Defining a childhood type 1 diabetes cohort, clinical practice measures and outcomes within administrative data in British Columbia

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Key Messages:

- Administrative data can describe chronic disease at a population level, but detailed description on how to establish administrative cohorts is lacking.
- We describe the development of a pediatric type 1 diabetes administrative cohort and key clinical practice and outcome measures within administrative data.
- Our results will serve as a resource for researchers using administrative data to describe the epidemiology and care quality of diabetes.

ABSTRACT

Objectives: We used administrative data to (1) establish a cohort of individuals with childhood-onset type 1 diabetes (T1D) in British Columbia (BC) and (2) define T1D-related clinical practice measures.

Methods: We applied a validated diabetes case finding definition and differentiating algorithm to linked administrative data (1992/93–2019/20). Cases were removed when they did not meet inclusion criteria for childhood-onset T1D. Clinical practice measures were defined based on clinical practice guidelines.

Results: We developed an administrative cohort that includes 5901 individuals with childhood diagnosed T1D between 04/01/1996 and 03/31/2020. The mean age was 22.31 (8.21). Clinical practice measures that were derived included diabetes outpatient visits (N=4935), hemoglobin A1C tests (N=4935), and screening for thyroid function (N=4457), retinopathy (N=1602), and nephropathy (N=2369).

Conclusions: We established an administrative cohort of ~6000 individuals with childhood-onset T1D with 20+ years of follow-up data that can be used to describe the association between clinical practice measures and clinical outcomes.

INTRODUCTION

Children and youth with type 1 diabetes (T1D) face significant health risks as they age.

Glycemic control [as reflected by hemoglobin A1C (A1C)] is directly linked to risk for complications such as retinopathy, nephropathy and macrovascular disease. Quality of and access to pediatric diabetes care has been shown to be associated with important health outcomes. For example, children seen for their diabetes 3-4 times per year versus 1-2 times per year have better A1C levels (8.3% vs. 9.1%). Also, compared to patients with continuous follow-up, those with irregular follow-up have more episodes of diabetic ketoacidosis (DKA) and higher rates of retinopathy. In the Canadian province of British Columbia (BC), children with T1D who traveled more than 2 hours to access their care reported lower child satisfaction with care and had an A1C that was 0.5% higher than children who travelled <2 hours. Describing care quality at a population-level is critical to better understand the association between healthcare utilization and health outcomes and is necessary to inform quality improvement interventions and strategies that support equitable access to care.

Several clinical practice guidelines (CPGs) exist that outline the level of care expected for pediatric T1D, including those published by *Diabetes Canada*, the *International Society for Pediatric and Adolescent Diabetes* and the *American Diabetes Association*. ^{6–9} These guidelines share similar fundamental recommendations on the frequency of follow-up visits with a multi-disciplinary diabetes team, monitoring of glycemic control and screening for diabetes-related complications and comorbidities. According to these guidelines, children and youth with T1D should have 3-4 diabetes focused clinician visits per year, 3-4 A1C tests per year, testing for

thyroid dysfunction at diagnosis and every 1-2 years, and screening for nephropathy and retinopathy every 1-2 years, once eligible.

Several studies have investigated whether diabetes care is being provided in accordance with published recommendations. Data sources have included electronic health records, provider and patient questionnaires, and administrative data^{4,10–15} Of the limited number of pediatric diabetes studies, many have been carried out in the United States, where the lack of universal healthcare may contribute to poor adherence to recommendations^{4,12,16}, limiting the generalizability of their results. Moreover, most research has been cross-sectional where results do not reflect the state of care being provided over time. In Canada, access to universal healthcare provides a unique opportunity to assess quality of care over time at a population level.

Though research utilizing administrative data has many unique strengths, it is not without limitations. Many studies have taken a simplistic approach to this work, which is likely to lead to incorrect conclusions. Moreover, studies using administrative data are often published without rigorous descriptions of their methods, limiting the reader's ability to evaluate the quality of the presented evidence. Therefore, before we investigate the association between quality of care provided to individuals with childhood-onset T1D and clinical outcomes, we must first ensure that the data we are using are of the highest quality possible and that our methods are transparent and comprehensive. Accordingly, the objectives of this study are twofold: (1) to establish a cohort of individuals with T1D diagnosed in childhood and (2) to define clinical practice measures and outcomes for pediatric T1D using administrative data.

