Provincial Council for Maternal and Child Health

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Ontario Paediatric Diabetes Network

PRACTICAL GUIDE FOR TRANSITION TO ADULT DIABETES CARE

OCTOBER 2016

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INTRODUCTION

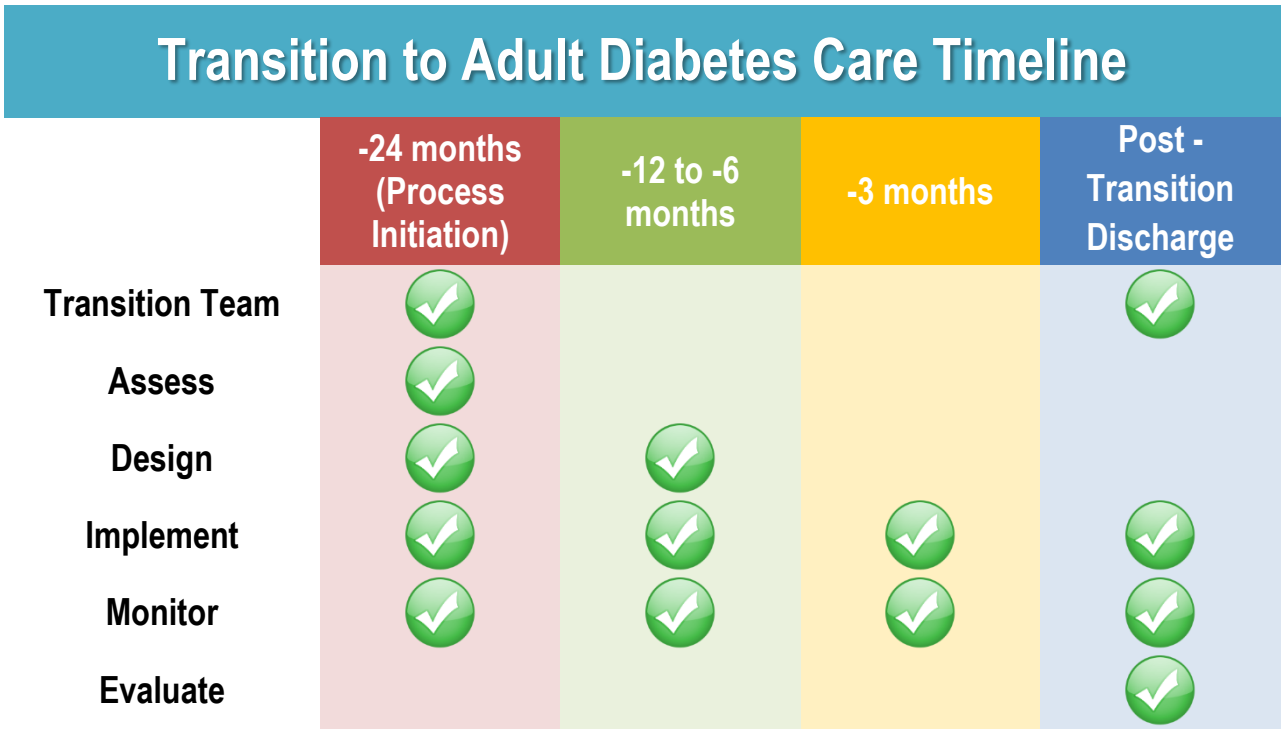
Transition to Adult Care

For adolescents and young adults living with diabetes, transitioning from paediatric to adult healthcare is instrumental to both their transition to adulthood and to their journey as a patient navigating the healthcare system. Research has shown that adolescents and young adults with diabetes transitioning to adult healthcare services are at a higher risk of developing diabetes-related complications and being lost to follow-up care (Spaic, et al., 2013). Furthermore, patients, families and healthcare providers have reported that the issues they encounter during this period of transition are often not addressed in a timely or organized manner, and can have a significant impact on the provision and continuity of care. The Ontario Paediatric Diabetes Network (PDN) established the Transition to Adult Care Working Group to address these issues and develop a comprehensive set of evidence-informed recommendations for a more structured and consistent provincial approach to transitioning youth living with diabetes from paediatric to adult diabetes care. The recommendations are based upon the concept of transition as a process, and take into consideration the needs of this patient population and the resources that currently exist within the Ontario healthcare system.

