consent and access. In general, as

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biobanking continues to grow at a rapid pace, identifying and becoming attentive to the concerns of researchers on the forefront of biobanking in LMICs will allow for the development of validated policies and regulatory frameworks that better account for the interests at stake without being generic. The concerns of biobank researchers in LMICs, given the unique settings in which they work, are likely to differ in important ways from the concerns of their higher income counterparts.

Background

A good deal of the existing literature on biobanking in LMICs to date has focused on the physical and intellectual resources available, or which ought to be available, to ensure the success of biobanking research. As we suggested above, less has been written about the tangible concerns and considerations of researchers operating on the ground. Authors have, for the better part of a decade, advocated for a greater degree of biobank development in LMICs and for increased research investment in those contexts.[1,2] Such biobanks, while still relatively few in number, are beginning to emerge,[3] although a number of important challenges exist. Many of these have been detailed in the literature, with challenges typically framed in one of two ways. On the one hand are physical infrastructure concerns. On the other are policy and guideline considerations.

On the first of these issues, a number of articles detail the institutional infrastructure concerns that may affect biobanking in LMICs. Mendy et al., for example, communicate findings on the infrastructure and resources available in a range of LMIC biobanking contexts.[4] Moodley and Singh[5] also identify infrastructure challenges facing LMIC biobanks. Some of these challenges include a lack of back-up power generators and the unavailability of reliable funding sources.[5] Klingström et al. point out that infrastructure and resources are generally less widely available in LMICs than they are for biobanks in higher-income settings.[3] Even where resources are available, Abayomi et al. suggest that inconsistent approaches to biobanking and a lack of sufficient biobank integration may decrease their utility in research programs.[6] Certain infrastructure considerations affect not simply the capacity for biobanking research, but the quality of work produced as well. Ellervik and Vaught outline the importance of preanalytical preparations of biospecimens for ensuring the integrity of downstream biobanking research.[7] Similarly, Schneider et al. underline the important role that capacity building and infrastructure development play in HIV-malignancy research biobanks in sub-Saharan Africa.[8]

A second set of challenges that may be discerned from the literature primarily concern biobank policies and guidelines for research, confidentiality, sample storage, and data sharing. These elements are increasingly recognized as crucial components of effective and efficient biobanking research programs.[9] Klingström et al. argue, for example, that many biobanks in LMICs are limited by having not adopted standardized biological sample collection and storage guidelines.[3,10] Similarly, Staunton and Moodley write that biobanks operating in Sub-Saharan Africa often have vastly different guidelines and policies.[11] Conflicting policies across national borders reduce opportunities for collaboration and, ultimately, the efficiency of research.[11] This situation has led some authors to advocate for reimagining the current, jurisdiction-dependent research paradigm and to instead utilize a global, technology-based biobanking governance model.[12] Nnamuchi details privacy and confidentiality frameworks for biobanking in place in Nigeria, concluding that systemic health challenges facing that country can, in part, be abated by serious attention to the promotion of biobanking research.[13] Recently, De Vries et al. undertook a sweeping analysis of genomic and biobanking research ethics guidelines, policies, and procedures in place in 22 African countries.[14] These authors find that policies in place on the African continent are not well suited to the changing biobanking research landscape, which emphasizes such principles as sample sharing and broad consent.[14]

Policy confusion, while especially acute in LMICs, is of more general concern in international biobanking. In the same way, the integration of genomics originating in biobank research with existing public health infrastructure is a challenge faced by a number of countries, but is especially prevalent in developing states.[10] This is typically best understood as a domestic challenge that is most easily addressed by local governments and agencies.[10]