METHODS

Ethics approval was obtained from the University of British Columbia's Children and Women's Hospital Research Ethics Board.

Study Context

This project is based in BC, Canada. BC is approximately two times the geographic size of California; however, the majority of the population resides in Vancouver (located in the Southwest corner of the province) and the surrounding area. The province has one pediatric tertiary care hospital, BC Children's Hospital (BCCH), located in Vancouver. The BCCH Diabetes Clinic has 8 pediatric endocrinologists, 6 diabetes nurse educators, 3 registered dietitians and 1 social worker who provide care to approximately 750 patients with diabetes. Some of this care is provided via telehealth or outreach, particularly to those living in more remote communities. Across the province, there are currently eleven community-based pediatric endocrinologists and several pediatricians with expertise in diabetes who provide community-based diabetes care with an interdisciplinary diabetes team that is supported by the local health authority. This distributed model of care delivered as close to home as possible has been shown to be beneficial to patients and families⁵; however, to carry out research that is truly representative of the provincial context, we must leverage administrative population-level health data.

Administrative Databases

Data was accessed through Population Data BC (https://www.popdata.bc.ca) that provides secure access to de-identified, individual-level data for all residents of BC, including all medical records within the province's public healthcare system. All data is accessed and analyzed on the *Secure*

Research Environment (SRE), a highly protected, monitored platform, from which only aggregate data can be extracted. Population Data BC also provides the infrastructure and processes to link data within the SRE to external data sources. The following internal and external data sources were used:

- (i) Medical Services Plan (MSP)¹⁸ a record of all out-patient medical encounters with a physician. From this data source, we used: the primary *International Classification of Diseases*, 9th revision (ICD-9) diagnostic code¹⁹, date of encounter, a claim specialty code indicating the type of physician rendering the service, the location of the encounter and a service code describing the type of medical care provided. MSP also includes fee items for individual laboratory investigations. This allows for identification of specific laboratory tests such as A1C and TSH (though not results), along with the date they were billed.
- (ii) Discharge Abstracts Database (DAD)^{20,21}— a record of all hospital admissions. We extracted admission and discharge dates, diagnostic codes [up to 16 ICD-9 codes up to 2000/01 and up to 25 *International Statistical Classification of, Tenth Revision, Canada* (ICD-10-CA) codes from 2001/02 onwards]²¹, and time spent in the intensive care unit (if any).
- (iii) Consolidation file²² a record of demographic data. We used sex, year and month of birth, first three characters of the individual's home postal code (this can differentiate rural vs non-rural addresses), health authority and health service delivery area, and neighbourhood income (socioeconomic status) quintile and decile.
- (iv) PharmaNet (external dataset)²³ a record of all prescriptions dispensed at community and outpatient hospital pharmacies in BC for specific drugs and drug supplies (as per

the data requested). Items are identified based on Drug Identification Number/Product Identification Numbers (DINPINs) assigned by Health Canada. Requested items for this project include all types of insulin, any drug classified as an anti-diabetic drug, glucose monitoring strips, pumps and pump supplies, and angiotensin converting enzyme inhibitors (ACE-inhibitors) (Appendix). We specifically extracted date of prescription dispensation and DINPIN.

- (v) LifeLabs (external dataset)²⁴ results of laboratory investigations for the largest outpatient laboratory in BC. Requested labs included:
 - Lipid panel
 - Hemoglobin A1C
 - Thyroid-stimulating hormone (TSH)
 - Urine albumin and creatinine/urine albumin to creatinine ratio (ACR)
 - Anti-tissue transglutaminase (TTG)
 - Serum creatinine
 - pH from blood gas
 - Serum bicarbonate (HCO3)
 - Apolipoprotein B

For each laboratory investigation, we extracted data on collection date, name of analyte, and result.