ABOUT THE ONTARIO PAEDIATRIC DIABETES NETWORK

Our Goal:
To ensure the best possible health outcomes for children and youth affected by diabetes across the province.

The Ontario Paediatric Diabetes Network (PDN) is a collaborative network comprised of the thirty-five specialized paediatric diabetes education programs (PDEPs) located in communities across the province of Ontario. The Provincial Council for Maternal and Child Health oversees the coordination of the PDN by fostering system improvement, providing opportunities for professional development, promoting linkages between the PDEPs, assisting with the development and dissemination of resources and guidelines, promoting consistency in standards of practice, and providing individual program support.



ABOUT THIS PRACTICAL GUIDE

This document has been developed to help guide a smooth and comprehensive transition for youth from paediatric to adult diabetes care by outlining specific activities, defining timelines and providing access to recommended tools. This practical guide is based upon the TAHS Discharge Planning Implementation Tool, which was developed by PCMCH's Transition to Adult Health Services (TAHS) Discharge Planning Implementation Work Group. The PDN Transition to Adult Care Working Group tailored the TAHS Discharge Planning Implementation tool for the paediatric diabetes population in Ontario, reflecting the recommendations put forth by the PDN Transition to Adult Care Working Group.

Please note that while this practical guide outlines discrete time periods, these are a guide for activities that will in fact be iterative and on a continuum over the 24 months leading up to the patient's 18th birthday and transition to adult diabetes care.

At a program level, it is important to consider the current workflow, processes, policies and procedures, decision support analyses and other enablers that could be used, modified or developed to enable the implementation of these discharge planning activities. Consider the following:

- Is there a policy or procedure in our organization regarding discharging an adolescent from paediatric care to adult services?
- Would it be possible to flag a clinic visit as a discharge consultation in order to track the number of patients who were provided a formal discharge planning discussion?
- How do we ensure that the discharge summary is shared with the patient and or family so they can be informed, and inform adult providers who may for some reason not have the discharge summary immediately available for the patient visit?
- Can we create or do we have a space within the discharge summary for patients to identify their goals for health and social development?

GUIDANCE TIMELINE

Process Initiation: 24 months before transition discharge (< or = 16 years old)

Transition team	A minimum of 24 months before the person's 18th birthday it is recommended that the paediatric diabetes team identifies a healthcare provider (HCP) as the primary transition lead or facilitator for the patient
Assess current state and gaps	**Identify:** • A primary care provider (not a paediatrician) • Primary medical supports (specialists) • Community supports; regional and or provincial • Supports: financial, social and or educational **Determine if there are:** • Organizational transition policies in place to guide transition processes • Transition clinics, specific to diabetes, or general youth transition • If there is no transition clinic in the organization, schedule a clinic visit to discuss the initiation of transition; every HCP needs to discuss the transition – in addition the HCP may be supported by a transition clinic • Have a discussion about consent and capacity; start to prep child and family for the difference between family-centered and patient-centered care. Begin to encourage independence /autonomy…. At this point it should be a discussion. **Identify gaps and issues between:** • Patient and family readiness • Current paediatric services versus available adult services • Develop a plan to address readiness gaps for patient and for family
Design individualized state	• **At every point of contact with the child and family, assess readiness using readiness tools for both the patient and the parents.** • Link patient and family to resources (developmental and chronic disease-focused)

Implement	☐ Paediatric HCP transition lead will aim to meet with the patient at most clinic visits (a minimum of 2 visits per year
	☐ Assess readiness by implementing the following:
	  • "Moving On…" With Diabetes - Diabetes Knowledge & Skills Self-Assessments (13-16 yrs) and/or
	  • "Moving On…" With Diabetes - Diabetes Educator Transition Checklist and/or
	  • Endocrine Society's Provider Assessment of Patient Skill Set and/or
	  • Young Adult Transition Guide
	☐ Help patient develop age-appropriate skills, independence and self-efficacy in managing their diabetes by implementing the following:
	  • Help Them Grow...so They're Good 2 Go" Diabetes Timeline or
	  • Keys to Independence… Stage 3 (Age 13-15) Checklist
	☐ Help patient complete Good to Go Passport, an online tool developed at SickKids to document key health information on a form that can be printed and folded into a wallet sized document; it includes the three sentence summary of health condition. If patient does not have a primary care provider, patient and or family supported in finding one.
	☐ Health update sent to (new) primary care provider
	☐ Document transition assessment and discussion in chart

