CAnadian PaediAtric diabetes ConsortIum (CAPACITY)

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

Community Report

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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HOW TO CITE THIS REPORT:

Zayd Hafiz, Sara Abdullah, Cilia Mejia-Lancheros, Ugonna Ofonagoro, Ian Zenlea. CAnadian Paediatric diabetes ConsortIum (CAPACITY): Co-designing a nationally coordinated person-centred paediatric diabetes registry: Community Report. Institute for Better Health, August 2024.

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Land Acknowledgement

We want to acknowledge that the land on which the Region of Peel operates is part of the Treaty Lands and Territory of the Mississaugas of the Credit. For thousands of years, Indigenous peoples inhabited and cared for this land. In particular, we acknowledge the territory of the Anishinabek, Huron-Wendat, Haudenosaunee, and Ojibway/Chippewa peoples; the land that is home to the Metis; and most recently, the territory of the Mississaugas of the Credit First Nation who are direct descendants of the Mississaugas of the Credit. We are grateful to have the opportunity to work on this land and, by doing so, give our respect to its first inhabitants. We recognize that our collective work in family and child health must actively center the voices and experiences of Indigenous people, families, and communities across Peel. We must continue to collectively think about how our health systems and practices across the region have historically and continue to impact the health and well-being of Indigenous people, families, and lands. We are all accountable for individual and collective action as we work towards decolonizing health systems and practices.

Introduction

Background

Diabetes is one of the most common chronic conditions in children/youth, affecting millions globally.[1] Canada specifically is among the top countries globally with one of the highest rates of type 1 diabetes (T1D) in children, with about 37.9 new cases per 100,000 people annually.[2] Additionally, type 2 diabetes (T2D) cases in Canadian children are also increasing, with an average of 47 new cases each month.[3] Despite advances in diabetes treatment, those who develop diabetes in childhood face higher rates of complications, such as heart disease, lower quality of life, and a shorter life expectancy compared to people without diabetes.[4,5,6,7] These outcomes are partly due to inequalities in income, education, ethnicity, and access to health insurance and treatment.[8,9,10,11,12] To understand how to prevent diabetes in early childhood and improve care outcomes for children/youth with diabetes, there is a need for high-quality data to understand the effectiveness of current healthcare practices, standardize care, and improve patient experience.[13,14] One way to help do that is by using a health registry.

Health registries are databases containing information about individuals with specific health conditions that can be used to improve care and inform policy.[15,16,17] Despite national diabetes registries being implemented in Europe and the United States, in Canada, no nationally coordinated database/registry

links all clinical data to allow shared learning and standardization. A national diabetes registry in Canada, particularly one focused on children with a chronic condition and co-designed using a person-centred approach, can enhance the understanding of care patterns and outcomes amongst healthcare providers, advocates, and community members.[17,18,19,20,21] A person-centred approach considers the needs and experiences of individuals and systematically incorporates their data beyond traditional medical encounters. This maximizes the effectiveness of a nationally coordinated registry and its data on quality of care, people's health and well-being, research, and health system optimization and standards.[18,22]

Goals & Objectives

The Canadian Paediatric Diabetes Consortium (CAPACITY) aims to create a national, person-centred registry for paediatric diabetes data. The main goals of this project are to co-design, co-implement, and co-evaluate this registry alongside clinicians, children/youth with diabetes and their caregivers, researchers, and community partners.

The first phase of this project focused on co-designing this registry and has now been concluded (March 2024). This report describes the initial co-design activities carried out by the Family and Child Health Initiative (FCHI) at the Institute for Better Health (IBH), Trillium Health Partners (THP), in Ontario, as part of phase 1. The co-design phase involved engaging diverse people with lived experiences of diabetes and their families, healthcare professionals, and researchers (i.e., “shareholders”) to ensure the registry being developed meets the needs of children/youth with diabetes and their caregivers and supports high-quality care and research through three main objectives:

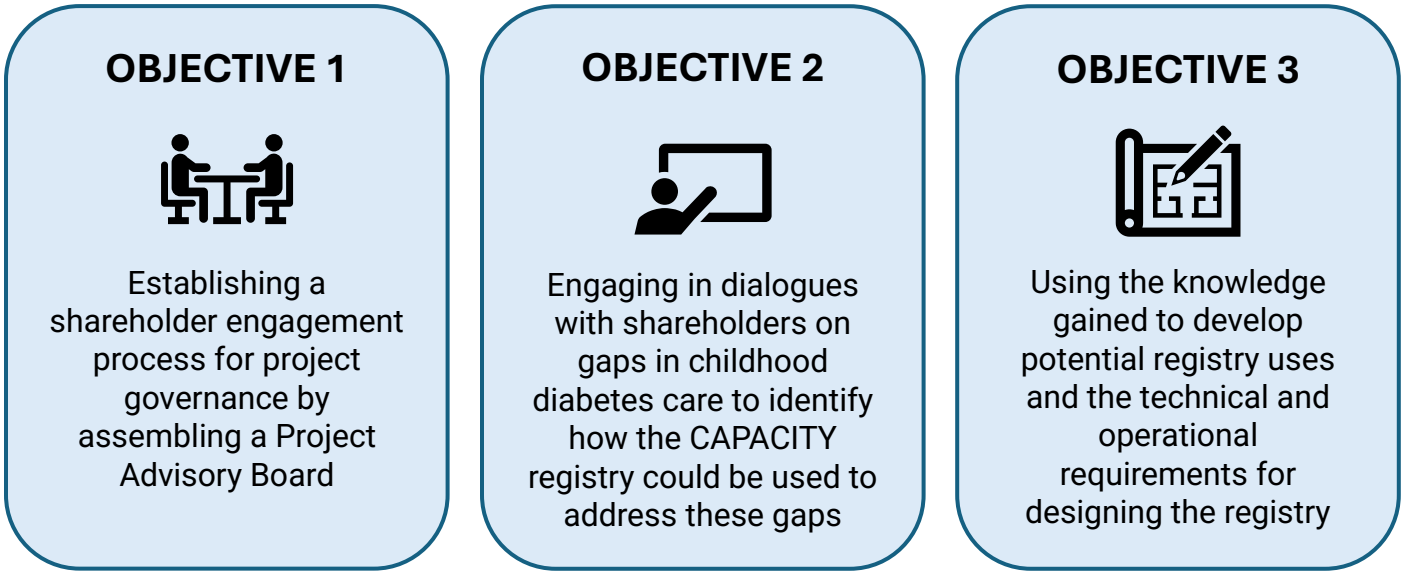

Figure 1: Objectives of Co-Design of the CAPACITY registry (Phase 1)

Methods

The CAPACITY registry's co-design phase aimed to involve the diabetes community from the beginning to ensure that youth with diabetes and their caregivers' needs and voices were centred throughout the project. This approach, known as community-based participatory research (CBPR), emphasizes working with the community to shape the project, ensuring that the research is practical and valuable for the people it's meant to help.[23] Therefore, in the spirit of CBPR, our project was designed to be flexible and allowed for ongoing adjustments based on feedback from the community, ensuring that it remained relevant and responsive to their needs. By involving people with lived experience, the project aimed to create solutions that fit the community's values and needs.[24,25]

To complete the co-design phase (Phase 1), we undertook a series of sequential steps, which can be summarized through three main activities (Figure 2):

1. **Establishing a Project Advisory Board (PAB)**
    - We recruited people representing different genders, ethnicities, professional and cultural backgrounds, and official language users (French, English).
    - The final PAB consisted of 19 members with diverse backgrounds, including two youth with diabetes, six caregivers of youth with diabetes, four clinicians who treat diabetes, three clinician-scientists, two researchers, and two data experts/analysts.
    - PAB members who were not part of CAPACITY's research team were paid $35/hour for participating in the PAB meetings and activities.
2. **Conducting 2 Virtual Knowledge Exchange Events (KEEs)**
    - We conducted two virtual knowledge exchange events using the Zoom platform.
    - During the events we used the 25/10 crowdsourcing method to generate ideas about the gaps our registry could address. The 25/10 crowdsourcing method has two main components: Idea generation and idea prioritization. The 25/10 crowdsourcing method ensures everyone has an equal opportunity to contribute ideas using a participatory process by rapidly generating a lot of ideas, scoring all the ideas out of 25, and identifying the top 10 ideas, thus 25/10 Crowdsourcing.[26,27]

- During both virtual KEEs, participants were allocated to groups of 3-5 using the Zoom break-out rooms feature. A study team member then facilitated each group.
- Under the facilitator's guidance, each group brainstormed various ideas of how the registry could enhance the health outcomes of individuals with diabetes, and each group generated up to three ideas.
- The ideas generated were then circulated amongst groups and scored (between 1 (not my cup of tea) and 5 (yes! This is precisely what we need). All scores were totaled for each idea, and top-scoring ideas were identified.

