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### Case 5 : Vaccination Under the Midnight Sun: Validation of an Immunization Registry in the Northwest Territories

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## CASE 5

# Vaccination Under the Midnight Sun: Validation of an Immunization Registry in the Northwest Territories

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Although some might refer to New York as the city that never sleeps, during the summer the Northwest Territories' capital city, Yellowknife, is the city that truly never sleeps. During the summer, Yellowknife receives an average of 20 hours of sunlight with no true darkness. The midnight sun provides residents with the unique opportunity to fish all through the night and for children to play outside late into the summer evenings.

### BACKGROUND

The mission of the Northwest Territories (NWT) Department of Health and Social Services (DHSS) is “to promote, protect and provide for the health and well-being of the people of the Northwest Territories” (Northwest Territories Department of Health and Social Services, 2009). The Epidemiology and Disease Registries Unit within the Population Health Division works on several projects that promote, protect, and enhance the health and wellbeing of all NWT residents by providing direction to stakeholders involved in these projects. For example, the Epidemiology and Disease Registries Unit is responsible for maintaining a territorial database of tuberculosis patient files dating back to the 1950s. This database allows public health nurses to easily retrieve patient files and make clinical decisions based on past treatment and diagnoses. The NWT Immunization Registry is another example of a project conducted by the Epidemiology and Disease Registries Unit that works toward the DHSS mission.

In 2012, the NWT Public Health Act mandated that health care providers report all immunizations administered in the territory to the Chief Public Health Officer (Northwest Territories Department of Health and Social Services, 2012). The immunization registry was thus established to provide an electronic record of all immunizations reported to the Office of the Chief Public Health Officer. After the introduction of the immunization registry, each community health centre was required to submit a spreadsheet at the end of each month indicating all vaccines they had administered. The health centres were obligated to record and report the information outlined in the NWT Public Health Act, including health care number, name, date of birth, gender, date of immunization, vaccine name, vaccine brand, manufacturer, lot number, route of immunization, site of immunization, immunization series, and volume/quantity of immunization. When a child is vaccinated, the health care professional records the required information on the child's immunization card, also referred to as a physical immunization record. The vaccine information is then entered into a spreadsheet, normally by an administrative assistant, which the health centre would submit at the end of the month. Exhibit 1 highlights the process from vaccination to reporting all vaccines administered at the health centre to the Office of the Chief Public Health Officer.

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The NWT's DHSS tasked an intern, Janet, with conducting an immunization coverage analysis to establish the level of immunizations delivered throughout the NWT among the cohort of children born between 2012 and 2014 inclusive. Janet was also tasked with conducting an audit of the immunizations that were recorded for the same cohort of children. The immunization coverage analysis identifies the territories' vulnerability to vaccine preventable diseases; however, Janet could not conduct this analysis until an evaluation of the immunization registries data was completed. Conducting the audit first was crucial to determine if a vaccination record was incomplete or incorrect prior to determining the percentage of the population that was fully vaccinated. For example, during the audit Janet discovered that there were several children born outside the NWT who were fully vaccinated, but had incomplete immunization records (i.e. no date of immunization). Not conducting the audit first would likely result in dismissing vaccines that were administered outside of the NWT (due to incomplete vaccine record) and therefore, children born outside of the NWT would likely have been reported as having incomplete vaccination records. The Territorial Epidemiologist, Laura Young, also challenged Janet to identify creative solutions that would enhance the reliability and validity of the data within the NWT Immunization Registry.

In the NWT, physicians or community health nurses administer publicly funded vaccines. At the time of administration, the physician or community health nurse records the vaccine name, manufacturer, lot number, quantity, etc. into the patient's chart. The vaccination record is then entered into a spreadsheet by the community health nurse or administrative staff. At the beginning of every month, the community health nurses are required to submit the spreadsheet, containing all vaccines administered in the previous month, to the Office of the Chief Public Health Officer. Each month the DHSS receives 33 spreadsheets, one for each community in the NWT. The Disease Registry Officer (DRO) validates demographic information such as patient name, date of birth, gender, and residence with information in the spreadsheet and the NWT Healthcare Management Information System. Exhibit 1 demonstrates how vaccines are administered and reported in Community Health Centres with the purple arrows.

