

Resources and Population Served: A Description of the Ontario
Pediatric Diabetes Network

Rayzel Shulman^{1,2,3}, MD, Fiona A. Miller^{2,4}, PhD, Therese A.
Stukel^{2,3}, PhD, Denis Daneman¹, MBBCh, DSc(Med), Astrid
Guttman^{1,2,3}, MDCM, MSc

Short Title: Description of the Ontario Pediatric Diabetes
Network

Affiliations: ¹Department of Pediatrics, Hospital for Sick
Children, University of Toronto, ²Institute of Health Policy,
Management and Evaluation, University of Toronto, ³Institute for
Clinical Evaluative Sciences, Toronto, Ontario, Canada, ⁴Toronto
Health Economics and Technology Assessment (THETA) Collaborative

Corresponding author: Dr. Astrid Guttman, Senior Scientist,
Chief Science Officer, Institute for Clinical and Evaluative
Sciences, G1 06, 2075 Bayview Avenue, Toronto, Ontario M4N 3M5
Ph. 416-480-4055 ext. 3783, Email: astrid.guttman@ices.on.ca

Word Count: 2, 467486

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60**Abstract**

Background: The Network of Ontario Pediatric Diabetes Programs was established in 2001 to provide access to specialized pediatric diabetes care. Universal funding for pediatric insulin pump therapy has been available in Ontario since 2006. The objective of this study is to describe the distribution of patients, resources, and pump use amongst centres within the Network.

Methods: This is a cross-sectional, descriptive study of 35 pediatric diabetes centres in Ontario. We conducted a survey in 2012 to measure centre characteristics, patient volume, and available clinical and social resources. Health administrative data from the provincial Assisted Devices Program were used to describe patients 0-18 years using insulin pumps by centre as a measure of technology uptake.

Results: All 35 centres participated, reporting a total of 6,676 children with type 1 diabetes (T1D) and 368 with type 2 diabetes (T2D). The vast majority (>80%) of children with T1D are followed at tertiary or large community centres. Nursing patient load was similar between centre types but there was a large range across centres within any type. Overall, percent pump use was 38.1% and varied widely across centres (5.3-66.7%) Funded 24 hr support for pump users was available at 5 (35.7%) small

1
2
3
4
5
6
7
8
9 community, 3 (18.8%) large community, and 2 (40.0%) tertiary
10 centres.
11

12
13 **Interpretation:** There are differences in availability to
14 specialized and after hours care for children with diabetes in
15 Ontario and pump use varied widely across centres. Further
16 research is needed to assess the impact of these observed
17 differences on quality of care and outcomes.
18
19
20
21

22
23 **Keywords:** Diabetes Mellitus, Type 1; Child; Child, Preschool;
24 Adolescent; Health Services Research; Quality Improvement
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Introduction

Canada has one of the world's highest incidence rates of type 1 diabetes (T1D) in children (25.9/100,000/year) [1] and the annual incidence is increasing by 3% [2, 3]. Given the short- and long-term consequences of diabetes starting in childhood [4], there is a need for a system with the capacity to provide high quality care. Although guidelines for the delivery of ambulatory diabetes care to children and adolescents with diabetes have been established [5-7], evidence linking particular aspects of care delivery to important diabetes outcomes is lacking [8-12]. Therefore, it is not surprising that there is marked heterogeneity in the organization and provision of services for pediatric diabetes care such as reported in Europe [13-15]. In Canada, provinces have responsibility for the majority of health service delivery. Nova Scotia and Ontario are the only provinces that have a dedicated pediatric diabetes network.

In 2001, the Network of Ontario Pediatric Diabetes Programs (NOPDP) was established under the mandate of the Northern Diabetes Health Network to improve access to specialized pediatric diabetes care for all children in Ontario [16]. As of 2013-2014, the Ontario Pediatric Diabetes Network (the Network) is coordinated by the Provincial Council for Maternal and Child

