McMaster University

Health Forum

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Evidence Brief Appendices

Developing a Type 1 diabetes screening program in Canada

18 & 19 September 2024

Appendices

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Appendix 1: Background to and methods used in preparing the evidence brief

This evidence brief mobilizes global and local research evidence about a problem, three elements for addressing the problem, and key implementation considerations. It draws insights from a series of five virtual citizen panels in July and August 2024 (with two panels on 5 July 2024, two on 19 July 2024, and one in French on 16 August 2024) with a total of 58 citizens. The panel participants were socio-economically and ethnoculturally diverse, were from across Canada, and were balanced in ages ranging from 18 to 65+. Given that screening would be at the population level (at least for children and adolescents), we sought to engage participants with a range of lived experiences with Type 1 diabetes, including those living with it, family members and/or caregivers of people with Type 1 diabetes, and people who had no lived experience with Type 1 diabetes.

Whenever possible, the evidence brief summarizes research evidence drawn from evidence syntheses and occasionally from single research studies. An evidence synthesis is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select, and appraise research studies and to synthesize data from the included studies. The evidence brief does not contain recommendations, which would have required the authors of the brief to make judgments based on their personal values and preferences, and which could pre-empt important deliberations about whose values and preferences matter in making such judgments.

The preparation of this evidence brief involved six steps:

1) regularly convening the project Steering Committee composed of representatives from partner organizations, key stakeholder groups, and the McMaster Health Forum to help inform the framing of the evidence brief
2) conducting key informant interviews
3) identifying, selecting, appraising, and synthesizing relevant research evidence for each section of the brief
4) conducting additional jurisdictional scans to identify initiatives related to the three proposed elements
5) hosting citizen panels to seek their input on the problem, the elements of a comprehensive approach to address the problem, and implementation considerations
6) drafting the evidence brief in such a way as to present concisely and in accessible language the global and local research evidence, and insights from the panels.

The three elements for addressing the problem were not designed to be mutually exclusive and could be pursued in a number of ways. The goal of the dialogue is to spark insights and generate action by participants and by those who review the dialogue summary.

Mobilizing research evidence about approach elements for addressing the problem

To identify the best-available research evidence about the approach elements, we primarily searched Health Systems Evidence (www.healthsystemsevidence.org), which is a continuously updated database containing more than 9,400 evidence syntheses and more than 2,800 economic evaluations of delivery, financial, and governance arrangements within health systems. We also searched HealthEvidence.org for evidence syntheses about the effects of public health topics. We also complemented this with searches in PubMed, and hand searches of the McMaster Health Forum's recently prepared evidence syntheses if there was overlap in the issues addressed or the elements considered. The authors' conclusions were extracted from the syntheses whenever possible. Some syntheses may have contained no studies despite an exhaustive search (i.e., they were 'empty' syntheses), while others may have concluded that there was substantial uncertainty about the approach elements based on the identified studies. Where relevant, caveats were introduced about these authors' conclusions based on assessments of the syntheses' quality, the local applicability of the syntheses' findings, equity considerations, and relevance to the issue.

