OBJECTIVES: Retaining residual newborn screening (NBS) bloodspots for medical research remains contentious. To inform this debate, we sought to understand public preferences for, and reasons for preferring, alternative policy options.

METHODS: We assessed preferences among 4 policy options for research use of residual bloodspots through a bilingual national Internet survey of a representative sample of Canadians. Fifty percent of respondents were randomly assigned to select reasons supporting these preferences. Understanding of and attitudes toward screening and research concepts, and demographics were assessed.

RESULTS: Of 1102 respondents (94% participation rate; 47% completion rate), the overall preference among policy options was ask permission (67%); this option was also the most acceptable choice (80%). Assume permission was acceptable to 46%, no permission required was acceptable to 29%, and no research allowed was acceptable to 26%. The acceptability of the ask permission option was reduced among participants assigned to the reasoning exercise (84% vs 76%; \( P = .004 \)). Compared with assume/no permission required, ordered logistic regression showed a significant reduction in preference for the ask permission option with greater understanding of concepts (odds ratio, 0.87; \( P < .001 \)), greater confidence in science (odds ratio, 0.16; \( P < .001 \)), and a perceived responsibility to contribute to research (odds ratio, 0.39; \( P < .001 \)).

CONCLUSIONS: Surveyed Canadians prefer that explicit permission is sought for storage and research use of NBS bloodspots. This preference was diminished when reasons supporting and opposing routine storage, and other policy options, were presented. Findings warrant consideration as NBS communities strategize to respond to shifting legislative contexts.
Repositories of residual newborn screening (NBS) bloodspots exemplify the promise and challenge of big data for translational research. They provide unbiased coverage of populations for medical and public health research but raise questions regarding appropriate governance. Policy and practice related to the storage and retention of residual NBS bloodspots for medical research remain variable and contentious.\textsuperscript{1–5} Lawsuits have challenged NBS programs’ right to retain samples for research without explicit parental consent, resulting in the destruction of some population-level biospecimen collections.\textsuperscript{6–11} However, supporters of the “opt-out” (ie, nonexplicit consent) model argue that it ensures high participation rates and is simply more feasible than seeking explicit permission.

Despite this apparent flexibility, proposed changes to the Common Rule, prompted by the NBS Saves Lives Reauthorization Act of 2014, suggest that US federally funded NBS research will require explicit consent for use of bloodspots, eliminating the ability of ethics boards to waive consent.\textsuperscript{24–27} Recent guidance from the American Society of Human Genetics also advocates parental choice regarding the use of bloodspots.\textsuperscript{28} What constitutes informed consent in this context, and how this legislation and professional guidance will affect other jurisdictions, remains unknown. Whether public preferences for explicit consent are robust in the face of practical and value-based challenges associated with consent also remains unknown. To deepen our understanding of public preferences for this complex policy issue and to inform the development of strategies related to storage and use of NBS bloodspots in a shifting legislative context, we report results from a study that engaged the Canadian public on this policy question.

METHODS
Sample and Data Collection
We conducted a cross-sectional, bilingual (English and French) national Internet survey of a representative sample of Canadians in 2013.\textsuperscript{29} We contracted with Survey Sampling International, specialists in online data collection for academic and market research. Respondents were recruited who met prespecified criteria for age, gender, and region of residence, in accordance with Statistics Canada data.\textsuperscript{30} We oversampled individuals with children aged <5 years to allow subgroup analysis comparing parents of young children with others. Eligible participants were sent an e-mail invitation to participate in the survey by following a link. The survey comprised 3 separate sections to optimize survey completion; respondents were given the option to continue after each section, with incentives (rewards points, prize draws, or cash) dependent on the section(s) completed. University of Toronto’s Health Sciences Research Ethics Board approved the study.

Study Questionnaire
The questionnaire was developed by our multidisciplinary team based on previous research\textsuperscript{15} and a literature review.\textsuperscript{31–36} It was pretested through 3 rounds of face-to-face cognitive interviews (n = 16) and piloted with members of the Internet panel (n = 87) to assess face and content validity and comprehension. The questionnaire was designed to educate respondents and measure knowledge and attitudes related to NBS (sections 1 and 2) and the use of residual bloodspots for medical research (section 3). We provided respondents with essential information about this type of research by specifying 3 minimum conditions: (1) all research would meet strict scientific and ethical standards (ie, reviewed and approved by an ethics board); (2) all personal information would be removed to protect privacy (ie, identification number used for sample identity, linking to personal health records possible but rigorously secured); and (3) the NBS program would be responsible for deciding what type of research could be conducted. The survey included professionally designed images to convey these concepts in a visually appealing way and included interactive quizzes (Supplemental Figure 1) to explain relevant content.

