



Lacey Phillips
Director, Quality Standards
Clinical Institutes and Quality Programs
Ontario Health

SENT VIA EMAIL

November 24, 2021

Re: Diabetes Canada & Canadian Paediatric Society Feedback on Quality Standards for Transitions From Youth to Adult Health Care Services

Dear Lacey Phillips,

Thank you for the opportunity to provide feedback on the draft report from Ontario Health, *Quality Standard: Transitions From Youth to Adult Health Care Services*. Diabetes Canada (DC) and the Canadian Paediatric Society (CPS) support the development of quality standards for this population.

Quality standards that inform patients, health-care providers, and organizations about high-quality care for health conditions or processes are deemed a priority for quality improvement. Ontario Health's proposed quality standards for transitions from youth to adult health-care services align with Diabetes Canada's recommendation that patients need the right care at the right time (1). This includes defining clear and efficient pathways to accessing care, which understand the varied needs of different patient populations with distinct diabetes subtypes, including type 1 diabetes, type 2 diabetes, cystic fibrosis-related diabetes, and other rarer diabetes forms. This level of care will likely reduce, delay, or prevent the progression of diabetes and its comorbidities and complications with timely access to care. Definition and implementation of quality standards can improve care for a population during a critical and vulnerable period in young people's lives.

We ask that you consider integrating the following feedback into *Quality Standard: Transitions From Youth to Adult Health Care Services*.

1. *General feedback: resource requirements.* We agree with the statement, "Too often, transition planning revolves around systems and providers, rather than the young person. Young people (and their parents and caregivers, where appropriate) bring important expertise to the discussion, and their involvement in co-designing the transition plan is essential." The young person and their support system must be involved in this process, but the implementation of the process must rest with Ontario Health, not individual health-care providers who are involved

1300 - 522 University Avenue, Toronto, ON, M5G 2R5
Call us: 1-800-BANTING (226-8464)
Diabetes.ca

**DIABETES
CANADA**

Charitable Number: 11883 0744 RR0001



in the transition process. It requires a true commitment and related funding from Ontario Health for three types of resources: health human resources, educational resources (both developmentally and culturally appropriate), and digital health resources. The first is required at an individual clinic/medical centre level, while the latter two are required at a population level.

- a. *Health human resources.* Insufficient staff and time may pose barriers to implementation of these quality standards. Staffing resources include clerks to manage bookings, diabetes educators to do the readiness assessments, social work (and/or psychology) support and coaching patients as needed. Addressing the role of, and shortage of, primary care providers (PCPs) during transition is essential to ensuring that youth have appointments with their PCP in the 2 years prior to transition. All too often, youth will have received care from a specialist regularly and have lost contact with primary care. This is a problem at transition when they are not familiar with their PCP. Increased staffing for health-care services in the community, rather than inpatient services, will be required across the province to adequately support youth as they transition to adult care. Virtual care may alleviate the staffing challenges, as a transition coordinator could be made available to work with many clinics, regardless of geographical location. This option would further alleviate access concerns for young people in rural, remote, and northern areas of the province.
 - b. *Educational resources.* There is a need for consistent messaging with regards to culturally and developmentally appropriate educational resources. This requires availability of relevant resources across the province, instead of placing the onus on each pediatric and adult centre to create their own resources. It can also include disease-specific resources, including disease sub-type resources (i.e., type 1 vs type 2 diabetes). Translation of information for young people and their support unit (parents and/or caregivers) will reinforce the quality statement's value of health equity and addressing the social determinants of health. Adoption of this quality statement would be supported by standardized resources and tools, including implementation plans for transition.
 - c. *Digital health resources.* The statement could more directly reference the power and potential of data-sharing technologies. In this way, systems resources could utilize electronic health records and administrative data to monitor successful transition from pediatric to adult care across the province. A central system could close the loop on successful transition. The Ministry of Health/Ontario Health should create this central system that generates a periodic report of outstanding transitions.
2. *Health system barriers for Indigenous Peoples.* We appreciate Ontario Health for acknowledging the impact of colonization on the lives of Indigenous Peoples throughout Canada. It is important to hold in mind that strategies, guidelines, and interventions created for the general population



may or may not be culturally appropriate for Indigenous Peoples, or worse, could harm them. Quality standards need to support the development of strategies, guidelines, and interventions that are trauma-informed and Indigenous developed, led, and implemented. These should not only respond directly to the Truth and Reconciliation Commission (TRC) of Canada's 94 Calls to Action, but also acknowledge the impact of continued colonial policies and programs today. Implementation of standards of care for Indigenous Peoples without system change will be incremental and insufficient to address the magnitude of the burden.

The quality standards should mention cultural safety and humility and provide guidance on the delivery of culturally responsive health care. Indigenous Peoples' interactions and engagement with diabetes care can expose individuals to culturally unsafe conditions. Feeling unsafe or stigmatized leads many to avoiding accessing care or disclosing symptoms during health-care interactions. Health-care relationships provide an opportunity to amend the ongoing colonial dynamics often present in Indigenous health care (2). We recommend exploring avenues to ensure that health-care services are provided in ways that are culturally safe for Indigenous Peoples. We recommend that all health-care professionals and organizations working with Indigenous groups receive cultural safety and humility training. Further, Indigenous learners in the health professions must be supported by creating safe and respectful clinical learning environments that are free of racism and discrimination. This may include engaging Indigenous System Navigators, when available, to help Indigenous youth and families navigate the health-care system.

