


Patient and family perspectives of a Pre-Transition Visit in a paediatric tertiary care diabetes clinic

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ABSTRACT

Introduction The need to better prepare youth with type 1 diabetes for the transition from paediatric to adult care is evident. As part of a regional quality improvement initiative, a novel Pre-Transition (Pre-T) Visit was developed and piloted at a paediatric tertiary care centre in January 2018 for patients aged 15–18 years to capture the status of their self-management skills, introduce transition tools and identify self-care goals and knowledge gaps to be addressed prior to transition.

Purpose To evaluate patient and family satisfaction, visit relevance and patient engagement with a novel Pre-T Visit.

Methods From May 2019 to March 2020 a survey was offered to all youth who attended a Pre-T Visit and their parent(s)/caregiver(s). Patient and family satisfaction with, relevance of and engagement with the Pre-T Visit were evaluated using a 5-point Likert scale. Multivariable regression was used to assess patient factors associated with patient level satisfaction.

Results Of the 63 youth who participated in a Pre-T Visit, 60 completed the survey. Mean age (SD) of participants was 16.7 (0.8) years; 47% were female. Mean (SD) haemoglobin A1C (A1C) was 8.2% (1.8). Patients reported high levels of satisfaction (95% quite or extremely satisfied) that were consistent across age, A1C, gender and disease duration. Visit relevance and engagement were also rated highly by youth. Parent participants (n=27) also reported high levels of satisfaction (89% quite or extremely satisfied) and relevance.

Conclusions Pre-T Visits were rated highly by patients and their parents. Their impact on glycaemic control and health outcomes following transition requires further study.

INTRODUCTION

The transition from paediatric to adult care can be challenging for emerging adults as they establish their autonomy and personal identity during this unique developmental period¹ while balancing the daily demands of the disease. For individuals with type 1 diabetes (T1D), as a result of both physiological and psychological factors, this stage is associated with deterioration in glycaemic control, increased diabetes complications and hospitalisations, decreased adherence to diabetes-related management tasks, decreased clinic

attendance, increased risk-taking behaviours and increased risk of psychiatric disorders.^{2–8}

Furthermore, gaps in care during the transition period are specifically associated with an increased risk of ketoacidosis or death.⁴ Herein, the term ‘transition’ refers to the transition from paediatric to adult diabetes care. This transition necessitates greater personal responsibility for diabetes care at a time when there are many competing priorities and developmental challenges which can impact diabetes management and control.⁹

A variety of identified factors may inhibit a successful transition process, leading to poor outcomes. Many patients in the transition age group have not discussed transition with their current care provider, have not been given the name and contact information for an adult care provider and describe a lack of transition preparation.^{2 10–14} Worsening glycaemic control during transition suggests suboptimal self-management at a time when there is an expectation that youth will function more independently. The years leading up to transition provide an opportunity to address self-management skills.

Despite initiatives aimed at improving the process and experience for adolescents and young adults with T1D, and technological innovation to improve glycaemic control, health outcomes in this age group remain worrisome with a significant increase in mean haemoglobin A1C (A1C) over the last decade.¹⁵ Interventions to address this issue have been evaluated with varying success. These include assessments of transition preparation, young adult clinics, transition clinics and the use of transition care coordinators.^{16–22} Outcomes of interest for transition-related interventions often include measures of glycaemic control, diabetes-related complications, clinic attendance and patient experience measures (including satisfaction). While these interventions to support transition

often initially improve patient satisfaction, glycaemic control and clinic attendance, impact wanes once the interventions are complete^{20–22} and indices of healthcare delivery and outcomes remain suboptimal.⁴¹⁵ Insufficient focus by T1D care teams on preparation for independent management and adult care likely contribute to these findings as self-management competency is associated with readiness to transition.²³ A focus on interventions that support development of and confidence in individual self-management skills for youth with T1D to help them to maintain or improve glycaemic control as their independence increases may result in more sustained impact. To do this, it is critical to understand the gaps in patient education and self-management skills so that education and support can be tailored to individual needs.

Improving transition care has been identified as a critical element of optimising healthcare delivery internationally.^{24 25} The transition process should begin in early adolescence and provide healthcare that is coordinated, uninterrupted and developmentally appropriate with a focus on self-management.^{26–28} In keeping with these recommendations, in 2016 a comprehensive set of recommendations for a more structured and consistent provincial approach to transition was published.²⁹ Subsequent implementation of these recommendations at our centre included the creation of the Pre-Transition Visit (Pre-T Visit). The purpose of the Pre-T Visit is to capture the status of the youth's self-management skills (an element of transition readiness) and introduce tools for transition so that specific goals and gaps in knowledge can be identified and addressed during the pre-transition/transition period.

Transition for youth with T1D remains a concern and likely requires multiple interventions and adjustments to the structure of care. No single intervention has proved to be universally helpful with benefits maintained beyond the immediate intervention period. The novel Pre-T Visit was designed to address care delivery recommendations in affiliation with the Diabetes Learning Center (DLC), our longitudinal diabetes education programme, within existing clinic resources. The Pre-T Visit is a step towards personalised transition preparation, allowing for identification of knowledge gaps and goals for optimising self-management skills which should result in more sustained health benefits. The primary objective of the study was to evaluate patient satisfaction with the Pre-T Visit in order to inform improvements of this novel programme.

METHODS

Setting and context

In our paediatric diabetes clinic, individuals with T1D transition once they are 18 years old, which aligns with local and regional care policies. The novel Pre-T Visit was an outcome of a transition implementation plan designed to address the prioritised provincial recommendations.²⁹ The implementation plan was developed by a working group consisting of multidisciplinary paediatric

and adult care providers (physicians, educators, social workers), administrators and patient/family representatives. The Pre-T Visit primarily aims to capture the status of a set of standardised skills in each youth in order to help guide future self-management education and self-efficacy support within our diabetes programme. Importantly, no extra funding or resources were allocated for the development or implementation of this intervention which required restructuring of existing clinic flow and staff responsibilities. No care provision resources were eliminated to allow for this intervention.

Pre-T Visits were implemented in January 2018 in our clinic and were ongoing until diabetes care became almost entirely virtual in March 2020 due to the COVID-19 pandemic. The Pre-T Visit is a 45 min scheduled appointment with a diabetes educator on the same day as a routine clinic appointment for youth aged 15–18 years. The educators evaluate self-management skills using a templated documentation tool embedded in the electronic health record as well as a guide to help ensure skills are evaluated systematically (online supplemental file 2). Patients are encouraged to independently participate in the visit, and, with youth consent, parents/caregivers are invited to join the youth and educator at the end for a visit summary (ensuring exclusion of any sensitive topics that youth prefers not to share). The visit summary is a verbal synthesis of the youth's transition readiness including three personalised transition-related goals. The visit is offered to as many eligible patients as possible within resource restrictions (one youth per half-day clinic). Youth at the younger end of the targeted age range (closest to 16.0 years) are preferentially selected if multiple patients are eligible in the same clinic to allow for more time to address the gaps while in the paediatric setting. Identified knowledge gaps are then addressed through focused education within the DLC.

Study design

From May 2019 to March 2020, all patients and their parents attending a Pre-T Visit were invited to participate in the study. Patients were eligible if they had a diagnosis of T1D, were followed in the diabetes clinic, and were 15–18 years of age. Patients were excluded if they were unable to consent due to lack of capacity or unable or uncomfortable completing the survey questions in English or French. There was no requirement for minimum duration of diabetes. At the end of the Pre-T Visit, the educator who led the visit introduced the study to the youth and if the youth agreed to learn more, an electronic survey was administered using a clinic iPad provided to the youth. The first screen was an explanation of the quality improvement initiative and (voluntary) option to participate. Once the youth survey was complete, the educator administered the survey to the parent/caregiver in the same way. Participants completed the surveys independently.

Study outcomes

The primary outcome was patient satisfaction with the Pre-T Visit. This was evaluated with one question about overall satisfaction with the visit as well as a combined outcome aggregated across six questions about satisfaction with specific components of the visit. Secondary outcomes included: (a) patient-reported self-engagement with the visit, which was evaluated with two questions, (b) patient-reported relevance of the visit to their own care which was evaluated as a combined outcome aggregated from the answers to six questions about relevance and (c) family-reported satisfaction and relevance with the Pre-T Visit after-visit summary.

Instrument development

Two surveys were developed—one for patients and one for parents/caregivers. Existing literature and study objectives informed the development of the surveys. Surveys were drafted by authors AM and EBG using the New World Kirkpatrick Model,³⁰ revised based on feedback from a survey methodologist, a statistician and two diabetes educators, then piloted with two patients and two parents who participated in Pre-T Visits prior to recruitment. Final versions (online supplemental file 1) incorporated their feedback. Data from these individuals were not included in the analysis.

