BORN Engagement with Indigenous Stakeholders: 2012-2013

For BORN Users and Stakeholders (2016)

Dear Colleagues:

We hope you find this report informative and useful for guiding policy decisions for maternal and newborn issues in your region. Please share this report and use it to guide discussions with colleagues about how to improve programs or learn from others about best practices.

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Acknowledgements

We would like to express our sincere appreciation to all the stakeholders who respectfully provided us with honest constructive feedback and suggestions on how we can make changes to ensure BORN data can be protected and appropriately used to improve the health and wellbeing of Indigenous mothers, children, families and communities.

About the Better Outcomes Registry and Network (BORN)

BORN is Ontario's pregnancy, birth and childhood registry and network. Established to collect, share and rigorously protect critical data about each child born in the province, BORN Ontario manages an advanced database that delivers reliable, secure and comprehensive information on maternal and child care. Combined with expert advice, current evidence and innovative tools, BORN information imparts vital knowledge to professionals across health care disciplines to help improve care and the system. BORN data is also used for research and program planning for prevention and health promotion.

Executive Summary

To realize the full potential and mandate of BORN to facilitate health among all mothers, babies and families, BORN requested feedback from First Nation, Métis, Inuit and other Aboriginal stakeholders to provide guidance on the collection, interpretation and data governance of information related to individual and community identifiers. This report includes the results of BORN's conversations with a selected group of stakeholders. It is not considered comprehensive, but rather the beginning of an ongoing process.

In March 2012, following preliminary conversations with a few individual stakeholders, a letter was sent from the BORN Director to 19 First Nation, Inuit, Métis and Aboriginal organizations, identified by the Chronic Care and Aboriginal Health Unit (Ministry of Health and Long Term Care), requesting a meeting to discuss how BORN could best meet the needs of mothers and children of Aboriginal identity, as well as those of Aboriginal health planners, funders, and other stakeholders. Representatives from 15 of the 19 organizations met with BORN. Other stakeholders as recommended were contacted in addition to the initial 19 resulting in a total of approximately 55 stakeholders. After several attempts to coordinate our schedules with the Inuit stakeholders, we were unable able to find a mutually agreeable time. Thus this report does not include feedback from Inuit.

Stakeholder feedback was qualitatively reviewed and grouped into common themes: data collection, individual identifiers, First Nation community identifiers, data governance, the value of BORN data to address key health information and health issues, issues and risks, general feedback, and suggestions and strategies.

Several key messages emerged.
- Data collection must be done in a culturally safe way.
- Release of both community identifiers and individual identifiers must be protected.
- The principles of ownership, control, access and possession (OCAP®) and other similar Indigenous guidelines must be adhered to in all areas of data collection, analysis, interpretation and release for any purpose.
- Maternal and child health is a priority for Indigenous stakeholders and BORN data can be a valuable source of information to address key health information and health issues.
- There are risks to Indigenous stakeholders engaging with BORN.

- There are many ways that BORN can take action to protect against the risks and facilitate the use of BORN data to improve the health and wellbeing of Indigenous people and communities.

BORN recognizes there is much more to be done and that our first round of conversations is a beginning. We welcome input, feedback and opportunities to partner with stakeholders to improve the completeness, accuracy, appropriateness and relevance of BORN data so it can be used to improve the health and wellbeing of First Nation, Métis, Inuit and Aboriginal mothers, children, families and communities. BORN has acted on some of the recommendations in this report and we look forward to hearing from stakeholders about next steps. This report was sent to all contributing stakeholders for review and feedback prior to release.

Introduction

The BORN Information System (BIS) was launched in April 2012 as the integration of five stand-alone databases or programs: congenital anomalies surveillance (formerly the Fetal Alert Network), pregnancy, birth and newborn information for women in hospitals (formerly the Niday Perinatal Database) , pregnancy, birth and newborn information for women giving birth under the care of a midwife (formerly the Ontario Midwifery Program database), prenatal screening (formerly the Ontario Maternal Multiple Marker Serum Screening) and newborn screening (the Newborn Screening Ontario database). Other data sources have been added since its inception (for example, Assisted Reproductive Technology in Ontario).

