# Review

# Bringing an end to diabetes stigma and discrimination: an international consensus statement on evidence and recommendations

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People with diabetes often encounter stigma (ie, negative social judgments, stereotypes, prejudice), which can adversely affect emotional, mental, and physical health; self-care, access to optimal health care; and social and professional opportunities. To accelerate an end to diabetes stigma and discrimination, an international multidisciplinary expert panel (n=51 members, from 18 countries) conducted rapid reviews and participated in a three-round Delphi survey process. We achieved consensus on 25 statements of evidence and 24 statements of recommendations. The consensus is that diabetes stigma is driven primarily by blame, perceptions of burden or sickness, invisibility, and fear or disgust. On average, four in five adults with diabetes experience diabetes stigma and one in five experience discrimination (ie, unfair and prejudicial treatment) due to diabetes, such as in health care, education, and employment. Diabetes stigma and discrimination are harmful, unacceptable, unethical, and counterproductive. Collective leadership is needed to proactively challenge, and bring an end to, diabetes stigma and discrimination. Consequently, we achieved unanimous consensus on a pledge to end diabetes stigma and discrimination.

## Introduction

People with diabetes require daily self-care to stay healthy and avoid, delay, or manage short-term and long-term complications. This burden can be exacerbated by stigma (ie, negative social judgments, stereotypes, and prejudices),<sup>1</sup> which takes many forms (panel 1). This burden can also be exacerbated by discrimination (ie, unfair or prejudicial treatment),<sup>2</sup> which has been described as the endpoint of the stigmatisation process.<sup>3</sup> Furthermore, evidence indicates that diabetes stigma has multifaceted effects on the dignity, health, self-care, and wellbeing of people with diabetes.<sup>45</sup> There is also growing evidence that diabetes stigma can affect public and government support and funding for diabetes research, prevention, care, and treatments.

In 2010, the International Diabetes Federation put out a call to action to "stop discrimination against people with diabetes".<sup>6</sup> The International Diabetes Federation recommended enabling people with diabetes to claim their rights and responsibilities (as later detailed in their Charter<sup>4</sup>); increasing public awareness of diabetes and reducing diabetes stigma; and supporting people with diabetes to be at the centre of this response. This call to action was a novel, ambitious, and crucial step forward. In 2013, the first systematic review of diabetes stigma showed wide-ranging potential harms but a scarcity of research focused on this important issue.<sup>1</sup> Subsequently, both advocacy and research on diabetes stigma have increased substantially, including raising awareness, sharing experiences, and understanding the nature, extent, and repercussions of diabetes stigma. Arguably, there has been greater and earlier recognition in research of the stigma associated with other health conditions (eg, cancer and mental illness in the 1960s, epilepsy in the 1970s, HIV in the 1980s–1990s, and obesity in the 2000s) than with diabetes.<sup>7-9</sup> Insights from these areas suggest that research and advocacy are both crucial but each is likely to be insufficient in isolation.<sup>10-13</sup>

The pivotal change required to bring an end to diabetes stigma starts with consolidation of, and international consensus on, the evidence and recommendations. Such consensus can have the power to galvanise collective leadership, commitment, and actions to challenge the status quo (ie, the embedded negative judgements, stereotypes, and prejudice present in discourse and decision making about diabetes).<sup>5</sup> To challenge the status quo, all sectors of the community—including, but not limited to, people with and affected by diabetes and those working in advocacy, research, health care, industry, policy, and media—need to state unequivocally that diabetes stigma and discrimination are not only harmful and unacceptable, but also counterproductive to achieving better outcomes among people with diabetes.

Our aims were to consolidate the evidence on diabetes stigma and discrimination; achieve panel consensus on brief statements of evidence and evidence-based recommendations; and call on the community to endorse an evidence-based pledge, showing collective leadership and commitment to doing what is needed to bring an end to diabetes stigma and discrimination.



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## Panel 1: Definitions of diabetes stigma and discrimination

## Diabetes stigma

This term refers to negative social judgments, stereotypes, and prejudices about diabetes, or about a person or group due to their diabetes, occurring typically in the context of a power imbalance. There are several types:

- Experienced (or enacted) stigma refers to tangible examples of diabetes stigma
- Perceived (or felt) stigma refers to belief in, or awareness of, the existence of diabetes stigma
- Anticipated stigma refers to the expectation or fear of experiencing diabetes stigma
- Internalised stigma (or self-stigma) refers to a cognitive bias in which diabetes stigma is absorbed and endorsed, leading to self-blame or shame
- Intersectional stigma refers to diabetes stigma converging with other stigmatised conditions (eg, obesity or schizophrenia) or characteristics (eq, race or ethnicity)

#### **Diabetes discrimination**

- At an individual level refers to the unfair or prejudicial treatment of a person due to their diabetes, occurring typically in the context of a power imbalance
- At a structural level refers to the societal or cultural norms, and institutional or organisational practices, that constrain a person's rights to social justice and fair and equitable treatment, due to their diabetes, occurring typically in the context of a power imbalance

# Methods

# Establishing an expert panel

An international multidisciplinary panel was established to inform, and serve as voting members on, the consensus. Potential panel members were identified via existing networks, snowballing techniques, and targeted searches for authors of research papers on diabetes stigma and were invited by JS, EHT, MG, or RS between December, 2022, and January, 2023. Members were required to have lived or professional experience of diabetes stigma (or both). The panel comprises 51 members, including 17 with lived experience of diabetes and 19 with at least one family member living with diabetes. Members are from 18 countries, across all seven International Diabetes Federation regions, including six from low-income and middle-income countries (appendix pp 2–3).

All panel members contributed to the consensus protocol, Delphi surveys, and report and agreed to advocate for the consensus, promoting it in their country or region to invite organisations to endorse the pledge. In addition, subgroups of self-nominated panel members contributed to various aspects (eg, rapid reviews; design or pilot of the Delphi surveys; and iterative refinement of draft statements and the pledge before each survey; appendix pp 2–3).

#### Generating statements and a pledge: rapid reviews

Subgroups of up to four panel members (appendix pp 2–3) completed 12 topic-focused rapid reviews (appendix p 3) informed by the framework for understanding diabetes stigma,<sup>114</sup> and the Health Stigma and Discrimination Framework.<sup>8</sup> Rapid reviews streamline knowledge synthesis in a resource-efficient manner.<sup>15</sup>

All rapid reviews involved extraction of relevant evidence (appendix p 5–20); consideration of evidence overall and by diabetes type, sex or gender, age, geographical region, race, and ethnicity; quality assessment (although formal quality appraisal was not conducted); preparation of a 2-page summary and draft statements of evidence and recommendations; peer review by at least two independent panel members (appendix pp 2–3); and revision as needed. To reduce redundancy, the subgroup consolidated and refined the 78 draft statements down to 50 draft statements and used this to inform a draft pledge, for inclusion in the Delphi surveys. An example of the development of a statement is shown in the appendix (p 21).

#### Achieving consensus: Delphi method

Following the Conducting and Reporting Delphi Studies guidance, three survey rounds were completed (figure).<sup>16</sup>

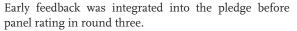
In rounds one and two, panel members rated each statement and the pledge on a 4-point Likert scale (fully disagree, slightly disagree, slightly agree, or fully agree),<sup>v</sup> or indicated "don't know", and were encouraged to explain responses or suggest revisions (via free-text responses). In round one, additional statements were also invited. In round three, the statements and pledge were rated "agree" or "disagree", with no opportunity for further refinements. In rounds two and three, to inform ratings, panel members received their own and the group's aggregated previous ratings.

Panel members received a copy of the proposed statements and pledge at least 24 hours before each survey round and were invited to each survey (hosted via Qualtrics), via personalised email. Each survey was open for 7 days, and two reminders were sent. The process was managed by an independent, non-voting moderator, with no previous relationship with any panel members or experience in diabetes stigma research. The moderator prepared and distributed the online surveys, tracked participants' confidential responses, and analysed data to inform subsequent surveys and the final consensus grade. A subgroup (appendix pp 2-3) reviewed the deidentified results of each survey round and refined the statements and pledge for the next survey, based on panel feedback regarding clarity, evidence, duplication, or omissions (see example in the appendix; p 21).

Before the final round, the acceptability of a public endorsement of the draft pledge was explored with the leads of over 10 organisations, including representation from Australian, Canadian, Dutch, and US advocacy organisations, professional associations, and universities.

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# Grading of Consensus statements and the pledge

Informed by the international consensus statement on obesity stigma,<sup>18</sup> consensus gradings were defined as grade U (100% agreement, unanimous); grade A (90–99% agreement, near unanimous); grade B (78–89% agreement); grade C (67–77% agreement); and no consensus (<67% agreement). Valid percentage was used to calculate consensus, excluding missing and "don't know" responses.

