Language variables in administrative health data hosted at ICES

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Background

Research on linguistic minorities have revealed important disparities in Canada. Numerous analyses have identified the need for further studies looking at health status, healthcare utilization access barriers and quality of care affecting francophone living in a minority contexts (FLMCs) in Canada.[1] The value and need to improve access and use of valid health information to support the planification of health and social services is well documented; however, important gaps and challenges have been recognized, which limit further progress in understanding the disparities in health and health care for some subpopulations.[2]

Linguistic group and language variables: implications for research

Language variables are used to identify a linguistic group. There are different criteria to define the linguistic group: the use of a single variable, such as the mother tongue, or the combination of several linguistic variables. Historically, Statistics Canada has generally used the criterion of mother tongue as one of the main approach to define the linguistic groups. More recently other approaches that combine several variables have been used. For example, the first official language spoken (FOLS), which is now used increasingly as a criterion for defining linguistic groups in studies on official-language minorities.

As some authors have pointed out, the objectives of the study should guide the approach used to define the linguistic groups.[3, 4] Noel et al. have examined the multiple approaches to define Francophones using census variables and described the strengths and limitations of each approach.[4] They also noted that the number of Francophones depends on the criteria used to define the linguistic group. According to this analysis, the definition that captures the greatest number of Francophones is based on the knowledge of official languages, however, it also captures a considerable number of people who know French but who do not identify with the Francophone community.

On the other hand, the definition combining mother tongue and knowledge of official languages captures the largest number of Francophones while also offering the advantage of excluding people whose mother tongue is English and who know French and English. This definition ensures that everyone who may potentially identify with the Francophone community is captured, without preventing them from identifying with other linguistic communities.[4]

Capitalizing in the value of combining mother tongue and knowledge and regular use of the official languages, in 2009 the government of Ontario adopted the inclusive definition of Francophones (IDF).[5] The IDF aims at identifying any resident in the province that identify itself with the Francophone community, particularly the newcomers. The IDF considers as Francophone, "*person whose mother tongue is French, plus those whose mother tongue is neither French nor English but have a good knowledge of French as an Official Language and use French at home*."[6] The impact of applying or using this definition is under regular evaluation by the Office of the French Language Services Commissioner.[7]

Linguistic data

One of the main issues identified in undertaking health research on linguistic minorities is the lack of good and reliable population–based data with language variables required to identify Francophones.[8, 9] This is a key challenge, especially in projects examining the health of Francophones living outside of Québec.[10] Where data exist, the sample size of Francophone respondents is usually insufficient for meaningful analyses. Moreover, the

inconsistencies and data quality issues impose additional concerns to the use of these data to support the planification of health and social services for the FLMCs in Canada.

In Ontario, the Réseau des services de santé en français de l'Est de l'Ontario (RSSFE), examined the linguistic variables in the databases used locally to plan health services. The study reviewed 19 administrative databases used by the Local Health Integration Network (LHINs), and revealed that only seven (37 %) included one or more linguistic variables.[3] Another study commissioned by the Centre National de Formation en Santé (CNFS), identified 24 administrative databases from Canadian Institute for Health Innovation (CIHI) and 7 survey databases from Statistics Canada that can be used to study the health status of FLMCs and its determinants, according to various levels of geographic division.[10] Given the limited scope of one of the studies to the local level, while the other provided an overall national perspective; there is still insufficient knowledge of the status of language variables in health data for research purposes at provincial level in Ontario. Although abundant health research has been conducted in the province using administrative data, very few studies have included the linguistic perspective to examine health and health care outcomes in linguistics minorities in Ontario.

The Institute for Clinical Evaluative Sciences (ICES), a renowned Ontario research institution, host a large and diverse data repository of nearly a hundred databases of different types (census, surveys, administrative health data and registries, research cohorts, etc.) and from different sources (Statistics Canada CIHI, Ontario Ministry of Health and Long-term Care (MHLTC)). ICES also has a strong capacity of data linkage, which offers an excellent opportunity to link health data with language variables included in administrative database to study the health status and the access, quality and safety of health care for Francophones in Ontario.

