Biobanking in a Fast Moving World: An International Perspective

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Diseases including the main chronic “killer” diseases have a global dimension and so has biobanking, the main cornerstone for biomarker discovery, validation and implementation in prevention, diagnosis, or therapy. Interconnecting biobanks associated with cohort studies or collections of diseased tissues raises many issues in terms of ethics, governance, regulations, technical standardization, quality control, and sharing of specimens and data. In this perspective article, we briefly address the importance of international networks of biobanks, identify the main challenges, and discuss different models of such networks, balancing the needs for centralization of specimens and resources with the reality of delocalized collection activities, in particular in a clinical context.

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In 2008, large research centers in Europe proclaimed in the so-called Stockholm Declaration that “the current explosion of new concepts and technologies emerging from molecular and cellular biology has made it necessary to bridge the gap between the various fields of basic, epidemiological, and clinical research. No single European cancer institution has the critical mass to deliver in all cancer areas. As a result, European institutions must work together to create a world-class infrastructure in which all disciplines are integrated with the aim of innovating in cancer care and prevention” (1). Biobanking is more than just one piece of this infrastructure: it is the critical platform for achieving convergence, interoperability, and integration of research developed in different centers and across various fields of basic, epidemiological, and translational research. Of course, this statement does not only apply to Europe: The same considerations support the development of worldwide biobanking networks.

Biobanking has a global dimension. Chronic diseases, such as cardiovascular, metabolic, or cancer diseases, are common scourges of humankind, irrespective of ethnicity or geography. The fact that risk factors, incidences, and gene–environment interactions vary considerably from one population or region to the other is an added value for research, making it possible to develop comparative geographical approaches, which accelerate the understanding of mechanisms and support the global fight against common diseases. In this respect, addressing the global dimension of biobanking helps in reducing gaps in health research between rich and poor countries and provides a backbone for unprecedented progress in human health worldwide. Moreover, there is obviously a need for large collections to provide adequate sample sizes for studies involving large numbers of biomarkers as well as for studies on rare disease types or on subtypes of more common diseases. Although these needs are clear, the strategy for achieving this is less obvious.

The globalization of biobanking raises ethical, regulatory, technical, and managerial questions addressed in recent publications (2). It requires that basic rules of fairness and openness in collaboration and exchange apply when biobanks and scientists of different countries team-up to develop joint projects. It necessitates that biobanks operate in a context of accountability that fulfills stringent international ethical standards. It also depends on mechanisms of cost recovery making biobanking sustainable in a wide variety of contexts. One of the main bottlenecks is the existence, in several countries, of restrictive regulations prohibiting or strictly limiting the export of human tissue samples. Although these regulations are guided by noble and understandable ethical and legal considerations, there is a need to develop flexible international exchange protocols to make sure that restrictive regulations do not result into the loss of opportunities for research contributing to global health. In this commentary, we take a pragmatic approach and focus on two aspects of biobanking globalization: the need for universal technical standards and the impact of networking on biobank structure and governance.

Until recently, biobanks have operated according to technical guidelines inspired by experience rather than scientific evidence. Today, it has become clear that variations in preanalytical procedures and in biobanking parameters are the main sources of errors in biomarker discovery and translation. Thus, it is urgent to move biobanking practice from a purely technical to a more scientifically-oriented methodology, with protocols based on published and verifiable scientific evidence. In a global perspective, this approach opens up a new field for research, that is, biospecimen science. Understanding and mastering the molecular, physiological, and pathological parameters that define the status of a biospecimen is much more than a matter of technicalities. It involves developing principles, methods, study designs, and quality control systems that strongly affect discovery research and the implementation of biomarkers in personalized medicine. Biospecimen science must develop its own international forums, journals, representative professional bodies, and training standards to claim a seat at the “high table” of scientific research. A number of international initiatives have taken on these tasks and are playing a leading role in moving the field forwards (Table 1).

