

National Survey on Immunization Data Standards:

The Current Practice.



Prepared for:
**Subcommittee on Data
and Technical Standards:
National Working Group
For an Immunization
Records Network**

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EXECUTIVE SUMMARY

Each province/territory does, within their jurisdiction, have a level of standardization for many of the data elements. This level ranges from formal adopted standards to those that may be called 'consensus' standards. In this case, 'consensus' standards are those that have evolved over time to ensure consistent communication of the information within a local region or within a local agency. In most cases there is no formal recognition of the standards.

The following recommendations are made based on one of the Immunization Registry Project objectives of communicating immunization profiles by March 2003. Should this objective be changed the following recommendations should be revisited.

1.0 Revisit the Immunization Data set to ensure all data is, indeed required.

2.0 Develop operational or 'consensus' standards and definitions for the minimum data set.

3.0 Define a National Immunization Network Message (NINM).

4.0 Base NINM on HL7 technology.

5.0 The Public Health Working Group should explore ways and means of supporting provincial/territorial Immunization Registries.

INTRODUCTION

In March 1998, Health Canada sponsored a Canadian Consensus Conference on a National Immunization Records System, and a proposed data set for immunization records data was established. A National Working Group for an Immunization Records Network was created, and a subcommittee on Data and Technical Standards was mandated to develop both data and technical standards for a national immunization record sharing. The first step was to undertake a survey, to determine the level of immunization documentation in each province/territory, to determine the level of compliance with the drafted data set, and to determine if there existed any coding consensus across the country. This report provides a response to those objectives, as supplied by contact persons in each province/territory, and documents the current status of provincial/territorial immunization records systems in Canada.

BACKGROUND

The Canadian National Immunization Conference 1996, recommended that:

“An immunization tracking system is urgently needed in Canada to identify children due, or overdue for immunization, to notify parents, to make appointments, to provide a database for health-care providers to monitor the immunization of patients at each encounter regardless of where the vaccine was administered, to assist in planning and identifying populations at risk for delayed immunization, to target interventions appropriately, and to evaluate the success of the program. In provinces where physicians deliver the bulk of immunizations, tracking systems adapted for practice, as well as for public health needs, must be developed. The positive exchange of ideas between conference participants suggests that the time has arrived for a national program to be administered provincially, thus ensuring compatibility between provinces so that this health-care information can be accessed when needed. A clearinghouse of current provincial, territorial, and local projects related to the issue and a consensus conference is needed to decide on standards and core information to be collected, and to ensure further compatibility of systems.”

The Consensus Conference, 1998, was organized to begin work on the above recommendations.

Using Issue Papers, prepared in advance of the conference, small groups reported on key issues, general issues being: Objectives, Barriers, Confidentiality, and Success Factors, and system issues being: General Systems Issues, Data Elements, Confidentiality and Reporting Functions. The following objectives represent consensus of the participants.

OBJECTIVES:

Overall goal for immunization registry

An immunization registry will facilitate the control and elimination of vaccine preventable diseases in Canada by ensuring the provision of information and knowledge necessary to achieve the best possible immunization coverage for Canadians.

General Objectives

Canada will establish an integrated and comprehensive immunization records system in all provinces and territories in Canada within five years of this conference (target date, March 2003).

There will be agreement on a common set of data elements and standards for all Canadian registries within one year of this conference (target date, March 1999).

Patient Care/Individual Level Objectives

1. The registries will provide current immunization status information to each individual and/or health care provider as necessary.
2. The registries will identify children due or overdue for immunization. They will notify parents/guardians and supply providers with information necessary to support follow-up.
3. The registries will provide information to parents/guardians and providers to avoid inappropriate immunization.
3. The registries will provide information to assist providers in determining the relationship between immunization and adverse events and follow individual patients if necessary.

Public Health/Surveillance Level Objectives

1. The registries will provide information on vaccine coverage to program planners and providers and assist in identifying poorly immunized populations and groups, targeting interventions and evaluating program efforts.
2. Registries will provide information to assist in the control of outbreaks of vaccine preventable diseases.
3. Registries will measure progress towards Federal/Provincial/Territorial objectives for vaccine coverage and disease control.
4. Registries will minimize costs to the health care system (including private providers), public health and the school system by providing efficient records management.
5. Registries will provide information that will assist in assuring accountability for effective vaccine use.

The Subcommittee on Data and Technical Standards developed a survey to determine the level of immunization documentation across the country, with the following objectives:

- To determine the level of concordance with the recommendations on data elements arising out of the Consensus Conference;
- To determine what data standards are used in each province/territory;
- To develop a data map that will assist providers to locate client data in other provinces/territories.

In early September, 1999 a package containing a cover letter and a copy of the survey was sent from the office of Dr. John Spika, Director, Bureau of Infectious Diseases, Laboratory Centre for Disease Control (LCDC), to the Provincial Epidemiologists, and copies were also sent to the Chief Information Officer of Health in each province/territory. The cover letter asked that a contact person(s) be appointed from each province/territory to review the survey, and be prepared to supply the information requested in the survey. Amaranth Health Consulting was retained to conduct the survey, and to produce an analysis of the responses.