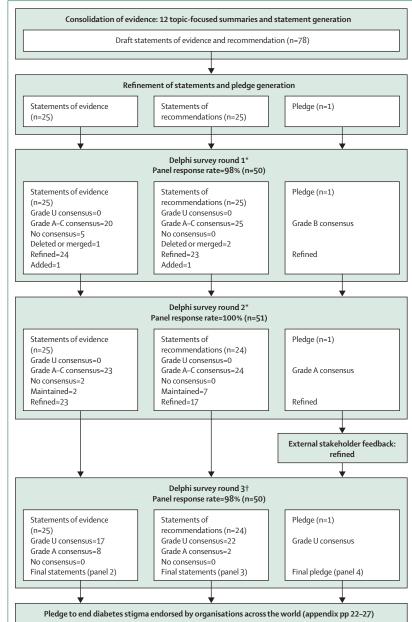
## Delphi process outcomes

The figure summarises the iterative three-round process of ratings and refinements of statements and the pledge. Each round had a response rate of 98% or higher. Unanimous consensus was achieved for 17 of the 25 statements of evidence (panel 2) and 22 of the 24 statements of recommendations (panel 3). Grade A consensus was achieved for 8 Statements of Evidence and 2 Statements of Recommendations. The final pledge to End Diabetes Stigma (panel 4) achieved unanimous consensus.

On July 31, 2023, the pledge was published on a dedicated, community-based website to enable widespread access. In its first 4 months, the pledge was endorsed by more than 2300 individuals and 270 organisations (appendix pp 22–27) in 100 countries, 58% of which are low-income to middle-income. The pledge has been translated into Arabic, two forms of Chinese (traditional and simplified), Danish, French, Italian, Japanese, Spanish, and Thai, with more to follow.

## Summary of evidence

Our systematic search retrieved 116 papers (appendix pp 6–20), including 96 published after 2013, representing an approximate 6-times increase in peer-reviewed publications in the 10 years since the first systematic review of diabetes-related stigma.1 The development and validation of scales to assess diabetes stigma17,19 enabled crucial research into its nature, prevalence, and associations. Conducted primarily among adults with type 1 or 2 diabetes in at least 28 countries, the research explores sources, settings, experiences, correlates, and effects. Evidence gaps remain related to people with gestational diabetes and rarer diabetes types; children and adolescents with diabetes; the wider community without diabetes; and in many countries and communities, including among Indigenous, migrant, and other minority populations. Research has mostly used qualitative methods or cross-sectional quantitative surveys, including some large-scale studies (n>1000). The evidence base remains scarce for determining mechanisms and the effectiveness of mitigating strategies. Guided by relevant frameworks,18,14 this summary details the supporting evidence, and evidence



#### Figure: Flowchart of steps towards an international consensus on diabetes stigma

Grade U=unanimous, 100% agreement. Grade A=90–99% agreement. Grade B=78–89% agreement. Grade C=67–77% agreement. No consensus<67% agreement. \*Round 1 and 2 consensus grading was based on valid "fully agree" responses. †Round 3 consensus grading based on valid "agree" responses.

gaps, informing the statements of evidence, statements of recommendations, and the pledge.

#### Drivers and facilitators of diabetes stigma

All health-related stigma, including diabetes stigma, are driven primarily by blame, fear, and disgust arising from negative stereotypes and misinformation.<sup>18,14</sup> Stigma is typically facilitated by media messaging and public discourse, health organisations and health professionals,

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See Online for appendix

For the **pledge website** see EndDiabetesStigma.org

### Panel 2: Consensus on diabetes stigma—statements of evidence

#### **Drivers and facilitators**

- "There is an inaccurate, and overly simplistic, societal view that people with diabetes are to blame for their condition and its complications—this societal view is a key driver of diabetes stigma."
  - Consensus grade=U.
- "Stereotypes about people with diabetes include assumptions that they are sick or weak; lazy or lacking motivation, willpower, self-control, or capability; or to blame for their condition and/or health outcomes."
  - Consensus grade=U.
- "Diabetes stigma can be driven by a lack of knowledge, fear and/or disgust about the condition, its causes, management and/or complications."
  - Consensus grade=U.
- "Diabetes stigma is facilitated by the use of oversimplified, sensationalist and/or fear-based messaging and imagery about diabetes and its complications in the media, health campaigns and in healthcare."
- Consensus grade=U.
- "Diabetes stigma is perpetuated by the use of words that are inaccurate, harmful, and judgmental in the context of diabetes, eg, 'lazy', 'non-compliant', 'uncontrolled', 'poor control', 'failing'."
  - Consensus grade=A.
- "Many people without diabetes do not perceive diabetes to be stigmatized."
- Consensus grade=A.

#### Manifestations—lived experiences

- "While diabetes stigma has emerged as a focus of research in the past decade, it has been a lived experience for people with diabetes for much longer."
  - Consensus grade=U.
- "Large, cross-sectional studies suggest up to four in five adults with diabetes (type 1 or type 2) experience diabetes stigma; and, on average, one in five has experienced discrimination due to diabetes. The prevalence varies by country and culture, but diabetes stigma is present everywhere that it has been investigated."
  - Consensus grade=U.
- "Diabetes stigma has been researched primarily among adults with type 1 or type 2 diabetes, using qualitative methods and cross-sectional surveys. Comparability of diabetes stigma prevalence and experience across studies is limited, in part due to differences between studies in design, methods, samples, measures, and settings."
  - Consensus grade=U.

#### Manifestations—sources

 "People with diabetes may experience diabetes stigma from numerous sources (eg, health professionals, health organisations, general public, family, friends, colleagues); and in multiple settings (eg, healthcare, popular culture, media, social media, schools, workplaces, and other community settings)."

- Consensus grade=U.
- "Some health professionals contribute to diabetes stigma, eg, by blaming, judging and/or mistrusting people with diabetes."
  - Consensus grade=A.
- "Some people with diabetes are stigmatized by other people with, or affected by, diabetes."
- Consensus grade=U.
- "Diabetes stigma may be perpetrated unknowingly eg, through implicit bias, and sometimes with good intentions, without realisation of the harm that it causes."
  - Consensus grade=A.

#### Correlates, outcomes, and effects

- "People with diabetes who experience or internalise stigma due to their condition are more likely to report depressive symptoms, anxiety symptoms, diabetes distress, and lower self-esteem."
- Consensus grade=U.
- "People with diabetes who anticipate, experience, or internalise diabetes stigma are more likely to hide their condition and self-management activities from others, eg, delaying or skipping essential medication taking and glucose monitoring in public, with implications for their health." • Consensus grade=U.
- "People with diabetes who experience diabetes stigma in healthcare settings are more likely to: have higher HbA1c and/or severe hypoglycaemia; experience lower quality healthcare consultations; disengage from healthcare; and experience delayed access to treatments, technologies, and specialist care."
- Consensus grade=U.
- "When people with diabetes internalise diabetes stigma as self-stigma (eg, shame and self-blame), the negative impacts of diabetes stigma are magnified."
  - Consensus grade=A.
- "Some people with diabetes experience unfair treatment and/or discrimination due to diabetes in relation to marriage, childbirth, healthcare, education, employment, insurance, and licensing (eg, to drive a vehicle)."
  - Consensus grade=A.
- "The experience of diabetes stigma is associated with certain demographics (female, younger, with lower socioeconomic status, and higher education); and clinical characteristics (recent diagnosis, intensive insulin therapy, overweight, diabetes-related complications)."
- Consensus grade=U.
- "Internalising diabetes stigma as self-stigma, e.g. shame and self-blame) is associated with lower self-esteem, and less social support, resilience, and empowerment."
  - Consensus grade=A

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# programmes, and research."

Consensus grade=U.

advocate for their rights."

Consensus grade=U.

(Panel 2 continued from previous page) Law, policy, regulations, and funding

## Interventions

 "There is a lack of research focused on what works to reduce diabetes stigma, self-stigma, and their impacts."

"Discrimination due to diabetes is not addressed universally

in laws, policies, and regulations; and complexity in these

can make it difficult for people with diabetes to know and

"Diabetes stigma may negatively impact public and financial

support for diabetes prevention, care, treatments,

• Consensus grade=U.

cultural and social norms, policy, and law.<sup>18,14</sup> This facilitation could be confounded by other health-related stigma, such as being due to obesity or mental illness. Stigma can also vary between and within communities, reflecting localised health, sociohistorical, cultural or religious beliefs (or a combination).

## Blame, responsibility, control, and compliance

There is widespread misunderstanding of the causes, management, and consequences of all types of diabetes. The dominant discourse portrays diabetes as self-inflicted, due to gluttony, laziness and irresponsibility.<sup>20</sup> Thus, managing diabetes has a perceived moral dimension, focused on how a person should live,<sup>21</sup> exemplified by the meta-narrative of questioning whether a person with diabetes should be eating certain foods.<sup>22</sup> This phenomenon traces back several centuries and appears to have been facilitated by biased popular interpretation of modern scientific discoveries.<sup>23</sup>

In the 1990s, landmark trials showed that intensive management can prevent or delay diabetes-related complications among people with type 1 and 2 diabetes.<sup>24,25</sup> In the early 2000s, similarly pivotal trials showed that rigorous health behaviours or medication-taking can prevent 55-58% of cases of type 2 diabetes.<sup>26,27</sup> In the past few years, remission of type 2 diabetes has been shown to be possible with intensive weight management in 46% of the intervention group (on a very low-energy diet) after 1 year and maintained in 36% after 2 years and 8% after 5 years.28-30 This evidence has generated widespread scientific, health, and media interest. Part of the legacy of these studies has been to greatly increase the perception of personal responsibility for preventing diabetes and its complications,31 emphasising personal control and compliance, particularly for glycaemia and food self-regulation.<sup>21,23,32</sup> Diabetes stigma is potentially facilitated by a hyperfocus on personal responsibility, without balanced attention to genetic, environmental, socioeconomic, psychosocial, and behavioural barriers

#### Intersecting stigma

- "There is limited research on the intersection of diabetes stigma with other forms of stigma and discrimination, eg, age, body size, disability, gender, other health conditions, race, sexuality, socio-economic status."
  - Consensus grade=U.
- "There is very little research about the experiences of diabetes stigma and its impact among disadvantaged, minority, and diverse populations (eg, Indigenous people, refugee and asylum seekers, migrants)."
  - Consensus grade=A.