Historically, most of these programs collected information on maternal ancestry for clinical reasons (screening algorithms) and due to requirements within their funding agencies for health information about vulnerable populations. These fields were removed when the BIS launched in 2012: it no longer includes the option to select 'Aboriginal' in the Maternal (and Paternal) Ancestry data elements for the Birth Mother Demographics and Antenatal Specialty encounters. Pick list items (First Nations, Inuit, Métis) related to Aboriginal identity or ancestry were removed because: 1) many stakeholders found the information difficult to capture, 2) there was a high rate of missing data, 3) some stakeholders expressed concerns regarding the appropriate collection and use of the information, and 4) prior engagement with First Nations, Inuit, Métis and other Aboriginal stakeholders had not been done.

One exception to the removal of individual ancestry identifiers is the capture of First Nation maternal ancestry by the provincial prenatal screening requisition. Evidence has shown that maternal serum screening risk is affected by race and therefore different calculations are needed to provide an accurate risk assessment. First Nation identity data has not been released or reported upon. In addition, BORN includes other data elements that can potentially identify Aboriginal populations: maternal primary language, Aboriginal midwife as a health care provider, 'birthing centre' as a location of birth (could include Six Nations Birthing Centre), city, postal code and residential address, which could potentially identify communities. Stakeholders were informed that BORN had not released this data.

Methods

In 2011 BORN had preliminary conversations with Dr. Janet Smylie (Centre for Research on Inner City Health, St. Michael's Hospital; Dalla Lana School of Public Health, University of Toronto) and Alethea Kewayosh (Director Aboriginal Cancer Control, Cancer Care Ontario). They provided additional resources and suggested key contacts to include in the engagement process. Key messages from these early conversations included:

- It is important to engage with First Nations (on- and off-reserve), Métis and Inuit provincial territorial organizations/political leadership, and service providers;
- It is important to ensure due diligence prior to engagement; know why this data is being collected and how it can benefit communities;
- Many Aboriginal communities want to be approached on a one-on-one basis;
- There is no blueprint for engagement that can be shared;
- OCAP® (Ownership Control Access and Possession) principals are of foremost importance with the First Nations.
- Due to the history of how the information was extracted and used in the past, the Aboriginal communities are extremely cautious in discussions about identifiers.
- BORN should not lose the historical data we have even if the data quality is poor, as some data is better than no data.

In March 2012 a letter (See Appendix A) was sent from the BORN Director to 19 First Nation, Inuit, Métis and Aboriginal stakeholder contacts, provided by the Chronic Care and Aboriginal Health Unit (Ministry of Health and Long Term Care), requesting a meeting to discuss how BORN could best meet the needs of mothers and children of Aboriginal identity, as well as Aboriginal health planners, funders, and other stakeholders. The letter noted that BORN was considering some type of Aboriginal identifier in the database, but recognized that it is extremely important to first discuss this with stakeholders and to request guidance on how the data should be collected and used. These meetings were a starting point to introduce BORN and explore proper processes for collecting information on Aboriginal identity. While the initial letter used the term Aboriginal as an umbrella term, the intent is to engage all Indigenous peoples: First Nation, Métis, Inuit and other Aboriginal groups.

The approach to conversations with stakeholders evolved with each meeting and suggestions were incorporated as they were shared, so early meetings may not have included all of these questions.

1. How can BORN information be used to improve the care and health of moms, babies and families in your community?

2. Would you use BORN data? Is it valuable to you? How?

3. Should FN/I/M ancestry or identity be included in BORN? How?

4. Suggestions on process for BORN to develop a governance policy for race/ethnicity data collection
      i. /storage /interpretation /release (honouring OCAP®)?

5. Any suggestions in general for BORN? What's missing?

6. Other stakeholders we should talk to?

7. Any other feedback/comment?

Stakeholders included First Nation, Métis, Inuit and Aboriginal organizations. The original list of 19 from the Ontario Ministry of Health and Long Term Care, Aboriginal Health Unit was divided into on- and off-

reserve political organizations and health service providers. First Nation stakeholders included the Chiefs of Ontario, Association of Iroquois and Allied Indians (AIAI), Nanishnawbe Aski Nation (NAN), Grand Council Treaty 3, Union of Ontario Indians (UOI), and Independent First Nations. The Métis organization, Métis Nation of Ontario (MNO) and one Inuit organization, Tungasuvvingat Inuit (TI), were identified. The Ontario Federation of Indigenous Friendship Centres (OFIFC) and Ontario Native Women's Association were identified as well as nine health service provider groups: Sioux Lookout Meno-Ya-Win Health Centre and Seventh Generation Midwives Toronto (both submit to BORN), Six Nations Health Services, two Aboriginal Health Authorities, Sudbury and District Health Unit, and three Aboriginal Health Access Centers (AHACs). These health service providers collect perinatal data as does the MNO (through local Canadian Perinatal Nutrition Program programs), some OFIFC Friendship Centres, and the TI centre. Representatives from 15 of the 19 organizations met with BORN. We were unable to meet with 2 organizations due to scheduling challenges. One of these was TI so an Inuit perspective was not possible. BORN was unable to connect with the Ontario Native Women`s Association and the Mohawk Council of Akwesasne.