Key Definitions

Index Date – the date that the first diabetes-related diagnosis code appears in the person's outpatient record (ICD-9 code 250 in MSP) *or* inpatient record (ICD-10-CA codes E10, 11 and 14 in DAD) *or* the first PharmaNet encounter with an anti-diabetes drug (Appendix) (whichever came earlier). Also referred to as 'date of diagnosis.'

Transfer date – the date that the individual transfers from pediatric to adult care identified as the time point when the individual is ≥ 18 years old.

Study Time Period

Data was obtained from 1992/93 to 2019/20 (fiscal years). PharmaNet and LifeLabs records were only available for part of the study period (from January 1, 1996 to March 31, 2020 and from 2001/02 to 2013/14 fiscal year, respectively).

Study Population

The study population was identified using a validated diabetes case finding definition and diabetes differentiating algorithm, both of which have been previously published. 25,26 The case definition for diabetes had a sensitivity of 97% using the BCCH Division of Endocrinology's clinical database as the reference standard and included any individual meeting any of the following criteria: (i) 2 claims in the outpatient medical system with diabetes as the diagnosis over a 1 year period (ICD-9 code 250 in MSP records), (ii) one diabetes-related hospitalization (within DAD, ICD-10-CA codes E10-14 from 2001 onward or corresponding ICD-9 codes prior to 2001), (iii) \geq 2 insulin prescriptions or \geq 2 oral anti-diabetic medication prescriptions (aside from metformin), over a 1 year period, or (iv) one MSP claim with a diabetes diagnosis plus either any combination of one insulin and one oral anti-diabetic agent or two metformin prescription dispensations within 1 year. 25

All individuals meeting the above listed criteria for diabetes (index date before 20 years of age and regardless of current age) were extracted by Population Data BC from the MSP, DAD and PharmaNet data sources up to fiscal year 2019/20 and assigned a unique identifier. To limit the

risk of over-diagnosis of diabetes, our team took additional steps to exclude all patients who never had diabetes as a 'primary diagnosis' within MSP or DAD encounters. Further, we only included those individuals who had a primary diagnosis of diabetes in either MSP or DAD datasets *and* had at least one prescription dispensation for glucose monitoring strips, insulin or an anti-diabetes medication.

To differentiate type 1 from type 2 diabetes, an algorithm validated against the BCCH Division of Endocrinology's clinical database was applied to the defined diabetes cohort (see Table 1) that used a combination of age and drug-utilization records (sensitivity of identifying type 1 diabetes 98.6%, specificity of 78.2% and positive predictive value of 97.8%).²⁷

From this point onwards, only the T1D cohort was studied. Between 1992 to 1996, the number of new T1D diabetes cases appeared to stabilize, suggesting that a four-year run-in period was sufficient to differentiate incident and prevalent cases. Therefore, we eliminated all cases with an index date before April 1, 1996. Next, we sought to remove individuals that were unlikely to be true cases of T1D. Any cases that were ever given a diagnostic code for cystic fibrosis-related diabetes mellitus (ICD-9 277.0 or ICD-10 E84) or were suspected cases of neonatal diabetes (index date before 6 months of age) were removed. All cases with an index date beyond 20 years of age indicating a diagnosis in adulthood were also removed. Cases with no encounters in MSP, DAD or PharmaNet (regardless of the reason) more than 30 days beyond their index date were assumed to be individuals that may have moved out of the province or were visiting BC at the time of T1D diagnosis, and were taken out of the cohort. This final cohort will hereafter be referred to as 'BC-PT1D,' for BC Pediatric T1D.

Clinical Practice Measures

Clinical practice measures are described in detail in Table 2 and were developed based on the pediatric T1D guidelines^{6–9} and are similar to the measures used in our previous work, which were established in consultation with a group of pediatric endocrinologists from across Canada.¹¹ For future analyses, each subject will be followed up from the index date, or the date that they became eligible for the specific clinical practice measure (whichever came later) to the transfer date or the end of the study observation period (whichever came earlier).