The patient survey consisted of 20 items assessing satisfaction with, engagement in, and relevance of the Pre-T Visit. There were seven questions pertaining to patient satisfaction where participants were asked to rate their satisfaction with the overall visit, the format of the session, the review of self-management skills, the materials received, the process of identifying self-management goals, the follow-up arranged to review goals and the introduction to transition evening (an interactive event for youth and families to learn about regional adult diabetes programmes and transition services), using a 5-point Likert scale ranging from 'not at all satisfied' to 'completely satisfied'. There were six questions pertaining to patient-reported visit relevance where patients were asked to report relevance of components of the visit to the review of self-management skills, the materials received, the process of identifying self-management goals, the follow-up arranged to review goals and the introduction to transition evening, using a 5-point Likert scale. They were also asked about ideal timing of the Pre-T Visit with respect to patient age.

The parent survey consisted of six questions about their satisfaction with, and relevance of, the Pre-T Visit summary that was shared with them.

Data collection was managed using Research Electronic Data Capture Database.^{31 32}

Data analysis

Baseline characteristics of the study participants were summarised using descriptive statistics, where mean and SD or median and IQR were used for continuous variables as appropriate. Categorical variables were summarised

using frequencies and percentages. To demonstrate the range of overall satisfaction across multiple items and for each of the items separately, a Likert plot was used. A composite outcome score was defined by aggregating satisfaction scores from participants who responded to all six questions (not including the overall satisfaction question). This score may provide a better estimate of satisfaction since it is constructed from individual items and allows for identification of potential factors associated with satisfaction. It can be more reliable than answering a Likert score question about overall satisfaction. Multivariable linear regression, with the composite outcome as a dependent variable, was performed with the aim of identifying potential factors associated with favourable outcome. The independent variables considered in the regression analysis were age, disease duration, gender and A1C on day of visit. The distribution of secondary outcome, relevance score, was illustrated using a Likert plot. Patient-reported engagement, and parent/caregiver satisfaction were described in the form of frequencies and percentages. In order to examine internal validity, consistency among the seven items within patient satisfaction and the six items within patient relevance were evaluated using Cronbach's α coefficient.^{33 34} All analyses were performed using the R statistical software.³⁵

Patient involvement

There was patient and parent representation within the transition working group that designed the Pre-T Visit as a way to address transition recommendations. Patients and families were also involved during the survey design phase. They were asked to pilot the survey and provide feedback with respect to how to make the survey more user friendly and whether the time required to complete it was acceptable.

RESULTS

Survey completion

Sixty-three youth with T1D completed a Pre-T Visit during the study period and 60 (95%) completed the survey (59 in English, 1 in French). Of those who chose not to complete the survey, reasons provided were: 'running out of time' (1), no comment (1), and unclear response (1). The mean age of those who completed a visit was 16.7 years (SD 0.8), 28 (47%) were female and the mean A1C was 8.2% (SD 1.7, range 4.2%–14%). Patient characteristics are displayed in [table 1](#) and did not appear to differ from the clinic population within that age range.

Of the 41 parents/caregivers approached, 27 consented to complete the survey. Of those, 19 (70%) were mothers and 8 (30%) were fathers. Reasons for parents/caregivers not completing the survey were not systematically collected but based on recall of diabetes educators, the physician being ready to see the patient may have interfered with survey completion.

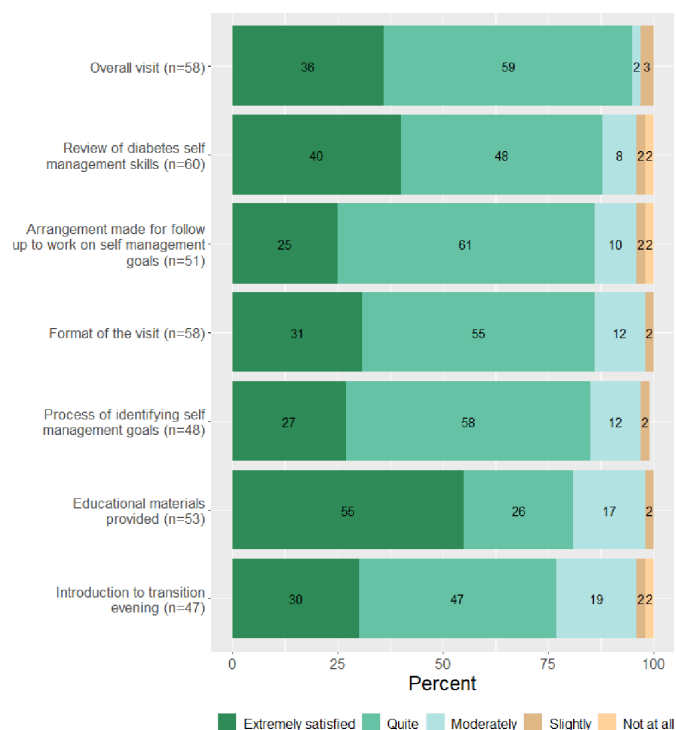
Table 1 Patient characteristics of Pre-T Visit survey participants (who completed survey) and diabetes clinic patients aged 15–18 years (from clinic report February 2019)

| Characteristic | Pre-T Visit participants (n=60) | | | Diabetes clinic patients, age 15–18 (n=209) | | |
|--------------------------|---------------------------------|-----------------|------------|---|----------------|------------|
| | n (%) | Median (IQR) | Mean (SD) | n (%) | Median (IQR) | Mean (SD) |
| Age at visit (years) | | | 16.7 (0.8) | | | 16.6 (0.9) |
| Gender, female | 28 (46.7) | | | 108 (51.7) | | |
| Disease duration (years) | | 6.4 (3.7, 11.2) | 7.3 (4.4) | | 5.6 (2.9, 9.3) | 6.2 (4.3) |
| A1C (%) at the visit | | 7.8 (7.1, 9.2) | 8.2 (1.8) | | 8.2 (7.3, 9.4) | 8.7 (2.1) |

A1C, haemoglobin A1C; Pre-T Visit, Pre-Transition Visit.

Patient satisfaction

Among those participants who answered the survey a small percentage answered questions with the response ‘I don’t know’ (selected a maximum of four times for a particular question (6.7%) or ‘not applicable’ (selected a maximum of nine times (15%) for a particular question (‘How satisfied are you with the process of identifying your top three self-management goals?’)). Results provided are for those who answered with a satisfaction level (figure 1). On a 5-point Likert scale from ‘not at all satisfied’ to ‘extremely satisfied’, the median (IQR) level of satisfaction with the *overall* visit was 4.0 (4.0, 5.0). Twenty-one (36%) patients were ‘extremely satisfied’, 34 (59%) patients were ‘quite satisfied’, 1 (1.7%) was ‘moderately satisfied’ and 2 (3.4%) were ‘slightly satisfied’. The results from Cronbach’s α coefficient show a strong internal consistency among the seven items related to satisfaction ($\alpha=0.79$, 95% CI 0.71 to 0.86), hence suggesting internal validity of the satisfaction measurements.

**Figure 1** Patient satisfaction with aspects of the Pre-Transition Visit.

Only patients who answered all six of these satisfaction items using a satisfaction level were included (39/60). Those who responded ‘I don’t know’ to any of the six items were removed from this specific analysis. The median (IQR) of the composite score was 25.0/30 (24.0, 26.5).

There was a negligible decrease in satisfaction level associated with higher A1C level and longer disease duration. A small increase in satisfaction was also observed for older patients and for females. These differences were not statistically significant nor felt to be clinically significant (table 2).

Patient-reported relevance of the visit

For questions in the relevance section of the survey, the answer ‘I don’t know’ was selected a maximum of seven times for a particular question (13%), and the answer ‘Not applicable’ was selected a maximum of nine times (15%) for a particular question. Results are provided for those who answered with a relevance level on a 5-point Likert scale ranging from ‘not at all relevant’ to ‘extremely relevant’, for various components of the Pre-T Visit (figure 2). In terms of internal validity related to relevance items, the estimated α coefficient shows a moderate to good level of internal consistency ($\alpha=0.57$, 95% CI 0.40 to 0.74).

Patient engagement

Patients were asked how much they participated during the Pre-T Visit on a scale from ‘I did not participate at all’ to ‘I participated a tremendous amount’. The majority (92%) reported participating ‘quite a bit’ or ‘a tremendous amount’, and 6.7% reported participating ‘a little bit’ or ‘some’. Patients were also asked at which age they thought the Pre-T Visit would be most relevant. Fifty-five (92%) selected 16 years and over, of which 43% answered 16 years exactly. Five (8.3%) answered 15 years and under.