To begin an audit of the existing immunization registry, Janet needed to locate and collect all newborn vaccine records to establish a true source for comparison against the existing registry. Since the NWT does not require health professionals to report vaccines that patients have received outside the NWT, the existing immunization registry presents incomplete records for several children. The physical immunization records present a complete record of all vaccines children have received, including vaccines administered outside the NWT. Therefore, the true source used for the NWT immunization registry audit was an amalgamation of all physical immunization records submitted to the DHSS. Furthermore, it was essential to use the original data submitted to the DHSS for comparison against the true source, as this would provide the ability to capture all errors in the original data submitted by the community health centres.

Janet began the audit by sending a request to all 27 health centres in the NWT asking that all immunization cards (i.e. paper records) for children born between 2012 and 2014, inclusive, be faxed through the DHSS's secure fax line. When the immunization cards arrived at the DHSS Janet abstracted the information and compiled the data in a spreadsheet. It took Janet almost six weeks to enter approximately 3,000 physical immunization records, equaling 26,000 immunizations, into the spreadsheet. Once the data were entered they needed to be cleaned: duplicate immunizations removed and missing immunizations identified. After the cleaning process was completed, Janet summarized the audit and conducted a full coverage analysis. The gray arrows in Exhibit 1 summarize the steps performed by Janet to complete the audit of the NWT Immunization Registry.

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### UNDERSTANDING THE NORTH

Receiving an average of 20 hours of sunlight during the summer and five hours in the winter, the Northwest Territories is the home of 11 official languages (Canadian Immigrant, 2011). The 43,234 residents of the NWT are dispersed throughout 33 different communities, 21 of which are fly-in only. These communities vary in population size from 70 to 20,000 residents (NWT Bureau Statistics, n.d.). Residents of NWT's fly-in communities face multiple challenges from high transportation costs on most consumer goods, to the inability to foster further economic development due to lack of education and training opportunities near their communities.

Northern public health also presents several challenges, particularly around remote northern communities where resources are limited. In the NWT there are only three birthing hospitals. All of the other communities are equipped with a health centre with trained nurses. Mothers from outside a birthing community are required to fly to the nearest birthing community four weeks prior to their due date to prepare for child birth. The birthing communities have established boarding homes for mothers and their families that offer various services, such as a shuttle to and from the hospital. Furthermore, the NWT has a difficult time recruiting and maintaining health care professionals in their remote and rural communities, which makes it difficult to meet the mission of the DHSS to protect and provide for the health and well-being for all of the NWT (NWT DHSS, n.d.). Due to the limited number of nurses at some of the community health centres, communication between the health centres and the DHSS is often quite difficult. Emails from the DHSS can sit in the health centre's inbox for weeks before the DHSS receives a reply, often due to limited staff, new staff, or the centre's hours of operation. In several health centres across the NWT there is only one nurse, referred to as the nurse in charge, who is responsible for everything from immunizations to traumas and daily paperwork.

During Janet's practicum with the DHSS she quickly began to understand the impact of living in a small Northern community. When a community of merely 100 individuals is faced with an outbreak, the DHSS is often confronted with several barriers they need to overcome to protect the health and well-being of the NWT. Laura Young realized that not all rules and guidelines proposed by the Centers for Disease Control and Prevention (CDC) or the Public Health Agency of Canada (PHAC) could be directly applied in the Northern setting. For example, in January of 2015, several cases of Pertussis were reported in *Community X*. It was later discovered that the index case attended a daycare facility, and, as per CDC guidelines, the daycare centre was closed down, and parents were forced to find alternative childcare. After the closure of the day care facility several small in-home day care facilities started. Unfortunately, the creation of multiple in-home day care facilities did not eliminate the transfer of disease among the children. Of the 22 children who attended the day care, 12 were confirmed Pertussis cases, while an additional 17 of 78 third party contacts were also identified as confirmed Pertussis cases. During outbreaks public health officials are often under a lot of pressure to stabilize the situation; therefore, having guidelines can help them manage it. However, the 2015 NWT Pertussis case emphasized that guidelines are only as good as the environment for which they are designed.

### DATA QUALITY

The Government of the Northwest Territories' Population Health Division's projects focus on monitoring the health of residents in the NWT and evaluating different health services that are offered throughout the territory. The immunization registry is used to document all immunizations administered within the NWT. It is essential that the Division has reliable and accurate public health data to monitor the health of the territory and evaluate health services offered throughout. When conducting the audit, Janet came to realize that the data in the immunization registry was far from complete.

