Access, Respect, Consent:
Inuit Women and Reproductive Healthcare Services in 2019

Summary Report

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PAUKTUUTIT
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Acknowledgements

The knowledge generated in this report is based on a one-year study that included an environmental scan and community visits in Inuit Nunangat. We talked about Inuit women's access to reproductive healthcare, from sexual and reproductive health education and information, temporary and permanent contraception, pregnancy options, pre- and post-natal care and birthing. This report is based on the belief that sexual and reproductive health and rights are fundamental human rights, and Inuit women must have equitable access and care.

The research was headed by Pauktuutit Inuit Women of Canada and with the support of Dianne Kinnon (Kinnon Consulting). We are appreciative to the many individuals and health service providers who contributed their insight, knowledge, and expertise to this report. This important work would not have been possible without them and their willingness to discuss very personal and sometimes disturbing information.

First and foremost, we extend our most sincere gratitude to the women from Rankin Inlet, Arviat, Kuujjuaq, Inuvik, Iqaluit and Nain who volunteered to participate in interviews and community consultations. The information they bravely shared on Inuit women's experiences as it relates to sexual and reproductive health and rights is necessary to achieving gender equality by ensuring that all Inuit women and girls can exercise their rights free from coercion, violence, discrimination and abuse.

As well, we are extremely grateful to the 22 sexual and reproductive health care service providers who contributed information on the challenges and constraints facing Inuit women and girls as they relate to their sexual and reproductive health needs and actualizing their rights.

Funding for this research was provided by the First Nations Inuit Health Branch of Indigenous Services Canada.

Prepared by Dianne Kinnon, July 2020
ISBN 978-1-988671-04-8

Introduction

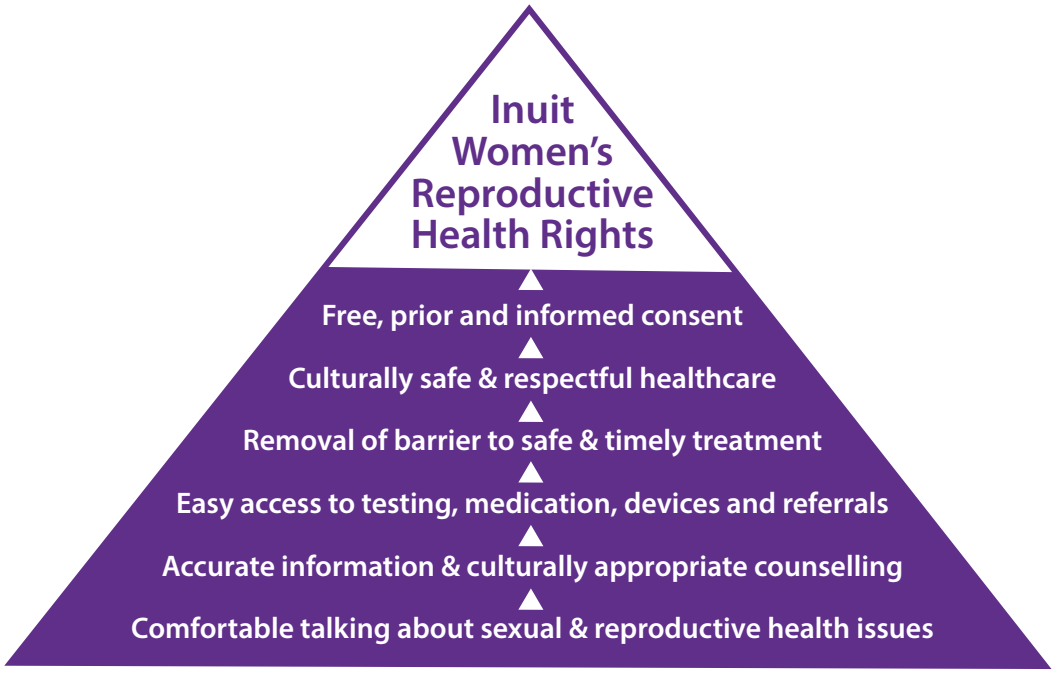
You [women] don't have to stay silent. You have the right to ask questions, ask for other options for treatment or choices. I have the right. But I was robbed of the choice. I didn't understand how the big engine worked. How hard it is to understand the health system, even knowing a little bit, it is still hard. **— Inuk woman from Nunavik**

Inuit women have the right to high quality reproductive healthcare services; free, prior and informed consent; and freedom from discrimination, as described in international declarations (United Nations Human Rights Office of the High Commissioner, 2019; United Nations Declaration of the Rights of Indigenous Peoples, 2007). In a Joint Policy Statement with Pauktuutit Inuit Women of Canada and other Indigenous organizations, the Society of Obstetricians and Gynecologists of Canada (2011) states that

> The sexual and reproductive health rights of First Nations, Inuit and Métis (FNIM) women include the right to prevention, treatment, education, information, and privacy (p. 633).