Measures
We solicited preferences for 4 specific policy options: no research (the samples are destroyed after NBS, and thus no research is possible), ask for permission for research (parents are asked for their permission to store their infant’s sample for future research; unless parents agree to
research, their infant’s sample will not be used), assume permission for research (parents are not asked for their permission to use their infant’s sample for future research; permission is assumed, but there is a clear process for parents to opt out), and no permission needed for research (parents are not asked for their permission to use their infant’s sample for future research; permission is not considered necessary). We specified that if parents are asked for permission, it would be for all potential medical research rather than for one specific study. Respondents were asked to rate the acceptability of each policy option on its own (4-point Likert scale: completely or somewhat unacceptable, somewhat or completely acceptable) (Supplemental Figure 2), and we included a forced choice question, asking respondents to identify which of the 4 policy options they preferred overall (Supplemental Figure 3).

Understanding of bloodspot storage was assessed by using true/false quizzes (Supplemental Figure 1). After each concept was explained, a quiz assessed understanding, followed by real-time feedback and corrected answers, as appropriate. We also assessed respondents’ trust in medical research by using 2 items from the Eurobarometer Social Values on Science and Technology Survey\textsuperscript{36} (5-point Likert scales, scored from strongly agree to strongly disagree) and 1 de novo item related to research privacy. Views regarding the importance of the public’s involvement in governing medical research, the sense of personal duty to participate in medical research, and views on the responsibility of others to participate (5-point Likert scales, scored from strongly agree to strongly disagree) were also solicited. We assessed previous awareness that NBS samples could be stored for future research (ie, samples are currently retained in Canada, albeit with variable consent processes, duration, and research use policies).\textsuperscript{37}

Finally, we drew from Johri et al\textsuperscript{31} to develop a novel approach to the use of value-based reasoning in the elicitation of public preferences. To test the effect of reasoning on policy preferences, one-half of the respondents were randomly assigned to an exercise that presented them with 6 pro/con reasons, developed by the authors to represent the most salient, countervailing logics driving this debate. Reasons were related to the goal of NBS, the challenge of consent, and trust in the research enterprise.\textsuperscript{38–40} Three reasons supported routinized bloodspot storage (research is an important opportunity, consent has costs, and medical research can be trusted), and 3 reasons opposed routinized storage (research is not the primary goal of NBS, consent is necessary, and research protections are not always enough) (Supplemental Figure 4). Participants were then asked to select the most influential reason for each of their judgments about the acceptability of the 4 policy options (Supplemental Figure 5) and for their overall policy preference (Supplemental Figure 6).

\textbf{Analysis}

Descriptive and multivariate statistics were used, and \( \chi^2 \) tests were used to assess proportional differences where applicable; 1-sided \( P \) values <.05 indicated statistical significance. Two composite measures were produced: correct responses to the quizzes were summed to produce the “understanding of screening and sample storage” measure, scored from 0 to 24, with higher scores indicating greater understanding of these concepts. The “trust in medical research” index was scored from 1 to 15 and normalized on a scale of 0 to 1 indicating less or more trust in research, respectively. The reliability of these measures was assessed; high Cronbach’s alphas (0.70 each) supported their inclusion in the regression model.

To identify the prevailing policy preference and understand the predictors of this preference, including the role of reasoning, policy preferences were categorized as “acceptable” (completely or somewhat acceptable) or “unacceptable” (completely or somewhat unacceptable). The proportional odds assumption was met (ie, odds ratio [OR] was the same irrespective of the cut-point between “no permission required,” “assume permission,” and “ask for permission”); thus, ordinal logistic regression was used to assess the association between sociodemographic characteristics, knowledge, and attitudes and the most popular policy option. Data were managed and analyzed by using Stata version 10.1 (Stata Corp LP, Station College, TX).

