The Changing Face of Paediatric Diabetes in Ontario

Summary Report

Paediatric Diabetes Network Professional Development Event
March 4th, 2016

April 2016
# 2016 Professional Development Event – Summary Report

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Executive Summary

The Ontario Paediatric Diabetes Network (PDN) is a collaborative network that strives to ensure the best possible health outcomes for children and youth living with diabetes. The PDN is comprised of thirty-five specialized paediatric diabetes education programs (PDEPs) located in communities across Ontario, with thirty programs located in secondary level healthcare organizations, and five tertiary-level programs.

Coordinating the PDN, the Provincial Council for Maternal and Child Health (PCMCH) provides opportunities for professional development, fosters formal and informal linkages between PDEPs, provides individual program support, supports the development and dissemination of guidelines and resources, and promotes consistency in standards of practice. The PDN hosts an annual professional development event for paediatric diabetes stakeholders to come together and collaborate, share lessons learned, discuss barriers and devise innovative solutions that can be brought back to the clinical care environment. The PDN hosted this year’s Professional Development Event on Friday, March 4th, 2016 (see Appendix A for the event agenda). This event brought together over 160 paediatric diabetes stakeholders, with representation from thirty-three PDEPs as well as representation from the LHINs, administrators, Manitoba, general paediatricians and ten exhibitor organizations. The purpose of this annual event is to provide a forum for paediatric diabetes care providers across Ontario to learn, collaborate, share and network in order to improve the health, social outcomes and wellbeing of their patients. The theme of this year’s event was The Changing Face of Paediatric Diabetes in Ontario and was addressed by an eclectic mix of guest speakers, captivating presentations and lively discussions. This report summarizes the information and insights that were presented, along with some of the solution-based strategies that were generated and discussed amongst attendees. The following key themes emerged throughout the proceedings of the day:

- There is an opportunity to curate media and leverage innovative technologies to effectively engage and interact with children, youth and families living with diabetes.
- The patients’ perspectives, resiliency and wisdom should be captured and integrated into the development of tools, resources and projects.
- Advancements in medicine and technology can be used to improve patient engagement and paediatric diabetes care.
- Enabling peer-to-peer healthcare can foster communities of support amongst those living with diabetes.
- We need to enhance the current translation of research to clinical care, build trust, and capitalize on opportunities to measure outcomes and integrate quality improvement into paediatric diabetes care.
- A combination of psychosocial, biomedical and socio-economical characteristics in children and families living with type 2 diabetes can affect their ability to manage their diabetes.
- Efforts are underway to ensure that the appropriate supports exist for children and youth with type 1 diabetes to thrive in school environments while managing their diabetes safely and effectively.

The PDN is a cohesive group of enthusiastic healthcare providers working together to provide optimal, state of the art diabetes education, management and support to children and families living with type 1 or type 2 diabetes. With advancements in medicine and technology, increasing complexity in patient care and a dynamic political landscape, the face of paediatric diabetes is evolving. The passion, ambition and innovative ideas shared throughout the 2016 Professional Development Event corroborate that the PDN is well-equipped as a network to adapt, innovate, leverage opportunities and overcome new challenges as they arise.
Plenary Sessions

Disruption, Peer to Peer Healthcare, Creativity and YouTube: How to Fail Well in Patient Engagement

Dr. Mike Evans, Staff Physician, St. Michael’s Hospital; Lead, Digital Preventive Medicine, Li Ka Shing Knowledge Institute; Associate Professor, Family & Community Medicine; Endowed Chair Patient Engagement, Centre for Child Nutrition & Health, University of Toronto

The 2016 PDN Professional Development Event began with an engaging keynote address delivered by Dr. Mike Evans, a leader in innovative health messaging. His plenary session highlighted the importance of building relationships with patients and how, with the integration of different technologies and creative means of communication in healthcare, the approach to relationship building and interaction with patients is changing. Dr. Evans also touched upon the changing landscape in healthcare communication and other topical subjects including the value of capturing the wisdom of patients, the importance of encouraging healthy living, how to cultivate peer-to-peer healthcare and innovative ways to empower patients and their families. Dr. Evans explored the concepts of choice architecture, nudge, the intent-behaviour gap and “healthy infections” while also introducing participants to emerging tools and sources of information that can help patients and families make informed health choices. His session was both thought-provoking and inspiring, making for a great way to kick start the event. To learn more about Dr. Mike Evans’ work, his approach to patient engagement and the whiteboard health videos he created, please visit: http://www.evanshealthlab.com/

Quote: “We [healthcare providers] often ask what is the matter while missing what actually matters”.

Enhancing the Patient Journey Through Quality Improvement

Dr. Ian Zenlea, Paediatric Endocrinologist & Scientist at the Institute for Better Health, Trillium Health Partners

With a heightened focus on quality improvement in the Ontario healthcare system, along with efforts underway to integrate quality improvement into paediatric diabetes care, Dr. Ian Zenlea provided a timely overview of the fundamental principles of improvement science and spoke to the differences between quality improvement initiatives and research projects. Dr. Zenlea also defined collaborative research networks and described existing opportunities to establish environments that are conducive to rapid prototyping. As well, he discussed how to strengthen the connection between enhancing the patient experience and enabling system change. His presentation emphasized the notion that quality improvement is a shared responsibility among everyone involved in the delivery of healthcare services and entails a systematic, collaborative approach in order to enhance patient health outcomes and the quality of care. Dr. Zenlea’s slides can be found online at: http://bit.ly/22KKHhn.

