

Tissue collections vary considerably, ranging from formal repositories to the informal storage of blood or tissue specimens in a researcher's freezer. Appendix A reviews the sources of stored tissue samples described in this report. Archives of human tissue range in size from less than 200 to more than 92 million specimens. Appendix B provides estimates for the number of cases and specimens of stored tissue for each category of tissue collection and an estimate of the overall number of stored tissue samples in the United States. Conservatively, more than 307 million specimens from more than 178 million cases of stored tissue exist in the United States, accumulating at a rate of over 20 million per year.

The two largest tissue repositories in the world, the National Pathology Repository and the DNA Specimen Repository for Remains Identification, are housed in a single institution, the AFIP. These two repositories alone store more than 94 million specimens (Appendix A). The tissue repositories supported by NIH may not be as large as those at AFIP, but NIH is probably the largest funder of extramural tissue repositories, supplying more than \$53 million in FY 1996. Finally, the pathology departments at GME teaching institutions collectively constitute the largest and oldest stores of tissue samples in the United States, with some specimens more than 100 years old. The tissue bank with the oldest samples in the world is the Egyptian Mummy Tissue Bank in Manchester, England, which contains mummy tissue dating back to 2686 B.C.

The vast majority of tissues were originally collected for diagnostic or therapeutic reasons. Three sources—the AFIP National Pathology Repository, GME teaching institution pathology departments, and Newborn Screening Laboratories—represent more than 265.5 million diagnostic and therapeutic specimens from more than 176 million cases. At the AFIP National Pathology Repository alone, more than 92 million pathologic specimens from more than 2.5 million cases are stored (Appendix A). Of the 1,687 GME Teaching Institutions with residency programs in cytopathology (68 institutions), hematology (54 institutions), and clinical and anatomic pathology (180 institutions), well

over eight million cases are accessioned cumulatively per year. Pathology departments at GME teaching institutions without pathology residency programs also accession pathology specimens but most likely not at the same rate as institutions with pathology residency programs. Most GME teaching institutions retain pathology specimens indefinitely, with the oldest tissues anywhere from 20 years old to more than 100 years old. Therefore, at a rate of eight million cases a year for 20 years, conservatively more than 160 million cases are stored at GME teaching institutions with pathology residency programs with several million more stored at those without pathology residency programs. By 1994, the majority of Newborn Screening Laboratories had accumulated less than 500,000 Guthrie cards over the years, seven have amassed more than 500,000 (greater than 3.5 million), four reported collections of between one million and five million cards (greater than four million), and one reported a collection of six million for a conservative estimate of more than 13.5 million Guthrie cards stored in the United States, Puerto Rico, and the Virgin Islands. Tissues collected for diagnostic or therapeutic reasons may sometimes be used for research, educational, and quality-control purposes. However, the vast majority are not.

Several repositories have been established specifically for use in research (see "Large Banks, Repositories, and Core Facilities" in Appendixes A and C). In addition, several very large longitudinal studies collect and bank samples from their study participants. Likewise, a fair amount of research simultaneously creates tissue collections or contributes to tissue banks. Collectively, these contain more than 2.3 million specimens. Because these tissues are collected specifically for research purposes, it is not surprising that the use of these tissues has resulted in numerous research publications: more than 8,000 publications have resulted from the use of cells from the Coriell Institute; 2,000 publications have resulted from studies using tissues from the Cooperative Human Tissue Network (CHTN); and more than 632 publications, three textbooks, and numerous monographs have been produced using samples and data from the Bogalusa Heart Study.

Other than for diagnostic purposes or for use in research, tissues are also collected and stored for a variety of reasons. Blood banks collect approximately 12 million units of blood a year, but only about 20,000 to 40,000 units are stored at any one time. Also, most of the blood collected is used for transfusions. Very little is used for research and quality control. Organ banks do not collect the same volume of tissue that blood banks do but are very similar in the respect that most of the organs and tissues collected are used for transplants and very little is available for research. Forensic DNA banks collect and store tissues for use in criminal investigations. The DoD DNA Specimen Repository and some commercial DNA banks store DNA samples for remains identification. Sperm,

ovum, and embryo banks store specimens for anonymous donation or for later use by the individual storing the material. Umbilical cord blood banks also store blood for anonymous donation and later use by families banking their newborns' cord blood.

Many valuable specimens and data resources exist from a variety of sources, but no centralized database allows researchers to obtain access to and information about them. The NCI is developing a national information database of breast cancer resources to centralize information on biological specimens available to the research and clinical community, promoting access to the specimens, and facilitating collaboration among basic, clinical, and epidemiologic researchers. This database will fulfill one of the priorities of the National Action Plan on Breast Cancer (NAPBC). However, this database is not an exhaustive national listing of all facilities holding breast cancer tissue but is limited to resources that have a breast tissue bank and have the capability and desire to provide tissues or to participate in collaborations.

This RAND national resource brings together information about several sources of stored tissue samples in the United States. It represents the first time that this information has been assembled in a single document and the first time the magnitude of the archives of stored tissues has been assessed. This document may serve as a reference for researchers to identify potential tissue resources. It may also serve as a basis for developing a national database.