U=unanimous consensus (100%). A=grade A consensus (90–99%), all eight grade A ratings were 98%.

and facilitators—nor to the intersecting social inequities and disadvantages that can also underpin those outcomes.<sup>33</sup> Relatedly, due to the focus on personal responsibility, another key driver of diabetes stigma is the belief that people with diabetes are less worthy or deserving than people with other conditions.<sup>34-36</sup>

#### Perceived burden and sickness

In many countries and cultures, people with diabetes are seen as physically inadequate, sick, weak or a burden on family, health care, and societal resources.<sup>14,20,37</sup> Diabetes is linked to fears of infertility or high-risk pregnancies.<sup>38–41</sup> Diabetes is viewed as a reminder of death,<sup>20,41</sup> due to perceptions of reduced life expectancy.<sup>38</sup> People might fear and be motivated to avoid relationships with someone who has a genetic predisposition to disease, both for their own health and for that of their future family.<sup>1,37,42</sup> The very use of the diagnostic label diabetic priorities a person's diagnosis over all other characteristics, leaving them vulnerable to stigma.<sup>43,44</sup>

### Visibility, fear, and disgust

Visibility (or invisibility) can drive diabetes stigma. In countries where diabetes is invisible (ie, has low prevalence), there are reports of those living with type 1 diabetes being described as monsters or strange.<sup>45-47</sup> Similarly, in some cultures, diabetes stigma is driven by fear—eg, due to beliefs that diabetes is caused by spiritual forces (eg, karma, kismet, curses, or an evil eye),<sup>48-50</sup> or that it is contagious.<sup>20,38,51</sup> In contrast, diabetes stigma might be less prevalent in countries and age groups where type 2 diabetes is seen as a normal cultural phenomenon.<sup>52,53</sup>

The physical or behavioural signs of the condition or its management can also elicit fear or disgust. For example, leg amputation, a potential consequence of diabetes-related complications, is considered taboo in many cultures, including some Indigenous Peoples, who view the physical integrity of the body as sacred.<sup>54</sup> Fear and disgust can also be due to myths, misunderstandings,

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#### Panel 3: Consensus on diabetes stigma-statements of recommendations

#### General

- "Bringing an end to diabetes stigma requires multi-faceted, long-term solutions; it involves international collaboration, and collective leadership from all sectors of the community (including people with diabetes, advocacy organisations, researchers, health professionals, media, industry and policy makers)."
  - Consensus grade=U.
- "There is opportunity to learn from other areas of health (eg, HIV, mental health, and obesity), where addressing stigma has been recognised as crucial."
   Consensus grade=U.
- "Planning, developing, and implementing research, initiatives, and policies to address diabetes stigma requires meaningful engagement with people with diabetes and their families."
  - Consensus grade=U.

#### Research—general

- "A comprehensive approach is needed to understand all aspects of diabetes stigma, including causes, facilitators, mechanisms, and impacts, as well as effective strategies for ending diabetes stigma. This will require a variety of study designs, including prospective, observational, and trial designs to test interventions."
  - Consensus grade=U.
- "Given the dearth of interventions designed to reduce diabetes stigma, there is need for research to examine the effects (both positive and negative) of existing educational, behavioural, psychosocial, and clinical interventions on diabetes stigma."
  - Consensus grade=A.
- "Further research is needed to understand the drivers and extent of beliefs, attitudes, and behaviours perpetuating diabetes stigma among health professionals, and in the general population."
  - Consensus grade=U.

#### **Drivers and facilitators**

- "To end diabetes stigma, the prevailing social narrative focused on personal responsibility needs to be challenged, and replaced with a balanced focus on genetic, biological, sociocultural, environmental, behavioural factors and the social inequities influencing health."
  - Consensus grade=A.
- "Given that it is unacceptable and counterproductive to stigmatise anyone for having diabetes, or its complications, we all must recognise, challenge and counter our own prejudice."
  - Consensus grade=U.

## Manifestations—experiences

- "International collaboration is needed to assess the experiences and extent of diabetes stigma across settings, ethnicities, cultures, and countries."
  - Consensus grade=U.

- "Further research is needed into the experience of diabetes stigma among those with gestational diabetes and rarer types of diabetes, across life stages, genders, socioeconomic status, ethnicities, languages, cultures, and countries. This includes qualitative research, longitudinal quantitative research, and the development/use of valid and reliable assessment tools."
  - Consensus grade=U.

### Communication, campaigns, and media

- "All communications about (people with) diabetes need to be clear, accurate, respectful, non-judgmental, and non-stigmatising. When relevant, refer specifically to the type(s) of diabetes without stigmatising other types."
   Consensus grade=U.
- "Due to the potential for harm, fear-based messaging is unethical and should not be used."
- Consensus grade=U.
- "To avoid perpetuating diabetes stigma and its harms, diabetes awareness campaigns need to be informed by theory and evidence and tested for negative consequences prior to implementation."
  - Consensus grade=U.
- "The print and news media needs to provide fair, accurate, and non-stigmatizing reporting of diabetes; and media organisations need to commit to stop facilitating diabetes stigma."
  - Consensus grade=U.
- "Further research is needed to understand and reduce diabetes stigma in the print and news media, social media, and popular culture."
  - Consensus grade=U.
- "Researchers and educators need to ensure that their communications with and about people with diabetes are stigma-free (including study information and tools, grant applications, presentation, and publication of research findings). Funding bodies, publishers, conference organisers, and employers have a role in ensuring stigmafree communications."
  - Consensus grade=U.

#### Health care

- "Health professionals supporting people with diabetes need to ensure their practice is stigma-free. Training in stigmafree consultation skills needs to be implemented early in clinical training and demonstrated through continuing professional development and accreditation; and professional bodies need to include stigma-free practice in their professional standards."
- Consensus grade=U.
- "Diabetes self-management education needs to acknowledge the existence of diabetes stigma and its impacts."
  - · Consensus grade=U.

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## (Panel 3 continued from previous page)

#### Policy, advocacy, and funding

- "Discrimination due to diabetes needs to be defined clearly, prohibited by law, and reflected in organisational policies (eg, in education and workplaces)."
  - Consensus grade=U.
- "Organisations that advocate for and support people with diabetes need to pursue an end to diabetes stigma in their strategic plans, communications, and research strategies."
   Consensus grade=U.
- "Political support and funding for diabetes prevention, care, treatments, and research should not be adversely impacted by diabetes stigma."
  - Consensus grade=U.

#### Intersecting stigma

 "Efforts to reduce diabetes stigma must avoid perpetuating stigma elsewhere (eg, among people with other types of diabetes, conditions, experiences, or identities), and

and lack of exposure.55 Hypoglycaemia can cause conspicuous behaviours or physical symptoms (eg, lack of coordination, altered mood or cognition, or seizure), which can be mistaken for intoxication, epilepsy, or mental illness (all of which carry their own stigmas),<sup>20</sup> causing fear or disgust in others.21 Witnessing insulin injections or finger-pricking can elicit facial reactions, giving the impression of disgust, but potentially reflecting an empathic brain response to perceived pain.<sup>56</sup> Alternatively, such reactions might reflect an assumption that the person is injecting illicit substances, and be an expression of addiction stigma.14,20 Finally, dietary modifications and the visibility and audibility (via alerts) of so-called wearable tech (including continuous glucose monitors, insulin pumps, and hybrid closed loop systems) makes an otherwise invisible condition visible,57,58 which could provoke varying reactions from empowerment to curiosity, fear, or disgust.

### Law, policy, and regulations

Discrimination due to diabetes is unlawful under disability discrimination acts in many countries (eg, Canada, Denmark, Japan, the UK, and the USA).<sup>59</sup> That is, diabetes is often considered a protected disability because it substantially limits the function of the endocrine system. However, if people with diabetes do not realise that their health condition is classed as a disability, or do not identify with the words disabled or disability, then they might not appreciate that the law protects them from discrimination. Furthermore, requiring someone to identify as disabled to defend their rights facilitates a power imbalance, and could facilitate both diabetes stigma and ableism.

In addition to ambiguity, key facilitators of diabetes stigma are the absence of or inconsistencies between law, policy, and regulations—both within and between organisations, jurisdictions, or countries—or due to these consider the impacts of intersecting stigma on individuals and communities."

- Consensus grade=U.
- "More research is needed to examine how diabetes stigma interacts with experiences of stigma related to other characteristics, e.g., age, gender, ethnicity, identity, other health conditions; and how to minimise negative consequences of intersecting stigmas among people with diabetes."
  - Consensus grade=U.
- "Culturally sensitive research is needed to understand diabetes stigma and its impacts among disadvantaged, minority, and diverse populations, eg Indigenous people, refugee and asylum seekers, migrants."
  - Consensus grade=U.

U=unanimous consensus (100%). A=grade A consensus (90–99%), both grade A ratings were 98%.

