Citizens' Values Regarding Research With Stored Samples From Newborn Screening in Canada

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KEY WORDS

newborn screening, storage, blood spots, policy, public engagement, public health, research

ABBREVIATION

NBS—newborn screening

Dr Miller led the study, and is the guarantor for the study. Drs Bombard, Miller, and Avard and Ms Bytautas and Axler conducted the focus groups. Drs Bombard and Miller and Ms Bytautas developed initial interpretations of the data and participated in data analysis. Dr Bombard drafted the manuscript; Drs Bombard and Miller revised the manuscript. Drs Hayeems, Allanson, Carroll, Chakraborty, Giguere, Little, and Wilson were involved in study design and oversight; they reviewed initial data analysis memos and suggested revisions to versions of the manuscript. All authors read and approved the final manuscript.

www.pediatrics.org/cgi/doi/10.1542/peds.2011-2572

doi:10.1542/peds.2011-2572

Accepted for publication Oct 31, 2011

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

FINANCIAL DISCLOSURE: *The authors have indicated they have no financial relationships relevant to this article to disclose.*

COMPANION PAPERS: Companions to this article can be found on pages 231 and 365, and online at www.pediatrics.org/cgi/doi/10.1542/peds.2011-0970 and www.pediatrics.org/cgi/doi/10.1542/peds.2011-3416.

WHAT'S KNOWN ON THIS SUBJECT: Newborn screening (NBS) programs may store bloodspot samples and use them for secondary purposes, such as research. Recent public controversies and lawsuits over storage and secondary uses underscore the need to engage the public on these issues.

WHAT THIS STUDY ADDS: This public engagement study identifies values underlying citizens' acceptance of and discomfort with research from NBS samples. Well-designed methods of public education and civic discourse on the risks and benefits of storage and secondary uses of NBS samples are required.

abstract

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OBJECTIVES: Newborn screening (NBS) programs may store bloodspot samples and use them for secondary purposes. Recent public controversies and lawsuits over storage and secondary uses underscore the need to engage the public on these issues. We explored Canadian values regarding storage and use of NBS samples for various purposes and the forms of parental choice for anonymous research with NBS samples.

METHODS: We conducted a mixed-methods, public engagement study comprising 8 focus groups (n = 60), an educational component, deliberative discussion, and pre- and post-questionnaires assessing knowledge and values toward storage and parental choice.

RESULTS: Canadian citizens supported the storage of NBS samples for quality control, confirmatory diagnosis, and future anonymous research (>90%). There was broad support for use of NBS samples for anonymous research; however, opinions were split about the extent of parental decision-making. Support for a "routinized" approach rested on trust in authorities, lack of concern for harms, and an assertion that the population's interest took priority over the interests of individuals. Discomfort stemmed from distrust in authorities, concern for harms, and prioritizing individual interests, which supported more substantive parental choice. Consensus emerged regarding the need for greater transparency about the storage and secondary use of samples.

CONCLUSIONS: Our study provides novel insights into the values that underpin citizens' acceptance and discomfort with routine storage of NBS samples for research, and supports the need to develop well-designed methods of public education and civic discourse on the risks and benefits of the retention and secondary use of NBS samples. *Pediatrics* 2012;129:239–247

Controversies and lawsuits have emerged internationally over the storage and secondary use of samples collected through newborn screening (NBS),[1–5] a routine population program in most industrialized countries.[6] These lawsuits have challenged NBS programs' capacity to retain and make samples available for research without express parental consent. In British Columbia, Canada, a class action lawsuit claimed that storage of samples represented an unlawful search and seizure, violating the Canadian Charter of Rights and Freedoms. The initial judgment rejected this claim but allowed that genuine issues remained, relating to "the use of the sample for purposes other than promoting the health of the infant"; thus, further legal action is likely.[7] In Minnesota, a similar case was resolved in the state's favor, but in Texas, the legal settlement led to significant change in the state's NBS program, with an increase in information for parents and the destruction of nearly 5 million stored NBS samples.[2,8] These cases exemplify the controversy that policy makers face in responding to numerous contentious issues linked with the storage and secondary uses of NBS samples.

