The Australian Centre
for Behavioural Research
in Diabetes

# 2024

# Annual Report

Partners for better health

diabetes vic

INSTITUTE FOR HEALTH
TRANSFORMATION

DEAKIN UNIVERSITY

# **Our Vision** is optimal health and quality of life for all people living with, at risk of, or affected by diabetes

## We are

- A partnership for better health between Diabetes Victoria and Deakin University.
- Established in 2010.
- Located in Melbourne, Victoria.
- The only national research centre in the world focused on the behavioural, psychological and social aspects of diabetes.
- Currently, 17 staff and PhD candidates, specialising in health psychology, clinical psychology, statistics, research methods and communication.

# Research
# Excellence

# Excellence in research: at a glance

**40***

Publications in peer-reviewed academic journals

**40%**

First author is early career researcher (at ACBRD or elsewhere)

**43%**

Led by the ACBRD (i.e. first or senior author)

**65%**

Publications with international co-authors

**15%**

In world's top 10% most cited publications

**93%**

In world's top 25% of journals

**29**

Countries in which researchers cited our research in 2024

**5**

Awards and recognition

**21**

Invited lectures, symposia or workshops at local, national & international meetings

**18**

Peer-reviewed abstracts presented at (inter)national conferences

**4**

PhD candidates supervised

**1**

PhD awarded

**117%**

Achieved (in 4.5 years) of 5-year funding target

**8**

New research grants awarded (Category 1, external other and internal)

**$876k**

Total value of new research income direct to ACBRD in 2024

**$959k**

Total value of new grants / income in 2024 supporting research on which ACBRD collaborates

*40 journal publications were indexed in Scopus. This exceeds our target of 25 by 60%. Many more articles are 'in press' for publication in 2025.

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The ACBRD website includes details of all journal articles published in 2024, plus invited presentations, and peer-reviewed abstracts presented at national and international conferences

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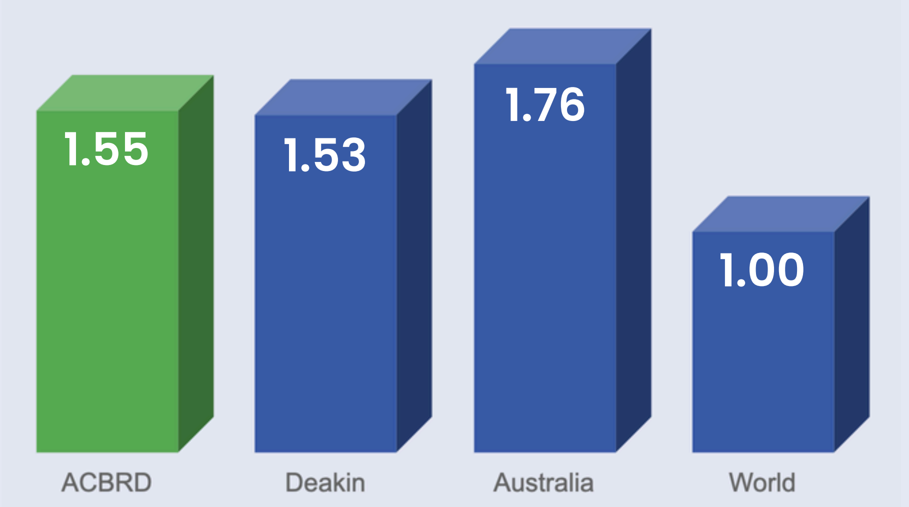
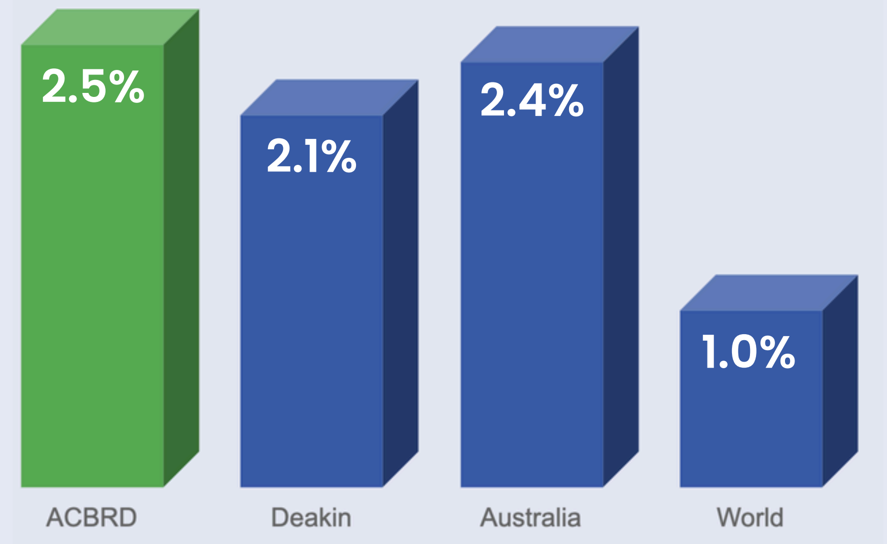
# 40 Journal articles: at or 'above world standard'

