

CANadian PaediAtric diabetes ConsortIum (CAPACITY)

Co-designing a nationally coordinated person-centred paediatric diabetes registry

Chapter 3: Examining Potential Use Cases for Registry Development

Prepared by the Family and Child Health Initiative team at the Institute for Better Health at Trillium Health Partners, Mississauga, Ontario, Canada

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Executive Summary

Introduction: In Phase 1, a multi-stage co-design approach was used to ensure the CAPACITY registry was developed as a patient-centred registry alongside healthcare providers, researchers, and caregivers of youth with diabetes. Throughout this process, we learned about registry priorities and functions (Chapter 1) and the data assets needed to achieve the desired outcomes from the registry (Chapter 2). We also learned about important health and well-being indicators that could be collected to improve healthcare delivery, quality, research, and innovation, recommendations around registry governance and access. In this chapter, we now aim to transition these learnings into action, by translating all the above findings into specific registry requirements through a technical use case methodology.

Methods: We employed a qualitative synthesis methodological approach to develop broad use case categories and sub-themes to inform the registry functions. By leveraging themes from our knowledge exchange events (KEEs) and insights from the data mapping workshops, we formulated "third-order interpretations" for the use case categories. This interactive, co-design process with four research team members enhanced the quality, rigor, and objectivity of the data synthesis. The process included reviewing key challenges from KEEs and aligning them with already high-level registry functions: Research, Lived Experience (LE)-Driven, and Quality Improvement. These challenges were re-examined through analytical thematic analysis to create co-designed "use cases" (serves to identify sequential interactions between the system and its users to achieve a goal) within each category. We then identified potential actors and desired impacts for each of these use cases. To visualize our findings and third-order interpretations, we used BioRender software to design a graphic that illustrates the interconnectivity among the main elements and reflects the CAPACITY registry's developmental, dynamic, and responsive model from the perspectives of healthcare providers, researchers, and caregivers of youth with diabetes.

Results: We identified seven key challenges from KEEs, which we used to develop broad use case categories and nested sample use cases for each registry function (Research, LE-Driven, and Quality Improvement). The broad use case categories for: research were diabetes challenges, evidence and resource utilization, LE-driven function were the provision of mental health and support, increasing awareness of diabetes and enabling research utilization by patients and their

families, and quality improvement were improving patient experience and support, and improving transition experience. Sample use cases (2-3) within each of the broad use case categories then showcased examples of how the objectives/goals of each of the use case category could be achieved. Potential actors (end users) interacting with these use cases and the registry include researchers, patients, caregivers, funders, the education system, the pharmaceutical industry, healthcare providers, governments, and policy and decision makers. The desired impacts of the CAPACITY registry included improved care quality, better educational systems, responsive health and social services, integrated health systems, and enhanced quality of life for paediatric diabetes patients and their caregivers.

Conclusion: The co-design process of the CAPACITY registry emphasizes creating a registry that meets the health and social needs of paediatric diabetes patients, caregivers, service providers, and researchers. This involves a dynamic and inclusive approach with continuous user participation, particularly from those living with paediatric-onset diabetes. Phase 1 of the co-design phase identified primary challenges, data gaps, and user experiences, and explored the integration of available data into the registry. It also examined the involvement of beneficiaries in data input, access, utilization, and oversight. This phase concluded with the development of potential use cases to guide the prototyping and co-implementation of the audit and feedback intervention in Phase 2. The findings aim to 1) inform the selection and collection of additional indicators for the registry, 2) support the development of the audit and feedback framework, and 3) inform data ownership and governance frameworks.

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INTRODUCTION

The Canadian Paediatric diabetes Consortium (CAPACITY) project aims to develop a nationally coordinated person-centred registry of paediatric diabetes data with healthcare providers, researchers, and people with lived experience, including youth and families. Specifically, the project has the following three objectives and phases 1) To co-design a Canadian paediatric diabetes registry; 2) To co-implement the registry; and 3) co-evaluate the impact of the registry. In Phase 1, the Family and Child Health Initiative at the Institute for Better Health, Trillium Health Partners in Mississauga, Ontario, spearheaded active engagement of a diverse range of potential registry users to center their experiences, voices, and expertise to guide the development, data content, usability, and governance of the CAPACITY registry.

