



NWT MEDICAL TRAVEL PROGRAM: PATIENT-ESCORT SUPPORTS

REPORT ON WHAT WE HEARD

MAY 2015



Disclaimer: DPRA has not independently verified the accuracy of the asserted anecdotes.

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EXECUTIVE SUMMARY

The Patient Supports: Stakeholder Engagement and Program Options Medical Travel Modernization Project was initiated to help the Government of the Northwest Territories (GNWT), Department of Health and Social Services (HSS) improve the Medical Travel Program so that it better meets patient needs and is **financially sustainable**. The intended outcome of the project, is the identification of patient support options that will help improve overall patient experiences with medical travel both within and outside of the Territory.

Recognizing the importance of the **Medical Travel Program to residents of the NWT**, this project supported a high level of engagement. The project provided opportunities for a cross-section of stakeholders, with very different experiences, to discuss current patient escort supports – what’s working, what’s not working – and future patient supports – what improvements are needed and what new supports should be introduced to enhance their medical travel trips. From December 2014 through to February 2015, seven communities in the NWT – Hay River, Trout Lake, Behchoko, Tuktoyaktuk, Fort Good Hope, Inuvik and Yellowknife – and one site outside of the territory – Edmonton - participated in the engagement process. In total, 212 individuals took part.

Information was gathered during focus group sessions, interviews (in-person and telephone), open houses (designated site for community members to drop by and chat informally when they had time), as well as through email correspondence, reviews of relevant published documents and media reports and second-hand feedback (due to weather and/or health, some individuals were not able to take part in the engagement process in-person. In certain situations, a third party – usually a family member but sometimes a friend – gathered information from that individual and passed it along).

Based on what we heard, there are a number of ways in which patients, families and service providers feel current patient escort services and supports can be improved. Examples of these suggested enhancements to the program and the policy include:

- Developing and implementing a territory-wide escort agreement form that clearly identifies the roles and responsibilities of an escort. This form would be signed by the patient and escort indicating that both parties are aware of the rules and expectations guiding the escort while travelling.
- Ensuring that Medical Travel Program and Medical Travel Policy information, generally and as it relates to escort approvals, is standardized and that it is available and accessible to all NWT residents.
- Revising the Medical Travel Policy so that it stipulates that escorts are approved for: Elders/Senior 60 years of age and older; patients with serious illnesses requiring significant pre- and/or post-operative caregiver support and/or with ‘unpredictable’ treatment outcomes; and women sent out of their home community for confinement.
- Ensuring that decisions regarding approvals for an escort are only made by the referring health care providers, within the parameters of the Medical Travel Policy.

Stakeholders indicated that changes to the current patient escort system, such as those noted above, would help to improve overall patient experiences with medical travel both within and outside of the Territory.

ACRONYMS

CHC	Community Health Centre
CHR	Community Health Representative
GNWT	Government of Northwest Territories
HSS	Department of Health and Social Services
MDF	Medical Directors Forum
NHSN	Northern Health Services Network
NIHB	Non-insured Health Benefits
NLF	Nursing Leadership Forum
NWT	Northwest Territories
OOT	Out of Territory



1. INTRODUCTION

This report presents information that was heard about the Medical Travel Program's patient-escort supports. Information was collected during stakeholder engagement sessions held across the NWT from December 2014 to March 2015.

The report is structured as follows:

- Introduction
- Overall Purpose and Objectives of the Project
- Stakeholder Engagement Purpose
- Engagement Methods
- Engagement Summary – Here is what we heard
- Next Steps
- Appendix A - Parking Lot

2. OVERALL PURPOSE AND OBJECTIVES OF THE PROJECT

The high level goal of the Patient Supports: Stakeholder Engagement and Program Options Medical Travel Modernization Project is to help the Government of the Northwest Territories (GNWT), Department of Health and Social Services (HSS) improve the Medical Travel Program so that it better meets patient needs and is financially sustainable. More specifically, the Project is intended to present patient support options that will help improve overall patient experiences with medical travel both within and outside of the Territory.

The objectives of the Project, as outlined in the Terms of Reference, are to:

- Analyze program options for patient supports using previous reviews and analysis as well as documented program gaps;
- Engage identified stakeholders in order to solicit input and feedback on patient supports;
- Ensure that the proposed changes to the Medical Travel Program associated with Patient Supports adequately address the needs of NWT residents;
- Compile, categorize and summarize information gathered through stakeholder engagement in an effective manner; and
- Produce program recommendations for Patient Supports integrating stakeholder input with the appropriate analysis, providing rationale and high-level costing models for submission to the Department.

The Project aims to support a high level of stakeholder engagement in order to ensure that NWT residents have an opportunity to discuss their experiences, voice their opinions and present options for supports that they feel would enhance their medical travel trips.



3. STAKEHOLDER ENGAGEMENT PURPOSE

The objective of the stakeholder engagement was to organize, attend and facilitate multiple, targeted engagement activities across the NWT in order to gather information from stakeholders on the Medical Travel Program’s patient escort supports. The engagement process provided an opportunity for a cross-section of stakeholders, with very different experiences, to talk about current patient escorts supports – what’s working, what’s not working – and future patient supports – what improvements are needed and what new supports should be introduced.

NOTE: Although the focus of this engagement was patient escort supports, stakeholders provided information about other aspects of the Medical Travel Program, including: administrative processes, appeals, the medevac system, and benefits. While not discussed directly in this report, this information is located in a ‘parking lot’ in Appendix A of the report. This information will be reviewed by GNWT HSS as they move forward with the Medical Travel Modernization Project.



4. ENGAGEMENT METHODS

The following section provides a high level overview of the methods used to collect information during the engagement phase of the project.

4.1 This is where we went

NWT communities were selected based on consultation with the Project Steering Committee and on ensuring regional representation. Table 1 identifies the eight locations selected for in-person stakeholder engagement and further rationale for their selection.

Table 1: Stakeholder Engagement Sites

No.	Location	Rationale
1	Yellowknife	<ul style="list-style-type: none"> • Location of Vital Abel – provides access to patients and escorts from across the Territory
2	Inuvik	<ul style="list-style-type: none"> • Location of Inuvik Medical Transient Centre – provides access to patients and escorts from the Beaufort Delta and Sahtu Regions • Minister commitment to speak with the Gwich'in Tribal Council
3	Tuktoyaktuk	<ul style="list-style-type: none"> • Represents a small, northern community
4	Fort Good Hope	<ul style="list-style-type: none"> • Sahtu is experiencing increasing rates of medical travel
5	Trout Lake	<ul style="list-style-type: none"> • Represents a community with only a Community Health Representative (CHR) – no nurse
6	Behchoko	<ul style="list-style-type: none"> • A community with road access to a medical facility
7	Hay River	<ul style="list-style-type: none"> • Represents a large, southern community • A community in which the band pays the salary of the medical travel officer
8	Edmonton	<ul style="list-style-type: none"> • Location of Larga House - provides access to NWT patients and escorts from across the Territory • Represents out of territory (OOT) travel • Represents access to representatives of the Northern Health Services Network (NHSN)

NOTE: Future engagements to examine other aspects of the Medical Travel Program are planned.



4.2 This is who we spoke with

Information was obtained from the following stakeholders:

- Medical Travel Program Participants
 - Patients
 - Family/Friends (Non-Medical Escorts)
- Medical Travel Program Systems Navigator
- Medical Travel Program staff in the communities
- Community Health Centre/Hospital staff (e.g., clerks, nurses, physicians/locums, nurse practitioner, long-term care coordinators, human resources, etc.)
- Northern Health Services Network (NHSN)
- Service/Support Agency Staff
 - NWT Disabilities Council
 - NWT Seniors' Society
 - Yellowknife Seniors' Society
 - Ingamo Hall Friendship Centre
 - Hay River Seniors' Society
 - Stanton Elder's Council
 - Canadian Cancer Society
 - Northwest Territories Breast Health/Breast Cancer Action Group
- Boarding Home Staff
 - Vital Abel
 - Larga Edmonton
 - Transient Centre

- Aboriginal Organizations
 - Gwich'in Tribal Council
 - Inuvialuit Regional Corporation
 - Tuktoyaktuk Community Corporation
 - Tłı̨chǫ Community Services Agency
- Medical Directors Forum (MDF) representatives
- Nursing Leadership Forum (NLF) representatives

Table 2 identifies the engagement dates and the total number of stakeholders that participated in the process by community.

