

Michigan

Michigan Department of Community Health (MDCH)

Public Health Issue

State health departments have the legal mandate for newborn screening, which involves the collection of blood samples from all babies born in the state and testing these samples for a variety of rare disorders. Each state maintains policies for protecting and storing the residual blood samples.

Over 160 biomarkers and compounds have been measured in residual blood samples, such as genetic material (DNA), proteins (the gene products), infectious agents (e.g., viruses), and harmful metals (e.g., lead). These samples provide an important resource that can be used in epidemiology studies, for example, to measure the frequency of genetic variations in a population or to understand how genes interact with environmental exposures.

Program Example

Since 1965, blood samples have been collected from almost every newborn in Michigan as part of their newborn screening program. Currently, the Michigan state public health laboratory screens newborns for 49 rare disorders; in addition, hospitals screen all newborns for hearing loss. In the early 1980s, the lab began to store all residual newborn screening samples for 21½ years based on a ruling by the state Attorney General's office. Based on a 1999 recommendation by the Governor's Commission on Genetic Privacy and Progress, the state legislature amended the public health code in 2000 to allow use of the blood specimens for medical research during the retention period as long as the research is conducted in a manner that preserves confidentiality and human subject protections. In early 2009, lab policy was revised to store all samples indefinitely unless parents (or legal guardians) request that their baby's sample: 1) be destroyed after screening is completed, or 2) not be used for any research. There are currently over three million samples in storage.

The genomics program in the Michigan Department of Community Health, in collaboration with many partners and stakeholders, is developing a biobank of residual blood samples for use in public health and medical research. Key partners include the major state research universities and the Van Andel Institute. The University of Michigan (UM) Center for Public Health and Community Genomics (CPHCG) and Michigan State University (MSU) Center for Ethics and Humanities in the Life Sciences have provided important support and consultation in developing and implementing a plan for community engagement to inform the public and assess support for a population-based biorepository. During 2008, approaches to community assessment and engagement included a series of four questions on the Behavioral Risk Factor Survey about public support for different types of research using dried blood spots; a deliberative jury process with in-depth examination of relevant issues; a full-day discussion session with MSU students; development of a FAQ booklet and PowerPoint presentation for use in informational sessions; a series of 10 focus groups reaching various vulnerable populations and different geographic areas of the state; as well as several presentations to a variety of professional groups. An informational webpage with online survey was prepared and will be available in the Spring of 2009 for all Michigan citizens over age 18 to share their opinions on the biobank.

The genomics program also worked closely with the state laboratory director, Wayne State University, and a steering committee on development of a business plan that outlines a mission and vision, timeline, possible governance structure, steps toward implementation and funding

Michigan (continued)

needs related to establishing a biobank. Program staff members were also involved in working with the department's institutional review board (IRB) to identify needed policies for ensuring human subjects protection; to begin designing a process for parental consent for storage of future specimens; and to develop methods for incorporating public input in the identification of research priorities through establishment of a Community Values Advisory Board.

Implications and Impact

Since Michigan first began newborn screening for Phenylketonuria (PKU), more than five million infants have been screened, and over 4,150 babies have been identified with disorders for which there are effective treatments. The state newborn screening program has saved lives and improved the quality of life for Michigan's children and their families. With rapid scientific advances in technology, it is now possible to use residual samples for additional public health purposes. The creation of a permanent biobank of residual blood samples is an important first step in establishing public health infrastructure to support new research and public health practices that will contribute to improving future health outcomes for Michigan residents.

Utah

Utah Department of Health Chronic Disease Genomics Program

Public Health Issue

In Utah, Hispanic/Latino students make up nearly 50% of all students in some school districts. Requests from teachers for educational materials in Spanish have increased. Also, wide achievement gaps in science, based on mandatory statewide tests, also demonstrate a need for culturally-appropriate health and genetics education materials.

Program Example

Starting in 2005, the Utah Department of Health collaborated with the University of Utah Genetic Science Learning Center, high school teachers, and Hispanic/Latino community members in Salt Lake City to adapt existing 5th and 10th grade classroom curricula to be culturally and linguistically appropriate for Hispanic/Latino students. Program staff developed these curricula based on recommendations from a Hispanic/Latino Community Advisory Committee. The 5th grade curriculum, Introduction to Heredity, consists of five classroom activities, three take-home family activities, and a teacher guide. The 10th grade curriculum, Using Family History to Improve Your Health, consists of four classroom activities, a promotional video, two take-home activities, and accompanying teacher materials.

Implications and Impact

The 5th and 10th grade curriculum meet national and state-level Health Education and Biology Standards and are available free of charge in English and Spanish (<http://learn.genetics.utah.edu>). Classroom testing of these curriculum were favorable. In 2007, the 5th grade curriculum was classroom tested with six 5th grade teachers and 159 students (54.2% Hispanic/Latino, 20.5% White, 14.5% Asian/Pacific Islander, 4.2% African American, 3.7% American Indian/Alaska Native, 3.2% Other). The materials received high ratings for their cultural appropriateness, student engagement, and achieving the intended learning objectives. The take-home activities were effective in engaging parents in their child's education. In 2008, the 10th grade curriculum was tested with six high school health education teachers and approximately 499 students (49.5% Hispanic). Teachers reported that the videos and take-home guide were culturally appropriate and conveyed the importance of family health history, and the classroom activities were engaging.