#### Panel 4: Pledge to end diabetes stigma

"I / We PLEDGE to contribute pro-actively to bring an end to diabetes stigma and discrimination by:

- Respecting people with all types of diabetes
- Recognising diabetes stigma exists and has harmful impacts
- Acknowledging and challenging my/our own prejudices about (people with) diabetes
- Using accurate, respectful, inclusive, non-judgmental, and strengths-based language, messaging, and imagery when communicating with or about people with diabetes
- Avoiding and challenging fear-based messaging and imagery
- Condemning discrimination due to diabetes and advocating for equal treatment and support for people with diabetes
- Encouraging initiatives, policies, and laws that promote equity for all people with diabetes

By taking this pledge, I am / we are committed, from here on, to creating a more compassionate and respectful world for people with diabetes, free from diabetes stigma and discrimination and the harms they inflict."

not being enforced or being inaccessible to people (eg, due to literacy). Such issues make it difficult for people with diabetes to know and advocate for their rights to health, which include access to affordable treatments and the freedom to use them wherever they need, in a clean and safe environment, without having to conceal their condition, as detailed in the International Charter of rights and Responsibilities of People with Diabetes.<sup>4,60</sup> In addition, it can also be difficult for people with diabetes to know and advocate for their broader rights, regarding education, employment, insurance, and obtaining and

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keeping a driving licence or a pilot's licence.<sup>60</sup> For example, although several countries (eg, Austria, Canada, Ireland, the UK, and the USA) now permit adults with insulin-treated diabetes to hold a commercial pilot's licence,<sup>61,62</sup> most still prohibit this. Most countries ban people with insulin-treated diabetes from joining or remaining in the military after diagnosis; however, the Finnish Government announced its intention to reverse its ban, facilitating a more inclusive environment and recognising that policies need to be evidence-based, with safety issues assessed on a case-by-case basis.<sup>63</sup>

Differential access to insulin administration and glucose monitoring devices (eg, by diabetes type, treatment, or age) could facilitate stereotypes—eg, that type 1 diabetes or insulin-treated diabetes is more serious than other types, that type 1 diabetes only affects children, or that children or adults with type 1 diabetes are more deserving than people with type 2 diabetes. Although the policies that create differential access might be based in evidence of treatment efficacy and cost-effectiveness, they might also be influenced by lobbying by health consumer groups or organisations. The influence of such groups can be affected by power relationships, resources, and public perceptions of worthiness.<sup>35,64</sup>

## Manifestations of diabetes stigma and discrimination

Across all socioecological layers—individual, interpersonal, community, organisational, and policy considerable evidence shows that people with diabetes experience, perceive, and anticipate diabetes stigma (defined in panel 1). In addition to common stereotypes of people with diabetes being lazy, unhealthy and negligent, type 1 diabetes is stereotyped as affecting only children,<sup>14</sup> therefore ignoring the needs of adults,<sup>65</sup> and portraying type 1 diabetes as the bad or serious type, where a so-called normal life is not possible.<sup>58</sup> Such stereotypes vary across countries and cultures.<sup>65</sup> In some cultures and countries, people with type 2 diabetes are stereotyped as poor, unintelligent, bad, and at the end of life,<sup>20</sup> whereas in other places type 2 diabetes is seen as a condition affecting those with wealth.<sup>49,53</sup>

Relatively little research has sought to explore the stigmatising attitudes and practices of those enacting diabetes stigma. Yet, observable accounts of diabetes stigma and discrimination have long been documented.<sup>60</sup> Across the globe, there is evidence that people with diabetes are subject to unjustified restrictions (defined in regulation or not) related to education, employment, health care, driving and other licensing, travel, insurance, and (more rarely) adoption.<sup>14,45,53,66</sup>

#### Print and news media and popular culture

Diabetes stigma is perpetuated frequently in the print and news media. A common theme is the hyperfocus on personal responsibility,<sup>53,67-72</sup> often accompanied by stigmatising imagery (eg, unflattering depictions of large bodies, junk food, or sugary drinks).<sup>70</sup> In addition, headlines, which are often sensationalist or inaccurate,  $^{14,68,70,73}$  focus on the burden diabetes represents to health care  $^{74-76}$  and society,  $^{73}$  due to the epidemic of type 2 diabetes.  $^{14,53,72}$ 

The stigmatising framing of diabetes in the media influences community attitudes and practices.<sup>35,77-79</sup> For example, a US study (n=2490) identified that news media framing of type 2 diabetes as caused by behavioural choices or social determinants reduced support for related public health policies compared with genetic disposition or no causal framing.<sup>70</sup> A UK survey found that, despite strong public support overall for type 2 diabetes prevention programmes,<sup>35</sup> type 2 diabetes received the lowest support of three conditions (HIV, human papilloma virus, and type 2 diabetes). Furthermore, support for type 2 diabetes was lowest when the question wording included attribution of type 2 diabetes to unhealthy eating and inactive lifestyles versus the control condition, which did not mention any cause.<sup>35</sup>

In addition, there is considerable, observable evidence that television and film productions include stigmatising portrayals of people with diabetes. These include inaccurate or judgmental, dramatic, or comedic parodies of diabetes symptoms, self-care, and complications<sup>80-83</sup> and a tendency to "place diabetics under others' protection", which emphasises their dependence on others to care for them.<sup>82</sup>

## Public health campaigns

Health organisations, diabetes associations or charities, and governments, have used and been criticised for stigmatising, overly simplistic, sarcastic, or fear-based messaging and imagery.68,79,84,85 Comparatively little published research has examined diabetes campaigns in terms of their effectiveness or unintended consequences, and the theoretical underpinnings or evidence-base (if any) of such campaigns is unclear.79,85 An Australian study found that although most participants (with and without diabetes) perceived no stigma, 15% perceived eight National Diabetes Week campaign videos (originally broadcasted from 2005 to 2015) as stigmatising diabetes and with little positive benefit.86 Qualitative studies corroborate this finding, showing that people with diabetes express dissatisfaction with the scare tactics used in diabetes awareness campaigns.14,53,68

## Health care, research, and funding

Although it is acknowledged that many health professionals are supportive,<sup>\$7,88</sup> numerous studies across the world show that people with diabetes experience implicit and explicit stigma from health professionals.<sup>114,17,51,53,87,89–92</sup> For example, people with diabetes report being blamed and judged to be a failure for having diabetes, its complications, or what they do wrong.<sup>114,17,39,51,53,67,93</sup> Pregnant people with preexisting or gestational diabetes can experience intensified scrutiny and judgement focused on the risk that their behaviours could cause to their unborn child.<sup>39,94</sup>

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There have been few studies focused on diabetes stigma as enacted by health professionals. The experiences reported previously of people with diabetes are corroborated by some studies investigating health professionals' biases and prejudices directly,95-99 Other studies show that health professionals perceive diabetes to be less stigmatised than other health conditions.100,101 Diabetes stigma has also been documented in medical and nursing trainees.<sup>36,95,97,98,102</sup> For example, a 2019 US survey of medical students showed that most believe that type 2 diabetes, in particular, is the result of so-called lifestyle choices; people who "let themselves gain ridiculous amounts of weight to be disgusting"; and people with type 2 diabetes are not as worthy of empathetic clinical care as those with type 1 diabetes.<sup>36</sup> Such stigma could deter trainees from specialising in diabetes.102

Studies show that stigmatising language (eg, showing bias, judgements, questioning credibility, and portraying the person as difficult or having failed) has been included in clinical records and communications.<sup>103,104</sup> Additionally, the eleventh edition of the International Classification of Diseases includes entries such as diabetic foot ulcer (BD54) and descriptions such as "occurring in 15–25% of diabetic patients... poor foot care... increases the risk".<sup>103</sup> Such entries and descriptions have considerable potential for transmitting bias and influencing health-care quality. Stigmatising language has also been observed in academic research papers and presentations.<sup>105</sup>

There is also real-world evidence of stigmatising language and prejudicial views influencing government policy and political decisions regarding the funding of diabetes care.<sup>35,77–79</sup> In 2017, the American Diabetes Association criticised the US budget director's stigmatising view on diabetes after he said "We have plenty of money ... That doesn't mean we should take care of the person who sits at home, eats poorly and gets diabetes".106 Although the effects of such attitudes on actual funding are unclear, public funding of diabetes research has been described as in crisis,  $^{78,107,108}$  and there is a mismatch in diabetes research funding allocations (ie, the US dollars per person affected by diabetes) compared with other conditions.<sup>109</sup> Furthermore, funded diabetes research focuses disproportionally on research into biomedical aspects, with little funding allocated to behavioural, economic, environmental, epidemiological, nursing, public health, psychological, or social aspects of diabetes.110

# Education and employment

In the context of school and university education, diabetes stigma appears to manifest largely in children, adolescents, and adults with type 1 diabetes. There are reports of people with diabetes being treated differently by teachers or staff; exclusion (eg, due to worries about hypoglycemia); or ridicule by other students.<sup>46,111-113</sup> Many adults with type 1 diabetes recall their school experiences vividly, including some teachers fuelling their feeling of being different by singling them out in the presence of classmates, in relation to activities and food choices, potentially creating a sense of isolation.<sup>14</sup> However, when exceptions are not made (eg, allowing access to their treatments and support for managing diabetes), this can cause short-term and long-term health consequences.<sup>14,114</sup> In some parts of the world, students might not have appropriate support to manage diabetes in the school setting.<sup>115</sup> Elsewhere, students with type 1 diabetes might stop attending, or be excluded entirely from, secondary and tertiary education due to discrimination.<sup>38,4550,116</sup>