A number of articles have sought to develop an understanding of the concerns and perspectives of biobank researchers in LMICs. Notably, Moodley and Singh study the perspectives of South African researchers on the controversial elements of biobanking in that country.[5] Among other things, the authors pointed to the importance of capacity building and promoting trust between the research community and participants.[15] Also, of note, Lawlor et al. published meeting notes from a 2012 European, Middle Eastern, and African Society for Biopreservation and Biobanking conference in *Biopreservation and Biobanking*.[16] The authors describe the outcome of two sessions on the challenges and opportunities of biobanking in LMICs.[16] One presentation in particular, given by Igbe, examined ethical issues arising from informed consent processes and content in biobanking in Nigeria.[16] In that context, the Nigerian public was surveyed, with some degree of wariness about the international sharing of samples, largely owing to a fear of discrimination or stigmatization having been expressed.[16] Other presentations detailed in Lawlor et al.[16] describe other aspects of biobanking in LMICs, but which are not directly related to the issues of consent and access described in these meeting notes.

The Lawlor et al.[16] meeting notes are important for having communicated the views and perspectives of biobank researchers facing the challenges and opportunities with which they engage. This work is situated within this context of increased attention being given to the voices of biobank researchers. In this study, we aim to provide a more sweeping sense of the concerns and challenges faced by similarly situated biobank researchers some 3 years after the assembly described by Lawlor et al.[16] On the one hand, these notes have a larger scale to the extent to which discussion was framed in terms of a set of questions posed to attendees, rather than in terms of presentations communicating scholarly work on the issue. On the other hand, these notes are more constrained, considering that we focus primarily on challenges and opportunities relevant to the consent and access dimensions of biobanking research. We intend for these notes to contribute an exposition of the organic concerns of biobank researchers on two critical dimensions of their work. Furthermore, we hope to provide a more thorough discussion of the social considerations

understood by researchers to be barriers to their work. These meeting notes underscore the role that religious and social values play in shaping the public's perception of biobank research and willingness to support its objectives.

Before moving on, it is worth noting that several international solutions to the challenges described above have been proposed and, to a degree, actualized—especially with respect to research capacity building and transnational data and sample sharing.[10] Examples of this include the Public Population Project in Genomics and Society (P3G)[10] and the Global Alliance for Genomics and Health.[17] Organizations of this nature attempt to solve some of the problems we have described above by promoting ''wide access to research tools and expertise''.[18] P3G, for example, works to promote data sharing that respects relevant legal and ethical obligations by providing access to databases of ''epidemiological, ethical, statistical, and IT instruments for the access and use of existing biobanks,'' which may be accessed online for free.[18] Such work aims to promote international coordination on biobanking research and address gaps in the biobanking policy regimes present in a number of LMICs.[17] This discussion indicates, however, that such work ought to continue.

In the following sections of the article, we will outline the discussions held at the 2015 Training Session and describe the challenges and opportunities facing biobank work in LMICs. As we will show, these views were collected in a relatively informal setting and should not be understood as generalizable to the biobanking community in LMICs more broadly. Their presentation in these meeting notes is meant simply to evoke the opinions of researchers on their own terms. They are, we propose, interesting in themselves and are suggestive of opportunities for future research. As we suggested above, these views provide a renewed assessment of challenges facing biobank researchers. We further propose that the work we present here is a step toward developing policy regimes and frameworks that are truly adaptable to biobanking in LMICs. To date, at least one such framework has been created by Human Heredity and Health in Africa (H3Africa), pioneered and drafted largely by stakeholders and investigators working in African states.[19] Importantly, while this guidance does not apply in all low- and middle-income settings, it could serve as a framework in future policy discussion. If such policy instruments, in addition to the concerns of biobank researchers engaged on the ground, are not considered in the development of future policy frameworks, then biobanking research may become hindered by increased dependence on generic policy frameworks that are not attentive to the unique legal and social settings considered in this study.