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The NWT population is constantly fluctuating, as the territory often attracts workers and their families from southern parts of Canada. Furthermore, NWT residents are also very mobile and do not tend to reside in one location for very long. With a transient population, several challenges arose in maintaining a complete health record for people in the territory. Janet focused on the challenges specific to maintaining a complete immunization record for newborns. The immunization registry was not designed to track children's immunizations administered outside the NWT. When families move to the NWT and visit the community health centre they are required to bring their child's immunization card with them to inform the health centre of immunizations they have already received. Unfortunately, it has been estimated that 30% of parents and legal guardians lose their child's immunization card before they are seven years old (Laroche, 2012). Referring back to Exhibit 1, after the child receives their vaccination it is recorded on their physical immunization card by the healthcare provider. A copy of the child's immunization card is kept in their patient chart, while another copy is kept with the child's parent or legal guardian.

There is currently no policy in place regarding the transcription of child immunization records from their previous province/territory. The inconsistency in record entries amongst community health nurses presented a gap in the NWT immunization registry. For example, Janet identified that when a child's previous immunization record was available, some nurses would manually copy all of the information onto the child's new NWT child immunization card, while others would only copy the date. However, when a child's immunization records were not available, nurses often consulted the child's parent (or legal guardian) to determine which immunizations the child has already received. When Janet entered the data from the individual immunization records into the spreadsheet, she started to question the integrity and validity of the data on the cards that had been transcribed from immunization records in other jurisdictions. Janet discovered that there were a lot of data that went missing during the transcription process.

Some communities record a single immunization event in up to three different locations (e.g. patient chart, spreadsheet for reporting to the Office of the Chief Public Health Officer, and electronic information system). The information that is documented by the health care professional on the immunization card is normally passed along to an administrative assistant to manually enter into the reporting spreadsheet. Unfortunately, the administrative assistants may not know the abbreviations for vaccines, routes, manufacturers, etc. and do their best to transcribe the cards. For these reasons, notations such as "LUL" instead of "LVL" (an abbreviation used by some nurses for left vastus lateralis) are used.

While conducting an audit of the immunization registry, Janet obtained the names, health care numbers, and addresses of children born between 2012 and 2014, inclusive, from the DHSS Healthcare Management Information System. This data not only provided Janet with the opportunity to validate the data she entered, but also to determine if there were children born between 2012 and 2014 who did not receive any immunizations. Exhibit 2 highlights the errors that were identified during the comparison between the electronic immunization records and paper immunization records for a single community.

Exhibit 3 highlights a few high problem areas including Brand Name, Health Care Number, Route, Date of Birth, and Name. Several communities have had the tendency to use trade names instead of brand names, resulting in large error rates in four of the five regions. The format of dates was also a common error in all regions. Some of the larger regions did not have this problem because they had an information system that auto-populated demographic information. Accents and multiple names (i.e. joined by dashes or space) were often the cause of errors with respect to name. It is important to note that the NWT health care number begins with a letter and is followed by seven unique characters. The letter at the beginning of the health

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care number identifies the child's aboriginal status. When a child is first born they receive a health care number in the format of N#####, where 'N' represents Non-Aboriginal. Parents must apply to have their child's health care number changed to match their aboriginal status; for example, H##### is consistent with an individual who identifies themselves as Métis. The majority of health care number errors were caused by incorrect status characters. Since NWT health care cards do not expire for three years, if a child's status is changed during this time period it will not be reflected on their physical card until they receive a new card at their third birthday. Therefore, every time they present their health care card to obtain health services they will be incorrectly identified as non-aboriginal.

Without reliable and accurate data the DHSS cannot determine how vulnerable a population is to certain vaccine preventable diseases. How reliable is a spreadsheet as a population health registry? How can real-time analysis be conducted in the middle of an outbreak with 33 rural and remote communities? These questions were lingering in Janet's mind as she prepared to establish a creative solution to address the data integrity issues with which Laura Young had challenged her.

### IMMUNIZATION COVERAGE

Immunization coverage analysis helps the DHSS determine how well protected the NWT is from vaccine-preventable diseases. The analysis also helps evaluate the effectiveness of programs in the different communities, as well as the parental perspective of immunization. High rates of immunization coverage in a community present the opportunity for that community to reach herd immunity, whereby individuals who did not receive their immunizations will be protected by the rest of their community who have been immunized. The concept of herd immunity exists due to the fact that the probability of disease transmission decreases with an increase in the number of individuals who are immunized (Public Health Agency of Canada, 2010).