International networking has important effects on the structure and governance of biobanks. A review of some of the major biobanks around the world has provided valuable “lessons learned”
Table 1. Biobanking organizations with an international scope

<table>
<thead>
<tr>
<th>Organization</th>
<th>Scope</th>
<th>Web site</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Society for Biological and Environmental Repositories</td>
<td>Leading international forum for promoting high standards and innovation in biobanking</td>
<td><a href="http://www.isber.org">http://www.isber.org</a></td>
</tr>
<tr>
<td>Public Population Project in Genomics (P3G) Observatory</td>
<td>Noncommercial organization promoting collaborations in population genomics</td>
<td><a href="http://www.p3gsobservatory.org/">http://www.p3gsobservatory.org/</a></td>
</tr>
<tr>
<td>Biomolecular and Biobank Research Infrastructure</td>
<td>Pan-European infrastructure for biomedical and biological research in Europe and worldwide</td>
<td><a href="http://www.bbmri.eu/index.php/home">http://www.bbmri.eu/index.php/home</a></td>
</tr>
<tr>
<td>Marble Arch Working Group</td>
<td>Investigator-driven international think tank aimed at harmonizing approaches in biobanking</td>
<td><a href="http://www.oncoreuk.org/pages/MarbleArchWorkingGroup.html">http://www.oncoreuk.org/pages/MarbleArchWorkingGroup.html</a></td>
</tr>
<tr>
<td>Forum of International Biobanking Organizations</td>
<td>Communication forum which seeks to enhance interactions between organizations involved in human biobanking at a global level</td>
<td>None</td>
</tr>
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and a useful guide for large biobanking initiatives in the future (3). There are essentially two main biobanking strategies for combining samples collections from a network of collection sites. First, the “centralized model” is to physically transfer samples from peripheral collection sites to a central biobank, where they are stored, processed, and accessed by researchers. Examples include BancoADN, Spain (http://www.bancoadn.org/en/presentacion.htm); kConFab, Australia (http://www.kconfab.org/Index.shtml); the Singapore Tissue Network, now the Singapore Bio-Bank (http://www.stn.org.sg/abt_mission.htm); and the UK Biobank (http://www.ukbiobank.ac.uk/). Second, the “federated model” is to store samples at peripheral collection sites, but to combine collections in virtual sense by transferring sample information to a central database. This allows researchers to identify collections or series of samples of interest and access them from multiple collection sites. Examples include the Australian Prostate Cancer BioResource (http://www.apcbrresource.org.au/), the Canadian Tumour Repository Network (https://www.ctrnet.ca/), the Wales Cancer Bank (http://www.walescancerbank.com/), Tubafrost (http://www.tubafrost.org/), as well as the P3G catalog of large epidemiology-based cohorts (http://www.p3g.org/).

The two models have different advantages. The centralized model allows the storage and processing of samples to be controlled and monitored in a standardized manner, which is an extremely important benefit. The federated model tends to be more acceptable to stakeholders at the peripheral collection sites because they remain intimately involved throughout biobanking and decision-making processes. In both models, an important factor is the motivation of stakeholders to participate at both peripheral and central sites. Surgeons, pathologists, and other clinical staff who make special efforts to collect and annotate samples for research must be stimulated to participate through a variety of incentives. They should have a clear perception of the added value of participating into a biobank network not only as a generous contribution to global health research but also as a direct way to improving their own scientific and medical activities. One incentive is to involve clinician stakeholders as collaborators in research using the samples they provide. This works well in an academic setting, and it enhances interdisciplinary translational research. This has been the experience of the Singapore Bio-Bank. Another incentive is to provide financial, training, and infrastructure support for biobanking activities that will help clinicians in their clinical duties. This might include support for additional staff or for new improved equipment and is likely to be equally effective as an incentive for both community hospitals and academic medical centers. In particular, this may involve training of local staff into using biomarkers, which in turn will benefit hospitals when implementing biomarkers in medical practice. Given the importance of standardized protocols in biobanking, the centralized model is a desirable approach for large-scale biobanks, in particular for project-driven initiatives such as the International Cancer Genome Consortium (http://www.icgc.org/). The key is to find the right incentives for the right circumstances. It is not an easy task, but as international experience shows, it can be done.

References


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