1
2
3
4
5
6
7
8
9 Health, a provincial program of the Ministry of Health and Long-
10 Term Care (MOHLTC) [17]. It is currently comprised of 35 centres
11 including 30 community and 5 tertiary centres, each employing
12 diabetes physicians, nurses, dietitians and social workers. ~~The~~
13 ~~five tertiary centres are located in the major pediatric~~
14 ~~academic health science centres in Ontario's major cities~~
15 ~~(Toronto, Ottawa, London, Hamilton and Kingston), and serve as~~
16 ~~referral centres from the community-based centres. Community~~
17 ~~centres are located in communities across Ontario.~~ All core
18 diabetes services and, since 2006, funding for insulin pumps and
19 75% of the cost of pump supplies for all youth (<19th birthday)
20 with T1D, are provided universally by the Ontario MOHLTC.
21
22
23
24
25
26
27
28
29
30
31
32
33

34 The rate of pump use and its distribution across centres, since
35 the introduction of universal funding has not been described. It
36 is not known whether there are barriers to pump use related to
37 centre resources or practice patterns. The unique set-up of this
38 coordinated network of care for children with T1D is ideal for
39 collecting data to study and improve the quality and outcomes of
40 pediatric diabetes care. The objective of this study is to
41 describe and compare the distribution of patient load and
42 resources, across centre types within the Network. We also aim
43 to describe percent pump use as a measure of technology uptake.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

These data are needed to examine whether variation in centre resources is associated with management and/or outcomes of pump use. This information can then be used to inform the design of interventions aimed at improving the quality of care.

Methods

This is a cross-sectional, descriptive study of 35 pediatric diabetes centres in Ontario using survey and administrative health data.

Questionnaire design

We collected data using a self-completed questionnaire designed to identify specific centre characteristics, patient volume by type of diabetes, and the clinical and social support resources available (Appendix 1). We asked centres to report the number of full time equivalent members of the diabetes team who provide comprehensive care at each centre. We asked about the training of physicians providing care and provision of funded 24 hour support for patients using insulin pumps. We captured data on mean hemoglobin A1c (HbA1c) for all children with T1D at each centre. HbA1c has been shown to vary within and between jurisdictions and has been used as a measure of the quality of

1
2
3
4
5
6
7
8
9 care [8, 18]. The centre mean HbA1c was self-reported and no
10 correction for assay differences was made.
11

12
13 The questionnaire was developed based on previous system-wide
14 surveys of adult diabetes [19] and asthma education centers
15 [20] in Ontario with input from key informants (specialist
16 physicians, experienced nurses) on both the content and style of
17 questions. As well, we presented the study objectives and
18 methods at the annual Network meeting in November 2010 and
19 invited feedback. Further, prior to the annual Network meeting
20 in November 2011, we met with the Network advisory committee to
21 get feedback on the survey.
22
23
24
25
26
27
28
29

30 31 *Survey Administration* 32

33
34 The questionnaire was mailed to the responsible diabetes nurse
35 or dietitian at each Ontario pediatric diabetes centre,
36 identified from a publicly available directory, within one week
37 of our presentation at the Network meeting in November 2011.
38 Clinical team members were expected to have access to the
39 information requested. If not, they were directed to consult an
40 administrator. Data were collected from November 2011-March 2012
41 using a modified Dillman method [21]. Up to six contacts were
42 made in two week intervals from the time the questionnaires were
43 mailed with telephone or email to centres who had not yet
44
45
46
47
48
49
50
51
52

1
2
3
4
5
6
7
8
9 responded. This was continued until 100% of responses had been
10 obtained.
11

12
13 *Data elements*
14

15
16 We reported the data elements for which we had the highest
17 response rates and which were of the highest quality. Centre
18 type was defined by categorizing the centres according to
19 whether they were a tertiary or community centre and by patient
20 volume. The five tertiary centres are located in the major
21 pediatric academic health science centres in Ontario's major
22 cities (Toronto, Ottawa, London, Hamilton and Kingston). Small
23 community centres were defined as those with a patient volume
24 <100 and large community centres as those with a patient volume
25 ≥100. A community size index, based on 2006 census population
26 data, was assigned to each centre using the centre's postal
27 code. Centres located in communities with a population <500,000
28 were considered rural and those with a population ≥500,000 were
29 considered urban. We measured the furthest distance that centres
30 report that patients travel to get to their centre. The model of
31 physician care at each centre was defined as 1) pediatric
32 endocrinologist; 2) generalist (general pediatrician(s) or
33 family physician(s) but no pediatric endocrinologist); and 3)
34 generalist with a visiting pediatric endocrinologist.
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9 To describe centre resources, patient load was calculated by
10 dividing the full time equivalent (FTE) for each of nurse,
11 dietitian, and social worker by the total number of patients
12 with T1D and T2D at each centre. In addition, we report the
13 proportion of centres that report having any FTE psychologists,
14 child life specialists, and psychiatrists by centre type. We
15 also measured the number of centres who reported having
16 telemedicine available.
17
18
19
20
21
22
23
24