Description of the Survey

The original survey was in two parts, the first page being a questionnaire regarding the technical aspects of each province/territories' system, referred to in the survey as the "Technical Page"¹. As responses to the survey were received and reviewed, it became clear that the contact persons for those provinces/territories, where an immunization registry was in place, were having difficulty in responding to the question on their immunization registry's functionality² and that further direction was needed. The surveyor, in discussions with the contact persons, determined that the question should be expanded, and an additional one page questionnaire, referred to as the "Functionality Page"³ was added, based on objectives that had been defined by the Consensus Conference, 1998.

The main body of the survey, presented in chart form consists of three components, Client Demographics, Client's Parent/Guardian Demographics, and Immunization Event. The left-hand side of each page listed data elements identified as desirable in the proposed national registry, and asked if they were collected, their field size, and their format characteristics. The right-hand side of the page, referred to as the "Provincial/Territorial Data Standards section" pertained to the provincial/territorial data standards, which govern the collection of each data element.

¹ Appendix A Survey – Technical Page

² Appendix A Survey – Technical Page, question 2, last item

³ Appendix A Survey – Functionality Page

Results of Survey

Responses to the survey have been presented, using a table for each of the six survey components: Technical Page – Table 1, the Functionality Page – Table 2, Data Element chart, consisting of: Client Demographics – Table 3, Client’s Parent/Guardian Demographics – Table 4, Immunization Event – Table 5, and Provincial/Territorial Data Standards – Table 6. Comments from each province are provided, with the tables, as supplied.

At the present time, the Northwest Territories supports the Nunavut immunization program, so throughout the survey responses for both jurisdictions are the same. The Yukon responded to the entire survey by commenting that there is no central level of data accumulation, since funding was discontinued in 1996.

A list of vaccine codes⁴ was requested from each province/territory, and received from all with the exception of Yukon Territory. Codes are not included in this report due to space. A sample of vaccine codes and a summary on vaccine codes responses are presented as part of the discussion - Section I – Technical Page. A discussion of the Data Element Chart, Tables 3, 4 and 5 is contained in Section II of this report. Although responses to the Data Standards of the survey were generally poor, a discussion of responses, and some observations are presented in Section III - Provincial/Territorial Data Standards. Report recommendations are presented in Section IV.

⁴ Appendix A Survey – Technical Page, Question 4

SECTION I: TECHNICAL PAGE

Table 1: Technical Data Page - Data and Technical Standards Survey

In spite of a wide variety of functional technological solutions, a relatively high level of immunization data is captured in the 0-7 age group, with British Columbia, Alberta, Manitoba, Prince Edward Island, Northwest Territories and Nunavut all reporting 95-100%. Northwest Territories and Nunavut, report that there is no immunization registry, and that immunization data for 100% of children 0-7 is included in their CHMIS system. Saskatchewan, shows a deceptively low level of immunization data collection (less than 10%), simply because their registry is so new, that not all children have been initiated into the registry. Ontario shows that current data is available on school age cohort only, and therefore immunization events prior to children entering school are not within their registry, accounting for the low percentage (approximately 28%) of 0-7 age children, as reported in the survey. Nova Scotia, where 70-80% of children are immunized by physicians, reported that, since data was based on doctors' billing, the only central level of data accumulation attained was on those children. There is no central level of data accumulation for the remaining 20-30% of children serviced by public health.

Perhaps the most positive aspect of this discussion is that despite low or non-existent levels of legislation and regulations governing the collection of immunization data, as in British Columbia, Manitoba, Nova Scotia, Northwest Territories, and Nunavut, health-care providers and information professionals have demonstrated their awareness of the need for an immunization tracking system, by working toward provincial/territorial immunization registries. Alberta and Quebec are presently in different phases of development and implementation, and Saskatchewan's system has only recently been implemented.

When discussing the technical aspects of the system, it should be noted that Alberta, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, Newfoundland, Northwest Territories and Nunavut all describe their systems as centralized, and of those Manitoba and Prince Edward Island report that their systems were developed under mainframes. British Columbia, Ontario, and Quebec describe their systems as having decentralized local programs, which support forwarding and reporting of immunization data to a central accumulation at the provincial level. The most commonly used database (British Columbia, New Brunswick, and

Newfoundland) is ORACLE. Northwest Territories, Nunavut, and Alberta provided a yes answer, but did not specify which database is used. All other databases are unique: Saskatchewan uses SQL server; Ontario uses FOXPRO; and Nova Scotia uses its MSI billing database. A client server exists in seven Provinces/Territories: British Columbia, Alberta, Saskatchewan, Quebec (specifies only at provincial level), New Brunswick, Nova Scotia, and Newfoundland. To date, only Alberta and Saskatchewan respond that their systems are web based; though British Columbia comments there are plans for this. All front end/presentation tools are unique to each province/territory, and are identified on Table 1. New Brunswick and Nova Scotia indicated that these were not part of their systems, and Manitoba responded, that this information was not available. Quebec answered that they did have front end/presentation tools, but they did not specify what kind. The most commonly used network protocol (British Columbia, Alberta, Saskatchewan, Manitoba, and Newfoundland) is TCP/IP. This will be of great benefit in establishing an integrated and comprehensive immunization records system nationally, as presently there is minimal data sharing between provinces.