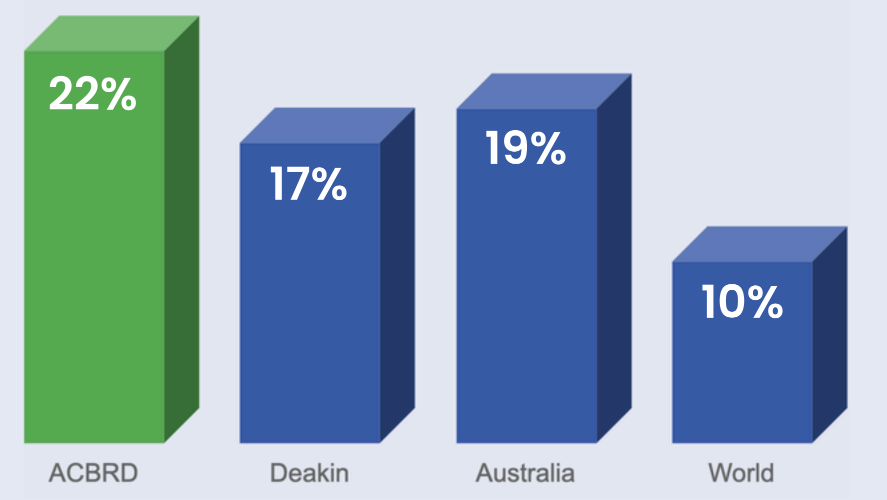
## Average citations per 2024 publication



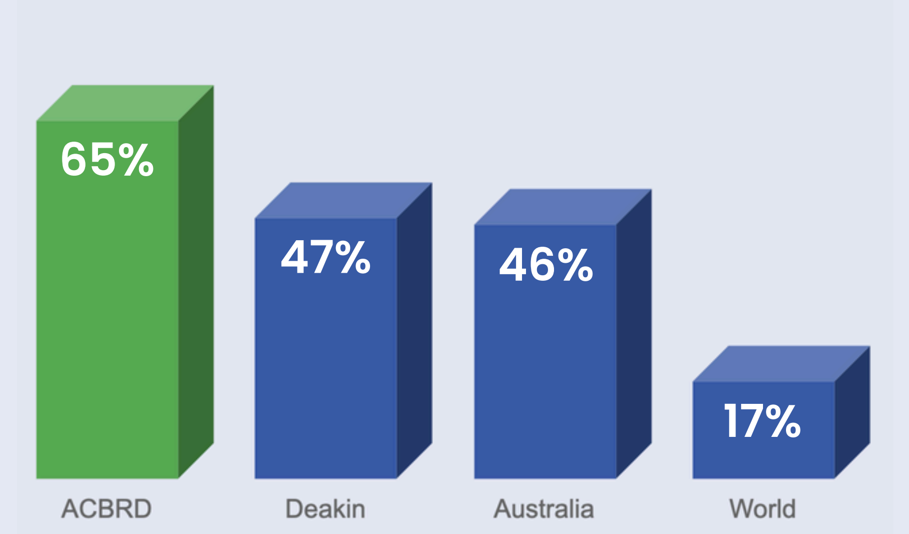
## % of 2024 publications among world's top 1% most cited papers



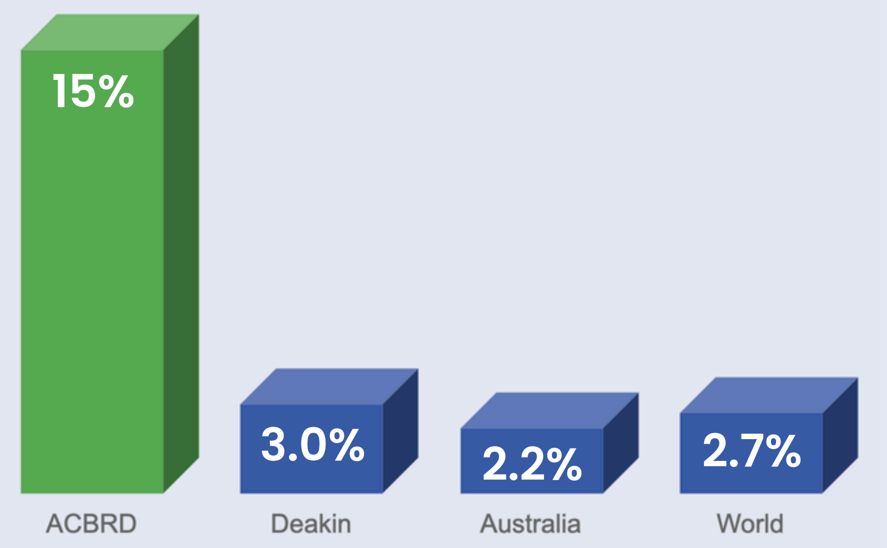
## % of 2024 publications among world's top 10% most cited papers