3. **Conducted a series of four Data Mapping Workshops**
   - We conducted four data mapping workshops where we collectively tried to identify and visualize (map) what data currently exists, what data is desired, and what data from all of those discussed the registry should prioritize
   - Workshop 1: Problem Identification (What problems exist in the type 1 diabetes community that the registry could solve?).
   - Workshop 2: Examining lived experience scenarios and conducting a survey to identify desired data outputs in paediatric diabetes care and management.
   - Workshop 3: Developing the registry data ecosystem (how will all of this data fit into the technological infrastructure being developed for the registry?).
   - Workshop 4: Reviewing the CAPACITY network’s governance structure and roles (how can the registry be managed and maintained over time?).

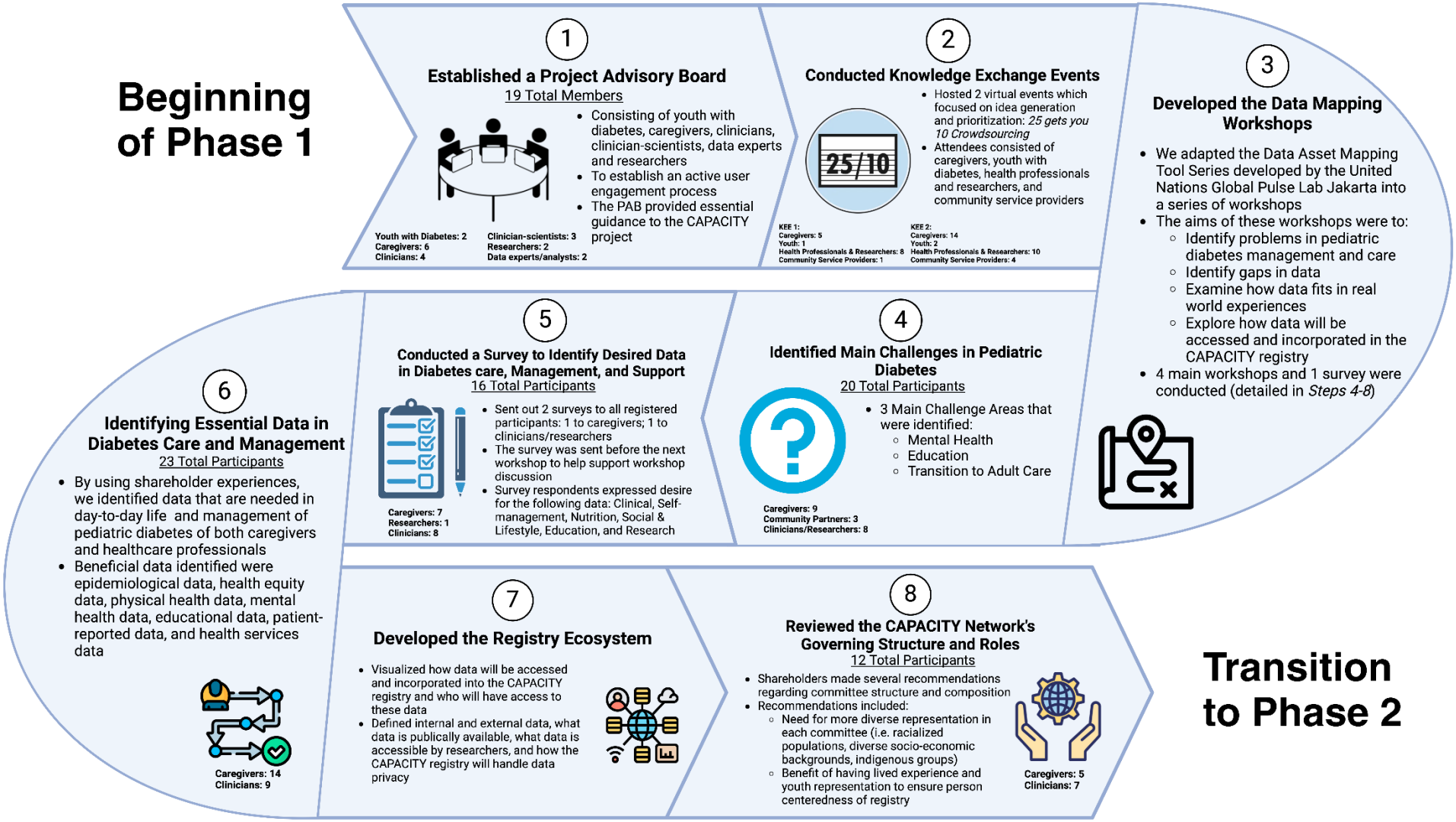

Figure 2: Steps taken during Phase 1 of the co-design of the CAPACITY registry

Findings & Recommendations

After completing the data mapping workshops and activities with caregivers of youth with diabetes, clinicians, researchers, advocates, youth with diabetes, and our PAB, our team used the information to develop potential registry uses to address key challenges and issues in paediatric diabetes (Figure 3). We accomplished this by examining the data collected to create a list of registry uses that addressed shareholder priorities. The potential registry uses we developed addressed the priority challenges and utilized the desired data elements identified and categorized into research, lived experience-driven, and care quality improvement (Table 1).

Table 1: Defining Data Priority Categories

Category	**Definition**
Quality Improvement (QI)	A focus on improving care, resulting in improved patient outcomes and experiences
Research	A focus on collecting and/or using data to generate knowledge and discover new findings in paediatric diabetes
Lived Experience (LE) - Driven	A focus on factors that are valuable to a person with lived experience, including healthcare experiences and comparing their health and self-management strategies and experiences to other people with diabetes

We then identified all shareholders necessary to achieve these objectives (referred to as actors), and the intended outcomes of the registry, which primarily aimed to effect positive change in paediatric diabetes care and management.