Monitor	• Record the contacts and completion of the relevant tools in the paper or electronic chart • Document refusal of contact with the Transition HCP or refusal to complete the tools
Evaluate	

GUIDANCE TIMELINE

12-6 months before transition discharge (< or = 17 years old)

Transition team	
Assess	

Design	• **Develop "a transition to adult health services document" that will provide an overview of the:**
	  • Transition process, issues and mitigation strategies
	  • Social, educational, developmental status and supports
	  • A comprehensive discharge summary, such as the Endocrine Society's Clinical Summary for New Health Care Team, with standard elements provided by all disciplines currently involved in care
	  • Standard formatting recommended to improve clarity of communication for reader
	  • Discharge summary sent to the adult diabetes physician, adult diabetes education team, the patient's primary care provider and copy given to patient

Implement	**At 12 months before transition discharge:**
	☐ Patient and or family to complete readiness assessment tools by implementing the following:
	  • Moving On…With Diabetes" Diabetes Knowledge & Skills Checklist (17-18 yrs) and/or
	  • "Moving On…" With Diabetes - Diabetes Educator Transition Checklist and/or
	  • Endocrine Society's Provider Assessment of Patient Skill Set and/or
	  • Young Adult Transition Guide
	☐ Continue to help patient develop age-appropriate skills, independence and self-efficacy.
	  • Help Them Grow...so They're Good 2 Go" Diabetes Timeline or
	  • Keys to Independence… Stage 4 (Age 16-17) Checklist)
	
	At 6 months before transition discharge:
	☐ Send referrals for adult diabetes care
	☐ Complete and include the Endocrine Society's Clinical Summary for New Health Care Team or equivalent comprehensive discharge summary that includes recommended elements
	☐ Document activity and confirm plans for adult diabetes care:
	  • Name of provider / service
	  • Contact information for provider / service
	  • Location address
	  • Transportation to get to provider / service
	☐ Implement the Modified Transition Teaching Content Template to guide the formal discharge discussion

Monitor	• Record the contacts and completion of the relevant tools in the paper or electronic chart • Document refusal of contact with the Transition HCP or refusal to complete the tools
Evaluate	

GUIDANCE TIMELINE

3 months before transition discharge (< 18 years old)

Transition team	
Assess	
Design	
Implement	**At the patient's last visit with the paediatric diabetes team:** ☐ Give written and verbal information to patient and family confirming all adult providers and services arranged: • Name of provider / point of contact at service • Date and time of appointment • Location of provider ☐ Provide patient with a copy of the completed discharge summary, such as the Endocrine Society's Clinical Summary for New Health Care Team ☐ Ensure written documentation of transition visit in chart ☐ Ensure family knows of the primary HCP transition lead to contact if problems arise ☐ Document and confirm with patient (and family if appropriate) that the paediatric diabetes team is available for care if required until their first visit with the adult provider
Monitor	• Record the contacts and completion of the relevant tools in the paper or electronic chart • Document refusal of contact with the Transition HCP or refusal to complete the tools
Evaluate	

GUIDANCE TIMELINE

Post-Transition Discharge

Transition team	**To ensure smooth transition:** • **Paediatric diabetes team:** let the patient and family know that the primary HCP transition lead can be contacted if problems arise prior to establishing the relationship / first visit with the adult provider • **Adult diabetes team:** it is recommended that a HCP is designated as the point person from the team who will begin to build and carry forward the relationship with the patient.
Assess	
Design	

Implement	Implementation of the Patient Follow-Up Care Pathway:
	☐ Adult diabetes team to send a mail-out information package to the patient. This package should include:
	  • An introductory letter with instructions for the patient's first visit
	  • Information about the adult diabetes team, such as a brochure
	  • A requisition for bloodwork
	☐ Adult diabetes team makes a reminder call to the patient. This should be done by the designated HCP.
	  • Note: Having point of care testing available means that the patient does not have to make a second trip for bloodwork. The patient's visit with the adult endocrinologist will not be useful until they have their bloodwork.
	☐ If an appointment is missed, the adult diabetes team contacts the patient to reschedule via telephone or email.
	☐ A letter dictated by the adult endocrinologist is sent to the patient, and the referring PDEP and the patient's primariy care provider.
	  • Note: The letter emphasizes the importance of follow-up in diabetes management and is written in a tone that empowers the patient as opposed to being threatening or punitive.
	☐ Repeat the last two steps until the patient is seen by the adult diabetes team. If repeated attempts are unsuccessful, adult diabetes team to enlist the help of the PDEP.
	  • Note: This action should be aligned with the organization's policies.
	☐ After the patient is seen by the adult diabetes team, the team closes the loop with the PDEP, and the patient's primary care provider. The communication should include a detailed note and care plan going forward.