Many programs retain NBS samples to facilitate confirmation of results, quality control, and postmortem diagnosis[9,10]; however, they may also be used for purposes unrelated to the initial NBS program, including research, public health surveillance, and occasional nonmedical purposes (eg, identifying disaster victims or law enforcement proceedings).[11,12] As an unbiased, population-wide source of data, NBS samples are especially valuable for research. Consequently, they have been used in epidemiologic research on infectious diseases, environmental exposures, and the etiology of birth defects.[13]

Controversies regarding the storage and secondary use of NBS samples raise anew the issue of parental consent for NBS. Explicit informed consent for NBS is uncommon in North America (NBS is strongly encouraged in Canada and mandatory in most US states, with consent not required in either country)[14,15]; yet, consensus is lacking regarding the appropriateness of this approach for the secondary use of stored NBS samples, and whether informed consent, of a general or specific nature, should be obtained before NBS samples may be used in research.[16] On the one hand, several commentators object to the lack of explicit informed consent for NBS generally,[17,18] and have suggested that individuals be given choices about the use of their samples for research.[17] Opponents argue that explicit consent should not be introduced because of high costs, limited capacity to inform parents,[19,20] and fears that consent processes for secondary uses may threaten NBS uptake.[15,21] In addition, some contend that research with unidentified NBS samples poses minimal risk and should not require consent.[22–24] Further, most international guidance permits secondary research on NBS samples without explicit consent under certain conditions.[16] In Canada, policy regarding the storage and secondary uses of NBS samples differs across provinces,[8,9,25–27] and remains underdeveloped. Few programs explicitly discuss the storage of NBS samples in publicly available educational material, or offer the opportunity to remove samples after a specific period of time.[28,29]

Given these contentions, various stakeholders' views have been explored. Most studies have found that parents, providers, and the public are willing to store infants' samples for research.[15,30–32] Findings regarding the need for parental consent vary by jurisdiction, stakeholder, and methods used, however[21,30–34]; moreover, the values underpinning these positions remain unexplored. Understanding these values is crucial for informing the development of evidence-informed public health interventions and policy initiatives.[21,35] Further, recent controversies and lawsuits underscore the need to understand public values on these issues.[5,36] Thus, we conducted a public engagement study to explore Canadian citizens' values regarding storage of NBS samples for various purposes and types of parental choice for anonymous medical research.

METHODS

Study Design

This mixed-methods study was designed to explore Canadian values regarding the scope of NBS and issues related to storage and secondary use of NBS samples.

Sample Recruitment

With approval from the University of Toronto Health Sciences Research Ethics Board and the McGill University Research Ethics Board, participants were recruited in the Greater Toronto and Montreal Areas in 2009. To generate a sample that was broadly representative of the community and fostered socioeconomic, age, and family-life diversity (eg, marital status, parenthood, etc), we worked through community agencies serving families and advertised through related forums. Only adults and those able to consent in English were included; no other exclusion or inclusion criteria were applied

Data Collection

Focus Groups

Semistructured focus groups were conducted, each of which included: an educational component, deliberative discussion, and pre- and post-questionnaires assessing knowledge and values toward NBS. The educational component covered the purposes of

storing NBS samples and the types of biomedical or health services research for which they are used. These topics were circulated as a pamphlet ~1 week before each focus group. The topics were reviewed before the session began. Discussions were guided by showcards that used a story with several "reveals" or outcomes, and were followed by questions on which the group was asked to deliberate (Appendix).

Educational Component, Questionnaire, and Administration

The educational component, pamphlet, and questionnaire were developed by a multidisciplinary team, based on a review of the literature,[16,34,37,38] and pretested with 10 individuals using cognitive interviewing techniques to assess comprehension, readability, and face and content validity. Knowledge was assessed by using 9 true/false questions about NBS, storage, and consent. The questionnaire assessed values about storing NBS samples for various purposes, and parental choice for anonymous research, by using 5-point Likert scales. We chose to focus on anonymous medical research (with identifying information removed, and linkage to other datasets possible through nonidentifying codes), as this reflects the current approach in Canada and most other jurisdictions. Questionnaires were administered at the start (before the topics were reviewed) and end of each focus group.