This document summarizes results from an environmental scan and community visits on Inuit women's reproductive health, in particular free, prior and informed consent to reproductive health procedures. Telephone interviews were conducted with 22 key contacts in sexual and reproductive health services in the four Inuit regions and southern referral centres. Community consultations and interviews also were held in Rankin Inlet, Arviat, Kuujjuaq, Inuvik, Iqaluit, and Nain.

Based on this scan, the diagram below presents the key factors that contribute to Inuit women's reproductive health rights.



Sexual and Reproductive Health Services and Programs

Inuit sexual and reproductive health is impacted by the quality and availability of programs and services for sexual health education, contraception, fertility treatment, emergency contraception, therapeutic abortion, pre- and post-natal care, birth, post-birth options, sterilization and the medical complaints process.

Sexual Health Education

Many Inuit may not be completely comfortable discussing sexual and reproductive health matters. Through the residential schools and their inter-generational effects Inuit learned shame and silence related to what was once a very open and pragmatic approach to sexuality. Nevertheless, sexual health education in schools and communities is steadily improving and online options for reproductive health information are available, including Nunavut's I Respect Myself, Pauktuutit's Naturally Curious, the CheckUp Project on Facebook, Nunavik's Good Touch, Bad Touch Program and Think Before you Start sex ed program as well as the Society of Obstetricians and Gynecologists of Canada's website Sex & U.

Nurses in northern community health clinics provide information on sexually transmitted infections (STIs), testing and treatment; contraceptives; therapeutic abortion and tubal ligation, also known as sterilization. However, the quality of information and counselling can vary greatly according to nurses' individual comfort with the topics, how current their knowledge is and their ability to relate to Inuit women's situations and needs. Understaffing, high staff turnover rates, vacant positions and acute and emergency care needs reduce the quality of sexual and reproductive health information and counselling.

Contraception

Nurses, midwives and physicians are able to provide oral contraceptives, hormone patches and vaginal rings and inject Depo Provera in most communities. Barrier methods such as condoms are readily available in the clinics, although patients may be reluctant to pick them up due to privacy concerns. Intrauterine devices (IUDs) must be implanted by a physician and therefore access is more restricted and may require travel outside of the community to where there is a physician who can perform the procedure. Contraceptives are free of charge through Non-Insured Health Benefits (NIHB).

> ***Yes, language barriers are also connected to language decline, not learning adult terms for sex and reproductive issues. Even the interpreters don't know terms if they are of the age that attended residential schools.*** **— Woman from Nunavut**

Fertility Treatment

While there is not a huge demand for assisted reproduction, there can be difficulties in accessing fertility treatment, which is not covered by provincial/territorial health insurance or NIHB. This may become a growing concern as high rates of STIs contribute to increasing fertility problems. All fertility treatment requires leaving the Inuit regions and is very expensive and beyond the means of most Inuit.

Emergency Contraception

Emergency contraception ("morning after" pill, Plan B and Ella) and use of IUDs to prevent pregnancy within several days of sexual contact are available in community health centres in cases of sexual assault and unprotected sex. It is unknown how aware of and comfortable Inuit women are with options for emergency contraception or how quickly community healthcare providers can offer information and access.

> ***Its very important that women have the time to consider their options. Ideally, information should be presented in more than one encounter, giving the client the chance to think about their choices, ask questions, consult supportive family members and then make a decision.***
> **— Woman from Inuvialuit Settlement Region**

Therapeutic Abortion

Community health nurses, midwives, nurse practitioners and physicians deliver pregnancy options counselling to a woman either continuing with a pregnancy or seeking a termination. However, there can be biases and discomfort related to adoption and abortion counselling. First trimester therapeutic abortions are only performed in Inuvik, Yellowknife, Iqaluit, Kuujjuaq and St. John's. Second and third trimester abortions are only available in larger urban centres. Unless the patient is a minor, escorts are not usually provided. Abortion aftercare at the community health centres should but doesn't always include counselling as there will be an emotional and physiological adjustment.