Throughout Phase 1, we applied multi-stage, interrelated co-design methods to ensure the voices and perspectives of healthcare providers, researchers, and people with lived experience (specifically caregivers of youth living with diabetes) guided the exploration of potential uses of the registry and the data required to achieve desired impacts¹. By involving key shareholders with different lived experiences and backgrounds, we aimed to inform the development of a patient-centred registry with clear objectives, data usage practices, and positive patient outcomes.² Furthermore, we sought to shift the role of children living with diabetes and their families from simply being data units in a large registry data set, to those whose voices and experiences can inform the registry's co-design, decision making, evaluation and further adaptation..³ Patient-centred registries are uniquely successful as they are well aligned with the community's needs while simultaneously identifying important health and well-being indicators that may have previously been ignored. For example, the patient-centred Swiss Multiple Sclerosis Registry (SMSR) highlighted the need to examine the cost of management and care within its patient-reported outcome measures (PROMs), an indicator not previously captured.⁴ In addition, patient-centred registries can greatly impact decision-making for changing healthcare and public policies, positively impacting outcomes.⁵ Moreover, registry data quality also seems to be closely tied with a registry being patient-centred, as lack of shareholder involvement leads to unclear role definition, insufficient data dissemination and a lack of knowledge translation and uptake, subsequently decreasing the quality of registry data and its impact. ²

The co-design activities conducted in Phase 1 primarily focused on active and continuous engagement with shareholders. Throughout these activities, we learned about registry priorities

and functions (Chapter 1) and the data assets needed to achieve the desired outcomes from the registry (Chapter 2). We also learned about data indicators that were considered valuable for improving healthcare delivery, quality and patient well-being as well as a desire for active participation by these shareholders in the registry's data governance and access structure.³ To move this acquired knowledge into action and co-create a patient-centred registry, we now seek to translate all of the above findings into specific registry requirements that can be leveraged in the next phase of registry co-design (implementation), through the synthesis and identification of use cases.

METHODS

To inform the identification of system requirements for the registry, while leveraging the registry needs and challenges identified previously during the different co-designing activities conducted with health care providers, researcher and caregiver of paediatrics patients living with diabetes, we applied a technical “use case” methodology and approach. A use case identifies the sequential interactions between the system and its users (actors) to achieve a particular system goal.⁶ Formulating use cases supports robust product development by circumventing errors, minimizing duplication, and ensuring the system is aligned with its sought impacts.⁷ Since the CAPACITY registry aims to address the health and social needs of those with paediatric diabetes and their caregivers, identifying and co-designing use cases would help translate previous findings into action. We utilized the use case methodology to provide broad use case categories that need to be explored and suggested sample use cases within each category for the previously identified research, quality improvement, and LE-driven functions.¹ These co-designed use case categories and sample use cases can then be used to inform the further development of operational use cases with technical partners based on identified priorities for the next phase.

We used the qualitative evidence synthesis methodological approach to develop our use case categories.^{8,9} Leveraging the salient themes from our KEE findings (Chapter 1) and the needs, gaps, and data assets identified from our workshops (Chapter 2), we developed analytical themes (also known as “third-order interpretations”)⁹ for the use case categories and their interrelated elements (category-specific use cases, involved actors, and desired impacts).

For our use case categories (“third order interpretations”), we utilized an interactive and collaborative co-design process with four research team members to enhance quality, validity

and objectivity. Our stepwise process consisted of reviewing and extracting key challenges from our knowledge exchange events (KEEs) findings. Next, we reviewed the identified key challenges according to the high-level registry functions, Research, LE-Driven, and Quality Improvement to create use case categories for each function. We re-examined the data asset mapping workshop findings through analytical thematic analysis regarding available, desired, and required data elements. This analysis helped create samples of co-designed use cases nested within each identified use case category. Finally, all findings from previous co-design activities were re-examined to identify potential registry users (actors) and the desired impacts.

We used the BioRender (website) software to integrate and visualize the results of this analytical process and the team's re-interpretation of the perspectives of the primary participants (those with lived experience, health providers, and researchers) from the co-design activities in Phase 1.

RESULTS

Figure 1 depicts the use case categories, associated nested use cases, and their elements. It also illustrates the iterative, interlinked, and cyclical nature of utilizing these use cases in the envisioned registry, allowing it to adapt according to emerging needs continuously. The main components that contribute to the proposed use case categories are the challenges being addressed, main registry functions, specific intra-category use cases, actors, and primary impacts.