The level of development of functionally technological solutions to support the collection of immunization data within provinces/territories is very high, but the level of development of data sharing protocols to support the flow of information between provinces/territories is very low. Three Provinces, British Columbia, Alberta, and New Brunswick report that they intend to have these in place sometime in the near future. British Columbia indicates, that this is developed, though not implemented yet. Corporate sharing protocols are being developed in New Brunswick and Alberta, the latter, intending that data should be shared, inter-provincially, at the provincial level, through the provincial epidemiologists' offices. Data sharing protocol, in Nova Scotia, is supported through its MSI billing system. Neither Manitoba, nor Prince Edward Island have systems that support data sharing protocols. Northwest Territories and Nunavut responded that non-nominal aggregate data was reported to their health boards, and then, sent on to their database, but made no comment on how this data is queried or shared, between provinces. Newfoundland and Ontario both utilize ODBC, and, in addition, Ontario uses OLE DB.

Generally, the highest level of client data accumulation (77%) is at the provincial/territorial level. Yukon Territory, Manitoba and Alberta all reported maintaining this at the local level, though Alberta comments, that under its proposed system, client data will reach the provincial level. Data accumulation at the provincial level is at a lower rate (69%) for those data elements concerning the

immunization event. Of the four Provinces/Territories: Alberta, Saskatchewan, Manitoba (in doctors' claims) and the Yukon Territory accumulating this data at the local level, Alberta comments, that this data will reach the provincial level with its new system.

Table 2: Functionality Page - Data and Technical Standards Survey

In reviewing the results of the Functionality Page⁵ – presented in Table 2, only six Provinces/Territories (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, and Quebec) indicated that they have an immunization registry. Two of these are, presently, being implemented, or soon will be. British Columbia with the PHIS project is the only Province/Territory that has 100 % compliance with the functional requirements of an Immunization Registry. Alberta reports that once their system is complete they, too, will meet the functional standards. Saskatchewan, now at 44% compliance with the national objectives, will soon increase to be 78% compliant, which is the same level presently attained by Manitoba. Although most province/territories, reporting no registry, have low levels of compliance, Northwest Territories and Nunavut report that immunization coverage can be assessed because immunization data is held within their centralized CHMIS (Canadian Health Management Information System), and report 100% compliance.

Each province/territory provided a list of vaccine/antigen codes as requested in Item 4 of the Technical Page⁶, except for the Yukon Territory, with no central level of data accumulation. Anecdotally, it was reported by many province/territories, that no codes conformed to any external coding systems. Disease, immunization event, and adverse reaction codes were all created internally. In some Provinces/Territories, like British Columbia, where the systems or registry have been developed recently, standards may be determined by provincial groups, pilot sites, Public Health Nursing departments, or Centres for Disease Control.

It is observed that agreement in coding is rare from one province/territory to another. Some provincial working groups, like Nova Scotia's, have developed alphabetic abbreviations, as for the

⁵ Appendix A Survey – Functionality Page

⁶ Appendix A Survey – Technical Page, item 4

data element used to collect “Manufacturer”, where the first letters of the manufacturer’s name form the code. Other Provinces/Territories, like Manitoba use numerical codes, particularly adaptable in reporting to their billing systems.

Because of the high degree of inconsistency, data sharing will need to undergo major development, before compliance is reached. Citing the random example of the collection of the vaccine code for “Hepatitis B”, the following illustrates the variety of data elements in existence.

HEPATITIS B

British Columbia	HEPB
Alberta	HBV
Saskatchewan	Hep B Recombivax
Manitoba	8911 to 8913
Ontario	HEP-B (speed code = HB)
Quebec	78
New Brunswick	HB
Nova Scotia	n/a
Prince Edward Island	16 to 18
Newfoundland	hepB
Yukon Territory	n/a
Northwest Territories	P54.11 to P54.13
Nunavut	P54.11 to P54.13

Although the cost of data accumulation in existing and proposed vaccine programs seems to be supported in most Provinces/Territories, this aspect did present a barrier in the Yukon Territory, which discontinued its registry two years ago, when funding was pulled. Alberta had a similar experience in the early 1990’s, though comments that presently, funding for the cost of data collection comes from the Health Districts. Ontario reports that provincial and regional/municipal agencies split the cost of data collection, equally. Funding for MDS is currently being negotiated

in Quebec, though the cost of other data collection is supported. British Columbia reports that the cost of data collection has yet to be provided.