> **[There is]** ***not enough aftercare support for reproductive procedures. Young women may brush off the experience [of abortion] when they really need the support. Older women might talk to family but don't always get the support.*** **— Woman from Nunavut**

Pre- and Post-Natal Education and Care

Pre- and post-natal education and support is offered to Inuit women by public/community health nurses, midwives and trained Inuit pre-natal program leaders in some communities. Pregnant women may have access to pre-natal group classes or one-on-one support, although access can vary according to the availability of trained educators. In Nunavik, Inuit and non-Inuit midwives provide pregnancy care, birthing assistance, breastfeeding support and post-partum home visits in four communities. Overall, there is concern over the lack of breastfeeding support.

Birth

The majority of Inuit women leave their communities at 36 weeks of pregnancy at the latest. Low-risk births occur in regional centres such as Inuvik, Cambridge Bay, Rankin Inlet, Iqaluit and Happy Valley-Goose Bay. In Nunavik, women can deliver either at the regional birthing centres or at home if they live in one of the four communities served by midwives — about 90% of women in Nunavik now give birth in the region. Higher-risk pregnant women go to Yellowknife, Edmonton, Winnipeg, Ottawa, Montreal and St. John's.

> ***Midwifery provides very safe care in Inuktitut by local women. It's the best way to give birth.***
> **— Woman from Nunavik**

Having to leave home to give birth is disruptive to family life and the father-infant bonding experience and creates a major hardship for most women and their families. Aside from Nunavut, where travel costs are covered for breastfed children under the age of 2, the government only pays for women to have one escort with them and since there is no financial or logistical support offered to bring along other children or family, they must often be left behind. Women await delivery in either a medical boarding home, a hotel or stay with friends or relatives depending on the facilities available. This is an especially difficult experience for first births and for young women unused to travel. Ironically, while intended to decrease risks in birthing, out-of-community births can increase risk to the mother and baby through stress, anxiety and depression.

Post-Birth Apprehensions

While rare, newborn child apprehension does occur and is traumatic for all concerned. Many individuals interviewed for this document, mentioned apprehension as a possibility for some women post-birth. In most of those cases, women would know ahead of time that there is a possibility of apprehension. Social workers work closely with high-risk women to prevent a separation at birth and ideally provide intensive support, including daily check-ins, home visits, etc. post-birth. When a midwife is involved, she also intervenes in the psycho-social aspects of the mother's care.

Sterilization

Inuit women can get information and discuss the option of sterilization (permanent contraception/ tubal ligation) with community healthcare providers. Depending on the region, women may be asked to wait six weeks to three months to have a tubal ligation to ensure they are comfortable with the decision. It was not clarified about operative waitlists adding to this waiting time. On the other hand, some women are encouraged to undergo the procedure at the time of birth. Sterilizations/tubal ligations are performed in Happy Valley-Goose Bay, Puvirnituq, Kuujjuaq, Iqaluit and urban centres. The same travel policies apply as with other minor surgeries.

Medical Complaints Process

While all health facilities have a formal patient complaint process, many Inuit women do not have much faith in the process or are unaware of who to contact. It could be especially difficult for women reporting problems with reproductive health services to raise these issues for fear of non-confidentiality. Complaints processes can also be inaccessible to those without the internet, computers or telephones. Inuit women may be afraid to make complaints about poor service because they fear not receiving proper care from frontline workers in the future. There is a major power imbalance between Inuit and non-Inuit. When one woman complained about a lot of pain:

> ***I was told "what do you expect, you are getting free healthcare" and that if I made any complaints I would be black-listed and not receive any healthcare.*** **— Woman from Nunatsiavut**

Barriers to Reproductive Healthcare

There are many barriers to reproductive healthcare for Inuit women, including attitudes and values, problems with access, an absence of trauma-informed care and gaps in services and programs.

Attitudes and Values

Many Inuit do not talk freely about sexuality, contraception, abortion and sterilization, making it difficult for women to explore their options and make informed decisions. Educators, healthcare providers, partners and family members might hold strong views or be reluctant to discuss these issues. Privacy is an issue for residents of small communities and there may be pressures and expectations within families for women to continue having children. In some cases, young women hide their pregnancies and do not seek pre-natal care, fearing judgement based on prior experiences with the healthcare and justice systems.