BCNet Training and General Assembly

The purpose of this section is to summarize the relevant ELSI sessions at the BCNet Training and General Assembly, hosted by the International Agency for Research on Cancer (IARC) in Lyon, France, between November 3 and 5, 2015. The training session was attended by 30 biobank researchers from a number of LMICs in Africa, Europe, Asia, and North America. The countries represented were Cameroon (2), Egypt (4), Ghana (2), Indonesia (1), Jordan (2), Kenya (1), Lithuania (1), Poland (1), South Africa (3), Sudan (3), Tanzania (1), The Gambia (2), Uganda (1), Zambia (1), Zimbabwe (3), Tunisia (1), and Mexico (1). Speakers at this session delivered an address focused on international policy perspectives on biobanking with the objective of familiarizing attendees with tools and resources available for the facilitation of policy development. Immediately following this address, attendees were divided into small groups for discussion. Two discussion themes were presented and a series of questions were posed (Table 1). Attendees were asked to identify challenges and possible solutions with respect to the development and implementation of better biobanking governance regimes, with a focus on consent and access practices. In all, discussion occurred over a period of 5 hours on November 3, the first day of the BCNet General Assembly.

Provided with the questions in Table 1, discussion was opened to the group. Session participants contributed an array of views on a number of topics in response to these questions. They identified challenges and proposed solutions. In general, the responses they offered touched on roughly a dozen specific issues (Table 2), including cultural concerns, compensation, and the recruitment of biobank participants. Half of the specific issues identified in discussion were relevant to the theme of consent, while the remaining issues broadly dealt with the theme of data and sample sharing.

With these issues in mind, Tables 3 and 4 detail the challenges and solutions session attendees identified. Table 3

Table 1. Questions Posed During the BCNet Training Session

Themes	*Questions*
Consent considerations	1. When preparing your informed consent documentations, what considerations did you take into account? Please elaborate whether these considerations relate to the setting, the stakeholders, the cultural background, and so on. 2. What difficulties did you encounter when developing your informed consent documentation? 3. What solutions do you propose and how can they be implemented? Please elaborate by specifying the nature of such solutions (procedural, legislative [or normative], managerial, etc.)?
Sharing of data and samples	1. List, if any, the current impediments to sharing data and samples in your respective institutions. 2. What solutions do you propose and how can they be implemented? Please elaborate by specifying the nature of such solutions (procedural, legislative [or normative], managerial, etc.)?

BCNet, Biobank and Cohort Building Network.

Table 2. Issues Considered in Response to the Questions Posed During the BCNet Training Session

Themes	*Issues considered in response*
Consent considerations	1. The recruitment process. 2. The social constraints of consent. 3. The content of consent. 4. Compensation. 5. Cultural and religious concerns. 6. The return of results and incidental findings
Sharing of data and samples	1. The use of samples. 2. Custodianship over samples. 3. Trust issues. 4. Benefit allocation. 5. Cultural concerns. 6. Practical concerns.

is meant to communicate the responses of attendees to issues raised under the theme of consent considerations, while Table 4 outlines discussion related to the sharing of data and samples. These responses are not ordered according to their frequency, importance, or by any measure other than the issue or set of issues to which they are directed. We have, instead, simply presented the challenges and solutions identified by session participants as they arose organically.

The discussion conducted at the BCNet General Assembly ELSI session concluded with a wide array of identified considerations touching on a diverse set of issues. In the following section, we discuss the outcomes of this session, suggesting how these considerations may be relevant in future policy development and how these issues affect our understanding of the challenges still facing biobanking in LMICs.

Discussion

The concerns and solutions highlighted in the section above provide insight into the array of unique challenges faced by biobank researchers in LMICs. Challenges concerning informed consent were prominent during the discussion session. A number of researchers pointed out that informed consent procurement is almost always project specific and is not applicable to biobanks themselves. While this is not, in itself, uncommon, researchers suggested that it is imperative that ethics committees understand this paradigm. It was suggested that one way of accomplishing that would be to require that ethics committee members undergo training and knowledge upgrading. Of equal importance to the researchers in attendance was the view that ethics committees understand the operational structures of biobanks, especially how they differ from other genomics research infrastructure. Many researchers stressed that there is a pressing need for more informed research ethics board approval processes, where members are more properly trained on and sensitized to the ethical issues in biobanking.