Data Analysis

Responses to the knowledge questions were summed to produce a "knowledge score" (range: 0–9). The Wilcoxon signed ranks test was used to assess differences between pre- and post-focus groups' knowledge scores; 2-sided P values of $<.05$ indicated statistical significance. Attitude data from the post-questionnaire were analyzed descriptively; Likert-scale items were trichotomized (ie, strongly agree, agree versus strongly disagree, disagree versus neutral). Data were managed and analyzed using SPSS 18.0 (SPSS Inc, Chicago, IL).

Discussions were transcribed verbatim and analyzed using a modified grounded theory approach,[39–41] based on the principles of constant comparison[42] and qualitative description.[43] Participants' views on storage were analyzed to identify major themes that supported, or were critical of, storage and secondary uses of NBS samples, and types of parental consent for such purposes. Thematically coherent arguments were identified and then fully described to capture underpinning values. Thematic arguments were then contrasted with, and modified by, emergent data. Themes are summarized below as supportive and critical arguments for storage and secondary use, and types of parental consent.

RESULTS

Study Participants

Eight focus groups were conducted with a total of 60 participants (5 focus groups in the Toronto area, $n = 36$; 3 focus groups in the Montreal area, $n = 24$). Most participants were women (60%), single/separated/divorced or widowed (60%), and had at least some postsecondary education (87%). Participants' ages were as follows: 27% were 18 to 29 years old, 43% were 30 to 49, and the remaining were older than 50 (Table 1).

Questionnaire Results

Knowledge

Participants' mean knowledge significantly increased from the beginning to the end of the focus groups, from 6.87 (SD: 2.68) (pre) to 7.80 (SD: 2.12) (post), $P < .0001$.

TABLE 1 Characteristics of the Participants

	Total ($n = 60$)	
	n	%
Gender		
Female	36	60.0
Age, y		
18–29	16	26.7
30–49	26	43.3
50+	18	30.0
Marital Status		
Single/separated/divorced/widowed	35	59.3
Married/common law/living with partner	24	40.7
Education		
High school and below	8	13.3
Some college or university and above	52	86.7
Children		
One or more children	25	43.1

Attitudes Toward Storing Infant Blood Samples for Various Purposes

Large majorities (>90%) agreed (strongly agree or agree) to storing NBS samples for quality control, confirmatory diagnosis, and anonymized research; about half agreed to storage for forensic investigations (54%) or unspecified purposes (50%) (Table 2).

Attitudes Toward Types of Parental Consent for Anonymous Research With Stored Samples

Most agreed that parents should be strongly encouraged to have their infant's sample stored for research purposes (77%) and be able to choose without pressure (77%); about half agreed that parents should be required to have their infant's blood stored (52%) (Table 3).

Qualitative Findings

There was broad support within and across focus groups for storing NBS samples for anonymous research; however, opinions were split about the use of NBS samples for research, and whether parents should be given a choice. Two arguments about parental

TABLE 2 Support of Storage and Secondary Uses of NBS Samples

Q: "I think that it is appropriate to keep dried blood spots in a storage facility……"	*n*	%
…to allow the people who run the newborn screening program to make sure it is working properly (ie, quality control) (*n* = 58)		
Agree[a]	57	98
Neutral	1	2
Disagree[b]	0	0
… to be available for physicians or families in case they need to check on a child's diagnosis (*n* = 58)		
Agree[a]	57	98
Neutral	1	2
Disagree[b]	0	0
… to be available as a resource for future anonymous medical research (when approved by a research ethics board) (*n* = 58)		
Agree[a]	53	91
Neutral	2	3
Disagree[b]	3	5
… to be available as a resource for law enforcement purposes (with a court order) (*n* = 57)		
Agree[a]	31	54
Neutral	3	5
Disagree[b]	23	40
… to be available as a resource for unspecified future uses (*n* = 58)		
Agree[a]	29	50
Neutral	10	17
Disagree[b]	19	33

[a] Respondents checking "strongly agree" and "agree" were included in this category.
[b] Respondents checking "strongly disagree" and "disagree" were included in this category.