Most stakeholder organization contacts invited additional participants to attend the meetings and 2 invited BORN to speak at their Health Council or Health Directors in a meeting. Following the meetings, BORN staff documented notes and circulated them back to the stakeholder participants for review. Other stakeholders as recommended were contacted in addition to the initial 19 resulting in a total of approximately 55 individuals. The majority of the meetings were held by teleconference. See Appendix B for the list of stakeholders.

In addition to the Indigenous stakeholders, BORN also contacted government organizations including the Ontario Ministry of Aboriginal Affairs. The following departments met with BORN: Aboriginal Health Unit, Ministry of Health and Long Term Care; E-health Liaison Branch, Ministry of Health and Long Term Care; Association of Ontario Health Centres; Ministry of Community and Social Services; Ministry of Child and Youth Services; and First Nations and Inuit Health, Ontario Region, Health Canada. In these conversations, BORN learned about consultation processes in place and funded Aboriginal programs.

Stakeholder Feedback
Feedback from Indigenous stakeholders was qualitatively reviewed and grouped into common themes: data collection, individual identifiers, First Nation community identifiers, OCAP®, the value of BORN data to address key health information and health issues, issues and risks, general feedback, and suggestions and strategies.

Data Collection

- At the point of data collection, consider principles of obtaining prior and informed consent as outlined in the United Nations Declaration on the Rights of Indigenous Peoples. It is unethical to identify another person's ethnicity for them; the mother needs to be asked. Trying to identify First Nations based on physical characteristics will result in some people being missed. In the hospital mom is not thinking about the fact that the data is being collected and may not have the social capital to question or say 'no' so it is important to explain how the data will be used and how it is helpful.

- "It is so hard for our people to 'self-identify' due to cultural beliefs and being skeptical of what this information is being used for."

- Women are not comfortable disclosing their identity in the hospital because it impacts their care.
  - Consider collecting this information earlier in Aboriginal settings.

- The data identifiers should be collected but with caution not to generalize and stereotype.

- The capture of ancestry or identity should be anonymous.

- "I have seen more discomfort among providers asking the question than among patients answering."

- Ancestry is part of the EMR (electronic medical record) so prenatal data could be linked with it to capture ancestry.

- Linkage is preferable to self-identifying at the point of care. At the point of care it is not seen to be relevant to care or there are concerns that it can negatively impact care.

Individual Identifiers

- Make an accurate and clear link from mother to baby. Utilize multiple identifiers, for example, for siblings with a different mother or father (involves a genetics encounter). Develop a multi-select list: First Nations, Metis, Inuit. Add an option for kinship adoption, as well as one to clarify whether or not they are from USA.

- An identifier needs to include FN/I/M and be comparable with identifiers established by other organizations, e.g. Statistics Canada Census categories were recommended in the Cancer Care Ontario pilot project.

- 'First Nations', 'Inuit' and 'Métis' response options are sufficient and preferable. Inclusion of 'On/off reserve' and 'status/non-status' options was not recommended.

- Should BORN collect information on maternal identity? Yes. It's important to track issues: For example, Diabetes, type 1, 2 and gestational; environmental impacts/challenges.

- "Our organization collects band number" (which links to community name).

- Band number is collected and required for Non-Insured Health Benefits to cover transportation. This could be used as a proxy for status FN.

- Mothers should be asked by the health professional – What is your ethnic background?

- Information on Aboriginal ancestry/identity will be helpful. Information/identifiers could be pulled from the chart and include guidelines for use. The antenatal record is complete and consistent.

- Interested in FN/I/M identifying data.

- "Maternal language is an identifier."

Community Identifiers

- Community identification is as important as individual identification.

  Postal code is an identifier for on-reserve First Nations communities.