25 We used available provincial administrative health data to
26 measure the proportion of children with T1D at each center who
27 are on insulin pumps as a measure of technology uptake. We used
28 claims data from the Assistive Devices Program (ADP), available
29 at the Institute for Clinical and Evaluative Sciences (ICES).
30 ICES is an independent, not-for-profit organization that,
31 through a comprehensive data sharing agreement with the Ontario
32 Ministry of Health and Long Term Care, conducts health services
33 research for the province of Ontario. Initial ADP forms are
34 completed at the time of application for pump funding and
35 identify the centre where the individual receives their diabetes
36 care. To determine the number of patients at each centre using
37 pump therapy in 2012, we counted the number of patients who ever
38 had an initial approved application for pump funding minus any
39 individuals who turned 19, moved out of province, or who
40
41
42
43
44
45
46
47
48
49
50
51
52
53

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

discontinued pump funding as of January 1, 2012. Percent pump use was calculated by dividing the number of patients using pump therapy at each centre, with a T1D patient volume of ≥ 6 (n=33), divided by the number of patients with T1D.

Data Analysis

Descriptive statistics were reported by centre type and were performed using SAS Enterprise 6.1.

Research ethics board approval was obtained from the University of Toronto, The Hospital for Sick Children, and Sunnybrook Hospital.

Results

Centre characteristics and resources

Table 1 shows centre characteristics and resources by centre type. The vast majority of patients with T1D in Ontario are followed at either large community (45.9%) or tertiary (40.8%) centres. Of all patients seen at Ontario pediatric diabetes centres, 5.2% have type 2 diabetes (T2D). More than half of large community centres (64.3%) and most small community centres (68.8%) are located in rural areas with a population of $< 500,000$ and most tertiary centres (60%) are located in urban areas with a population of $\geq 500,000$. All tertiary centres are staffed by

1
2
3
4
5
6
7
8
9 pediatric endocrinologists, a mix of physician models at large
10 community centres, and mostly generalist and visiting pediatric
11 endocrinologist models at small community centres. More than
12
13
14 half of all centres have telemedicine available.
15

16
17
18
19
20 Table 2 shows the case load ~~by of~~ specialists by centre type.
21
22 Overall, the median patient load per nurse, dietician, and
23 social worker was 244, 395, and 527 respectively. None of the
24 centres had a psychiatrist. Psychologists were not available at
25 community centres and only 40% of tertiary centres had any FTE
26 psychologist.
27
28
29
30
31

32 *Glycemic control and insulin pump use*

33
34
35 Median HbA1c for all centres ~~The mean HbA1c was 8.6%. Overall~~
36 percent pump use was 38.1% and varied between 5.3% and 66.7%.
37
38 25.7% of centres had centre-specific eligibility criteria for
39 insulin pump initiation. Table 3 shows glycemic control and pump
40 use by centre type. ~~percent pump use, and percent of centres~~
41 ~~using centre-specific eligibility criteria for insulin pump~~
42 ~~initiation by centre type are reported in Table 3.~~
43
44
45
46
47

48 **Interpretation**

49
50 Main Findings
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

This population-based study describes the resources available across the pediatric diabetes network in Ontario. We observed variation in availability of resources and services for pediatric diabetes across centres including diabetes nurses, dietitians and social workers as well as availability of 24 hour support. There are very few centres with psychologist or psychiatrist team members. Finally, we found variation in glycemic control, pump use, and use of centre-specific eligibility criteria for pump therapy across centres.

Explanation and comparison with other studies

To put our findings into context, we compare our results to studies that are either population-based or use data from large diabetes registries.