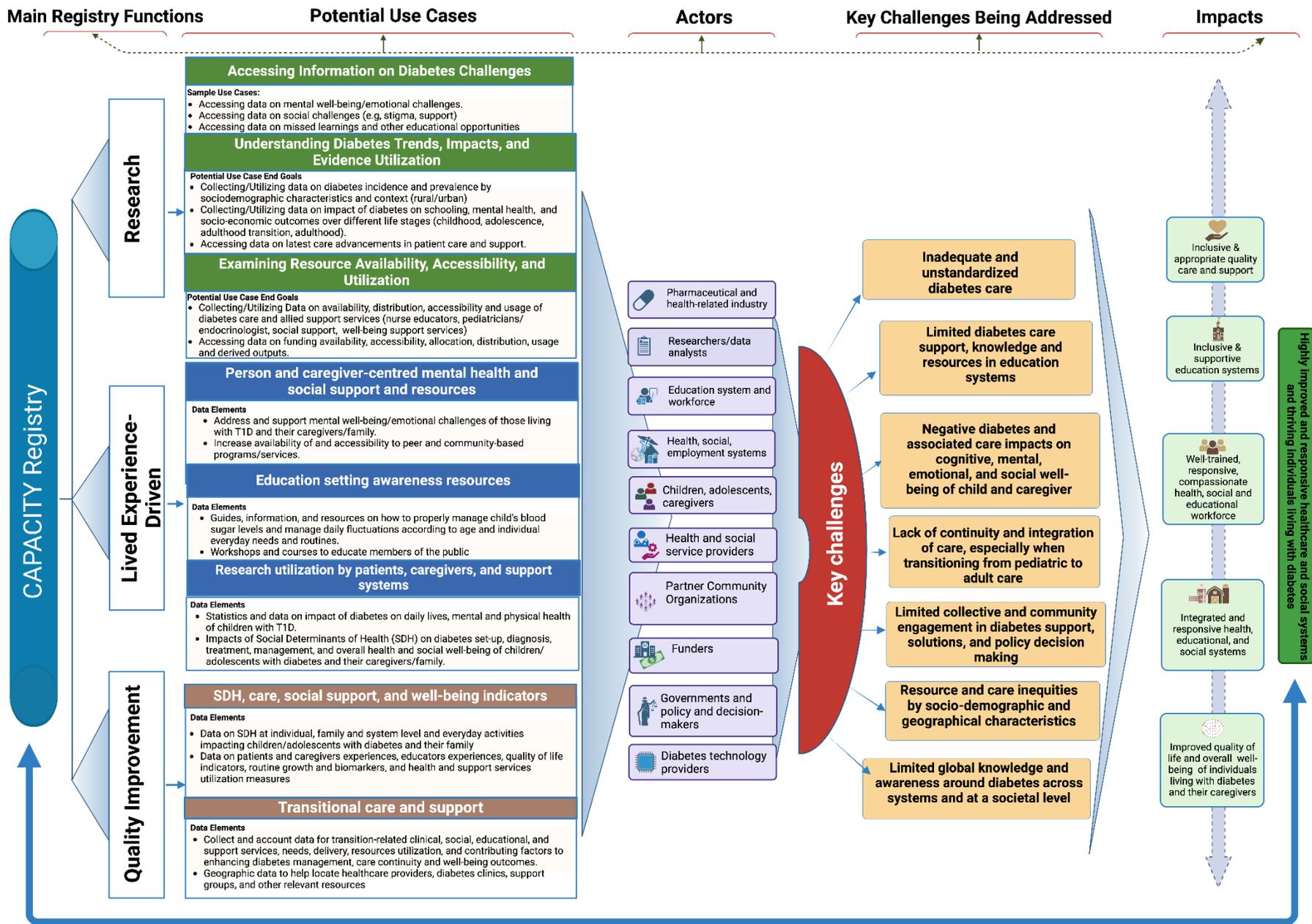


Figure 1: Use Case Categories and Sample Use Cases identified with Actors for the CAPACITY Registry (created in BioRender.com)

Key Challenges the Use Cases Address

Seven key challenges represented participant views from the Phase 1 activities. These challenges consisted of inadequate diabetes care, lack of support and resources in educational settings, negative diabetes impacts on mental and social well-being, lack of preparation for transition and transfer from paediatric to adult care, lack of community engagement to inform decision-making regarding diabetes care, lack of support and management in the healthcare and education systems, regional and socio-demographic disparities and inequities in access to resources and care, and limited awareness of diabetes within and across systems exacerbating negative outcomes such as diabetes-related stigma (Figure 1).