Quote: “The question, "How will we know if change is an improvement?" can only be answered with data.”
What Our Patients Can Teach Us – Building on Strengths and Learning from a Holistic Model

Dr. Stasia Hadjiyannakis, Paediatric Endocrinologist, Children’s Hospital of Eastern Ontario
Julie E. Rochefort-Wood, Registered Dietitian, Noojimowin Teg Health Centre
Dr. Allison Dart, Paediatric Nephrologist & Research Scientist, Children’s Hospital Research Institute of Manitoba

The members of this multidisciplinary panel shared their unique perspectives, experiences and reflections on caring for and learning from children and families living with type 2 diabetes. In doing so, the panelists took the audience on an enlightening journey through the epidemiology, clinical features, complications and holistic treatment models for type 2 diabetes in children and youth. The participants gained an understanding of the diverse needs and strengths of children and youth living with or at risk of developing type 2 diabetes from three different Canadian communities – Ottawa, Winnipeg and Manitoulin Island. This session and its accompanying case studies showcased the complex interplay between psychosocial, biophysical and socio-economic factors associated with complications in youth with type 2 diabetes, and how these factors can have a significant impact on the children’s and families’ ability to manage diabetes. The panelists presented key strategies for diabetes management with a focus on a strength-based, holistic approach that fosters resiliency in patients and families. There were a number of overarching themes interwoven throughout this session, relevant to the management of both type 1 and type 2 diabetes and aligned with the themes that emerged earlier in the day. These themes included the importance of caring for the person as a whole, acknowledging and valuing the wisdom of the patient and focusing on a person’s strengths and resiliency.

Quotes:
“Everywhere I look, I see someone I know living with complications from type 2 diabetes. It’s scary but it’s also manageable if I take charge of my health and do what I can. I can live a healthy life with type 2 diabetes. I don’t have to die from this disease.”
“We need to show the different faces of type 2 diabetes and stop the stigma”
“There is a sport for every body and a body for every sport.”

School Supports for Children and Youth with Type 1 Diabetes – An Update

Dr. Sarah Lawrence, Chief, Division of Endocrinology and Metabolism, Children’s Hospital of Eastern Ontario
Elizabeth Moreau, Director of Communications & Knowledge Translation, Canadian Paediatric Society

Given the complexities of managing type 1 diabetes, and the fact that children spend upwards of 30 hours in school per week, it is important to ensure that school personnel are well equipped and adequately prepared to help children manage their diabetes. The level and type of supports available in the school environment vary considerably across the province, with different supports available by jurisdiction, school board and even by school. A lack of support and understanding of diabetes management in schools can impact a child’s ability to thrive in the school environment and may raise fear in parents and families as to whether their child’s safety is at risk. This plenary session provided attendees with an overview of the current available school supports and an update on the national and provincial efforts underway to move policy recommendations to action in order to improve the availability and consistency of school supports for children and youth living with type 1 diabetes.
diabetes. The presenters shared patient stories that shed light upon the intricacies, dynamics and challenges encountered by children and their parents when a child has type 1 diabetes. The presenters also spoke to some of the upcoming opportunities for paediatric diabetes care providers to take part in and support these efforts. The presenters referred to the BC Children’s Hospital basal-bolus insulin with MDI resources, which can be found online here: [http://www.bcchildrens.ca/health-info/coping-support/diabetes](http://www.bcchildrens.ca/health-info/coping-support/diabetes).

**Quote:** “Paediatric diabetes patients are kids first, and kids with diabetes second.”
Morning Breakout Session (By Topic)
The event attendees participated in one of five morning breakout sessions. Each session focused on a priority area related to paediatric diabetes care in Ontario. The aim of these breakout sessions was to provide attendees with an opportunity to delve deeper, discuss enablers and barriers related to a specific priority topic and share best practices. Each session was moderated by an event attendee with a particular expertise in that area. This section of the report provides an overview of the ideas shared, challenges explored and proposed solutions at each of the morning breakout sessions.

Moving from recommendation to action: improving access to mental health supports for paediatric diabetes patients
Ruth Slater (The Hospital for Sick Children)
This breakout session was moderated by one of the co-chairs of the Mental Health and Psychosocial Working Group (MHP-WG). During this session, participants reviewed the seven recommendations of the PDN’s Mental Health and Psychosocial Working Group and considered potential priorities for action moving forward, based on their experiences with this population. The aim was not to rank the recommendations at this time, as a prioritization exercise would be undertaken following the event, but to consider priorities during the session in anticipation of the prioritization exercise. The themes that emerged are listed below (see Appendix 2 for more details).

- It is important to take into consideration the complexities and unique needs of children, youth and families living with diabetes.
- Sufficient training and time for mental health clinicians to provide effective interventions and follow up is required.
- There are opportunities to work with, and learn from, existing systems and partners that should be leveraged.
- There is an integral role for data related to patient needs, interventions and cost effectiveness of intervening early for children and youth living with diabetes and a comorbid mental health condition.

Innovative approaches to supporting difficult family situations
Jeff Packer (Charles H. Best Diabetes Centre)
This session was moderated by Jeff Packer, a social worker from the Charles H. Best Diabetes Centre who also maintains a private practice. During this session, participants discussed the circumstances that may impact family dynamics and create stress or difficulties for children with diabetes and their caregivers. Jeff facilitated the session, focusing on the three pillars 1) the challenges that may exist, 2) the impact that a difficult family situation may have on children, family members and healthcare providers, and 3) strategies or solutions to alleviate some of the difficulties and improve familial circumstances. Participants discussed the individual, familial, community and societal factors that can contribute to increasing difficulty for families, such as socioeconomic factors and other barriers such as communication or parental mental health concerns. Some of the solutions discussed include setting clear boundaries and expectations for the child and the parents, providing more flexibility in clinic visits and consider increasing the frequency of visits to meet the needs of the families and patients.
The Achilles heel of paediatric diabetes management – How to address fear of hypoglycemia with families

Helen Gies (Charles H. Best Centre)

The management of hypoglycemia can present unique challenges and often fosters fear amongst families of children with type 1 diabetes. This session entailed a focused discussion on the fear of hypoglycemia and how paediatric care providers can support and advise patients and parents who are trying to cope with this fear. Participants were divided up into groups that explored topics related to fear of hypoglycemia for different age groups. These groups included paediatric diabetes patients under the age of 6, between 6 and 12 years of age, and older than 12 years of age. Each group answered a number of questions related to the concerns of the various age groups and their parents. These questions pertained to the signs and symptoms that may arise with fear of hypoglycemia, risk factors that may be associated with fear of hypoglycemia, how technology can help or hinder this fear, frequency of blood glucose testing and common strategies to prevent hypoglycemia and the fear of hypoglycemic episodes. A full summary of what was discussed during this breakout session can be found in Appendix 3.