Centre characteristics and resources

In Ontario tertiary centres are exclusively staffed by pediatric endocrinologists and the model of care differs significantly between centre types. The provision of 24 hr clinical support at 30.3% of all centres for pediatric patients using insulin pump therapy in Ontario is slightly lower compared to the UK, where 44% of centres provided 24 hour support for all pediatric diabetes patients in 2008 [13]. Although we report availability of funded 24 hour support for patients using pumps, from

1
2
3
4
5
6
7
8
9 clinical experience, centres which provide this service are
10 likely to do so for all diabetes patient regardless of their
11 insulin regimen.
12
13

14
15 Further study of the relationship between centre characteristics
16 including model of physician care and provision of 24 hour
17 support and performance while taking into account centre and
18 patient-level confounders is needed to inform optimal resource
19 allocation and team approach.
20
21
22
23

24
25 Patients travelled the furthest distance to tertiary centres
26 despite that the majority of centres had access to telemedicine
27 services. Further study to explore how this service is being
28 used and its association with management and outcome of diabetes
29 is important to inform optimal use of this technology with the
30 Network.
31
32
33
34
35
36
37
38
39
40

41 *Patient load*

42
43 In Europe in 2009, 80% of the smallest, compared to 100% of the
44 largest centres had a diabetes nurse educator, [14]. In the UK
45 in 2008, 94% of centres had a pediatric diabetes specialist
46 nurse, 88% of whom worked solely in pediatrics[13]. The number
47 of patients per nurse in the European study ranged from 140-184
48
49
50
51
52

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

across centre size and was 92 in the UK study, considerably lower than the mean (range) in the Ontario network. In the UK, 93% of clinics report having a pediatric dietitian and only 21% of clinics have a psychological professional.

In Ontario, the Network has been instrumental in ensuring that each pediatric diabetes centre has a multidisciplinary core team [22], however, the ratio of diabetes nurse specialist to patients is above the recommended 70 patients per nurse by the Royal College of Nurses in the United Kingdom [23] and slightly above the recommended 100 patients per nurse, under optimal conditions, by a European guideline [24].

The patient load of social workers is relatively higher at large community centres compared to the other centre types. Further exploration to understand whether this disparity is due to variation in need for social work services based on centre type and its association with outcomes is needed. None of the centres had any FTE psychiatrist and only 40% of tertiary centres had any FTE psychologist. Child life specialists were mostly available at tertiary centres. Further work to elucidate the availability of these professionals from outside the Network for consultation and ongoing care of children with diabetes is needed to assess the quality of access to these important resources.

1
2
3
4
5
6
7
8
9 *Glycemic control*

10
11 The mean HbA1c levels reported by Ontario centres are similar to
12 pediatric and adult regional or national T1D registries (2010-
13 2013) that report median HbA1c of 7.4% -9.4% across countries
14 and age groups [25]. Patient level data is required to control
15 for known confounders of glycemic control and to make meaningful
16 between-centre comparisons.
17
18
19
20
21
22
23

24 *Insulin pump use*

25
26 Pump use in Ontario appears to be comparable to other countries
27 such as Germany and Austria where 41% of youth <18 years old
28 were using pump therapy in 2010-2012 [26]. Data collected in
29 regional or national registries (2010-2013) about children
30 and/or adults with T1D show wide variation in pump use both
31 between and within populations [25]. Pump use at each centre
32 type appeared similar, however, there was marked variation in
33 the percent pump use between individual centres. This variation
34 may be related to differences in patient characteristics between
35 centres, however, currently it is only possible to identify
36 those children by centre who are on insulin pumps using health
37 administrative data. Further, more than a quarter of all centres
38 have centre-specific eligibility criteria for pump therapy. This
39 suggests that there are likely differences in team philosophy
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9 and approach to pump therapy that may be contributing to the
10 observed variation in pump use across centres and warrant
11 further study.
12
13