While examining the 2012 to 2014 cohort, Janet noticed that several parents were deferring their child's immunizations, and even more were refusing them all together. Health professionals have several theories for parents' refusal of immunizations, varying from celebrity influence to misleading and conflicting online resources (Busby & Chesterley, n.d.). In fact 59 (3%) parents in the 2012 to 2014 cohort refused to vaccinate their children. There is currently no place for healthcare providers to identify that an immunization has been deferred or refused. Since Janet obtained all of the original paper immunization records from the communities and entered them all into the computer, she was able to track those where the healthcare provider had written 'refused' on the card. It is likely that the true number of refusals is higher.

Janet conducted a thorough immunization coverage analysis of the cohort of children born between 2012 and 2014, inclusive, who had at least one immunization record at the DHSS. Children born in 2012 were considered fully vaccinated if they received all seventeen immunizations by their second birthday with the correct spacing as indicated by the NWT immunization schedule. Similarly, children born in 2013 were considered fully vaccinated if they received all fifteen immunizations by their first birthday with the correct spacing as indicated by the NWT immunization schedule. Children born in 2014 were considered fully vaccinated if they received all doses of the vaccines on the NWT immunization schedule with the correct timing by the end of the follow up period. Children who did not receive all doses of a vaccine, or did not follow the NWT immunization timing, were considered partially vaccinated. Children who did not receive any immunizations were considered not vaccinated. Although data was collected in May of 2015, for children born in 2012 child immunization status was assessed on their second birthday. Janet also conducted a follow up analysis to assess coverage after the cohort turned two years old, and those who were completely immunized were now considered "completely

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vaccinated by end of follow up”. Exhibit 4 includes results from the coverage analysis for Community X.

### FEASIBILITY

While working on the immunization audit Janet began to question whether the DHSS should continue to use its current immunization registry or invest in a new information system to support the immunization registry. The DHSS employs one full time Disease Registries Officer to maintain the existing immunization registry. It is the responsibility of the Disease Registries Officer to validate the information submitted to the DHSS in the spreadsheets from the community health centres regarding immunizations administered in the past month. The Disease Registries Officer then amalgamates the spreadsheets from all the communities to form the existing immunization registry. The process of data validation is timely, tedious, and sometimes incomplete.

If the DHSS conducts an immunization coverage analysis without requesting the paper immunization records it is likely that the NWT immunization coverage rate would be underestimated. Exhibit 2 highlights the tremendous discrepancy between the number of immunization records reported monthly to the DHSS through the spreadsheet and those from the physical immunization cards. This table emphasizes the importance of collecting the physical immunization records from the communities prior to conducting a coverage analysis. For example, Region 4 was missing 58% of its immunizations records. Therefore, conducting an immunization coverage analysis with the registries’ data alone would not provide accurate community level projections. Although it was a cumbersome task, if Janet had not entered all child immunization records, the DHSS would have missed 36% of vaccinations.

As the end of Janet’s placement approached, she realized that the key to Laura’s challenge was not only to be creative, but also to be resourceful and collaborative. With an extremely high turnover of nurses in the communities any data integrity solution was only going to be as good as its end user. Therefore, incorporating the nurses in the planning process was essential to success.

### RECOMMENDATIONS

Although the DHSS was working toward the implementation of a new information system to support the immunization registry, it was unclear as to when implementation of the system would take place. In the meantime, there were several things that needed to be taken into consideration to improve data quality. A large portion of the errors could be eliminated with the creation of a new data entry template with vaccine, brand, manufacturer, site, and route names embedded in the program. Janet also identified that errors in name, date of birth, and community could also be minimized by auto-populating the corresponding fields by health care number. Janet’s creative solution to Laura’s challenge involved creating a data entry form in Microsoft Excel to be sent to each community health centre to enter their monthly vaccines administered.

Through collaboration with the DHSS Communicable Disease Consultant in charge of the NWT immunization program, Janet also recommended that the vaccine names, brand names, and manufacturer names be consistent and up to date with those provided by the National Advisory Committee on Immunizations (NACI). The most common variable that community health nurses substitute with their own terminology is ‘site’ (location on body where child was vaccinated); therefore, it is likely that the list provided on the current immunization registry was not comprehensive. Sequential roll out of the new data entry template would provide the DHSS Disease Registries Officer more time to deal with inquiries (i.e. calls and emails) from front line

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staff. Furthermore, feedback during each roll out could be used to improve the data entry form for the next community.