Caregiver responses

Twenty-seven caregivers/parents completed the survey following the visit summary, of which 93% were ‘extremely satisfied’ or ‘quite satisfied’ with the Pre-T Visit, and 7.4% were ‘moderately satisfied’. The majority of caregivers (89%) found the Pre-T Visit summary to be ‘extremely relevant’ or ‘quite relevant’ to the patient’s needs and 78% found it ‘extremely relevant’ or ‘quite relevant’ to the family’s needs, while 11% and 22% of caregivers

Table 2 Multivariable modelling of overall patient satisfaction with the Pre-Transition Visit

| Variable | Univariate | | | | Multivariate | | | |
|--------------------------|-------------|--------|-------|---------|--------------|--------|-------|---------|
| | Coefficient | Lower | Upper | P value | Coefficient | Lower | Upper | P value |
| Age at the visit (years) | 0.692 | -0.554 | 1.939 | 0.283 | 0.413 | -0.859 | 1.685 | 0.529 |
| Disease duration (years) | -0.224 | -0.452 | 0.004 | 0.062 | -0.221 | -0.475 | 0.034 | 0.097 |
| A1C at the visit (%) | -0.295 | -0.930 | 0.341 | 0.369 | -0.099 | -0.747 | 0.549 | 0.766 |
| Gender (female vs male) | 1.179 | -0.815 | 3.174 | 0.254 | 1.513 | -0.470 | 3.496 | 0.143 |

A1C, haemoglobin A1C.

found it 'moderately relevant' or 'slightly relevant' to the patient and family's needs respectively.

DISCUSSION

Overall, we found that both patients and their families had high levels of satisfaction with the Pre-T Visit which reinforced this as a good use of resources (ie, patient, administrative and educator time) in our clinic, with respect to the patient experience. These findings were consistent across patients despite differences in age, gender, diabetes duration and A1C. Furthermore, patients reported high levels of engagement/participation in the visit. The preferred age to conduct this visit was 16 years or older. Importantly, the sample of patients who underwent and evaluated the Pre-T Visit was representative of our overall clinic population as seen in [table 1](#).

Our findings of high levels of satisfaction are consistent with results of other studies evaluating transition-related initiatives but direct comparisons are difficult due to small sample size²⁰ and heterogeneity in type of intervention.²¹ In larger studies, patient satisfaction was rarely the primary outcome^{21 22} and when it was evaluated, it was usually satisfaction with overall care rather than with the specific study intervention/tool.²² We evaluated patient-reported satisfaction with a specific transition-related intervention as our primary outcome using a comprehensive survey. Patient experience and satisfaction are critical components of any sustained quality improvement interventions.^{36 37} Moreover, they are increasingly recognised as important outcomes since they have been shown to be linked to patient outcomes and patient safety.³⁷ Our findings support the acceptability of the Pre-T Visit, though further patient follow-up would be required to conclude that it resulted in improved health outcomes, such as improvement in glycaemic control.

While the Pre-T Visit provides an opportunity to systematically introduce the concept of transition and identify gaps in knowledge and management skills, it does not, in itself, address these gaps. Therefore, other interventions must be incorporated into routine diabetes care to accomplish this. In our clinic, we recently implemented a separate quality improvement initiative aimed at increasing confidence and competence in diabetes self-management skills; a partner to the Pre-T Visit. Youth with T1D who are age 13 years or older attend the DLC immediately prior to their physician visit where they work on various self-management skills with customised worksheets to support this learning. Once gaps in management are identified at the Pre-T Visit, DLC visits can be used to address these gaps. A separate evaluation of the DLC including the assessment of patient-reported change in confidence in diabetes-related knowledge and visit satisfaction is underway. The DLC was implemented after the Pre-T Visit, however, now that the infrastructure is in place to address self-management skill gaps, the importance of delivering the Pre-T Visit by age 16 years is greater to allow time to systematically address the gaps.

There are limitations to this study. First, our study has a smaller sample size than originally intended due to the suspension of Pre-T Visits at the start of the COVID-19 pandemic. However, we were still able to conduct a

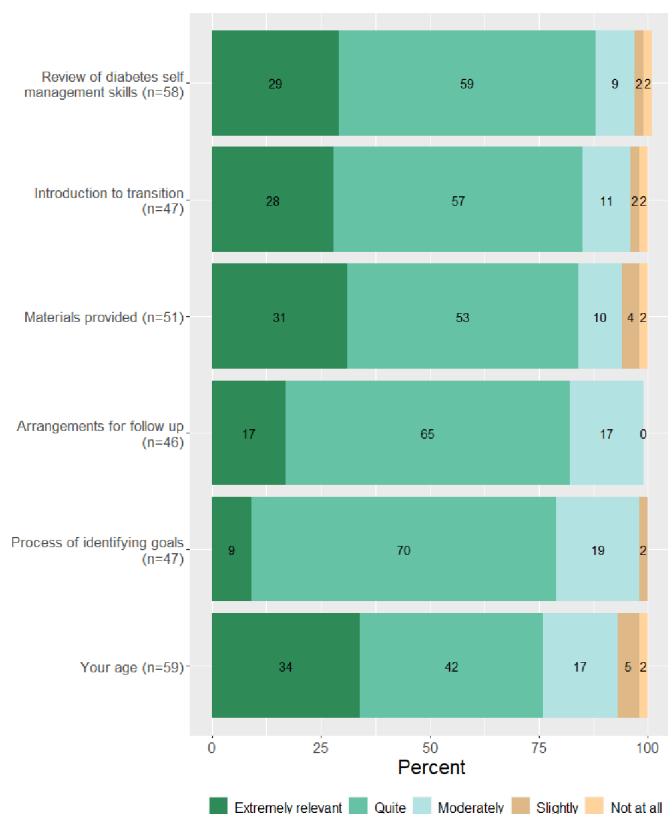


Figure 2 Patient-reported relevance of aspects of the Pre-Transition Visit to their needs.

complete analysis and draw important conclusions from our data. Based on collected clinical information, participants were representative of our overall clinic population, but important demographics related to social determinants of health were not collected and could limit internal and external generalisability. While the response rate of youth who participated in the programme was high, significantly fewer parents and caregivers completed the survey. Our impression is that clinic time constraints impacted parent/caregiver survey completion. By the time they were asked to complete the survey, their youth had already spent time with educator, time completing the survey and the visit with physician was still upcoming. The validity and reliability of conclusions drawn from parent/caregiver perspectives are therefore limited due to small sample size and possible selection bias. Since this visit was introduced as a quality improvement initiative embedded in standard diabetes care aligned with international guidelines in providing 'comprehensive expert-structured education' that is continuous and repeated, easily accessible, adaptable and *able to be personalised*, to all patients within our diabetes clinics,³⁸ we did not have a control group consisting of patients who did not attend a Pre-T Visit. While patient satisfaction with the Pre-T Visit was high in our study, without a control group, we cannot draw conclusions about the impact of the Pre-T Visit on overall satisfaction with care. Finally, while a comparison of A1C pre-Pre-T Visit and post-Pre-T Visit was planned, this was not possible due to the COVID-19 pandemic. During the pandemic, most participants did not have A1Cs measured due to limited visits to the hospital and/or laboratories. Furthermore, the impact of the pandemic on glycaemic control would have been a confounder.

Given the high levels of patient and family satisfaction and relevance of the Pre-T Visit, we plan to continue to offer Pre-T Visits as part of routine care, ideally at age 16 based on the respondents stated age preference. This timing also allows the subsequent 2 years in paediatric care to be focused on closing gaps in diabetes knowledge and self-management skills and addressing transition-related issues. Given that in our study the average age at Pre-T Visit was 16.7 years, we will adjust our clinic procedures to try and achieve the target age of 16 years. Furthermore, now that the DLC is implemented, several elements of transition preparation can be addressed prior to the Pre-T Visit which may allow for more personalisation, consolidation and focus in the 2 years leading to transition.