14 15 Strengths and Limitations 16

17
18 A strength of our study is the complete response rate and the
19 availability of population based data on insulin pump use.
20
21 However, the self-reported data of the survey is a limitation.
22
23 We did not independently verify answers, however an internal
24 survey in 2013 by the Network showed close correlation of mutual
25 data elements [22]. The method for calculating the mean HbA1c
26 at each centre is not specified nor was any correction made for
27 assay differences used to measure HbA1c between centres.
28
29 Finally, we measured applications for pump funding, not actual
30 pump use. Therefore, it is possible that some individuals who
31 applied for pump funding are not using a pump, and conversely,
32 that others who did not apply for funding via the government
33 program are using a pump covered by private insurance or payment
34 out-of-pocket. However, given the expense of the pump and the
35 move of private insurers to not cover since the universal
36 funding policy, the latter limitation is unlikely. In addition,
37 some individuals who applied for pump funding may have been
38 using pump therapy prior to the introduction of universal
39 funding.
40
41
42
43
44
45
46
47
48
49
50
51
52

Conclusions and implications for practice and future research

Although the Ontario network of care for children with diabetes is highly structured, some centers are resourced below international guidelines, and variation exists in patient use of new technology and hemoglobin A1C. Future work should include the collection of patient level data to enable comparative effectiveness studies around differences in resources and models of care to diabetes outcomes to inform Ontario and other jurisdictions.

Table 1: Centre characteristics by centre type

	Large Community n=14 centres	Small community n=16 centres	Tertiary n=5 centres
*T1D patients, n (% of all T1D patients in Ontario)	2739 (41.0%)	1211 (18.1%)	2726 (40.8%)
**T2D patients, n (% of all T2D patients in Ontario)	169 (45.9%)	102 (27.7%)	97 (26.4%)
Physician model of care, n(%)			
Generalist	4 (28.6%)	8 (50.0%)	0 (0%)
Pediatric Endocrinologist	5 (35.7%)	1 (6.3%)	5 (100%)
Visiting Pediatric Endocrinologist	5 (35.7%)	6 (37.5%)	0 (0%)
Missing	0 (0.0%)	1 (6.3%)	0 (0%)
Community size, n(%)			
Rural (<500,000)	9 (64.3%)	11 (68.8%)	2 (40.0%)
Urban (≥500,000)	5 (35.7%)	3 (18.8%)	3 (60.0%)
Missing	0 (0%)	2 (12.5%)	0 (0%)

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Furthest distance travelled to centre (km), median (IQR)	100 (70, 108)	100 (60, 200)	350 (200, 388)
Missing: n(%)	2 (14.3%)	1 (6.3%)	0
Telemedicine, n(%)			
Yes	9 (64.3%)	11 (68.8%)	3 (60.0%)

*T1D = Type 1 diabetes
**T2D = Type 2 diabetes

Formatted: Space Before: 0 pt, After: 0 pt

Confidential

Table 2: Diabetes (type 1 and 2) patient load by centre type

	All Centres n=35	Large Community (n=14)	Small community (n=16)	Tertiary (n=5)
Patients per nurse, median (IQR) Missing: n (%)	244 (195, 275) 2 (5.7%)	248 (203, 291) 0	262 (197, 275) 2 (12.5%)	195 (177, 218) 0
Patients per dietitian, median (IQR) Missing: n (%)	395 (293, 403) 2 (5.7%)	398 (307, 403) 0	373 (284, 405) 2 (12.5%)	363 (293, 397) 0
Patients per social worker, median (IQR) Missing: n (%)	527 (405, 635) 2 (5.7%)	538 (488, 694) 0	480 (367, 600) 2 (12.5%)	390 (379, 635) 0
Any *FTE psychologist, n (%)				
Yes	2 (5.7%)	0	0	2 (40.0%)
missing	3 (8.6%)	1 (7.1%)	2 (12.5%)	0
Any FTE psychiatrist, n (%)				
Yes	0	0	0	0
missing	3 (8.6%)	1 (7.1%)	2 (12.5%)	0
Any FTE child life specialist, n (%)				
Yes	5 (14.3%)	0	2 (12.5%)	3 (60.0%)
missing	5 (14.3%)	3 (21.4%)	2 (12.5%)	0