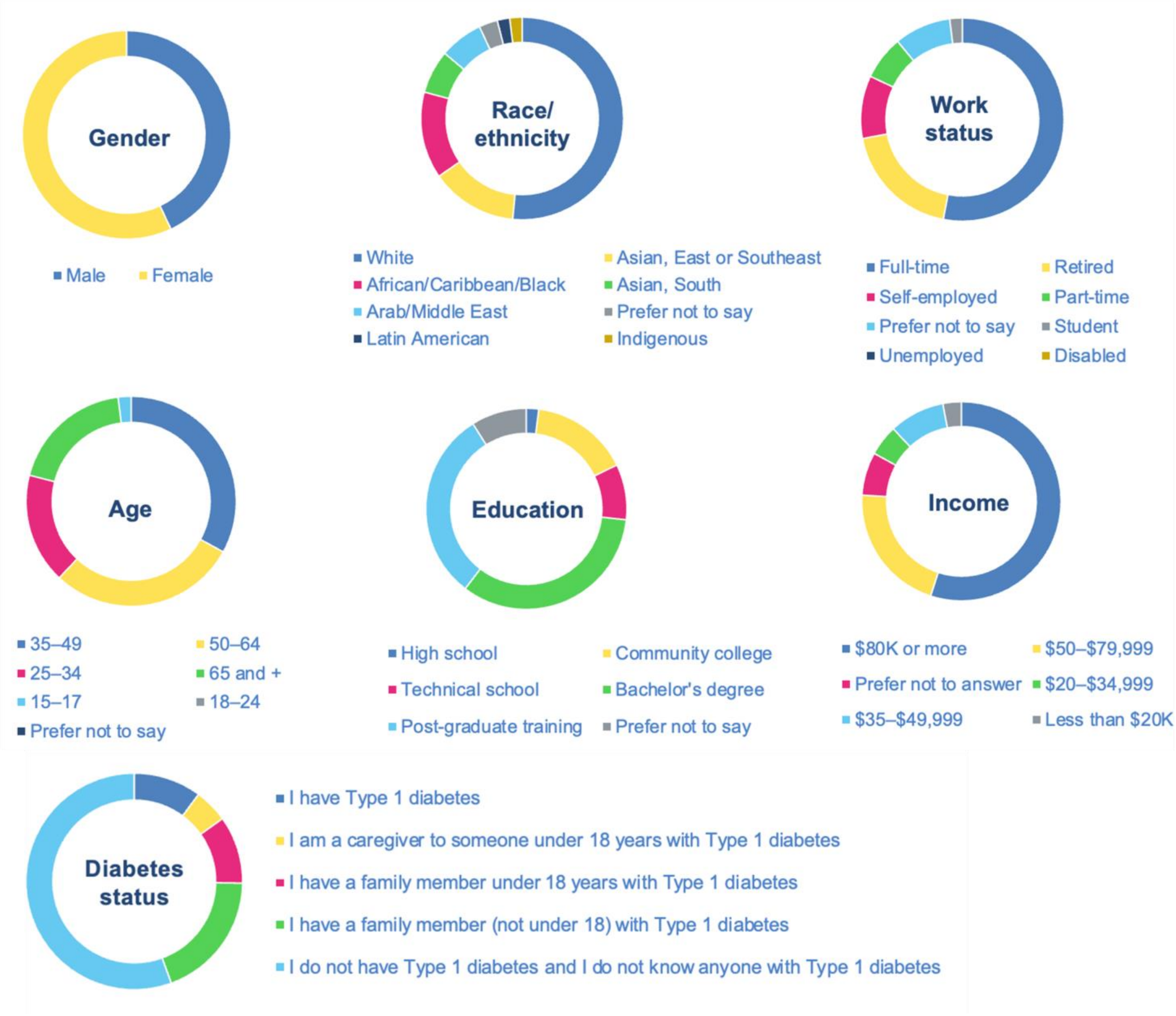
Being aware of what is not known can be as important as being aware of what is known. When faced with an empty synthesis, substantial uncertainty or concerns about quality and local applicability or lack of attention to equity considerations, primary research could be commissioned, or an element could be pursued and a monitoring and evaluation plan designed as part of its implementation. When faced with a synthesis that was published many years ago, an updating of the synthesis could be commissioned if time allows. No additional research evidence was sought beyond what was included in the evidence syntheses. Those interested in pursuing a particular element may want to search for a more detailed description of the element or for additional research evidence about the element.

Appendices 3–5 provide detailed information about the evidence syntheses identified that relate to the three elements. In the first column we list the sub-elements and provide the breakdown of number of identified syntheses for each sub-element according to their quality. In the second column, we provide a hyperlinked 'declarative title' that captures the key findings from each synthesis. Columns 3 to 6 list data related to the criteria that can be used to determine which reviews are 'best' for a single category (i.e., living status, quality, last year literature searched, and availability of a GRADE profile, which provides insights about the strength of the evidence included in a particular synthesis).

As noted above, the fourth column presents a rating of the overall quality of the review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to evidence syntheses pertaining to delivery, financial, or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1): S8.)

Appendix 2: Characteristics of citizen panel participants

Box 2: Profile of participants



Appendix 3: Evidence syntheses relevant to element 1 – Deciding on whether, when, where, and who should offer screening