SECTION II: DATA ELEMENT CHART

Table 3: Client Demographics Page - Data and Technical Standards Survey

In general the proposed data elements for client demographics are being collected by the provinces/territories, but there are some gaps that need filling. There are other instances, where the close relationship between schools and public health, provide alternative tracking systems and shared data standards in regulation or legislation. The field sizes and format structures though similar, are far from uniform, demonstrating that presently compatibility and data sharing, among provinces would be difficult.

In reviewing the table, it is encouraging to find that every province/territory supplies demographic information with a Provincial Unique Identifier, except for the Yukon Territory, which has no central level of data accumulation. A client's first and last name is collected 93% of the time, and middle name is collected 62% of the time. Of those collecting the data element "Middle Name", its collection is only mandatory in British Columbia, Manitoba, New Brunswick (where first and middle name is combined), and in Nova Scotia (under "given names"). Alberta and Newfoundland report its collection to be optional. "Other" names are collected 50% of the time, and "aliases", about 67%. Compliance is also 93% for the data elements used for "date of birth" and to identify "sex". Only one Province, Prince Edward Island, does not collect the data element identifying the "Health Authority/Region" serving the individual client, even though the province has 5 health regions.

Data elements identifying the client's address ("Street Number", "Street Name", "Apartment Number", "Box Number", and "City/Town") are consistently collected, and a number of Provinces/Territories (British Columbia, Quebec, Prince Edward Island, Newfoundland, Northwest Territories, and Nunavut) have opted to use the unstructured Address 1 and Address 2. Prince Edward Island does not identify "Province", and Nova Scotia does not collect "Postal Code". 67% of province/territories do not collect "Country" data elements. A high level of compliance is noted in the collection of phone numbers, both "Home" and "Other". Alberta, Yukon Territory, Nunavut, and the Northwest Territories do not collect "Other" at this time.

“Language Spoken”, is only collected in Manitoba, Ontario, and New Brunswick, and its collection is optional in Newfoundland. British Columbia collects this data element in note form. Only two provinces collect the data element, “Country of Origin”, Alberta, using a comment section with a field size of 250, and Ontario, with an alpha-numeric of 3. Although Quebec notes that a client is from another country, that country is not specified. “Arrival in Province” is collected in comment section form in Alberta, in numeric in Manitoba and Nova Scotia, and in date type in Northwest Territories and Nunavut. Its collection in Nova Scotia serves mainly the clients, who come there for treatment from other provinces. “Aboriginal Status” is captured in Manitoba, and its collection is optional in Newfoundland. It is also held at the provincial/territorial level in Northwest Territories and Nunavut, as the first digit in the client’s PIN.

Table 4: Client’s Parent/Guardian Demographics Page - Data and Technical Standards Survey

It is noted that the level of compliance in this section is much lower than for client demographics. In the case of the Yukon Territory, with no central level of data accumulation, and with Alberta, where Client’s Parent/Guardian demographics are collected, but are kept at the regional health agency level, none of this information exists at the provincial/territorial level. This is also the case in Quebec, where it is recommended, but not required, that Parent/Guardian data be collected, but it, too, is held at the local or regional level. It is reported that, in Northwest Territories and Nunavut, though there is provision to track a parent, this data has not been maintained since redevelopment of the registration database, in 1994. Data elements, in this section, reach the highest compliance at the most basic type of information.

In only 46% of the Provinces/Territories (British Columbia, Saskatchewan, Manitoba, Ontario, New Brunswick, and Newfoundland) is the data element “Relationship/Agency” collected, and of those, Newfoundland’s collection of this element, is optional. “Last Name” and “First Name” data elements are consistently collected, except for those already noted: Alberta, Yukon, Quebec, and Newfoundland, where the collection of these elements is optional. As in Client Demographics, field sizes vary greatly, though there are similarities in format structures used, with five Provinces/Territories (Manitoba, Nova Scotia, Newfoundland, Northwest Territories, and

Nunavut) using alpha, four Provinces/Territories (Ontario, Quebec, New Brunswick and Prince Edward Island) using alpha-numeric, and two Provinces/Territories using character. The data element “Middle Name” is collected in five Provinces/Territories (British Columbia, Manitoba, Newfoundland, Northwest Territories, and Nunavut) though its collection is optional in Newfoundland. Two other Provinces (New Brunswick and Nova Scotia) collect this data combined with the “First Name” data element. Nova Scotia identifies this combined data element in the term “Given Name”.

The remaining data elements, dealing with personal information of the Client’s Parent/Guardian, are not collected consistently. “Other Name” is collected in three Provinces (British Columbia, Manitoba and New Brunswick), and “Aliases” is collected in three Provinces (British Columbia, Manitoba and New Brunswick) with its collection in a fourth, Newfoundland, being optional. Although “Date of Birth” is collected in only four Provinces (British Columbia, Manitoba, New Brunswick and Prince Edward Island), with a fifth, Newfoundland being optional, the way in which it is collected is similar. In all cases the field size is 8 and the format structure is numeric, as dictated in standard Date Type. The data element “Sex” is collected in three Provinces (British Columbia, Manitoba, and New Brunswick), with a fourth, Newfoundland, being optional.