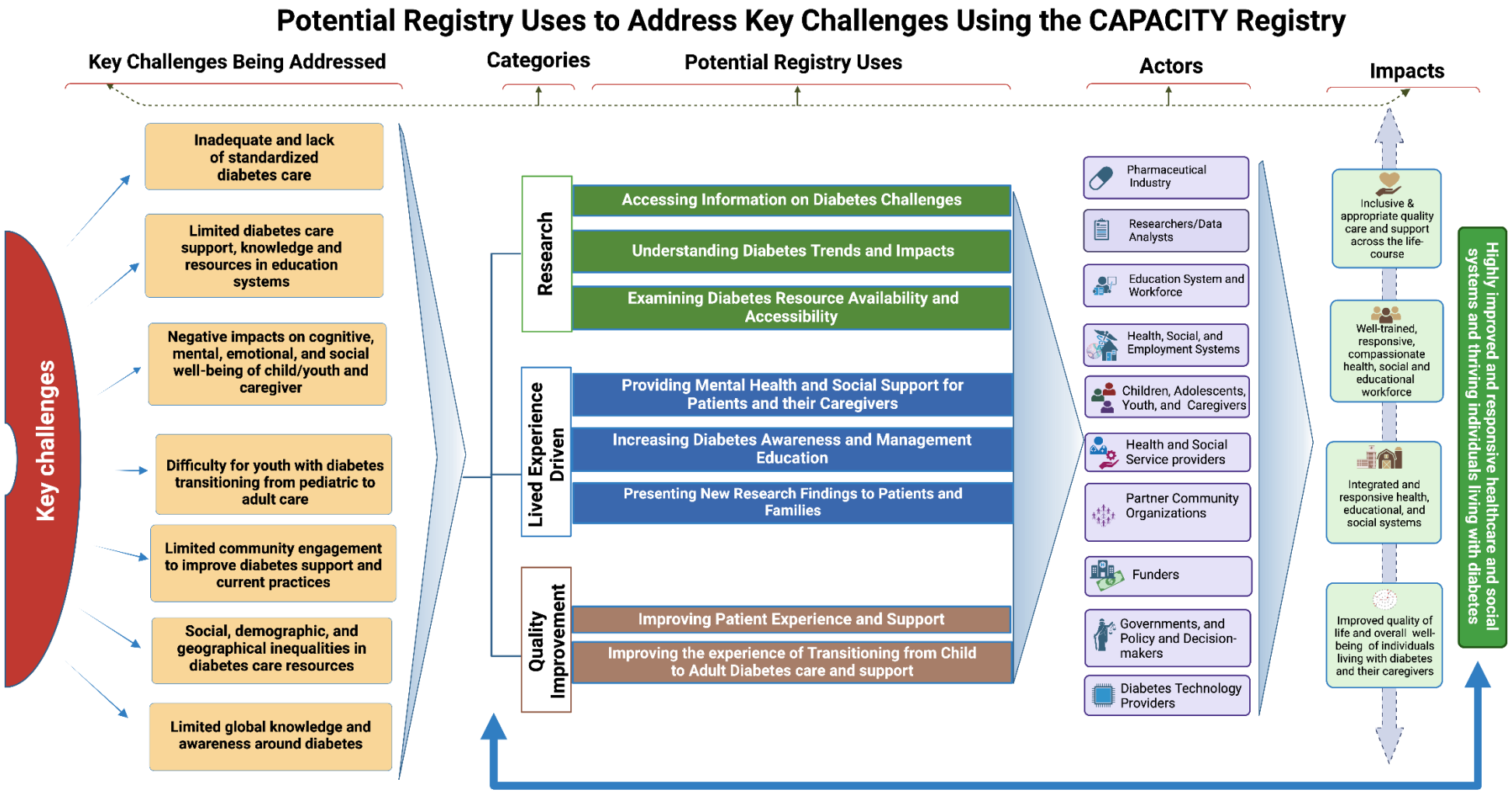

Figure 3: Potential Registry Uses identified with Key challenges and Actors for the CAPACITY Registry (created in BioRender.com)

Given that our findings will inform the co-implementation phase of the registry, we knowledge gained during the co-design process to develop some key **recommendations** for the CAPACITY registry moving into Phase 2. These were:

1. **Reviewing and Improving Data Collection:** The CAPACITY project aims to collect important data that can inform research and quality care practices. During the initial work that was done, we looked at which data the CAPACITY registry should collect and was able to confirm that much of the data we had planned to collect aligns with what shareholders require (e.g. medications taken, medical insulin usage, number of medical and hypoglycemic events, etc.). Based on our findings, we suggest that in Phase 2, the team consider adding additional data indicators such as racial and ethnic identity, Indigenous identity, geographic location, educational attainment, employment status, and family structure.
2. **Exploring Patient Experiences and Outcomes**: In phase 2, interviews will be conducted with shareholders as part of the audit and feedback initiative to understand their experiences and outcomes better. Using the potential registry uses we have provided (Figure 3), we suggest developing questions for those interviews that specifically target some of the user experiences documented in Phase 1.
3. **Creating an Easy-to-Use Dashboard:** It was important for all our participants, especially those with lived experience, to benefit from the knowledge the registry would generate. We recommend that an easy-to-use dashboard be developed for this purpose. When designing a dashboard to display the project's findings, we recommend using simple language and visuals that are easy to understand. This will make the information more accessible to everyone, especially those directly affected by the findings. Involving people with lived experience in the design process will also make the dashboard more effective and encourage its use.
4. **Registry Use Should Align with Identified Priorities:** We recommend that when deciding who is able to access the data collected for the CAPACITY registry, the decision should be based on whether their research question aligns with the priorities identified by the shareholders. We thus also recommended that the decision-making process for providing registry access should prioritize identified needs and uses, be flexible, and adapt to new challenges, ensuring that the registry remains useful, relevant, and trustworthy.
5. **Sharing Knowledge in Simple Terms**: Based on the need for knowledge translation and utilization by our shareholders, we recommend sharing research data and information on the CAPACITY website to keep everyone informed about how their data is being used. Shareholders in Phase 1 emphasized

the importance of this knowledge being valuable and accessible to everyone, including children/youth with diabetes and their caregivers**.** We recommend that those accessing the registry also translate their findings into layman's language, which can also be uploaded on the registry website/dashboard.