Participant comfort, moreover, was a particularly salient consideration for the researchers in attendance. A number of them expressed concern that complex or unintuitive recruitment processes would overwhelm research participants. Similarly, they worried that research participants could become confused by simultaneous consent procurement for both research projects and biobanks. As a result, it was imperative for many of the researchers in question that the process of informed consent procurement be streamlined. Some researchers suggested accomplishing this by combining documents or by adopting clear language.

The unique religious, cultural, and social considerations present in many LMICs were of similarly prominent concern throughout the discussion. Importantly, researchers pointed out that the extent to which women are empowered to provide informed consent to participate in research is not uniform across cultural contexts. Moreover, it is not consistently possible for women to provide informed consent on behalf of their children. Pediatric consent in general was identified as a complicated issue, particularly with respect to reconsent or reassent over the course of long-term research projects. Against the backdrop of various religious and cultural considerations, a number of session participants proposed integrating religious and cultural figures into the consent procurement and ethics approval processes. In particular, some researchers suggested that consent committees could include insight from religious leaders.

Not all of the issues highlighted during the discussion session were unique to the biobanking context in LMICs. For example, many researchers identified incidental findings as a critical concern. This, of course, is a challenge facing biobanks in high-income countries and has been discussed extensively in the literature.[20–22] In particular, researchers identified concerns about the timing and content of returns of incidental findings and to whether incidental finding consent should be included in general consent documents or presented to prospective participants separately. To be sure, these considerations are likely to pose a more direct problem in LMICs, given the resource disparity between these and biobanks in high-income countries. The solutions offered by session participants to problems posed by incidental findings included approaches often pursued in high-income countries. For example, several researchers proposed that only relevant, valid, and clinically actionable results be returned. Others suggested that results only be returned if access to counseling or consultation services is provided. These suggestions are noteworthy for the resemblance they bear to solutions pursued in contexts beyond LMICs. It underscores that common challenges exist in a diverse range of biobanking contexts.

The theme of data and sample sharing raised a number of similar considerations. As above, the unique character of the relevant cultural and religious considerations in LMICs was a topic of prominent concern. Many session participants were keenly aware of the challenges posed by regimes that promote the sharing of samples across borders. They pointed out that different cultural circumstances could make efficient sample and data sharing a challenge. To remedy this, some participants proposed that an international body be established, which would be responsible for providing interoperability guidance to national and local ethics review boards. Furthermore, this body could help to ensure that these boards are informed of the current trends at the international level. This will help them provide guidance, while being fully cognizant of the broader context in which the issues they are reviewing are being debated. Such an international body could also help to promote more aligned research ethics programs, allowing for simplified sharing across borders.

Table 3. Consent Considerations, Challenges, and Solutions

Issues raised	*Challenges*	*Proposed solutions*
1. Recruitment process	Concern that persons who present informed consent might not be best placed to explain the research in question.	Dedicated personnel for the presentation of informed consent documents. Research nurses dedicated to participant communication and blood collection. Biobank personnel dedicated to donor communication.
2. Social constraints	Concern about the achievement of public trust and community consent.	Positive media coverage. Pursuing partnerships with hospitals with positive reputations. Engagement with community leaders and elders. Community education and training. Careful tempering of patient expectations.
3. Content of informed consent	Concern that participants may not understand the content of informed consent documents, the purpose of biobanks generally, or the scope of the research and projects to be carried out.	Sufficient time should be dedicated to explanations of research projects. Text should use simple, comprehensive language. Trained research nurses should be available to communicate with participants. The same research nurse should collect relevant biospecimens. Allow participants to consult consent documents at home before signing. Allow participants to keep consent documents for later consultation. Make translation of documents easily available. Use visual depictions to assist illiterate participants.
4. Compensation	Concern over the precise nature of participant compensation, including considerations about which participant expenses (public transit fares, etc.) should be reimbursed.	Provide reimbursement for travel insofar as it does not become interpretable as the purchase of biospecimens (e.g., travel compensation should not be seen as a windfall). Reimbursement should be made only on fair costs of involvement. Researchers should better explain the scope of research and result expectations.
5. Culture and religion	(a) Concern about the power of women to provide consent for their children in certain cultural contexts. (b) Concern about pediatric consent generally, especially requirements of assent or reconsent. (c) Concern about two-level consent, in which both participants and trusted advisors are required to consent.	Consent committees that include religious leaders.
6. Return of results and incidental findings	(a) Concern over the content and timing of the return of incidental findings. (b) Concern over where consent for the return of incidental findings should appear in consent documents, for example, whether it should be incorporated into the general consent document, or be separate and independent from the remainder of the consent process.	Specify plans for results return. Develop plans to ensure that only relevant, clinically validated, and actionable results are returned. Only return results where counseling or consultation is available as part of the process of return.