Sub-element (and search strategy used)	Available evidence syntheses to inform decision-making about the sub-elements	Living status	Quality (AMSTAR rating from McMaster Health Forum)	Last year literature searched	Availability of GRADE profile
Features of screening programs that could inform how to enhance uptake (to complement the features outlined in the element)	Implement theory-driven interventions combining antenatal group education, flexible screening methods, multimodal approaches (including reminders and system changes), and context-specific strategies, while addressing barriers and aligning with prevention (1) • Reminders were the most common intervention, but did not have a significant effect on uptake ○ Reminders involved letters, messages, and telephone calls regarding screening appointment time and importance of screening • Antenatal group education was the most effective intervention across randomized control trials, providing social support, behaviour modification, and knowledge sharing • Education was the second most common and effective intervention ○ Education typically focused on increasing awareness for women and importance of screening encouragement by healthcare professionals ○ Education could occur through written materials, reminders, prompts, and online supports • Guideline and screening method interventions were focused on increasing the accessibility of screening and education on its importance	No	8/10	2023	Not available
	Implement comprehensive, multi-level strategies in primary care that address systemic constraints (time, resources, training, payment) while tailoring approaches for specific health topics, streamlining processes for multiple screenings, ensuring confidentiality, and optimizing tools to creating an efficient, sustainable screening system in primary care settings (2) • Time constraints were a barrier to screening that could be addressed by doing screening before visits and using technology • Demographic characteristics could impact screening as one study found that adolescents who identified as Black, Hispanic, multiracial, and non-White were less likely to be screened for substance abuse • Certain conditions faced unique barriers to screening ○ HIV screening requires physical tests that are limited by availability of on-site laboratories or external transportation costs, confidentiality breaches, and local specific consent laws ○ Depression screening was often forgotten ○ Clinician beliefs could impact likelihood of suicide screening	No	4/9	2021	Not available
	Develop integrated, community-based strategies combining nurse-led interventions, targeted education, improved access, and provider support, tailored to local needs and involving stakeholders, to increase cancer screening uptake across diverse populations (3) • Only using one-on-one education or client reminders did not produce a significant increase in screening uptake • Targeted mass campaigns and nurse-led interventions could increase screening uptake in rural areas	No	8/11	2017	No

Sub-element (and search strategy used)	Available evidence syntheses to inform decision-making about the sub-elements	Living status	Quality (AMSTAR rating from McMaster Health Forum)	Last year literature searched	Availability of GRADE profile
	• Involving community members and local nurses in delivering community-based interventions can help address social inequities and increase uptake in equity deserving groups by bridging a link between the community and healthcare systems • Multimodal approaches seemed to be most effective in increasing screening uptake				
	Implement comprehensive, theory-based school education programs using multimodal and active learning approaches, reinforced with follow-up techniques, to improve knowledge, risk perceptions, and intentions, while addressing barriers to enhance cervical cancer screening uptake, particularly in low- and middle-income countries (4) • In female students, school-based education programs increased knowledge about cervical cancer, but not risk perception of HPV infection • Active learning approaches and printed educational materials may led to better effects	No	10/11	2020	No

Appendix 4: Evidence syntheses relevant to element 2 – Changing system-level arrangements to integrate a new screening program

Sub-element (and search strategy used)	Available evidence syntheses to inform decision-making about the sub-elements	Living status	Quality (AMSTAR rating from McMaster Health Forum)	Last year literature searched	Availability of GRADE profile
Helping parents, guardians, and caregivers make decisions on whether they want to have screening done	Patient decision aids have been found to help people make better-informed decisions, feel better about their decisions, and have better patient experiences (5)	No	11/11	2022	Not available
	Telehealth interventions, particularly mobile applications, video plus telephone, and text message plus telephone, have been found to support cancer screening decision-making by providing convenient access to health information, reducing barriers like travel and embarrassment, and potentially improving communication about sensitive health topics, especially for breast and cervical cancer screening (6) • While screening via telehealth did show statistically significant increases in youth and middle-aged adults, this was not seen in the older adult population ○ This may be because older adults are less likely to trust technology • Telehealth interventions increased screening in rural populations by increasing accessibility • Telehealth was most effective for breast and cervical cancer screening, and less for colorectal cancer, potentially because it limits public embarrassment and increases accessibility as women tend to neglect their health over other competing needs • Mobile devices were more likely to improve screening thanks to their proficiency in audio/image capturing and data sharing/storage	No	8/11	2023	Not available
Changing pathways of care to follow people identified as at-risk for Type 1 diabetes	Telemedicine interventions for people living with Type 1 diabetes show potential for improving care pathways by enabling more frequent patient-provider interactions, facilitating remote monitoring and timely management adjustments, delivering self-management education through various digital modalities, and modestly improving glycemic control compared to usual care (7)	No	7/11	2020	Not available
	Telehealth interventions, primarily involving diabetes self-management education delivered through telephone calls, text messages, web portals, and virtual visits, can significantly improve glycemic control among Black and Hispanic diabetes patients, reducing glycated hemoglobin (HbA1c) levels by 0.465% (8) • Most studies used the diabetes self-management education intervention and suggested that limited education is a barrier to care • Few studies assess barriers among Black and Hispanic diabetes patients, which may affect efficacy of interventions • Future systems-level telehealth interventions should include information about food insecurity, digital tools for self-management, and access to low-costs treatment	No	8/11	2021	Not available
Culturally appropriate care	Bilingual community health workers can help with use of disease-prevention strategies in culturally and linguistically diverse communities to improve communication, screening, health status, health behaviour, health system satisfaction, awareness, and cultural understanding (9) • Bilingual and culturally competent health workers are able to provide better awareness about services • Health programs provided by people from the community are considered culturally sensitive	No	6/11	2009	Not available

