

What Parents Want to Know about the Storage and Use of Residual Newborn Bloodspots

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Erin Rothwell, PhD

NHGRI (R01HD062762;
Botkin, PI)



Newborn Screening

- Newborn screening (NBS) is conducted to enable the early identification and treatment of asymptomatic infants with certain genetic, metabolic, and endocrine disorders.
- Education of both clinicians and parents is an important component of NBS.



Newborn Screening Education

- Parents primarily receive information through printed material provided in the newborn nursery and in some prenatal clinics.
- Davis and colleagues identified “seven things parents want to know about newborn screening”
 - few, relatively simple facts regarding these programs



Newborn Screening Research

- Many states' programs store residual bloodspots after the completion of NBS.
- Currently more than half of the states retain specimens for more the 6 months and at least 20 for greater than one year, longer than what is necessary for clinical use.
- These can be used for quality improvement, biomedical research, and forensic applications.



Newborn Screening Research

- Controversy has emerged over this practice: two state health departments (TX, MN) were sued by parents who objected to the retention of these samples without parental knowledge and consent, leading to fundamental changes in those programs.

Help!!! The Gov't Has My DNA





Public Opinion about NBS Research

- Research evidence clearly indicates that the public, particularly parents of young children supportive of:
 - Newborn Screening
 - Newborn Screening Research
- Secretary's Advisory Committee on Heritable Disorders in Newborns and Children recommended to improve education of parents and clinicians about retention and use of residual bloodspots

Methods

- This was one component of a larger, NIH funded randomized controlled trial
 - Prenatal Education and Choice about Newborn Screening and Bloodspot Retention
 - Comparing three interventions:
 - Prenatal Newborn Screening only
 - Prenatal Newborn Screening and Bloodspot Retention
 - Control group

Methods

- Semi-structured Interview Guide
 - Rothwell, E., Clark, L., Anderson, R., & Botkin, J.R. (2012). Residual Newborn Screening Samples for Research: Parental Information Decision Needs. *Journal of Specialists in Pediatric Nursing, 18*(2), 115-122. DOI: 10.1111/jspn.12017
- Intervention Development
 - Video Development
 - Genetic Science Learning Center



Focus Groups

- 1.5 and 2 hours
- 11 focus groups (n = 128)
 - February and May 2012
 - Utah, Washington, California, and Minnesota
 - Women who were pregnant, partners of a pregnant woman, or parents of children who were 5 years of age or younger

Gender	N	%
Female	70	54.7
Male	58	45.3
Ethnicity/Race		
White	41	32.0
Latino	43	33.6
African American/Black	36	28.1
Asian/Pacific Islander	7	0.8
Multi-Racial	1	5.5
Income (missing n = 12)		
< \$25,000	23	19.8
\$25,000-\$45,000	43	37.1
\$46,000-\$65,000	25	21.6
>\$65,000	25	21.5

Age	N	%
18-29 years	46	35.9
30-39 years	71	55.5
40-49 years	11	8.6
Education		
< High School	4	3.1
High School	18	14.1
Some College/Bachelors Degree	72	55.3
Technical/Associate Degrees	22	12.2
Graduate Degree	12	9.4

Data Analysis

- Qualitative content analysis
 - Atlas.ti
- The coding template systematically applied to transcripts
- Independent reviewer of coded data
 - No discrepancies emerged
- All coded data was queried and reviewed for content
 - Review density and type of codes.
 - No differences between states were identified.
- The emerging categories from these analyses were presented and discussed by the research team and by an advisory committee comprised of national experts in newborn screening



Results

- Limitations
 - Influenced by what we told them about the topic and the movie presentations
- Protocol was designed to provide:
 - broad background on the issues
 - extensive group discussion
 - prioritize key information

Results

- Priorities emerged from the groups that we had not highlighted or predicted in our presentation of background information.
- additional heel pricks were conducted for the storage of DBS
- the expectation that research results would be returned to parents
- not feasible for care providers in the newborn nursery to describe the types of research being conducted with DBS

7 Things Parents want to know about leftover NBS bloodspots

- Some states save leftover bloodspots after newborn screening is complete.
- Leftover bloodspots can be used to improve the public's health in many ways.
- No extra heel pricks are done to collect blood for other potential uses of the spots.
- Safeguards are in place to protect the privacy of babies and families and to ensure the ethical conduct of research.
- The baby's name or other identifiable information is not attached to the leftover bloodspots used in most research.
- Because most research with leftover bloodspots is done anonymously, parents will usually not get results back from the research.
- A parent may request that their baby's bloodspot not be used in research after newborn screening.



Discussion

- Current educational approaches for parents about NBS are inadequate
 - Timing of newborn screening
 - Brochure format
- Prenatal education is an option
- Informing prospective parents about key points about leftover NBS bloodspots is important
- Accepted for publication in the American Journal of Medical Genetics

Current Grant Progress

- >32 weeks pregnant
- Delivered in clinical setting
- Telephone follow up 2-4 postpartum
- N = 642
 - Utah: 215
 - New York: 174
 - California: 253

External Advisory Board

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