Given the large amount of information gathered during the co-design process (Phase 1), we also propose several important recommendations that should be noted for the CAPACITY registry. It is recognized that this may not be possible in the upcoming phases of the registry and would require additional funding and projects. These included:

1. **Moving to a Real-Time System**: The current data architecture only allows for a data snapshot at a particular moment. Switching to a regularly updated system would allow for continuous monitoring and improvements. Until this change happens, we recommend frequent updates to the current system as much as resources allow.
2. **Enhancing the CAPACITY Website**: We recommend expanding the CAPACITY website to become a central resource hub, including educational materials and links to external services based on user needs. The website should offer tools that make it easier to understand and use the information collected.
3. **Adding More Data**: We recommend that as the registry evolves, other data indicators should continue to be added, especially in areas like mental health, diabetes-related stigma, school experiences, and the transition from paediatric to adult care.
4. **Building Connections**: The registry should strengthen connections with community programs and partners. This would help users find relevant programs near them, share knowledge across different organizations, and connect young people with diabetes and their caregivers to various healthcare professionals.
5. **Seeking Future Funding**: The project should seek more funding to repeat the co-design activities, focusing on racialized and marginalized communities, especially Indigenous populations. Working with organizations like the National Indigenous Diabetes Association (NIDA) and tracking the demographics of participants will help make the registry more inclusive, ensuring that the project better represents all communities.

Conclusion

Our co-design process of the CAPACITY registry has highlighted the importance of building a registry aligned with the needs and desires of all our shareholders, including children/youth with T1D and their caregivers, researchers, and clinicians. During our project, we identified the main challenges around paediatric diabetes, “walked in the shoes” of those navigating access and provision of diabetes care and examined the data gaps. We then honed in on the critical data desires essential to all our shareholders and translated this information into a series of proposed registry uses. These co-designed registry uses will now serve as the foundation for the project's next phase (Phase 2), the development of the CAPACITY registry, ensuring that the final registry is, as envisioned, patient-centred.

References

1. Diabetes Canada Clinical Practice Guidelines Expert Committee. *Diabetes Canada 2018 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada*.; 2018.
2. International Diabetes Federation. *IDF Diabetes Atlas, 10th Edn*.; 2021.
3. JDRF. Type 1 Diabetes Facts. Accessed August 26, 2024. https://jdrf.ca/t1d-basics/facts-and-figures/#:~:text=Type%201%20diabetes%20is%20a,flash%20or%20continuous%20glucose%20monitor.
4. Huo L, Harding JL, Peeters A, Shaw JE, Magliano DJ. Life expectancy of type 1 diabetic patients during 1997–2010: a national Australian registry-based cohort study. *Diabetologia*. 2016;59(6):1177-1185. doi:10.1007/s00125-015-3857-4
5. Petrie D, Lung TWC, Rawshani A, et al. Recent trends in life expectancy for people with type 1 diabetes in Sweden. *Diabetologia*. 2016;59(6):1167-1176. doi:10.1007/s00125-016-3914-7
6. Livingstone SJ, Levin D, Looker HC, et al. Estimated Life Expectancy in a Scottish Cohort With Type 1 Diabetes, 2008-2010. *JAMA*. 2015;313(1):37. doi:10.1001/jama.2014.16425
7. Rawshani A, Sattar N, Franzén S, et al. Excess mortality and cardiovascular disease in young adults with type 1 diabetes in relation to age at onset: a nationwide, register-based cohort study. *The Lancet*. 2018;392(10146):477-486. doi:10.1016/S0140-6736(18)31506-X
8. Willi SM, Miller KM, DiMeglio LA, et al. Racial-Ethnic Disparities in Management and Outcomes Among Children With Type 1 Diabetes. *Pediatrics*. 2015;135(3):424-434. doi:10.1542/peds.2014-1774