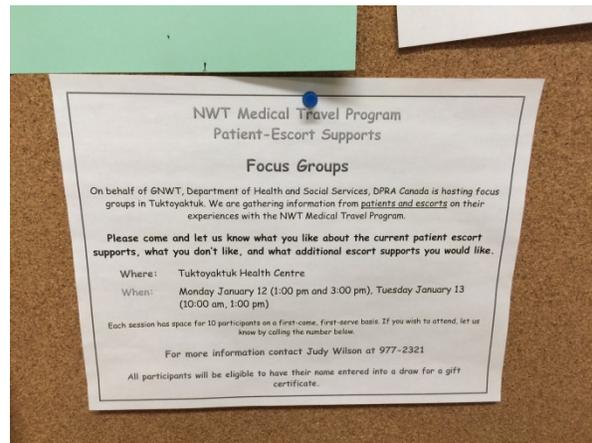
Table 2: Stakeholder Engagement Dates and Participant Numbers

Community/Group	Engagement Dates	Total Participant Number
Hay River	December 12, 2014	48
Edmonton – Larga House and NHSN	January 5 – 8, 2015	18
Tuktoyaktuk	January 12 – 14, 2015	24
Inuvik	January 14 – 16, 2015	32
Behchoko	January 20 – 22, 2015	14
Yellowknife	February 4 – 17, 2015	48
Fort Good Hope	February 17 – 19, 2015	22
Trout Lake	February 25, 2015	6

4.3 This is what we did

The following targeted engagement methods were employed during the community visits:

- Focus groups
 - In-person
 - Telephone
- Interviews (individual and group)
 - In-person
 - Telephone
- Open house
 - When availability of space permitted, DPRA “set up shop” in a designated community office/room for the time they were in the community. This open house concept provided community members with an opportunity to drop by when they had time to discuss their experiences.



DPRA also received information on patient escort experiences through the following ways:

- Email correspondence

- Media reports
- Published NWT reports
- Hansard transcriptions
- Second-hand feedback
 - Due to weather and/or health, some individuals were not able to take part in the engagement process. In certain situations, a third party – usually a family member but sometimes a friend – gathered Medical Travel Program information from that individual and passed it along to DPRA.



5. ENAGAGEMENT SUMMARY – HERE IS WHAT WE HEARD

The follow sections summarize what was heard during the engagement sessions. This report does not attempt to analyze the findings - its intent is to present the opinions, experiences and perceptions told to us by stakeholders. The information is organized in the following way:

- Roles and Responsibilities of Escorts
- What’s Working Well
- What’s Not Working Well
- Suggested Improvements / Additional Supports

5.1 Roles and Responsibilities of Escorts

Stakeholders described in detail what they perceived to be the roles and responsibilities of an escort.

5.1.1 Best Escort Characteristics

The best escort was described by stakeholders as someone who is:

- Close to the patient
- Understands what the patient is going through
- Reliable
- Compassionate
- Willing to spend time doing - with no reward
- Caring/loving
- Respectful – especially with elderly
- Trustworthy



“It’s like a full-time job, and it’s hard.”

5.1.2 Perceived Roles and Responsibilities

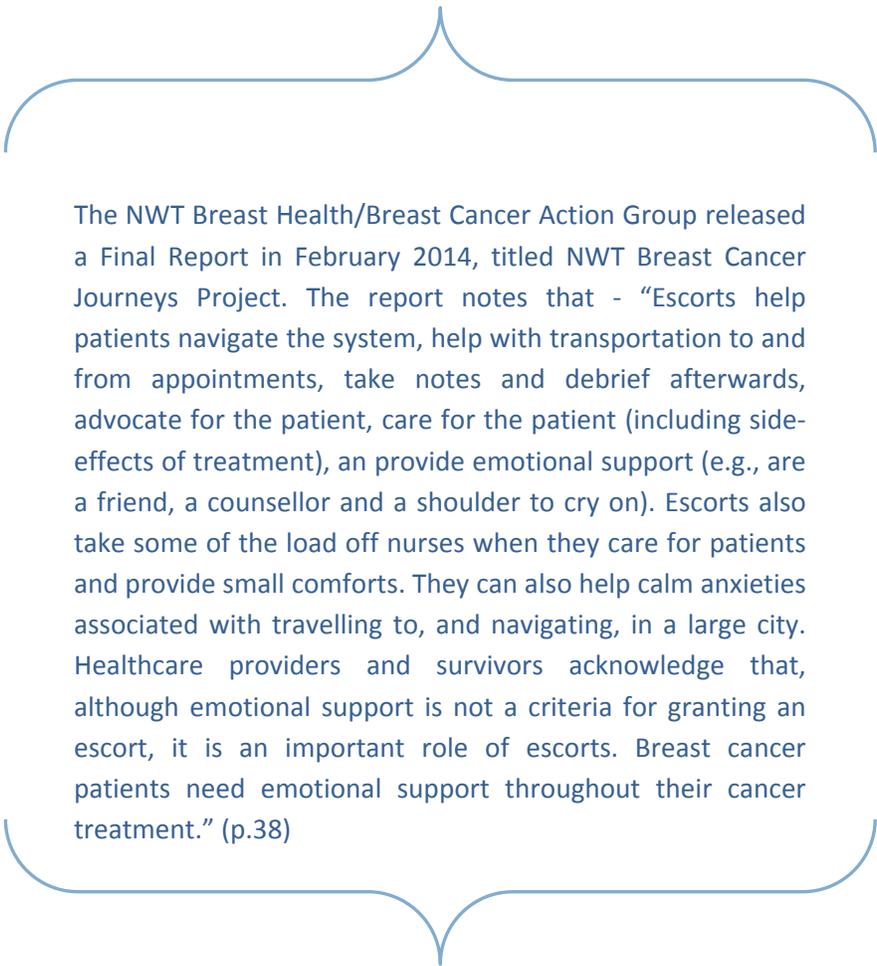
Stakeholders identified what they felt were the roles and responsibilities of an escort:

- Ensure patient safety.
- Understand the medical condition of the patient and the reason the patient is travelling so that they can support them in the best way possible.
 - Understand disability of the patient – mobility, cognitive, sensory
- Be able to recognize patient distress.
- Be with the patient at all times (24 hours a day/7 days a week).
 - That being said, it was noted that this expectation needs to be tempered with some realism and include a degree of flexibility based on patient health, needs and length of medical travel trip. It was noted that both patients and escorts may want some time on their own.
 - Escorts should not leave the patient to go drinking, gambling or shopping.
 - Medical travel should not be considered a holiday for either the patient or escort.
- Accountable for patient support.

- Ensure patient’s physical, medical, emotional, and social needs are met during the medical travel period. This includes a variety of activities such as:
 - Mobility support (e.g., helping them get in and out planes and other modes of transportation, supporting them as they move around, helping them with their wheelchair)
 - Navigation support (getting patients to their appointments)
 - Dietary support (making sure that they are eating properly)
 - Bathing support
 - Changing support for adults (clothing, incontinence)
 - Medication support
 - Making sure that the patient is taking their medication as prescribed
 - Helping to administer medication if knowledgeable and if required/requested
 - Pre-operative and post-operative support (ensuring the patient follows the instructions provided)
 - Help to alleviate stress
 - Be good company
- Assist with translation of information into the patient’s first language.
- Accompany patient to appointments and if approved by patient, be present during the healthcare provider consultation so that they can listen, ask questions and take notes on behalf of the patient regarding medical information and instructions.
 - Help patient comprehend the medical jargon if the patient is unable to understand.
 - The patient and escort can work as a team to better understand the doctor.
 - Help patient understand the medical outcomes and instructions
 - Side effects
 - Medication dosage
 - What to expect/look out for after treatment/surgery
 - How to use a needle if expected to self-administer injections
 - Importance of self-care
 - The patient may not want the escort to be privy to their medical information. So, it is up to the patient to decide on the extent of confidentiality.
- Maintain confidentiality.
- Act as a liaison; speaking on the patient’s behalf if s/he cannot speak for him or herself.
- Advocate for the patient.
- Upon return to the home community, brief healthcare providers and family if they were involved in the medical discussions.