- "Postal codes don't work in the city." They can't be used to identify urban Indigenous communities.

- Postal codes could be used to identify certain regions/urban areas where Aboriginal people reside in high density.

- Many people are from the north. Postal codes for a patient may be that of their Inuit relatives/family living in Ottawa or the address may be for the mother's residence in the north.

- When mom is delivering away from home, using the address of a relative, hostel or Aboriginal centre for the mother's address will negatively impact the quality of the data regarding how many births occurred in a region.

Data Governance

- It is important to work collaboratively with Aboriginal organizations to use the data and to incorporate OCAP® principles. There are some gray areas in applying these principles.

- Canadian Institutes of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People have additional information that is not included in the Tri-Council Policy statement; it reflects OCAP® and collective approaches, and provides guidance to the development of Research Agreements.

- It is important to honour OCAP® principles.

- "It's a violation to collect data without OCAP®."

- BORN needs to give credit to OCAP®.

- New Research Principles are being developed. MNO doesn't use those from the National Aboriginal Health Organization which are based on the Tri-council Policy on Research with Aboriginal people, chapter 9.

- "I think if a database were developed and used strictly in FN communities it would be more accepted. We would be in control of the data."

- "OCAP® is applicable to all information and not just research; OCAP® applies to research and all data management."

- "We would not authorize or support the dissemination of data to the health units and would perhaps have to do an information management agreement with the province to clarify this."

- "[I] appreciate your reference to OCAP®."

- In accordance to OFIFC's USAI principles, Indigenous stakeholders must have access to BORN data, and BORN needs to be accountable to the Indigenous stakeholders for the collection and management of the data.

Value of BORN Data to Address Key Health Information and Health Issues

- "Our babies are born at four hospitals. It would be helpful to have information on our births." The continuum of care is important. Women having children with special needs require services at the community level. Data is helpful. There would be benefits to HBHC (Healthy Babies Healthy Children program) to have data on these needs. There are also gaps in outcomes for babies related to prescription drug abuse, for example, stillbirths and sick babies.

- Birth registration is an issue. On-line entry is not working. Research needs to be done to find the gaps.

- "Maternal health has been identified as an area of focus for our organization."

- Moms go to Brantford and Hamilton hospitals and Six Nations doesn't get the information. The diabetic rate is a challenge.

- "The data is valuable and we would like to access it for program planning purposes."

- There are data gaps, for example, in discharge planning. Discharge plans need to be honored. Isolation from family is another issue (data can inform distance travelled from home to hospital).

- Tracking issues is important. For example, Diabetes (type 1, 2 and gestational) and environmental impacts on health.

- "We would benefit from the data – we need stats."

- "We are interested in government programs addressing Aboriginal needs; these are helpful in planning and advocating for OFIFC."

- Ideally, for the mom and baby, relevant prenatal care information is shared with the hospital (if they are involved) and relevant hospital information is shared with the follow-up care.

- "Information on Aboriginal ancestry/identity will be helpful because there is a growing population of Aboriginal mothers in the area; 50% are First Nations. There has been an increase in unplanned teen pregnancy. This supports work we are doing with moms on prevention."

- The ability to track pre-natal care is needed.

- "We used our BORN data. Everyone knew each other. The data quality for identity was good.
  - Approximately 50% were Aboriginal. We used it for care; post-discharge follow-up issues and impacts on care and breastfeeding. We partnered with some local Bands to work with the community and to help with birth registration."

Issues and Risks

- "As a registry, BORN is susceptible to Freedom of Information requests." If an *Access to Information* request is made for community-identifying information then BORN must release it.

- Aboriginal moms describe traumatic/unsupportive birthing experiences in hospitals linked to their identity.

- A woman reported being kept in the hospital and didn't know why. The hospital was delaying her release while waiting for CAS [Children's Aid Society] to come and assess her. Women fear losing their children if they self-disclose.

- The main problem is that women repeatedly experience and report racism in the hospital and do not want to self-identify. Self-identifying impacts their care.

- There are risks of misinterpretation, lack of cultural understanding, damaging comments and conclusions.

- Would it work to ask women their ancestry when they are leaving, to capture the information but not have their care negatively impacted? Response: "Not necessarily, we have seen women held and CAS called in before discharging them."

- Public Health Units have released reports about First Nations that were presented and interpreted from a perspective that did not understand the culture and was damaging.