TABLE 3 Support of Various Forms of Parental Consent for Storage of NBS Samples for Anonymous Research

Q: "Where newborn screening programs store dried blood spots as a resource for future anonymous medical research, I think…"	Total	
	n	%
…parents should be required to have their infant's dried blood spot stored (*n* = 56)		
Agree[a]	29	52
Neutral	4	7
Disagree[b]	23	41
…parents should be strongly encouraged to have their infant's dried blood spot stored (*n* = 57)		
Agree[a]	44	77
Neutral	7	12
Disagree[b]	6	11
…parents should be able to choose without pressure whether they want their infant's dried blood spot stored (*n* = 56)		
Agree[a]	43	77
Neutral	6	11
Disagree[b]	7	13
…dried blood spots should not be stored (*n* = 55)		
Agree[a]	8	15
Neutral	5	9
Disagree[b]	42	76

[a] Respondents checking "strongly agree" and "agree" to these questions were included in this category.
[b] Respondents checking "strongly disagree" and "disagree" to these questions were included in this category.

choice emerged around 3 themes: the level of trust in authorities, level of concern for harms, and extent to which participants prioritized population or individual interests (Fig 1 presents a thematic overview). Participants generally agreed, however, that there was insufficient transparency in storage practices, and called for improved efforts at informing parents that NBS samples are stored for secondary purposes.

Support for Research

There was broad support among participants for storing samples for research. Some stated this explicitly, [I am a] "big proponent of it [samples] being used for research. I think that's a great thing" [Tracy] (pseudonyms are used to protect participants' identities). They highly valued research because of the "advances that have been made in science" [Mandy].

Sources of Support

Among many participants, support for research justified a "routinized" approach to parental choice, which emerged from a perception that the population's interest trumped the interests of individuals, authorities could be trusted, and potential harms were not concerning (Table 4).

These participants were highly supportive of a population-based resource for research and emphasized the importance of high participation rates to preserve its integrity. Although conceding that individuals might not wish to take advantage of NBS, they argued that "society" has an expansive interest in knowledge, best harnessed when there is broad participation in these databases:

> "I think there are a lot of research benefits that can come from testing these kids, to finding [discoveries]. And, even if you don't want to know and I think you have a right not to know—I think society might have a right to know what the prevalence of these diseases are." [Tracy]

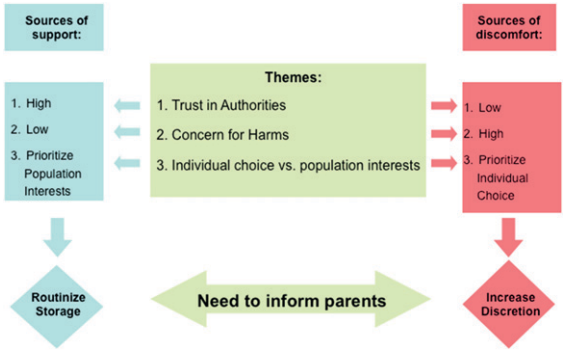

FIGURE 1
Thematic framework of participants' values toward the storage and secondary uses of NBS samples.

At 1 extreme, some argued that the value of an unbiased database might justify a rather coercive approach to participation in storage. Indeed, for these participants, the potential benefits from research "outweighed" [Francis] the opportunity to offer parents choices:

> "I believe that research is more important. I think that the health of our country is an obligation for all of us and that this should be mandated." [Diana]

For these participants, support for a routinized approach for parental choice stemmed from trust in authorities that govern research and the comfort offered by anonymized samples. This participant's support for storage for research hinged on her "trust in the governing bodies":

> "I have trust in the governing body to use it appropriately and I really hope that they do. I hope that they can make improvements and, you know, to other people's lives. I don't mind sharing for that purpose." [Diana]

Some assumed that the general public would be supportive of the endeavor because the benefits of storage for research were clear, and the risks minimal. However, others were less convinced, harboring concerns about governance mechanisms for storage and research use of samples.