During the COVID-19 pandemic, our clinic converted all of our routine T1D-related visits to virtual and we plan to continue to deliver the majority of diabetes follow-up care this way. Due to necessary pandemic-related restructuring (eg, to address staff shortages due to redeployment), certain diabetes care services, including Pre-T and DLC Visits, were temporarily put on hold. We are currently in the process of reinstating these visits in a primarily virtual format (with in-person alternatives for patients unable to access virtual technology). Virtual Pre-T Visits will allow for greater flexibility in scheduling as they would not need to be tied to an

in-person clinic visit. While telemedicine delivery of care for adolescents with T1D has been shown to be effective,^{39 40} we need to evaluate its use for the delivery of Pre-T Visits to ensure patient satisfaction or relevance is not compromised. Since we were able to sustain the Pre-T Visit in our clinic for over 2 years prior to the pandemic, we feel confident that, once re-established as part of our virtual diabetes care programme, it will be sustainable long-term. Similar to our initial Pre-T Visit design, the implementation of virtual Pre-T Visits will be integrated within our restructured diabetes programme. We acknowledge that Pre-T Visits require educator time that draws from time otherwise used toward other facets of our programme, however, through routine, focused evaluation of our patients' transition readiness, we anticipate time saving by reducing need for urgent and last-minute education. Duration adequacy of Pre-T Visit was not formally evaluated but diabetes educators reported that 45 min was sufficient.

Although optimal patient experience is integral to high-quality diabetes care, it is also important to measure the impact of quality improvement interventions on quantitative health outcomes including measures of glycaemic control (A1C and glucose time in range) and diabetes complications. Transition-related interventions with high levels of satisfaction with care do not always translate into improved glycaemic measures.²² Once Pre-T visits are restarted following the hold due to the pandemic, we aim to evaluate their impact on glycaemic control and the patient experience using qualitative methods, such as a patient focus group. Other important outcomes to quantify include timely attendance at adult diabetes visits and diabetes-related emergency visits and hospital admissions. Finally, our diabetes care delivery model is undergoing restructuring to ensure that the Pre-T Visit can work synergistically with other quality improvement initiatives, such as the DLC described above, to better prepare youth with T1D for their transition.

CONCLUSION

A novel Pre-T Visit was rated highly by youth and their parents with regards to visit satisfaction and relevance. This new type of visit is a feasible first step to implementing a programme to address existing recommendations to improve transition care without added costs or resources and has potential to impact short and long-term health outcomes. We expect the impact of this improvement to be greatest when combined with other quality improvement initiatives focused on preparing youth for transition—many of which can be delivered virtually as the current pandemic necessitates.

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Contributors AM designed the study with EBG, contributed to patient recruitment, led the data acquisition, drafted the initial manuscript, interpreted the data, revised

the manuscript and produced the final version of the manuscript with EBG. AT led the data analysis with JSH, helped interpret the results, revised the manuscript and approved the final version for publication. JC contributed to development of the study protocol, revised the manuscript and approved the final version for publication. JSH contributed to development of the study protocol and developed statistical analysis plan, led the data analysis with AT, helped interpret the results, revised the manuscript and approved the final version for publication. JS-D-M and LS contributed to development of the study protocol, led participant recruitment and contributed to data acquisition. They revised the manuscript and approved the final version for publication. AA provided input into the implementation of the Pre-Transition Visit, revised the manuscript and approved the final version for publication. EBG led the development and implementation of the Pre-Transition Visit with JS-D-M and LS with input from the CHEO diabetes team, designed the study with AM, interpreted the data, revised the manuscript critically for important intellectual content and produced the final version of the manuscript with AM. EBG is responsible for overall content as the guarantor.

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Competing interests The authors declare that the following financial interests/personal relationship which may be considered as potential competing interests: AA and EBG are coinvestigators for the Medtronic study entitled 'Multi-center, Randomized, Parallel, Adaptive, Controlled trial in Adult and Pediatric Patients with Type 1 Diabetes Using Hybrid Closed Loop System and Control (CSII, MDI, SAP) at Home'. Medtronic provided funds to cover the cost of supplies and research staff time for this study, but investigators did not receive payment. LS is receiving payment as research staff for the Medtronic study entitled 'Multi-center, Randomized, Parallel, Adaptive, Controlled trial in Adult and Pediatric Patients with Type 1 Diabetes Using Hybrid Closed Loop System and Control (CSII, MDI, SAP) at Home'. JS-D-M is receiving payment from Tandem and Medtronic for her role as an insulin pump educator.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants but CHEO Research Ethics Board exempted the study from requiring REB approval as it was deemed quality improvement. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information. All data relevant to the study are included in the manuscript or uploaded as supplementary information (questionnaires). Additional data are available upon request.

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Page 1

Patient Survey

Please complete the survey below.

Thank you!

How many parents/guardians are present?

- ☐ 0
☐ 1
☐ 2
☐ 3

What is your preferred language?
Quelle langue préférez-vous?

- ☐ English
☐ Français

Patient and Family Perspective of a Pre-Transition Visit in a Pediatric Tertiary Care Diabetes Clinic

As a patient being followed in the CHEO pediatric diabetes clinic, you are invited to participate in a survey for a quality improvement research study to assess overall patient and family satisfaction with the current Pre-Transition Visit for youth with type 1 diabetes. These one-time visits, for patients between the ages of 15 and 18 years, were introduced in early 2018.

The Pre-Transition Visit is a 45-minute scheduled appointment with a diabetes educator on the same day as your routine clinic appointment. The visit includes a review of your diabetes management, setting goals for yourself related to your diabetes management and an introduction to the transition process. With this visit, we hope to help you with your transition to adult care.

Taking part in this survey is voluntary. You are free to withdraw from the study at any time without any penalty.

The attached survey is made up of 20 questions and should take no longer than 10 minutes to complete. Your consent will be implied by submission of the completed survey.

All information gathered from the surveys will be kept strictly confidential. Information that we will collect includes your responses to our questions as well as your A1C from today's clinic visit, your age, your gender and your duration of diabetes. If we publish or present the study results, we will not use any identifying information. We will keep all survey data on a password-protected computer at CHEO. Following completion of the research study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

You may or may not directly benefit from the study. However, your input and perspective would be of tremendous value to us. Should you be uncomfortable answering any of the questions you may chose not to answer.

It is important to know that the CHEO Research Ethics Board (REB) has reviewed and approved this study.

Please feel free to contact Alexa Marr at amarr@cheo.on.ca , if you have any questions about the study.

Your assistance with this survey is greatly appreciated. Thank you for your time and consideration

Sincerely,

Alexa Marr, MD
Pediatric Endocrinology Fellow, PGY-4
Principal Investigator
amarr@cheo.on.ca

Ellen Goldbloom MD, FRCPC
Pediatric Endocrinologist
Supervisor

Having read the above, would you like to participate in this study?

- ☐ I would like to participate in this study
☐ I won't be participating in this study

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Why did you decline to participate in this study?
(This is just to help us better understand your
decision. If you'd rather not say why, simply type in
"no comment")

Point de vue du patient et de sa famille concernant la rencontre pré-transition dans une clinique pédiatrique de soins tertiaires pour diabétiques

En tant que patient suivi en soins pédiatriques à la Clinique du diabète du CHEO, vous êtes invité à participer à un sondage dans le cadre d'une étude d'amélioration de la qualité visant à évaluer la satisfaction globale du patient et de sa famille à l'égard de la rencontre pré-transition pour les jeunes vivant avec le diabète de type 1. Cette rencontre, destinées aux patients âgés de 15 à 18 ans, ont été mises en œuvre au début de 2018.

La rencontre pré-transition consiste en un rendez-vous de 45 minutes avec un éducateur spécialisé en diabète le même jour que le rendez-vous habituel à la clinique. La rencontre permettra de passer en revue votre gestion du diabète, d'établir vos objectifs en matière de gestion du diabète et de présenter le processus de transition. Nous espérons ainsi pouvoir faciliter votre transition vers les soins pour adultes.

La participation au sondage est volontaire. Vous êtes libre de vous retirer de l'étude à n'importe quel moment sans aucune pénalité.

Le questionnaire ci-joint comprend 20 questions et ne devrait pas prendre plus de 10 minutes à remplir. Lorsque vous soumettrez le questionnaire de sondage dûment rempli, votre consentement sera implicite.

Tous les renseignements recueillis à l'aide du sondage resteront strictement confidentiels. Les renseignements que nous recueillerons comprennent vos réponses à nos questions, le résultat du test d'hémoglobine A1C qui sera effectué lors du rendez-vous d'aujourd'hui, ainsi que votre âge, votre sexe et la durée de votre diabète. Si nous publions ou présentons les résultats de l'étude, nous n'utiliserons aucun renseignement identificatoire. Toutes les données du sondage seront conservées sur un ordinateur protégé par un mot de passe au CHEO. Une fois l'étude terminée, les données seront conservées pendant sept ans après la dernière publication de cette étude. Ils seront ensuite détruits.