- There is a lack of continuity and information for the continuum of care due to overlapping jurisdictions. For example, there is a need to work with Nursing Stations, First Nations Health Authorities, etc.

- Data quality for calculating distance travelled from home to deliver is negatively impacted by the practice of using temporary address where mother stays to give birth instead of her actual residential address.

General Feedback

- Appreciation to BORN for asking stakeholders before adding data elements.

- Expressed support for the work BORN is doing to engage Aboriginal stakeholders; agreed to meet again.

- It is the right approach to talk with First Nations first before taking action.

- "We do not recognize the term Aboriginal, but are First Nations. Using the word 'Aboriginal' is not appropriate and does not include us as First Nations."

- There are different opinions among on and off reserve stakeholder groups.

  "Our organization values data."

- "The Ontario Aboriginal Health Policy is gathering dust. It should be honored."

- Midwifery training is now a 4 year program but Aboriginal Midwives were chosen by the community. It was a very honorable role – Midwives followed the family tree to look for history of difficulties, e.g. Congenital anomalies. [More detail sent via email in next bullet.]

- "Many good things happen when people visit and learn from each other. I would like you to reference what First Nations people are all about especially with the chronology of midwifery from our culture. In the past, our midwives were very important people and service providers. One of the areas that we did not capture or is not mentioned, I told you that midwives worked with the family trees. *It must be noted that we consider a human life at the commencement of conception and not after birth. We find it to be more protective within our families to have this involvement* when a couple announces this to the community." The work with the family trees was to understand and address risks of congenital anomalies. "…it also was done to view the intermarriage within the clan system and other tribes as well. All these issues are passed on to the next generation to be aware of…..the promotion of strong, healthy children is never to be forgotten."

- "This group is in full support of this initiative. We were frequent Niday users."

- The term "cultural safety" is preferred (rather than "cultural sensitivity").

- Advised not to use "Aboriginal" for "First Nations" groups.

- Only 1 in 10 Aboriginal people have health access in Ontario.

- Additional data, such as having access to the traditional services of a health care provider, is not collected.

Suggestions and Strategies

- Pilot with a First Nation community that has a designated postal code; work with community members.

- Link data with other registries and databases (e.g. ICES, INAC registry) and develop data sharing agreements.

- Further explore how self-identification has worked and not worked in other organizations. For example, Cancer Care Ontario.

- Explore potential to link with Health Canada data.

- Further explore possible benefits and risks of data collection and reporting (following OCAP®).

- "Our health unit and Health Policy Analyst may be interested. The Deputy Grand Chief will decide how to proceed. He may want to meet with the hospitals."

- "A pilot project is a good way to learn what works and demonstrates to others how it can be done. We would be interested in this." Several pilots would be preferable to include on-reserve First Nations as well, for example, with Chiefs of Ontario or a PTO (political territorial organization). There is a Cancer Care pilot study in chemotherapy treatment; patients are randomly selected; the consent for FN/I/M to participate in the study includes information on how the participant will have good follow- up and will be taken care of (promotes safety in identifying and participating).

- Community Health Representatives (CHRs) go to the hospital with mom to provide support and advocacy for First Nations patients – maybe they can be trained to enter the data.

- "Is there a way that the patient can enter their own data into the system to avoid the impact of staff racism?"

- Consider (Antenatal General) pilot with the Aboriginal organizations and some local hospitals. Need to train hospital staff in cultural safety. Maybe start with some local hospitals. Learn how data should be collected. There needs to be an educational component: Illustrate why we need the data. Importance of cultural safety.

- With genetic congenital conditions there can be stigma around how First Nations approach it, for example, some believe the Creator decides. It may be helpful to look at causes/triggers, for example, mercury.

- Interest in exploring opportunities for data sharing, e.g. Under the Children and Youth mandate of the Ministry of Child and Youth Services (ISCIS database) there's a new Aboriginal Unit. Perhaps we can work through them. "One of our goals is to increase research capacity."

- BORN must be able to answer the following questions to the Aboriginal communities:
    a. Why is BORN collecting the information?
    b. How will this benefit their community?

BORN Response

BORN recognizes that First Nation, Inuit and Métis are three distinct peoples within which there are diverse cultures, governance structures and historical impacts and outcomes, as well as those who identify as Aboriginal or Indigenous. In alignment with the Royal Commission on Aboriginal People (RCAP) Report and the World Health Organization Rights of Indigenous People, BORN will work to facilitate self-governance and self-determination among First Nation, Inuit and Métis people and communities. BORN supports OCAP® and other Indigenous research and data governance principles to the extent possible under the Personal Health Information Privacy Act (PHIPA).