Transition to adult care: Recommendations and future directions

Rayzel Shulman (The Hospital for Sick Children)

Participants in this session discussed aspects of patients transitioning from paediatric diabetes to adult care settings along with the recommendations put forth by the PDN’s Transition to Adult Care Working Group. Such aspects include the challenges of transitioning to adult diabetes care, discharge planning, common knowledge gaps and communication issues that often arise. Participants also had an opportunity to provide preliminary feedback on a research proposal regarding integration of care providers in the transition process. The key takeaway messages from this session are:

- Ensuring that patients who are discharged from pediatric clinics to adult diabetes care remains a challenge and it is not always known to the PDEPs whether or not patients are seen at the adults centre
- Pediatric centres have differing set-ups in terms of continuity with their diabetes physician and non-physician team members.
- The transition to adult care working group recommendations were felt to be a good resource for PDEPs

Learnings from paediatric diabetes performance measurement in 2015-16

Renee Lebovitz (Champlain LHIN) and Margery Konan (Toronto Central LHIN)

This session was co-moderated by two representatives from the Local Health Integration Networks who are directly involved in the paediatric diabetes performance measurement efforts. The paediatric diabetes education programs (PDEPs) were encouraged to have at least one representative from their team attend this session. During this session:

- PDEPS shared their concerns and challenges in the reestablishment of performance measurement reporting in 2015-16. All programs are currently reporting and recommendations were put forward for future consideration. These recommendations will be brought back to the PDOC (Pan-LHIN Paediatric Diabetes Oversight Committee) for review to better streamline future reporting. It was highlighted that there is a need to have both quantitative and qualitative measures. A longer term goal is to use more
quality and outcomes measures rather than process/workload measures. For 2016-17, reporting will remain the same as last year.

- Feedback was provided to the PDEPs from the LHINs on how the data provided by PDEPs has been used and will be used in the future.
- PDEPs reflected on the benefits of developing a work plan and the opportunities created.
**Afternoon Breakout Session (by Professional Group)**

The event attendees also participated in one of the afternoon breakout sessions, which were designated by the following professional groups: 1) registered dietitians, 2) registered nurses, 3) social workers and mental health clinicians, 4) physicians, and 5) management and administrative representatives. The purpose of the afternoon breakout sessions was to provide new and experienced staff with dedicated time to connect and engage in discussion regarding emerging or priority topics as they relate to their specific specialties. Participants met with others from their professional group to share best practices, barriers they have encountered and experiences they have gained in paediatric diabetes management. To facilitate constructive brainstorming in the afternoon breakout sessions, participants were asked to use a discussion framework to address one of the following topics as it relates to their specific expertise. Some of the common themes that emerged amongst the various professional groups are summarized below.

<table>
<thead>
<tr>
<th>Topic</th>
<th>Common themes</th>
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</table>
| **Utilizing social media outlets and technology to enhance communication in paediatric diabetes care and patient education** | • The use of technology for communication varies based upon the organization (e.g. some programs can text their patients while others cannot)  
• Patients and families are interested and motivated to use social media  
• Legal and privacy barriers, concerns and implications of using technology to communicate with patients and families  
• Some social media resources include: JDRF Facebook page, Type 1 Diabetes Think Tank, [https://ichallengediabetes.org/](https://ichallengediabetes.org/),  
• The RD group discussed the Bluewater Health E-mail Communications with Patient Agreement, which can be found in Appendix 4 |
| **How to build competencies, confidence and expertise amongst staff** | • Providing staff with educational opportunities  
• Learning from other providers and centres – visiting, mentorship and participating in rounds  
• Time, funding, geographical isolation, maintaining mentor relationship  
• Sharing and accessing resources  
• Updated directory of programs with special interests |
| **How to foster a robust, collaborative, integrated team environment** | • The role of multidisciplinary communication, weekly team rounds, access to education and different healthcare providers such as mental health clinicians and paediatricians, and electronic charting in fostering a robust, collaborative and integrated team environment  
• Encourage all team members to take responsibility for comprehensive care of the patient  
• Recruitment of highly trained paediatric diabetes care providers  
• Large geographical areas can hinder the continuity of care  
• Concerns about confidentiality in the communities  
• Patient-centered approach to paediatric diabetes care where all members of the team conduct the visit together, seeing the patient altogether. |
| **Care pathways for newly diagnosed** | • Most of the paediatric diabetes education programs cover the same topics with their newly diagnosed patients and families; however the education |
| patients                                                                 | process varies greatly.  
|                                                                         | • Same staff conduct the initial patient education from start to finish  
|                                                                         | • Checklist for both the patients and the healthcare providers regarding ongoing education and management  
|                                                                         | • Scheduling to meet parent and family availability  
|                                                                         | • Need to adapt to different cultures and literacy levels  
|                                                                         | • Funding issues and how they impact the team, patient education and ability to communicate with patients and their families  
| Programs and/or practice strategies that help to address the increased prevalence of obesity in paediatric diabetes patients | • Better screening for food security, carbohydrate counting and lobby for more supports for families living with diabetes  
|                                                                         | • Conduct an assessment of activity and screen time in order to find ways to increase activity and explore patient’s interests  
|                                                                         | • More flexible insulin regimens as they can allow for more normal/natural eating/follow appetite not meal plan  
|                                                                         | • Avoid the concept of forbidden foods  
|                                                                         | • ↑ use of CGM re: fear of Hypoglycemia and ↑ MDI/CSII to improve control and less ↓ BG  
|                                                                         | • Healthy foods – validation and sharing of reliable apps  
|                                                                         | • Need to increase community resources and involvement  
|                                                                         | • Re-visit the basics of diabetes education, especially how to treat a low blood sugar  
| Innovative ideas, strategies and/or programs for at-risk patients with prolonged elevated A1c’s and for those with high incidence of DKA | • Increase frequency of visits and regular communication with the patient and their family via email or telephone  
|                                                                         | • Encourage small changes and patient empowerment  
|                                                                         | • Social media and text messaging for communication and build relationships  
|                                                                         | • Social work investment and psychosocial support groups  
|                                                                         | • Peer-to-peer mentorship and support  
|                                                                         | • Multifactorial causes of prolonged elevated A1c  
|                                                                         | • Some challenges include socioeconomic barriers, lack of mental health supports, diabetes burnout, access to insulin pump  
| Emerging dietary programs and philosophies that may be contrary to evidence-based practice | • Promoting balanced ideas of eating for children and youth with diabetes.  
|                                                                         | • Timing of carb counting  
|                                                                         | • Gluten free diet for asymptomatic patients  
|                                                                         | • The effect of protein and fat on blood sugars  
|                                                                         | • Label reading for sugar alcohols, referring to the Canadian Diabetes Association position statement, which can be found here:  