Vous pouvez ou non profiter directement de l'étude. Cependant, vos commentaires et votre point de vue nous seraient extrêmement utiles. Si vous ne vous sentez pas à l'aise de répondre à l'une des questions, vous pouvez choisir de ne pas y répondre.

Pour toute question concernant l'étude, n'hésitez pas à communiquer Alexa Marr à amarr@cheo.on.ca.

Votre participation à ce sondage nous est très précieuse. Merci de votre temps et de votre intérêt à cet égard.

Veuillez agréer nos sincères salutations.

Alexa Marr, M.D.
Boursière en endocrinologie pédiatrique, poste de formation postdoctorale de niveau 4
Chercheuse principale
amarr@cheo.on.ca

Ellen Goldbloom, M.D., FRCPC
Endocrinologue pédiatrique
Superviseure

Aimeriez vous participer dans cette étude?

- ☐ Oui, Je voudrai participer
☐ Non, Je ne désire pas participer
-

Pourquoi ne désirez vous pas participer dans cette
étude? (La question est pour nous aider a mieux
comprendre votre décision. Si vous ne désirez pas
répondre, inscrire "non applicable")

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Satisfaction**[record_id]**

| | |
|---|--|
| 1. Overall, how satisfied are you with the pre-transition visit? | <input type="radio"/> I am not at all satisfied <input type="radio"/> I am slightly satisfied <input type="radio"/> I am moderately satisfied <input type="radio"/> I am quite satisfied <input type="radio"/> I am extremely satisfied <input type="radio"/> I don't know |
| 2. How satisfied are you with the format of the visit (i.e., a 45-minute in person session with one of the diabetes educators)? | <input type="radio"/> I am not at all satisfied <input type="radio"/> I am slightly satisfied <input type="radio"/> I am moderately satisfied <input type="radio"/> I am quite satisfied <input type="radio"/> I am extremely satisfied <input type="radio"/> I don't know |
| 3. How satisfied are you with the review of the diabetes self-management skills? | <input type="radio"/> I am not at all satisfied <input type="radio"/> I am slightly satisfied <input type="radio"/> I am moderately satisfied <input type="radio"/> I am quite satisfied <input type="radio"/> I am extremely satisfied <input type="radio"/> I don't know |
| 4. How satisfied are you with the educational materials provided (for example, illness management handout, alcohol with diabetes handout, driving with diabetes handout)? | <input type="radio"/> I am not at all satisfied <input type="radio"/> I am slightly satisfied <input type="radio"/> I am moderately satisfied <input type="radio"/> I am quite satisfied <input type="radio"/> I am extremely satisfied <input type="radio"/> I don't know <input type="radio"/> I did not receive any educational materials during this visit |
| 5. How satisfied are you with the process of identifying your top three self-management goals? | <input type="radio"/> I am not at all satisfied <input type="radio"/> I am slightly satisfied <input type="radio"/> I am moderately satisfied <input type="radio"/> I am quite satisfied <input type="radio"/> I am extremely satisfied <input type="radio"/> I don't know <input type="radio"/> I did not identify any goals during this visit |
| 6. How satisfied are you with the arrangements made for follow up to work on identified diabetes management skills (For example, if carb counting was identified as an area for improvement, arrangements would be made for follow up with a Dietitian either at the next visit or via phone/email or plans to attend the Diabetes Learning Lab)? | <input type="radio"/> I am not at all satisfied <input type="radio"/> I am slightly satisfied <input type="radio"/> I am moderately satisfied <input type="radio"/> I am quite satisfied <input type="radio"/> I am extremely satisfied <input type="radio"/> I don't know <input type="radio"/> I did not arrange for any follow up during this visit |

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7. How satisfied are you with the introduction of the Transition Evening to learn more about transition to adult care?

- ☐ I am not at all satisfied
☐ I am slightly satisfied
☐ I am moderately satisfied
☐ I am quite satisfied
☐ I am extremely satisfied
☐ I don't know
☐ The Transition evening was not introduced to me during this visit

1. Dans l'ensemble, dans quelle mesure êtes-vous satisfait(e) de la rencontre pré-transition?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas

2. Dans quelle mesure êtes-vous satisfait(e) du format de la rencontre (c'est à dire une rencontre en personne de 45 minutes avec un éducateur spécialisé en diabète)?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas

3. Dans quelle mesure êtes-vous satisfait(e) de la revue des connaissances en matière d'autogestion du diabète?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas

4. Dans quelle mesure êtes-vous satisfait(e) du matériel d'information qui a été fourni (par exemple le matériel sur la gestion de la maladie, la consommation d'alcool et le diabète, la conduite automobile et le diabète)?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Je n'ai reçu aucun document d'information lors de cette rencontre.

5. Dans quelle mesure êtes-vous satisfait(e) du processus visant à déterminer vos trois principaux objectifs en matière d'autogestion?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Je n'ai établi aucun objectif lors de cette rencontre.

6. Dans quelle mesure êtes-vous satisfait(e) des résolutions qui ont été prises afin d'assurer le suivi concernant certaines connaissances en matière de gestion du diabète (par exemple s'il était déterminé que le calcul des glucides est un domaine à améliorer, des résolutions seraient prises afin d'assurer un suivi avec un diététiste lors de la prochaine visite, ou par téléphone ou courriel, ou des arrangements seront fait pour que vous participiez à un labo diabète)?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Je n'ai pris aucune disposition de suivi lors de cette rencontre.

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7. Dans quelle mesure êtes-vous satisfait(e) de l'explication de la soirée sur la transition afin de vous permettre d'en apprendre davantage sur la transition vers les soins pour adultes?

- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Il n'a pas été question de la soirée sur la transition lors de cette rencontre.

Engagement

8. How much did you participate during this visit?

- ☐ I did not participate at all
☐ I participated a little bit
☐ I participated some
☐ I participated quite a bit
☐ I am participated a tremendous amount
☐ I don't know

9. How much did you participate in the process of identifying your top three self-management goals?

- ☐ I did not participate at all
☐ I participated a little bit
☐ I participated some
☐ I participated quite a bit
☐ I am participated a tremendous amount
☐ I don't know

10. Do you plan on filling out the MyChart (CHEO's online secure patient portal where you can view your health information and communicated with your health care team) application form?

- ☐ Yes
☐ No
☐ I am already on MyChart
☐ We did not discuss MyChart during this visit
☐ I don't know what MyChart is

8. Dans quelle mesure avez-vous participé à cette rencontre?

- ☐ Je n'ai pas du tout participé
☐ J'ai un peu participé
☐ J'ai modérément participé
☐ J'ai beaucoup participé
☐ J'ai énormément participé
☐ Je ne sais pas

9. Dans quelle mesure avez-vous participé au processus visant à déterminer vos trois principaux objectifs en matière d'autogestion?

- ☐ Je n'ai pas du tout participé
☐ J'ai un peu participé
☐ J'ai modérément participé
☐ J'ai beaucoup participé
☐ J'ai énormément participé
☐ Je ne sais pas

10. Avez-vous l'intention de remplir le formulaire d'inscription à MyChart (le portail sécurisé pour les patients de CHEO qui vous permet de consulter les renseignements personnels sur votre santé et de communiquer avec votre équipe de soins de santé)?

- ☐ Oui
☐ Non
☐ Je suis déjà inscrit(e) à MyChart.
☐ Nous n'avons pas discuté de MyChart lors de cette rencontre.
☐ J'ignore ce qu'est MyChart.

Confidential

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Relevance/ Pertinence

11. How relevant to your needs did you find the review of the diabetes self-management skills?

- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

12. How relevant to your needs did you find the educational materials provided (for example, illness management handout, alcohol with diabetes handout, driving with diabetes handout)?

- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

13. How relevant to your needs did you find the process of identifying your top three self-management goals?

- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

14. How relevant to your needs did you find the arrangements made for follow up to work on identified diabetes management skills (For example, if carb counting was identified as an area for improvement, arrangements would be made for follow up with a Dietitian either at the next visit or via phone/email or plans to attend the Diabetes Learning Lab)?

- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

15. How relevant to your needs did you find the introduction of the Transition Evening to learn more about transition to adult care?

- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

16. Given your age, how relevant did you find the pre-transition visit?

- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

17. At what age do you think the pre-transition visit would be most relevant ?

- ☐ 18
☐ 17
☐ 16
☐ 15
☐ 14
☐ 13
☐ 12
☐ I don't know

18. Do you have any additional feedback or suggestions regarding the format of this visit?

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19. Do you have any additional feedback or suggestions regarding the information/topics covered in this visit?