“I think it’s important for the escort to be an advocate for the patient.”



The NWT Breast Health/Breast Cancer Action Group released a Final Report in February 2014, titled NWT Breast Cancer Journeys Project. The report notes that - “Escorts help patients navigate the system, help with transportation to and from appointments, take notes and debrief afterwards, advocate for the patient, care for the patient (including side-effects of treatment), and provide emotional support (e.g., are a friend, a counsellor and a shoulder to cry on). Escorts also take some of the load off nurses when they care for patients and provide small comforts. They can also help calm anxieties associated with travelling to, and navigating, in a large city. Healthcare providers and survivors acknowledge that, although emotional support is not a criteria for granting an escort, it is an important role of escorts. Breast cancer patients need emotional support throughout their cancer treatment.” (p.38)

5.1.3 Understanding of Roles and Responsibilities

Many engagement participants believe that escorts are not fully aware of the scope of responsibilities assigned to a non-medical escort. In particular, they do not understand that they have to be with the patient at all times – during travel, at their appointments, in the hospital, at the hotel/boarding home. They also do not understand how long they may be required to stay with the patient (up to 21 days) before they can return home and a new escort can be sent as a replacement.

“Not clear what the roles and responsibilities are for an escort.”

Some stakeholders commented on an Escort Agreement Form that highlights the responsibilities of an escort. The form is used in some communities, to educate escorts about their roles and the expectations placed on them and/or as a tool to help ensure that escorts follow the rules by having them sign the form. Although this is not a legally binding contract, it is believed that having reviewed the form and having asked people to commit to following the rules, that escorts are more likely to do so.

5.1.4 Escort Selection Criteria

If approval for an escort is granted, it is up to the patient to find someone to travel with them. There are no criteria to help guide the selection of that individual. In most cases, the escort is a family member or a close friend. However, in some instances, a patient may not have anyone to accompany them on a trip. In these situations, one of the following may occur: they may decide to travel alone; if the community has a pool of escorts, they may select someone compatible from a list; an individual from the CHC/Clinic may elect to travel with them (e.g., someone from Home Care); or they may decide to not go at all. The Medical Travel Policy does not include any criteria for selecting escorts as it is the responsibility of the patient to choose someone they prefer to travel with.

“The Medical Travel Policy does not articulate the expectations of an escort in relation to the patient.”

Stakeholders also indicated their belief that patients themselves are not aware of the roles and responsibilities that their escort may have to fulfil when they accompany them on a medical travel trip.

As such, patients do not always select the most appropriate escort – based on their physical, cognitive, and emotional needs - to accompany them on their travel. Stakeholders provided a number of examples in which they felt the escort to be inappropriate:

- Mobility – When elderly couples escort each other, sometimes it does not work if the escort cannot physically support the patient.
- Age – When the escort is too immature and requires looking after themselves.
- Gender – When an escort of the opposite sex is sent and the patient feels uncomfortable disclosing/discussing personal medical information in front of them (e.g., prostate cancer).

“You can’t be an escort if you need an escort.”

- Language – When the escort speaks the same language as the patient but is not fully literate in English.

Stakeholders commented on the importance of patients having a better understanding of what their escort will be required to do when they travel with them on a medical trip. It was thought that if patients had a better idea of the escort responsibilities, with regard to their specific health condition (or mobility limitations), that they may, choose a more appropriate escort.



5.2 What's working well?

When asked what was working well with respect to the patient escort supports system, most people commented on the overall Medical Travel Program system more generally. The response most often

“We are so fortunate to have medical travel. We are the envy of other people in the provinces.”

heard was – we are very lucky to have the system in place. This was often followed by statements such as – ...it just needs some improvements or some work done to it. Stakeholders also noted that they consider the system to be working well when information is communicated to them by medical travel staff in a timely fashion (i.e., well in advance of their appointments so that they can make plans) and when they can see that the Medical Travel Policy is being applied consistently and equitably.

With reference to the patient escort support system, community-level medical travel staff noted that things work well when information is communicated to the patient and escort in simple terms and when patients understand why the decision to approve or not approve an escort has been made. In Tuktoyaktuk, one CHC staff noted that things are working better with the patient escort system because patients are becoming more knowledgeable about how decisions are made around approvals and escorts are asking patients more questions prior to travel so they are better prepared to assist them.

The establishment of a volunteer escort service in several communities across the NWT is also viewed as a positive measure as some Elders are having trouble finding an escort. The pool of escorts allows Seniors/Elders the opportunity to choose, from a list of volunteers, the person they would be most comfortable having support them with their medical travel needs. Of course, there is still a need for more escorts.

A number of stakeholders commented on the excellent service – staff, food, communication, and transportation – received at Larga House in Edmonton, the Transient Centre in Inuvik and Vital Abel in Yellowknife. In particular, Larga house was singled out for its commitment to patients and escorts: - “Amazing.” “They go out of their way to help each patient.” “It takes a special kind of person to work at a boarding home.” “They know where you need to be and when.” Some stakeholders also spoke positively about the support they received from the Northern Health Services Network (NHSN) staff – noting that they were knowledgeable and took care of everything. Sorrentino’s Compassion House was also described as a wonderful place to stay for women undergoing breast cancer treatment.

“Boarding homes are good-excellent treatment and services.”



5.3 What's not working?

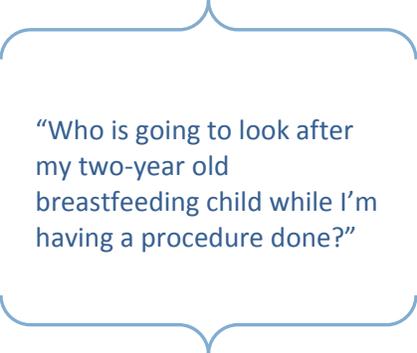
When asked what was not working well with the current patient escort support system, stakeholders identified a wide variety of issues.

Lack of Elder Escort

- Almost every stakeholder spoke about the fact that many Elders/Seniors are being expected to travel unescorted to their medical appointments. Many made reference to a time when Elders, 65 years of age and up, were provided with an escort regardless of whether they met any of the other policy eligibility requirements. There was a high degree of support for returning to this procedure. Stakeholders felt Elders needed an escort for a number of different reasons – poor eyesight, poor hearing, poor mobility, limited cognitive function at times, co-morbid conditions, and fear of travelling to a large community on their own. It was also mentioned that some Elders will not ask questions - when they should - because they don't want to be a bother. A couple of stakeholders spoke about having to 'adopt' an Elder at the airport because they had travelled unaccompanied and could not navigate their way to the exit.

“Need to put the human aspect back in this.”

Eligibility Criteria

- Stakeholders expressed frustration over the lack of escort approval for the following medical treatments/procedures:
 - **Cancer** - Many people spoke about the lack of escort supports provided for cancer patients undergoing treatment. While escorts are approved for the first appointment/consultation, they are not automatically approved for subsequent visits; so patients have to go on their own. This was described as problematic because each visit may result in a different outcome as a result of the treatment (i.e., they may feel sick after the treatment and require assistance on the travel home) –cancer treatment outcomes were described as unpredictable.  “Medical travel is part of every cancer patient’s journey.”
 - **Confinement** - Pregnant women in the smaller communities must travel to Inuvik, Yellowknife or OOT (if there are complications) prior to the birth of their child for confinement.¹ Evacuation generally occurs between 36 – 38 weeks, with confinement lasting until after birth. Evacuation for birth has been documented as a stressful event as it removes birthing mothers from their home communities, supports, family and children. Women are not approved for an escort during their confinement unless they are under age. If they are under age, they must still be living with their parent(s) or they are considered an emancipated minor and are not approved for an escort. This means that women may be on their own, without the support of their family, friends and community for weeks at a time. Not until after the birth is the partner approved to travel in order to assist the mother with her trip back home. One nurse stated that the hospital gets strangers to sit with the mother during pre-delivery to keep her company. After the delivery, when the mother is in recovery, the doctor then signs the form requesting that the partner travel. A number of nurses spoke about the need for a woman to have someone they know with them during confinement and to have her partner present at the birth. They note that delivery is a very important time for parent bonding so both parents should be present. It was reported that some women are actually returning home before the birth of their baby because they want to be with their family.  “Who is going to look after my two-year old breastfeeding child while I’m having a procedure done?”
 - **Breastfeeding** - There were some individuals that spoke about the fact they had to fight for an escort even though they were breastfeeding and were going to be undergoing a procedure for which they needed someone to take care of their child during and after the treatment (i.e., they could not lift their child).