It is observed that the next group of data elements, those dealing with the Client’s Parent/Guardian address, is more often compliant with immunization data standards. The exceptions to this are Alberta, Northwest Territories, Yukon Territory and Nunavut. Of the eight provinces collecting data elements, “Street Number”, “Street Name”, “Apartment Number”, and “Box Number”, 50% have chosen to employ an unstructured format, such as Address 1 and Address 2. Saskatchewan uses a section of 255 characters to capture these data elements. The remainder of the provinces collecting this all use the alpha/alpha-numeric format structure, in which the collection of data elements, remains somewhat unstructured. Only New Brunswick collects these data elements, individually, in a structured format.

The last three data elements having to do with address, “City/Town”, “Province”, and “Postal Code”, are consistently collected by those provinces collecting the previous address data elements, and are sometimes contained in the Address 1, Address 2 format. Both Manitoba and Prince Edward Island include “City/Town” in their Address 1 & 2 data element, along with the data element for “Province”. Nova Scotia collects “City/Town”, “Province”, and “Postal Code” in two

separate addresses for mailing and home, both, in a format structure of alpha-numeric with a field of 3 lines of 30 characters. A format structure in character is used by British Columbia, with a field of 25, and Saskatchewan, with a field of 50. All provinces capturing “Province” as an individual data element have small field sizes of 2 or 4, in alpha, alpha-numeric, or character, except for New Brunswick which utilizes a drop down value, in numeric. Of the seven Provinces (British Columbia, Saskatchewan, Manitoba, Ontario, New Brunswick, Nova Scotia, and Prince Edward Island) collecting “Postal Code”, six collect it in alpha-numeric, and the seventh (British Columbia), in character. The field size, at 6, is consistent in three Provinces, (Manitoba, Ontario, and Prince Edward Island). British Columbia and Saskatchewan collect 7 characters, and New Brunswick collects 13.

The data elements “Home Phone Number”, and “Other Phone Number” are collected identically, in each province, with the exception of New Brunswick where the field size for the former is 19, and for the latter is 25. British Columbia and Saskatchewan both use a character format structure, while New Brunswick, Nova Scotia and Prince Edward Island use numeric. Prince Edward Island specifies that they define “Other Phone Number”, as father’s work number or mother’s work number. Ontario uses an alpha-numeric format structure, containing 11 characters.

The Client’s Parent/Guardian personal data elements, “Language Spoken” and “Aboriginal Status” are rarely collected. “Language Spoken” is collected in Ontario in alpha-numeric with a field of 3, and in New Brunswick, with a drop down value, in numeric. Although optional in British Columbia, the user can enter “Language Spoken” and “Aboriginal Status”, in a notes field. Other than this optional collection, “Aboriginal Status” is not collected as a data element.

Although not compliant with the immunization data elements presented in the survey, Quebec’s alternate method of tracking by school is certainly notable, as an example of the close relationship that exists in some provinces, in the collection of data, between the school system and immunization provider. Under recommendation, not requirement, only the names and addresses of the client’s mother, father, and/or guardian are collected, without other Client’s Parent/Guardian data elements. The school age child is attached to a school. A set of data

elements, specific to schools, are collected, as in: its code (7-N), its name (45-AN), school employee responsible (usually the principal) (30-AN), and his/her first name (20-AN), its address (40-AN), its municipality (25-AN), its postal code (6-AN), its telephone number (10-N), and its fax number (10-N). These school data elements are kept at the local/regional level, and pertain only to the portion of the 0-7-age target group, attending school.

Table 5: Immunization Event Demographics – Data and Technical Standards Survey

The data elements contained within the immunization event demographics are well captured, and are held at the provincial/territorial level, in most provinces/territories. An important part of this section is the vaccine codes, provided as requested, as part of this survey. Vaccine codes frequently capture data elements in some form of integrated code, where more than 1 element is included. British Columbia, for example, does not have a specific code for “antigen”, but that information is inherent in the description of the vaccine.

The data element for “Vaccine” is always captured, and held at the provincial level, except in the Yukon Territory, which has no central level of data accumulation. The dominant format structure used, is alpha or alpha-numeric (Alberta, Ontario, Nova Scotia, Prince Edward Island, Newfoundland, Northwest Territories and Nunavut). There is a large variance in field size. Quebec captures “Vaccine”, “Antigen”, “Trade Name”, and “Manufacturer”, in one numeric structure with a field size of 3. New Brunswick captures the same 4 data elements in numeric, using a drop down value. Newfoundland with an alpha field size of 100, captures “Vaccine”, “Antigen”, “Trade Name”, “Manufacturer”, “Dose Number: Vaccine”, “Dose Number: Antigen”, “Vaccine Lot Number”, and “Expiry Date”. Remaining fields, for the data element “Vaccine”, collected on an individual basis, fall between 3 and 15. “Vaccine” and “Antigen” data elements are collected, identically to each other, in five Provinces/Territories: Alberta (15-AN), New Brunswick (DD-N), Nova Scotia (6-AN), Northwest Territories (3-AN), and Nunavut (3-AN). Of all the Provinces/Territories collecting “Antigen”, only Ontario collects this in a non-integrated data element, differing from the way in which “Vaccine” is collected, in alpha-numeric format with 27 logical fields. Ontario reports that in a unique code, called speed code, an alpha format of

