

Study of human specimen collections in the US offers first look at their huge diversity

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Photo shows specimen storage containers in a biobank facility. Credit: NIGMS/NIH

Biobanks are organizations that collect, store and share human specimens (e.g., blood, solid tissues, hair) for research purposes. The rise of the human genome project and of large-scale genetics studies have spurred a dramatic increase in the number of biobanks in the last decade, increasing their importance in biomedical research.

But until now, biobanks in the U.S. have never been studied systematically, leaving few clear details as to how they are run or the

policies and practices they use in managing their work.

A new study from the University of North Carolina published January 25, 2013 in the journal [Genome Medicine](#) reveals the huge diversity of U.S. biobanks and also raises questions about the best way to manage and govern them.

"Biobanks are increasingly important to [scientific advances](#), but our decentralized, fragmented research enterprise system in the U.S. has encouraged their development without necessarily providing them with the tools to survive," says study leader Gail Henderson, PhD, professor and chair of [social medicine](#) at the University of North Carolina. She also heads UNC's Center for Genomics and Society.

Henderson and colleagues from UNC decided to address this paucity of information by inviting more than 600 biobanks in the U.S. to participate in an [online survey](#). These included private and public, commercial and noncommercial, and many biobanks affiliated with hospitals and academia. Representatives of 456 U.S. biobanks (72 percent of the list invited) participated in the survey.

Among the main findings is their great diversity. "They get established for a variety of reasons; some accidental, some intentional. They vary in size, in when they were established, how formal they are as organizations, what kinds of specimens they hold, who pays for them, and where those specimens come from," Henderson notes.

In the survey, just over half (53 percent) listed research on a particular disease, such as cancer, as the most important reason for establishment. Twenty-nine percent listed research generally. Other reasons included response to a gift or grant, and "intent to centralize, integrate, or harmonize" older specimen collections.

The size of U.S. biobank collections varies, in number of specimens (from tens to millions) and in the types and where they come from – individuals, clinics, hospitals, public health programs, and research studies.

Henderson also points out that only a small minority are commercial businesses. "So, not surprisingly, most biobanks do not perceive being in a competitive market. But the majority are quite worried about funding, and many are concerned that the specimens they collect aren't being adequately utilized."

"Researchers and people whose specimens are being held need to be concerned that we don't have a system that is as efficient and effective as it could be," Henderson adds. "If you collect specimens but don't use them, this is a failure to deliver on the promise of advancing translational research, and thus an ethical as well as technical concern."

Biobanks, like the researchers who depend on their services and [specimens](#), need guidance informed by knowledge of their practices and challenges, the authors state. Required are policies "as nuanced as the biobanks themselves," whether these policies address issues of privacy or identity protection, or advancement of research goals.

"Given the diversity in biobank organizational characteristics identified in our survey, it's likely that management and governance policies will have to be tailored to fit the particular context. One-size policies will not fit all," says Henderson.

Provided by University of North Carolina Health Care

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