Public Awareness is Essential for Bio-Banking and Development of Personalized Medicine

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Our modern healthcare system requires high quality, highly-specific treatments for common diverse pathologies including cancer, obesity, diabetes, neurodegenerative, cardiovascular, and autoimmune diseases. Development of personalized medicine for these diseases is a major challenge currently faced by scientists and clinicians. Personalized medicine-based approaches target specific treatments and therapies for a particular individual based on that individual’s molecular data or genetic makeup, and represents a fundamentally different approach from the conventional practice of prescribing general drugs for patients who share similar disease symptoms [1]. In order to develop personalized treatments and cures, as well as for evaluation of ‘high risk’ individuals for developing diseases it is essential that researchers collect and analyze data from large numbers of normal and affected individuals. In the face of modern scientific and computational methodologies, perhaps the most important bottleneck in this endeavor lies in the acquisition and curation of tissue samples. The most promising route through this bottleneck is bio-banking. In essence, bio-banking involves the collection, storage, and provision of data and information gathered from individuals and patients for molecular research. The information is generated through –omics analysis of specimens/tissue samples collected from the individual. RNA, DNA, tumors, cells, tissue, blood or other body fluids, as well as residual tissue samples left over after surgeries or biopsies are archived electronically and documented by bio-banks for genomics and proteomics research purposes [2]. In order to develop and implement personalized medicine approaches, genomic data is integrated with one patient’s clinical information. On a broader level, proteomic approaches have resulted in the creation of a far-reaching and extensive database of genomic mutations and corresponding proteomic expression patterns for global use [3]. Omics-research has focused largely on the analysis of multi-factorial diseases, and has opened new windows for healthcare innovations. These have included the development of novel biomarkers for early detection and improved treatment. Although the gap between discovery of biomarkers and their clinical implementation is long and complex, the continuing validation of biomarkers and assessment of their effectiveness in clinical applications is vital [4].

As the value of bio-banking depends on the support provided by the public, as donors, as funding authorities, or as participants, it is of high importance to communicate the purpose and the aims of bio-banking as well as of the importance of personalized medicines in treatment of chronic and currently intractable diseases. In order to enhance the formation of successful personalized medicine methods, it is essential that there be effective communication between bio-bank personnel and the public, resulting in trust and confidence among community members. Teaching the purposes and necessities of bio-banking should begin in high-school, and platforms should be available to recruit volunteers/donors from the community. Generally, people or patients who have little or no knowledge of the aims of bio-banking often express unwillingness to participate. They have concerns about privacy of their individual medical information as well as their family health history. Potential donors need to be assured of the confidentiality of their clinical information, and need to understand the purposes of bio-banking; thus, communication needs to be clear and framed in appropriate language to educate patients that their personal health information is fully protected and all biospecimens are deidentified. The clinicians must provide informed education to communicate clearly with patients that all safeguard to confidentiality is in practiced in the institution. The compliance department of the clinical institution must be actively involved to enforce the confidentiality of patient’s personal information. At the level of local clinic, family doctors could play a significant role in delivering this message, and by encouraging patients to donate specimens. Additionally, internet forums, public seminars, discussions in popular media, health center workshops, surveys, and public library meetings are good communication tools that can address concerns regarding sharing tissue samples or personal health data [5]. In hospital-associated tissue banks, in order to facilitate the active participation of patients in contributing tissue or other biospecimens, efficient dissemination of information and proper education should be provided by the bio-bank personnel before consent forms are presented to the patient. An informed consenting, discussion to answer all questions from patients and educating the patient regarding the transfer, sharing, and use of donated tissues might increase interest and even enthusiasm for bio-banking.

In bio-banking, acquiring policy compliance assertions for transferring bio-specimens from a pathology section to a tissue repository can create significant challenges, including documenting the consent forms and de-identification of personal health information. Procedures to address these challenges must be in place to ensure patient confidentiality. A recent study of public attitudes toward participation in Qatar bio-bank revealed concerns of donors about confidentiality of their medical data, fear of infection through contaminated lab equipment, and questions about accessibility of bio-bank locations [6]. The participants suggested raising public awareness through public gatherings and social events. Potential donors suggested volunteering to spread the word about bio-banking in order to foster trust from the public. Similarly, concerns from community members regarding ethical, legal, and social issues involved in procuring biospecimens could be addressed by consultation given by community members who have already donated samples. These community outreach efforts could help to explain the necessity of quality research, data security assurance, protection of participants, and addressing local public health issues [7]. This community outreach is important to convince the public to make individual contributions to healthcare research for the sake of the health of future generations. This can be accomplished through targeted and articulated communications with exact information.

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about current and future healthcare using appropriate language, short video clips, surveys, and seminars in the community environment. Recent studies have suggested that ‘returning research results’ to the participants can create transparency and credibility of research, especially among minority communities. Providing an opportunity to learn the results of a study in which they participated can be an effective approach for engaging a community. Community outreach efforts are perhaps the most effective means to balance the interests and burdens of investigators and donors [8].

Funding is another important aspect of bio-banking. Adequate funding is essential for the establishment, proper management, coverage of operating cost, and sustaining bio-bank projects. Funding can be either public, public-private, or private depending upon the nature of the bio-bank. Usually, government and charitable organizations support large scale population bio-banks, while private funding supports smaller, pharmaceutical or hospital-associated bio-banks. Study of diseases in large populations requires continuous contributions to infrastructure and educational activities. Establishing bio-banks as a major component of our public health infrastructure and embedding them in the public healthcare system might invite long-term funding to support bio-bank projects. To achieve this, bio-bank personnel, investigators, and fundraisers have to work together with policy makers to ensure harmonization of all associated systemic integration strategies in the governance of bio-banks [9]. In order to ensure sustainable funding, donations from various sources such as science-related organizations, universities, and government are essential. Public awareness of the function and purpose of bio-banks is necessary for establishing and maintaining properly functioning bio-banks. Bio-banks archive biospecimens for healthcare research and development of personalized medication. Public awareness and trust can be achieved through various communication media such as internet, discussion forums, surveys, public gatherings, and seminars. Schools can promote the idea of bio-banks from the high school level onward to ensure that the future generation is aware of personalized medicine. These efforts are an essential component of the effort to conquer lethal diseases such as cancer. The –omics based approach depends on a treatment tailored to an individual’s genetic makeup rather than a ‘one size fits all’ medication. The identification of predictive biomarkers from analysis of biospecimens archived in bio-banks has diverse medical applications ranging from pharmacodynamics to therapeutics [10]. Public support and funding are essential prerequisites for establishing a bio-bank, whether small or large. Sufficient funding is necessary for sustaining long-term operation of bio-bank projects. In large population bio-banks, automation and unattended sample processing requires robots and sophisticated instrumentation [11]. Small, community bio-banks also need funding for archiving tissues and other biospecimens. The long term success of bio-banking will depend on societal awareness of the importance of bio-banking to research goals and health care innovations.

References