

Paediatric Diabetes Registry



Patient Label Here

CREATE A PATIENT

DEMOGRAPHICS:

Family Name: _____

Given Name 1: _____

Given Name 2: _____

Given Name 3: _____

Given Name 4: _____

OHIP ID#: _____

ID#: _____

ID Type: Chart

Sex at Birth: *(Select One)*

Male Female Unknown

Date of Birth: dd / mm /yyyy

No Fixed Address

Postal Code: _____

City: _____

Province: _____

Country: _____

Telephone: _____

Alternative Telephone: _____

VISIT INFORMATION

*Date of Visit: dd / mm /yyyy

*Visit Method: *(Select One)*

Video visit Clinic visit Telephone visit

Community visit Other

If Other, please specify: _____

Providers in attendance for the visit: *(Select All That Apply)*

Endocrinologist Pediatrician Nurse Practitioner

Registered Dietitian Registered nurse Psychologist

Registered Social Worker Registered Practical Nurse

If Other, please specify: _____

*Diabetes Diagnosis: *(Select One)*

Type 1 Type 2 MODY

Cystic Fibrosis related Neonatal Secondary diabetes

Unspecified

If Other, please specify: _____

*Date of Diagnosis: dd / mm /yyyy

INITIAL DIAGNOSIS

Please complete this section for clinical information related to the diagnosis event only.

At diabetes diagnosis did the patient experience the following?:

- DKA HHS Mixed DKA/HHS
 None Unknown

What was the HbA1C at the time of diagnosis?:

(result in %) _____

What was the serum glucose value?:

(result in mmol/L) _____

What was the pH level?: _____

What was the Bicarbonate level? _____

What was the serum osmolality value?:

(result in mOsm/kg) _____

Was the patient's diabetes autoantibodies test completed?

(Select One) Yes No Unknown

Anti-GAD status: (Select One) Positive Negative

Inconclusive Unknown

Anti-Insulin Status: (Select One) Positive Negative

Inconclusive Unknown

Anti-Islet Cell Status: (Select One) Positive Negative
 Inconclusive Unknown

Anti-Islet Cell Status Date: dd / mm /yyyy

DIABETES CLINIC VISIT

ANTHROPOMETRIC MEASUREMENTS

Height (cm) at this visit: _____

Weight (kg) at this visit: _____

Systolic Blood Pressure at visit: _____

Diastolic Blood Pressure at visit: _____

GLUCOSE MONITORING & GLYCEMIC CONTROL

Measured HbA1C for this visit: (%) _____

Date of measured HbA1C: _____

Method of HbA1C:

Community Laboratory/External Lab

Hospital Laboratory

*If yes, enter name of device _____

Point of Care Testing

*If yes, enter name of device _____

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Type of glucose monitoring device: *(Select One)*

- rtCGM IsCGM/FGM SMBG Other Unknown

RtCGM/isCGM/FGM usage % in the last 14 days:

- Less than 80% 80% to 85% 86% to 90%
 91% to 95% 96% to 100% Unknown

If CGM/FGM use is <80%, no need to enter time in range questions below

What is the percentage of time in the last two weeks where the range is between 3.9 and 10.0mmol/L: (%) _____

What is the percentage of time in the last two weeks where the range is between 3.0 and 3.8mmol/L: (%) _____

What is the percentage of time in the last two weeks where the range is below 3.0mmol/L: (%) _____

What is the percentage of time in the last two weeks where the range is above 10.0mmol/L: (%) _____

The average sensor glucose in the last 14 days reported by CGM/FGM: (mmol/L) _____

The standard deviation reported in the last 14 days: (mmol/L) _____

DIABETES REGIMEN

How is insulin being administered:

- Injection Pump Patient not on insulin

Injection frequency: *(Select One)*

- MDI Bid Tid Basal only Bolus only
 Premixed insulin (Premixed analogue or Premixed regular)

Type of pump: *(Select One)*

- Standalone pump Low glucose suspend (PLGS)
 Predicted low glucose suspend (PLGS)
 Automated insulin delivery (AID)
 DIY loop Other (please specify)

If Other, please specify: _____

Total Daily Insulin Dose (average over past 14 days): _____

Total Daily Basal Dose (average over past 14 days): _____

External barriers influencing ability to use MDI or insulin pump: *(Select One)*

- Inadequate supports in school Financial barriers
 Currently not meeting ADP criteria for insulin pump
 Pump start wait list Unsure Other None

Is the patient prescribed Biguanides?:

- (Select One)* Yes No Unknown

Is the patient prescribed a DPP-4 inhibitor?:

(Select One) Yes No Unknown

Is the patient prescribed a GLP-1 agonist?:

(Select One) Yes No Unknown

Is the patient prescribed a SGLT2 inhibitor?:

(Select One) Yes No Unknown

Is the patient prescribed an insulin secretagogue?:

(Select One) Yes No Unknown

Please list any other oral diabetes medication not listed above which the patient is taking: _____

ADVERSE EVENTS

Number of severe hypoglycemic episodes since last visit: _____

Was an ER visit associated with the severe hypoglycemic event: (Select One) Yes No Unknown

Number of Diabetic Ketoacidosis (DKA) episodes since last visit: _____

Number of hyperglycemic hyperosmolar syndrome (HHS) Episodes since last visit: _____

DIABETES-ASSOCIATED HEALTH CONDITIONS

AUTOIMMUNE CONDITIONS

Date of Thyroid test: dd / mm /yyyy

Thyroid Stimulating Hormone (TSH) level: _____

Does the patient have positive thyroid peroxidase antibodies: (Select One)

Positive Negative Unknown Not tested

Does the patient have positive thyroid anti-thyroglobulin antibodies?: (Select One)

Positive Negative Unknown Not tested

Indicate if the patient has autoimmune hypothyroidism:

(Select One) Yes-being monitored/not on Thyroxine

Yes-on thyroxine No

Indicate if the patient has hyperthyroidism:

(Select One) Yes No Unknown

Was the patient screened for celiac disease for this visit?

(Select One) Yes No Unknown

Date of celiac disease screening: dd / mm /yyyy

Indicate if the patient has celiac disease:

(Select One) Yes No Unknown

Does the patient have autoimmune adrenal insufficiency (Addison's Disease)?: (Select One) Yes No Unknown

Date of autoimmune adrenal insufficiency (Addison's Disease) diagnosis: dd / mm /yyyy

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COMORBID CONDITIONS

Indicate if the patient has metabolic dysfunction-associated steatotic liver disease (MASLD):

(Select One) Yes No Unknown

Date of metabolic dysfunction-associated steatotic liver disease (MASLD) diagnosis: _____

Indicate if the patient has Polycystic Ovary Syndrome (PCOS): (Select One) Yes No Unknown

Date of Polycystic Ovary Syndrome (PCOS) diagnosis:

dd / mm / yyyy

Indicate if the patient has Obstructive Sleep Apnea (OSA):

(Select One) Yes No Unknown

Date of Obstructive Sleep Apnea (OSA) diagnosis:

dd / mm / yyyy

DIABETES-ASSOCIATED COMPLICATIONS

Has retinopathy screening been performed in the last 12 months? (Select One) Yes No Unknown

Date of retinopathy screening: dd / mm / yyyy

Does the patient have Diabetic Retinopathy or Maculopathy? (Select One) Yes No Unknown

Date of Diabetic Retinopathy or Maculopathy Diagnosis:

dd / mm / yyyy

Date of last kidney function test: dd / mm / yyyy

Urine albumin creatinine ratio (ACR) result: _____

Urine albumin excretion rate (AER) result (mg/mmol): _____

Does the patient have persistent albuminuria? (Select One)

Yes No Unknown

Is patient taking an antihypertensive medication?: (Select One)

Yes No Unknown

Is the patient taking a lipid lowering agent: (Select One)

Yes No Unknown

Date lipid test was completed: dd / mm / yyyy

Total cholesterol measure in mmol/L: _____

Triglycerides measured in mmol/L: _____

High density lipoproteins (HDL) measured in mmol/L: _____

Low density lipoproteins (LDL) measured in IU/L: _____

Non HDL-C in mmol/L: _____

Alanine aminotransferase (ALT) level measured in IU/L: _____

Date of ALT test: dd / mm / yyyy

Aspartate aminotransferase (AST) level measured in IU/L: _____

Date of AST test: dd / mm / yyyy

Was neuropathy screening performed at this visit: (Select One)

Yes No Not applicable

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MENTAL HEALTH

Mental health diagnosis: *(Select All That Apply)*

- Depression Anxiety
- Self-Injurious / Self-harm / Suicidal behaviors
- Diabetes distress Disordered eating
- Disruptive behavior disorder ADHD
- Other mental health diagnosis, please specify (free text)
- Prefer not to answer

If Other, please specify: _____

Psychological health treatment: *(Select All That Apply)*

- Internal diabetes mental health team (e.g., social worker, psychologist)
- Intern hospital-based mental health provider (e.g., therapist, psychologist, psychiatrist)
- External/community mental health provider (e.g., therapist, agency, psychologist, psychiatrist, primary care)

Was psychological screening completed?