¹ Unless they live in Fort Smith or Hay River and are under the care of a midwife who deems their condition safe for delivery in the community.

- **Fear of Flying** - Some people, especially those from the smaller communities, may have never been on a plane before. They experience a high level of anxiety about the flight particularly if they are expected to take the trip on their own without support from a friend or family member.
- **Surgery** - When a patient is going to be undergoing surgery, they are scared and worried. Not approving an escort to travel with them, but waiting until after the surgery for the escort to travel, adds to this anxiety.
- **Eye Appointment** - Sending a patient on their own for an eye appointment means that the patient is often left without support on the return trip, when they cannot see properly as a result of the treatment (e.g., laser) or the drops placed in their eyes for an examination. One stakeholder spoke about the fact that patients are often left helping other patients, in this situation, find their way through the airport and onto the plane.
- **Hard of Hearing** – Stakeholders spoke about the fact that even though many Elders are hard of hearing, they are expected to travel on their own. This is problematic because they cannot engage in a proper dialogue with the healthcare providers nor can they accurately hear instructions that are being provided; or they may not hear instructions while travelling (e.g., airport announcements).

Caesarean-section

- Nurses commented that even though mothers who will be undergoing a caesarean-section are entitled to an escort; the physician is still required to write a letter supporting approval. This was viewed as an unnecessary step that slowed down the process of getting the escort to the mother in a timely manner.

Political

- **One** of the main problems noted by stakeholders was political interference in decision making regarding escort approvals. People spoke about the fact that if someone goes to their MLA and complains, they end up getting approval for an escort, whether they really needed one or not. This interference results in the policy being applied inequitably, with the ‘squeaky wheel’ almost always getting what they want, rather than what the policy dictates. Community level medical travel staff mentioned that political meddling is frustrating for them because it undermines their authority and it leaves community members thinking that staff do not know how to do their job properly.

“System is not being applied fairly.”

Doctor's Decisions

- Many stakeholders described instances in which medical travel staff overrode physician decisions regarding escort approvals. Everyone who commented on this issue was in agreement that if a doctor/nurse states that an escort is required, medical travel staff should not question or have the authority to deny the request. It was pointed out that medical travel staff do not have the clinical background to question a doctor's decision.

“Some doctors are telling patients that the decision regarding escorts is not up to them – it's up to medical travel staff.”

Community-level Medical Travel Decisions

- Some of the community-level medical travel staff stated that they should have more autonomy to approve escort requests (rather than the decision making always residing with Inuvik or Stanton), given they know the people in the community and know who should and should not be approved for an escort. They described cases in which, on paper an individual should not receive an escort, but in reality, there was no way the individual could travel without an escort (e.g., someone with a mental disability that was not diagnosed).

“There was a time when the Authorities/Agencies had more power but slowly Stanton absorbed it all.”

No Escort, No Travel

- When some patients are denied an escort, they will not travel for their appointment. In the cases in which this was mentioned, the patient was described as being fearful and anxious about travelling on their own and about having to attend a medical appointment without the support of someone they know. As a consequence, the health of the individual is compromised. This situation was described as occurring for all ages. For example, a young patient refused to go to Edmonton for a medical appointment without an escort because they were scared of trying to navigate the airport on their own.

Lack of Monetary Support

- A number of stakeholders spoke about the fact that escorts sometimes run out of money when on a medical travel trip, especially when the trip lasts a long time. Some patients stated that they gave escorts money so that they could buy small items such as cigarettes and chips.
- In one instance, it was noted that Elders, because they are in such a vulnerable position - in poor health and having to depend on the escort for support - are being placed in situations in which they feel they have to give an escort money or they will not help them out. This was referred to as an instance of Elder abuse.

- Communities themselves are raising money to help support community members who are travelling out of the community frequently (e.g., for cancer treatment) and/or for long periods of time.

Lack of Policy Knowledge

- Stakeholders mentioned that as a result of the high rates of staff turnover, the Medical Travel Policy as it relates to escorts is not being consistently applied. For instance, locum physicians who are unfamiliar with the policy are requesting escorts when one would not typically be approved. This places the medical travel staff in an uncomfortable position as they are forced to deny the request because it does not align with the policy.
- It was noted that most NWT residents are unfamiliar with the Medical Travel Policy regarding patient escort eligibility and as a result they do not understand why an escort request is denied. Because they are unfamiliar with the policy and because the policy is not consistently applied, NWT residents are left feeling like decisions are made in a haphazard manner.



Out of Territory Travel

- Some stakeholders mentioned that there is a gap in the Medical Travel Policy with regards to out of territory (OOT) medical travel. The current policy does not cover the costs of an escort to travel when patient diagnosis and/or patient referral originates outside of the NWT. This means that students attending school outside of the NWT or people travelling for business or pleasure will not be approved for an escort to join them unless the patient returns to the NWT for a referral that may then have them travelling back to where the illness originated. It was noted that

the NWT will support students for school and sports, but it will not support a parent travelling to be with a student if they get sick out of the territory.

Cross Community Travel

- In one instance, a woman was asked to travel to another community in order to escort a family member to one of the larger centres for medical care. The woman was then informed that she had to pay her way from her home community to the community of the family member that she would be accompanying. There was no coverage offered for her travel.

Overwhelmed

- While not a criteria for escort selection, a significant number of stakeholders spoke about the overwhelming feeling of fear and apprehension that many people, young and old, feel when they are forced to fly on their own from their small community to a large city, whether it be Yellowknife or Edmonton. They noted that this was too much for some individuals who were also in poor health and/or worried about an upcoming medical appointment.

Abuse of System

- Many stakeholders provided examples of instances in which they had witnessed the patient escort support system being abused by escorts. They spoke about Elders being left on their own in the boarding home or hospital while their escort went gambling or shopping.



“Some people take advantage of the system and ruin it for the others.”

Lack of Planning Time

- Both patients and escorts expressed considerable frustration with the last minute notification of medical travel plans. They spoke about how stressful it was scrambling around at the last minute getting things organized in preparation for the trip. Patients commented that this added to the stress they already had regarding their health. Some stakeholders thought that this late notification revealed a high level of disrespect on the part of medical travel staff for patients and escorts.

Lack of Escort Availability

- If a community lacks sufficient numbers of available escorts, then health care staff (e.g., Home Care staff) may travel with a patient to ensure they have the required supports. This may handicap the CHC/clinic while they are away because there is no one available to replace that person.



5.4 Suggested Improvements / Additional Resources

Stakeholders identified a wide range of improvements and additional resources they felt would help to enhance patient and escort experiences with the Medical Travel Program.

Agreement Form

- It was recommended by many stakeholders that all escorts sign an Agreement Form indicating that they understand and are committed to fulfilling the responsibilities and expectations outlined on the form.

Increase Education and Awareness

- Many stakeholders indicated that increasing the knowledge and awareness of NWT residents about the Medical Travel Policy as it relates to patient escort supports would help them to understand why their escort requests were being approved or denied.
 - It was suggested that medical travel staff take more time to explain the decision-making process and to help patients navigate the system in a timelier manner.
 - It was also suggested that information about the Medical Travel Program be communicated using the local radio, social media, community events and print medium and that it be available in all official languages.
 - A website that contains all of the required information about the Medical Travel Program would be helpful for those with access to a computer.