9. Addala A, Auzanneau M, Miller K, et al. A Decade of Disparities in Diabetes Technology Use and HbA1c in Pediatric Type 1 Diabetes: A Transatlantic Comparison. *Diabetes Care*. 2021;44(1):133-140. doi:10.2337/dc20-0257
10. Shulman R, Stukel TA, Miller FA, et al. Low socioeconomic status is associated with adverse events in children and teens on insulin pumps under a universal access program: a population-based cohort study. *BMJ Open Diabetes Res Care*. 2016;4(1):e000239. doi:10.1136/bmjdrc-2016-000239
11. Hawkes CP, Lipman TH. Racial Disparities in Pediatric Type 1 Diabetes: Yet Another Consequence of Structural Racism. *Pediatrics*. 2021;148(2). doi:10.1542/peds.2021-050333
12. Hershey JA, Morone J, Lipman TH, Hawkes CP. Social Determinants of Health, Goals and Outcomes in High-Risk Children With Type 1 Diabetes. *Can J Diabetes*. 2021;45(5):444-450.e1. doi:10.1016/j.jcjd.2021.02.005
13. Adane K, Gizachew M, Kendie S. The role of medical data in efficient patient care delivery: a review . *Risk Manag Healthc Policy*. 2019;Volume 12:67-73. doi:10.2147/RMHP.S179259
14. Streisand R, Monaghan M. Young Children with Type 1 Diabetes: Challenges, Research, and Future Directions. *Curr Diab Rep*. 2014;14(9):520. doi:10.1007/s11892-014-0520-2
15. Burry E, Ivers N, Mahmud FH, Shulman R. Interventions using pediatric diabetes registry data for quality improvement: A systematic review. *Pediatr Diabetes*. 2018;19(7):1249-1256. doi:10.1111/pedi.12699
16. Tricco AC, Ivers NM, Grimshaw JM, et al. Effectiveness of quality improvement strategies on the management of diabetes: a systematic review and meta-analysis. *The Lancet*. 2012;379(9833):2252-2261. doi:10.1016/S0140-6736(12)60480-2
17. Bak JCG, Serné EH, Kramer MHH, Nieuwdorp M, Verheugt CL. National diabetes registries: do they make a difference? *Acta Diabetol*. 2021;58(3):267-278. doi:10.1007/s00592-020-01576-8
18. Nelson EC, Dixon-Woods M, Batalden PB, et al. Patient focused registries can improve health, care, and science. *BMJ*. Published online July 1, 2016:i3319. doi:10.1136/bmj.i3319
19. Zuijdwijk CS, Cuerden M, Mahmud FH. Social Determinants of Health on Glycemic Control in Pediatric Type 1 Diabetes. *J Pediatr*. 2013;162(4):730-735. doi:10.1016/j.jpeds.2012.12.010
20. Shulman R, Luo J, Shah BR. Mental health visits and low socio-economic status in adolescence are associated with complications of Type 1 diabetes in early adulthood: a population-based cohort study. *Diabetic Medicine*. 2018;35(7):920-928. doi:10.1111/dme.13633
21. Shulman R, Stukel TA, Miller FA, Newman A, Daneman D, Guttmann A. Insulin pump use and discontinuation in children and teens: a population-based cohort study in Ontario, Canada. *Pediatr Diabetes*. 2017;18(1):33-44. doi:10.1111/pedi.12353
22. Göttgens I, Oertelt-Prigione S. The Application of Human-Centered Design Approaches in Health Research and Innovation: A Narrative Review of Current Practices. *JMIR Mhealth Uhealth*. 2021;9(12):e28102. doi:10.2196/28102
23. Melles M, Albayrak A, Goossens R. Innovating health care: key characteristics of human-centered design. *International Journal for Quality in Health Care*. 2021;33(Supplement_1):37-44. doi:10.1093/intqhc/mzaa127

24. Goodkind JR, Amer S, Christian C, et al. Challenges and Innovations in a Community-Based Participatory Randomized Controlled Trial. *Health Education & Behavior*. 2017;44(1):123-130. doi:10.1177/1090198116639243
25. Klaprat N, Benjamin C, Brandt J, et al. Restructuring Clinical Trials in Type 1 Diabetes and Exercise in the Context of Adult Patient-Oriented Research: An Intervention Codevelopment Protocol. *Can J Diabetes*. 2020;44(8):734-739. doi:10.1016/j.jcjd.2020.10.019
26. Holskey MP, Rivera RR. Optimizing Nurse Engagement. *JONA: The Journal of Nursing Administration*. 2020;50(9):468-473. doi:10.1097/NNA.0000000000000918
27. McDonald CR, Weckman AM, Wright JK, Conroy AL, Kain KC. Developmental origins of disease highlight the immediate need for expanded access to comprehensive prenatal care. *Front Public Health*. 2022;10. doi:10.3389/fpubh.2022.1021901