Event Evaluation

A brief evaluation survey was circulated to participants following the PDN Professional Development Event. A total of 71 participants completed the evaluation survey and provided their feedback on the plenary presentations, breakout sessions, venue, and the event overall. The feedback and proposed priority topics provided by the respondents of this evaluation survey will be integrated into the planning process for next year’s PDN Professional Development Event. The following section of the report provides a high-level overview of the evaluation results.

Plenary Sessions

The majority of the respondents rated the plenary sessions as either excellent or good.

Breakout Sessions

Overall, the breakout sessions were well received, however there was some feedback indicating that participants would benefit from longer sessions in order to have more in-depth discussions and to focus the discussion on the identification of possible solutions and action plans.

<table>
<thead>
<tr>
<th>Breakout sessions were:</th>
<th>Average Score</th>
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<tbody>
<tr>
<td>Relevant</td>
<td>3.2</td>
</tr>
<tr>
<td>Engaging</td>
<td>3.0</td>
</tr>
<tr>
<td>Informative</td>
<td>2.8</td>
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</table>
The Overall Event
More than two thirds of the respondents either agreed or strongly agreed that the 2016 event was informative and beneficial.

Overall, the event was informative and beneficial

Respondents were asked to rate a variety of aspects related to the event agenda and venue using a scale of 1 to 4 where 1 represents strongly disagree and 4 represents strongly agree. The tables below demonstrate the average scores for these aspects.

<table>
<thead>
<tr>
<th>The Event:</th>
<th>Average Score</th>
<th>The Venue:</th>
<th>Average Score</th>
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<tbody>
<tr>
<td>Was well-paced</td>
<td>3.5</td>
<td>Was comfortable</td>
<td>3.5</td>
</tr>
<tr>
<td>Had sufficient breaks</td>
<td>3.5</td>
<td>Was conveniently located</td>
<td>3.5</td>
</tr>
<tr>
<td>A good mix of listening and participation</td>
<td>3.4</td>
<td>Provided adequate food and refreshments</td>
<td>3.7</td>
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## Appendix 1 – 2016 PDN Professional Development Event Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Agenda Item</th>
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<tbody>
<tr>
<td>7:45 – 8:45</td>
<td>Registration / Morning Breakout Session Sign-Up / Continental Breakfast</td>
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<tr>
<td>8:45 – 8:50</td>
<td>Opening Remarks</td>
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<tr>
<td>8:50 – 10:00</td>
<td>Disruption, Peer to Peer Healthcare, Creativity and YouTube: How to Fail Well in Patient Engagement</td>
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<tr>
<td></td>
<td>Dr. Mike Evans, MD, CCFP, Staff Physician, St. Michael's Hospital</td>
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<td></td>
<td>Lead, Digital Preventive Medicine, Li Ka Shing Knowledge Institute</td>
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<td></td>
<td>Associate Professor, Family &amp; Community Medicine</td>
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<td></td>
<td>Endowed Chair Patient Engagement, Centre for Child Nutrition &amp; Health, University of Toronto</td>
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<tr>
<td>10:00 – 11:00</td>
<td>Enhancing the Patient Journey Through Quality Improvement</td>
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<td></td>
<td>Dr. Ian Zenlea, MD, MPH, Paediatric Endocrinologist, Trillium Health Partners</td>
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<tr>
<td></td>
<td>Scientist, Institute for Better Health, Trillium Health Partners</td>
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<tr>
<td>11:00 – 11:10</td>
<td>Break</td>
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<tr>
<td>11:10 – 12:10</td>
<td>Morning Breakout Session (by Topic)</td>
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<td></td>
<td>See page 3 for session details</td>
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<tr>
<td>12:10 – 12:50</td>
<td>Lunch</td>
</tr>
<tr>
<td>12:50 – 1:50</td>
<td>What Our Patients Can Teach Us – Building on Strengths and Learning from a Holistic Model (Panel Session)</td>
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<td></td>
<td>Dr. Stasia Hadjiyannakis, MD, FRCPC, Paediatric Endocrinologist, Children’s Hospital of Eastern Ontario</td>
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<td></td>
<td>Julie E. Rochefort-Wood, RD, MHSc, Registered Dietitian, Noojmowin Teg Health Centre</td>
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<td></td>
<td>Dr. Allison Dart, MD, MSc, FRCPC, Paediatric Nephrologist &amp; Research Scientist, Children’s Hospital Research Institute of Manitoba</td>
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<tr>
<td>1:50 – 2:00</td>
<td>Break</td>
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<tr>
<td>2:00 – 2:50</td>
<td>Afternoon Breakout Session (by Professional Group)</td>
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<tr>
<td></td>
<td>See page 3 for session details</td>
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<tr>
<td>2:50 – 3:50</td>
<td>School Supports for Children and Youth with Type 1 Diabetes – An Update</td>
</tr>
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<td></td>
<td>Dr. Sarah Lawrence, MD, FRCPC, Chief, Division of Endocrinology and Metabolism, Children’s Hospital of Eastern Ontario, Associate Professor, Faculty of Medicine, University of Ottawa</td>
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<td></td>
<td>Elizabeth Moreau, MMgt, Director of Communications &amp; Knowledge Translation, Canadian Paediatric Society</td>
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<tr>
<td>3:50 – 4:00</td>
<td>Adjournment</td>
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Plenary Sessions

Disruption, Peer to Peer Healthcare, Creativity and YouTube: How to Fail Well in Patient Engagement

Dr. Mike Evans, Staff Physician, St. Michael’s Hospital; Lead, Digital Preventive Medicine, Li Ka Shing Knowledge Institute; Associate Professor, Family & Community Medicine; Endowed Chair Patient Engagement, Centre for Child Nutrition & Health, University of Toronto

This session will address:
1. The changing landscape in healthcare communication (email clinics, apps, quantified self),
2. The critical elements of care that are not changing (relationships, self-care, attitudes),
3. Emerging tools and sources of information that help the public inform their health choices.