The attitudes of employers and colleagues<sup>117</sup> can facilitate diabetes stigma and discrimination, evident for those with type 1<sup>46,66</sup> and 2 diabetes.<sup>66,118</sup> This discrimination limits employment opportunities and career advancements,<sup>68,74,75,117-121</sup> particularly for people experiencing frequent hypoglycaemia or living with overweight, obesity, or diabetes-related complications.<sup>74,122,123</sup> In the USA, a review of 328738 allegations of employment discrimination found that 3.5% (n=11437) involved diabetes and that people with diabetes were more likely to encounter job-retention discrimination.<sup>124</sup>

#### Family, friends, and the general public

Some people with diabetes report feeling that their family and friends become the diabetes police,<sup>49</sup> but that the blaming, shaming, or judging could be founded in good intentions.<sup>14,53</sup> Known as miscarried helping, this phenomenon is well recognised in the context of adolescents with type 1 diabetes and their parents,<sup>125</sup> and to a lesser extent among adults with type 2 diabetes<sup>126,127</sup> or gestational diabetes.<sup>51,128,129</sup> Across diabetes types, family and friends scrutinise the food consumption and self-management behaviours of people with diabetes.<sup>14,53,93,11,130,131</sup> For adolescents with type 1 diabetes, peers without diabetes can also be also a source of stigma, including instances where friends look away when they inject insulin or check their glucose levels "because they feel strange or afraid".<sup>111</sup>

In some countries and cultures, where arranged or brokered marriages are the norm or where women's family or societal status is linked to marriage and childbearing, people with diabetes (in particular, type 1 diabetes) have reported social status loss and rejection because of their condition which leads to them being perceived as a less desirable spouse.<sup>38,41,44,45,46,47,51,132,133</sup> People with gestational diabetes report not disclosing their diabetes, experiencing blame from their family for their diagnosis, and being accused of having unhealthy babies.<sup>39,51,128,129</sup> Parents of a child with type 1 diabetes might hide the diagnosis from family, friends, and their community, and, in extreme cases, abandon or not invest in a child with type 1 diabetes, as type 1 diabetes is assumed to reduce life expectancy and is "like a black mark on the family".46,50,58

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Research suggests that people who do not live with diabetes might, incorrectly, perceive it as non-stigmatised or less stigmatised than other conditions, such as HIV or mental illness.<sup>1,100,101,134</sup> Yet, people with diabetes report the public as a key source of stigma.14,53 In addition, reports suggest that some of the general public believe that type 1 diabetes is a condition affecting "children who are lazy, unhealthy, fat, obese, lacking exercise, and having eating disorders".135 Social media analyses illustrate that public commentary links diabetes with obesity,136 gluttony,137 and perpetuates other common negative attitudes, rooted in problematic sociocultural phenomena, such ableism and anti-fat bias.100,136 For example, a content analysis showed that Instagram posts with the trending hashtag #diabetesonaplate depict energy-dense foods and are characterised as gluttonous.138

#### The diabetes community

Given that stigma-by-association with type 2 diabetes is salient among people with type 1 diabetes,<sup>139-141</sup> and parents of children with type 1 diabetes,<sup>46</sup> it is unsurprising that there are reports that these people resent people with type 2 diabetes and perceive that type 2 diabetes attracts more research and societal resources than type 1 diabetes.<sup>14</sup> Some people with type 1 diabetes distance themselves by emphasising their membership of their type 1 diabetes in-group to create a moral boundary through which to separate themselves from those with the so-called lifestyle disease,<sup>34</sup> who are stereotyped as lazy and fat.<sup>14,68</sup> One study found that 19% of adults with type 1 diabetes and parents of children with type 1 diabetes suggested changing the name to disassociate from type 2 diabetes.<sup>74</sup>

In turn, people with type 2 diabetes might believe stigma is specific to type 2 diabetes and perceive that people with type 1 diabetes are judged less harshly on account of perceptions of causality and seriousness,<sup>53</sup> and that people with type 1 diabetes receive more assistance, support, and access to advanced management options, such as continuous glucose monitoring.<sup>14,53</sup>

## Internalised diabetes stigma

Some people with diabetes endorse and internalise diabetes stereotypes, known as self-stigmatisation or self-stigma. Adults with type 2 diabetes report feelings of embarrassment, shame, self-blame, and guilt for developing diabetes.<sup>53,07,142–146</sup> People with gestational diabetes report feelings of guilt and personal responsibility (eg, for previous miscarriages and beliefs that they failed their unborn child), particularly if insulin is required to manage their condition.<sup>51,128,129</sup> Self-stigma might be less common among people with type 1 diabetes, and adoption of a positive diabetes identify might protect against self-stigma.<sup>14</sup> However, adolescents and young adults with type 1 diabetes describe feeling ashamed to manage diabetes in public,<sup>130</sup> or internalising negative self-images—eg, that they are weak, inferior,

a burden, or a social outcast—due to the reactions of others to their diabetes.  $^{{\scriptstyle\rm III},139}$ 

# Prevalence of diabetes stigma and discrimination

Prevalence estimates of diabetes stigma and discrimination are limited largely to adults with type 1 and type 2 diabetes as there are no validated measures designed for adults with other diabetes types nor specifically for children with diabetes. Prevalence estimates are also limited by variations in the type of stigma assessed, study designs, and the small number of countries in which diabetes stigma has been researched. Furthermore, prevalence could be underestimated, as people with diabetes might be unaware of or might not readily adopt such terms to describe their experiences.<sup>53,147</sup>

Nevertheless, research suggests diabetes stigma is a pervasive, global problem. Several large, cross-sectional quantitative studies (n=800-12000) provide consistent estimates that around four in five adults with type 1 or type 2 diabetes have experienced some aspect of diabetes stigma.<sup>17,19,74,75,91,148-150</sup> Diabetes stigma is also reported by 65-99% of adolescents and young adults with type 1 diabetes151,152 and 83% of parents of children with type 1 diabetes.<sup>74</sup> Two prospective studies in the USA report consistent diabetes stigma prevalence rates of approximately one in three adults with type 1 diabetes or type 2 diabetes (assessed over a 6 or 9 month period via a brief diabetes distress stigma-specific subscale).153,154 Furthermore, around 10% of those reporting no issues with diabetes stigma in the past month at baseline reported an experience at follow-up, and three of four reporting stigma in the past month at baseline scored similarly at follow-up, suggesting that diabetes stigma is enduring without intervention.153,154

In the multinational DAWN2 study<sup>155</sup> (which included 8596 adults across 17 countries), a single item asked adults with type 1 or type 2 diabetes whether they had been "discriminated against because of diabetes". On average, 19% of participants endorsed the item (varying from 10-30% across countries). A strong theme in the qualitative data from DAWN2 was public misunderstanding and discrimination at work.88 Elsewhere, cross-sectional research shows up to 11% of adults with type 2 diabetes report workplace discrimination or differential treatment due to diabetes.<sup>122</sup> Both diabetes stigma and discrimination appear more prevalent among women,74,156 people with lower socioeconomic status,157 and people with type 1 diabetes or insulin-treated type 2 diabetes versus noninsulin-treated diabetes.<sup>74,156,158-160</sup> There is also some evidence that diabetes stigma is associated with younger age, shorter diabetes duration, and higher education level.<sup>17,19,149,157,161-166</sup> The emerging evidence is mixed regarding diabetes stigma and use of diabetes technologies, such as insulin delivery and glucose monitoring devices.159,160,167,160

Rates of diabetes stigma endorsed or enacted by individuals without diabetes remain largely absent from

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the research literature, and there are few validated measures for use among the wider population. In Singapore, a survey of the general public (n=2895) found that around a quarter were unwilling to have someone with diabetes marry into their family, employ someone with diabetes, or travel in a taxi or bus driven by someone with diabetes.76 Furthermore, they would not be comfortable seeing someone inject insulin, and believe that people with diabetes are responsible for "bringing this condition on themselves".<sup>76</sup> This evidence showed variation in public stigma by ethnicity, age, education level, and proximity to someone living with diabetes.76 In a US study of 208 medical students, 29% endorsed a single item, "do you have any stigma against people with diabetes?" and those particpants were statistically significantly less likely to endorse the seriousness of type 2 diabetes relative to their counterparts.<sup>36</sup> In the DAWN2 study, societal discrimination against people with diabetes was reported by 33% of health professionals169 and 22% of family members.170

## Intersecting stigmas

Intersectional stigma describes the concept whereby people live with multiple stigmatised or prejudicially treated conditions or characteristics. However, there is little research exploring the experience and effects of multiple stigmas among people with diabetes.

