



MICHIGAN BRFSS SURVEILLANCE BRIEF

A NEWSLETTER FROM THE CHRONIC DISEASE EPIDEMIOLOGY SECTION, MDCH Public Opinion Regarding the Use of Newborn Screening Dried Blood Spots: Results from the 2008 MiBRFS

Background. Newborn Screening is an important public health program to detect serious or potentially life-threatening conditions that benefit from early treatment, such as cystic fibrosis, sickle cell anemia, and PKU. Since the Michigan Department of Community Health (MDCH) Newborn Screening Program began in 1965, a small blood sample has been collected from the heel of nearly every baby born in Michigan. Recent technological advances now allow the state public health laboratory to screen newborns for 49 rare disorders. Dried blood spot samples (DBS) left over after this testing have been stored by MDCH since 1984, as directed by the State Attorney General. In 2000, the Michigan legislature amended the public health code to allow for the use of these leftover DBS in medical research as long as it is conducted in a manner that preserves the confidentiality of the test subjects and protects these subjects from any and all research risks.¹

MDCH, in collaboration with others, has taken steps to identify the utility of residual DBS and the infrastructure needed to support more widespread use of them for public health and medical research by forming a dried blood spot archive, or the Michigan BioTrust for Health. However, the transition to a more formal specimen biobank brings up certain public policy issues.² Partnership and feedback from the public are a vital part of this process.

Methods. MDCH collaborated with the University of Michigan Center for Public Health and Community Genomics to include four questions on the 2008 Michigan Behavioral Risk Factor Survey (MiBRFS) intended to gauge public support for the use of DBS for health research. Funding for this collaboration was made possible through the Centers for Disease Control and Prevention Cooperative Agreement U10/CCU525093.

These four questions focused on whether or not Michigan adults support the use of residual DBS for research in the following areas: research intended to benefit the overall health of Michigan residents in general; research on childhood disease or conditions, such as juvenile diabetes, birth defects or autism; research on adulthood diseases, such as cancer, heart disease or diabetes; and research on the effects of pesticides, lead or other possibly harmful substances on the health of both children and adults. For each of the above research areas the respondents were asked if they “strongly favor”, “somewhat favor”, “somewhat oppose”, “strongly oppose”, or “have no opinion” in regard to using DBS for each type of research. A response of “have no opinion” was considered as a valid response for all four questions.

Rates of support for each category were estimated for each of the four questions. Statistical comparisons were made across demographics and response categories.

References

- ¹ Public Act 33 of 2000 (Senate Bill 0807 of 1999). <http://archive.legislature.mi.gov/>
- ² Couzin-Frankel J (2009) Science Gold Mine, Ethical Minefield. *Science*. 324:166-68.

Table 1. Levels of Support for the Use of Leftover DBS for Health Research, 2008 MiBRFS

	%	95% CI
Research to benefit the health of Michigan residents		
- Strongly Favor	49.9	47.6-52.2
- Somewhat Favor	22.4	20.5-24.4
- Somewhat Oppose	2.6	2.0-3.4
- Strongly Oppose	3.0	2.2-4.0
- No Opinion	22.2	20.2-24.3
Research on childhood diseases		
- Strongly Favor	62.1	59.8-64.4
- Somewhat Favor	22.8	20.9-24.9
- Somewhat Oppose	1.6	1.1-2.2
- Strongly Oppose	1.9	1.3-2.7
- No Opinion	11.6	10.2-13.3
Research on adult diseases		
- Strongly Favor	61.7	59.4-64.0
- Somewhat Favor	25.1	23.0-27.2
- Somewhat Oppose	1.7	1.2-2.4
- Strongly Oppose	2.3	1.6-3.1
- No Opinion	9.3	8.0-10.7
Research on harmful substances		
- Strongly Favor	59.5	57.1-61.8
- Somewhat Favor	24.7	22.7-26.9
- Somewhat Oppose	2.0	1.4-2.7
- Strongly Oppose	3.0	2.3-3.8
- No Opinion	10.9	9.4-12.5

MiBRFSS News:

- The 2008 MiBRFS preliminary tables have been released and can be found on the Michigan BRFS website (www.michigan.gov/brfs) under the “Annual Tables” link.
- The MiBRFS Data Users and 2010 Question Solicitation Meeting will be held on Friday, June 5th from 1:00-3:00 in the Capitol View Building, 1st Floor, Manty Conference Room C. All interested persons are invited to attend. For further information please contact the MiBRFSS at MiBRFSS@michigan.gov.

Results. Among 3,082 respondents, support for research using leftover DBS was high. Table 1 shows that more than 72% of respondents strongly or somewhat favored the use of DBS for research intended to benefit the health of Michigan residents in general (72.3%), while more than 84% somewhat or strongly favored the use of blood spots specifically for research on childhood diseases (84.9%), adult diseases (86.8%), or the effects of harmful substances (84.2%). There was greater uncertainty (i.e. having no opinion) to the more general question about research intended to benefit health (22.2%) compared with the more specific questions (child: 11.6%; adult: 9.3%; harmful substances: 10.9%). Opposition to all research areas was very low (<= 5.6%). In addition, there were no significant differences across the four questions for the percentage of respondents somewhat favoring, somewhat opposing, or strongly opposing research.