- The Medical Travel Policy needs to be more easily accessible to NWT residents. This refers to accessibility on the website and accessibility with regards to the language. It was suggested that a plain language version of the policy be readily available.
- It was also suggested that patients and escorts need to have a better understanding of the costs associated with medical travel. It was thought that if people realized how much the program cost, that there would be less abuse of the system by patients and escorts.
- It was recommended that someone ensure all medical travel staff are fully aware of the Medical Travel Policy and that they are implementing it appropriately and consistently across the territory. It is important that patients and escorts are receiving the same information and the same messaging.

Resource Booklet

- In order to address the lack of readily available information on the Medical Travel Program, it was suggested that a resource booklet be developed for patients and escorts that includes the following types of information:
 - Checklist to ensure patients have all appropriate documentation with them
 - Maps – city and hospital
 - Resource phone numbers
 - Accommodations (offering reduced rates for medical travel patients and escorts) as well as nearby amenities
 - List of common medical terms
 - Where they can get special medical equipment for home
 - List of wheelchair accessible taxis
 - Tourism information
 - List of helpful hints
- The booklet should also have space for patients to attach any required documents (e.g., listing of appointments, medical records) and a place to write notes.

Navigator Services

- A number of stakeholders recommended the creation of patient navigator positions in the hospitals frequented most often by NWT residents. The navigator would have a variety of roles and responsibilities including: meeting and greeting the patient and escort when they arrive at the hospital; ensuring they get to their appointments within the hospital; helping to answer any questions they may have (or knowing who to go to for answers); visiting them in their room each day and asking if they need help; acting as a liaison between the hospital, the boarding home and medical travel staff when required (e.g., updating appointment/travel schedules); and, acting as an overall support system for the patient and escort.

Patient and Escort Preparation

- Many stakeholders recommended that a process be put in place that helps to prepare both the patient and the escort for the upcoming medical travel trip. The extent and focus of the preparation will vary depending on the needs of the patient.

- At a very basic level, someone needs to walk through with the patient and escort the list of appointments – confirm they know where they are going and what the appointment is for.
- Patients and escorts need to be made aware of the responsibilities and expectations of the escort and the escort needs to be prepared to stay with the patient longer than might be expected (e.g., up to 21 days).
- Patients who will be undergoing cancer treatment or a major surgery need to be better equipped to deal with upcoming event. It was suggested that someone at the CHC or a volunteer/support group member (who has gone through the experience themselves) walk the patient and escort through what they should expect (from start to finish) – timelines, the types of healthcare providers they will interact with, how they will feel after surgery/treatment, the types of medications they may have to take, etc.
- It was suggested that developing and making available a video that clearly explains what will happen before, during and after surgery/treatment for certain medical conditions would be helpful for mentally preparing patients and escorts.

Monetary Compensation

- It was suggested by many stakeholders that escorts should be compensated for their time and efforts particularly if they are required to stay with the patient for extended periods of time. While some suggested the provision of enough money to cover off the expense of incidental items such as cigarettes and candy, others felt that compensation should be more comprehensive in nature. They commented that when an escort is accompanying a patient they are no longer generating income for their family and as such when they return from the medical travel trip they often come home to no money and many bills.
- One suggestion was that escorts who are required to travel with a patient for extended time periods should get the community health nurse or nurse in charge to sign a Productive Choice Form so that they can receive income support while they are away.
- It was also suggested that consideration be given to introducing a territorial level tax measure that credits patients and escorts for some of the expenses incurred during medical travel trips.

“The Canadian Cancer Society calls for additional financial, practical and emotional assistance for caregivers [escorts].”

Job Security

- It was suggested that NWT employers explore the possibility of increasing the flexibility around labour laws and benefits programs to ensure that escorts have the time they need off work to care for their loved ones.

Decision Making

- It was recommended that doctors or nurses, depending on the community, be given the ultimate authority to approve escorts based on a patient’s physical, cognitive, sensory or emotional state.



Alter Eligibility Criteria

- Many stakeholders suggested that the following changes be made to the escort eligibility criteria to better reflect the needs of the patients.
 - Elders/Seniors
 - All Elders/Seniors over the age of 60 years should be automatically approved for an escort.
 - Cancer Patients
 - Cancer patients should always have the opportunity to have an escort if they so desire, regardless of age, and nature of the appointment.

“No cancer patient should ever travel alone.”

- **Open-heart Surgery**
 - Patients undergoing open-heart surgery require an escort to be present both pre- and post-operative so that they have the opportunity to hear the information/instructions and ask questions about the follow-up care/support required.
- **Illiterate Patients**
 - Patients, who are unable to read English, irrespective of whether they can speak English, should be provided with an escort to help them navigate the medical travel trip (e.g., reading signs, understanding medical instructions, etc.).
- **Never Travelled out the Community**
 - Further consideration for provision of an escort should be provided to those patients who have never travelled outside their community or to a large urban centre (even if they are physically and mentally able).
- **Anaesthesia**
 - Anyone undergoing anaesthesia should be provided with an escort to help them get home after the procedure.
- **Compassionate/Palliative Care Travel**
 - Travel for compassionate or palliative care reasons should be included in the policy and should be approved regardless of age for two family members.
- **Pregnancy/ Caesarean-section**
 - It is suggested that a mother, regardless of age, who has had to leave her home community for confinement have an escort present for some of that time and that at a minimum, an escort (preferably the father/partner) should be present for the birth.
 - An escort should be automatically approved for a woman undergoing a C-section.
- **Breastfeeding**
 - A nursing mother should be approved for an escort if she is undergoing a procedure that requires someone to look after her child during and after the procedure.
 - If a mother is breastfeeding, then she and the baby should be considered as one entity and the father/partner considered the escort.
- **Two Escorts**
 - The policy needs to better reflect the need for two escorts in situations in which the patient has very complex medical and/or behavioural needs.
- **21-day Stay**
 - It was suggested that escort services be reviewed after 10 days to ensure that there is still a need for the escort to stay with the patient.

Volunteer Pool

- It was suggested that each community have the supports in place to create a (volunteer) pool of trained and qualified escorts for those patients who do not have anyone to travel with them or do not have an appropriate escort given their medical condition. Having a pool of escorts would then provide patients with the opportunity to choose the individual they would feel most comfortable travelling with (e.g., gender, age). It was also suggested that a selection criteria be developed and imposed for those who were willing to act in the role of escort. It was also suggested that these escorts be paid for their time and effort.

Escort Training

- It was proposed that GNWT HSS invest money in training escorts so that they can more safely support patients during their medical travel trips. It was suggested that the Elders in Motion Program - a partnership program between the NWT Recreation and Parks Association, the Dene Nation, the Canadian Centre for Activity and Aging with support from the NWT Seniors' Society and the NWT Department of Health and Social Services - may be an appropriate vehicle for this training.
- It was also suggested that escorts obtain some training in understanding medical terms so that they can more effectively assist the patient during healthcare provider discussions.



Extended Stays

- Some patients and escorts would like the opportunity to spend an extra day or two out of the community after their appointment in order to visit family and friends and/or to shop. Assuming they cover the cost of their accommodation and food for this time and since the cost of the flight does not change, there no additional expense to be borne by the GNWT.

Streamlined System

- If an escort has been approved once, then the escort should be automatically approved for the next trip if they are accompanying the same patient with the same health condition or the same type of appointment. This would help streamline the system thereby making the process easier and more seamless. As was noted – “...we shouldn't have to fight for an escort every single time.”

Administrative Burden

- Requests were made to find ways to decrease the administrative burden placed on patients and escorts. It was suggested that streamlining the system so there were less points of contact would significantly decrease the opportunity for miscommunication to occur.



Debriefing

- Given that the escort often acts as the 'eyes and ears' for the patient, it was suggested that escorts debrief with a nurse (and possibly the patient's family, if requested) upon arrival back in the community. This will also provide the opportunity for any documents/records to be provided to healthcare staff.

Confidentiality/Consent Forms

- Since escorts are often privy to very personal patient medical information, it has been suggested that escorts (particularly if they are volunteers and from a small community) sign a confidentiality agreement stating that they will not share patient information with anyone other than those approved by the patient (e.g., doctor, nurse, family).
- It was also suggested that patients sign a consent form to release information to the escort should the need arise.

