Biospecimens and People: A Fundamental Connection

Deborah E. Collyar

Correspondence to: Deborah E. Collyar, Patient Advocates In Research (PAIR), 3677 Silver Oak Place, Danville, CA 94506 (e-mail: deborah@tumortime.com).

This commentary includes the public- and patient-oriented perspective on research biospecimens and the National Cancer Institute’s cancer HUman Biobank (caHUB) project. Definitions of biospecimens and the importance to the research community and the public are included, as are conditions that caused the impetus of the caHUB.

J Natl Cancer Inst Monogr 2011;42:41–42

The National Cancer Institute’s (NCI) public definition for “biospecimens” states that they are: “Samples of material, such as urine, blood, tissue, cells, DNA, RNA, and protein from humans, animals, or plants. Biospecimens are stored in a biorepository and are used for laboratory research. If the samples are from people, medical information may also be stored along with a written consent to use the samples in laboratory studies” (1). The NCI Office of Biorepositories and Biospecimen Research (OBBR) further defines a biospecimen as “A quantity of tissue, blood, urine, or other human-derived material. A single biopsy may generate several biospecimens, including multiple paraffin blocks or frozen biospecimens. A biospecimen can include subcellular structures (DNA), cells, tissue (bone, muscle, connective tissue, and skin), organs (eg, liver, bladder, heart, and kidney), blood, gametes (sperm and ova), embryos, fetal tissue, and waste (urine, feces, sweat, hair and nail clippings, shed epithelial cells, and placenta). Portions or aliquots of a biospecimen are referred to as samples (NCI Best Practices working definition)” (2).

If you ask the average person about “biospecimens,” you get a range of reactions, from “I don’t know” to “some kind of alien?” to “part of my body and soul.” They have no idea what an integral part they can play in helping to advance medical research, and why they might want to. It’s time to engage people as partners in the scientific process, and truly turn promising leads into better results as in any medical research endeavor, ultimate success will only be accomplished if people willingly contribute their samples. In today’s information world, clarity, transparency, and dialog are primary expectations, and privacy protections take on even more significance. After all, physical samples are vital because they hold invaluable information when put together with key clinical, cultural, and biological data. In so doing, we owe each individual donor respect, credible assurances that their privacy is of utmost importance, and continual efforts that will help protect privacy as technology advances. This also means respecting and honoring cultural influences and beliefs that can delve into the very essence of what being human means. Although the risks to biospecimen donors are primarily related to inadvertent release of protected health information, which are relatively small in comparison to donors are primarily related to inadvertent release of protected health information, which are relatively small in comparison to risks in a therapeutic clinical trial, they are still valid and require diligence in guarding against careless procedures.

People who donate their biospecimens want them to be used to advance medical research. This means honoring them by sharing biospecimens and the data that are generated from them in as many ways as possible while protecting their privacy at each juncture. Many also wish to learn about research, which creates an excellent opportunity to engage their continued support by reporting on aggregate research results, explaining the role they play, and how science uses biospecimens to advance both knowledge and results. Instant feedback loops and ongoing dialog also help scientists learn what interests people and how to meld those interests into critical scientific advances. Patient advocates and advocacy groups are only two of many partners that can help make this happen.

To realize success, the culture of science must also continue to advance as more scientific discoveries are revealed. Individuals and institutions primed for more interaction, integration, and collaboration must renew their efforts to build effective workflows and
systems that quickly transform “cool” scientific ideas into useful realities. It takes many groups working together to create a cohesive dialog between science, medicine, and people. The good news is that many are ready and willing to challenge old dogmas and to move ideas into action. caHUB is poised to become a major contributor to bring more effective answers to people.

References

Affiliation of author: Patient Advocates In Research (PAIR), Danville, CA.