For the questions regarding the use of leftover DBS for research on childhood diseases, adult diseases, and the effects of harmful substances, other, non-Hispanic respondents reported significantly lower levels of support for each question compared to White, non-Hispanics (Table 2). The percentage of Black, non-Hispanic respondents who reported strong support for research intended to benefit health, in general, was significantly lower than that of other racial/ethnic groups (data not shown).

When compared to all other age groups, respondents aged 18-24 years and those over age 75 were less likely to strongly favor the use of DBS for general health research (Table 3). All age groups were similar in terms of level of uncertainty (i.e. having no opinion). There was also a correlation between education level and strong support of research in each of the four focus areas (Figure 1). Increasing levels of education were associated with a larger percentage of respondents strongly favoring each type of research.

Conclusions. When asked about a more specific type of research, more than 84% of respondents strongly or somewhat favored the use of residual DBS for research. The data suggest that having more in-depth information about the types of research that would be performed makes an individual more likely to form an opinion, and for that opinion to be in support of using DBS for research. Continuing engagement with the public is vital, and groups with higher percentages of respondents expressing no opinion may be particularly important for outreach. MDCH is currently conducting a more extensive, web-based survey of Michigan residents focusing on the BioTrust. This survey can be accessed through the newborn screening webpage at <http://michigan.gov/newbornscreening>.

Table 3. Support for DBS Research to Benefit the Health of Michigan Residents, in General, By Age, 2008 MiBRFS

	Strongly Favor % (95% CI)	No Opinion % (95% CI)
18-24 years	36.9 (27.8-46.9)	24.2 (16.3-34.3)
25-34 years	56.0 (48.8-63.0)	25.4 (19.4-32.6)
35-44 years	53.4 (48.0-58.7)	19.5 (15.6-24.2)
45-54 years	51.9 (47.4-56.3)	21.1 (17.5-25.1)
55-64 years	52.1 (47.8-56.3)	19.7 (16.4-23.3)
65-74 years	50.4 (45.3-55.5)	20.8 (17.1-25.2)
75+ years	40.7 (35.5-46.0)	28.3 (23.8-33.2)

Figure 1. Strong Support of DBS Research, By Education Level, 2008 MiBRFS

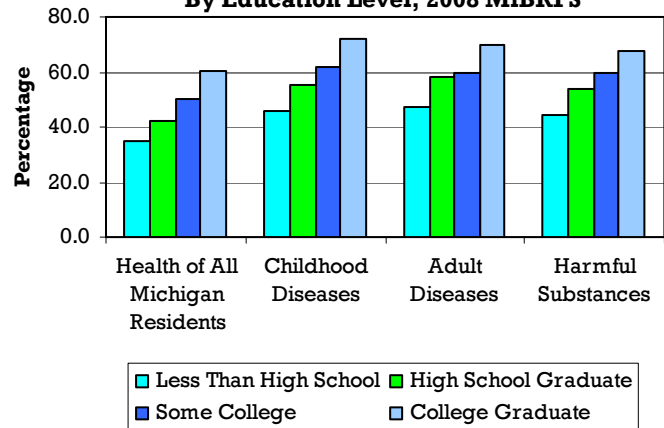


Table 2. Percentage of Michigan Adults Who Somewhat or Strongly Favor the Use of Leftover DBS for Health Research, By Race, 2008 MiBRFS

	Childhood Diseases		Adult Diseases		Harmful Substances	
	%	95% CI	%	95% CI	%	95% CI
White, non-Hispanic	87.0	85.0-88.7	88.4	86.6-90.0	85.4	83.4-87.2
Black, non-Hispanic	78.6	71.8-84.1	82.0	75.9-86.9	82.1	76.2-86.7
Other, non-Hispanic	76.3	65.9-84.2	74.8	64.5-82.9	72.4	62.0-80.8
Hispanic	79.0	62.2-89.6	91.6	78.7-97.0	86.7	71.1-94.5

The Michigan Behavioral Risk Factor Surveillance System (MiBRFSS)

The MiBRFSS comprises annual, statewide telephone surveys of Michigan adults aged 18 years and older and is part of the national BRFSS coordinated by the CDC. The annual Michigan Behavioral Risk Factor Surveys (MiBRFS) follow the CDC BRFSS protocol and use the standardized English core questionnaire that focuses on various behaviors, medical conditions, and preventive health care practices related to the leading causes of mortality, morbidity, and disability. Interviews are conducted across each calendar year. Data are weighted to adjust for the probabilities of selection and a poststratification weighting factor that adjusts for the sex, age, and race distribution of the adult Michigan population. All analyses are performed using SAS-callable SUDAAN® to account for the complex sampling design.

Suggested citation: Gehring J, Fussman C, Rafferty AP, Duquette D, Bach J. Public Opinion Regarding the Use of Newborn Screening Dried Blood Spots: Results from the 2008 MiBRFS. *Michigan BRFSS Surveillance Brief*. Vol. 3, No. 2. Lansing, MI: Michigan Department of Community Health, Chronic Disease Epidemiology Section, May 2009.