Sub-element (and search strategy used)	Available evidence syntheses to inform decision-making about the sub-elements	Living status	Quality (AMSTAR rating from McMaster Health Forum)	Last year literature searched	Availability of GRADE profile
	• Culturally competent health workers can bridge communities and health systems to advocate for increased accessibility of health services • More research supporting implementation of this model and supporting culturally competent healthcare workers is needed				
	Culturally sensitive, multicomponent interventions using different modes of information delivery (such as brochures and visual media) and involving community health workers or promotors were most effective at increasing cervical screening uptake among immigrant women, with a meta-analysis showing higher effect sizes for these approaches compared to single-component or non-culturally tailored interventions (10) • Multifaceted interventions addressing behavioural change and logistic challenges are helpful • HPV self-sampling may help to address religious and/or comfort barriers to screening, but more research is needed to support this statement	No	6/11	2021	Not available

Outreach to connect people to the health system	Outreach for screening can be achieved through 1) individually scheduled appointments and postal/telephone reminders, 2) widespread mass media educational campaigns, and 3) decreasing logistical barriers (11)
	• Reaching populations for screening can be done at
	  ○ an individual level through postal reminders and telephone recalls
	  ○ signed reminders from general practitioners provided a modest effect on screening uptake
	  ○ telephone reminders seem most effective, but have limited supporting evidence
	  ○ those with lower education levels may be discouraged by lengthy educational letters
	  ○ mailed self-sampling devices can increase cervical cancer screening
	  ○ at a population level through mass media campaigns and community education
	• Using scheduled appointments instead of open appointments helps reduce logistical barriers for people to attend their appointments
		No	10/11	2012	Not available

Engaging citizens in health-system decision-making processes	Shared decision making promotes patient-centred care by promoting consideration of patient values and concerns and promoting patent empowerment; however, its application in practice is highly variable (12) • Shared decision-making is very important for careful consideration and deliberation during screening regarding information about the disease, patient and family fears, values, and beliefs, and their previous experiences • Shared decision making promotes patient-centered care • Studies of shared decision-making show that people choose options that are less invasive and start treatments earlier • Only 39% of studies included a key shared decision-making feature, suggesting there is ambiguity in how the process is perceived • Most studies included components of deliberation and empowerment	No	5/9	2015	Not available

Appendix 5: Evidence syntheses relevant to element 3 – Supporting people identified as at risk for Type 1 diabetes

Sub-element (and search strategy used)	Available evidence syntheses to inform decision-making about the sub-elements	Living status	Quality (AMSTAR rating from McMaster Health Forum)	Last year literature searched	Availability of GRADE profile
Patient decision aids	• See first row of previous table				
Patient portals or patient-held records for communicating results or health information over time	Patient portal use by individuals with Type 1 and Type 2 diabetes mellitus is associated with personal traits, technology, and provider engagement (13) • Enabling patients to access certain parts of their electronic health record data, such as visit summaries, medical history, physical examination results, and lab results • Patients receiving general education related to their health conditions and prescribed medications • Providers assisting patients in using web-based portals to respond to messages, review and upload their blood glucose readings and food intake, and adjusting medications	No	4/9	2017	No
	Patient-perceived facilitators of electronic patient portal use include provider encouragement, control over health information, and improved communication, while barriers consist of lack of awareness or training and concerns about privacy and security (14)	No	3/9	2016	No
	Mobile health apps for the management of Type 1 diabetes mainly support the collection of measurements and lack features for a personalized self-management approach (15) • Gaps existing between literature and available apps for Type 1 diabetes self-management and patient empowerment include: ○ literature emphasizes aspects such as gamification, rewards, and social communities ○ available apps primarily focus on disease management aspects like data recording and appointments • Commercial apps should focus on prevalent empowerment features such as personalization	No	5/10	2018	No
	Clients' perceptions and experiences of targeted digital communication on reproductive, maternal, newborn, child, or adolescent health revealed that, while many appreciated receiving messages via mobile phone, their experiences were influenced by challenges such as network access, phone availability, language barriers, privacy concerns, and the timing, frequency, content, and sender of the messages (16) • Clients' experiences with digital health programs were mixed • Some clients felt supported and connected, sharing messages with friends and family • Challenges included poor access to cell networks, lack of phones or airtime, and controlled phone access, especially among women and teenagers • The cost of messages was a concern; clients believed they should be free • Language, literacy, and mobile phone skills were barriers • Privacy concerns were significant for clients with stigmatized health conditions like HIV or abortion care • Clients suggested neutral language and tailored message content, timing, and frequency to address privacy issues • Clients preferred receiving messages at convenient times, through different channels, and from specific senders	No	8/9	2017	No