To address this knowledge gap, an examination of multiple databases hosted at ICES was performed to identify and describe the linguistic variables and their respective validity. This report provides the results of the review.

Methodological Approach

A thorough examination of ICES's databases for the linguistic variables was carried out. All databases in ICES data repository were reviewed for the presence of a language variable. The linguistic variables were catalogued for each dataset, identifying the type of language variable included. The definitions of Statistics Canada of language variables were used to guide this process[i] (see definitions in Appendix 1). For this review, the main variables examined described were:

- Mother tongue
- Language often spoken at home
- Knowledge of official language
- Language of preference
- Language of interview
- Other language variables (primary language, language of education, language of work, language spoken to doctor, etc.).

These language variables are clearly identified in census and survey data, but administrative health data and derived cohorts don't have a clear and consistent definition of the language variable collected or registered. Therefore, when it was not possible to classify the language based on the above definitions, as the specific type

[i] Languages Reference Guide, Census of Population, 2016. http://www12.statcan.gc.ca/census-recensement/2016/ref/guides/003/98-500-x2016003-eng.cfm

was not clearly or explicitly indicated, it was identified as 'Primary language'. This category is often described as "primary language" or simply "language" in the dataset. Another category 'Other types' was used to include other less frequent types of language variables, such as the language spoken to the doctor or the language of education, which are collected in specific databases.

A total of 91 databases were examined to identify the language variable (by April 31st, 2018). Each database was searched for a language variable. Then, the characteristics of those variables were described: type of language variable, values, categories of response, format, period of availability, etc. (see complementary excel file). The results were summarized and tabulated for the main categories of data in the repository: Population and Demographic, Coding & Geography, Surveys, Health Services, Health care providers, Health Facilities, Financial and Research Cohorts.

Results

From the total 91 databases in the repository, 25 datasets contained at least one language variable. By category, the largest number of datasets with language variable (11) is in health services data, which represents one third of that category (Table 1). However, the most consistent category including language variables are the surveys as all datasets contain a language variable, usually multiple variables. (see complete list in Appendix 2)

*Table 1. Number of datasets including language variables in ICES data repository**

	Has language variable?			
Type of database	**No**	**Yes**	**Total**	**% Yes**
Acquired Cohorts / Registries	13	4	17	23.5
Care Providers	4		4	
Coding & Geography	5		5	
Facilities	1		1	
Financial	2		2	
Health Services	21	11	32	34.4
ICES-derived Cohorts	13		13	
Population & Demographics	7	3	10	30.0
Social		1	1	100
Surveys		6	6	100
Total	**66**	**25**	**91**	37.9

* until April 2018

Using the standard language definitions, the most frequent language variables were *Mother tongue* (9 (10%) datasets) and *Language most often spoken at home* (8 (8.9%) datasets). As expected, mother tongue was most common in surveys and population and demographic data (Table 2). The *Primary langua*ge was the most common type of language in health services datasets, accounting for 78% of this variable type. The *Language of preference* was also prominent in health service data, as it is usually used to select the language of health care services. The variable of *Knowledge of Official Languages* was exclusively identified in surveys and demographic datasets.

All surveys and the census datasets included at least one language variable, and usually provides a great richness of language variables, which encompass several types of linguistic concepts (e.g. mother tongue, language spoken at home, language spoken at work). The Canadian Community Health Survey (CCHS) contains the most

comprehensive set of language variables, which includes derived variables based on the combination of several simple language concepts. For example, FOLS, which is defined within the framework of the Official Languages Act and represents a combination of several language variables (mother tongue, language often spoken at home and knowledge of Canadian official languages), and is often used in analyses and regular reports by Statistics Canada to define the official language groups.[11-13] Appendix 3 presents a list of all databases that include a language variable.