Several examples focus on experiences of race and gender.<sup>44,74,157,171-173</sup> For example, in a qualitative study, Black and African American adolescents with type 1 diabetes spoke of how the duality of diabetes and race negatively affected their relationships with peers and their diabetes management.<sup>174</sup> A meta-analysis shows that racial or ethnic differences exist in relation to diabetes management and risk of complications.<sup>175</sup> In some cultures and countries, due to prevalent social and gender norms, girls and women with diabetes could be particularly vulnerable, as they are judged more harshly, considered damaged, not an ideal marriage partner, and a potential health and financial burden.<sup>38,39,40,41,44,51,171</sup>

Among women with type 2 diabetes (or prediabetes) and binge eating disorder, experiences of stigma from health professionals include judgement for their bodyweight and lack of weight loss and being viewed as non-compliant.<sup>176</sup> Experiences of weight-related stigma are more frequently reported by people with diabetes,<sup>14,53,68,138</sup> with pejorative labelling and associated stereotypes (eg, lazy), common to both diabetes and obesity.<sup>53,171</sup> Furthermore, among adults with type 2 diabetes there is a moderate-to-strong association between diabetes stigma and weight stigma, including feeling judged by health professionals due to their weight.<sup>173</sup>

Other studies show experiences of the double stigma of having comorbid physical health conditions (eg, diabetes and HIV), or physical and mental health conditions, which distinguish them both physically and psychologically from their healthy peers.<sup>171,177,178</sup> In several African countries, people with type 2 diabetes are mislabelled through gossip and misinformation as having HIV or AIDS, and thought to be wasting resources.<sup>165</sup> In Cameroon, people with type 2 diabetes express concerns about accepting weight loss as a legitimate approach to managing type 2 diabetes because of their fear that people will assume they have HIV and because overweight is considered a sign of health and wealth.<sup>178</sup>

## Consequences for people with diabetes

Although prospective research is scarce, mounting crosssectional evidence shows ubiquitous, negative experiences of diabetes stigma for people living with diabetes. This evidence is corroborated by rich, qualitative accounts of the multidimensional effects of diabetes stigma on health, defined as a complete state of psychological, social, and physical wellbeing.<sup>79</sup>

## Psychological wellbeing

Quantitative studies show that diabetes stigma is associated with depressive symptoms,<sup>17,19,89,158,164,180-185</sup> anxiety symptoms,<sup>17,19,75,158,183</sup> and reduced general emotional wellbeing.<sup>120,183,186</sup> Typically, there are moderate-to-strong positive correlations between diabetes stigma and diabetes distress.<sup>17,19,51,74,75,89,139,148,149,157,158,162,164,181,184-190</sup> Qualitative studies support the premise that both general and diabetes specific emotional distress is a consequence of diabetes stigma.<sup>14,51,53,130,139,191</sup>

People who experience diabetes stigma have a lower general quality of life<sup>75,192</sup> or life satisfaction<sup>192,193</sup> and greater negative effect of diabetes on quality of life than people with diabetes who do not experience this stigma.<sup>120,188,189,194</sup> Many such effects are illustrated in the previously mentioned issues in, for example, education, employment, marriage, and relationships. Diabetes stigma is also associated with lower general self-esteem,<sup>17,19,144,157,180,195</sup> general self-efficacy,<sup>144,157,180</sup> and resilience.<sup>161</sup> These could be outcomes of diabetes stigma or mechanisms of the internalisation of diabetes stigma.

Internalised stigma appears to magnify the effects of diabetes stigma. Compared with experienced or perceived stigma, diabetes self-stigma is more strongly associated with greater diabetes distress,<sup>148,158</sup> lower self-esteem,<sup>145</sup> and lower general self-efficacy.<sup>148</sup> The negative cognitive and emotional consequences of diabetes stigma appear to be more prevalent among women than men<sup>74</sup> and people with type 1 diabetes than type 2 diabetes or insulin-treated type 2 diabetes.<sup>74,158</sup>

## Social wellbeing

Qualitative studies show that the effects of diabetes stigma can include social withdrawal and avoidance of social contact, resulting in isolation or little social, professional, or other opportunities.<sup>577,112,139,145,191,196</sup> People experiencing

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diabetes stigma are more likely to report worse interpersonal relationships with family, friends, and health professionals; less social support; stronger feelings of isolation and loneliness;<sup>51,74,75,116,129,131,157,164,165,194,197,198</sup> and that unsupportive friendships have come to an end.<sup>53</sup> In family settings, women (with type 1, type 2, or gestational diabetes) might be particularly disadvantaged—eg, due to hiding the diagnosis from a prospective spouse, fearing abandonment, or experiencing intimidation from her husband and his family, with emotional, social and financial implications.<sup>20,39,44,45,94,199,200</sup> In workplaces, one in three adults with type 1 diabetes and almost one in four adults with type 2 diabetes conceal their condition from colleagues,<sup>121,186</sup> due to anticipated stigma or discrimination.<sup>53,121,145</sup>

Finally, diabetes stigma negatively affects relationships and support in the health-care setting,157 and affects access to quality health care. There is increasing evidence that when health professionals' response to above-target glucose levels is disease-focused, dehumanising, and judgmental (or anticipated to be so), people with type 1 and 2 diabetes could avoid clinic visits, HbA<sub>1c</sub> and retinal screening, and disengage from diabetes self-care tasks, due to the feeling that their efforts are not valued. 41,87,93,148,201 People with type 2 diabetes also report limited access to treatments, technologies, and specialist care due to stigma: "they say 'no, because you're type 2'".53 Similarly, women with gestational diabetes experiencing diabetes stigma also report lower engagement in health care (including avoidance of screening during and after pregnancy), not wanting more children, and not prioritising their own health after pregnancy. 39,128,129

#### Physical wellbeing and self-care

Among people with type 1 and 2 diabetes, positive associations have been shown between diabetes stigma and glycaemic metrics above the recommended targets.<sup>116,118,143,144,151,152,156,158,181,182,184,189,202,203</sup> Although these associations are mostly small, and typically involve selfreported HbA<sub>ic</sub>, the findings are corroborated by some laboratory assessments showing up to three-times higher odds of above-target HbA,...<sup>151,152,156</sup> Diabetes stigma is also associated with more frequent severe hypoglycaemia,<sup>116,156,162</sup> diabetes-related ketoacidosis,<sup>156</sup> retinopathy,<sup>156</sup> and hospitalisations<sup>118</sup> and a higher BMI.<sup>162</sup> Although qualitative data support the premise that such outcomes are a consequence, rather than a determinant, of diabetes stigma and some prospective research exists,189 more is needed to define this relationship and some studies find no association with HbA1.18

Non-disclosure of diabetes, a common behavioural consequence of diabetes stigma,<sup>14,51,53,145,165,191</sup> could lead to people with diabetes compromising their self-care in public or social situations. For example, delaying or omitting glucose monitoring and medications (particularly insulin),<sup>1,14,116,128,130,139,204–206</sup> accepting specific foods due to fear of disclosure, or binge eating as a coping

strategy when faced with diabetes stigma.51,116,128,150 In general, people who feel stigmatised due to their diabetes are less likely to undertake necessary self-care behaviours118,128,143,144,148,157,158,165,181,184,187,192,193,202,206 as they do not have the social opportunity to do so without retribution.<sup>207</sup> People experiencing diabetes stigma are also less likely to have self-efficacy or activation for managing their condition,<sup>158,183,188,195,208</sup> or to attend the programmes that could help them to develop it.209,210 Among people with type 1 diabetes, diabetes stigma is associated with fear of hypoglycaemia,<sup>185</sup> hypoglycaemia avoidant behaviours,<sup>164</sup> and insulin omission.<sup>184</sup> Among adults with type 2 diabetes and adolescents with type 1 diabetes, diabetes stigma and self-stigma are associated with negative insulin appraisals, which are associated with greater omission of oral medications and insulin.116,162,204,208 Diabetes stigma could contribute to the acceptability of diabetes technology (eg, drawing unwanted attention or, conversely, adding legitimacy by medicalising their socalled lifestyle disease).168,211

## Interventions to reduce diabetes stigma and its effects

To date, very little empirical research has focused on strategies to reduce diabetes stigma and its effects. However, efforts to mitigate diabetes stigma could draw on research from other health-related stigmas. For example, the Lancet Commission on Ending Stigma and Siscrimination in Mental Health<sup>212</sup> reports that direct or indirect social contact between people who do and do not have lived experience of mental health conditions was the most effective approach across context and cultures. Examples of other hallmarks of stigma-reduction programmes include involving people with lived experience in all aspects of intervention development; early consideration of programme scalability and sustainability; targeting policy change and funding; integration into existing services (such as clinical training); use of champions to advocate for organisational change; and evidence-based programme development. Such themes could inform the development of the diabetes stigma interventions.

Importantly, interventions to reduce diabetes stigma and its effects need to be informed or led by people with or affected by diabetes (and facilitated, for example, by diabetes organisations<sup>213</sup>), therefore observing the social media mantra #NothingAboutUsWithoutUs.

## Changing the narrative

Endorsement of this consensus statement represents a public commitment to bringing an end to diabetes stigma. For some organisations, this will require a narrative shift in their communications about diabetes and people with diabetes. This shift includes changing the prevailing social narrative focused on blame, responsibility, control, and compliance, which needs to be replaced with a balanced focus on genetic, biological, sociocultural, environmental, and behavioural factors, as well as the

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social inequities influencing health.<sup>214</sup> Over a decade ago, Diabetes Australia's position statement on communicating with and about people with diabetes recognised the power of language,<sup>215,216</sup> and inspired an international diabetes Language Matters movement, with at least 14 similar national statements since.<sup>217–219</sup> The recommendations in these statements and other resources (eg, dStigmatize. org) are designed to support changing the narrative. Some journal publishers, conferences, and funding bodies now require adoption of such language.