1 or 2 is used to facilitate data entry. Entering the speed code data element in the vaccine field flags each specific antigen data element in the antigen field. It is noted that, although Prince Edward Island does not collect data under the data element “Antigen”, antigen information is collected and held in a separate field.

As specified above, “Trade Name” is contained in an integrated field in Quebec, and Saskatchewan, and is linked to the vaccine code number in Newfoundland. British Columbia links this information by containing it in a description of the vaccine specified, and does not have a separate data element for either “Trade Name”, or “Manufacturer”. The data element “Trade Name” is collected in the same manner as “Vaccine” in Ontario, with an alpha-numeric format of 5. Of the remaining Provinces/Territories, five do not collect “Trade Name”. Of the five Province/Territories, that responded affirmatively to the collection of “Manufacturer”, only Alberta, with a field size of 3 in alpha format, and New Brunswick with a drop down value in numeric, collect this data element, individually.

Neither “Dose Number: Vaccine”, nor “Dose Number: Antigen” is collected in seven province/territories. It should be noted that Quebec, included in this number, uses a second data element, which identifies the amount of vaccine each client has received, by using a data element, which notes the quantity of vaccine administered. This information is captured in numeric, in a field size of 1, and is held at the local/regional level. British Columbia uses an identical field size and format structure (1-N) to capture “Dose Number: Vaccine”, but does not collect “Dose Number: Antigen”, and Alberta, Northwest Territories, and Nunavut’s collection is similar for both data elements, with a numeric field of 2. Newfoundland collects the information “Dose Number: Vaccine”, and links it to the vaccine code number, but does not indicate that “Dose Number: Antigen” is collected. Newfoundland collects “Vaccine Lot Number” and “Expiry Date”, in the same manner, with a link to the vaccine code number, consisting of a field size of 100, in alpha. The data element “Vaccine Lot Number” is collected, and held at the provincial level, in eight Provinces/Territories (British Columbia, Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Prince Edward Island and Newfoundland), in a variety of field sizes and coding formats. Format structures in five province/territories use an alpha-numeric, but without consistent field sizes. British Columbia and Saskatchewan use character format structures. There

is only agreement of field size, using 20 each, between Alberta and New Brunswick. Field sizes range from 8 to 25. The data element “Expiry Date” is only collected, individually, in two provinces. Both British Columbia and Quebec capture this, with a field size of 8 in date type format structure. As noted above, this information is also collected by Newfoundland, but is linked to the vaccine code number.

The most frequently captured data element in the survey, “Date of Vaccination Event” also shows a high degree of agreement in both field size, and format structure. All field sizes are 8, and format structures are reported as date type or numeric. Only Quebec, who collects this data element, but holds it at the local/regional level, and the Yukon Territory, with no central level of data accumulation, are not compliant at the provincial/territorial level. Both data elements, having to do with anatomical aspects of the immunization event, are gathered at a combined level of compliance of 50%. “Site of Vaccination - Anatomical”, and “Route of Vaccine Administration” are collected in seven provinces/territories and six provinces/territories, respectively, in a variety of field sizes and format structures, but with a high degree of agreement between these elements, within each province. Both data elements are collected in: Alberta, in a field of 2 alpha, Quebec, in a field of 1 numeric, New Brunswick in a drop down value captured in numeric, and in Newfoundland, with a field size of 11 in a numeric format structure. Neither data element is collected in Manitoba, Ontario, Nova Scotia, Prince Edward Island, Northwest Territories, Yukon Territory or Nunavut, but British Columbia does capture “Site of Vaccination - Anatomical”, in character, with a field size of 2.

Of the six Provinces/Territories collecting information under the data element, “Source of Immunization Information”, British Columbia and Alberta (proposed and ready January 31, 2000) use/will use comment sections. Manitoba, with a field size of 6, and Ontario, with a field size of 1, both employ an alpha-numeric format structure. Newfoundland and New Brunswick, both have a numeric format structure, the former with a field size of 11, and New Brunswick with drop down value. Although this specific data element is not collected in Northwest Territories or Nunavut, vaccine coding reflects whether specific vaccine and dose numbers have been reported verbally, whether the information received was documented, or if immunization was actually given by the provider. In Saskatchewan, the service provider collects information contained within this data element, by paper, and holds it at the local/regional level. “Provider Identification” is collected in