Sub-element (and search strategy used)	Available evidence syntheses to inform decision-making about the sub-elements	Living status	Quality (AMSTAR rating from McMaster Health Forum)	Last year literature searched	Availability of GRADE profile
	Healthcare professionals face challenges discussing recovery in acquired neurological conditions due to the uncertain trajectory of recovery, the need to maintain patients' hope and motivation in rehabilitation, and lacking training in discussing recovery and delivering bad news (17) • Patients and caregivers want more information about an individual's potential for recovery • When information is provided, patients and caregivers emphasize that it should be honest, delivered with kindness and compassion • Role-play and group discussions can be effective in increasing clinicians' confidence and patient satisfaction	No	6/9	2019	No
	Communication skills training is a promising approach for enhancing empathic communication between the radiotherapy team members and patients; existing evidence suggests that the communication skills developed through communication skills training can effectively reduce patient anxiety and concerns when applied in clinical practice (18)	No	6/10	2018	Not available
Ensuring confidentiality of health information	The views and attitudes expressed by participants regarding data sharing converge around these key conditions: value, privacy and confidentiality, risk minimization, data security, transparency, control, information, trust, responsibility, and accountability (19) • People generally had similar motivations for sharing their data and recognized comparable benefits, though there were some differences between patients and the public • Concerns about data sharing included confidentiality, data security, awareness of access and control, and potential harms from these risks • Both patients and the public indicated that certain factors could influence their willingness to share data: ○ privacy-protecting measures (e.g., data deidentification, secured databases) increased willingness ○ transparency and information about data sharing processes and responsibilities also enhanced willingness	No	2/9	2019	Not available
Psychology assessment for anxiety and other mental health conditions	To effectively address the psychosocial needs of families during the dynamic new-onset period of Type 1 diabetes, it is crucial to conduct longitudinal observational studies that incorporate diverse backgrounds and relevant biomarkers, while also prioritizing early psychological assessments to identify and manage depression and anxiety, which can significantly impact diabetes management and outcomes (20)	No	2/9	2022	Not available
	Digital interventions, when designed with sound theoretical foundations, evidence-based psychological therapies, and active input from youth, offer unique advantages and are likely to produce more effective outcomes for improving mental health well-being for youth with Type 1 diabetes (21) • Findings regarding the potential efficacy of digital interventions for improving psychological and physical health outcomes are mixed • The current review suggests that digital health interventions for youth with Type 1 diabetes are largely ineffective for improving psychological outcomes • A key concern is the lack of theory-based digital health interventions • Most interventions focus on improving self-care behaviours and had psychological or behavioural measures as secondary outcomes	No	4/10	2021	No

Sub-element (and search strategy used)	**Available evidence syntheses to inform decision-making about the sub-elements**	**Living status**	**Quality** (AMSTAR rating from McMaster Health Forum)	**Last year literature searched**	**Availability of GRADE profile**
Equitable engagement in research	Timeframes, visibility, and accessibility are ways to embed an ethical perspective into patient and public engagement opportunities (22) • Building realistic timeframes that include at least two weeks for public involvement in the research design stage to allow time for reading, clarification, and feedback • Making public contributions visible and being transparent about the extent of public involvement • Ensuring that information provided to public members and the research team during the design stage is accessible and understandable, using plain language • A key aspect of patient and public engagement, especially in priority setting, is the evaluation of patient involvement in decision-making activities, which includes understanding the patient perspective on how, when, and why they are engaged ○ Highlights the importance of cataloguing engagement activities and using validated tools to solicit feedback from the public, patients, researchers, policymakers, and organizations	No	5/9	2017	Not available

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