Other solutions included promoting a greater degree of public engagement and education, an approach that may be equally applicable to other concerns raised in the session.

In a related way, session participants also raised concerns about securing public trust for biobanking research. A number of them expressed a worry that samples or data could be lost or mismanaged during the transfer process—an apprehension evocative of the position in the literature described above that pointed to gaps in biobanking infrastructure in LMICs. As a solution, researchers again proposed greater

Table 4. Sample Sharing and Data, Challenges, and Solutions

Issues raised	*Challenges*	*Proposed solutions*
1. Use of samples	(a) Concern about the monitoring of shared samples, including verification that such samples are used for reasons intended. (b) Concern about commercialization or sample use by big pharma. (c) Concern that samples may be underused (or not used at all).	(a) Agreements between institutions and researchers should be clear and concise. They should cover publication policies and proposals for monitoring data use. Areas of common interest should be identified and subjected to mutual agreement. Sample accompaniment abroad for usage control may provide opportunities for training and knowledge exchange. (b) Researchers should discuss the potential for sample use in big pharma with donors. (c) The biobank may join the BCNet catalogue or similar initiatives to provide greater visibility to their samples and reduce incidences of waste or nonusage.
2. Trust	Concern that donors will lose control of samples and of the final disposition of data.	Pinpoint level of relevant trust, for example, whether at the level of government, institution, or researcher. Engage with and educate members of responsible government agencies, for example, ministries of health. Ensure that material transfer agreements are drafted by appropriate experts. Create material transfer agreement minimal requirements. Ensure that mechanisms are in place that allows the return of leftover or unneeded samples where appropriate.
3. Benefit	Concern that the benefits of sharing will not be returned to the relevant research institution, biobank, or country.	Specify terms of benefit sharing in material transfer agreement. Specify relevant benefits in the material transfer agreement, for example, publications, co-authorships, acknowledgments, and final data deposition.
4. Cultural considerations	Concern about sharing samples and data across cultural settings.	Indicate an international regulatory body for national and local ethics review board consultation. Engage in public education, for example, by allowing general public access to advances in medicine and public health. Engage public advocates to shift cultures of sample hoarding.
5. Practical considerations	Concern that formats for data sharing are not always readily available. No harmonized sharing system is currently in place.	Make use of BCNet best practices, develop software and databases to enable information sharing. Success story promotion could help foster a culture conducive to scientific research and sample and data sharing. Clear custodianship policies and agreements between institutions should be established.

public engagement. Beyond that, they were optimistic about the potential for civil servant and government official outreach programs and the enactment of minimum standards for material transfer agreements that could be negotiated between states or institutions. These worries are related to concerns presented about the use of samples stored in biobanks. Infrastructure deficiencies appear to underlie the worry that samples may not be used for their intended purpose or their storage will be inadequately monitored. Session participants also indicated that samples could be used or commercialized without express permission. Interestingly, the solutions proposed did not explicitly involve physical infrastructure amendments, but rather turned largely on stricter, more directed agreements between research institutions. On the issue of commercialization, researchers suggested that they could engage more concretely in conversations with donors about

the possibility that their samples, or work emerging from research conducted on their samples, could eventually be of commercial application.