Registry Functions and Co-Designed Use Case Categories with Nested Use Cases

Research Function:

For the research function, the use cases relate to gaining further insight into existing challenges within paediatric diabetes, the resources available and their utilization to mitigate these challenges, and the trends surrounding diabetes prevalence in Canada based on specific socio-economic indicators such as household income, residency area, cultural background, educational level of caregiver and children, having private health insurance, legal residency status, and others.

Within this function, **we identified three main analytical use case categories:** The first use case category is **accessing information on diabetes challenges**. Sample use cases about accessing information on diabetes challenges consist of accessing data on mental well-being challenges through systematic screening and standardized assessment tools, assessing social experiences (such as stigma) using patient-reported outcome measures, and examining impacts on school attendance and performance through linkages with educational administrative datasets or by self- or caregiver-proxy report, and diabetes-related healthcare utilization. The second use case category we identified was **understanding diabetes trends, impacts, and evidence utilization**. For this category, specific use cases included collecting and examining data on diabetes incidence and prevalence according to socio-demographic indicators. Another use case includes examining the impacts of diabetes longitudinally by administering mental health, educational and socioeconomic data surveys at fixed time points. To encourage evidence utilization, another use case examines registry linkages with provincial and national administrative databases and pulls data related to adherence to clinical practice guidelines and

research on advancements in diabetes-related care to account for new therapeutics and innovative technologies. Finally, the third use case category is **examining resource availability, accessibility, and utilization**. Sample use cases from this category explore the collection and use of data about models of diabetes care, including allied support services, and collecting and analyzing data on diabetes-related program funding and allocation regionally and nationally.

Lived Experience (LE)-Driven Function:

For the LE-driven function, proposed use cases relate to knowledge translation of registry findings, including creating lay reports of research findings, providing information about evidence-based and state-of-the-art models of care, cutting-edge educational tools, real-time knowledge of the latest advancements in therapeutics and technologies, and resources for mental health and social support.

Subsequently, we identified three main use case categories within the LE-driven function. The first use case category is **providing mental health and social support to patients and caregivers**. Specific use cases related to mental health and social support included gaining a better understanding of the trajectory of identified mental health challenges, the impacts of these challenges over the patient's life course and providing information to patients and caregivers about community-based programs and services to address these challenges. The next category we identified is **increasing diabetes awareness and providing education about diabetes management**, in which sample use cases include access to self-management education resources and diabetes-awareness products. Another use case specifically targeted providing this access to those external to the diabetes community. Multiple pathways can be taken to provide this access via the CAPACITY website or a dedicated dashboard. However, access should include easy-to-understand language and a mechanism for providing up-to-date information. Finally, for the third category identified, **enabling research utilization by patients, and families**, sample use cases suggest providing layman language-based statistics and information about diabetes impacts according to the socio-demographic differences.

Quality Improvement Function:

Finally, for the quality improvement function, the sample uses provided relate to the improvement and enhancement of patient experiences with diabetes care and management in both educational and healthcare settings, along with the improvement of existing healthcare

services and care strategies to make transitioning to adult diabetes care a more seamless, efficient, and patient-centred experience for youth living with diabetes and their families.¹⁰

Within this function, we identified **two main use case categories**. The first is **improving patient experience and support** in which the sample use cases pertain to collecting and tracking patient-reported experience measures (PREMs), patient-reported outcome measures (PROMs), including health-related quality of life, home and community care supports, and data on available support and accommodations in educational settings. Suggested data to be collected in educational settings is related to accommodations that are present in schools for youth with diabetes, provincial and municipal laws about protecting children with diabetes, existing diabetes management plans, and each school's adherence to their guidelines, as all have shown to impact experience and outcomes of children living with diabetes.¹¹ Lastly, the sample use cases for the next category, **improving the transition experience from paediatric to adult care**, including applying evidence-based transition frameworks and using transition readiness assessment tools to allow for a continuous examination and perhaps even predictive modelling to determine optimal transition times. Also included is a use case for developing a geographic database of health providers, healthcare facilities and support groups for clinicians to refer transitioning patients based on their future plans effectively. This would allow for a more seamless transition, reduce fragmented care, and improve provider knowledge, all of which have been effectively documented to impact the quality of care at transition.¹²