Available Counsellor

- It was suggested that the boarding homes consider hiring a counsellor to help support the emotional needs of both the patient and the escort.²

Cultural and Religious/Spiritual Supports

- Patients and escorts requested enhanced access to religious and spiritual supports when the patient is in the hospital and likely to pass away.
- Patients and escorts noted that additional cultural supports – food, traditional healers – should be available at the boarding homes and hospitals.

Waiting Areas

- To address the fact that patients are often left waiting for hours before their flight leaves to take them home, and that patients are often in poor physical health, it was suggested that a comfortable space be made available to rest in Yellowknife³ and Edmonton.

Ground Travel

- Local ground transportation should be made available for patients and escorts needing to get to and from the airport. Additionally, it was suggested that the cost of that travel should be covered/subsidized by the Medical Travel Program for both the patient and the escort.

Partnerships

- It was suggested that a concerted effort be made to form partnerships with other GNWT Divisions and outside agencies in order to better support the implementation of the Medical Travel Program.

² It is important to note, that the provision of mental health services is not within the mandate of the boarding homes.

³ It was mentioned that Vital Abel has a day room that can be accessed by patients and escorts, if requested.

6. NEXT STEPS

Based on the feedback received during the engagement sessions, interviews with Stanton/Inuvik Medical Travel Program staff, a review of the Medical Travel Program documents and further discussions with GNWT HSS senior management, a report outlining potential patient escort support options and recommendations will be prepared for the GNWT HSS for consideration.



APPENDIX A – PARKING LOT

Appendix A contains information that we heard from stakeholders but which falls outside of the scope of the project.

Trout Lake

Accommodation

- Food at the boarding homes is too spicy for Elders
 - Elders primarily eat country meats – won't eat meat not from their territory
- Put 'like' patients together – it is uncomfortable to sleep next to a patient recovering from surgery that is up with pain all night
- Staying at Vital Abel there is nowhere to go – no activities
 - Have to go to YK one month before due date
 - Had to move from room to room to accommodate other patients – hard when nine months pregnant

Safety

- Would like to know who is liable for safety during flights, taxi, boarding home

Transportation

- Small planes are too hard for Elders (old, overweight) to get in and out of
 - Need larger planes that are more accessible/comfortable
- Elders need bigger aircraft for mobility/comfort
 - Sometimes Elders are cramming themselves into small planes with oxygen tanks, bad joints
 - Airline will send small plane because only told it is one person with one bag – mobility and other issues not identified to airline
- Some Elders have been given a taxi ride on the ice road instead of a flight
 - This is a four hour trip after hospital stay and travel from YK
 - Elders are worn down - tired and hungry
 - The road is too rough for Elders and it's too long to sit in a car
- Travelling by road from Ft. Simpson to Trout Lake is too hard for patients

Dental Care

- Travel for dental care is very restrictive

Streamlining

- Often there will be three patients going out of the community in one day on three different planes
 - Why not fly them together all at once?
 - Workers Compensation Board and Medical Travel do not coordinate efforts
- Chief and Council see these high cost in the Government statistics – Trout Lake spends \$50,000 per year on medical travel flights

Medical Travel Processing/Notification Times

- Medical travel is a rushed process with very little lead time on travel
 - Elders move a slower pace
 - Causes undo stress
- Travel is usually 1-2 days to get to Yellowknife
 - Always take a charter to Ft. Simpson and then transfer to commercial flight to Yellowknife
- Travel in and out of Ft. Simpson for an appointment is booked same day – this is very rushed and stressful
- Sometimes paperwork only comes in at the last minute and finding escorts is too difficult – time off work, babysitter, etc.

Travel timing

- When booked on the last flight into Ft. Simpson from Yellowknife, patients are spending the night in Ft. Simpson airport waiting for their flights the next day
 - Gap – Medical Travel is not booking accommodations for layovers
 - Taxi service is not arranged in Ft. Simpson
 - Need contact numbers for Ft. Simpson
 - Often weather delays

Differential Treatment

- GNWT employees receive different treatment
 - Get to stay in a hotel
 - The Band Office staff does not get this treatment

Policy Information

- Would be nice to receive more information about the Medical Travel Policy

Communication

- Communication gaps with Medical Travel in Fort. Simpson – always have to call the airlines to double check flights for patients
 - Often flights/connections in Ft. Simpson are wrong
 - Sometimes connecting flights have not been booked for patients
- Medical Travel only does travel logistics
 - Who else to call when you are having issues
 - E.g., suffering post-partum and did not want to leave hospital/get on a plane two days after giving birth – having panic attack

Fort Good Hope

Accommodation

- Sometimes you have to stay in a room with other people who don't speak the same language, this is difficult – you should be able to communicate with your roommates in a boarding home
- Availability of country food at boarding home for long term patients
 - Issue for Aboriginal people – won't eat spaghetti or pizza
 - Western foods are high in hidden sugars and salt
 - Escort can be advocate for patient's dietary needs
- Inuvik has the worst food – quality is poor
 - Health Board salaries are taking away the food budget

Communication

- Medical staff in Edmonton and Yellowknife do not communicate/work well together, which filters straight down and effects patients
 - Edmonton and Yellowknife hospitals do not follow-up with each other
 - Doctors clash with each other

Transportation

- Sometimes open seats on aircraft are given to police/nurses instead of escorts
 - Priority should be given to escorts
 - No coordination happening
- Elders space at Norman Wells airport needs to be better maintained
 - Sometimes a four hour wait in uncomfortable chairs
 - No water

Medical Needs

- Patients should be sent home with enough medication/dressings to get them through their trip home (maybe 3-4days) plus enough time to get to the clinic for re-supply

Northern Understanding

- Doctors in Alberta do not understand the 'North' and our medical system
 - Sometimes ordered to follow-up with family doctor in a few days after release from hospital – “we don't have family doctors up North”

Behchoko

Translation

- Medical Travel needs to do follow-up for patient support – Stanton automatically assigned a translator – wrong assumption
 - should be some follow-up
 - extra money not needed for this service

- Edmonton hospital should have Tłjcho interpreter (on-call)
- Need a translator in Yellowknife hospital during the weekends

Patient/Escort Awareness

- Patient should understand how much it costs for their medical travel trip (flights, accommodation, apartment)
- Financial cost to the system: annual cost of \$100K to \$200K for people who don't show up for appointments
- Medical Travel needs to be advertised better to community members (re: costs)
 - Informed/educated
- Control cost of Medical Travel by educating people in communities to improve health
 - Improving people's health is the way to control medical travel costs – health promotion should be the focus
- Costs system more if patient doesn't show up
- Education in the communities on what medical travel is and what is expected
 - Facebook posting of Medical Travel information
 - Radio – Tłjcho language, educate people on Medical Travel
- Educate public on how much money it costs if patient doesn't show up

Communication

- Have local medical travel staff from each region go into Stanton and sit down and talk/discuss process, etc.

Transportation

- Dettah provides van to take people to appointment – should have that in Behchoko
- Drivers should know not to drive fast and should know that some patients have had surgery – should be qualified drivers

Accommodation

- If GNWT employees get sick, they have the option to stay in hotel because they are not eligible to stay at boarding home - some would prefer to stay at hotel (rather than boarding home)
- Medical Travel should have a list of hotels that are wheelchair friendly
- Doctors agree that traditional foods are best for people – should be process where if you are staying at a boarding home for a week or more then they provide traditional foods or you are able to stay where you can cook your own food
- With the last minute notification I took the patient to Yellowknife after work. I was told to take him to Vital Abel boarding home. When we got there no arrangement had been made for him so they had to put him up at Discovery Inn.
 - Discovery Inn has safety issues
 - When I got to Discovery Inn we were given a room. The room was filthy – the washroom was not clean, the room was hastily cleaned – the rug by the bed was soaked (my socks were soaked right through). I phoned the front desk and demanded another room. The

patient was under NWT Health and yet as a patient he had to deal with hotel rooms that could have made him sicker. I was also stressed out and angry that we had to be treated like this. I was so angry that I took photographs of the room.

