



# Biobanking Concepts Specific for Developing Countries

# 6

Svetlana Gramatiuk, Mykola Alekseenko, Tamara Sarkisian,  
Armen Muradyan, and Karine Sargsyan

## Abstract

Biobanks currently describe and report being present and working on every continent of the earth, with the highest density detected in North America and Europe. However, this development changes very quickly. Some countries, especially low- and middle-income countries, have recruited and invested money and excessive work for the construction of their own biobanks and biobanking networks. The biobanking activities in these countries are mostly based on the collaboration of large organizations, such as the African Society of Human Genetics, the National Institutes of Health in the United States and the Wellcome Trust. In this chapter, we list and investigate several problems and information of developing countries regarding the construction of biobanks.

## Keywords

Biobank networks · Low- and middle-income countries · Biobanking societies

---

S. Gramatiuk · M. Alekseenko  
Institute of Cellular Biorehabilitation, Kharkiv, Ukraine

T. Sarkisian  
Department of Medical Genetics, Yerevan State Medical University, Yerevan, Armenia

A. Muradyan  
Yerevan State Medical University, Yerevan, Armenia

K. Sargsyan (✉)  
International Biobanking and Education, Medical University of Graz, Graz, Austria  
Department of Medical Genetics, Yerevan State Medical University, Yerevan, Armenia  
Ministry of Health of the Republic of Armenia, Yerevan, Armenia  
e-mail: [karine.sargsyan@medunigraz.at](mailto:karine.sargsyan@medunigraz.at)

Biobanks in developing countries have some particular features. Biobanks presently describe and report to be present and work on every continent of the earth, even in Antarctica, with the highest density detected in *North America and Europe* [1, 2]. However, this spreading pattern is shifting promptly. Several countries, including *China, Gambia, Jordan, Mexico and South Africa*, and many others have recruited invested money and excessive work for the construction of their own biobanks and biobanking networks [2–7].

The above-mentioned countries have several partners among biorepository facilities in high-income countries. One of the known initiatives is the consolidated *Gambian National DNA Bank*, which has been implemented based on the support of the *Centre d'Etude du Polymorphisme Humain*, which is an international scientific centre for genetics situated in *Paris, France*. As a known example, one can also mention the *Kadoorie Study of Chronic Disease in China* [8] and the *Mexico City Prospective Study*, which work together with *Oxford's Clinical Trial Service Unit and Epidemiological Studies Unit* [8]. There are several other examples worth mentioning, such as the *KHCCBIO project in Jordan* which intends to collect and store cancer samples from all over the country and also has collaborations with the *Trinity College in Dublin, Biostór Ireland and Accelopment AG, Switzerland* [9]. Also well spread and known is the initiative called *Human Heredity and Health in Africa (H3Africa)* [10]. This biobanking activity is built with a cooperation of three organizations, the *African Society of Human Genetics*, the *National Institutes of Health in the United States* and the *Wellcome Trust* [10].

The creation of biorepositories is the essential phase on the road to launching a national genomics research programme. Nevertheless, the expansion of many different biobanks is facing difficulties. Sustaining these biobanks and generating effective research results, which are based on the systematic and organized biobanking resources, can become tricky, especially without an appropriate framework and dedicated management capacity. Additionally, several countries with specific political regimens—for example, *China and South Africa*—have deficiency in acceptable legislative structures and regulations that may standardize or control the usage and progress of biobanks [9, 11–15].

In high-income countries, biobanks and their organizations support scientists to carry out human and especially genetic research. This can be an additional benefit, as human biological material can be studied from whole populations, especially those known to be rich in genetic diversity compared to low- and middle-income countries (LMICs). For these investigations, human biological material can be transported from a LMIC biorepository from the above-mentioned institutes, and researchers can have a secondment in the given biorepository [16]. This human biological material can cause difficulties in LMICs, as the majority of these countries apply insufficient and/or non-existent regulations and laws to protect donors. The mentioned deficiency in jurisdictional frameworks can result in vulnerability of the country and its population to exploitation [17].

*The Washington Post* printed (in December 2000) a six-part sequence of articles with the title: “The body hunters that surveyed research subjects in China, Africa and Latin America”. The population was used as a research subject, yet people

complained, that as partaking in biomedical research, which was led by high-income country scientists, they did not obtain the promised and estimated benefits—for instance healthcare services [18–21]. There are several further stories of investigators coming from developed countries, who were gathering human biological materials from *Hagahai* individuals in *Papua New Guinea*, *Havasupai* people in *Arizona* and *Karitiana* folk in *Brazil* not having any or appropriate informed consents [22]. The contributors stated their disappointment, as they did not obtain any of the expected benefits, which should have been financial remuneration and medicines.

In 2002 in India, a strict governmental regulation against biopiracy was issued, but it is still poorly realized, and human biological specimens are quietly being distributed abroad for research lacking a proper ethical and authority approval [11]. There is a very interesting systematic review on existing human genetic projects including DNA specimens from the Cameroon population, which were conducted between 1989 and 2009. This review reports of only 14% of the organizations coming from Cameroon and only 28% of Cameroonian authors, who were somehow related to the identified 50 articles. Additionally, only a few of the published research articles have mentioned topics that focus on Cameroon and the common genetic diseases in Africa. The worst result, however, showed that almost all the DNA samples of the Cameroonian population were stored far away from Africa [9, 12–14].