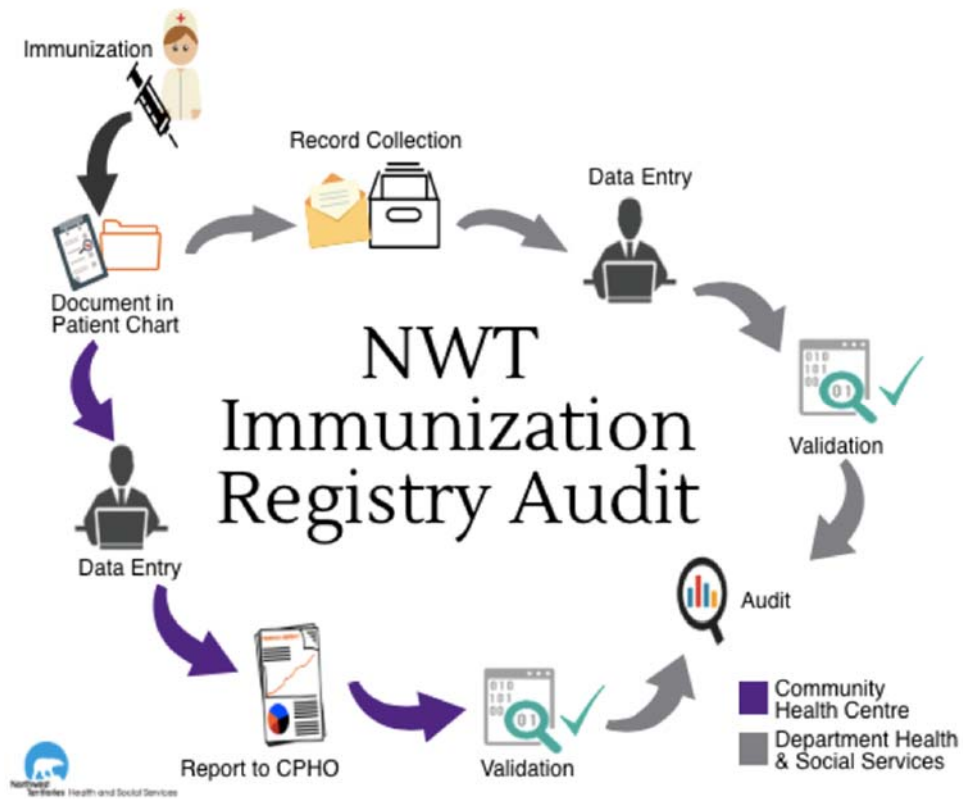
### CONCLUSION

The NWT is very unique and the health care guidelines followed should resemble its uniqueness in hopes of protecting the health and well-being of its people. Even though we might live in a time period where technological advancements have provided us with an increased access to data, by no means does this imply that the data are accurate and dependable. Although it is a time consuming process, data validation is crucial for maintaining an immunization registry that is reliable and accurate.



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## EXHIBIT 1 NWT Immunization Registry Audit



Source: Created by author.

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### EXHIBIT 2

#### Discrepancies Between Electronic Immunization Records and Paper Immunization Records

Health Centre	Cohort Summary		
	Paper records	Missing electronic records	Total flags
REGION 1	1620	646(39%)	1510(93%)
REGION 2	1467	354 (24%)	1145 (78%)
REGION 3	517	96 (19%)	424(82%)
REGION 4	737	431 (58%)	593(80%)
REGION 5	645	261 (40%)	550(85%)
<b>TOTAL</b>	<b>4986</b>	<b>1778 (36%)</b>	<b>4222(85%)</b>

Total records = Total number of unique immunization records

Missing records = Number of paper immunization cards that were not in the electronic immunization registry

Total flags = Total number of records that had one or more errors

Source: Northwest Territories Department of Health and Social Services, n.d.

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### EXHIBIT 3 NWT Immunization Registry Audit

Health Centre	Total Records	Health Care Name	Health Care No.	Date of Birth	Vaccine Date	Vaccine Name	Brand	Manufacturer	Lot Number	Route	Site	Series	Quantity
<b>Region 1</b>	4566	17.1%	47.4%	5.7%	7.5%	1.0%	23.3%	36.9%	9.8%	18.3%	2.5%	13.4%	1.1%
<b>Region 2</b>	3788	10.2%	58.4%	3.1%	5.2%	0.3%	22.2%	28.4%	8.4%	16.5%	1.4%	12.5%	1.0%
<b>Region 3</b>	1515	12.3%	55.8%	4.9%	9.4%	2.0%	21.1%	28.1%	9.2%	19.3%	1.3%	21.8%	2.2%
<b>Region 4</b>	2255	8.7%	34.7%	2.0%	6.4%	9.9%	13.5%	11.3%	8.2%	3.3%	0.0%	6.6%	3.0%
<b>Region 5</b>	10647	6.6%	43.4%	1.5%	5.9%	0.4%	16.0%	15.2%	7.6%	7.1%	0.7%	17.4%	1.3%
<b>TOTAL</b>	<b>22,771</b>	<b>9.9%</b>	<b>46.7%</b>	<b>2.9%</b>	<b>6.4%</b>	<b>1.6%</b>	<b>18.6%</b>	<b>22.2%</b>	<b>8.3%</b>	<b>11.3%</b>	<b>1.2%</b>	<b>15.0%</b>	<b>1.4%</b>