Although few of these resources have undergone specific evaluation, studies have examined the extent to which the general narrative has shifted over several years. For example, a study published earlier this year identified that 60% of diabetes scholarly articles published since 2011 used person-first language (in addition to or in the absence of condition-first language), with a 3% annual increase.105 With regard to the media, two studies have evaluated changes in language used in Australian newspaper coverage of diabetes.<sup>220,221</sup> One study observed a statistically significant reduction in the use of problematic language between 2010 and 2014,221 but both identified continued use of labelling (commonly referring to diabetics) and little specificity regarding diabetes type.<sup>220,221</sup> Nonetheless, these findings suggest incremental uptake of the Language Matters movement in scholarly and media reporting on diabetes. Further research is needed to examine the adoption of recommended language and to optimise implementation in other settings, such as by diabetes and health organisations, among health professionals, and on social media. For example, one group has developed and shown the acceptability of a brief video to train health professionals to decrease the use of stigmatising language in health-care encounters,<sup>222</sup> which warrants further evaluation.

Positive portrayals of people with visible signs of diabetes, and its potential complications, are also important to counter stereotypes and promote inclusivity.<sup>223</sup> Yet, stereotyping imagery continues to be used in the print and news media, popular culture, public health campaigns, and health information sheets,79 the latter often aiming to scare or shock people into acting to prevent or manage diabetes.<sup>224</sup> In addition to the Language Matters movement, there is a call to consider more carefully the imagery associated with diabetes. A study of Facebook posts about diabetes found that positive imagery was the strongest predictor of liking a post and of sharing it.225 Such images included healthy foods, activity, and achieving goals. Drawing inspiration from strategies to reduce weight stigma,226 development and implementation of diabetes-specific image banks could support use of respectful imagery.

# Policy, advocacy, and funding

Health and diabetes organisations play a key role in communicating and protecting the rights of people with diabetes and access to quality health care, information and education about diabetes, and social justice, including fair treatment.<sup>4</sup> Diabetes organisations have a strong history of advocacy and providing support for people experiencing diabetes discrimination. The International Diabetes Federation focused on calling out diabetes stigma and discrimination in its global diabetes plan and advocacy toolkit.<sup>6,227</sup> Since 2013, the International Diabetes Federation's Kids and Diabetes in Schools project has addressed diabetes-related stigma by fostering a safe and supportive school environment for children with diabetes.<sup>228</sup> In addition, many organisations provide legal advocacy,<sup>229–231</sup> provide training to prevent discrimination in workplaces or schools,<sup>231</sup> and advocate for equitable and sustained access to diabetes treatments and technologies.<sup>227,232–234</sup>

Increasingly, diabetes organisations across the world are making public commitments to address diabetes stigma and discrimination. In their multiyear strategic plans, highlighting the pivotal need to challenge diabetes stigma, Diabetes Canada has committed to "change the conversation"<sup>235</sup> and Diabetes UK has prioritised preventing discrimination due to diabetes<sup>236</sup> and recognised that more research into diabetes stigma is pivotal to improving the mental wellbeing of people with diabetes,<sup>237</sup> dedicating funding to support this.<sup>235</sup> In 2022, the diaTribe Foundation launched dStigmatize.org.

In the past few years, Diabetes New Zealand, Diabetes Australia, and Diabetes UK have used their national campaigns to raise awareness of diabetes stigma,<sup>238-240</sup> and many more organisations address diabetes myths and misconceptions about diabetes. Although such campaigns respond directly to the call to action against diabetes stigma, and have been widely viewed, no formal evaluations have been published. Thus, it is unclear whether these campaigns had reach or impact. It is also unclear whether such campaigns are based on theory or evidence for how to bring about such change.<sup>579</sup>

Given the complexities of health, and the numerous conditions affected by stigma and discrimination, taking an intersectional approach to stigma could assist with identifying and tailoring solutions to address diabetes stigma, drawing on effective stigma reduction initiatives in other conditions, while accounting for the diverse characteristics, experiences, and needs of people with diabetes. Furthermore, it has been argued that to bring an end to health stigma broadly, research must evolve beyond specific interventions, such that an intersectional approach, requiring cross-disciplinary advocacy and action.<sup>241</sup>

#### Health care

Improving attitudes (and practices) among health professionals is an important strategy to mitigate diabetes stigma, since they occupy positions of power and influence and have frequent contact with people with diabetes.<sup>242</sup> However, to date, little research has examined strategies to combat enacted diabetes stigma in health-care settings.<sup>243</sup> For more on the Language Matters movement see https:// www.languagemattersdiabetes. com/

For the **dStigmatize website** see https://www.dstigmatize.org/

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There is some evidence for contact-based approaches in diabetes, 97,36 corroborated by studies in obesity or mental health conditions,<sup>212,242,244-247</sup> whereby positive exposure and interaction with individuals who have experienced stigma can reduce bias and stigma through increased empathy and understanding. Furthermore, diabetes specialists are more likely to be aware of diabetes stigma among people with type 2 diabetes than non-specialists, potentially indicating greater understanding and empathy with increased contact with people.134 There is a crucial need to provide training for health-care professionals in stigmafree communication and consultations. Education in empathic, person-centred care, including use of preferred diabetes language, could mitigate stigmatisation in diabetes care settings.199,216,219,248 However, little research has explored the role of such education in minimising diabetes stigma.

There remains a fundamental barrier to ending diabetes stigma in health care. The medical model prevails across health systems, and, in parallel, psychosocial and environmental determinants of health and wellbeing are underestimated. Many health professionals intervene to treat diabetes, rather than care holistically for the person with diabetes. The power imbalance inherent in the medical model places the person with diabetes in a passive role as the recipient of care given by the clinician and reduces diabetes management to the behaviour of the person (ie, their compliance) without acknowledging the complex biopsychosocial and socioecological factors that affect their capability and opportunities for behaviour change and optimal health. Professional bodies can play an important role in the provision of stigma-free practice guidance and training. Arguably, the American Diabetes Association and European Association for the Study of Diabetes consensus reports on managing type 1 diabetes<sup>249</sup> and type 2 diabetes<sup>250</sup> represent the greatest progress to date in acknowledging these complexities. For example, both include relatively detailed recommendations regarding psychosocial care, which will require a major shift (in many countries) in the provision of clinical care and a reimagining of health systems and settings. Thus, there remains far more progress to make.

#### Supporting people living with diabetes

It is crucial that society takes up the call to reduce enacted stigma at all levels, but such multilevel societal change will take time. While diabetes stigma persists, it is important that people living with diabetes can recognise, challenge, and cope with diabetes stigma, maintain their self-esteem and avoid self-stigma. It has been asserted that "addressing self-stigma might be equally as essential as measuring HbA1c".<sup>203</sup> However, there is little research on what works.

There is a need to examine the protective mechanisms of diabetes stigma, with prospective follow-up, and to develop and test the effectiveness of novel interventions to reduce the internalisation of diabetes stigma, based on such mechanisms. These interventions include endorsing genetic causal beliefs;<sup>193</sup> enhanced resilience;<sup>161</sup> self-esteem;<sup>144,145,158,195,196,251</sup> self-confidence or self-efficacy;<sup>92,143,144,195,251</sup> accepting and integrating diabetes as a part of ones' own identity;<sup>145,251</sup> performing effective self-care activities to achieve the optimal diabetes management;<sup>144,145,189,195,196,202,251</sup> and social support.<sup>158,251,252</sup>

As a starting point, intervention might include acknowledgment of diabetes stigma and its effects within existing programmes and resources (eg, diabetes education, psychoeducation, and peer and social support). Furthermore, researchers might consider examining the effects of existing programmes and interventions on internalised diabetes stigma with comprehensive assessment tools (appendix pp 28). Studies have shown a reduction in "negative social perceptions" (according to the Type 1 Diabetes Distress Scale subscale) after 12 weeks of continuous glucose monitoring in children and adolescents with type 1 diabetes168 and in the T1-REDEEM trial<sup>253</sup> among adults with type 1 diabetes and elevated HbA<sub>1c</sub>. This is promising evidence, given neither study specifically focused on reducing diabetes stigma. The use, and potential optimisation, of existing interventions and programmes might be a more timely and cost-effective approach to supporting those affected by diabetes stigma than the development of novel stigma-specific interventions. For example, family members and peers have been identified elsewhere as an underused resource for ongoing support,<sup>254</sup> and their inclusion in diabetes selfmanagement education could facilitate increased empathy and improved understanding of how they can best support people with diabetes. Strategies for disclosure could inform useful interventions to enable people with diabetes to seek and receive support.255 In Iran, a qualitative study investigated culturally appropriate strategies to inform the development of a multilevel intervention for adults with type 1 diabetes experiencing diabetes stigma.<sup>199</sup> Several strategies were identified: condition acceptance, enhancing self-esteem and self-confidence, effective diabetes self-management, and having a peer support network. However, the intervention has not been evaluated systematically. In Japan, researchers and adults with type 2 diabetes experiencing self-stigma designed a 10-week psychoeducational intervention (eg, brief videos incorporating lived experience narratives, accompanied by homework).256 The intervention appeared acceptable and probably beneficial in a small feasibility study,256 and warrants further evaluation in a larger study.

## Strengths and Limitations

The broad strengths are that this consensus was informed by a diverse expert panel, published peerreviewed evidence, and a rigorous, independently conducted Delphi survey process. International panellists included people with lived or family experience or clinical or research experience in diabetes stigma (or both). Thus, from beginning to end, there was meaningful

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engagement and collaboration across communities directly affected by diabetes. Although the expert panel comprised 51 members from 18 countries, most are from high-income countries. We acknowledge the inherent potential for selection bias in the international consensus, including the scarcity of representation of experts from low-income and middle-income countries, with rarer types of diabetes, or from Indigenous, migrant, and other minority populations. The relevance of the evidence and recommendations need to be examined within local contexts. The acceptability of a public endorsement of the draft pledge was not explored exhaustively before finalisation. However, the pledge has since been taken by organisations and individuals in 100 countries, 58% of which are low-income and middle-income countries, suggesting the pledge is relevant and being embraced across the world.