Table 2. Type of language variable by category of the dataset

Category of dataset	Mother tongue	Lang. often spoken/ on a regular basis	Know Can. Off. Lang.	Lang. Convers.	Lang. of preference	Lang. Interview	Primary Language*	Other type+
Acquired Cohorts / Registries	2	1		1	1		1	
Health Services	2	2	1		2		6	1
Population & Demographics	3		3					
Social					1			
Surveys	5	3	3	3	2	4		1
Total	**12**	**6**	**7**	**4**	**6**	**4**	**7**	**2**

* Main language spoken by the person or regularly used for everyday communication
\+ For example: Language to talk to doctor, language of education

Language Variables in Health Services Data

Health services data represents the main category of administrative data at ICES, accounting for over 35% of all datasets. A total of 11 (34.3%) out of the 32 datasets in this category contained at least one language variable (see details in Appendix 3). Among these datasets are: Continuing Care Reporting System (CCRS), for Chronic or Long-term Care, the Resident Assessment Instrument (RAI), for Home Care, Ontario Mental Health Reporting System (OMHRS) for inpatient mental health information, the National Rehabilitation Reporting System (NRS) for rehabilitation services, and the Ontario Trauma Registry (OTR) for patients receiving care after trauma events.

The most common type of language variable in these datasets was the 'Primary language', which can reflect different types of language variable, but usually refers to the language primarily spoken at home on a regular basis. For example, in Canadian Organ Replacement Registry (CORR), Client Profile Database (CPRO), RAI, NRS, OMHRS the description of the language variable often indicates 'Primary language' or just 'Language', without any specification or explanation of what type of language is referring to. The language of preference was the second most frequent type of language variable in health services databases.

Final considerations

This review revealed that language variables are included in numerous databases housed at ICES that could be used for health research purposes. The analysis of these results shows that surveys and population data provide the most complete and consistent collection of linguistic variables. It is notable that census data and the CCHS database contain the richest set of language variables, which have been frequently used in population-based studies. The review also showed that administrative health data do contain language variables, but the type of linguistic variable is not always clearly specified and defined.

Given the great capacity for data linkage developed at ICES, the combination of administrative health data and population-based data (census and surveys databases) could be a valuable option to examine numerous health

and healthcare issues comparing linguistic groups. This would allow us to use different types of language variables or linguistic concepts to define the linguistic group.

Data quality

These results are encouraging for who want to conduct research to examine the health and healthcare outcomes in different contexts (ambulatory care, home care, hospital and residential long-term care) in relation to patient language. However, although language variables are present in administrative health data, their quality needs to be considered when using these variables. There is not a systematic procedure to collect and register these variables, nor current evidence on the reliability and validity of these data. Thus, an assessment of those attributes is required. As some analyses have shown, the collection or registration of these data is not consistent, which hampers the quality of the data.[3] In consequence, it may have detrimental effects on the validity of the analyses performed. Therefore, the assessment of the quality of these variables is important when using these variables in future studies. A first study on its reliability and validity has been performed and is currently under publication process.

Language concepts and approaches to define linguistic groups

Finally, as some experts have already discussed, the use of one or the combination of several types of language variables should be driven by the goals of the specific objectives of the study. There is no unique approach, on the contrary one single variable or a combination of variables could be used to define a linguistic group. The approach chosen should be guided by the question and or context of the research and the expected effect of the research outcomes.[4] The use of language concept or approach have advantages and limitations that must be considered in the research process.

In Ontario, a consultation performed by the RSSFE , emphasizes on the importance to make the distinction between *linguistic identity* and *linguistic preference*, as they are different concepts that should be applied base on the contexts.[14] The concept of *linguistic identity* refers to the linguistic group to which a person belongs or with which a person identifies, and normally remains unchanged over time. This concept is usually defined by the mother tongue. The concept of *linguistic preference* refers to a person's language of choice in a specific context, therefore, this preference may change in different situations. In the context of requesting or receiving services, the knowledge and use of the official language can be more relevant. Since the IDF considers both concepts, they suggest that linguistic identity data must always be collected, but the *linguistic preference* data should also be collected in the context of service delivery.[14]

There are at least three concepts that would be relevant in the decision to define a linguistic group in the Canadian context: mother tongue, language often spoken at home (LOSH) and knowledge of official languages. Mother tongue is considered relevant as it indicates belonging/membership to an ethnolinguistic or cultural identity. It expresses legitimacy of origin in relation to the Francophone or Anglophone community. It would be relevant when examining social interactions and determinants of the health status of the population or population subgroups. However, when exploring access and use of social services, such as healthcare services, language often spoken at home or knowledge of official languages used are variables that might be more relevant.