\textbf{RESULTS}

\textbf{Survey Respondents}

Response rates are not typically measured for Internet surveys, where recruitment is designed to achieve quotas.\textsuperscript{41} The participation rate was 94%, reflecting the proportion of respondents who agreed to participate (\( n = 2345 \)) of the number of unique individuals who visited the first survey page (\( n = 2499 \)). The survey completion rate was 47%, reflecting the proportion of respondents who completed all 3 sections of the survey and met predetermined response quality criteria from those who agreed to participate (ie, we removed respondents who completed sections in less than the minimum prespecified time or “straight-lined” through the same response column for blocked items). Of the 1102 respondents who completed sections 1 through 3, a total of 547 were randomized to receive the reasoning exercise.
Compared with the general population, the sample was better educated and had higher median income (Census 2013) (Table 1). Compared with those who completed only sections 1 and 2 (n = 780), respondents who completed sections 1 through 3 (n = 1102) were more likely to be female (P < .001), older (P < .01), and score better on the understanding questions (P < .01). There were no differences between groups according to the other demographic variables, nor demographic differences between those randomized or not to participate in the reasoning exercise.

**Prevailing Policy Preference**

The rating exercise for each policy option indicated that ask for permission was acceptable (completely or somewhat) to 80% of respondents, assume permission was acceptable to 46%, no permission needed was acceptable to 29%, and no research was acceptable to 26%. When forced to choose among policy options, ask for permission was selected by the largest proportion (67%) and no research was selected by the fewest (1%) (Table 2).

**Reasons Associated With Policy Preferences for Those Randomized**

Table 3 summarizes the relationships between the ratings for each of the 4 policy options (i.e., individually and forced choice) and the reasons available to participants to justify their choices. Across all policy options, the most frequently selected reason endorsed routinized storage (ie, important research opportunity; up to 85%), whereas the next most frequently selected reason opposed "..."
routinized storage (ie, consent is necessary; up to 73%); small minorities selected consent has costs (2%–10%), medical research can be trusted (7%–9%), research is not the goal of NBS (2%–4%), and research protections aren’t always enough (4%–11%).

**Effect of Reasoning Exercise**

Those randomized to the reasoning exercised found that the ask permission policy option was less acceptable than those not randomized: 76% vs 84% ($P = .004$). Exposure to reasoning was not significantly associated with attitudes toward the acceptability of the other 3 policy options.

**Attitudes, Understanding, and Awareness Regarding Medical Research**

The majority demonstrated a strong understanding of screening and storage concepts once introduced to them (mean, 22/24 correct; SD, 2.39), although most were unaware that NBS blood samples could be stored for medical research (83%). Most expressed trust in medical research (81%–87%), and a majority positively valued public involvement in the governance of medical research (65%). With respect to perceived duties and the responsibilities of others, a majority were disposed to donate their own residual biological material to medical research (88%) but fewer believed that others were obliged to do so (33%) (Table 4).

**Ordinal Regression**

Respondents with lower knowledge and trust scores were more likely to have selected the ask permission policy option (OR, 0.88 [95% confidence interval (CI), 0.82–0.95]; OR, 0.14 [95% CI, 0.04–0.45], respectively). This option was also more likely to be selected by those who did not believe it a personal duty or a responsibility of others to participate in research (OR, 0.34 [95% CI, 0.14–0.83]; OR, 0.40 [95% CI, 0.28–0.57], respectively), as well as by those who positively valued public involvement in research governance (OR, 1.59 [95% CI, 1.36–1.86]; $P < .001$). Demographic factors (including having children), awareness of sample storage, and participating in the reasoning exercise were not associated with this policy preference (Table 5).

**DISCUSSION**

In light of the ongoing debate related to storage and research uses of newborn bloodspots, our findings provide timely insight. Seeking explicit permission is highly valued, even when respondents are probed, and some of the practical and value-based challenges associated with this approach are exposed. When asked to rate the acceptability of the ask permission...
policy option on its own, the vast majority of respondents (80%) were supportive. Support for this option remained high (76%) but was significantly reduced among those offered credible reasons for supporting or opposing routinized storage, relative to those not offered such reasons. As well, when forced to choose among 4 different policy options, a smaller majority (67%) selected ask permission than the 80% who deemed it an acceptable option. Furthermore, the ordered logistic regression suggests that the preference for the ask permission policy option was sensitive to respondents’ knowledge about and attitudes toward research more generally. Specifically, a greater understanding of screening and research concepts, trust in research, and a perceived responsibility to participate in research were associated with reduced support for explicit permission.