Enhancing the Patient Journey Through Quality Improvement

Dr. Ian Zenlea, Paediatric Endocrinologist & Scientist at the Institute for Better Health, Trillium Health Partners

Objectives:
1. Introduce the differences between quality improvement initiatives and research projects,
2. Define the key components of quality improvement and research networks,
3. Explore opportunities for collaborative networks related to paediatric diabetes care.

What Our Patients Can Teach Us – Building on Strengths and Learning from a Holistic Model

Dr. Stasia Hadjiyannakis, Paediatric Endocrinologist, Children’s Hospital of Eastern Ontario
Julie E. Rochefort-Wood, Registered Dietitian, Noojmowin Teg Health Centre
Dr. Allison Dart, Paediatric Nephrologist & Research Scientist, Children’s Hospital Research Institute of Manitoba

Objectives: Participants will
1. Hear from a multidisciplinary panel with unique insights, perspectives and experiences in caring for children and youth at risk or living with type 2 diabetes,
2. Gain an understanding of the different needs and strengths of children and youth living with or at risk of developing type 2 diabetes within three Canadian communities (Ottawa, Winnipeg, Manitoulin Island) and how these may apply to their own communities,
3. Learn about key biopsychosocial factors associated with complications in youth with type 2 diabetes and key strategies for managing patients with a focus on a strength-based, holistic approach that fosters resiliency in patients and families.

School Supports for Children and Youth with Type 1 Diabetes – An Update

Dr. Sarah Lawrence, Chief, Division of Endocrinology and Metabolism, Children’s Hospital of Eastern Ontario
Elizabeth Moreau, Director of Communications & Knowledge Translation, Canadian Paediatric Society

Objectives:
1. Provide an overview of the current school supports for children and youth with type 1 diabetes in Ontario, and how they relate to recommendations put forth by the Canadian Paediatric Society and the Canadian Pediatric Endocrine Group,
2. Describe efforts currently underway to transform these recommendations into provincial policy,
3. Describe how to support this collaborative initiative, next steps in moving forward with these recommendations, and opportunities for paediatric diabetes care providers to get involved.
### Morning Breakout Session (by Topic)

The purpose of this breakout session is to provide attendees with an opportunity to engage in discussion and debate regarding an emerging or priority area of interest related to paediatric diabetes care in Ontario.

<table>
<thead>
<tr>
<th>Title</th>
<th>Details</th>
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</table>
| Moving from recommendation to action: improving access to mental health supports for paediatric diabetes patients | **Objectives:** With the imminent release of the recommendations report by the Network’s Mental Health & Psychosocial Working Group, gathering input on this set of recommendations from the frontline is critical to successful implementation. Join us for an opportunity to share your thoughts on the feasibility, considerations and impact of these recommendations in paediatric diabetes settings across the province.  
**Moderator:** Ruth Slater (The Hospital for Sick Children)  
**Room:** Kingsway Room |
| Innovative approaches to supporting difficult family situations     | **Objectives:** To explore the circumstances that may contribute to increasing difficulty for patients and their families, and to share ideas, strategies and resources that can be used to improve both their situations and our approaches to helping them.  
**Moderator:** Jeff Packer (Charles H. Best Centre)  
**Room:** Caledon Room |
| The Achilles heel of paediatric diabetes management – How to address fear of hypoglycemia with families | **Objectives:** A focused discussion on the fear of hypoglycemia and how scientific evidence can be used to assist patients and families in coping with this fear.  
**Moderator:** Helen Giles (Charles H. Best Centre)  
**Room:** Halliburton Room |
| Transition to adult care: Recommendations and future directions      | **Objectives:** 1. To identify knowledge gaps about transition to adult care,  
2. To discuss the benefits/potential barriers of implementing some of the recommendations by the Network’s Transition to Adult Care Working Group,  
3. To consider how research might address existing knowledge gaps and provide useful information for centres within the PDN  
**Moderator:** Rayzel Shulman (The Hospital for Sick Children)  
**Room:** Humber Room |
| Learnings from paediatric diabetes performance measurement in 2015-16 | **Objectives:** To share and discuss lessons learned from implementation of paediatric diabetes performance measurement tools and resources, introduced in 2015-2016; and to share the work plan and activities of the Pan-LHIN Paediatric Diabetes Oversight Committee.  
**Moderators:** Renee Lebovitz (Champlain LHIN) and Margery Konan (Toronto Central LHIN)  
**Room:** Ontario and Niagara Room |

### Afternoon Breakout Session (by Professional Group)

The purpose of this breakout session is to provide new and experienced staff with dedicated time to connect and engage in discussion regarding an emerging or priority topic related to paediatric diabetes management. Participants will have an opportunity to draw upon their experience, lessons learned and the challenges they’ve encountered.

<table>
<thead>
<tr>
<th>Title</th>
<th>Details</th>
</tr>
</thead>
</table>
| Registered Nurses                 | **Moderators:** Marlene Grass (Charles H. Best Centre) and Michele Smith (Pembroke)  
**Room:** Ontario and Niagara Room |
| Registered Dietitians                  | **Moderator:** Janet Baker (Bluewater Health)  
|                                     | **Room:** Caledon Room |
| Social Workers & Mental Health Clinicians | **Moderator:** Lorell Stevenson (Orillia Soldier's Memorial Hospital)  
|                                     | **Room:** Kingsway Room |
| Physicians                           | **Moderator:** Dr. Karen McAssey (McMaster Children’s Hospital)  
|                                     | **Room:** Humber Room |
| Management & Administrative Representatives | **Moderator:** Trixie Williams (Rouge Valley Health System)  
|                                     | **Room:** Halton Room |
Appendix 2 – Breakout Session Summary: Moving from recommendation to action: improving access to mental health supports for paediatric diabetes patients

First, the session participants reviewed the seven recommendations of the PDN’s Mental Health and Psychosocial Working Group. They were then asked to reflect upon the recommendations, taking into consideration potential priorities for action moving forward, based on their experiences with this population. They were advised that they did not necessarily need to rank recommendations at this time, as a prioritization exercise would be undertaken following the event, however they were encouraged to consider priorities during the session in anticipation of the prioritization exercise.