a variety of formats, in eight Provinces/Territories, with British Columbia and Saskatchewan using character format, Manitoba, Quebec, and New Brunswick, using numeric, Nova Scotia using alpha-numeric, and Northwest Territories and Nunavut using alpha. Newfoundland reported that this data element is collected, although neither field size, nor format structure was specified. Prince Edward Island captures “Provider Identification”, “Provider’s Health Authority/Region”, and “Provider’s Location” with an integrated data element of 4, in an alpha-numeric format structure. The collection of the “Provider’s Health Authority/Region” reaches a high level of compliance, with ten provinces/territories using field sizes ranging between 2 and 8. British Columbia and Manitoba, both having a field size of 2 use a numeric format structure, as do Quebec, with a field size of 5, New Brunswick, with a drop down value and the Northwest Territories and Nunavut. The latter two, base “Provider’s Location”, collected in alpha, and “Provider’s Health Authority/Region”, collected in numeric, on community codes, and no field sizes were reported. Of the remaining Provinces/Territories collecting “Provider’s Health Authority/Region.” Alberta, with a field size of 3, and Prince Edward Island, with a field size of 4 use alpha-numeric format structures. Saskatchewan with a field size of 4, uses an integer format structure, (also used for “Provider’s Location”), and Newfoundland, uses an alpha structure. The field size for “Provider’s Location” is small, ranging from 2 to 5, in all province/territories except for Quebec, which uses an unstructured alpha-numeric format structure, Address 1 & 2, with a field size of 40 in each line. New Brunswick, once again, uses a numeric structure, with drop down value.

“Exemptions” as defined in the survey table, Note 2 is used to indicate exemption by reason of evidence of immunity, contraindications, or on a philosophical basis. In British Columbia, most regions use manual data entry forms from physicians, and Saskatchewan’s service providers collect this information by paper. Alberta uses an alpha format structure of 2, to collect this data element. Ontario and Quebec, with a field size of 1, and Newfoundland, with a field size of 11, all use a numeric format structure. Ontario comments that start and end dates are noted for each exempted antigen, and that its dose numbers are based on date given, and intervals between immunization events. Newfoundland, in addition to the collected data element, notes refusals in a separate comment section. New Brunswick notes that it does not collect this data element, in isolation. It has, instead, an automated assessment, “Immunization Protocol”, in its database, for informed consent process, with specifics, such as contra-indications.

Those Provinces/Territories collecting the immunization data elements established in the survey, but holding them at the local/regional level, like Alberta, should not find compliance at the provincial level difficult. Newfoundland, who has provision for collecting some of the data elements, specified, could easily make their collection mandatory, as opposed to optional, as it is presently. The Yukon Territories, which prior to 1996, had a registry in place, may have the means of collecting the specified data elements, once funding is made available. The Northwest Territories also had a provision for tracking Parent/Guardian information, until the redevelopment of the registration database in 1994. Perhaps this could be resurrected, to include Nunavut.

Within the province, it is noted that there is a close link between the collection of data elements by the school system, and the health authorities, for school age children in the 0-7 year age range. The benefit to those provinces without an immunization registry in place, is that there may already be a collection of the required data elements, contained within the education system, that could be adapted to the needs of Regional and Provincial/Territorial Health Authorities. (Data Standards may already be in place within the Education Act, requiring collection of at least some of the elements.) The drawback, of course is that for pre-school children, there would have to be a separate immunization registry, created.

The collection of the data elements for: “Language Spoken”, “Country of Origin”, “Arrival in Province”, and “Aboriginal Status” on a more consistent basis by the provinces/territories could improve client tracking, avoid inappropriate immunization, and help to identify at risk populations. In addition, knowing the “Country of Origin” and “Arrival in Province”, at a provincial level could assist greatly in the control of outbreaks of vaccine preventable diseases, by identifying the source.

As in Client Demographics, there is duplicity in the term “Other Phone Number”. Does it mean a parent/guardian’s work phone number, or a number at the second residence of the client? Both definitions provide information that would expedite tracking of a parent/guardian. Would the committee, then, look at making provisions for gathering both data elements? Other areas of low compliance, similar to those in client demographics, are the data elements “Language Spoken” and “Aboriginal Status”. Collection of the former could vastly improve communication with the

Parent/Guardian, resulting in a higher quality of immunization information concerning the client. The collection of the data element “Aboriginal Status”, mandatory only in the PIN of residents of the Northwest Territories and Nunavut, needs standardized collection in all provinces/territories. The “Date of Birth” data element, in client demographics, is identical in all Provinces/Territories, having a central level of data accumulation, except for Saskatchewan. This data element could easily be extended to capture the same information, for Client’s Parent/Guardian demographics.

In most data elements, field sizes and format structures vary greatly. As in Client Demographics, Parent/Guardian data elements having to do with address would work best across the country if an unstructured format, such as Address 1& 2 was adapted by all. This would provide for the exceptions such as, Prince Edward Island, The Northwest Territories, and Nunavut, where addresses do not necessarily follow the traditional format of street number and street name.