\*\*NOTE: Numbers are not representative of real regions in the NWT. The numbers have been changed for confidentiality purposes until the report is released to the authorities.

Source: Northwest Territories Department of Health and Social Services, n.d.

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**EXHIBIT 4  
Community X n=237  
Percent of Cohort Receiving Immunizations**

<b>Vaccine</b>	<b>Number of doses</b>	<b>% coverage rate (95%CI)</b>
<b>Hepatitis B</b>	2	49.1 (43.0-55.1)
<b>Bacillus Calmette-Guerin</b>	1	85.7 (80.6-89.6)
<b>Diphtheria, tetanus, acellular pertussis, inactivated polio, Haemophilus influenza type B</b>	4	65.2 (59.1-70.9)
<b>Meningococcal conjugate C</b>	2	90.4 (86.1-93.5)
<b>Pneumococcal conjugate 13</b>	4	52.7 (46.6-58.8)
<b>Measles Mumps Rubella</b>	2	81.86 (76.67-86.13)
<b>Varicella</b>	2	81.5 (76.1-85.9)
<b>Rotavirus</b>	2	46.3 (41.6-51.0)

\*\*NOTE: Numbers are not representative of a real population in the NWT. The numbers have been changed for confidentiality purposes until the coverage analysis is released to the public.

Source: Northwest Territories Department of Health and Social Services, n.d.

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## INSTRUCTOR GUIDANCE

### Vaccination Under the Midnight Sun: Validation of an Immunization Registry in the Northwest Territories

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#### BACKGROUND

With the implementation of mandatory reporting of all immunizations in the Northwest Territories (NWT) in 2012, the Department of Health and Social Services' (DHSS) Disease Registry Unit was working toward the implementation of a new immunization registry similar to those implemented across the country. However, the current immunization registry was in the format of an Excel workbook. The DHSS noticed several issues with the quality of the data maintained in the spreadsheets. As part of Janet's practicum, she conducted an audit of the immunizations for the cohort of children born between 2012 and 2014, inclusive, within the registry.

Community health centres are required to submit immunizations they have administered via a monthly spreadsheet. The Disease Registry team then validates and cleans the information submitted and consolidates all the data into the immunization registry on one master Excel workbook. It is important to note that the original data submitted to the DHSS from the health centres is only added to the immunization registry after the Disease Registries Officer has confirmed that the data are clean.

To assess the validity and reliability of the data, the community health centres were contacted and asked to submit all paper immunization records for children in this cohort, which were then entered into another spreadsheet. The cohort spreadsheet and the immunization registry were compared to determine the number of errors across various variables.

To summarize, the audit was a comparison of the original community spreadsheet submitted to the DHSS with the paper immunization cards, which Janet entered into a separate spreadsheet to easily compare the two datasets.

#### OBJECTIVES

1. Recognize the challenges that arise when dealing with data from health services in remote northern communities.
2. Understand the importance of data quality when assessing a population's vulnerability to disease and public health initiatives.
3. Indicate the benefits of implementing a new information system to support the existing immunization registry in the NWT.
4. Interpret immunization coverage data.

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### DISCUSSION QUESTIONS

1. Why did Janet compare the spreadsheet she created (i.e. populated with data from paper immunization records) with the original immunization data (i.e. spreadsheets submitted from the community), instead of directly comparing it with the existing immunization registry?
2. What are some of the difficulties working with population level data in northern remote communities?
3. What are the advantages and disadvantages of establishing an Immunization Registry in the NWT?
4. Why would the DHSS be under-reporting immunization coverage if they did not perform an audit of paper immunization records?
5. What limitations does the NWT's mobile population present with respect to conducting a coverage analysis with the current immunization registry?

### KEYWORDS

Immunization coverage; immunization registry; information system; original immunization data; paper immunization records.