- They moved us to another room which was not much better. I went to Walmart and bought a blanket for the patient. I am not sure how clean the sheets were. Again my stress level went up worrying about the elderly patient getting sick because of a bug he may have gotten from the filthy room.
- That evening the people next door became noisy and rowdy. Here I am with a patient who needs his rest and has to be at the hospital by 7:30. How was he going to get the rest he needed? So, again I phoned to the front desk and complain about the noise and the banging on the wall and slamming of doors next door. Again, why did I had to deal with this.

Appeals

- No way to appeal decisions currently
 - Now going to Ministries, Deputy Minister, Managers, etc.
 - No process for dealing with appeals/complaints
- Add in an appeal process – a very simple process for dealing with complaints

Medical Travel Processing/Notification Times

- One day notice for appointments is sometimes a problem - cancellation list
- Appointment clinic/hospital – call medical travel staff etc. asking where patient is
 - People cannot be forced to show up
 - Appointment staff often get very angry when people don't show up
- Medical travel staff phone a couple of days before appointment
- With GNWT, Medical Travel don't know until last minute that approved
- Process is splintered/broken – do our best to make it all work
- My relative was scheduled for an eye surgery and needed an escort. Since I was on his emergency contact list I was contacted and asked if I could escort him the following day for his surgery. Since this was the last minute I ask them to find someone from homecare since he was under their day program but I was told that only immediate family could escort him (due to financial restraint).

Differing Systems

- Two Medical Travel systems (one out of Human Resources and one out of Stanton) because GNWT and public
 - Should be one system – no differentiating between public and GNWT
 - One run by HR is not efficient

Policy

- Anything in place for a young person who is in transition to moving out on their own (care is a concern) ?
- Local Medical Travel has no power to approve anything

- TSCA should have some authority – but Stanton has all the power and it doesn't make sense
 - There was a time when the Authorities/Agencies has more power but slowly Stanton absorbed it all
- Big problem when patient misses flight back (by bad choices) - Medical Travel should still pay for travel back
- Has happened where on vacation and someone gets sick, companion has to leave and left alone - Medical Travel will not pay for return trip and will not send/pay for an escort
- Flexibility needs to be built in
- Policy is contradictory and is open to interpretation
- Add cultural consideration to policy
- Include community involvement when policy changes
- Policy-makers not seeing from small community perspective
 - Having more community members involved in the process

Streamlining

- One system would be more cost-effective - Money could be reallocated to make system work better
- Handing over some of the power to medical travel personnel in communities would likely make Medical Travel job easier too
- Decision-making power – not clear who makes decisions and may not be clear to residents who makes decision

Gaps

- Tlichho Government filling in some of the gaps:
 - Subsidizes Medical Travel to \$500K per year
 - Pays for families to go
 - Palliative care – someone expected to die, they pay for families and friends and food
 - Big enough priority

Dental care

- Medical Travel can pay for travel to dentist (dentists come into community only every 4 to 6 months)

Lack of Understanding

- People in Stanton or whoever is booking appointments books for 8:00am - Pay no attention to the fact that the patient lives in Behchoko
- Doctors and healthcare providers should use simple words

Larga Edmonton

Continuity of care

- Complaint:
 - Husband condition complex
 - Doctors change so much because specialist for each part of the body
 - Should have a doctor that follows patient through whole stage

Communication

- Poor communication between facilities

Medical Travel Processing/Notification Times

- Made very late flight – medical travel waited too long to make travel arrangements (2 times)

Transportation

- Larga needs a vehicle that can accommodate disability issues: crawling over people to get to seats
- Larga doesn't know where to pick up and who needs a wheelchair
- Better transportation for people with less mobility
- Medical travel should mention to Larga about specific mobility issues (increase leg room when can't bend leg)
- Larga Shuttle drivers should know how to help people get in the van
 - If patient does not have escort with them
 - Increase training

Hay River

Communication

- A lot of times we go to Yellowknife, Vital Abel doesn't know we're coming - Sometimes they have room, otherwise we need to get the travel agent.

Medical Travel Processing/Notification Times

- Doctors made appointments in Edmonton, but medical travel approvals were very slow, almost last minute. So what's happening?
- Difficult to make plans
- Sometimes they don't check the approvals and notify us. I called ____, said it's been sitting here for a week

Accommodation

- "we're really, really lucky to have those places to go, like Larga and Abel"

Dental Care

- Does medical travel cover dental surgery or root canals? (It has to be medically necessary)

Transportation/Travel Timing

- Alberta 10 hour layover in Yellowknife, get in to Edmonton at 9:30, bus to Large House had already gone. Stressful on someone already not feeling good.
- People who are really sick go to Yellowknife then Edmonton, when they could go direct. Plane only goes direct three a days a week – but not the airline the GNWT has a contract with.
- Waiting in Yellowknife, wonder if people could stay at Vita Abel for a few hours. (Yes, that’s what we’ve heard) – a place to wait would take stress off
- [Buffalo Air has a lounge for you to wait too, and they will take you to your appointment too.]
- First Air flight from Edmonton is 7:30 am, and if you’ve had surgery, that is hard on you. “That flight almost knocks you back to square one”
- The Northwestern flight is an option to avoid overnighing in Yellowknife. The routing is a dollars and cents issue, but if someone can’t overnight in Yellowknife they should have the option to take the shorter flight
 - If you go to your doctor, they can write you a note to say that travel schedule or route is better for you

Lack of Preparation

- Delayed in Yellowknife but no one told me anything (hard to prepare, pack medication for stay, etc.)
- *[someone tells a similar story of a day trip going into overtime, having to go to emergency to get meds – now recommends patients to bring a 3 day supply of meds]

Accommodation

- Got in late on one trip, got to hotel (Chateau Louis) but no handicapped bathroom – the patient was handicapped. Not safe.

Differential Treatment

- One of the issues is that different people have different coverage, creates confusion as to who gets what services
- Big difference going through HRHSSA or government, booked hotels not Larga - Creates an appearance of wealth or social strata. Two-tier system, always there.
- Government members, middle class and the poor – it is three tiers.

Inuvik

Medications

- Had to get medication for his son in Alberta
 - Even though drugs downstairs in Royal Alex hospital – how was pharmacy getting paid?
- Need to recognize NWT health card to get medication
- Medication was needed promptly but took several hours to get it
- Burden should not be on patient / escort to figure things out
- Should be no question if NWT health card shown

Navigation

- Easy access to appointments – get into U of Alberta hospital – piece of paper with room number (e.g. E3) means little to everyone
 - Finding rooms can be really difficult
 - Perhaps provide layout of hospital so that it is easier to find appointment room
- Difficult to find appointment locations sometimes so perhaps more information so easier for patient / escort (if taxi driver can't find it)

Accommodation

- Larga should be Aboriginal-specific
 - Original intent of Larga – for Aboriginal peoples
- Who goes to Larga and who not is unclear
- Lots of non-Aboriginal people at Larga – serviced as you come
- Non-Aboriginal people are taking an Aboriginal space
 - May be that Elderly get placed in a hotel and that's' difficult for them
 - Scared by themselves
 - Not familiar
 - No one to help them
- Beds are too hard at Vital Abel

Communication

- When patients requested to stay an extra day by a doctor for another test
 - Sometimes patient doesn't know who to call to extend stay at the hotel in Alberta

Telehealth

- Some doctors send patients out on unnecessary trips which can be resolved locally
 - E.g., send x-ray to hospital instead of flying / transporting patient and escort

Differential program

- NIHB – not fully understood the difference between the two NWT medical travel programs

Scheduling Problems

- Elders travel to Yellowknife, Edmonton – arrive and no appointment scheduled
 - Miscommunication between Inuvik and Yellowknife and Edmonton
 - (appointment confirmed) approval process is not effective
- Need more time to prepare travel (advanced notice)
 - Find health card
 - Childcare arrangements
 - Get money
- Staff change created problems

NIHB

- NIHB – federal program, vitally important
 - Should be border neutral, friendly between provinces
- NIHB managed through Territorial government – not maybe the best way, perhaps gets mixed up with other medical travel programs
- Should be able to access NIHB support regardless of what province/territory get treatment from
 - May not recognize NWT health card/Aboriginal
 - Should be able to show Aboriginal identification and get care needed
 - NIHB beneficiary