There is still a big "cultural divide" between Inuit and non-Inuit regarding attitudes toward family size, teen pregnancies and adoption. This can create judgement by healthcare providers, especially if they are new to Inuit communities. Some women do not access reproductive health-care including pre-natal care due to past experiences of paternalism, disapproval and disrespect.

> ***Aboriginal people are treated terrible in the health system, hey?*** **— Woman from Nunatsiavut**

Inuit women have reported that sterilizations/tubal ligations were very common in the 1970s when they were told that other births would be dangerous for their health. If people were not educated, they did not necessarily know their health rights. In the past, there was no birth control available for older women and birth control was not talked about

> ***Not everyone that comes up here has a good heart.***

Service Barriers

Staff shortages in northern health centres directly affect the quality of contraceptive and therapeutic abortion counselling. A lack of cultural sensitivity and cross-cultural communication problems with transient non-Inuit healthcare providers also are big issues. Privacy in small communities is a concern, particularly for youth. Non-Inuit service providers breach confidentiality by discussing patient information with each other, contributing to further distrust. This may not be a culture specific issue, as all frontline health care providers should be aware of the ethical and legal responsibility of confidentiality (regardless of their ethnicity). However, breaches of confidentiality by newcomers/rotating service providers can have more profound negative impacts.

> ***Confidentiality in small communities is a problem — you could have friends and relatives working at the health centre. You don't want to talk about abortion there.***
> **— Woman from Inuvialuit Settlement Region**

While most reproductive healthcare procedures and travel costs are covered, there are still considerable out-of-pocket expenses and loss of income in leaving the community for healthcare. Travelling without a partner, other children or another family member creates anxiety and worry for expecting mothers. Language can be a barrier to care and even with interpreters it can be difficult "to know what is going on" in large southern facilities. Added to this is the stress and emotional strain related to birth complications, neo-natal conditions, therapeutic abortion or sterilization.

Trauma-Informed Care

Trauma-informed reproductive healthcare is essential in a population with a high incidence of child sexual abuse, sexual assault, intimate partner violence and colonial experiences but is unfortunately often lacking. Past trauma can have a big impact on reproductive health. Truly trauma-informed care is ongoing and requires continual checking in with the client, slowing down examinations and interventions, adjusting procedures and making referrals to mental health care if needed.

Gaps in Services and Programs

Some specific service and programming needs that impact Inuit women's reproductive health include:

- easily understood reproductive health education materials (pictorial, plainly written and available in Inuktut);
- outreach and follow-up to ensure that youth in particular attend health appointments and comply with treatment and aftercare;
- consistently available pre-natal education and post-natal support;
- better supports for children left at home when women travel outside the community for care; and
- better coordination among primary care, mental health, public health and social services.

I met a woman at [a medical boarding home] who needed more support than she got for her hysterectomy. She said she felt like an experiment… **— Woman from Nunavut**

Free, Prior and Informed Consent

Free (not coerced or forced), prior (not at the time of a procedure or after the fact) and informed (with the appropriate literacy level and in the preferred language of the patient, sufficient to make a decision) consent to any medical procedure is a basis for Inuit reproductive health rights. Difficulties in meeting each of these conditions are having an impact on Inuit women today.

Free Choice versus Encouragement, Pressure, Coercion, Force

There can be a "fine line" between "advice" and "encouragement" and pressure or coercion/force related to reproductive health decisions.

Inuit women report being pressured by physicians to have hysterectomies or undergo sterilization according to the biases and beliefs of individual healthcare providers. Physicians might strongly "suggest" that a woman have a tubal ligation following a caesarian birth if she already has several children, is poor or lacks housing. Conversely, a woman's right to choose sterilization also can be denied through a reluctance among physicians to perform the procedure in case a patient later regrets the decision.

Prior Consent

Inuit women who are asked while in labour about having a tubal ligation are not giving prior informed consent. Women need time to consider their options. Ideally, information should be presented in more than one encounter, giving the woman the chance to think about her choices, ask questions, consult supportive family members and then make a decision.