These findings endorse that the public prefers explicit consent, extend related research by identifying the robustness of this preference in the face of reasoning, and highlight public attitudes to which this preference may be sensitive. Arguably, these findings leave the NBS community with 2 policy options. One option would be to align with the apparent majority preference and develop an explicit permission-based model. Although the precise method of consent mandated by the NBS Saves Lives Reauthorization Act has not been articulated, an explicit consent approach would presumably meet its bar. However, claims related to lack of feasibility and concerns about reduced uptake persist\(^12,20\) and suggest that optimizing voluntariness and collective public health remains a delicate balancing act. Some evidence suggests that it is feasible to implement permission-based models.\(^{17,20,42–44}\) Of note, Charles et al\(^{20}\) tested this approach by using a 2-stage written consent protocol. They allowed parents to provide separate consent for: (1) their infant to be screened; and (2) secondary use of the sample for research. NBS participation remained >99%, and only 6.5% of parents opted out of research use. However, other consent-based biorepository models (eg, Michigan BioTrust for Health) achieve more moderate uptake (ie, 60%), raising questions about whether explicit consent compromises the ability of programs to conduct generalizable research.\(^{44}\)

A second option might be informed by the results of the logistic regression and the evidence of somewhat diminished enthusiasm for explicit consent among those exposed to the reasoning exercise. Such an approach would mobilize efforts

---

### TABLE 4 Respondents’ Knowledge, Awareness, and Attitudes Related to Newborn Screening and Medical Research

<table>
<thead>
<tr>
<th>Construct</th>
<th>Item</th>
<th>Total (N = 1102)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge(^a)</td>
<td>Index of understanding composite score (maximum, 24), mean ± SD</td>
<td>21.72 ± 2.39</td>
</tr>
<tr>
<td>Awareness</td>
<td>Aware that blood samples collected for NBS could be stored and made available for research</td>
<td>Yes</td>
</tr>
<tr>
<td>Attitudes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trust in medical research(^b)</td>
<td>Medical research will help to cure illnesses such as AIDS and cancer</td>
<td>Strongly agree/agree</td>
</tr>
<tr>
<td></td>
<td>Most medical researchers want to work on things that will make life better for the average person</td>
<td>Strongly agree/agree</td>
</tr>
<tr>
<td></td>
<td>The privacy and confidentiality of people who participate in medical research will be protected</td>
<td>Strongly agree/agree</td>
</tr>
<tr>
<td>Public involvement in research governance</td>
<td>To direct medical research in the right way, it would be better to take more account of what the public thinks, in other words people like you and me</td>
<td>Strongly agree/agree</td>
</tr>
<tr>
<td>Willingness to participate in research</td>
<td>After my doctor uses my blood sample for my care, I would let my leftover sample be used for medical research</td>
<td>Strongly agree/agree</td>
</tr>
<tr>
<td>Perceived obligation of others to participate in research</td>
<td>After a doctor uses a blood sample for someone’s health care, I think it would be irresponsible for them to refuse to let their leftover sample be used for medical research</td>
<td>Strongly agree/agree</td>
</tr>
</tbody>
</table>

Unless otherwise indicated, data are presented as n (%).

\(^a\) Index sums the number of correct responses given to 24 questions (Cronbach’s \(\alpha\) = 0.70).

\(^b\) “Trust in medical research” index (Cronbach’s \(\alpha\) = 0.70; 0–1 scale; mean ± SD, 0.80 ± 0.16).
to optimize educational strategies and build trust to support a more passive opt-out model. In response to parents’ stated preferences for receiving information prenatally about NBS and the use bloodspots for research,¹ ⁴ ⁵ ⁶ and the Division of Health and Human Services Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children’s recommendations regarding these goals,⁷ efforts to develop educational tools are underway. For example, a recent study¹ ⁴ identified 7 things parents want to know about residual bloodspots (ie, details about storage, potential uses, risks and burdens, safeguards, anonymity, return of results, parental choice) and suggested that implementing this knowledge base would improve understanding, trust, and acceptance toward retaining and using stored bloodspots. Whether an opt-out model supported by a robust educational process would comply with the notion of choice recommended by the American Society of Human Genetics,²⁸ meet the requirements of the NBS Saves Lives Reauthorization Act,²⁷ and be feasible to implement remains to be seen.