The IDF is calculated based on three questions in the census: mother tongue, language spoken at home and knowledge of the official languages. Thus, using census or survey language variables the IDF could be estimated.

Survey data also includes derived variables such as the FOLS, which is very close to the definition of the IDF and is being increasingly used in many studies to define the linguistic group. Furthermore, other approaches combining multiple language variables can also be applied.

For example, when studying access, the knowledge of the official languages may be more relevant as it might be facilitating that people who are competent speaking these languages feel more confident seeking the services that they need and would then have better access to those services. When studying specific health outcomes, the LOSH or regularly used could be pertinent to explore communication barriers that might be influencing those outcomes.

These elements should also be taken into account to perform future validity analyses of language variables, to understand the linguistic concept captured by the language information in health data. For that purpose, the variety of language variables in CCHS and censuses are an important source of reference standards. Thus, if we want to explore access to healthcare services FOLS could be a relevant standard, but if we were interested in understanding barriers to access to health services, the LOSH would be the concept to focus on.

In summary, this review demonstrates the availability of linguistic information in administrative health databases and confirmed that survey and census data contain a richness of language variables. It also showed that health data include language variables that could be used in research projects to examine health problems among linguistic groups. However, the quality and reliability of these language variables may need further assessment. Using data linkage procedures to combine the two types of data may help to address these gaps.

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Appendixes

Appendix 1. Language variables definitions

Source: Languages Reference Guide, Census of Population, 2016. http://www12.statcan.gc.ca/census-recensement/2016/ref/guides/003/98-500-x2016003-eng.cfm

- Mother tongue: refers to the first language learned at home in childhood and still understood by the person at the time the data was collected. If the person no longer understands the first language learned, the mother tongue is the second language learned.
- Home language: this category includes, 'Language spoken most often at home' and 'Other language(s) spoken regularly at home'[ii]
    - Language spoken most often at home: refers to the language the person speaks most often at home at the time of data collection. A person can report more than one language as "spoken most often at home" if the languages are spoken equally often.
    - Other language(s) spoken regularly at home: refers to the languages, if any, that the person speaks at home on a regular basis at the time of data collection, other than the language or languages he or she speaks most often at home.
- Knowledge of official languages: refers to whether the person can conduct a conversation in English only, French only, in both or in neither language. For a child who has not yet learned to speak, this includes languages that the child is learning to speak at home. In Canada, 'official languages' refer to English and French. 'Non-official languages' refer to all other languages.
- First official language spoken: FOLS is specified within the framework of the *Official Languages Act*. It refers to the first official language (i.e. English or French) spoken by the person. FOLS is derived. The derivation method is based on the regulations concerning use of official languages for the provision of public services. The derivation first takes into account the knowledge of the two official languages, second the mother tongue, and third the home language (i.e., the language spoken most often at home).
- Knowledge of non-official languages: refers to whether the person can conduct a conversation in a language other than English or French. For a child who has not yet learned to speak, this includes languages that the child is learning to speak at home.
- Language of work: this category includes, 'Language used most often at work' and 'Other language(s) used regularly at work'.
    - Language used most often at work: refers to the language the person uses most often at work. A person can report more than one language as "used most often at work" if the languages are used equally often.
    - Other language(s) used regularly at work: refers to the languages, if any, that the person uses in their job on a regular basis, other than the language or languages he or she uses most often at work.

Other types of language variables are used for administrative purposes during the data collection process: language of interview, language of preference, etc.

[ii] Until the 2001 Census, the question asked individuals for the language spoken most often at home, which now represents part a) of the question that has been asked since 2001. Part b) on other languages spoken on a regular basis at home has been added since the 2001 Census. This was done in order to reflect a more complete picture of the linguistic situation of Canadian households. When comparing 2016 Census data on home language with data from 1996 or before, only the language spoken most often at home is to be used since, before the 2001 Census, there was no question asked regarding other languages spoken on a regular basis. For more information on language variables, please refer to the *Languages Reference Guide, Census of Population, 2016*.