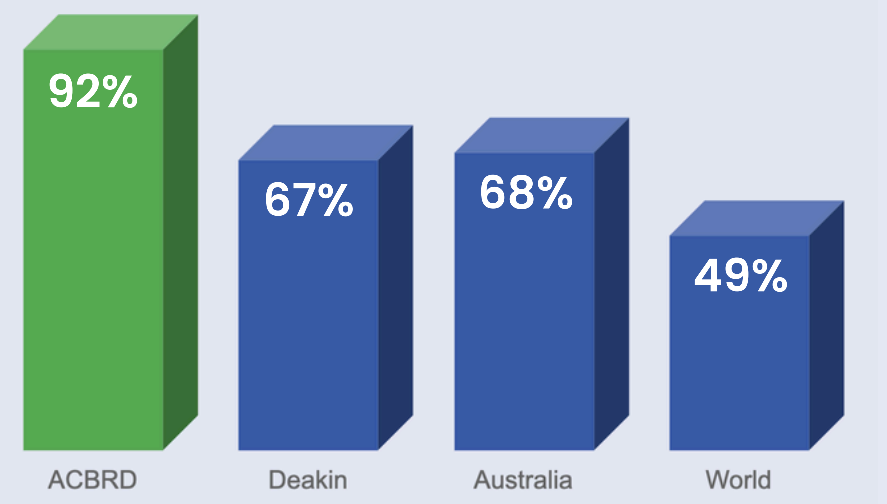
## % of 2024 publications with international co-authors



## % of 2024 publications with industry co-authors



## % of 2024 publications in world's top 25% journals



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# 3 International Consensus Statements

THE LANCET
Diabetes & Endocrinology

Review

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

*Jane Speight*, Elizabeth Holmes-Truscott*, Matthew Garza, Renza Scibilia, Sabina Wagner, Asuka Kato, Victor Pedrero, Sonya Deschênes, Susan J Guzman, Kevin L Joiner, Shengxin Liu, Ingrid Willaing, KatieM Babbott, Bryan Cleal, Jane K Dickinson, Jennifer A Halliday, Eimear C Morrissey, Giesje Nefs, Shane O'Donnell, Anna Serlachius, Per Winterdijk, Hamzah Alzubaidi, Bustanul Arifin, Liz Cambron-Kopco, Corinna Santa Ana, Emma Davidsen, Mary de Groot, Maartje de Wit, Phyllisa Deroze, Stephanie Haack, Richard I G Holt, Walther Jensen, Kamlesh Khunti, Karoline Kragelund Nielsen, Tejal Lathia, Christopher J Lee, Bridget McNulty, Diana Naranjo, Rebecca L Pearl, Suman Prinjha, Rebecca M Puhl, Anita Sabidi, Chitra Selvan, Jazz Sethi, Mohammed Seyam, Jackie Sturt, Mythily Subramaniam, Helle Terkildsen Maindal, Virginia Valentine, Michael Vallis, Timothy C Skinner*

**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),[1] which takes many forms (panel 1). This burden can also be exacerbated by discrimination (ie, unfair or prejudicial treatment),[2] which has been described as the endpoint of the stigmatisation process.[3] Furthermore, evidence indicates that diabetes stigma has multifaceted effects on the dignity, health, self-care, and wellbeing of people with diabetes.[4,5] 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".[6] The International Diabetes Federation recommended enabling people with diabetes to claim their rights and responsibilities (as later detailed in their Charter[4]); 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.[1] 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.[7–9] Insights from these areas suggest that research and advocacy are both crucial but each is likely to be insufficient in isolation.[10–13]

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).[5] 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.