11. Dans quelle mesure avez-vous trouvé pertinent, par rapport à vos besoins, la revue des connaissances en matière d'autogestion du diabète?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

12. Dans quelle mesure avez-vous trouvé pertinent le matériel d'information qui a été fourni (par exemple le matériel sur la gestion de la maladie, la consommation d'alcool et le diabète, la conduite automobile et le diabète)?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

13. Dans quelle mesure avez-vous trouvé pertinent le processus visant à déterminer vos trois principaux objectifs en matière d'autogestion?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

14. Dans quelle mesure avez-vous trouvé pertinentes, par rapport à vos besoins, les résolutions qui ont été prises afin d'assurer le suivi concernant certaines connaissances en matière de gestion du diabète (par exemple s'il était déterminé que le calcul des glucides est un domaine à améliorer, des résolutions seraient prises afin d'assurer un suivi avec un diététiste lors de la prochaine visite, ou par téléphone ou courriel, ou des arrangements seront fait afin que vous participiez à un labo diabète)?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

15. Dans quelle mesure avez-vous trouvé pertinente l'explication de la soirée sur la transition afin de vous permettre d'en apprendre davantage sur la transition vers les soins pour adultes?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

16. Compte tenu de votre âge, dans quelle mesure avez-vous trouvé pertinente la rencontre pré-transition?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

17. À quel âge croyez-vous que la rencontre pré-transition serait plus pertinente?

- ☐ 18
☐ 17
☐ 16
☐ 15
☐ 14
☐ 13
☐ 12
☐ Je ne sais pas

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18. Avez-vous d'autres commentaires ou suggestions concernant le format de cette rencontre?

19. Avez-vous d'autres commentaires ou suggestions concernant les renseignements ou les sujets abordés lors de cette rencontre?

Patient demographics/ Renseignements démographiques sur la patiente ou le patient

20. What is your gender?

- ☐ Female
☐ Male
☐ Other

I identify as:

20. Quel est votre sexe?

- ☐ Femelle
☐ Mâle
☐ Autre :

Je m'identifie comme :

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Parent/Guardian/Caregiver Survey

Please complete the survey below.

Thank you!

[record_id]

What is your preferred language?
Quelle langue préférez-vous?

☐ English
☐ Français

Patient and Family Perspective of a Pre-Transition Visit in a Pediatric Tertiary Care Diabetes Clinic

As the parent or guardian of a patient currently being followed in the CHEO pediatric diabetes clinic, you are invited to participate in a survey for a quality improvement study assessing overall patient and family satisfaction with the current Pre-Transition Visit for youth with type 1 diabetes. These one-time visits, for patients between the ages of 15 and 18 years, were introduced in early 2018.

The Pre-Transition Visit is a 45-minute scheduled appointment with a diabetes educator on the same day as a routine clinic appointment. The visit includes a review of your youth's diabetes management, setting goals for your youth related to their diabetes management and an introduction to the transition process. With this visit, we hope to help your youth with their transition to adult care.

Taking part in this survey is voluntary. You are free to withdraw from the study at any time without any penalty.

The attached survey is made up of 6 questions and should take no longer than 5 minutes to complete. Your consent will be implied by submission of the completed survey.

All information gathered from the surveys will be kept strictly confidential. If we publish or present the study results, we will not use any identifying information. We will keep all survey data on a password-protected computer at CHEO. Following completion of the study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

You may or may not directly benefit from the study. However, your input and perspective would be of tremendous value to us. Should you be uncomfortable answering any of the questions you may chose not to answer.

Please feel free to contact Alexa Marr at amarr@cheo.on.ca , if you have any questions about the study.

Your assistance with this survey is greatly appreciated. Thank you for your time and consideration

Sincerely,

Alexa Marr, MD
Pediatric Endocrinology Fellow, PGY-4
Principal Investigator
amarr@cheo.on.ca

Ellen Goldbloom MD, FRCPC
Pediatric Endocrinologist
Supervisor

Would you like to participate along with the patient in this study?

☐ Yes, I would like to participate
☐ No, I decline to participate

Why did you decline to participate in this study?
(This is just to help us better understand your decision. If you'd rather not say why, simply type in "no comment")

Confidential

Page 10

Point de vue du patient et de sa famille concernant la rencontre pré-transition dans une clinique pédiatrique de soins tertiaires pour diabétiques

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Alexa Marr, M.D.
Boursière en endocrinologie pédiatrique, poste de formation postdoctorale de niveau 4
Chercheuse principale
amarr@cheo.on.ca

Ellen Goldbloom, M.D., FRCPC
Endocrinologue pédiatrique
Superviseure

Aimeriez vous également participer avec le sujet?

- ☐ Oui, Je voudrai participer
☐ Non, Je ne desire pas participer

Pourquoi ne désirez vous pas participer dans cette étude? (La question est pour nous aider a mieux comprendre votre décision. Si vous ne désirez pas répondre, inscrire "non applicable")

Confidential

Page 11

Satisfaction**[record_id]**

1. How satisfied are you with the end-of-visit summary ? (The after visit summary in the time spent at the end of the visit with yourself, the patient and the diabetes educator where the visit was summarized along with reviewing the goals that were set and next steps moving forward)
- ☐ I am not at all satisfied
☐ I am slightly satisfied
☐ I am moderately satisfied
☐ I am quite satisfied
☐ I am extremely satisfied
☐ I don't know
☐ An end-of-visit summary was not provided

1. Dans quelle mesure êtes-vous satisfait(e) du résumé de fin de rencontre? (Le résumé de fin de rencontre est le temps que vous avez passé à la fin de la rencontre avec le patient et l'éducateur spécialisé en diabète dans le but de faire un résumé de la rencontre et de passer en revue les objectifs fixés et les prochaines étapes.)
- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Il n'y a pas eu de résumé à la fin de la rencontre.

Relevance/ Pertinence**[record_id]**

2. How relevant to the patient's needs did you find the end-of-visit summary?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

3. How relevant to your family's needs did you find the end-of-visit summary?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

4. Given the patient's age, how relevant to their needs did you find the pre-transition visit?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know
☐ I did not participate in the visit

2. Dans quelle mesure trouvez-vous que le résumé de fin de rencontre a été pertinent par rapport aux besoins de la patiente ou du patient?
- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

Confidential

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3. Dans quelle mesure trouvez-vous que le résumé de fin de rencontre a été pertinent par rapport aux besoins de votre famille?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

4. Compte tenu de l'âge de la patiente ou du patient, dans quelle mesure avez-vous trouvé pertinente la rencontre avant la transition par rapport à ses besoins?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas
☐ Je n'ai pas participé à la visite

Demographics/ Renseignements démographiques

[record_id]

5. What is your relationship to the patient?

- ☐ Mother
☐ Father
☐ Grandmother
☐ Grandfather
☐ Aunt
☐ Uncle
☐ Sister
☐ Brother
☐ Foster parent
☐ Other, please specify
☐ I prefer not to specify

Please specify other

6. Is there anything else you would like to share with us about the visit?

5. Quel est votre lien avec la patiente ou le patient?

- ☐ Mère
☐ Père
☐ Grand-mère
☐ Grand-père
☐ Tante
☐ Oncle
☐ Sœur
☐ Frère
☐ Parent d'accueil
☐ Autre, veuillez préciser
☐ Je préfère ne pas répondre.

Veuillez préciser:

6. Avez-vous quoi que ce soit d'autre à mentionner au sujet de la rencontre?

Confidential

Page 13

Second Parent/Guardian Survey**[record_id]**

What is your preferred language?
Quelle langue préférez-vous?

☐ English
☐ Français

Patient and Family Perspective of a Pre-Transition Visit in a Pediatric Tertiary Care Diabetes Clinic

As the parent or guardian of a patient currently being followed in the CHEO pediatric diabetes clinic, you are invited to participate in a survey for a quality improvement study assessing overall patient and family satisfaction with the current Pre-Transition Visit for youth with type 1 diabetes. These one-time visits, for patients between the ages of 15 and 18 years, were introduced in early 2018.

The Pre-Transition Visit is a 45-minute scheduled appointment with a diabetes educator on the same day as a routine clinic appointment. The visit includes a review of your youth's diabetes management, setting goals for your youth related to their diabetes management and an introduction to the transition process. With this visit, we hope to help your youth with their transition to adult care.

Taking part in this survey is voluntary. You are free to withdraw from the study at any time without any penalty.

The attached survey is made up of 6 questions and should take no longer than 5 minutes to complete. Your consent will be implied by submission of the completed survey.

All information gathered from the surveys will be kept strictly confidential. If we publish or present the study results, we will not use any identifying information. We will keep all survey data on a password-protected computer at CHEO. Following completion of the study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

You may or may not directly benefit from the study. However, your input and perspective would be of tremendous value to us. Should you be uncomfortable answering any of the questions you may chose not to answer.