Use Case Actors

We identified eleven groups of actors who would potentially interact (as data providers, data users, decision-makers, knowledge translation agents etc.) with the diabetes registry. These actors included researchers/data scientists, adolescents with diabetes and their caregivers, health and social service providers, community organizations and hospitals, diabetes technology or pharmaceutical industries, funders, decision-makers, and partners from education, social and employment systems. These identified actors can be involved with the registry as single actors or groups of actors, engaging with one or more use case categories and category-specific use cases, depending on their interests and needs.

Desired Impacts

Exploring these proposed use case categories and their associated elements (sample use cases, challenges addressed, and actors) could enable positive impacts related to inclusive and

appropriate, high-quality care; better educational systems for those living with diabetes; a responsive health and social workforce; integrated health systems; and improved quality of life for those living with diabetes and their caregivers. These impacts would ultimately improve the health and well-being of children living with diabetes, their caregivers and communities. Continuous data collection related to these use cases can promote improvements in current care practices, education systems, and quality of life for people with diabetes and their families, creating a feedback loop that would continue to enhance the CAPACITY registry.

DISCUSSION

The objective of Phase 1 was to co-design a first-of-its-kind Canadian national paediatric diabetes registry by aiming to center the voices of patients and their families, providers, and researchers, using an equity, diversity, and inclusion lens to improve health care quality, research opportunities, and outcomes for children living with diabetes and their families. The proposed use cases encapsulate what a patient-centred national diabetes registry should be able to achieve to address the disparities and challenges identified by those living with paediatric diabetes, their caregivers, health service providers, community partners, and researchers.

As we move into Phase 2, where we seek to co-implement the registry and co-design an **audit and feedback initiative**, it is important to examine how subsequent registry-based activities can be informed, modified, and co-designed to translate the above findings into tangible outcomes and actions effectively. There is also a need to begin determining what is feasible (in scope) for the upcoming phases and what needs to be part of the subsequent expansion and maintenance of the CAPACITY registry over time (out of scope).

Examining the project's goals and objectives alongside the proposed use case categories and the extant published literature, we believe the following recommendations may fall within the scope of the existing project and should be considered when moving forward.

Recommendations for Upcoming Project Phases (In Scope)

1. **Examining and Expanding Data Indicators:** The CAPACITY registry aimed to collect key indicators of equity and diversity for all shareholders involved in the registry. Of the existing variables being collected from each data center and harmonized by Maelstrom, we have categorized those well aligned with the expressed needs and desires of the participants engaged in Phase 1 and should be retained (Table 1). We have also included

variables that are currently not being collected and harmonized but should be considered for inclusion, especially if they are already being collected at some of the pilot sites. These suggested variables address many of the above use cases and are also included in the core set of sociodemographic data elements recommended by Ontario Health, which also provides their detailed definitions.¹³

Table 1: Existing Variables and Variables to be considered for inclusion to address the use cases identified

Existing CAPACITY variables that align with expressed needs and desires of participants engaged in Phase 1:	Variables that <i>should</i> be considered for inclusion to inform the use cases identified:
<ul style="list-style-type: none"> ○ Sex ○ Ethnicity ○ Diabetes Type (1, 2, Neonatal, etc.) ○ Presentation of Onset Symptoms (DKA, Hyperglycemia) ○ Age at and Cause of Death ○ Age at Diagnosis and Age at Visit ○ A1C level ○ Medical Insulin Use (Yes/No) ○ Injections per day (1-4) ○ Pump type ○ Sensor Use (TIR, TBR) ○ Number of medical visits ○ Number of hypoglycemic events ○ DKA leading to hospitalization ○ Medications taken ○ Laboratory Data (Cholesterol, triglycerides, etc.) ○ Anthropometric measurements at visit 	<ul style="list-style-type: none"> ○ Expanded Social Determinants of Health Data such as: <ul style="list-style-type: none"> ▪ Racialized Group (Groups that encounter Racism – separate from Ethnicity) ▪ Indigenous Identity ▪ Canadian status (Born or Arrived to Canada & When) ▪ Sexual Orientation ▪ Gender & Transgender Identity ▪ Religion/Spiritual Affiliation ▪ Disability Status ▪ Geographic Location ▪ Housing Status (owns or rents residence, lives in social or subsidized housing, or is underhoused or experiencing homelessness) ▪ Food access/insecurity ▪ Educational Attainment (Highest Level of Education for youth and/or caregiver) ▪ Employment Status (for youth and/or caregiver) ▪ Household Income ▪ Use and Access of Health Services ▪ Family structure and Composition ▪ Birthplace ▪ Preferred Language of Communication ▪ Mode of Transportation ○ Mental health challenges <ul style="list-style-type: none"> ▪ Distress