Monitor	• Primary HCP transition lead to contact patient within three months after discharge to confirm first visit to adult provider(s) has taken place. Based on the phone call consider whether further action is required.
Evaluate	• Plan to gather feedback from patients and family on transition process benefits and gaps (organization level) • Further provincial evaluation activity will be considered within the context of PCMCH strategic work review and strategic planning • **The frequency of contacts, completion of tools and knowledge and skills assessment will be evaluated in relation to A1C and adult clinic attendance in the first year after discharge form pediatric care**

Transition Tools and Additional Resources

Help Them Grow...so They're Good 2 Go" Diabetes Timeline

Keys to Independence Booklet

"Moving On…" with Diabetes: Adolescent Transition Resources

Young Adult Transition Guide

Good 2 Go Transition Program -- MyHealth Passport

Endocrine Society's Clinical Summary for New Health Care Team

Endocrine Society's Provider Assessment of Patient Skill Set

Modified Transition Teaching Content Template

PDN Patient Follow-up Care Pathway

PDN Transition to Adult Care Working Group Recommendations Report developed by the Ontario Paediatric Diabetes Network through the Provincial Council for Maternal and Child Health

Transition to Adult Health Services resources developed through the Provincial Council for Maternal and Child Health

Modified Transition Teaching Content Template

(Adapted from the Modified Transition Teaching Content Template developed by the London Health Sciences Centre)

This content is to be covered in the 6 months prior to transfer of diabetes care.

1. The importance of transitioning well	
• Patient's future health and well-being, as well as the importance of chronic disease management	
• Risks involved in not connecting with an adult diabetes centre	
• Consider a tool to deal with change	
2. Differences between expectations and structure between pediatric and adult visits	
• Philosophy of family centred care vs autonomy of young adult, parents/family members may attend but you are in charge, take responsibility for knowing A1C	
• Team approach vs. separate appointment with DEC	
• Difference in appointment schedule: 3mth vs 6-9 months (outside the study period) (as compared to 4 times per year as a paediatric patient)	
• Be in charge of your clinic appointment: no reminder letters or calls, if you miss appointment-you are responsible for re-scheduling (may take up to 6 months for next appointment)	
• Length of appointment (30-90 minutes for first visit)	
• Access to healthcare team and information by family members (parents need to know that they will need their young adults patients permission to contact their health care team)	
• Do you wear a Medic Alert?	
• Housekeeping tips at Adult Centre: location, parking areas and costs, etc.	
• Think about setting goals for yourself!!!	
3. Differences in medical expectations for clinic visits	
• Review of diabetes regime (is this the best for you?), *bring record log, glucometer, and any medications you are taking endocrine appointment, will have physical including BP, heart lungs, injection sites and foot exam.	
• Greater focus on complication screening - Discuss micro (eyes, kidney, lower extremity nerve damage, foot problems) and macro (stroke, heart disease, high BP and foot problems) complications of diabetes	
• Greater focus on tighter control-A1C <7	
• Greater emphasis on carb counting vs. sliding scale	
• Focus on control of blood sugars but also greater focus on control of BP, cholesterol and weight.	
• Assess patient's knowledge and understanding of long term complications associated with diabetes and how to avoid them	
4. Age-related themes and concerns	
• Driving "5 to Drive" assess patient's diabetes habits with driving (i.e. checking BG before driving, access to treatment for lows etc.)	
• Smoking- does patient smoke? Is he aware of health risks?	
• Uses of alcohol - does patient consume alcohol? How often? How many drinks? Binge drinking? Assess patient's knowledge of effect of alcohol and diabetes, review safety practices around drinking	