We took a systematic approach to identifying, understanding, and communicating the available evidence in the form of brief statements of evidence and recommendations and the pledge. We conducted a systematic search, but not a systematic review. Neither the search terms nor the databases searched were exhaustive, and papers were only returned if the search terms appeared in the title (ie, were a focus of the paper) and were published in English. Panellists responsible for the rapid reviews were encouraged to add relevant papers identified by other means. Evidence synthesis was necessarily succinct; thus, detail might have been omitted that could have been informative. In addition, the evidence base is further limited by the apparent absence of published stigma research focused on rarer types of diabetes, other subpopulations, or conducted in low-income and middle-income countries. Although the rapid reviews that created the basis for this consensus statement were undertaken by expert panel members, and peer reviewed by other panel members, the evidence was not formally appraised or weighted for quality.

# Conclusion

For this consensus, a multidisciplinary panel applied their lived and professional expertise to the goal of making explicit the nature and extent of diabetes stigma and discrimination, key drivers and facilitators, consequences, and interventions, as well as making evidence-based recommendations for what is needed to bring an end to diabetes stigma, discrimination, and their harmful effects. Near unanimous consensus was achieved on the evidence and recommendations (panel 2; panel 3) and unanimous consensus was achieved on a pledge to end diabetes stigma and discrimination (panel 4). Although we acknowledge that prospective research is needed, our consensus is that there is convincing evidence that diabetes stigma and discrimination are ubiquitous, insidious, pervasive, counterproductive and can be harmful to both physical and mental health. Bringing an end to diabetes stigma

#### Search strategy and selection criteria

A systematic search was designed (by JSp and EHT) and done of the Scopus and PubMed scientific literature databases (searching from database inception on Jan 31, 2023, by JSp), with the following terms (with no set limits):

- Scopus: "(TITLE(diabet\*) AND TITLE(stigma OR bias OR prejudice OR discriminat\*))"
- PubMed: "diabet\*[Title] AND (stigma[Title] OR bias[Title] OR prejudice[Title] OR discriminat\*[Title])"

Search strings were limited to TITLE to maintain the focus on diabetes stigma. Search returns were uploaded to Covidence for duplication removal. Applying inclusion/exclusion criteria (appendix p 5), JSp and EHT screened titles and abstracts independently, followed by full texts where needed, and discussed and resolved discrepancies.

Scopus returned 465 titles and PubMed 395, resulting in a combined 504 titles after duplicates were removed. Of these papers, 344 were excluded on the basis of title and abstract screening and 43 following full-text review. In total, 116 relevant articles were shared with panel members to inform 12 topic-specific rapid reviews (appendix p 4).

When developing the evidence summaries of the 12 topicfocused rapid reviews, panel members had autonomy to add references not delivered via the systematic search, on the basis of searches of reference lists or known literature (appendix pp 6–20). Following peer-review and revisions, the summaries were synthesised further (see summary of evidence section).

and discrimination is both necessary and urgent. These changes will require multifaceted, long-term solutions, involving international collaboration and collective leadership from all sectors of the community (including people with and affected by diabetes and those working in advocacy, research, health care, media, industry, and policy). Such action will require all of us to challenge our own biases and to recognise how we might be contributing to, or facilitating, diabetes stigma and discrimination (which includes both action and inaction).

We extend an open invitation to individuals and organisations across the world to endorse and, most importantly, implement the pledge. To implement the pledge, meaningful community engagement with people with diabetes is necessary to identify localised stigmatising practices (as it might not be apparent to those perpetuating them) and plan, develop and implement research, initiatives, and policies to address diabetes stigma. We hope that the pledge and the statements of recommendations will provide the necessary impetus for collective leadership, commitment, and action across sectors. Without this, there might be further exacerbation of the potential harms of diabetes stigma and discrimination. Together, everyone can change the social norm from stigma to support.

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#### Contributors

This consensus was conceived by JSp and operationalised with contributions from EH-T, MG, and RS. JSp, EH-T, MG, and RS identified and invited panel members. EH-T and JSp prepared the consensus methods (which were reviewed by the panel) and conducted the systematic search and abstract screening. A subgroup of panel members (appendix pp 2-3) conducted rapid reviews and prepared or peer-reviewed draft evidence summaries, and draft statements of evidence and recommendations. JSp, EH-T, MG, RS, and TCS refined the draft statements of evidence and recommendations and drafted a pledge before the first survey and informed by panel feedback after the first and second survey rounds. The three surveys were designed by EH-T and JSp with input from panel members. Panel members reviewed, rated, and provided feedback on the draft statements of evidence and recommendations and the pledge, via three Delphi surveys. EH-T double-checked anonymised survey data to ensure accuracy of analyses and reporting. JSp and EH-T prepared the first draft of the consensus manuscript, and led subsequent revisions, based on panel review and feedback. All named authors have formally endorsed the statements of evidence and recommendations and taken the pledge.

#### Declaration of interests

In the past 3 years, JSp and EH-T have received competitive research grants from the Diabetes Australia Research Program, the Medical Research Future Fund Targeted Translational Research Accelerator, and the National Health and Medical Research Council of Australia. JSp and EH-T have received an investigator-initiated research grant from Sanofi Diabetes and an unrestricted educational grant from Diabetes Australia and are supported by core funding to the Australian Centre for Behavioural Research in Diabetes derived from the collaboration between Diabetes Victoria and Deakin University. JSp has also received a competitive research grant from the Ian Potter Foundation: a research contract from the Australian Government Department of Health; a consulting fee from Diabetes Canada; honoraria to present at educational meetings from Novo Nordisk and Sanofi Diabetes; honoraria for participating in advisory boards from Insulet and Sanofi Diabetes; and support for attending meetings (including travel) from the Novo Nordisk Foundation. EH-T received honoraria for presentation at educational meetings from Roche Diabetes Care. All these payments have been made directly to the Australian Centre for Behavioural Research in Diabetes; this research centre owns the copyright of the type 1 and type 2 Diabetes Stigma Assessment Scales. JSp is the Chair, JSt the Vice-chair, and EH-T website redevelopment lead of the international PsychoSocial Aspects of Diabetes Study Group (unpaid roles). MG has received project funding from One Drop, Eli Lilly, Boehringer Ingelheim and Eli Lilly Alliance, Abbott, and Genentech and honorarium from Sanofi and Diabetes Sisters (all paid to the diaTribe Foundation). IW has shares in Novo Nordisk. ASe has received competitive research grants from the Juvenile Diabetes Research Foundation and Auckland Medical Research Foundation (all paid to the University of Auckland) and conference attendance support (as an invited speaker) from the International Society for Pediatric and Adolescent Diabetes. BA received conference funding support to present at a RAPID conference hosted by PsychoSocial Aspects of Diabetes and Steno. MdG has received competitive research grants from the American Diabetes Association and National Institute on Aging and received consulting fees from Mediflix and Kenner Family Foundation. SH has received consulting fees from Novo Nordisk, Lilly Diabetes Care, Medtronic Diabetes Care, and Dexcom Germany; received payments of honoraria from Novo Nordisk and Ascensia Diabetes Care; payment for expert testimony from VitalAire; received support for attending meetings from Ascensia, Diabetes Center Berne, Diabeloop, Dexcom, Lilly, Medtronic, Novo Nordisk, Sanofi, Tandem, embecta, and dotcool; received medical equipment from Abbott Diabetes Care, Dexcom, and Ypsomed; and is Head of Communications for #dedoc°, Dedoc Labs. RIGH has received research support from Novo Nordisk; speaker honoraria from EASD, Eli Lilly, Encore, Liberum, Novo Nordisk, and ROVI; and conference attendance funding from Novo Nordisk and Eli Lilly. KK is supported by the UK National Institute for Health Research's Applied Research Collaboration East Midlands and Leicester Biomedical Research Centre; has received research funding from AstraZeneca, Boehringer Ingelheim, Eli Lilly, MSD, Novartis, Novo Nordisk, Roche,

Oramed Pharmaceuticals, and Sanofi; received consultancy fees from AstraZeneca, Boehringer Ingelheim, Eli Lilly, MSD, Novo Nordisk, Roche, Sanofi, and Servier; and received payments of honoraria from AstraZeneca, Boehringer Ingelheim, Eli Lilly, Novartis, Novo Nordisk, Roche, and Sanofi. RLP has received research funding from the US National Institutes of Health (paid to institution); received presentation honorarium from the Diabetes Leadership Council; and is Chair of Policy Track for The Obesity Society Annual Meeting Program Committee (unpaid role). RMP has received research funding and consultancy fees from Eli Lilly. MSe has received conference funding support from the International Diabetes Federation and the International Society for Pediatric and Adolescent Diabetes. MV has received investigator-initiated research funding from Abbott, Bausch, and Novo Nordisk; received consulting feeds from Abbott, Abbvie, Boehringer Ingelheim, and Novo Nordisk; received payments and travel support from Abbott, Abbvie, Boehringer Ingelheim, Novo Nordisk, Eli Lilly, Merck, and Pfizer; has a pending patent with AmpHealth for a digital health intervention; and is a Diabetes Canada Mission Committee member (unpaid role). All other authors report no competing interests.

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