The following themes emerged during the participants’ discussion:

**Taking into consideration the complexities in the needs of diabetes children, youth and their families, it is important to:**
- Be able to effectively identify such things as diabetes burnout and depression
- Recognize the potential for standard diabetes management directives to create disordered eating behaviours
- Further research and recognition of how chronically high blood sugars may impact cognition and reasoning skills
- Recognize that the diagnosis of diabetes is often traumatic for the family
- Consider the unique needs of rural versus urban settings

**Sufficient training and time for mental health clinicians to provide effective interventions and follow up is required.**
- Differences in social work training and clinicians’ comfort in providing psychotherapy
- The skills that mental health clinicians possess in “nudging” (e.g., facilitating change by making use of systemic factors)
- The need for staff time in order to be able to provide adequate follow up (e.g., psychotherapy)
- Potential benefits of standardizing some of the aspects of the mental health clinician role description
- Consider whether interventions are best offered “in house” or referred out or some combination of both

**Opportunities to work with, and learn from, existing systems. Some ideas included:**
- Collaborate with community agencies and schools
- Creation of an information “package” of some kind for clinicians in the community regarding diabetes
- Consider the complexity, length of treatment, and most appropriate setting (Day hospital? Inpatient?) to address the needs of the subset of pediatric diabetes patients who have a comorbid mental health condition (e.g. an eating disorder)
- The need to consider models of school-based treatment from other conditions (e.g., epilepsy classroom) that might apply to diabetes and to consider, for example, whether a “diabetes boarding school” of some kind might well serve youth and parents (through parenting enhancement, and parenting relief)
- The need to look at staffing and team composition models – for example, a Social Worker who is only one day/week with diabetes but employed in a hospital for five days/week has the potential to be flexible in responding to patients’ and families’ needs throughout the week
- Suggestion that the pediatric diabetes community network with organizations focused on other chronic pediatric conditions, to share knowledge and, perhaps, treatment interventions (e.g., groups for patients from multiple teams within a hospital or treatment centre)

**There is an integral role for data related to patient needs, interventions and cost effectiveness of intervening early for children and youth living with diabetes and a comorbid mental health condition. There is a need to:**
- Conduct research regarding social work/mental health interventions for children and youth living with diabetes
- Build a business case to convey the needs and opportunities that exist in addressing the mental health needs of pediatric diabetes patients and their families
- Identify and communicate to funding directors and administrators the substantive costs of hospital admissions for diabetes ketoacidosis
- Collect data on patients’ needs, outcomes and responses to interventions
- Explore the benefits of preventative efforts (e.g. building coping skills and family cohesion from the time of diagnosis; recognizing that any interventions targeted at children are, by definition, preventative)
- Undertake initiatives in a timely fashion, to build on the interest at several levels of government in addressing mental health needs
- Solicit and incorporate patient input and feedback (e.g. by surveying clients/patients)
### Appendix 3 – Breakout Session Summary: How to address fear of hypoglycemia with families

**Group: <6 years of Age**

1. **Fears of Hypoglycemia- Signs and Symptoms**
   - **Parent**
     - child cannot recognize signs and symptoms
     - afraid of hypoglycemia happening overnight
   - **Child**
     - Afraid to tell someone that they feel of hypoglycemia exp. Daycare, teacher
     - May confuse being hungry with signs and symptoms of hypoglycemia

2. **What are the risk factors for developing hypoglycemia?**
   - **Parent**
     - previous experience with self or child
     - knowledge of potential risk factors with severe hypoglycemia (unconscious, seizures, death)
   - **Child**
     - previous experience with self or parent/ care giver
     - think they will get in trouble or learned behaviour for getting treats / juice
     - may fear glucagon injection / larger needle

<table>
<thead>
<tr>
<th>BG Targets for not Afraid</th>
<th>BG Targets for Afraid</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.0-10.0mmol/L</td>
<td>6.0-12.0mmol/L</td>
</tr>
</tbody>
</table>

3. **How often should you test blood sugar?** Before meals, when symptomatic, before/ during/ post activity

4. **When is it too much?** There is no one answer – when it begins to interfere with regular activity it is too much

5. **What do you do to help address fears?** Educate how common it is and it is a normal part of diabetes management. Educate on how to prevent hypoglycemia.

6. **Common Strategies that can be used to prevent hypoglycemia?** Routine with meals / activities / knowing when to test / include snack at hs / sensor use/ MDI vs mixed insulin/ MDI vs. mixed insulin /education (mini dose glucagon/ sick day management).

7. **Does technology help or hinder fears?**
   - may become too dependent on CGMs – decreasing SMBG
   - increasing stress as parent become hyper diligent of BG results
   - can be reassuring if parent is afraid of lows overnight or when not with child
   - becoming less aware of physical signs of lows
   - reacting to CGM trends may cause difficulty with adjusting insulin doses accurately
   - very expensive and with no benefits can cause increased stress

8. **What supports are available?** mfg of technology staff, diabetes educators, CDA guidelines, physician, pharmacist

9. **Follow ups how often?** Doctors and diabetes educators at least quarterly, emailing blood sugars in between appointments for assistance with adjustments

10. **Do you communicate findings with the team/ physician?** Do not know when and how often suspect not often enough

11. **Tips and Tricks** (what do you do in your current setting)
   - flagging chart for hx of severe low blood sugar or fearful of low blood sugar, education completed, consider yearly review of incidents and fears.
### Group: 6-12 years of Age