Scientists can indeed receive financial repayments, but also individual recognition and standing, by giving industrial partners access to biorepositories and—even worse—by commercializing biobank resources without considering and/or ignoring that this may potentially harm the welfare of donors. Biased profit sharing with research participants (donors) of an area and/or with entire populations can cause exploitation. This kind of acting leads to a population-wide distrust in biomedical research. Additionally, lacking or partly performed consent procedures and insufficient commitment (individual and organizational) cover up the relationship between science and the public [17, 18, 23, 24].

Scientific or financial profit-distribution questions due to human biological material and associated information movements across borders have been actively discussed. Numerous investigations have deliberated and provided suggestions for possible non-discriminatory profit distributions of genetic investigation partnerships across different nations [17–21, 23–25]. Nonetheless, this very essential matter and its theoretical and practical complexity remain unresolved. Specific ethical and legal strategies and guidelines have been developed and issued by several international organizations for the access to samples and the corresponding information, such as *the Human Genome Organization Ethics Committee's Statement on Benefit Sharing* (2000), *the United Nations Educational, Scientific and Cultural Organization's (UNESCO's) International Declaration on Human Genetic Data* (2003) and *the Organisation for Economic Co-operation and Development's Principles and Guidelines for Access to Research Data from Public Funding* (2007) [26]. Still, the mentioned establishments and their published rules are unreliable and incomplete

because not one of these regulations has a “supranational” position, power or assertiveness.

## References

- Mascalzoni, D., Dove, E. S., Rubinstein, Y., Dawkins, H. J., Kole, A., McCormack, P., Woods, S., Riess, O., Schaefer, F., Lochmüller, H., Knoppers, B. M., & Hansson, M. (2016). International charter of principles for sharing biospecimens and data. *European Journal of Human Genetics*, 24(7), 1096. <https://doi.org/10.1038/ejhg.2015.237>
- De Souza, Y. G., & Greenspan, J. S. (2014). Biobanking past, present and future: Responsibilities and benefits. *AIDS*, 27(3), 303–312. <https://doi.org/10.1097/QAD.0b013e32835c1244>
- Watson, P. H., Nussbeck, S. Y., Cater, C., O’Donoghue, S., Cheah, S., Matzke, L. A. M., Barnes, R. O., Bartlett, J., Carpenter, J., Grizzle, W. E., Johnston, R. N., Mes-Masson, A.-M., Murphy, L., Sexton, K., Shepherd, L., Simeon-Dubach, D., Zeps, N., & Schacter, B. (2014). A framework for biobank sustainability. *Biopreservation and Biobanking*, 12(1), 60–68. <https://doi.org/10.1089/bio.2013.0064>
- Cormier, C. Y., Mohr, S. E., Zuo, D., Hu, Y., Rolfs, A., Kramer, J., Taycher, E., Kelley, F., Fiacco, M., Turnbull, G., & LaBaer, J. (2010). Protein structure initiative material repository: An open shared public resource of structural genomics plasmids for the biological community. *Nucleic Acids Research*, 38, 743–749. <https://doi.org/10.1093/nar/gkp999>
- Cormier, C. Y., Park, J. G., Fiacco, M., Steel, J., Hunter, P., Kramer, J., Singla, R., & LaBaer, J. (2011). PSI: Biology-materials repository: A biologist’s resource for protein expression plasmids. *Journal of Structural and Functional Genomics*, 12(2), 55–62. <https://doi.org/10.1007/s10969-011-9100-8>
- Seiler, C. Y., Park, J. G., Sharma, A., Hunter, P., Surapaneni, P., Sedillo, C., Field, J., Algar, R., Price, A., Steel, J., Throop, A., Fiacco, M., & LaBaer, J. (2014). DNASU plasmid and PSI: Biology-materials repositories: Resources to accelerate biological research. *Nucleic Acids Research*, 42, D1253–D1260. <https://doi.org/10.1093/nar/gkt1060>
- Lamesch, P., Li, N., Milstein, S., Fan, C., Hao, T., Szabo, G., Hu, Z., Venkatesan, K., Bethel, G., Martin, P., Rogers, J., Lawlor, S., McLaren, S., Dricot, A., Borick, H., Cusick, M. E., Vandenhaute, J., Dunham, I., Hill, D. E., & Vidal, M. (2007). hORFeome v3.1: A resource of human open reading frames representing over 10,000 human genes. *Genomics*, 89(3), 307–315. <https://doi.org/10.1016/j.ygeno.2006.11.012>
- Tapia-Conyer, R., Kuri-Morales, P., Alegre-Díaz, J., Whitlock, G., Emberson, J., Clark, S., Peto, R., & Collins, R. (2006). Cohort profile: The Mexico City prospective study. *International Journal of Epidemiology*, 35(2), 243–249. <https://doi.org/10.1093/ije/dy1042>
- Moe, J. L., Pappas, G., & Murray, A. (2017). Transformational leadership, transnational culture and political competence in globalizing health care services: A case study of Jordan’s king Hussein cancer center. *Globalization and Health*, 3(11). <https://doi.org/10.1186/1744-8603-3-11>
- H3Africa. (2021). Retrieved March 12, 2021, from <https://h3africa.org>
- Hewitt, R. E. (2011). Biobanking the foundation of personalized medicine. *Current Opinion in Oncology*, 23(1), 112–119. <https://doi.org/10.1097/CCO.0b013e32834161b8>
- CNIO Stop Cancer (2021). *The CNIO biobank*. Retrieved March 12, 2021, from <http://www.cnio.es/ing/grupos/plantillas/presentacion.asp?grupo=50004308>
- Wales Cancer Bank. (2021). Retrieved March 12, 2021, from <http://www.walescancerbank.com>
- Gaffney, E. F., Madden, D., & Thomas, G. A. (2011). The human side of cancer biobanking. *Molecular Profiling*, 2012(823), 59–77. [https://doi.org/10.1007/978-1-60327-216-2\\_5](https://doi.org/10.1007/978-1-60327-216-2_5)