• Sex, birth control, pregnancy-assess patient's knowledge and possible need for prescription	
• Drugs, tattoos, body piercing	
• Leaving home, living in residence (what to tell your roommate), work and future careers, financial issues (insurance coverage – how to access help)	
• Making sure you know how to access health care or help for diabetes when away at school	
• Travelling/Vacations	
• Importance of having a primary care provider (family MD) for general health	
5. Information that should be provided to the young adult at the last visit to their paediatric diabetes program *Please note: The patient's last visit to their paediatric diabetes program should be labelled and identified to the patient that this is the last transfer meeting and care should be taken to ensure that the key topics above have been reviewed. This is a summary and formal ending to the pediatric diabetes care.*	
• Laboratory form and map for external laboratory	
• Bio-sketch of adult endocrinologist given	
• Directions to adult diabetes clinic	
• Adult appointment should be made at the penultimate pediatric visit (so patient leaves with date, time, name and place for adult endo appointment (adult clinic should notify the patient as well as the peds clinic of the date/time of the first appointment to adult care)	

• Tool(s) for the patient that including (at a minimum):
  ○ Short summary of diabetes diagnosis (date)
  ○ Last A1c
  ○ Current therapy
  ○ If screened for complications (may have a copy of flow sheet)
Recommended tool: The Endocrine Society's Clinical Summary for New Health Care Team - https://www.endocrine.org/~/media/endosociety/Files/Education/Practice%20Management/Type%201%20Updated%20March%2012%202014/Clinical_Summary.pdf	

Patient Follow-up Care Pathway

Step 1: Patient is discharged from the paediatric diabetes education program (PDEP) with the appropriate medical summary, a referral to the adult diabetes team*, information about the providers, and a date for their first visit. A letter with this information is also sent to the patient's primary care provider.
Note: Where appropriate, some centres conduct transition evenings/meet and greets between patients and the adult diabetes team to assist with bridging the divide.

Step 2: Adult diabetes team sends a mail-out information package to the patient.
Note: This package should include:
1. An introductory letter with instructions for the patient's first visit
2. Information about the adult diabetes team, such as a brochure (see example below)
3. A requisition for bloodwork

Step 3: Adult diabetes team makes a reminder call to the patient. This should be done by a point person from the team who will begin to build and carry forward the relationship with the patient.
Note: Having point of care testing available means that the patient does not have to make a second trip for bloodwork. The patient's visit with the adult endocrinologist will not be useful until they have their bloodwork.

Step 4: If an appointment is missed, the adult diabetes team contacts the patient to reschedule via telephone or email.

Step 5: A letter dictated by the adult endocrinologist is sent to the patient, the referring PDEP and the patient's primariy care provider.
Note: The letter emphasizes the importance of follow-up in diabetes management and is written in a tone that empowers the patient as opposed to being threatening or punitive.

Step 6: Repeat steps 4 and 5 until the patient is seen by the adult diabetes team. If repeated attempts are unsuccessful, adult diabetes team to enlist the help of the PDEP.
Note: This action should be aligned with the organization's policies. Contigencies for consideration have been included below.

Step 7: After the patient is seen by the adult diabetes team , the team closes the loop with the PDEP, and the patient's primary care provider. The communication should include a detailed note and care plan going forward.

The adult diabetes team consists of adult diabetes education programs (DEPs) and adult endocrinologists. In some circumstances, an adult endocrinologist may not work within an adult DEP. If this is the case, a separate referral to the adult endocrinologist is required.

Examples and Contingencies

Step #2: Example of an introductory letter, from St. Michael's Hospital

St. Michael's
Inspired Care.
Inspiring Science.

Date: _____

We have received a referral for you to attend the **Young Adult Diabetes Clinic** at St. Michael's Hospital for an appointment with Dr. Andrew Advani (Endocrinologist) and the Health Care Team. The clinic is located in the **St. Michael's Health Centre across from the main hospital at 61 Queen Street East, 7th floor.**

Your appointment is schedule for: Date: _____ Time: _____

If you cannot attend this appointment, please call our booking office at 416 867-3679. You will need to complete fasting blood work at least two weeks before you see the Endocrinologist. For your first time to our clinic, we request that your blood work be done at our lab. Please contact us at 416 867-3679 if there are extenuating circumstances that would make it difficult for you to come down to our hospital for the blood tests so that alternative arrangements can be made.