#### 1. Fears of Hypoglycemia - Signs and Symptoms

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>- frequent testing</td>
<td>- outdated BG targets</td>
</tr>
<tr>
<td>- over correcting blood sugars</td>
<td>- not reporting low blood sugars</td>
</tr>
<tr>
<td>- avoidance of events / activity</td>
<td>- not testing blood sugar</td>
</tr>
<tr>
<td>- high A1C, purposely keeping BG higher activity/event</td>
<td>- embarrassed of low / avoidance of physical activity/event</td>
</tr>
<tr>
<td>- reluctance of insulin adjustment</td>
<td>- carrying lots of treatments / over treating</td>
</tr>
<tr>
<td>- SMBG overnight or +++</td>
<td>- SMBG +++</td>
</tr>
<tr>
<td>- above target at hs and not correcting blood sugar</td>
<td>- increased cho consumption at hs or activity</td>
</tr>
<tr>
<td>- increased cho consumption at hs or activity</td>
<td>- lack of trust with other caregivers/ school staff</td>
</tr>
</tbody>
</table>

#### 2. What are the risk factors for developing fear of hypoglycemia?

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>- previous experience with self or child</td>
<td>- previous experience with self or parent/ care giver</td>
</tr>
<tr>
<td>- knowledge of potential risk factors with severe hypoglycemia (unconscious, seizures, death)</td>
<td>- school issues – being different / excluded from sports</td>
</tr>
<tr>
<td>- type A personality (over achiever)</td>
<td>- stories from other’s / internet (dead in bed)</td>
</tr>
<tr>
<td>- stories from other’s / internet (dead in bed)</td>
<td>- treated with glucagon/ seizure/ bad experience/911 call</td>
</tr>
<tr>
<td>- treated with glucagon/ seizure/ bad experience/911 call</td>
<td>- Mental Health</td>
</tr>
<tr>
<td>- Mental Health</td>
<td></td>
</tr>
</tbody>
</table>

### BG Targets for not Afraid

<table>
<thead>
<tr>
<th>BG Targets for not Afraid</th>
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</thead>
<tbody>
<tr>
<td>5.0-10.0mmol/L</td>
</tr>
</tbody>
</table>

### BG Targets for Afraid

<table>
<thead>
<tr>
<th>BG Targets for Afraid</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.0-12.0mmol/L</td>
</tr>
</tbody>
</table>

#### 3. How often should you test blood sugar? Before meals, when symptomatic, before/ during/ post activity

#### 4. When is it too much? There is no one answer – when it begins to interfere with regular activity it is too much >10 with no reason for (activity/ illness)

#### 5. What do you do to help address fears?

- educate how common it is and it is a normal part of diabetes management
- educate on how to prevent hypoglycemia
- acknowledge fear / explore reason for fears
- ease targets initially while gradually working towards targets. Exp. Increase target at hs in order to correct at hs once correcting and no episodes of hypoglycemia/ work slowly to tightening target
- if available refer for counselling / support groups with parents of children in the same age group
- increase frequency of appointments/ being flexible

#### 6. Common Strategies that can be used to prevent hypoglycemia?

- Do not skip meals, SMBG at least 4 x a day, cho counting ability, following CDA guidelines for insulin injections / rotating sites / activities / knowing when to test / insulin pump and using features such as temporary basal/ sensor use/ attending appointments with diabetes team/ education (mini dose glucagon/ sick day management/signs and symptoms of hypoglycemia/ mini dose glucagon for prevention of severe hypo) be prepared carry treatment and or snack is meal is delayed or having increased activity/ low glucose suspend

#### 7. Does technology help or hinder fears?

- may become too dependent on CGMs – decreasing SMBG
- increasing stress as parent become hyper diligent of BG results
• can be reassuring if parent is afraid of lows overnight or when not with child (Dario meter/ Night Scout watch/One Touch reveal)
• reacting to CGM trends may cause difficulty with adjusting insulin doses accurately
• very expensive and with no benefits can cause increased financial stress

8. **What supports are available?** mfg of technology staff, diabetes educators/team, CDA guidelines, physician, pharmacist, peer support groups, other families.

9. **Follow ups how often?** Doctors and diabetes educators at least quarterly, emailing blood sugars in between appointments for assistance with adjustments/ having flexibility with evening appointments/ ability to increase frequency of contact if had sever hypoglycemic episode or increased incidents of hypoglycemia

10. **Do you communicate findings with the team/ physician?** Do not know when and how often suspect not often enough/ not always

11. **Tips and Tricks (what do you do in your current setting)**
   - flagging chart for hx of severe low blood sugar or fearful of low blood sugar, education completed, consider yearly review of incidents and fears.
   - blood glucose awareness training
   - cognitive behavioural therapy
   - initiating hypoglycemia fear survey
   - education – type 1 diabetes differs in age and developmental stage, more than ½ of severe hypoglycemic episodes occurred during the night, impaired awareness, age, duration of diabetes, hx of severe hypoglycemia, recognizing signs of nocturnal hypo, counter regulatory responses to hypoglycemia are decreased during sleep

<table>
<thead>
<tr>
<th>Group: &gt;-12 years of Age</th>
</tr>
</thead>
</table>

### 1. Fears of Hypoglycemia- Signs and Symptoms

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>nagging to test/frequent testing</td>
<td>outdated BG targets</td>
</tr>
<tr>
<td>over correcting blood sugars</td>
<td>not reporting low blood sugars</td>
</tr>
<tr>
<td>avoidance of events/ activity</td>
<td>not testing blood sugar</td>
</tr>
<tr>
<td>high A1C, purposely keeping BG higher activity/event</td>
<td>embarrassed of low/ avoidance of physical</td>
</tr>
<tr>
<td>reluctance of insulin adjustment omission</td>
<td>not blousing for cho consumed (snacks) or intentional</td>
</tr>
<tr>
<td>SMBG overnight</td>
<td>over tx of lows/ under treat high BG</td>
</tr>
<tr>
<td>above target at hs and not correcting blood sugar</td>
<td></td>
</tr>
<tr>
<td>increased cho consumption at hs or activity</td>
<td></td>
</tr>
<tr>
<td>premature treatment of suspected hypoglycemia without testing</td>
<td></td>
</tr>
</tbody>
</table>