15. Bernini, P., Bertini, I., Luchinat, C., Nincheri, P., Staderini, S., & Turano, P. (2011). Standard operating procedures for pre-analytical handling of blood and urine for metabolic studies and biobanks. *Journal of Biomolecular NMR*, *49*(2–3), 231–243. <https://doi.org/10.1007/s10858-011-9489-1>
16. Yu, X., Bian, X., Throop, A., Song, L., Del Moral, L., Park, J., Seiler, C., Fiacco, M., Steel, J., Hunter, P., Saul, J., Wang, J., Qiu, J., Pipas, J. M., & LaBaer, J. (2014). Exploration of Panviral proteome: High-throughput cloning and functional implications in virus-host interactions. *Theranostics*, *4*(8), 808–822. <https://doi.org/10.7150/thno.8255>
17. Fortin, S., Pathmasiri, S., Grintuch, R., & Deschênes, M. (2011). ‘Access arrangements’ for biobanks: A fine line between facilitating and hindering collaboration. *Public Health Genomics*, *14*(2), 104–114. <https://doi.org/10.1159/000309852>
18. Guerin, J. S., Murray, D. W., McGrath, M. M., Yuille, M. A., McPartlin, J. M., & Doran, P. P. (2010). Molecular medicine Ireland guidelines for standardized biobanking. *Biopreservation and Biobanking*, *8*(1), 3–63. <https://doi.org/10.1089/bio.2010.8101>
19. Chandrasekar, A., Warwick, R. M., & Clarkson, A. (2011). Exclusion of deceased donors post-procurement of tissues. *Cell and Tissue Banking*, *12*(3), 191–198. <https://doi.org/10.1007/s10561-010-9184-6>
20. Bevilacqua, G., Bosman, F., Dassel, T., Höfler, H., Janin, A., Langer, R., Larsimont, D., Morente, M. M., Riedman, P., Schirmacher, P., Stanta, G., Zatloukal, K., Caboux, E., & Hainaut, P. (2010). The role of the pathologist in tissue banking: European consensus expert group report. *Virchows Archiv*, *456*(4), 449–454. <https://doi.org/10.1007/s00428-010-0887-7>
21. Campbell, B., Thomson, H., Slater, J., Coward, C., Wyatt, K., & Sweeney, K. (2007). Extracting information from hospital records: What patients think about consent. *Quality and Safety in Health Care*, *16*(6), 404–408. <https://doi.org/10.1136/qshc.2006.020313>
22. Garrison, N. A., & Cho, M. K. (2013). Awareness and acceptable practices: IRB and research reflections on the Havasupai Lawsuit. *AJOB Primary Research*, *4*(4), 53–63. <https://doi.org/10.1080/21507716.2013.770104>
23. Colledge, F., Elger, B., & Howard, H. C. (2013). A review of the barriers to sharing in biobanking. *Biopreservation and Biobanking*, *11*(6), 339–346. <https://doi.org/10.1089/bio.2013.0039>
24. Colledge, F., Persson, K., Elger, B., & Shaw, D. (2013). Sample and data sharing barriers in biobanking: Consent, committees, and compromises. *Annals of Diagnostic Pathology*, *18*(2), 78–81. <https://doi.org/10.1016/j.anndiagpath.2013.12.002>
25. Clément, B., Yuille, M., Zatloukal, K., Wichmann, H. E., Anton, G., Parodi, B., Kozera, L., Bréchet, C., Hofman, P., & Dagher, G. (2014). EU-US Expert Group on cost recovery in biobanks. *Science Translational Medicine*, *6*(261), 261fs45. <https://doi.org/10.1126/scitranslmed.3010444>
26. UNESCO (2019). Retrieved March 12, 2021, from <http://portal.unesco.org/en/>