	<ul style="list-style-type: none"> ▪ Depression ▪ Anxiety ▪ Eating behaviours ○ Sleep Quality ○ Insurance coverage (Public and/or Private) ○ Impacts on access to therapeutics and technologies ○ Patient reported experience and outcome measures (PREMs and PROMs)- some suggested variables to include: <ul style="list-style-type: none"> ▪ Health, Social and Emotional Quality of Life ▪ Patient Satisfaction ○ Academic Performance
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2. **Exploring Other PREMs and PROMs:** To address the sample use cases mentioned above during Phase 2, tailored prompts based on the above findings should be included during shareholder interviews and subsequent PAB and decision-making meetings. Although we have proposed some PREMs and PROMs variables in Table 1, our co-design activities highlighted how individuals perceive, interpret and manage their diabetes is unique and impacted by a variety of factors ranging from socioeconomic to behavioural, and environmental (e.g. work, school), all which is also extensively documented in the literature.¹⁴ Therefore, centering the use cases and the challenges above, key prompts should be developed to explore this intersectionality and identify and include additional PREMs and PROMs.
3. **Developing an Easy-to-Use Dashboard:** When exploring interactive dashboards for the audit and feedback in Phase 2, it is essential to incorporate layperson language and easy-to-understand visuals to allow wider access to this information, especially for the lived experience population. Our findings also suggest a continued desire for those with lived experience to be involved in the development and early stages of the audit and feedback initiative. This is well aligned with Phase 2 activities and can be leveraged to build an easy-to-use dashboard and build motivation for utilization. This strategy of engaging those with lived experience to co-design audit and feedback mechanisms have been shown to be successful in other settings.¹⁵ A study involving end users in the development of an audit and feedback initiative in the emergency department setting

found that having a human-centred approach to design for the audit and feedback initiative and understanding the culture and needs of the end user resulted in a positive impact on the feasibility and adoption of the end product.¹⁵

4. **A Well-Aligned Decision – Making Criteria:** The decision-making criteria, within the governance and access framework, for registry access requests, should weigh the research question being examined against priorities (use cases) indicated by the shareholders in Phase 1. This would allow the use case priorities to inform proposed research studies or quality improvement projects that stem from the registry. In addition, mechanisms should be developed that allow the developed criteria to be fluid and adaptable to change in response to new challenges and learnings. Built-in mechanisms and decision tools that would allow the criteria to adapt and learn will result in efficient and timely responses, maintain registry product quality, and build trust via its transparency, all factors previously linked to registries' success.¹⁶
5. **Prioritizing Knowledge Translation:** Lastly, introducing a requirement for those requesting CAPACITY data to share layperson abstracts (at project initiation) and layperson reports (for interim and final findings) that can be uploaded on the CAPACITY website to inform shareholders regarding how their data is being used. The participants in our Phase 1 activities emphasized the importance of benefitting from the generated knowledge. Effective registries are easy to access, have a high degree of data completion and participation, and the data is both easy to understand and useful to all levels of shareholders including youth with diabetes and their caregivers.¹⁷

Recommendations for Future Expansion & Grants (Out of Scope)

For future expansion and maintenance of the registry beyond the scope of this project, based on our use cases, and existing literature we recommend exploring the following:

1. **Shifting to a Live Registry:** A facet of the registry identified and desired by our participants was a shift from a nationally coordinated database to a “live” registry. A live registry is defined as one with a constantly dynamic dataset that records new information as it is collected, which then informs up-to-date indicators. Live registries can provide real-time feedback regarding processes and outcomes of care to all shareholders involved.¹⁸ This feedback can be used to benchmark data against other centers regionally in Canada and internationally, resulting in improved quality of care and quality of life

outcomes for youth living with diabetes along with their caregivers.¹³ Along with being regularly updated and providing regular feedback, the registry allows timely improvements in care and management.¹⁸ Throughout our discussion in Phase 1, longitudinal monitoring for trends, providing real-time data on diabetes prevalence and incidence, and being able to see the evolution of practices in response to these data have constantly featured. Within the current format, CAPACITY can only offer a snapshot in time. Transitioning to a live registry could allow algorithms to analyze data in real-time.² Until this can be realized, we recommend that the CAPACITY registry sets a high frequency of data sync as resource and time considerations allow.