Further exclusion criteria were applied to some of the clinical practice measures. For example, any individual who had no outpatient diabetes visits AND no insulin prescriptions for the entire study period was excluded, as were those with an age of diagnosis ≥18 years old and those who did not have one complete time interval of follow up (i.e. one or two full years since index date, depending on the quality indicator).

Clinical Outcome Measures

Diabetic Ketoacidosis (DKA)

All hospitalizations related to DKA will be identified through the DAD dataset. DKA will be defined as any admission with 250.1X as a diagnostic code (where X = any integer) in ICD-9 or E10.1X in ICD-10, as outlined in our previous work.²⁸ DKA admissions will be subdivided into the following categories based on the timing of DKA in relation to the diagnosis of diabetes (i.e. index date):

- DKA at diagnosis (primary) DKA diagnostic code as the primary diagnosis, and the admission occurs ≤14 days of the individual's index date.
- DKA at diagnosis (secondary) as above, except the DKA diagnostic code is not the primary diagnosis listed for the admission.
- DKA after diagnosis (primary) DKA diagnostic code as the primary diagnosis,
 and the admission occurs >14 days after the individual's index date.
- DKA after diagnosis (secondary) as per DKA after diagnosis (primary), except the DKA diagnostic code is not the primary diagnosis listed for the admission.

To prevent double-counting admissions when a patient is transferred between hospitals, if two encounters have the same admission date, this will be counted as one admission. Similarly, if there is a second encounter for DKA <7 days after the first encounter's discharge date, this will also be considered as one admission, as both encounters may have been related to the same episode of DKA. This outcome will be reported as the distribution of individuals with DKA occurrence and the number of DKA episodes per individual (for DKA after diagnosis). We will also explore whether certain variables are predictors of DKA (i.e. years since index date, age of diagnosis, current age, adherence to quality indicators).

Hemoglobin A1C Results

A1C results from all LifeLabs Laboratories will be extracted (different from the number of A1C tests performed, as described in Table 2). We will report distribution of A1C per individual. Like DKA, we will explore potential predictors of A1C (i.e. years since index date, age of diagnosis, current age, adherence to clinical practice measures).

RESULTS

Study Population

Please see Figure 1 for a description of how the cohort was cleaned, ultimately leaving 5901 individuals in the cohort.

Cohort Demographics

Table 3 outlines demographic data reported as of March 31, 2020. The mean age of the cohort was 22.31 years [standard deviation (SD) 8.21]. The majority of individuals fell into the 15–19-year-old and 20-24 year-old age categories (19.0% and 22.7%, respectively). There were slightly more males than females (54.0%). The mean age of diagnosis was 10.4 years (SD 4.9). The highest percentage of children were diagnosed between the ages of 10 and 14 years-old (33.0%), followed by children 5 to 9 years-old (30.1%) (Figure 2).

Clinical Practice Measures

Please see Table 2 for a list of the number of eligible individuals for each clinical practice measure.

DISCUSSION

Using administrative data, we established a cohort of individuals living in BC, Canada with childhood onset T1D. Novel to our methodology is the ability to differentiate T1D and T2D using administrative PharmaNet data²⁶ that captures drug utilization patterns for every BC citizen (regardless of age). Through several steps of data cleaning and management, we attempted to capture only those persons with a likely diagnosis of T1D. We also developed five clinical

practice measures that reflect the Diabetes Canada CPGs⁹ (outpatient diabetes visits, A1C testing, and screening for thyroid dysfunction, nephropathy and retinopathy), as well as two clinically relevant diabetes outcome measures (DKA and A1C).

The Canadian provinces of Ontario and Quebec have used administrative datasets to establish pediatric diabetes cohorts and describe epidemiological trends and clinical outcomes such as DKA^{29,30}; however, these provincial cohorts included all diabetes sub-types. Manitoba, through linkage with a clinical registry, has developed an administrative cohort of individuals with a physician-diagnosis of T1D during childhood (n=1011). The mean age of our cohort was similar to the group from Quebec (10.3 years, SD 4.8 vs. 10.1 years, SD 4.8, respectively), while higher than Manitoba (8.9 years, SD 4.3) (25,26). BC, Quebec and Manitoba had nearly identical proportions of males and females (52.5%-54.0%; not reported by Ontario) in their cohorts.