Please feel free to contact Alexa Marr at amarr@cheo.on.ca , if you have any questions about the study.

Your assistance with this survey is greatly appreciated. Thank you for your time and consideration

Sincerely,

Alexa Marr, MD
Pediatric Endocrinology Fellow, PGY-4
Principal Investigator
amarr@cheo.on.ca

Ellen Goldbloom MD, FRCPC
Pediatric Endocrinologist
Supervisor

Would you like to participate along with the patient in this study?

☐ Yes, I would like to participate
☐ No, I decline to participate

Why did you decline to participate in this study?
(This is just to help us better understand your decision. If you'd rather not say why, simply type in "no comment")

Confidential

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Point de vue du patient et de sa famille concernant la rencontre pré-transition dans une clinique pédiatrique de soins tertiaires pour diabétiques

En tant que parent ou tuteur d'un patient qui est suivi en soins pédiatriques à la Clinique du diabète du CHEO, vous êtes invité à participer à un sondage dans le cadre d'une étude d'amélioration de la qualité visant à évaluer la satisfaction globale du patient et de sa famille à l'égard de la rencontre pré-transition pour les jeunes vivant avec le diabète de type 1. Cette rencontre, destinées aux patients âgés de 15 à 18 ans, ont été mises en œuvre au début de 2018.

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Veuillez agréer nos sincères salutations.

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Chercheuse principale
amarr@cheo.on.ca

Ellen Goldbloom, M.D., FRCPC
Endocrinologue pédiatrique
Superviseure

Aimeriez vous également participer avec le sujet?

- ☐ Oui, Je voudrai participer
☐ Non, Je ne desire pas participer

Pourquoi ne désirez vous pas participer dans cette étude? (La question est pour nous aider a mieux comprendre votre décision. Si vous ne désirez pas répondre, inscrire "non applicable")

Confidential

Page 15

Satisfaction**[record_id]**

1. How satisfied are you with the end-of-visit summary ? (The after visit summary in the time spent at the end of the visit with yourself, the patient and the diabetes educator where the visit was summarized along with reviewing the goals that were set and next steps moving forward)
- ☐ I am not at all satisfied
☐ I am slightly satisfied
☐ I am moderately satisfied
☐ I am quite satisfied
☐ I am extremely satisfied
☐ I don't know
☐ An end-of-visit summary was not provided

1. Dans quelle mesure êtes-vous satisfait(e) du résumé de fin de rencontre? (Le résumé de fin de rencontre est le temps que vous avez passé à la fin de la rencontre avec le patient et l'éducateur spécialisé en diabète dans le but de faire un résumé de la rencontre et de passer en revue les objectifs fixés et les prochaines étapes.)
- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Il n'y a pas eu de résumé à la fin de la rencontre.

Relevance/ Pertinence**[record_id]**

2. How relevant to the patient's needs did you find the end-of-visit summary?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

3. How relevant to your family's needs did you find the end-of-visit summary?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

4. Given the patient's age, how relevant to their needs did you find the pre-transition visit?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know
☐ I did not participate in the visit

2. Dans quelle mesure trouvez-vous que le résumé de fin de rencontre a été pertinent par rapport aux besoins de la patiente ou du patient?
- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

Confidential

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3. Dans quelle mesure trouvez-vous que le résumé de fin de rencontre a été pertinent par rapport aux besoins de votre famille?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

4. Compte tenu de l'âge de la patiente ou du patient, dans quelle mesure avez-vous trouvé pertinente la rencontre avant la transition par rapport à ses besoins?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas
☐ Je n'ai pas participé à la visite

Demographics/ Renseignements démographiques

[record_id]

5. What is your relationship to the patient?

- ☐ Mother
☐ Father
☐ Grandmother
☐ Grandfather
☐ Aunt
☐ Uncle
☐ Sister
☐ Brother
☐ Foster parent
☐ Other, please specify
☐ I prefer not to specify

Please specify other

6. Is there anything else you would like to share with us about the visit?

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- ☐ Mère
☐ Père
☐ Grand-mère
☐ Grand-père
☐ Tante
☐ Oncle
☐ Sœur
☐ Frère
☐ Parent d'accueil
☐ Autre, veuillez préciser
☐ Je préfère ne pas répondre.

Veuillez préciser:

6. Avez-vous quoi que ce soit d'autre à mentionner au sujet de la rencontre?

Confidential

Page 17

Third Parent/Guardian Survey**[record_id]**

What is your preferred language?
Quelle langue préférez-vous?

☐ English
☐ Français

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Ellen Goldbloom MD, FRCPC
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Supervisor

Would you like to participate along with the patient in this study?

☐ Yes, I would like to participate
☐ No, I decline to participate

Why did you decline to participate in this study?
(This is just to help us better understand your decision. If you'd rather not say why, simply type in "no comment")

Confidential

Page 18

Point de vue du patient et de sa famille concernant la rencontre pré-transition dans une clinique pédiatrique de soins tertiaires pour diabétiques

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Superviseure

Aimeriez vous également participer avec le sujet?

- ☐ Oui, Je voudrai participer
☐ Non, Je ne desire pas participer

Pourquoi ne désirez vous pas participer dans cette étude? (La question est pour nous aider a mieux comprendre votre décision. Si vous ne désirez pas répondre, inscrire "non applicable")

Confidential

Page 19

Satisfaction**[record_id]**

1. How satisfied are you with the end-of-visit summary ? (The after visit summary in the time spent at the end of the visit with yourself, the patient and the diabetes educator where the visit was summarized along with reviewing the goals that were set and next steps moving forward)
- ☐ I am not at all satisfied
☐ I am slightly satisfied
☐ I am moderately satisfied
☐ I am quite satisfied
☐ I am extremely satisfied
☐ I don't know
☐ An end-of-visit summary was not provided

1. Dans quelle mesure êtes-vous satisfait(e) du résumé de fin de rencontre? (Le résumé de fin de rencontre est le temps que vous avez passé à la fin de la rencontre avec le patient et l'éducateur spécialisé en diabète dans le but de faire un résumé de la rencontre et de passer en revue les objectifs fixés et les prochaines étapes.)
- ☐ Je ne suis pas du tout satisfait(e)
☐ Je suis un peu satisfait(e)
☐ Je suis modérément satisfait(e)
☐ Je suis très satisfait(e)
☐ Je suis extrêmement satisfait(e)
☐ Je ne sais pas
☐ Il n'y a pas eu de résumé à la fin de la rencontre.

Relevance/ Pertinence**[record_id]**

2. How relevant to the patient's needs did you find the end-of-visit summary?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

3. How relevant to your family's needs did you find the end-of-visit summary?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know

4. Given the patient's age, how relevant to their needs did you find the pre-transition visit?
- ☐ I did not find it relevant at all
☐ I found it slightly relevant
☐ I found it moderately relevant
☐ I found it quite relevant
☐ I found it extremely relevant
☐ I don't know
☐ I did not participate in the visit

2. Dans quelle mesure trouvez-vous que le résumé de fin de rencontre a été pertinent par rapport aux besoins de la patiente ou du patient?
- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

Confidential

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3. Dans quelle mesure trouvez-vous que le résumé de fin de rencontre a été pertinent par rapport aux besoins de votre famille?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas

4. Compte tenu de l'âge de la patiente ou du patient, dans quelle mesure avez-vous trouvé pertinente la rencontre avant la transition par rapport à ses besoins?

- ☐ Je ne l'ai pas trouvé du tout pertinent
☐ Je l'ai trouvé un peu pertinent
☐ Je l'ai trouvé modérément pertinent
☐ Je l'ai trouvé très pertinent
☐ Je l'ai trouvé extrêmement pertinent
☐ Je ne sais pas
☐ Je n'ai pas participé à la visite

Demographics/ Renseignements démographiques

[record_id]

5. What is your relationship to the patient?

- ☐ Mother
☐ Father
☐ Grandmother
☐ Grandfather
☐ Aunt
☐ Uncle
☐ Sister
☐ Brother
☐ Foster parent
☐ Other, please specify
☐ I prefer not to specify

Please specify other

6. Is there anything else you would like to share with us about the visit?

5. Quel est votre lien avec la patiente ou le patient?

- ☐ Mère
☐ Père
☐ Grand-mère
☐ Grand-père
☐ Tante
☐ Oncle
☐ Sœur
☐ Frère
☐ Parent d'accueil
☐ Autre, veuillez préciser
☐ Je préfère ne pas répondre.