Sources of Discomfort

Criticism toward routinized storage emerged from a distrust in authorities, concern about potential harms, and prioritization of individual over population interests. These values underpinned support, among some, for a substantive degree of parental choice for storage for research purposes (Table 4).

Criticism stemmed, in part, from perceived lack of transparency. Some were surprised when they learned that NBS samples are already stored and available for research. This engendered suspicion:

> "Like, I'm all for the research part, but how come we don't know that? … I may think there's something maybe that you're not telling, you know... Like, ok, you must be hiding something." [Valerie]

Some disagreed with the assumption that the public would support all research. Others questioned the appropriateness of mechanisms governing research approval, and suggested that these mechanisms may not align with individuals' values:

> "One might say just because a research ethics board approves it doesn't mean it's my ethics. You know, the board is approving it, but maybe I think something differently. Maybe they want to do research for something that I don't agree with for whatever reason." [Martina]

Some were concerned with the "blanket consent" for NBS that was used to imply consent for storage and research with stored samples:

> "So for you to say yes to your doctor thinking that it's going to be used for your baby, that's not true because it's actually going to be used for broader population between now and 30 years from now. So, are you consenting for that?" [Adrian]

Others were concerned about the security of storage facilities or "nervous" [Tracey] that samples might fall into the wrong hands, such as insurers or other "corporations" [Aisha].

In light of these concerns, some critics preferred a more meaningful form of parental choice for storage for research. Although they found short-term storage for quality control and confirmatory diagnosis acceptable, they did not feel it was appropriate to have consent for screening in a "package" [Avery] with consent for storage for research:

> "By virtue of the fact that I agree to the testing does not mean that I agree to the storage of my baby's blood. So, I think that that's 2 different things. I think if my child was determined to have an illness and there was a positive, I would agree to a short-term storage because then you can revisit that blood and you can do your quality control checks and, you know, you can check it against others. I think that's valid and I could agree to that, but for an indefinite period of time, that requires a different type of consent." [Evelyn]

Despite these disparate views on the value and degree of consent for storage for research, one issue was uniformly clear: the need to inform parents.

Sources of Agreement: The Imperative to Inform Parents

A theme that was persistent across respondents in discussions about storage was the need to inform parents that storage for secondary use occurred following NBS. Information was considered a necessary precondition to create some minimal opportunity for parents to opt out.

For many, an informational pamphlet that included "2 to 3 lines" about anonymous storage of samples and potential use, with a link to a Web site, was considered sufficient. These participants believed that responsibility to seek further information rested with the parents. However, some others valued the opportunity to engage in a dialogue and a decision-making "process."

TABLE 4 Supplemental Quotes Regarding Participants' Sources of Support and Discomfort