As shown in Table 4, many other issues were identified at this stage of discussion, including concerns about research benefits and the use of samples. However, perhaps the most enlightening, from the perspective of biobank researchers in LMICs, are the practical concerns that affect daily working life in these contexts. On the theme of data sharing in particular, session participants were largely concerned that harmonized data sharing systems are not often accessible to them. They expressed a worry that data formatting is often a barrier to effective sharing. To remedy this, researchers proposed something fairly intuitive, namely, the development of software infrastructure and consolidated databases that would assist the movement of data across institutions and national boundaries. Beyond that, session participants recommended that clear custodianship guidelines be established and a culture of data and sample sharing be promoted through the dissemination of success stories and colleague insight. Finally, session participants identified the more widespread adoption of BCNet best practices and the IARC Common Minimum Technical Standards and Protocols for Biobanks Dedicated to Cancer Research[23] by institutions as a possible approach to ensuring more consistent data sharing platforms.

To be sure, there are certain clear limitations to the discussion we have presented in this study. Most obviously, this is not a formal study with controlled variables. Subjects, for example, were not recruited with an intention to preserve demographically representative sample. The discussion results communicated in this study are similarly not the product of a formal mediated focus group. Beyond that, not every response we received at the Training Session has been communicated here—only those captured by the group reports. Further research should be conducted to ascertain the views of biobank researchers in LMICs in a more formal, controlled setting. This meeting report should indicate the important role that the social and cultural features of biobank research may play in ensuing the success of these endeavors, which should be an area for further study.

Conclusion

The goal of these meeting notes has not been to provide conclusive solutions to issues faced in LMIC biobanking. Rather, it has been to contribute to an ongoing discussion in the literature and to develop an understanding of the particular perspectives of biobank researchers, to provide points of consideration in future policy development and research. It is our hope that this discussion will begin a dialogue in LMIC settings that, it will promote further controlled study of biobank researchers in the hope of developing policy and regulation that is attentive to their needs and understanding of the challenges they face. This position follows a line of research advocating for policies that account for the perspectives of various stakeholders.[24–26] We maintain that the unique perspectives of biobankers in LMICs are especially valuable. Understanding the challenges and opportunities they face in their work will help to contextualize and refine consent and access policymaking in these contexts. It will help to ensure that enacted polices are not simply generic frameworks that have been implemented in higher income countries that have their own set of distinct challenges. Gottweis and Zatoukal, for example, maintain that it is crucial for biobanking governance regimes to effectively account for relevant social and political considerations.[25] One way of ensuring that such considerations are taken seriously is by directly engaging in dialogue with researchers in the field. We hope to have contributed to such dialogue in this meeting report and hope that it will continue in future research. In turn, access and consent policies that are shaped by the unique social and political contexts of LMICs will help to build broader social license and, ultimately, will help to promote more successful biobanking research.