We acknowledge several limitations. First, in presenting the policy options, we did not include parental “notification” as a specific policy option or as an element of any of the policy options because we could not guarantee that such would occur. Ask permission was, arguably, the only mechanism in which parents were involved in an explicit decision. Second, we cannot determine from our findings if respondents’ conceptualized “permission” as equivalent to the notion of consent, itself having a legal connotation. Although an explicit link between permission and consent is made itself having a legal connotation. Although an explicit link between permission and consent is made to implement only one-half of our respondent group. Third, because of the structure of the questionnaire, which considered screening before issues of storage and research, we cannot shed light on the effect issues of storage and research, we cannot shed light on the effect policy preferences might have on screening uptake. Fourth, the reasoning exercise had a significant impact on the public’s preferences in only 1 instance; this outcome may be explained by the stability of participant opinion, incomplete ascertainment of considered judgments, the inconsistency of some

---

**TABLE 5 Predictors of “Ask for Permission” Policy Preference: Ordered Logistic Regression**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Ask Permission Policy Preference, Odds Ratio (SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (reference: male)</td>
<td>1.01 (0.16)</td>
</tr>
<tr>
<td>Female (CI, 0.74–1.58)</td>
<td></td>
</tr>
<tr>
<td>Age (reference: ≥55 y)</td>
<td></td>
</tr>
<tr>
<td>18–35 y (CI, 0.81–2.30)</td>
<td>1.36 (0.36)</td>
</tr>
<tr>
<td>36–54 y (CI, 0.78–1.64)</td>
<td>1.14 (0.21)</td>
</tr>
<tr>
<td>Geographic region (reference: Quebec)</td>
<td></td>
</tr>
<tr>
<td>Eastern Canada (CI, 0.48–1.59)</td>
<td>0.88 (0.27)</td>
</tr>
<tr>
<td>Ontario (CI, 0.72–1.57)</td>
<td>1.07 (0.21)</td>
</tr>
<tr>
<td>Western Canada (CI, 0.89–2.04)</td>
<td>1.35 (0.28)</td>
</tr>
<tr>
<td>Income (reference: $80 000 or higher)</td>
<td></td>
</tr>
<tr>
<td>Less than $40 000 (CI, 0.90–2.12)</td>
<td>1.39 (0.30)</td>
</tr>
<tr>
<td>$40 000–$78 999 (CI, 0.78–1.64)</td>
<td>1.13 (0.21)</td>
</tr>
<tr>
<td>Education (reference: postsecondary)</td>
<td></td>
</tr>
<tr>
<td>High school or less (CI, 0.66–1.50)</td>
<td>1.00 (0.21)</td>
</tr>
<tr>
<td>College/CEGEP (CI, 0.78–1.61)</td>
<td>1.11 (0.21)</td>
</tr>
<tr>
<td>City size (reference: ≥50 000)</td>
<td></td>
</tr>
<tr>
<td>&lt;30 000 (CI, 0.75–1.72)</td>
<td>1.13 (0.24)</td>
</tr>
<tr>
<td>30 000–499 999 (CI, 0.52–1.05)</td>
<td>0.74 (0.13)</td>
</tr>
<tr>
<td>Relationship status (reference: not married/not common law)</td>
<td></td>
</tr>
<tr>
<td>Married/common law (CI, 0.84–1.66)</td>
<td>1.18 (0.21)</td>
</tr>
<tr>
<td>Children (reference: children aged &lt;5 y)</td>
<td></td>
</tr>
<tr>
<td>Children aged &gt;4 y (CI, 0.49–1.32)</td>
<td>0.80 (0.20)</td>
</tr>
<tr>
<td>Plan/pregnant, no children (CI, 0.66–2.33)</td>
<td>1.24 (0.40)</td>
</tr>
<tr>
<td>No plan/pregnant, no children (CI, 0.38–1.18)</td>
<td>0.67 (0.19)</td>
</tr>
<tr>
<td>Knowledge/awareness</td>
<td></td>
</tr>
<tr>
<td>Index of understanding (CI, 0.82–0.95)</td>
<td>0.68 (0.03)</td>
</tr>
<tr>
<td>Aware of sample storage for medical research (CI, 0.70–1.51)</td>
<td>1.03 (0.20)</td>
</tr>
<tr>
<td>(reference: not aware)</td>
<td></td>
</tr>
<tr>
<td>Attitudes toward research</td>
<td></td>
</tr>
<tr>
<td>Trust in medical research (CI, 0.04–0.45) (reference: not agree on trust items)</td>
<td>0.14 (0.08)</td>
</tr>
<tr>
<td>Public involvement important (CI, 1.36–1.86) (reference: not important)</td>
<td>1.59 (0.12)</td>
</tr>
<tr>
<td>Personal duty to participate (reference: neutral)</td>
<td></td>
</tr>
<tr>
<td>Disagree personal duty (CI, 0.13–2.07)</td>
<td>0.51 (0.36)</td>
</tr>
<tr>
<td>Agree personal duty (CI, 0.14–0.83)</td>
<td>0.34 (0.16)</td>
</tr>
<tr>
<td>Perceived responsibility of others to participate (reference: neutral)</td>
<td></td>
</tr>
<tr>
<td>Disagree irresponsible of others not to donate (CI, 0.92–2.01)</td>
<td>1.37 (0.27)</td>
</tr>
<tr>
<td>Agree irresponsible of others not to donate (CI, 0.28–0.57)</td>
<td>0.40 (0.07)</td>
</tr>
<tr>
<td>Reasoning exercise (CI, 0.67–1.22)</td>
<td>0.91 (0.14)</td>
</tr>
<tr>
<td>Pseudo R²</td>
<td>0.12</td>
</tr>
<tr>
<td>N</td>
<td>914</td>
</tr>
<tr>
<td>Test of proportionality of odds</td>
<td>24.24 (P &gt; .05)</td>
</tr>
<tr>
<td>Brant test of parallel regression assumption</td>
<td>25.54 (P &gt; .05)</td>
</tr>
</tbody>
</table>