2. **Expanding the CAPACITY Website:** For future expansion, further developing the CAPACITY website to act as a hub of various resources, including awareness and educational materials, and connect people to external services based on the information they share should be explored. There are examples where this has been done successfully and shown to increase patient autonomy and satisfaction.¹⁹ Additionally, registries that contain a substantial amount of knowledge translation resources and tools have been found to have increased users and interest which show the benefit and demand for keeping knowledge translation as a core element of the CAPACITY registry going forward.²⁰ The BETTER registry has been working towards some of this knowledge translation by holding webinars for patients to understand and benefit from the information being generated.²¹ We now suggest that the CAPACITY registry explores a permanent hub for this knowledge to live on to provide continued access.
3. **Continued Expansion of Data Indicators:** The registry should focus on incorporating any remaining data variables not determined to be in scope in the previous phases. Priority should be given to indicators of mental health and well-being, diabetes-related stigma, experiences within educational settings and experiences transitioning from paediatric to adult care.
4. **Developing Further Linkages:** The registry should continue developing linkages with community partners and programs, allowing users to search appropriate programs by location, allow for knowledge exchange as well as collaborative initiatives across programs and partner organizations, and connect youth with diabetes and their caregivers to professionals and individuals from diverse healthcare disciplines.¹⁹

5. **Future Grants to be Explored:** Lastly, applying for future funding to repeat the co-design activities of Phase 1, focusing on racialized and marginalized communities, especially Indigenous populations should be considered. Our engagement with the National Indigenous Diabetes Association (NIDA; <https://nada.ca/>), combined with a lack of representation of ethnic minorities (Black, African, and Caribbean, South Asian) has indicated the need for these perspectives to be integrated for the registry to be fully inclusive. Until then we recommend tracking demographic indicators of participants for all future activities to identify if such gaps remain while actively continuing to engage with NIDA and other organizations to address these challenges in diversity, equity and inclusion.

LIMITATIONS

One limitation of the development of potential use cases for the CAPACITY registry is that they only represent the perspective of a limited group of potential users and do not represent the views of all potential registry actors, including many of those presented in Figure 1. The perspectives and voices of those directly impacted, as well as the data providers, children, and adolescents with diabetes, are also not presented here and are greatly needed. Our activities highlighted the need for youth involvement in data collection and the selection of variables, and therefore future project activities should explore targeted recruitment for the youth. Additionally, as indicated above, and previously, our participants lacked representation from certain geographic areas and ethnic groups, and therefore, some views may be missing. Finally, we presented co-designed use case categories and sample use cases without specific technical requirements. Therefore for the operationalization of these proposed use cases into the registry, additional technical considerations with system partners will need to be incorporated, which will be the scope of future work.

CONCLUSION AND NEXT STEPS

The co-design process of the CAPACITY registry highlights the importance of building a registry that is technically and impactfully responsive to the health and social needs of paediatric diabetes patients and their caregivers, as well as health and social service providers and researchers. This could be achieved through a dynamic, comprehensive, and inclusive approach with the continuous participation of key users, including those living with paediatric-onset diabetes.

In summary, Phase 1 of the co-design phase of the CAPACITY registry has successfully identified primary challenges, delineated existing data gaps, and gained insights into user experiences and associated data desires. The phase has also explored available data and its integration into the CAPACITY registry and examined beneficiaries of the registry and their involvement in data input, access, utilization, and oversight. We have now concluded this phase by developing a series of potential use cases that the CAPACITY registry and its team can use to translate these findings into positive action in the upcoming phases.

These use cases could guide the prototyping and co-implementation of the audit and feedback intervention in Phase 2. We hope that our findings will 1) inform the selection and collection of additional indicators/variables for co-implementation of the registry, 2) support the development of the audit and feedback framework, and 3) inform the data ownership and governance frameworks.

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CONFLICTS OF INTEREST

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