### 2. What are the risk factors for developing fear of hypoglycemia?

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child/ Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>previous experience with self or child</td>
<td>previous experience with self or parent/ care giver</td>
</tr>
<tr>
<td>knowledge of potential risk factors with severe hypoglycemia (unconscious, seizures, death)</td>
<td>stories from other’s/ internet (dead in bed)</td>
</tr>
<tr>
<td>type A personality (over achiever)</td>
<td>treated with glucagon/ seizure/ bad experience/911</td>
</tr>
<tr>
<td>stories from other’s/ internet (dead in bed)</td>
<td>duration of type 1 impaired awareness</td>
</tr>
<tr>
<td>Mental Health</td>
<td>hypoglycemia unawareness</td>
</tr>
<tr>
<td>child diagnosed at young age</td>
<td>lack of knowledge on prevention/ treatment</td>
</tr>
<tr>
<td>marital status</td>
<td>marital status</td>
</tr>
</tbody>
</table>
-literacy level  -literacy level
-cultural practice  -cultural practice
-perceived support  -perceived support
-partying – risky behaviours as child is drinking/ recreational drug use
-treated with glucagon/ seizure/ bad experience/911 call -Mental Health

BG Targets for not Afraid  BG Targets for Afraid
40-7.0mmol/L  5.0-10.0mmol/L

3. **How often should you test blood sugar?** 4x a day + PRN Before meals, when symptomatic, before/ during/ post activity

4. **When is it too much?** There is no one answer – when it begins to interfere with regular activity it is too much >10x a day with no reason for (activity/ illness)

5. **What do you do to help address fears?**
   - educate how common it is and it is a normal part of diabetes management
   - educate on how to prevent hypoglycemia /acknowledge fear / explore reason for fears
   - raise targets initially while gradually working towards targets. Exp. Increase target at hs to correct at hs once correcting and no episodes of hypoglycemia/ work slowly to tightening target *small changes*
   - if available refer for counselling
   - increase frequency of appointments/ contact
   - trial sensor
   - building therapeutic relationships
   - diabetes alert dogs

6. **Common Strategies that can be used to prevent hypoglycemia?** Do not skip meals, SMBG at least 4 x a day, cho counting ability, following CDA guidelines for insulin injections / rotating sites / activities / knowing when to test/ insulin pump and using features such as temporary basal/ sensor use/ attending appointments with diabetes team/ education (mini dose glucagon/ sick day management) be prepared carry treatment and or snack is meal is delayed or having increased activity/ knowledge with advanced pump features/ how to adjust for increased activity and or illness/ driving guidelines.

7. **Does technology help or hinder fears?**
   - mostly helps but can sometimes hinder
   - may become too dependent on CGMs – decreasing SMBG
   - increasing stress with seeing blood sugar results in between testing exp. Trending lower overnight and was unaware
   - can be reassuring if afraid of lows (Dario meter/ Night Scout watch/One Touch reveal/ meters that calculate insulin dose and ISOB)
   - reacting to CGM trends may cause difficulty with adjusting insulin doses accurately
   - very expensive and with no benefits can cause increased financial stress

8. **What supports are available?** mfg of technology staff, diabetes educators , CDA guidelines, physician, pharmacist, peer support groups.

9. **Follow ups how often?** Doctors and diabetes educators at least quarterly, emailing blood sugars in between appointments for assistance with adjustments/ having flexibility with evening appointments/ ability to increase frequency of contact if had sever hypoglycemic episode or increased incidents of hypoglycemia

10. **Do you communicate findings with the team/ physician?** Do not know when and how often suspect not often enough

11. **Tips and Tricks (what do you do in your current setting)**
   - flagging chart for hx of severe low blood sugar or fearful of low blood sugar, education completed, consider yearly review of incidents and fears.
Appendix 4 - Bluewater Health E-mail Communications with Patient Agreement

Bluewater Health

E-Mail Communications With Patient Agreement

Patient name ____________________________________________

I, ____________________________________________________

NAME IN FULL OF PATIENT OR SUBSTITUTE DECISION MAKER

the __________________________________________________

RELATIONSHIP TO PATIENT OR SUBSTITUTE DECISION MAKER

of __________________________________________________

NAME OF PATIENT

have discussed communicating with Bluewater Health via e-mail.

I acknowledge and agree that:

• E-mail is not a secure or confidential form of communication. As the message leaves Bluewater Health, it is sent across the internet, where it could be intercepted and read. For this reason, Bluewater Health cannot guarantee the security of messages sent to and by me.

• My care provider will not use e-mail to communicate sensitive personal or health information.

• Specific issues that will not be discussed via e-mail include: ___________________________________________________________

• E-mail will not be used to communicate emergency or urgent health matters, as I understand that:
  • email messages can be delayed for both technical reasons and issues relating to the availability of the health practitioner and
  • my condition or the emergency situation cannot be adequately assessed via e-mail.

• Clinical decisions about treatment or care may be made on the basis of health information conveyed in e-mail messages.

• A printout of any e-mail communication related to treatment or care will be stored in my/the patient’s hospital record.

• Either party may stop communication via e-mail at any time if the conditions in this agreement are not adhered to. Notice must be given in writing to the patient/SDM or health care provider as applicable, if this form of communication is to stop.

E-mail may be used for:

• Conveying routine test results
• Scheduling appointments
• Certain counseling, e.g. nutritional
• Other reasons as agreed upon by myself and my health care provider:

Date: _____________________________ (DD/MM/YYYY) SIGNATURE OF PATIENT OR SUBSTITUTE DECISION MAKER

PRINTED NAME OF PATIENT OR SUBSTITUTE DECISION MAKER

Date: _____________________________ (DD/MM/YYYY) SIGNATURE OF HEALTH CARE PROVIDER

PRINTED NAME OF HEALTH CARE PROVIDER

Other individuals to receive and send e-mail on behalf of the health care provider to be indicated on page 2.

Completed form to be placed on the patient’s hospital record.

IM 437 C MR10 1ol2

IM00437