The majority of individuals in the cohort fell into the 15–19-year-old and 20-24 year-old age categories (19.0% and 22.7%, respectively). Given this is known to be a high-risk period with poor follow up/follow through with care recommendations, this may skew our results when looked at as a whole. However, by analyzing the outcome measures by age category, we will be able to differentiate age effect and effect of transfer from pediatric to adult care.

Other groups have investigated quality of diabetes care using administrative data. A study by Keating et al. in the United States compared the use of administrative data versus medical records to detect various practice measures for diabetes in adults, including A1C testing and retinopathy screening.³¹ Similar to our methodology, within the administrative data any visit to

an ophthalmologist or optometrist that included an eye examination was considered an encounter for retinopathy screening while from the medical records, documentation of a dilated retinal exam or retinal photography was considered a screening event. With this approach, more retinopathy screening encounters were detected through administrative data compared to medical records. A1C testing was evaluated through billing codes in the administrative data and by looking for any A1C result in the medical records. In this case, medical records were more sensitive than administrative data.³¹ It is difficult to compare our methodology to those described in papers from the United States, as there are likely differences in the quality of administrative data given the differences between our healthcare systems.

In Canada, Amed et al. evaluated quality of care for childhood T1D in BC using administrative data (i.e., diabetes related physician visits, A1C testing, screening for complications) and showed that quality of care was poor for the majority of individuals in the cohort. Due to the inherent limitations of using administrative data, the researchers were unable to identify system, provider or patient-level factors contributing to poor adherence. To address this knowledge gap, surveys of healthcare providers (HCP) and caregivers of children living with T1D from across BC were conducted to better understand *why* adherence to CPGs was poor. HCP identified inadequate resources (i.e., funding, mental health support) as a key contributor to poor adherence³² while caregivers of children with T1D reported difficulty attending appointments due to barriers such as distance to clinic and the need to take time off work. These cross-sectional survey-based studies are resource intensive, only provide a 'snapshot' in time, and are not representative of the entire population because of poor response rates and selection bias.

Our methodology outlined in this paper has several strengths and will expand our use of administrative data to describe quality of pediatric diabetes care in BC. First, we are analyzing population-level data; hence, we avoid the risk of non-response bias, a type of selection bias. Second, we have access to over 25 years of data, which allows us to look at trends over time and identify novel variables that may be impacting quality of care. Third, as described earlier, BC is unique in having access to PharmaNet data across all ages, as this information is not available in most Canadian provinces. These data will support future research endeavours such as assessing outcomes in individuals using different management regimens (i.e. insulin pumps vs. multiple daily injections) and describing complication rates based on medication utilization patterns (i.e. angiotensin converting enzyme inhibitors for nephropathy). Finally, the ability to link datasets with external data sources, such as LifeLabs, will allow us to ask questions that cannot typically be answered by administrative data, such as whether quality of care is linked to glycemic control.

There are limitations to using administrative data for research. Misclassification, a type of information bias, is a common concern. However, the diabetes case definition and differentiating algorithm used to establish this cohort were validated against a clinical database^{25,26}, which should limit the risk of this type of bias. There are also concerns about incorrect ICD-9/ICD-10 coding, an inherent weakness of administrative data. For example, a study evaluating pulmonary embolism ICD-10 codes found a 17.7% false positive rate and an 8.9% false negative rate compared to medical records.³³ A significant issue with administrative data is that certain types of care are systematically left out. For instance, encounters with other health professionals, such as nurses and allied health, would not be captured. Yet, a visit with a nurse may be clinically equivalent to an outpatient diabetes physician visit. This may be more common in smaller