Veuillez préciser:

6. Avez-vous quoi que ce soit d'autre à mentionner au sujet de la rencontre?

Confidential

Chart Review

Date of pre-transition visit

(dd-mm-yyyy)

A1C Values

A1C at pre-transition visit

A1C at 6 months after pre-transition visit

Date of A1C at 6 months

(dd-mm-yyyy)

A1C at 1 year after pre-transition visit

Date of A1C at 1 year

(dd-mm-yyyy)

Birth Date

Month of Birth

- ☐ January
- ☐ February
- ☐ March
- ☐ April
- ☐ May
- ☐ June
- ☐ July
- ☐ August
- ☐ September
- ☐ October
- ☐ November
- ☐ December

Year of Birth

(eg. 2002)

Date of Diagnosis



Confidential

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Month of Diabetes Diagnosis

- ☐ January
☐ February
☐ March
☐ April
☐ May
☐ June
☐ July
☐ August
☐ September
☐ October
☐ November
☐ December

Year of Diabetes Diagnosis

(eg. 2002)

Diabetes Learning Lab

Has the patient had a session in the diabetes learning lab?

- ☐ Yes
☐ No

How many diabetes learning lab session have they previously participated in?

When was their first diabetes learning lab session?

(dd-mm-yyyy)

When was their second diabetes learning lab session?

(dd-mm-yyyy)

When was their third diabetes learning lab session?

(dd-mm-yyyy)

When was their fourth diabetes learning lab session?

(dd-mm-yyyy)

When was their fifth diabetes learning lab session?

(dd-mm-yyyy)

When was their sixth diabetes learning lab session?

(dd-mm-yyyy)

When was their seventh diabetes learning lab session?

(dd-mm-yyyy)

When was their eighth diabetes learning lab session?

(dd-mm-yyyy)

Confidential

When was their ninth diabetes learning lab session?

(dd-mm-yyyy)

When was their tenth diabetes learning lab session?

(dd-mm-yyyy)

Cancelling Appointments

Has this participant previously cancelled pre transition visits?

- ☐ Yes
- ☐ No

How many pre-transition visits have they missed?

SUPPLEMENT 2

Pre-Transition Visit Educator Guide (CREATED Nov 16, 2018)**Target Audience:**

- Youth aged 16-18 years with type 1 diabetes
- Using a customized electronic health record (EHR) report, the diabetes administrative assistant will run the report the 1st of each month to identify eligible patients for the following 2 months (e.g., Feb 1 – run report for appointments in March and April; April 1 – run report for appts in May and June). One appointment per half day clinic will be scheduled with priority given to patients closest to 16 yrs. Appointment tracking in the EHR “Diabetes Interim Clinic Report”.

Format:

- 45-minute scheduled appointment with diabetes educator (nurse educator or dietitian) same day (right before or right after) routine clinic appointment
- Independent appointment (without parent/guardian)

General goals of visit:

- Identify status of self-management skills/tools for transition so that achievements and goals can be specified. Gaps in knowledge/health management to be addressed over next two years and beyond. You might instinctively want to address gaps as they arise but try to “park it” for further discussion at an upcoming visit
- Introduce MyChart (patient portal)
- Brief discussion re: transition to adult care

TASK LIST:**Explain limits of confidentiality first.**

- 1. Review and complete “Self-Management Skills” section of “Diabetes Interim Clinic Report Flowsheet” within the EHR.**
 - NB – THIS IS A GUIDE ONLY. Time may not be sufficient to address all items and that's OK. Not all items applicable to each patient. Some items will be obvious and ideally completed at prior visit (e.g., glucometer testing). ITEMS IN CAPS SHOULD BE PRIORITIZED.
 - Answers are: can do this alone, some help needed, lots of help needed, unable, does not apply, other (if you choose other, write a comment).
 - See “Diabetes Interim Clinic Report: Self-Management Skills with Sample Questions” (below) for specific questions for each item (items listed in order of appearance in flowsheet which is alphabetical with an attempt to keep categories together).
- 2. Provide applicable educational material (e.g., illness management handout if identified as a gap)**
- 3. Identify TOP 3 SELF-MANAGEMENT GOALS to be achieved within 1-2 years (educator can help identify these) and documents these in “patient instructions”. Route encounter to the**

patient's physician to help ensure follow up. If appropriate, can copy and paste key point/goals into "Specialty Comments" in "Snapshot" of the EHR.

4. Arrange for follow-up as appropriate (e.g., if carb counting identified as a weakness, arrange f/up with dietitian either at next visit or via email/telephone).
5. Check MyChart (patient portal) status. Provide application form or link, and pamphlet (need MRN too) and encourage sign-up. This will allow two way messaging as well as easy access to appts, results, health issue list, medications, allergies (which they can update).
6. Mention that there are options with respect to transition to adult care (at age 18 yrs) and that the best way to find out about these will be to attend the transition evening (held twice per year). Provide "Adult Diabetes Clinic in Champlain handout"
7. Offer opportunity to bring parent/guardian in for summary (particularly of goals). This is not required and should be up to the youth.

Diabetes Interim Clinic Report: Self-Management Skills with Sample Questions

Each bullet is a row item. Sub-bullets show guiding questions to aid evaluation.

- A1C – Understands meaning
 - What is A1C a measure of? Over what time period?
- A1C – Understands implications if high
 - Why is it important to keep it in target/close to target?
- ALCOHOL SAFETY PRECAUTIONS
 - What effect does alcohol have on BGs?
 - What can be done to ensure safety while drinking?
- Appointment management
 - Who is responsible for this?
- Carb counting
 - “Do you feel that you can carb count on your own? (“Could do a mini quiz here – what’s a typical lunch for you... how many carbs is that?”)
- CGM insertion
 - “Can you insert your CGM?”
- CGM uploading
 - “Can you upload your CGM to your computer?”
- CGM programming
 - “Can you make changes to settings, alarms etc.?”
- CGM interpretation and response
 - “Let’s say you have a normal BG at bedtime, have a snack and bolus but keep waking up high. You notice that your CGM is in target until about 3 am. What might the problem be? How will you address this?”
- Complication and comorbidity screening understanding
 - “Do you know why we do blood and urine tests every few years? Eye exams?”
- DKA PREVENTION
 - “When should you check for ketones and what would you do if positive?”
- DRIVING SAFETY PRECAUTIONS
 - “What do you do to make sure you are safe to drive?”
- EXERCISE/ACTIVITY COMPENSATION
 - “Do you manage your diabetes differently (extra food/less insulin) before/during/after activity/exercise and can you manage this?”
- FGM x 4 (same questions as for CGM)
- Glucometer programming
 - “Can you change date, change settings etc?”
- Glucometer testing (this should be a given, but is in there so that we can start tracking at a young age)
- Glycemic trend tracking (paper or eLogbook)
 - “Do you keep track of your BGs somewhere?”
- Glycemic trend recognition
 - “Do you look back at your BGs and notice when a change needs to be made?”
- Glycemic trend response/ADJUSTMENTS
 - “If you noticed a pattern, like always high at supper, what would you do?”
- HYPOGLYCEMIA TREATMENT (ORAL)
 - “When (at what BG level) would you treat a low, and how?”
- Hypoglycemia treatment (glucagon minidosing)

- “Do you know how to do this?”
- Hypoglycemia treatment – severe (including glucagon use) (*I’m realizing that this one may not be appropriate as they would need help with this... maybe making sure it’s up to date, accessible for others etc.?*)
- ILLNESS MANAGEMENT
 - “How does illness affect your BGs? What should you do differently while sick?”
- Insulin calculations (understands how ratios, corrections... work)
 - “If your ratio is 1:5, what does that mean?”
 - “How (generally) is your ISF used for corrections? If corrections weren’t working (not bringing BG down enough), how would you adjust your ISF?”
- Injections (pen, syringe) – simply, can they do this?
- Insurance coverage understanding – general understanding
- Prescription and supplies management – are they doing this?
- Pump boluses – simply, do they know how (should be yes at this age)
- Pump insertions
 - “Can you insert your own infusion set?”
- Pump settings changes
 - “Can you make changes to basal, ratios, ISF, set temp basals etc.?”
- Pump uploads
 - “Can you upload to your computer?”
- Pump upload understanding
 - “Can you make sense of the reports you see on upload? Let’s say you have a normal BG at bedtime, have a snack and bolus but keep waking up high. What might the problem be? How will you address this?”
- Site rotation
 - “Are you rotating sites? Do you know why it’s important?”
- Support resources (who and when to contact)
 - General inquiry about who/when to call for help/support
- Travel precautions
 - “What sort of precautions do you take to make sure travel goes smoothly?” (letter, extra supplies, phone numbers, checked vs carry-on”