*Lancet Diabetes Endocrinol* 2024; 12: 61–82

*Joint first authors

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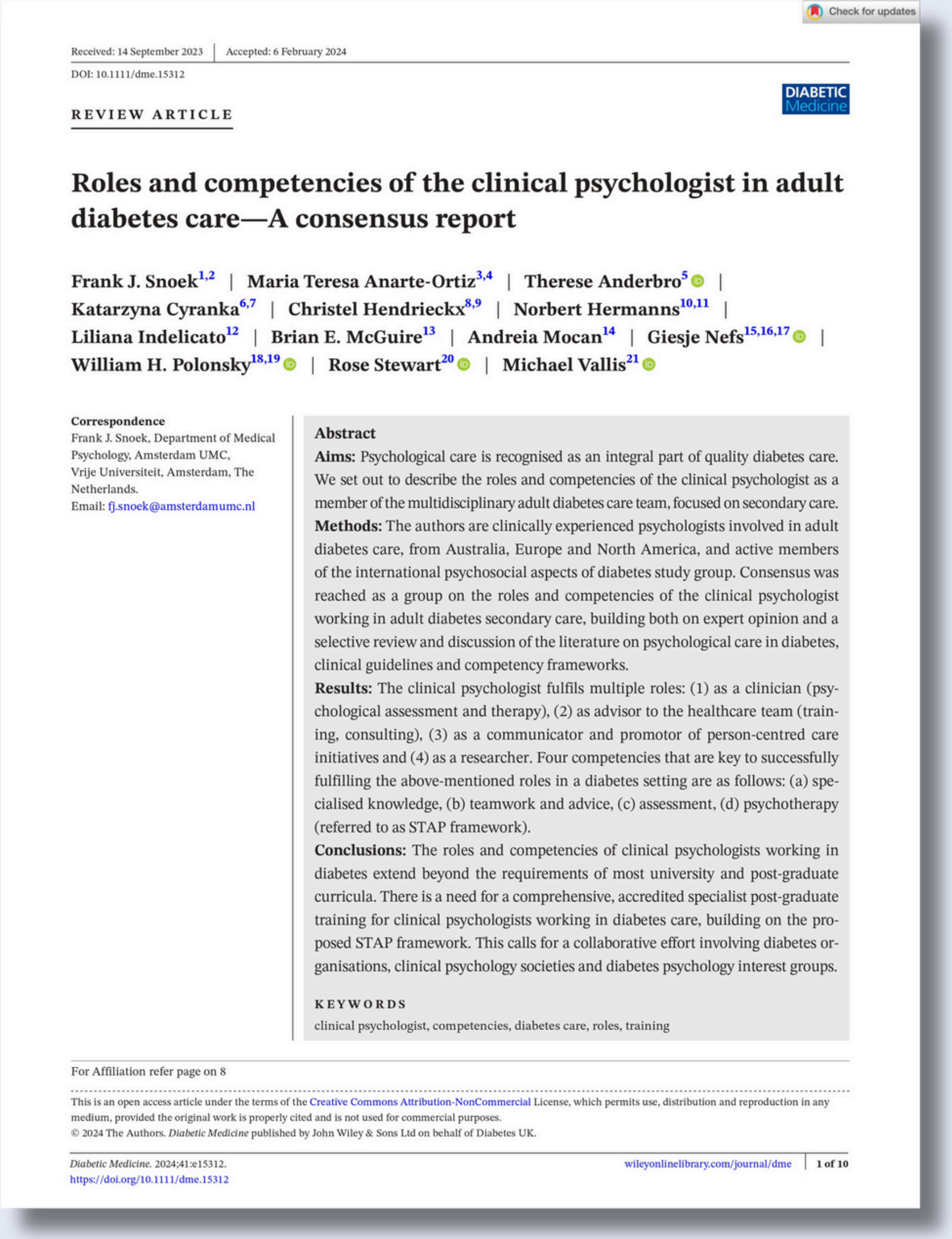

Received: 14 September 2023 | Accepted: 6 February 2024
DOI: 10.1111/dme.15312

REVIEW ARTICLE

DIABETIC Medicine

## Roles and competencies of the clinical psychologist in adult diabetes care—A consensus report

**Frank J. Snoek[1,2] | Maria Teresa Anarte-Ortiz[3,4] | Therese Anderbro[5] | Katarzyna Cyranka[6,7] | Christel Hendrieckx[8,9] | Norbert Hermanns[10,11] | Liliana Indelicato[12] | Brian E. McGuire[13] | Andreia Mocan[14] | Giesje Nefs[15,16,17] | William H. Polonsky[18,19] | Rose Stewart[20] | Michael Vallis[21]**

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**Abstract**

**Aims:** Psychological care is recognised as an integral part of quality diabetes care. We set out to describe the roles and competencies of the clinical psychologist as a member of the multidisciplinary adult diabetes care team, focused on secondary care.

**Methods:** The authors are clinically experienced psychologists involved in adult diabetes care, from Australia, Europe and North America, and active members of the international psychosocial aspects of diabetes study group. Consensus was reached as a group on the roles and competencies of the clinical psychologist working in adult diabetes secondary care, building both on expert opinion and a selective review and discussion of the literature on psychological care in diabetes, clinical guidelines and competency frameworks.