(Select One) Yes No Unknown

Date of psychological screening: / /

Indicate what tool was used in the psychological screening:

What were the psychological disorder screening actions?:

(Select All That Apply)

- None-no psychological concerns identified
- Internal referral diabetes mental health team (e.g., social worker, psychologist)
- Internal referral to hospital-based mental health provider (e.g., therapist, psychologist, psychiatrist)
- External referral to community mental health provider (e.g., therapist, agency, psychologist, psychiatrist, primary care)
- Referral to emergency department (e.g., inpatient psychiatric hospital evaluation)
- Other, please specify

If Other, please specify: _____

SOCIAL DETERMINANTS OF HEALTH (SDOH)

Does the patient have a primary care provider?

(Select One) Yes No Unknown

Is the patient eligible for government insurance?: *(Select One)*

- OHIP+ Ontario Disability Support Program (ODSP)
- Ontario Disability Support Program (ODSP) Others
- None Unknown

Does the patient have any additional supplemental or private health insurance?:

(Select One) Yes No Unknown

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How is the patient paying for rtCGM/isCGM/FGM?:

(Select All That Apply)

- ACSD (Assistance for Children with Severe Disabilities)
- ADP (Assistive Devices Program)
- Government insurance (other)
- Private insurance Out of pocket
- Not applicable Unknown

Does the patient/family household experience difficulty paying for basic needs?: *(Select One)*

- Yes No Unknown Prefer not to answer

Is the patient rationing medications and or diabetes supplies (e.g., insulin, needles, pump, CGM...etc):

(Select One)

- Yes-rationing quarterly
- Yes-rationing monthly
- Yes-rationing weekly or more
- Prefer not to answer
- Unknown
- Never/not applicable

What language(s) does the patient / family feel most comfortable speaking with their health care provider?

(select all that apply):

- English (Canadian Official Language)
- French (Canadian Official Language)
- Albanian Amharic Arabic
- ASL (American Sign Language)
- Bengali Bulgarian Burmese Georgian
- Greek Cantonese Czech Dari
- Farsi Gujarati Hausa Hebrew
- Hindi Hungarian Italian Karen
- Korean Mandarin Nepali Pashto
- Polish Portuguese Punjabi Rohingya
- Romanian Russian Serbian Slovak
- Somali Spanish Swahili Turkish
- Twi Ukrainian Tagalog Tamil
- Thai Tibetan Tigrinya
- Taishanese/Toishanese Urdu
- Vietnamese Other language
- Unknown Prefer not to answer

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Which of the following best describes the patient's racial group(s)? *(Select all that apply):*

- Black (e.g., African, Afro-Canadian, Afro-Caribbean, Afro-Egyptian, etc.)
- East Asian (e.g., Chinese, Korean, Japanese, Taiwanese, etc.)
- Latin American (Hispanic or Latin American descent)
- Middle Eastern, Arab or West Asian (e.g., Afghan, Egyptian, Iranian, Lebanese, Persian, Turkish, Kurdish, etc.)
- South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan, etc.)
- Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc.)
- White (e.g., European descent)
- Another race category
- Unknown Prefer not to answer

Does the patient have or identify as having a disability? *(Select all that apply):*

- Physical disability Sensory disability (e.g., hearing, vision)
- Intellectual disability Learning disability
- Autism Spectrum Disorder (ASD)
- Non-ASD developmental disability
- None Other Unknown Prefer not to answer

Was the patient born in Canada? *(Select One)*

- Yes No Unknown Prefer not to answer

If no, when did they arrive?: *(Select One)*

- Less than 5 years ago 5 to 9 years ago
- 10 years ago or more Unknown Prefer not to answer

TRANSITION, TRANSFER AND MORTALITY

Referral to adult provider sent: *(Select One)*

- DEP Adult Endocrinologist General Internist
- Primary Health Care Provider
- Other adult services (specify)
- No Unknown

If Other, please specify: _____

Date of last PDEP visit prior to transition: dd / mm /yyyy

First visit date with adult diabetes provider: dd / mm /yyyy

TRANSFER

Type of service patient has been transferred to: *(Select One)*

- PDEP Ontario PDEP outside of Ontario

MORTALITY

Date of patient's death: dd / mm /yyyy

Cause of death: *(Select One)* DKA Hypoglycaemia

- Not diabetes related Unknown