*FTE= full time equivalent

Table 3: Glycemic control and insulin pump use by centre type

	All Centres n=35	Large Community (n=14)	Small community (n=16)	Tertiary (n=5)
Mean <u>HbA1c</u> reported by centres (%), median (IQR) Missing, n (%)	8.6 (8.2, 9.0) 14 (40.0%)	9.0 (8.5, 9.1) 6 (42.9%)	8.4 (8.0, 9.0) 5 (31.3%)	8.1 (7.5, 8.6) 3 (60.0%)
Percent of patients with <u>**T1D</u> using pump therapy, (n=33) mean (range)	38.1% (5.3-66.7%)	41.4% (28.7-66.7%)	34.6% (5.3-65.6%)	38.7% (27.8-55.0%)
Funded 24 hour support for patients using pumps, n (%) Yes	10 (28.6%)	5 (35.7%)	3 (18.8%)	2 (40.0%)
Centre-specific eligibility criteria for pump therapy Yes, n (%) Missing, n (%)	9 (25.7%) 1 (2.9%)	4 (28.6%) 0	2 (12.5%) 1 (6.3%)	3 (60.0%) 0

*HbA1c= Hemoglobin A1c

**T1D= type 1 diabetes

Contributors' statement

R.S. conceptualized and designed the study, designed the data collection instrument, collected the data, carried out the initial analyses, contributed to the analysis and interpretation of data, drafted the initial manuscript, critically reviewed the manuscript, and approved the final manuscript as submitted. T.S. conceptualized and designed the study, contributed to the analysis and interpretation of data, critically reviewed the manuscript, and approved the final manuscript as submitted. F.M.

1
2
3
4
5
6
7
8
9 conceptualized and designed the study, contributed to the
10 interpretation of data, critically reviewed the manuscript, and
11 approved the final manuscript as submitted. A.N. contributed to
12 the design and the analysis of the study, critically reviewed
13 the manuscript, and approved the final manuscript as submitted.
14 D.D. conceptualized and designed the study, contributed to the
15 interpretation of data, critically reviewed the manuscript, and
16 approved the final manuscript as submitted. A.G. conceptualized
17 and designed the study, secured the funding, contributed to the
18 analysis and interpretation of data, reviewed and revised the
19 manuscript, and approved the final manuscript as submitted.
20
21
22
23
24
25
26
27
28
29
30
31

32 Funding Statement

33
34
35 AG receives salary funding from a Canadian Institute for Health
36 Research Applied Chair in Child Health Services and Policy
37 Research. Funding for the administrative data analysis was
38 supported (in part) by a Creative Professional Activities grant
39 from the Department of Pediatrics, Hospital for Sick Children.
40
41
42
43
44
45

46 Financial Disclosure

47
48
49 The authors have no financial relationships relevant to this
50 article to disclose. This study was supported by the Institute
51
52

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the Ontario Ministry of Health and Long-Term Care (MOHLTC). The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by ICES or the MOHLTC is intended or should be inferred.

Conflict of Interest

The authors have no conflicts of interest to disclose.