Progress to Date

- This report *BORN Engagement with Indigenous Stakeholders* was sent to all participating stakeholders for review and feedback prior to release and will be posted on the BORN website with an invitation for further input and feedback from stakeholders.

- A *BORN Governance Policy for Data Pertaining to Indigenous Peoples* was drafted and distributed to stakeholders for review and feedback. The policy references the First Nations' OCAP® (Ownership, Control, Access, and Possession) principles, the Métis Nation of Ontario, the Ontario Federation of Indigenous Friendship Centres (OFIFC) *USAI: Utility, Self-Voicing, Access and Inter-Relationality Research Framework* and the Canadian Institutes of Health Research guidelines pertaining to Aboriginal people. Protection of data is understood to apply to all aspects of data collection, use, interpretation, reporting and release for the purposes of research, monitoring and surveillance, statistics and cultural knowledge etc. The data governance policy notes that BORN does not release information unless there has been documented evidence of appropriate engagement and consent by the community/stakeholder or the request has been from an Indigenous organization or government.

- BORN dedicates resources to facilitate the release of BORN data to Indigenous stakeholders who request it for program planning and delivery of maternal, newborn and early childhood services.

- As of March 2014, BORN sent data to the Institute for Clinical and Evaluative Sciences (ICES) including Niday from 2006-2012 and BORN from April 1, 2012 to March 31, 2013. This was requested by stakeholders who have developed Data Governance Agreements with ICES for the purposes of conducting health related analysis on their behalf.

- A methodology has been developed to identify six digit postal codes that represent communities where all or the majority of residents are located in a First Nation reserve/community and these postal codes have been withheld from Public Health Unit reports.

- BORN has identified a technical solution to enable identifying information to be entered by Indigenous stakeholders while restricting access to that data by all other users of BORN data.

BORN recognizes there is much more to be done and that our ability to fully implement these recommendations requires resources, relationships, partnerships and time. We will continue to collect input and feedback, and seek out opportunities to partner with stakeholders to improve the completeness, accuracy, appropriateness and relevance of BORN so it can be used to improve the health and wellbeing of First Nation, Métis and Inuit mothers, children, families and communities.

Recommended References

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Appendices

Appendix A - Initial letter to 19 stakeholders

March 28, 2012

BORN Ontario (Better Outcomes Registry & Network) recently launched the new *BORN Information System* to collect data on maternal and child health in hospitals and midwifery practices across the province.

We would like to discuss with you how we can use this system to best meet the needs of mothers and children of Aboriginal identity, as well as those of Aboriginal health planners, funders, and other stakeholders. The Ministry of Health and Long Term Care, Chronic Care and Aboriginal Health Unit recommended we contact your group in this regard.

BORN collects information during pregnancy, at time of labour and birth, and in the early newborn period for births taking place in hospitals and at home, and combines this information with lab test results collected during pregnancy and in the early newborn period. In the coming years, we will also be expanding to collect information during childhood, and wish to collect information from birthing centers. We have rigorous privacy protection rules and regulations in place for the personal health information we hold, and are designated by the Office of Information Privacy Commission as a Prescribed Registry under PHIPA. We currently capture almost 100% of births in the province and have the ability to provide data or develop summaries and reports for pregnancy, birth and newborn outcomes.

BORN would like to add a few data elements about Aboriginal identity to the database. However, we recognize that it is extremely important to first discuss this with you and ask for your guidance on how we should collect and use this data. As a starting point, we would be interested in exploring with you the proper process for collecting information on maternal Aboriginal identity and birth location. Collection of complete and high quality information will help you to better understand maternal and child health in your community.

We would very much appreciate the opportunity to set up a meeting with your group so we can provide more information about our organization and to discuss this project. We are open to setting up a teleconference or face-to-face meeting, but are asking to schedule an initial telephone conversation with you to determine your preference. The following BORN members are looking forward to meeting you during this initial call:
Ann Sprague, Scientific Manager and Sherrie Kelly, Epidemiologist.