SECTION III - DATA STANDARDS

Response levels were poor in the area of Provincial/Territorial Data Standards⁷. The development of effective legislation, regulations or other governance, establishing data standards, for the collection of a given data element took place, in some cases, long ago. This was reviewed with several of the contacts, who indicated that it would require significant additional time to undertake completion of this section of the survey. The issue was particularly acute for those provinces/territories that did not have a registry in place, and for those who had yet to enter into a planning process to develop a registry in their province/territory.

The data standards survey was to determine the level of standardization, by data element, within each province/territory. In addition, it was to identify the level of enforcement of such standards, be it via policy, regulation, or legislation. Table 6 – Provincial/Territorial Data Standards displays the results. No response was received from two (Saskatchewan, Manitoba) Provinces. Results from the survey indicate that there is no standardization process in the territories, this includes the Yukon Territory.

The remaining eight jurisdictions all reported some level of standardization. Many have indicated that there are organizations in place to review, adopt, and implement standards within Health. Although the nation's standards body, CIHI, was not canvassed, they have initiated some standards that would affect the current minimum data set, and have issued suggested coding for immunizations. They have used a similar approach to that used for the Canadian Classification for Interventions (CCI)⁸.

It is reported, through anecdotal information that many believe consistent usage within their province/territory constitutes a standard for the immunization data set. Many of the elements are stipulated in Health Acts, as required reporting. Although helpful, neither of these constitutes sufficient definition to create standard data elements. There are six Provinces (British Columbia, Alberta, Quebec, New Brunswick, Nova Scotia, and Prince Edward Island) that do have

⁷ Appendix A Survey – Data Element Chart

⁸ Appendix C – Canadian Classification for Interventions (CCI)

organizations in place to review data elements and ensure adequate definitions are provided and that there is/will be a process in place to extend the standard for such things as new vaccines.

SECTION IV - RECOMMENDATIONS

The survey document indicates that there is considerable variation to the extent that the provinces/territories comply with the minimum immunization data set as defined by the Consensus Conference of March 1998. There is even more variation in the characteristics of the data. Consistent standards associated with the data elements are all but non-existent.

1.0 Revisit the Immunization Data set to ensure all data elements are indeed required.

There is only selective compliance with the list of data elements across the country. To seek full compliance at this time would necessitate not only system and documentation changes but would increase the demands on the providers to capture the additional information. It is recommended that a subgroup to the National Working Group on Immunization Registries (NWGIR), be established to review the immunization data set with a view to ensure only essential information is required.

2.0 Develop operational or ‘consensus’ standards and definitions for the minimum data set.

Data sharing between provinces, at this time is difficult, because of the lack of standardization in field size, codes and format structure. The Communicable Disease subcommittee of the Health Surveillance Working Group is charged with the responsibility of creating standards by July 2000, a very ambitious time frame. During the course of this study it became apparent that there is significant interest in the topic of immunization data standards, and the Working Group must ensure that this forecast completion date allows for wide consultation on the topic. Should the Working Group find this time frame difficult, it is recommended that the Group consider setting ‘consensus’ or interim standards.

3.0 Define a National Immunization Network Message (NINM).

This would enable each province/territory to construct and decipher a message that would reflect the immunization record of an individual. ‘Consensus’ standards exist in each province/territory. The effort to introduce new formal standards will be considerable. The use of a standard message would see each province/territory introducing communication transactions into their existing immunization registries to send, receive and interpret a the

message using formal or 'consensus' data standards. Reference should be made to the work in this area undertaken by United States: All Kids Count Initiative, at CDC Atlanta.

- 3.1 Agreement to this approach will be sought from the province/territory Health CIO's.
- 3.2 A subgroup of the NWGIR will define the standard message(s), business transactions, and rules for the standard message.
- 3.3 The business rules and message standards will be widely circulated with a view to adoption.
- 3.4 A pilot site to test the NINM, consisting of at least three provinces/territories will be undertaken.

4.0 The NINM will be based on HL7 technology.

The HL7 approach to electronic messaging is common practice and has been adopted as a standard in some provinces/territories and by CIHI. Responses to the survey indicate that a possible accepted data sharing protocol in Canada is, HL7. This standard has been adopted by such initiatives as HeathNet BC and SmartHealth in Ontario. Prior to adoption, a scan of the provinces and territories should be made to confirm HL7, as being the optimal standard.

5.0 The Public Health Working Group should explore ways and means of supporting provincial/territorial immunization registries.

Although most immunization event data reaches the provincial level, it can also remain at the health agency level as in Alberta and Saskatchewan. In addition, provinces currently do not collect many of the proposed data elements concerning the immunization event. These issues require resolution before certain NINM sharing can be attained. Improved data accumulation could: assist providers in to determine the relationship between immunization and adverse events; minimize costs to the health care system by providing efficient records management; and assist in assuring accountability for effective vaccine use. Currently, provinces/territories see collection as a provincial/territorial responsibility, but data sharing standards, between province/territories, as a federal responsibility.