**Results:** The clinical psychologist fulfils multiple roles: (1) as a clinician (psychological assessment and therapy), (2) as advisor to the healthcare team (training, consulting), (3) as a communicator and promotor of person-centred care initiatives and (4) as a researcher. Four competencies that are key to successfully fulfilling the above-mentioned roles in a diabetes setting are as follows: (a) specialised knowledge, (b) teamwork and advice, (c) assessment, (d) psychotherapy (referred to as STAP framework).

**Conclusions:** The roles and competencies of clinical psychologists working in diabetes extend beyond the requirements of most university and post-graduate curricula. There is a need for a comprehensive, accredited specialist post-graduate training for clinical psychologists working in diabetes care, building on the proposed STAP framework. This calls for a collaborative effort involving diabetes organisations, clinical psychology societies and diabetes psychology interest groups.

KEYWORDS
clinical psychologist, competencies, diabetes care, roles, training

For Affiliation refer page on 8

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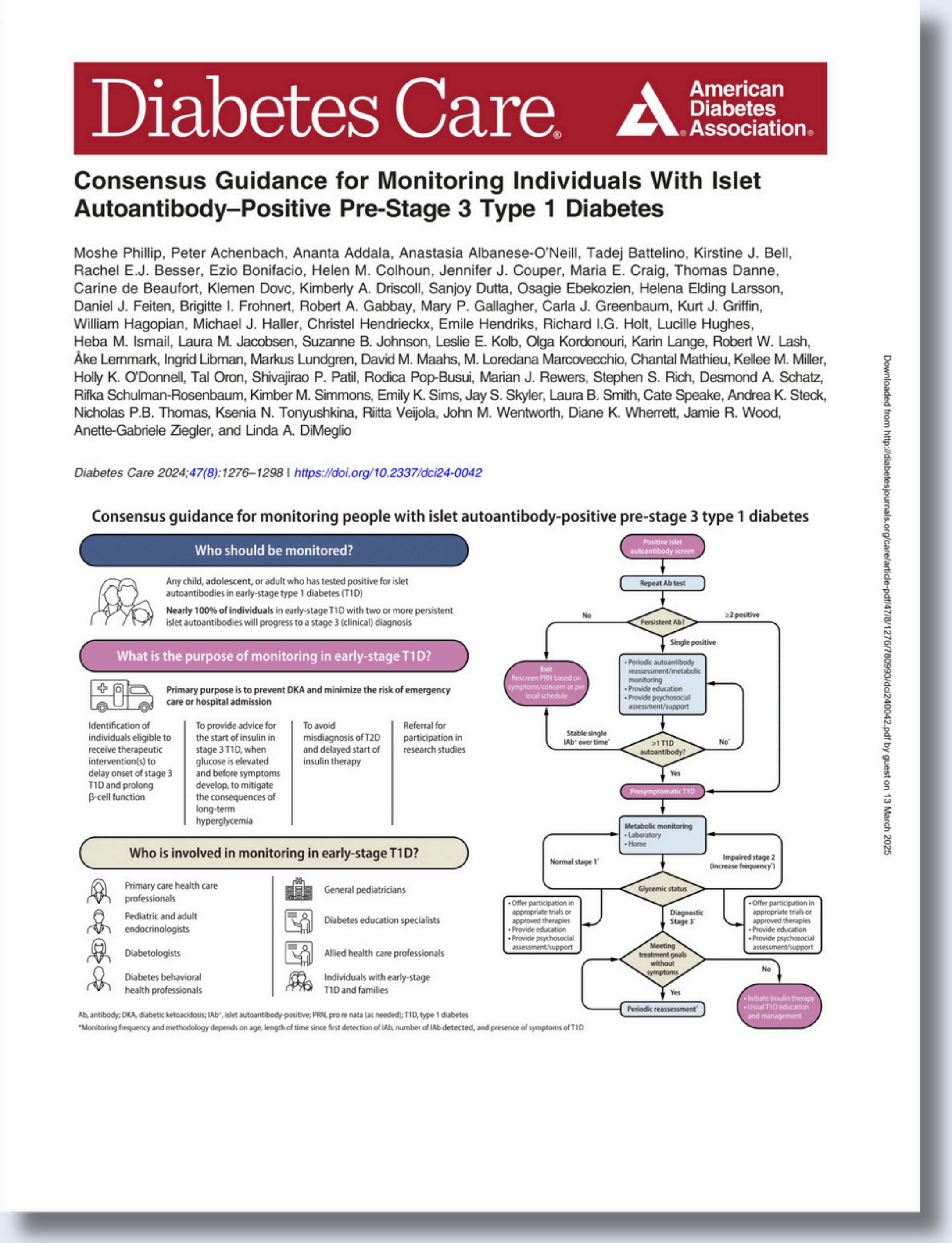