Sources of Support:	Sources of Discomfort:
Some reasoned that anonymizing samples protected them from possible harms:	Some suspected that others might not feel comfortable with all types of research:
"I'm fine with, like, my kid's blood being kept indefinitely as long as it's anonymous. It's not doing any harm to anyone. It's never going to have any repercussions. By allowing them to use this blood for research, you're never saying that, somewhere down the road, an insurance company can say, oh, well, your blood got tested for this and you have this disease so we're not going to cover you. It's not admissible for anything else. It's just for the purposes of their anonymous research and for quality control. So if it never has any repercussion to the kid, then I don't see any harm in it." [Sheryl]	"I can foresee there are certain types of research that not everyone is going to be ok with; probably even a majority of Canadians would not be OK with." [Tracey]
	Others were concerned about the security of storage facilities or "nervous" [Tracey] that samples might fall into the wrong hands, such as insurers or other "corporations" [Aisha]:
	"It could be subpoenaed later to get… or, like, someone can request and through a court get a court order to go and get this genetic material that belongs to your baby. That I find I'm a little more nervous about." [Tracey]
	"One of the corporations is going to pay for all these blood samples which is there thousands. And they might be using it for different purposes." [Aisha]
Others assumed that the general public would be supportive of the endeavor because the benefits of storage for research were clear. For example, this participant wondered why storage for research would even be questioned:	Some also questioned the limits of the secondary uses of the samples for research. One critic explained her concern about the lack of governance of these "secondary purposes":
"What are the consequences? I don't understand why it's even a problem. Why wouldn't anybody want [the samples] stored for further research? Why are they even asking? Like, why are you asking?" [Joan]	"And there is a risk because you don't know. Once it's out of someone's hand and there's a secondary purpose, you don't know what the end result will be. You don't know where that end user might possibly be." [Evelyn]
Some believed the benefits of research outweigh the risks:	Some did not feel it was appropriate to have consent for screening in a "package" with consent for storage for research:
"There will always be negatives, you know, but I think the true research outweighs [them]." [Francis]	"I think they [parents] should have an option. It shouldn't be a package of yes or no for everything." [Avery]

> "Access to information to me is really important and involving me in the process and giving me the option to agree or disagree means a lot to me. That's the difference between whether or not I pursue a lawsuit or not…But, if you don't give me the option to say 'yay' or 'nay' and you take that choice away from me—no way. I don't care what it is. I have a hard time surrendering choice, you know. Even if it's something small like a spot of baby's blood." [Evelyn]

Participants agreed it was important to inform parents so they would feel respected, otherwise they believed parents might feel that they were taken advantage of.

DISCUSSION

Our quantitative data demonstrate strong support among Canadian citizens for storage of NBS samples for quality control, confirmatory diagnosis, and future anonymous research. In addition, our data suggest ambivalence about the type of parental consent that should be implemented for retention and research with NBS samples, as equal proportions preferred that parents be strongly encouraged to have their infant's sample stored and be able to choose without pressure regarding storage.

Our qualitative findings echo these results and provide some insight into the values underpinning these positions. In particular, we show that Canadian citizens' acceptance of or discomfort with a routinized approach to research with stored samples varied along axes of trust, concern for harms, and individual versus collective interests. In addition, our qualitative findings point to consensus on the need for greater transparency about the storage and secondary use of NBS samples.

The strong support for use of NBS samples for research identified is consistent with several other studies.[30,31,34,44] The desire to advance research and sense of trust that motivated support for research in our study resonates with others on biobanking.[44–46] The equivocal stance regarding choice that we found is also consistent with other literature.[31,33,47–51] Although explicit permission is endorsed by some potential participants, most are supportive of future research on anonymous samples,[47,48] because they rely on ethics committees to judge the value and rigor of studies for which their samples would be used.[52] Collectively, these findings imply that the Canadian public is supportive of the storage and secondary uses of NBS, provided that an informed and transparent process exists that describes the purposes of storage and uses as well as the safeguards in place to protect the samples and ensure privacy and confidentiality.

Our study provides novel insights into the values that underpin these positions. We found that trust in authorities, lack of concern for harms, and an assertion that the population's interest took priority over the individual's interest appeared to justify a "routinized" approach to parental choice regarding storage of samples, whereas the lack of trust, concern for harms, and prioritization of individuals' interests justified more meaningful parental choice. Importantly, Canadian citizens uniformly called for increased efforts to inform parents about storage and secondary uses of samples.