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References

1. Rudan I, Marušić A, Campbell H. Developing biobanks in developing countries. J Glob Health 2011;1:2–4.
2. Sgaier SK, Jha P, Mony P, et al. Biobanks in Developing Countries: Needs and Feasibility. Science 2007;318; 1074–1075.
3. Klingström T, Mendy M, Meunier D, et al. Supporting the development of biobanks in low and middle income countries. IST–Africa 2016 Conference Proceedings 2016, Durban, South Africa.
4. Mendy M, Caboux E, Sylla B, et al. Infrastructure and facilities for human biobanking in low- and middle-income countries. Pathobiology 2014;81:252–260.
5. Moodley K, Singh S. ''It's all about trust'': Reflections of researchers on the complexity and controversy surrounding biobanking in South Africa. BMC Med Ethics 2016;17:57.
6. Abayomi A, Christoffels A, Grewal R, et al. Challenges of biobanking in South Africa to facilitate indigenous research in an environment burdened with human immunodeficiency virus, tuberculosis, and emerging noncommunicable diseases. Biopreserv Biobank 2013;11:347–354.
7. Ellervik C, Vaught J. Preanalytical variables affecting the integrity of human biospecimens in biobanking. Clin Chem 2015;61:914–934.
8. Schneider JW, Sanderson M, Geiger D, et al. A biobank to support HIV malignancy research for sub-Saharan Africa 2016;106:867–969.
9. Bull S, Cheah PY, Denny S, et al. Best practices for ethical sharing of individual-level health research data from low- and middle-income settings. J Empir Res Hum Res Ethics 2015;10:302–313.
10. Hardy B-J, Séguin B, Goodsaid F, et al. The next steps for genomic medicine: Challenges and opportunities for the developing world. Nat Rev Genet 2008(Suppl 1):S23–S27.
11. Staunton C, Moodley K. Challenges in biobank governance in Sub-Saharan Africa. BMC Med Ethics 2013;14:35.
12. Kaye J. From single biobanks to international networks: Developing e-governance. Hum Genet 2011;130:377–382.
13. Nnamuchi O. Biobank/genomic research in Nigeria: Examining relevant privacy and confidentiality frameworks. J Law Med Ethics 2015;43:776–786.

14. De Vries J, Munung SN, Matimba A, et al. Regulation of genomic and biobanking research in Africa: A content analysis of ethics guidelines, policies and procedures from 22 African countries. BMC Med Ethics 2017;18:8.
15. Public Population Project in Genomics and Society. Biobank toolkit. Available at: http://p3g.org/resources/biobank-toolkit 2017 (accessed January 23, 2018).
16. Lawlor RT, Sluss PM, Langer R, et al. European, Middle Eastern, and African Society for biopreservation and biobanking (ESBB). 2012 Conference Session on Biobanking in Emerging Countries. Biopreserv Biobank 2013;11:176–181.
17. Global Alliance for Genomics and Health. Our work. Available at: https://genomicsandhealth.org 2017 (accessed January 23, 2018).
18. Public Population Project in Genomics and Society. About P3G. Available at: http://p3g.org/about-p3g 2017 (accessed January 23, 2018).
19. H3Africa Working Group on Ethics and Regulatory Issues for the Human Heredity and Health (H3Africa) Consortium. H3Africa guidelines for informed consent. Available at: http://h3africa.org/images/FinalPoliciesDocuments/H3A%20WG%20Guidelines%20Informed%20Consent_FINAL_01082013.pdf 2013 (accessed January 23, 2018).
20. Bennette CS, Trinidad SB, Fullerton SM, et al. Return of incidental findings in genomic medicine: Measuring what patients value—development of an instrument to measure preferences for information from next-generation testing (IMPRINT). Genet Med 2013;15:873–881.
21. Middleton A, Morley KI, Bragin E, et al. Attitudes of nearly 7000 health professionals, genomic researchers and publics toward the return of incidental results from sequencing research. Eur J Hum Genet 2016;24:21–29.
22. Fernandez CV, O'Connel C, Ferguson M, et al. Stability of attitudes to the ethical issues raised by the return of incidental genomic research findings in children: A follow-up study. Public Health Genomics 2015;18:299–308.
23. International Agency for Research on Cancer. Common minimum technical standards and protocols for biobanks dedicated to cancer research. IARC Technical Publication No. 44, Lyon, France; 2017.
24. Murphy M, Garrett SB, Boyd E, et al. Engaging diverse stakeholders to inform biobank governance. Biopreserv Biobank 2017;15:393–395.
25. Gottweis H, Zatloukal K. Biobank governance: Trends and perspectives Pathobiology. 2007;74:206–211.
26. Myskja BK. Lay expertise: Why involve the public in biobank governance? Genomics Soc Policy 2007;3:1–16.

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