International Biobanking Summit II: Future Directions

The second International Biobank Summit was organized in Graz, Austria, September 17, 2013. The summit provides a forum for idea exchange, discussion and priority setting towards the common goal of developing biobanking for the improvement of human health. This year's summit built upon two priority areas that emerged from the IBS-I organized in Sweden last year: *Biobanks as Bridges between Research and Health Care* and *Does "Big" Science mean "Big" ELSI?* The IBS-II gathered more than 200 participants representing 35 countries and was jointly organized by BioSHaRE.EU, BBMRI-ERIC, P^{3}G, ISBER, BBMRI-LPC and ESBB.

The summit emphasized many of the reciprocal advantages to be reaped when bridging discovery science with clinical care through biobanks. Although research and health care have traditionally been considered to be distinct disciplines, this old divide is becoming obsolete. With the emergence of new biotechnologies and a better comprehension of biological mechanisms underlying disease, there are unique opportunities for researchers and clinicians to join forces to increase medical knowledge and improve patient care. For instance, patient-centric research to support health care decisions can be developed while patient data can be used to feed research and contribute to increased knowledge production.

Health care systems worldwide are strained due to the exponential growth of aging populations, rising health costs, and increases in morbidity. These dramatic increases in health care costs are not paralleled by advances in diagnostics and treatment. The Summit emphasized the need for new models to accelerate discovery, improve diagnostics and develop targeted treatments; and illustrated the role of biobanks in realizing these goals. Integration of data was a recurring theme and presentations at the Summit provided many examples where biobanks were bridging research and health care. For instance, the Electronic Medical Records and Genomics Network (eMERGE), an NIH-funded consortium, enables researchers to quickly identify new genotype–phenotype associations thanks to the combination of DNA biorepositories with electronic medical records (EMR). Simultaneously, by integrating research and sequencing data into the EMR of patients, clinicians are enabled to make early risk assessment for their patients and develop more targeted prevention strategies. Networks of EMR-linked biobanks that share samples and data offer several advantages: they have the potential to increase statistical power to detect genetic associations; they improve overall research efficiency and significantly contribute to increase the quality of EMR.

Using biobanks as bridges between research and health care offers many opportunities but also encounters many challenges. Steps to facilitate such bridging were identified at the summit:

1. **Develop common infrastructures and platforms to support big data**

As technology advances, the size and complexity of the data to be integrated, coordinated and exchanged between research and health care will increase dramatically. However, the current ICT gap between research and health care, differences in cultures and practices between the relevant professions compiling and using biobank data and the lack of incentives to encourage interdisciplinary collaboration impede the development of tools and solutions at a global level. Solid data management infrastructures, which handle big data originating from both research and clinical environments, must be developed. The development of standards that guarantee the quality of the data and facilitate data sharing across sites and disciplines are also needed.

2. **Develop public-private partnerships**

Research and patient data are generated through both public and private initiatives but data are seldom exchanged between these sectors. The current lack of co-operation between public and private actors does not serve the future of health care and public health. Public-private partnerships have the potential to increase the quality of research data, accelerate the development of data management infrastructures across public and private sites and accelerate discovery science and drug development. Public-private partnerships should be developed, for instance through models like those proposed in the BBMRI expert centres, to facilitate multiple access to biological samples, data and medical expertise originating from both public and private initiatives.

3. **Develop global legal and ethical frameworks**

Current legal and ethical frameworks supporting research are too complex, too segmented, and still largely impede interdisciplinary collaboration across borders. These frameworks should be streamlined, and harmonized across clinical and research environments and across countries. The recently launched Global Alliance involves 70 leading health care, research, and disease advocacy organizations who have agreed to create a system to enable sharing of genetic and clinical information. The Alliance may play a central role in developing a global ethical framework which supports the handling of big data "in an interoperable, secure, and trusted manner that preserves diversity of approach and application" and simultaneously protects the interests of participants. Safe harbor approaches to facilitate cross-border data sharing according to commonly defined standards may also provide good solutions for international data sharing.

4. **Educate stakeholders**

Many biobanks are still underused. Research and clinical milieus, both public and private, must dedicate efforts to work together to help optimize the use of biobank resources. Educating all stakeholders about the benefits for all was one of the priorities identified at the first International Biobanking Summit and was reiterated in Graz. Increased awareness surrounding the opportunities offered by a more extensive use and integration of biobanks can be created by providing communities with good examples of successes and novel ways forward. Targeted communication towards all relevant stakeholders including health care professionals, ethics review boards, industrial partners, patient advocacy groups, governmental agencies, funders, researchers and the general public is particularly needed.

Plans for IBS-III

The next International Biobank Summit is already under planning for 2014 and news will be forthcoming regarding the date and venue.

The IBS-II program and presentation slides can be found on the website http://bbmri-eric.eu/conferences-and-meetings.