Understanding these values is crucial for informing the development of evidence-informed public health

interventions and policy initiatives. These values provide clear direction regarding the need to inform the public about retention and secondary use of NBS samples and the safeguards in place for their protection. Indeed, greater public awareness may alleviate concerns about harms, lack of transparency and preserve public trust: an approach echoed by one commentator in a response to this impending "public policy emergency."[36]

Our value elicitation exercise does not provide clear direction regarding parental choice, however, in part because the balance between individual and collective interests is difficult to establish, and because this balance concerns a research enterprise that is situated within a public health program. Although some participants were uncomfortable with having consent for storage and secondary use effectively "packaged" into the consent structure for NBS, others accepted it. These positions are consistent, on the one hand, with discourse that supports the need for more active forms of parental decision-making[17,53–56] and, on the other, with pragmatic arguments endorsing a "packaged" consent structure because it maintains high participation in NBS and storage,[15,21] and because the capacity to inform parents about NBS itself in addition to sample retention and secondary use is limited.[17,19,38,57] Ultimately, although public engagement exercises may elucidate values, enhance transparency, and inform policy, they may not necessarily provide explicit policy direction.

There are several limitations to our study. We explored one form of governance—parental consent—among a highly educated and unrepresentative sample. Research exploring other forms of governance (eg, ethics boards, oversight committees, different forms of control over use, and identifiability of research samples) with generalizable samples, in other countries and with underrepresented communities, is warranted. Finally, we focused on research with "anonymous" data, but recognize that developments in genetics and genomics make it possible to identify individuals even within pooled "anonymous" datasets.[58]

CONCLUSIONS

Despite these limitations, our study demonstrates Canadian citizens' strong support for storage of NBS samples for quality control, confirmatory diagnosis, and future anonymous research; and provides novel insights into the values that underpin their acceptance and discomfort with routine storage of NBS samples for research. Our findings support the need to develop well-designed methods of public education and civic discourse on the risks and benefits of the retention and secondary use of NBS samples.

APPENDIX: FOCUS GROUP DISCUSSION QUESTIONS–NBS STORAGE AND SECONDARY USES

Here are some questions to consider:

1. Were you aware that NBS blood spots are stored?
2. Were you aware that NBS blood spots are used for medical research?
3. What are the perceived benefits and risks raised with storing and using NBS blood spots?
4. Should the anonymous dried blood spots be shared with researchers?
5. Should parents be informed and/or give consent for their use in anonymous research?
6. Should consent be required for their use in anonymous research, from the individual/parent, each and every time a dried blood spot is used for research?
7. How long should the dried blood spots be kept?
8. Should children be asked for their consent for the use of their dried blood spot when they reach the age of legal majority?

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CELEBRATING WITH GOOSE: *"That is the most exotic bird we have here and is almost never served" wrote my friend from Thailand. We were swapping recipes for the holiday meals and in particular what I planned to serve for Christmas Eve dinner. I had written that I was going to follow family tradition and serve goose. My wife and I have been serving goose most Christmas Eve dinners for the past 25 years. The tradition started while living in Germany. We lived in a small town and really enjoyed going to the local butcher for our meat. The week before our first Christmas in Germany we asked the butcher for "ein Ganz, bitte" (our German was never very good but eventually he got the idea). We had no idea what we were doing but we cooked the bird in our tiny kitchen. I am not sure how good it was but our friends seemed happy enough. Since then we have tried a variety of cooking methods (including rendering the fat over steaming water). It always tastes good and makes for an enjoyable, if quite expensive, feast. As reported in* Saveur *(Techniques: December 2, 2011), goose has long been a feast dish. In Western Europe, goose historically was most often served on the feast day of the Archangel Michael, which occurs at the end of September. In Jewish communities, geese were fattened in the autumn for butchering at the beginning of the winter season, roughly the time of Hanukkah. The Pilgrims brought domesticated geese with them and goose was a popular feast dish until displaced by the turkey in the 19th century. Of course, the most famous feast goose is the one served by the Cratchit family in Charles Dickens' "A Christmas Carol." Never has a cooked goose been so exalted. Our goose rarely moves people to such rapture but being able to serve such a majestic bird makes us pause to consider our good fortune, connect with friends, and think about those who are less fortunate. Maybe next year, my friend from Thailand will be able to join us. Now that would be a holiday feast.*

Noted by WVR, MD

Citizens' Values Regarding Research With Stored Samples From Newborn Screening in Canada

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DOI: 10.1542/peds.2011-2572 originally published online January 16, 2012;

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