Dependent Variable: 0 = no permission required; 1 = assume permission; and 2 = ask for permission.

¹ Index sums the number of correct responses given to 24 questions (α = 0.70).

² Selected items from the Eurobarometer Social Values on Science and Technology Survey. "Trust in Medical Research" index created (α = 0.70; 0–1 scale; mean ± SD, 0.80 ± 0.16).

³ P < .10.

⁴ P < .05.

**P < .001.
reasoning, or participant disinterest. A final limitation concerns the structure of our public engagement exercise, which was consultative, rather than deliberative. Recent research suggests the value of deliberative engagements in the context of population screening, but our study suggests that carefully composed Internet surveys can also be used to elicit considered judgments and thereby provide more quantitative data on the strength of preferences and the structure of tradeoffs. Our efforts to increase the intensity with which participants considered the issue (using an explicit reasoning exercise) were novel, and our findings make an important contribution to the NBS dialogue and to public engagement methodology.

Despite these limitations, we engaged a demographically diverse and representative public in a complex public policy issue by using a detailed online training module and a range of strategies to deepen participant involvement. Finally, we reiterate the value of engaging lay publics rather than invested consumers, parents, and professionals because the research at stake is considered to be a public good.

CONCLUSIONS

Members of the Canadian public prefer that explicit permission be sought for storage and research use of NBS bloodspots. Although enthusiasm for this option was not without qualification, the majority remained committed to an explicit permission model. In the context of a shifting legislative context, these findings warrant consideration.

ABBREVIATIONS

CI: confidence interval
NBS: newborn screening
OR: odds ratio

REFERENCES


41. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys.


Using Newborn Screening Bloodspots for Research: Public Preferences for Policy Options
Robin Z. Hayeems, Fiona A. Miller, Carolyn J. Barg, Yvonne Bombard, Celine Cressman, Michael Painter-Main, Brenda Wilson, Julian Little, Judith Allanson, Denise Avard, Yves Giguere, Pranesh Chakraborty and June C. Carroll
Pediatrics 2016;137; originally published online May 17, 2016; DOI: 10.1542/peds.2015-4143

Updated Information & Services
including high resolution figures, can be found at:
/content/137/6/e20154143.full.html

Supplementary Material
Supplementary material can be found at:
/content/suppl/2016/05/13/peds.2015-4143.DCSupplemental.html

References
This article cites 43 articles, 10 of which can be accessed free at:
/content/137/6/e20154143.full.html#ref-list-1

Subspecialty Collections
This article, along with others on similar topics, appears in the following collection(s):
Ethics/Bioethics /cgi/collection/ethics:bioethics_sub
Genetics /cgi/collection/genetics_sub

Permissions & Licensing
Information about reproducing this article in parts (figures, tables) or in its entirety can be found online at:
/site/misc/Permissions.xhtml

Reprints
Information about ordering reprints can be found online:
/site/misc/reprints.xhtml
Using Newborn Screening Bloodspots for Research: Public Preferences for Policy Options
Robin Z. Hayeems, Fiona A. Miller, Carolyn J. Barg, Yvonne Bombard, Celine Cressman, Michael Painter-Main, Brenda Wilson, Julian Little, Judith Allanson, Denise Avard, Yves Giguere, Pranesh Chakraborty and June C. Carroll
Pediatrics 2016;137;; originally published online May 17, 2016;
DOI: 10.1542/peds.2015-4143

The online version of this article, along with updated information and services, is located on the World Wide Web at:
/content/137/6/e20154143.full.html