PLEASE READ THE FOLLOWING INSTRUCTIONS CAREFULLY:

1 WEEK BEFORE YOUR APPOINTMENT, YOU SHOULD HAVE A FASTING BLOOD TEST:

- A requisition for your blood work is enclosed with this letter.
- You should fast (nothing but water) for 12 hours before the test. Bring a snack or breakfast to eat after you have had your blood taken at the lab.
- The lab is located on the ground floor of St. Michael's Health Centre, 51 Queen Street East and is open from 7:30 am to 3:30 pm. Please bring the enclosed lab requisition. This requisition cannot be used at an outside lab.
- You should bring your health card with you.

ON THE DAY OF YOUR APPOINTMENT:

- Bring your Ontario Health Card
- Eat breakfast and lunch and take your medications as usual.
- It is helpful if you bring all of your medications with you and if you test your blood sugar levels at home, please bring both your meter and your log book/records.
- You may want to bring a snack in case your appointment is longer than expected. While it is likely to be shorter, the total time for your first visit may be 2-3 hours.

WE LOOK FORWARD TO SEEING YOU FOR YOUR APPOINTMENT

Step #2: Example of a brochure, from St. Michael's Hospital

St. Michael's
Inspired Care.
Inspiring Science.

YOUNG ADULTS CLINIC

St. Michael's Hospital
61 Queen Street East, Toronto, ON

Welcome to St Michael's Hospital. We understand that turning 18 is both an exciting and challenging time in your life. It is a time when there are changes in school, work and your diabetes care.

One of these changes is transitioning to a Young Adult Diabetes Clinic. Our goal is to make the transition smooth, and at the same time encourage and empower you to manage your diabetes.

OUR TEAM


Dr. Andrew Advani
Endocrinologist


Jane Mason
Diabetes Nurse


Sandi Williams
Registered Dietitian


Suela Cela
Social Work

ALSO AVAILABLE


Psychiatrist

Our goal is to help you learn to live realistically with diabetes.

You have the right to:	We encourage you to:
• Make your own decisions • Meet with your healthcare provider on your own and • Ask questions so that you understand your diabetes and treatment options	• Attend your appointments • Bring your blood sugar records with you • Have your blood-work done as requested • Share with the team any issues and concerns you have that may or may not impact on your diabetes care

How will our clinic be different?

Transition is an opportunity for young adults to establish independence from family. While we welcome family members to be involved in your care, our aim is to help you learn to manage your diabetes on your own. Information about your health, your appointments and your care is confidential and only available to you.

We will ensure that you have a primary contact within the clinic with whom you can communicate by email or phone.

Booking Line:
416 867-3679

We have regular clinic days and are also available in between clinic visits. Our hours are 8:00 am to 4:30pm.

Our Location and Visit Specifics

St. Michael's Health Centre is located at 61 Queen Street East, across from the main hospital.

We are close to Ryerson University, George Brown and University of Toronto. We are next door to the Eaton Centre and the Queen Street Subway.

On your first visit you will meet with the endocrinologist and the rest of the team.

Follow Up Visits are scheduled every 3-4 months with the endocrinologist. You can schedule individual appointments with the Diabetes Nurse, Dietitian, Social Worker or Psychiatrist at any time outside of the clinic and between your visits with the endocrinologist. Your Health Care Team can help you work on improving your diabetes management and fitting diabetes into your busy life.

We look forward to working with you to help you manage your diabetes and act as a resource for you as you move along the journey into adulthood.

Step #6 – Consider the following contingencies when access to an adult endocrinologist or adult diabetes education program (DEP) is difficult:

- Send referral earlier to ensure the patient can access and adult provider in the recommended time frame following their paediatric discharge.
- Paediatric diabetes teams can see the patient for an extra visit if necessary until a visit with the adult diabetes team can be scheduled.
- Pending models of the PDN Outreach Linkages Working Group, patients may be able to see an adult endocrinologist over OTN until they can be attached to a more local endocrinologist.
- An interim solution for diabetes management is for the patient to be seen by their primary care provider. However, many patients may not have a primary care provider and some primary care providers may not be comfortable with the management of type 1 diabetes. (Asking whether or not the patient has a primary care provider should be included as part of the discharge planning).
- Adult diabetes teams should try to be welcoming to patients lost to follow-up regarding the need for re-referral. Some centres require re-referral after one or two years, yet consideration should be given to not introduce unnecessary barriers.

Feedback

Please let us know if you use this guidance and how useful you found it.
If you are willing to provide helpful feedback to further improve the tool please send it to info@pcmch.on.ca

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