Appendix 2. Complete list of databases and presence of language variable

Category and Description of the database	Has language variable? No	Yes	Total
Acquired Cohorts / Registries			
A cohort study of HIV-infected Ontarians, collected by the Ontario HIV Treatment Network (OHTN.)		x	
Bariatric Registry	x		
Better Outcomes Registry and Network		x	
Canadian Cystic Fibrosis Data Registry	x		
Cancer Activity Level Reporting	x		
Cardiac Care Network Data	x		
CT/MRI Abstracted Data	x		
Dialysis Measurement Analysis & Reporting System	x		
Enhanced Feedback for Effective Cardiac Treatment	x		
New Drug Funding Program	x		
Ontario Breast Screening Program		x	
Ontario Cancer Registry	x		
Ontario Renal Reporting System	x		
Organ Donor Registry	x		
Registry of Canadian Stroke Network		x	
Symptom Management Database	x		
The Pediatric Oncology Group of Ontario Networked Information System	x		
Acquired Cohorts / Registries Total	**13**	**4**	**17**
Care Providers			
College of Family Physicians Canada Membership Information	x		
Corporate Provider Database (physician & group data from MOH), lso Includes Family Health Team (FHT) data	x		
GAPP decision support systems (physician payments)	x		
ICES Physician Database (annual demographics, specialization and workload)	x		
Care Providers Total	**4**		**4**
Coding & Geography			
Data sets of postal code information, used as input to %pccf20xx macro	x		
List of drugs from ODB formularies with DINs, generic and trade names, strengths, etc.	x		
Lookup tables for LHIN (Local Health Integration Network)	x		
Lookup tables including Rescode, Census Subdivision, PRCDDA, DA, SPECTAB, LHIN and subLHIN.	x		
Ontario Marginalization Index	x		
Coding & Geography Total	**5**		**5**
Facilities			
Information about Ontario health care institutions funded by the Ministry of Health and Long-Term Care (MOHLTC)	x		
Facilities Total	**1**	**0**	**1**

Financial			
Estimated Schedule of Benefits (SOB) price associated with each OHIP feecode and suffix.	x		
Management Information System (Financial and statistical data for the entire hospital sector)	x		
Financial Total	**2**	**0**	**2**
Health Services			
Assistive Devices Program	x		
Canadian Joint Replacement Registry	x		
Canadian Organ Replacement Registry		x	
Client Profile Database		x	
Community Business Intelligence	x		
Continuing Care Reporting System (for Chronic Care)		x	
Discharge Abstract Database DAD (Inpatient hospitalizations)	x		
Electronic Medical Records Administrative Linked Database – Master Linking Crosswalk	x		
Gamma Dynacare Medical Laboratories	x		
Health Outcomes for Better Information and Care		x	
Home Care Database	x		
Home Care Database - alternate dataset	x		
Lab data from SW Ontario hospitals	x		
Levels of Care Classification System (for Long-Term Care)		x	
Narcotics Monitoring System	x		
National Ambulatory Care Reporting System	x		
National Rehabilitation Reporting System		x	
OHIP Emergency Claims Database (created at ICES from OHIP claims)	x		
Ontario Drug Benefit Claims	x		
Ontario Health Insurance Plan Claims Database	x		
Ontario Home Care Administrative System	x		
Ontario Mental Health Reporting System		x	
Ontario Trauma Registry		x	
Ontario Case Costing Initiative	x		
Quarterly Discharge Abstract Database DAD (Inpatient hospitalizations)	x		
Quarterly National Ambulatory Care Reporting System	x		
Quarterly Same Day Surgery Database	x		
Resident Assessment Instrument (RAI) - Contact Assessment		x	
Resident Assessment Instrument (RAI) - Home Care		x	
Resident Assessment Instrument (RAI) - Home Care - alternate dataset		x	
Same Day Surgery Database (SDS)	x		
Trillium Gift of Life Network	x		
Health Services Total	**21**	**11**	**32**
ICES-derived Cohorts			