Diabetes Care
American Diabetes Association

## Consensus Guidance for Monitoring Individuals With Islet Autoantibody–Positive Pre-Stage 3 Type 1 Diabetes

Moshe Phillip, Peter Achenbach, Ananta Addala, Anastasia Albanese-O'Neill, Tadej Battelino, Kirstine J. Bell, Rachel E.J. Besser, Ezio Bonifacio, Helen M. Colhoun, Jennifer J. Couper, Maria E. Craig, Thomas Danne, Carine de Beaufort, Klemen Dovc, Kimberly A. Driscoll, Sanjoy Dutta, Osagie Ebekozien, Helena Elding Larsson, Daniel J. Feiten, Brigitte I. Frohnert, Robert A. Gabbay, Mary P. Gallagher, Carla J. Greenbaum, Kurt J. Griffin, William Hagopian, Michael J. Haller, Christel Hendrieckx, Emile Hendriks, Richard I.G. Holt, Lucille Hughes, Heba M. Ismail, Laura M. Jacobsen, Suzanne B. Johnson, Leslie E. Kolb, Olga Kordonouri, Karin Lange, Robert W. Lash, Åke Lernmark, Ingrid Libman, Markus Lundgren, David M. Maahs, M. Loredana Marcovecchio, Chantal Mathieu, Kellee M. Miller, Holly K. O'Donnell, Tal Oron, Shivajirao P. Patil, Rodica Pop-Busui, Marian J. Rewers, Stephen S. Rich, Desmond A. Schatz, Rifka Schulman-Rosenbaum, Kimber M. Simmons, Emily K. Sims, Jay S. Skyler, Laura B. Smith, Cate Speake, Andrea K. Steck, Nicholas P.B. Thomas, Ksenia N. Tonyushkina, Riitta Veijola, John M. Wentworth, Diane K. Wherrett, Jamie R. Wood, Anette-Gabriele Ziegler, and Linda A. DiMeglio

*Diabetes Care 2024;47(8):1276–1298* | *https://doi.org/10.2337/dci24-0042*

Consensus guidance for monitoring people with islet autoantibody-positive pre-stage 3 type 1 diabetes

**Who should be monitored?**

Any child, adolescent, or adult who has tested positive for islet autoantibodies in early-stage type 1 diabetes (T1D)

**Nearly 100% of individuals** in early-stage T1D with two or more persistent islet autoantibodies will progress to a stage 3 (clinical) diagnosis

**What is the purpose of monitoring in early-stage T1D?**

**Primary purpose is to prevent DKA and minimize the risk of emergency care or hospital admission**

- Identification of individuals eligible to receive therapeutic intervention(s) to delay onset of stage 3 T1D and prolong β-cell function
- To provide advice for the start of insulin in stage 3 T1D, when glucose is elevated and before symptoms develop, to mitigate the consequences of long-term hyperglycemia
- To avoid misdiagnosis of T2D and delayed start of insulin therapy
- Referral for participation in research studies

**Who is involved in monitoring in early-stage T1D?**

- Primary care health care professionals
- Pediatric and adult endocrinologists
- Diabetologists
- Diabetes behavioral health professionals
- General pediatricians
- Diabetes education specialists
- Allied health care professionals
- Individuals with early-stage T1D and families

Ab, antibody; DKA, diabetic ketoacidosis; IAb⁺, islet autoantibody-positive; PRN, pro re nata (as needed); T1D, type 1 diabetes
*Monitoring frequency and methodology depends on age, length of time since first detection of IAb, number of IAb detected, and presence of symptoms of T1D

# 3 Examples of our Community Engagement Work

The Patient - Patient-Centered Outcomes Research (2024) 17:441–455
https://doi.org/10.1007/s40271-024-00688-5

ORIGINAL RESEARCH ARTICLE

## Diabetes Research Matters: A Three-Round Priority-Setting Survey Consultation with Adults Living with Diabetes and Family Members in Australia

**Christel Hendrieckx[1,2,3] · Sienna Russell-Green[1,2] · Timothy Skinner[2,4] · Ashley H. Ng[5] · Chris Lee[6] · Siobhan Barlow[7] · Alan Davey[7] · Caitlin Rogers[7] · Elizabeth Holmes-Truscott[1,2,3] · Jane Speight[1,2,3]**

Accepted: 7 March 2024 / Published online: 6 April 2024

### Abstract

**Objective** We aimed to identify the health and quality-of-life research priorities of Australians with diabetes or family members.