Confidential

1
2
3
4
5
6
7
8
9 **References**

- 10
11
12
13
14
15 1. *International Diabetes Federation Diabetes Atlas 6th edition*. 2013 Aug 14, 2014]; 6th edition:[
16 2. *DIAMOND Project Group. Incidence and trends of childhood Type 1 diabetes worldwide 1990-*
17 *1999*. *Diabet Med*, 2006. **23**(8): p. 857-66.
18 3. Patterson, C.C., et al., *Incidence trends for childhood type 1 diabetes in Europe during 1989-2003*
19 *and predicted new cases 2005-20: a multicentre prospective registration study.[see comment]*.
20 *Lancet*, 2009. **373**(9680): p. 2027-33.
21 4. *Effect of intensive diabetes treatment on the development and progression of long-term*
22 *complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and*
23 *Complications Trial. Diabetes Control and Complications Trial Research Group. J Pediatr.*, 1994.
24 **125**(2): p. 177-88.
25 5. Wherrett, D., et al., *Type 1 diabetes in children and adolescents*. *Can J Diabetes*, 2013. **37 Suppl**
26 **1**: p. S153-62.
27 6. Silverstein, J., et al., *Care of children and adolescents with type 1 diabetes: a statement of the*
28 *American Diabetes Association. Diabetes Care*, 2005. **28**(1): p. 186-212.
29 7. Pihoker, C., et al., *The delivery of ambulatory diabetes care: structures, processes, and outcomes*
30 *of ambulatory diabetes care. Pediatr Diabetes.*, 2008. **9**(6): p. 609-20.
31 8. de Beaufort, C.E., et al., *Metabolic outcomes in young children with type 1 diabetes differ*
32 *between treatment centers: the Hvidoere Study in Young Children 2009. Pediatr Diabetes*, 2013.
33 **14**(6): p. 422-8.
34 9. Rosenbauer, J., et al., *Improved metabolic control in children and adolescents with type 1*
35 *diabetes: a trend analysis using prospective multicenter data from Germany and Austria.*
36 *Diabetes Care*, 2012. **35**(1): p. 80-6.
37 10. Svensson, J., et al., *Improved metabolic outcome in a Danish diabetic paediatric population aged*
38 *0-18 yr: results from a nationwide continuous Registration. Pediatr Diabetes*, 2009. **10**(7): p. 461-
39 7.
40 11. Doggen, K., et al., *Care delivery and outcomes among Belgian children and adolescents with type*
41 *1 diabetes. Eur J Pediatr*, 2012. **171**(11): p. 1679-85.
42 12. Nordly, S., et al., *Factors associated with glycaemic outcome of childhood diabetes care in*
43 *Denmark. Diabet Med*, 2005. **22**(11): p. 1566-73.
44 13. Gosden, C., et al., *The fifth UK paediatric diabetes services survey: meeting guidelines and*
45 *recommendations? Arch Dis Child*, 2010. **95**(10): p. 837-40.
46 14. Cinek, O., et al., *Heterogeneity in the systems of pediatric diabetes care across the European*
47 *Union. Pediatr Diabetes*, 2012. **13 Suppl 16**: p. 5-14.
48 15. Hawkes, C.P. and N.P. Murphy, *Paediatric type 1 diabetes in Ireland--results of the first national*
49 *audit. Ir Med J*, 2014. **107**(4): p. 102-4.
50 16. Griffis, S. and C. Beauvais, *A System-wide Response to Diabetes: Networks Meet the Challenge.*
51 *Canadian Journal of Diabetes*, 2007. **31**(1): p. 16-17.
52 17. *Paediatric Diabetes Network Working Group –Terms of Reference*. 2013, The Provincial Council
53 for Maternal and Child Health.
54 18. Peterson, A., et al., *Improved results in paediatric diabetes care using a quality registry in an*
55 *improvement collaborative: a case study in Sweden. PLoS One*, 2014. **9**(5): p. e97875.
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

19. Cauch-Dudek, K., et al., *Disparities in attendance at diabetes self-management education programs after diagnosis in Ontario, Canada: a cohort study*. BMC Public Health, 2013. **13**: p. 85.
20. Garvey, N.J., et al., *The association of asthma education centre characteristics on hospitalizations and emergency department visits in Ontario: a population-based study*. BMC Health Serv Res, 2014. **14**: p. 561.
21. Dillman, D., *Mail and internet surveys: The tailored design method*. 2007, Hoboken, NJ: Wiley.
22. *Ontario Pediatric Diabetes Network Current State Survey Report*. 2013, Provincial Council for Maternal and Child Health.
23. *Specialist nursing services for children and young people with diabetes* http://www.rcn.org.uk/data/assets/pdf_file/0009/78687/003015.pdf, in *Paediatric and Adolescent Diabetes Group of the Royal College of Nursing*. 2006: London.
24. de Beaufort, C., et al., *Harmonize care to optimize outcome in children and adolescents with diabetes mellitus: treatment recommendations in Europe*. *Pediatr Diabetes*, 2012. **13 Suppl 16**: p. 15-9.
25. McKnight, J.A., et al., *Glycaemic control of Type 1 diabetes in clinical practice early in the 21st century: an international comparison*. *Diabet Med*, 2015. **32**(8): p. 1036-50.
26. Maahs, D.M., et al., *Insulin pump use in pediatric type 1 diabetes: multinational comparison with 54,768 pediatric patients from the T1D exchange (US), national pediatric diabetes audit (England and Wales), and the DPV initiative (Germany and Austria)*, in *40th Annual Conference of the International Society for Pediatric and Adolescent Diabetes (ISPAD)*, M.A. Sperling, Editor. 2014: Toronto, Canada. p. 47.