communities, where physician resources are limited. Moreover, visits completed by physicians who are paid through Alternative Payment Plans may be missing from MSP records, as payments are made per block of time, rather than per patient encounter.³⁴ However, physicians are requested to shadow bill (submit claims for non-payment purposes), which partially circumvents this issue. When Amed et al validated the diabetes case finding definition, they tested a definition that only included prescription utilization and found that this performed similarly to a definition that included hospitalization or MSP claims, indicating that Alternative Payment Plans did not significantly impact MSP and hospitalization claims.²⁵ Another aspect of diabetes care that is not captured with administrative data is point of care (POC) testing for A1C. Many clinics in BC use POC instruments to measure A1C. In some cases, these results are then processed through a laboratory, resulting in an MSP claim, while other times they are simply documented in the patient's health record (hence, no MSP billing). Amed et al faced the same issue when they explored adherence to T1D CPGs. 11 Thus, they informally surveyed diabetes clinics across BC that care for children and youth and ultimately concluded that although some POC tests are being missed, this likely affects a small segment of individuals. We do not have information as to how often POC testing is used once patients transfer to adult care. Lastly, patient reported outcomes (i.e. quality of life, satisfaction with care) are not captured in administrative health data yet represent a critical outcome that should be measured over time to assess impact of quality improvement initiatives. To address many of these limitations to administrative data, we are establishing clinical registries in BC that capture clinical data from medical records³⁵, data from diabetes devices such as glucose sensors and insulin pumps³⁶ and patient reported outcomes that can be linked to administrative data in the future.

Conclusion

Here, we have outlined how we established our pediatric T1D cohort from British Columbia, referred to as 'BC-PT1D.' Studies using administrative data require rigorous methodology to ensure the validity and reliability of the results. We have described in great detail the data management and cleaning conducted to establish the cohort and the definitions of five key clinical practice measures and two clinical outcome measures. This paper serves as an example of the detailed methodological approach required for T1D administrative data research and will be a resource for other researchers in this field.

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Table 1. Diabetes Differentiating Algorithm

Type 1 Diabetes	Type 2 Diabetes
i. Age <10 years old at diagnosis (index date)	i. Age ≥10 years old at diagnosis (index date)
OR	AND
ii. Age ≥10 years old at diagnosis AND prescription for insulin and/or glucose monitoring strips within 730 days from index date AND no metformin prescriptions within 730 days of index date	 ii. Prescriptions as follows: Insulin AND metformin within 730 days from index date; OR Insulin starting >730 days after index date; OR *At least two of the three items below with NO insulin use: Metformin Glucose monitoring strips Oral anti-diabetes drug

^{*}Of note, the subset of individuals who had no insulin use and only one of metformin, glucose monitoring strips or oral anti-diabetes drugs were excluded as the diabetes subtype could not be determined with confidence.

Table 2. Description of Quality Indicators

Quality Indicator	Definition / Inclusion, Exclusion criteria	Follow-up period	Reporting time interval	Outcome to report	Eligible Patients Included	Data Considerations
DM Outpatient Diabetes Encounters	 Data source: MSP Inclusion criteria: Encounters with diabetes diagnosis: ICD9 = "250X or 250XX, where X=any integer"; Encounters submitted by one of the following providers (as identified by claim specialty codes), indicating primary diabetes management:	From index date to the transfer date (when turning 18 years old) OR the end of the study observation period (i.e. March 31, 2020) (whichever came earlier).	Each complete year since patient's index date.	Distributions of: • the median annual number of visits per individual; and • the number of visits per year per individual.	4935	