**Methods** Through an iterative, three-step, online survey process we (1) qualitatively generated research topics (long list) in response to one question "What research is needed to support people with diabetes to live a better life?"; (2) determined the most important research questions (short list); and (3) ranked research questions in order of importance (priorities). We aimed to recruit $N = 800$ participants, with approximate equal representation of diabetes type and family members.

**Results** Participants ($N = 661$) were adults (aged 18+ years) in Australia with a self-reporting diagnosis of diabetes (type 1, $n = 302$; type 2, $n = 204$; prior/current gestational, $n = 58$; less common types, $n = 22$, or a family member, $n = 75$). Retention rates for Surveys 2 and 3 were 47% ($n = 295$) and 50% ($n = 316$), respectively. From 1549 open-text responses, 25 topics and 125 research questions were identified thematically. Research priorities differed by cohort, resulting in specific lists developed and ranked by each cohort. The top-ranked research question for the type 1 diabetes cohort was "How can diabetes technology be improved …?" and for the type 2 diabetes cohort: "How can insulin resistance be reversed …?". One question was common to the final lists of all cohorts: "What are the causes or triggers of diabetes?" Within cohorts, the top priorities were perceived as being of similar importance.

**Conclusions** The research priorities differ substantially by diabetes type and for family members. These findings should inform funding bodies and researchers, to align future research and its communication with community needs.

### 1 Introduction

Diabetes is a global health priority, presenting a significant challenge to the health and well-being of individuals living with the condition, their families and societies [1, 2]. In Australia, more than 1.5 million people have diabetes, with around 9% with type 1 diabetes (T1D), 85% with type 2 diabetes (T2D) and 3% with gestational diabetes mellitus (GDM) [3]. In 2018–19, the direct diabetes costs to the Australian health system were estimated at $3 billion, with 40% spent on hospital services [4]. Australian diabetes research is funded mostly by government bodies (e.g. National Health and Medical Research Council, Medical Research Future Fund [5]) and peak organisations (e.g. Juvenile Diabetes Research Foundation, Diabetes Australia). Over the past decade, the National Health and Medical Research Council

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5 Monash Partners Academic Health Science Centre, Melbourne, VIC, Australia
6 National Aboriginal Community Controlled Health Organisation, Canberra, ACT, Australia
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THE LANCET
Diabetes & Endocrinology

Comment

## Living between two worlds: lessons for community involvement

Genuine consumer and community involvement offers multiple benefits to people with diabetes, health-care professionals, health services, researchers, and diabetes community organisations.[1,2] Co-designed solutions, led by the community, facilitate interventions that better meet the needs of the community, resulting in increased acceptability and uptake.[3,4] With growing acknowledgment and acceptance of consumer and community involvement, some international and national health research funding bodies now mandate the involvement of lived experience across research.[5,6] Such requirements are essential in promoting greater community involvement; however, their implementation varies widely, with people working in the field being potentially ill-equipped to support authentic community involvement from project conception through to implementation and advocacy beyond the project.[7] This Comment offers reflections and recommendations on consumer and community involvement from an Australian authorship with lived experience of diabetes (across type 1 diabetes, type 1b diabetes, type 2 diabetes, gestational diabetes, and latent autoimmune diabetes of adults) as well as professional or volunteer roles within the diabetes workforce (eg, health care, research, or advocacy). Although we acknowledge the official terminology of consumer and community involvement, the term community involvement will be used hereafter, in recognition of the preference of those with lived experience and the implied passivity of patient, consumer, and engagement roles.[8,9]

The diabetes community is not a homogenous group, yet the involvement of a single person with diabetes can meet guideline requirements for community involvement. The perspectives a single person can represent are limited, and this approach fails to recognise and respect the broad and diverse backgrounds, experiences, and needs of the community. At times, community members might also be asked or assumed to represent those with different types of diabetes or different demographic characteristics (eg, gender, age, or ethnicity). Although individuals might appreciate the opportunity to convey common community sentiments (if they are connected with the broader community), this approach relies heavily on their ability to acknowledge their own biases and their skills to advocate beyond themselves. As such, those seeking to involve the community have a responsibility to consider a well connected, diverse, and representative population that is reflective of the project aims.[6,9] Where possible and appropriate (ie, considering power dynamics), community members might also choose to advocate for greater representation in terms of numbers and intersectionality.

People who live with diabetes and work in the field have the right, but not necessarily the obligation, to disclose their condition, and to choose if and when to engage as a community member. Disclosure of a health condition, such as diabetes, can leave an individual vulnerable to stigma and bias from others, including workplace discrimination.[10] Willingness to disclose can change over time and as a result of circumstances and is often dependent on a person's capacity to share their vulnerability as well as their sense of safety in the environment in which they are working. Those working with diabetes community members must respect an individual's choice to disclose their condition and what they choose to share in any given situation. A greater understanding of the barriers and enablers surrounding disclosure and advocacy from the diabetes community are also needed to increase meaningful engagement, particularly as we have observed stark disparities in involvement across the diabetes community. For example, people with type 2 diabetes make up approximately 90% of the diabetes population, yet individuals with this condition are less commonly represented in community engagement, the online diabetes community, and positive media stories.