3. *Cultural relevance of standards for other high-risk Canadians.* Diabetes is a disease that brings with it many serious health challenges that disproportionately affects multiple groups of Canadians including those of African, Arab, Asian, Hispanic, and South Asian heritage. While the quality standards identify the importance of health equity and addressing the social determinants of health in the underlying values and guiding principles of the statement, they do not provide guidance on how the quality standards can be implemented differently among high-risk groups, based on their unique needs. Improvements in diabetes management and care means that everyone has access to culturally relevant care when and where they need it. For example, culturally appropriate tools need to be developed in collaboration with high-risk groups to support them in preventing diabetes and its comorbidities and complications. The consideration of social context and tradition is essential to developing an acceptable care plan. We see these steps as lacking in the current quality statement and recommend that Ontario Health adopt our recommendation of population-specific educational resources to address it.
4. *Rural and remote care:* Youth living in rural and remote communities face increased barriers to accessing regular care, particularly if they are required to travel regularly to larger urban centres



for monitoring and management of a chronic condition. These geographical barriers—which also involve commitments of time and financial resources that may be lacking in a family unit—can further exacerbate continuity of care and motivation to engage in regular self-management. Diabetes Canada recommends that Ontario Health explicitly address the unique challenges for youth who may be required to travel for routine medical care and identify the responsibilities of health-care personnel to maintain a connection before, during, and after transition to adult care. As mentioned previously, virtual care can help to address the challenge of providing support to young people residing outside large urban centres.

5. *Quality Statement 1, Early Identification and Transition Readiness:* We support this statement. The tools provided in the draft document will assist in assessing transition readiness, the performance measures are specific. It should be a routine part of scheduled visits starting at a specific age for all patients and then adjusted based on individual needs. Sharing of disease-specific (disease sub-type-specific, where appropriate) resources between clinics—checklists, readiness assessment tools, and educational modules to bridge the gaps identified in knowledge and skills—may help alleviate some of inconsistencies across health service providers. This period in a young person’s life can be challenging; if they are lacking support at home, it may be more difficult for them to fully engage in self-management of their health condition. They may also fluctuate between levels of independence, relying on their support unit more or less at varying times. Regular check-ins with their designated most responsible provider may need to be increased in these circumstances: i.e., the health-care team should not presume that a young person who’s already been classified as “transition ready” will always stay at this level. Additionally, we recommend that providers consider the presence of a parent/caregiver during transition meetings. In many cases, the young person will have a parent or caregiver present to advocate for them, share insights, etc. However, it can sometimes be “too much” interaction by the non-patient; in these cases, the youth may require and/or desire more one-on-one interactions with the health-care team. Finally, we recommend Ontario Health define “regular assessments” for the purposes of this statement.
6. *Quality Statement 2, Information Sharing and Support.* We support this statement and have specific recommendations on how to personalize the transition plan and enhance information sharing and support.
 - a. Providing access for health-care teams to examples of developmentally appropriate information would be helpful so that each clinic is not spending precious resources (staff, time, and money) to create their own materials. Additionally, this will ensure consistency in messaging overall.



that virtual care may offer options that should be addressed. In both cases, time and availability may limit the practicality of this step. As indicated above, a central system, could close the loop on successful transition—for example, digital access to the patient’s transition care plan would monitor and report where teens are in the process, could indicate a successful transition or a flag when a file is still open. It is not feasible for each centre to create a shared system between each and every pediatric and adult clinic. The Ministry of Health/Ontario Health should create this central system that generates a periodic report of outstanding transitions.

10. *Quality Statement 6, Transfer Completion.* We support this statement, particularly the requirement that both the young person and the health-care team—as represented by the designated most responsible provider—deem the transition to be complete. We recommend inclusion of an optional reconnection meeting with the designated most responsible provider. This type of meeting may assist the young person in achieving closure with their move from pediatric services, especially if they have been with child-oriented and youth-oriented services for a long time. Additionally, it can serve as an opportunity to understand what went well and areas of improvement in the transition process for each provider and the system.

Diabetes Canada is an organization that produces world-renowned, evidence-based clinical practice guidelines and represents health care providers who practice evidence-based medicine. Treatment standards should be based on currently available evidence and widely adopted by health care providers, organizations, and people living with diabetes. We look forward to people living with diabetes, health care providers, and organizations in Ontario having access to the quality standards for youth transitioning to adult care.

The Canadian Paediatric Society is the national association of paediatricians, committed to working together to advance the health of children and youth by nurturing excellence in health care, advocacy, education, research and support of its membership.

Sincerely,

Seema Nagpal, PhD
VP, Science & Policy
Diabetes Canada



References

1. Diabetes 360°: A Framework for a Diabetes Strategy for Canada. [Internet]. Toronto, ON: Diabetes Canada; 2018 [cited 2020 Nov 17]. Available from: <https://www.diabetes.ca/DiabetesCanadaWebsite/media/Advocacy-and-Policy/Diabetes-360-Recommendations.pdf>
2. Jacklin KM, Henderson RI, Green ME, Walker LM, Calam B, Crowshoe LJ. Health care experiences of Indigenous people living with type 2 diabetes in Canada. *CMAJ*. 2017 Jan 23;189(3):E106–12.
3. Diabetes Canada Clinical Practice Guidelines Expert Committee, Wherrett DK, Ho J, Huot C, Legault L, Nakhla M, et al. Type 1 Diabetes in Children and Adolescents. *Canadian Journal of Diabetes*. 2018 Apr 1;42:S234–46.
4. Van Walleggem N, Macdonald CA, Dean HJ. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care*. 2008 Aug;31(8):1529–30.
5. Butalia S, Crawford SG, McGuire KA, Dyjur DK, Mercer JR, Pacaud D. Improved transition to adult care in youth with type 1 diabetes: a pragmatic clinical trial. *Diabetologia*. 2021 Apr;64(4):758–66.