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	4. L o T	v. Individuals who did not have 1 complete year of follow-up since index date; vi. Individuals who had no outpatient diabetes visits and no insulin prescriptions for the entire study period. Limit to one encounter per day, even if 2 or more encounters are billed in MSP. This minimizes the risk of overestimating the number of DM visits.					
Hemoglobi n A1C Testing	 In the second of the second of	Data source: MSP nclusion criteria: i. Encounters with A1C tests, identified based on specific fee items; Exclusion criteria: i. Individuals ≥ 18 years old at diabetes diagnosis; ii. Individuals who did not have 1 complete year of follow-up since index date; iii. Individuals who had no outpatient diabetes visits and no insulin prescriptions for the entire study period. One unique A1C check was defined as one encounter per individual per day even if 2 or more encounters are billed for in MSP).	From index date to the transfer date (when turning 18 years old) OR the end of the study observation period (i.e. March 31, 2020) (whichever came earlier).	Each complete year since patient's index date.	 Distributions of: the median annual number of A1C checks per individual; the number of A1C checks per individual per year; and the individuals with ≥3 A1C checks per year (indicating proportion of individuals at goal). 	4935	MSP captures all A1C tests run at outpatient and inpatient laboratories. Point of care tests will not be captured in MSP.
Thyroid Function Screening - Thyroid Stimulating Hormone (TSH)	2. In	Data source: MSP inclusion criteria: i. Visits with TSH tests, identified based on specific fee items; Exclusion criteria: i. Individuals ≥ 18 years old at diabetes diagnosis;	From index date to the transfer date (when turning 18 years old) OR the end of the study observation period (i.e. March 31, 2020), (whichever came earlier.)	Every rolling 2 complete years since index date.	Distributions of: the median number of TSH checks for rolling 2 years per individual; the number of TSH checks per	4457	MSP records should reflect all TSH checks in outpatient and inpatient settings

	 ii. Individuals who did not have 2 complete years of follow-up since index date; iii. Individuals who had no outpatient diabetes visits and no insulin prescriptions for the entire study period. 4. One unique TSH check was defined as one encounter per individual per day (even if 2 or more encounters are billed in MSP). 			individual per rolling 2 years; • the individuals with ≥1 TSH check per rolling 2 years (indicating proportion of patients at goal); and • the median time interval between 2 TSH checks per individual.		
Retinopathy Screening - Eye Examination	 Data source: MSP Inclusion criteria: Encounters with responsible provider's specialty as below:	From the time an individual is eligible for an eye exam to end of observation: • eligibility was defined as the latter of these two dates: (i) 15th birthday or (ii) the date when DM duration was >5 years; • the end of observation was defined as the earlier of these two dates: (i) transfer date (18th birthday) or (ii) end of the study observation period (i.e. March 31, 2020)	Every rolling 2 complete years since index date.	Distributions of: • the median number of eye exams for rolling 2 years per individual; • the number of eye exams per individual per rolling 2 years; • the individuals with ≥1 eye exam per rolling 2 years (indicating proportion of individuals at goal); and • the median time interval between 2 eye exams per individual.	1602	We included all encounters with an ophthalmologist or optometrist in MSP, as we are assuming that any visit to one of these providers will include retinopathy screening. Diagnostic codes are unhelpful as these would only indicate whether a diagnosis of diabetic retinopathy has been made. As optometry assessments are covered by MSP for individuals with systemic disease (including diabetes), they will be captured in this dataset.

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	1.		From the time an	Each	Distribution of:	2369	MSP records should
	2.		individual is eligible	complete	• the median		reflect all ACR
			for ACR screening to	year since	annual number		checks in outpatient
		*	end of observation:	patient's	of ACR checks		and inpatient
		items: "91985" or "9569";		index date.	per individual;		settings
		= 3	 eligibility was 		• the number of		
		having had T1D for a minimum	defined as the		ACR checks		
	2	of 5 years. Exclusion criteria:	latter of these		per individual		
Nephropath	3.	' T 1' '1 1 > 10 11 /	two dates: (i) 12 th birthday or (ii)		per year;		
y Screening		i. Individuals ≥18 years old at diabetes diagnosis;	the date when		• the individuals		
– Albumin		ii. Individuals who did not have 1	DM duration was		with ≥1 ACR		
to		complete year of follow-up since	> 5 years;		check per year (indicating		
Creatinine			• the end of		proportion of		
Ratio		iii. Individuals who had no	observation was		individuals at		
(ACR)		outpatient diabetes visits and no	defined as the		goal); and		
(ACK)		insulin prescriptions for the	earlier of these		• the median		
		entire study period.	two dates: (i)		time interval		
	4.	One unique ACR check was defined as	transfer date (18th		between 2 ACR		
		one encounter per individual per day	birthday) or (ii)		checks per		
		(even if 2 or more encounters are billed	the end of the		individual.		
		for in MSP).	study				
			observation				
			period (i.e.				
			March 31, 2020)				1