Ontario Asthma dataset	x		
Ontario Chronic Obstructive Pulmonary Disease dataset	x		
Ontario Congestive Heart Failure dataset	x		
Ontario Crohn's and Colitis Cohort dataset	x		
Ontario Diabetes Dataset	x		
Ontario HIV dataset	x		
Ontario Hypertension dataset	x		
Ontario Mother-Baby linked dataset	x		
Ontario Multispecialty Physician Network dataset	x		
Ontario Myocardial Infarction Dataset	x		
Ontario Paediatric Inflammatory Bowel Disease dataset	x		
Ontario Rheumatoid Arthritis Dataset	x		
Primary Care Population	x		
ICES-derived Cohorts Total	**13**	**0**	**13**
Population & Demographics			
Canada Census Area Profiles		x	
Client Agency Program Enrolment	x		
Immigration, Refugees and Citizenship Canada (IRCC)'s Permanent Resident Database		x	
Ontario Census Area Profiles		x	
Registered Persons Database files (RPDB)	x		
Surname-based Ethnicity Group	x		
Vital Statistics - Death (Office of the Registrar General - Deaths)	x		
Yearly Canada intercensal and postcensal estimates by age and sex.	x		
Yearly health services contact & RPDB eligibility summaries	x		
Yearly Ontario intercensal and postcensal population estimates and projection	x		
Population & Demographics Total	**7**	**3**	**10**
Social			
Ministry of Community and Social Services		x	
Social Total	**0**	**1**	**1**
Surveys			
Canadian Community Health Survey (CCHS)		x	
Health Care Experience Survey		x	
National Longitudinal Survey of Children		x	
National Population Health Survey		x	
Ontario Health Survey		x	
Primary Care Access Survey		x	
Surveys Total		**6**	**6**
Total	**66**	**25**	**91**

Appendix 3. Detailed list of datasets including a language data and type of language variable

Database description	Mother tongue	Lang. often spoken/ on a regular basis	Know Can. Off. Lang.	Lang. Conversation	Lang. of preference	Lang. Interview	Primary Language*	Other type+
Acquired Cohorts / Registries	**2**	**1**		**1**	**1**		**1**	
Cohort study of HIV-infected Ontarians, Ontario HIV Treatment Network – HIVOHTN		X						
Better Outcomes Registry and Network – BORN	X							
Ontario Breast Screening Program – OBSP	X			X	X			
Registry of Canadian Stroke Network – RCSN							X	
Health Services	**2**	**2**	**1**		**2**		**6**	**1**
Canadian Organ Replacement Registry – CORR							X	
Client Profile Database – CPRO	X							X
Continuing Care Reporting System (for Chronic Care) – CCRS		X						
Health Outcomes for Better Information and Care – HOBIC					X			
Levels of Care Classification System (for Long-Term Care) – LOC			X		X		X	
National Rehabilitation Reporting System – NRS							X	
Ontario Mental Health Reporting System – OMHRS	X							
Ontario Trauma Registry – OTR		X						
Resident Assessment Instrument (RAI) - Contact Assessment – RAICA							X	
Resident Assessment Instrument (RAI) - Home Care – RAIHC							X	
Resident Assessment Instrument (RAI) - Home Care - alternate dataset – RAIHCMOH							X	
Population & Demographics	**3**	**2**	**3**					
Canada Census Area Profiles – CENSUSCA	X	X	X					X
Immigration, Refugees & Citizenship Canada (IRCC)'s Permanent Resident Database – CIC	X		X					
Ontario Census Area Profiles – CENSUS	X	X	X					X
Social					**1**			
Ministry of Community and Social Services – MCSS					X			
Surveys	**5**	**3**	**3**	**3**	**2**	**4**		**1**
Canadian Community Health Survey (CCHS) – 2015	X	X	X	X	X	X		X
Health Care Experience Survey – HCES	X					X		
National Longitudinal Survey of Children – NLSCY	X	X	X					X
National Population Health Survey – NPHS			X	X				
Ontario Health Survey – OHS	X			X	X	X		
Primary Care Access Survey – PCAS	X	X				X		
Grand Total	**12**	**6**	**7**	**4**	**6**	**4**	**7**	**2**