For this initial telephone meeting, if you could please enter your availability for **April 2-5**th and **April 11- 12**th, 2012 in the scheduling poll using the following link: (INSERT URL). Brittan Fell with BORN Ontario (bfell@bornontario.ca) will follow-up with you to book this meeting once we have received your response in the scheduling poll.

Thank you in advance for your consideration. We value your input and advice.

Best regards,
Mari Teitelbaum, Director BORN Ontario

Appendix B – First Nation/Inuit/Métis Stakeholders Contacted

On-reserve Group	Details – Date and Participants
Chiefs of Ontario (COO)	Teleconference April 11, 2012: Tracy Antone, Health Director; Bernadette deGonzague, Senior Health Policy Analyst; Sarah Perrault, Research Project Manager; Lily Menominee-Batise, Health Information Systems Coordinator, Panorama
Association of Iroquois and Allied Indians (AIAI)	Teleconference October 5, 2012: Cathryn Mandoka, Health Director
Grand Council Treaty #3	Teleconference May 24, 2012: Harmony Redsky, Health Policy Analyst; Becky Holden, AHWS Health Policy Analyst; Deanna Major, Junior Health Policy Analyst

Teleconference/webinar June 26, 2012: Presentation to Health Council |
Nishnawbe-Aski Nation (NAN)	Teleconference October 15, 2012: Wendy Trylinski, Community Program Manager
Union of Ontario Indians (UOI)	Teleconference July 24, 2012: Jamie Restoule, Health Director and Anishinabek Advisory Council on Health
Independent First Nations	Unable to schedule: Lyndia Jones, Health Liaison

Off-reserve Group	Details – Date and Participants
Métis Nation of Ontario (MNO)	In-person August 15, 2012: Wenda Watteyne, Director of Health Services
Tungasuvvingat Inuit (TI)	Unable to schedule.
Ontario Federation of Indigenous Friendship Centres (OFIFC)	Teleconference April 24, 2012: Magda Smolewski, Research Director; Marilyn Morley, Health Specialist

On and off-reserve Group	Details – Date and Participants
Ontario Native Women's Association	No response received

Health Service Provider Groups	
Sioux Lookout Meno Ya Win Health Centre	Teleconference February 18, 2013: Helen Cromarty, Special Advisor on First Nations Health
Seventh Generation Midwives of Toronto	Teleconference April 27, 2012: Sara Wolfe, Midwife; Cheryllee Bourgeous, Midwife
Six Nations Health Service (Birthing Centre)	Teleconference October 26, 2012: Julie Wilson, Aboriginal Midwifery Training Program Coordinator/Director of Birthing Program
Noojimawin Health Authority	Teleconference October 11, 2012: Leslie McGregor, Executive Coordinator; Deb McGregor, Director, Centre for Aboriginal Initiatives, University of Toronto
Weeneebayko Area Health Authority	Teleconference March 12, 2013: Rachel Cull, Executive Director Patient Care
Sudbury and District Health Unit	Teleconference April 3, 2012: Shannon Dowall-Smith, Specialist, Foundational Standard; Marc Lefebvre, Manager, Resources, Research and Evaluation; Dar Malaviarachchi, Epidemiologist; Sandra Djivre, Health Promoter
Wabano Centre for Aboriginal Health Inc.	In-person July 25, 2012: Allison Fisher, Executive Director; Dr. Sandra de la Ronde, Obstetrician
Noojmowin Teg Health Centre	Teleconference April 12, 2012: Pamela Williamson, Executive Director; Tammy Maguire, Nurse Practitioner/Admin Lead
Mohawk Council of Akwesasne	No response

Additional Stakeholders:	
Association of Ontario Health Centres	Teleconference October 12, 2012: Lou Anne Meloche, Aboriginal Health Access Centre Program Coordinator
Association of Ontario Midwives	Teleconference December 19, 2013: Ellen Blais AM, BSc. BHSc. (Midwifery) , Policy Analyst, Aboriginal Midwifery, Association of Ontario Midwives
Community Wellbeing Centre, Tyendinaga Mohawk Territory	In person June 6, 2012 and by email: Dorothy Green, Aboriginal Midwife
Lake of the Woods District Hospital	Teleconference June 26, 2012: Tracy Stasiuk, Patient Care Manger Obstetrics/CSR/Nursing Resources
The Society of Obstetricians and Gynaecologists of Canada (SOGC)	Teleconference November 9, 2012: Nicole Robinson, Aboriginal Health Initiative Coordinator