Second Opinions

- Communities told entitled to a second opinion
 - See locum doctor
 - If not satisfied, supposed to get another opinion if they want
 - But who pays for this – people cannot afford this

Costs

- Communities raising money to help members with travel

Tuktoyaktuk

Communication

- Arrive at destination in both Yellowknife and Edmonton and there are no accommodations
 - Lack of communication between CHC and destination
 - At destination told to find their own accommodation
 - In one instance, when put in accommodation, placed in unopened hotel with no food vouchers
- Travel Tuk to Inuvik - then no plane tickets at Inuvik for travel to Yellowknife; so couldn't get to appointment
- Not booked at Vital Abel upon arrival with Medical Travel
 - Still got picked up by shuttle

- Supposed to go on medical bus but prior to departure realized that they didn't have her name on the list

Transportation

- Relative was placed on medical bus when road was freshly open. He was nervous to travel on newly open road as creeks were still open.
 - CHC said he didn't want to go for his appointment – was willing to go but nervous about road conditions
- Delays in pick up from Vital Abel
 - Hard for Elder to wait so long (no meds, no breakfast – got very upset)
 - Answering machine at Vital Abel – no response
- Was supposed to go for an appointment on the medical bus and needed to take my child with me
 - The medical bus didn't have seat belts
 - Couldn't accommodate my child's car seat

Travel Timing

- Travel should be arranged a day ahead depending on the weather
 - Policy should be to travel a day ahead
 - Would prefer to have travel provided a day or two earlier based on anticipated weather conditions

Accommodation

- Didn't like being put in room with person she didn't know – it was uncomfortable

Yellowknife

Lack of Places to Hang Out

- No coordination between flight and appointment – can't stay in the hotel – no place to go after biopsy when I felt poorly
- Need support after appointments – especially if on your own

Communication

- Lack of communication between Cross Cancer Centre and NWT CHC – medical records are not being shared effectively
- Communications are often difficult between health workers and medical travel and boarding home
- There are miscommunications regarding appointments – have seen people arrive for appointments on the wrong week (people flying to Alberta)

Travel Timing

- Timing of the scheduling of medical travel portion – know about the appointment for ages but don't get flight information until the day before
 - Makes it very difficult to make plans for yourself and escort (work, family, etc)
- Often times have to wait (sometimes up to an hour) at the airport to be picked up

Contact Information

- Need contact numbers to call to help out in these situations

Aligning Appointments/Telehealth

- Greater efforts should be made to align appointments so that less travel is required.
- Telehealth should be used more often in order to decrease the need for travel

Benefits

- Increase benefit amounts for patients and escorts – they do not get enough money for hotel and food. It is hard to eat a healthy diet when you receive so little money for food allowance.

Customer Service

- Medical Travel Program in Yellowknife provides poor customer service – creates high levels of frustration – little information provided – lack of coordination of appointments and referrals
 - I feel like I'm bothering them when I call to ask a question – like I'm not following the rules
 - Poor treatment of clients
 - Makes me agitated because I'm trying to figure out what's going on
- Email response times from Medical Travel Program not in real time – don't know if they're not there or they're ignoring your email
- People shut down before medical travel shuts them down
- Lack of dignity associated with some of the ways they treat Elders especially those with disabilities – no ramps to get on plane – planes too small for Elders to get into easily
- Should be a transparent system that is easier to access

Patient Preparation

- Need to give patients something about what to expect during the medical travel trip – a flowchart – especially when you will have multiple appointments like with cancer

Appeal Process

- There should be an appeal process in place.
- It would help eliminate the arbitrary 'no'

Resources

- Used to have a cancer navigator
- Need to have more information about resources that are available in Yellowknife and Edmonton
- Cross Cancer Centre
 - Lots of information there
 - Lots of volunteers

- Lots of resources – should get in advance so know what to expect
- Need some of these in NWT

Continuum of Care

- Continuum of care – not really happening – DIS-integrated

Accommodation

- Found out about the Sorentino Compassion House – intended for women with breast cancer
 - Communal space
 - Allows you to look after yourself with the help of the escort – better than a hotel
- Compassion House and the wonderful staff and volunteers – I attribute much of my healing on my own cancer journey to that place – but I had to advocate for myself to go there
- Cross has a list of places to stay during and after treatment – people need to see that list before they leave the NWT
- Vital Abel used to be good – take patients to directly to appointments but now the only drop patients off at the front door or in front of airport – this is an issue for elderly without and escort – can become confused
 - If not given an escort then boarding home should step up to ensure patient gets to appointment
- Vital Abel only has one wheelchair accessible washrooms (not in a bedroom). Vital Abel rooms are not wheelchair accessible
- Vital Abel serves the same food every day (soup is too spicy)
- 180-day limit of stay at Vital Abel is a an added stress for those who might get ‘kicked out’ because they have stayed too long
- Medical travel needs to have more accommodation options for long term patients. Give patients the opportunity to cook for themselves
- Patients are kept at Vital Abel if not at hospital – not allowed to go anywhere else – many hours spent just waiting around
- No nursing care at Vital Abel is an issue for some
- Vital Abel provides prescription pick-up services which is good
- Only spending the day in Yellowknife but Vital Abel provides a bed to have an afternoon rest before flight. But have to request it.
- Vital Abel driver is too slow and patient ends up missing appointments or being late or long wait at the airport
- Sister waited yesterday for 2 hours at airport and ended up calling a cab and paying out of pocket
- Medical vans – should also do criminal checks on drivers and have a drugs and alcohol policy
- Vans often stop to pick up non-medical passengers which slows down the trip and patient experience

Policy Interpretation

- Concern from inside the system that the Medical Travel Program is being abused

- The policy can be lenient in some ways
- Interpretation versus implementation
 - Where is the problem?

Patient Empowerment

- Need to empower patients and inform them better and encourage them more
 - Then people would be happy to save the system some money
- “the policy cannot address the complexity of humans”
- Need to pilot test patient empowerment and see what happens – compare standard application of policy with a more empowering application of the policy

Awareness

- Lack of communication likely costs the system a lot of money
- Need to improve advertising about the Medical Travel Program
 - Maybe a pictogram so that literacy and language issues can be addressed
 - One pager – plain language

Navigation

- Need some regional capacity for navigation
 - Perhaps networks of volunteers
 - Volunteers paid based on their use
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Medical Travel Processing/Notification Time

- Medical Travel needs to communicate better
- Should know 2 week in advance when travel is going to be booked (not always possible)
- Feel service is slow – could be better
- Don’t notify of travel soon enough – more notice so can prepare. People have responsibilities at home, i.e., children
- Notification of travel is too short – hard to get things organized.

Vital Abel

- Vital Abel is sometime expecting patients who are not shows, other time people just show up or call from the airport unannounced. Medical travel does not keep Vital Abel informed about patient movements
- Sometime patients arrive without paper work or knowledge of their appointments – they rely on Vital Abel to have this information
- The MTO staff have no accountability
- MTO staff do not communicate information very well

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- The MTO staff have no accountability
- MTO staff do not communicate information very well
- It is hard to track down case reports from Medical Travel – people often don't have them with them
- Inuvik MTO is good with providing information about patients travelling from that community
- Need to increase communications between everyone - boarding homes – patients and escorts – medical travel – medical staff
- There are a lot of missed appointments. Sometime Medical travel offices send the case reports to the Boarding Home after the scheduled appointment and it gets missed. Vital Abel takes on the responsibility of logistical support for all appointments and travel for patients/escorts
- Vital Abel does not have access to patient files from Medical Travel offices
- Medical travel require email communications only – cannot even call for simple questions/answers about patients arriving without appointment info – often leads to missed appointments
- Direct phone line to Vital Abel available at the airport for arriving patients
- Patients are not allowed to piggy back appointments not booked by medical travel (i.e., dental, eye, etc.).
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- Having advanced notice of patients' needs (dietary, etc.) would be very helpful

Other

- Repatriation of remains to home community should be done with dignity