Table 3: Cohort Demographics, as of March 31, 2020

Characteristic	Cohort (n=5109)			
Age*				
Mean (SD), y	22.31 (8.21)			
Age category - No. (%)			
0.5-4 y	61 (1.0)			
5-9 y	334 (5.7)			
10-14 y	817 (13.9)			
15-19 y	1122 (19.0)			
20-24 y	1338 (22.7)			
25-29 y	1105 (18.7)			
30-34 y	732 (12.4)			
35-39 y	330 (5.6)			
40-44 y	62 (1.1)			
Sex, No. (%)				
Male	3188 (54.0)			
Diabetes duration*				
Mean (SD), y	11.89 (6.70)			
No. (%)				
0-4 y	1170 (19.8)			
5-9 y	1296 (22.0)			
10-14 y	1277 (21.6)			
15-19 y	1298 (22.0)			
20-24 y	860 (14.6)			

^{*}Based on March 31, 2020

SD = standard deviation; y = year

Figure 1. Steps in applying inclusions and exclusions for the BC-Pediatric Type 1 Diabetes Cohort

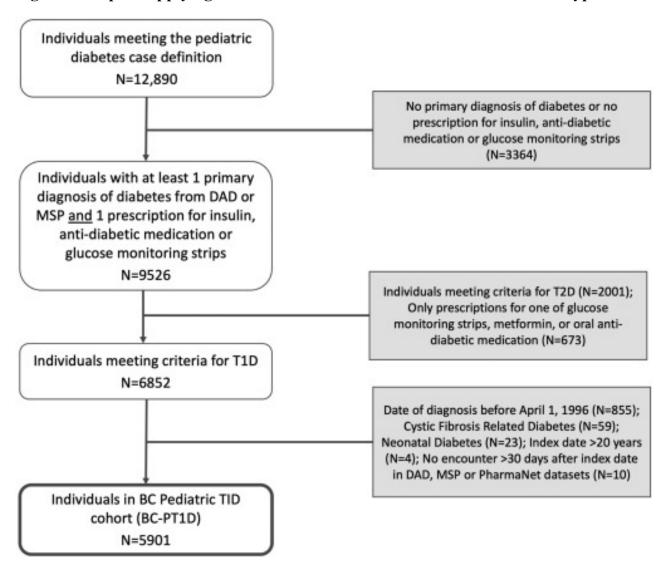
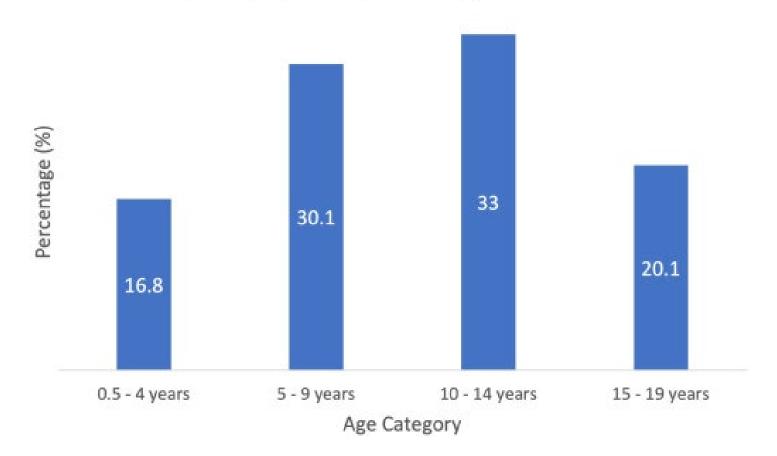


Figure 2. Distribution of age at diagnosis of type 1 diabetes within the administrative cohort.

Age category at diagnosis of type 1 diabetes



Supplementary Appendix 1.

Category	DIN_PIN
GLUCOSE TESTING	44123001, 44123002, 44123003, 44123004, 44123005, 44123006, 44123007, 44123008, 44123009, 44123010, 44123011, 44123012, 44123013, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 44123012, 4412
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