With high community nursing turnover and brief encounters with surgeons, it is difficult for Inuit women to establish relationships over time that provide continuity of care and build trust. Most often, women are discussing life-changing choices with rotating "strangers." Providers need to be tuned in to the patient's needs and state of mind. Midwives can provide continuity of care, place women at the centre of decision-making and provide the time for carefully considered consent.

> ***Its important for women to know about giving consent. If the doctor doesn't tell her, she won't know. They need to explain so she will understand.*** **— Woman from Nunavut**

Informed Consent

Truly informed consent occurs through an engaged process, not just an exercise to meet legal obligations and to "get a signed piece of paper." Some providers want to "get it done" and may not fully explain options and procedures and make sure they are understood. This is compounded by the fact that outside of Nunavik, consent forms for medical procedures are not translated into Inuktitut. Besides a potential language or English literacy barrier, many Inuit still subscribe to a —first and foremost- oral tradition. In order to be culturally sensitive, perhaps verbal and/or audio recorded consent needs to be considered. Informed consent can only be achieved if women understand the pros, cons, risks, benefits and consequences of the decision they are making. Cultural distance, communication barriers and lack of understanding of northern health systems can impede this process.

Cultural Safety in Healthcare

Language and Communication

Language barriers can be subtle and play a significant part in cultural distance between patient and provider. Barriers may result from miscommunication and inexperience rather than overt discrimination. However, many healthcare providers also make no effort to learn about Inuit culture and history. Northern physicians are often young and from outside the Inuit regions. While they are trained in a patient-centred approach, this can get "lost in translation" and their cultural biases and stereotypes of Inuit (violent, addicted, dysfunctional) directly affect the quality of care they provide.

> ***When Inuit go to the health centre, the first question they ask are: "Are you an alcoholic? Are you a smoker? Are you a drug addict?"*** **— Woman from Nunavik**

Cultural Safety Training

Mandatory Inuit cultural safety training for healthcare providers would go a long way in creating a safer healthcare system for Inuit and provide the basis for free, prior and informed consent to sexual and reproductive health procedures. Presently, many physicians and nurses who work in the North do not get any cultural safety training — they "get off the plane and go to work."

> ***How do you teach someone kindness, I wonder?*** **— Inuk woman from Nunatsiavut**

Effective training will be delivered by Inuit, inform service providers in how Inuit culture and history impacts their health and their interaction with the healthcare system, strengthen communication skills and provide real-life examples of Inuit patient experiences. Several jurisdictions are working to improve and increase training of healthcare providers.

Key Issues

- Indigenous women's reproductive rights include access to high quality healthcare services, free, prior and informed consent, and freedom from discrimination.
- Inuit must travel to larger centres in both the North and southern Canada for much of their diagnostic, treatment and surgical care. This creates hardship and stress for women and their families.
- While most reproductive healthcare procedures and travel costs are covered by territorial or private insurance or Non-Insured Health Benefits, there are still considerable out-of-pocket expenses and loss of income in leaving the community for births, pregnancy terminations and sterilization.
- Sexual health education, information, counselling and access to reproductive health services are impacted by an understaffed healthcare system, the cultural divide between Inuit and their non-Inuit healthcare providers, and attitudes and values toward pregnancy, abortion and sterilization.
- Lack of privacy, confidentiality and trust are significant barriers to care, especially among youth and Inuit who have had previous bad experiences with healthcare.
- Many women have little faith in the medical complaints process, are embarrassed to report reproductive health concerns and fear a complaint will affect future care. An effective process requires addressing power imbalances between service providers and service users and ensuring the process is accessible and fair.
- Prior physical, sexual and emotional trauma affects women's access and safety in receiving reproductive health services. Trauma-informed reproductive healthcare is essential but often lacking.
- Free, prior and informed consent is heavily influenced by how culturally safe Inuit women feel at each stage of the information and decision-making process. Mandatory Inuit cultural safety training is needed so women will have sufficient trust in the health system to seek information, discuss their situations and express their fears and concerns.
- Improper pressure may be applied to Indigenous women, including Inuit, to undergo sterilization according to the biases and beliefs of individual healthcare providers. Pressure and coercion are occurring in the present day but are not being openly talked about or officially reported.
- Truly informed consent occurs through an engaged process, not just an exercise to meet legal obligations. Information on medical procedures and consent forms needs to be available in regional dialects of Inuktut and also fully explained verbally by healthcare providers and professional interpreters. Shared Decision-Making tools may be useful.

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