Appendix 1: Questionnaire

RESOURCE SURVEY OF THE NETWORK OF ONTARIO PEDIATRIC DIABETES PROGRAMS

PART ONE: PEDIATRIC DIABETES CENTRE INFORMATION

1. Centre name _____
2. What is the furthest distance that patients travel from home to get to your centre? _____ km
3. Do you have telemedicine available at your centre?
Yes No
4. How many youth (<19 years) with diabetes are currently followed at your centre?
Number of youth: Type 1 Diabetes _____ Type 2 Diabetes _____ Other types _____
5. When does your centre transition patients to adult care? _____
6. What is the average HbA1c of youth (<19 years) with type 1 diabetes (T1D) at your centre? _____
7. For pediatric diabetes care, how many full time equivalent (FTE) staff does your centre have for each of the following roles?

Role	FTE	Role	FTE
Diabetes Nurse Educator		Registered Social Worker	
Registered Dietician		Psychiatrist	
Psychologist		Child life	
Administrative staff (clerk, coordinator, secretary etc.)		Other (please specify):	

8. On average, how often do the following team members meet with youth (<19 years) with T1D at your centre each year?

Role	Visits per year	Role	Visits per year
Physician at your centre		Registered Dietician	
Visiting physician (Outreach program)		Registered Social Worker	
Diabetes Nurse Educator		Other (please specify):	

9. How many of each of the following types of physicians at your centre sees youth with T1D?

Physician specialty	Number	Role	Number
Pediatric endocrinologist		Adult endocrinologist	
Visiting pediatric endocrinologist		Family physician	
General pediatrician		Other (please specify):	

10. Are there medical doctors in training (residents and/or fellows) at your centre who see youth with T1D?

Yes No

PART TWO: PEDIATRIC INSULIN PUMPS AT YOUR CENTRE

11. The Ontario Ministry of Health and Long-Term Care announced funding for pediatric insulin pumps in November 2006. You may need to refer to your records to respond to questions 9a and 9b.

a. How many youth (<19 years) with T1D were followed at your centre in 2006? _____

b. Of those, how many were actively using an insulin pump? _____

12. a) Does your centre have its own eligibility criteria (in addition to the ADP criteria) for initiation or renewal?

Yes No

b) If yes, please describe here, email as an attachment, or mail in pre-addressed envelope.

[Redacted area for question 12b]

13. a) Does your centre have any specific ineligibility criteria (in addition to the ADP criteria)?

Yes No

b) If yes, please describe here, email as an attachment, or mail in pre-addressed envelope.

[Redacted area for question 13b]

14. a) Does your centre provide education for pump starts?

Yes No

b) If yes, who does the teaching? (Check all that apply)

Staff physician	<input type="checkbox"/>	Diabetes nurse educator from your centre	<input type="checkbox"/>
Registered nurse	<input type="checkbox"/>	Diabetes nurse educator provided by a pump company	<input type="checkbox"/>
Registered dietician	<input type="checkbox"/>	Other (please specify) _____	<input type="checkbox"/>

c) If no, where is the education provided? _____

15. Does your centre have a teaching protocol/schedule for:

a) Pump starts?

Yes No

b) Ongoing pump education?

Yes

No

c) If yes to 15a and/or 15b, please describe here, email as an attachment, or mail in pre-addressed envelope.

[Redacted area]

16. Does your centre provide any written material for:

a) Pump starts?

Yes

No

b) Ongoing pump education?

Yes

No

c) If yes to 16a and/or 16b, please email as an attachment or mail in pre-addressed envelope.

[Redacted area]

17. a) Do you have a funded 24 hour support service for pediatric pump patients (other than what is provided by pump companies)?

Yes

No

b) If yes, who responds to the calls?

Physician

Certified Diabetes Educator

Registered nurse

Other (please specify) _____

18. a) Do you have interpreter services for pump teaching and follow-up visits?

Yes

No

b) Are you satisfied with your interpreter services for the purpose of pump teaching and follow-up visit?

Yes

No

c) If no, please explain:

19. Please add any comments about the pediatric insulin pump program at your centre.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Thank you for taking the time to complete this survey.

Confidential

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.