When people with lived experience of a condition choose to share their story and be involved with projects, they do so with the intent of creating positive change. When that expectation is not met because of tokenistic involvement or instances in which the lived experience perspective is not valued, there is a potential for frustration—at times leading to burnout—and feelings of distrust in the community involvement process and outcomes. Such negative experiences

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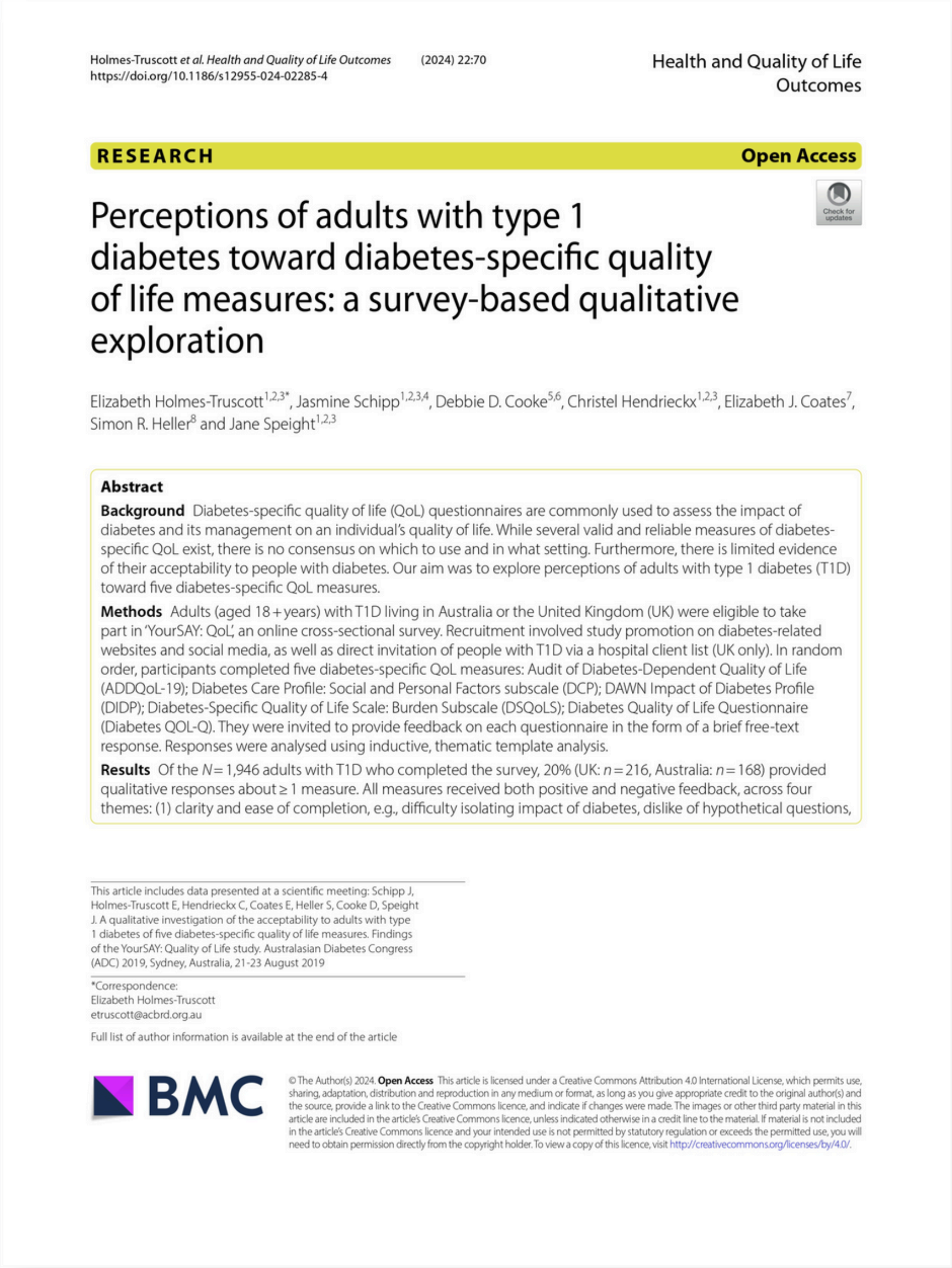

Holmes-Truscott *et al. Health and Quality of Life Outcomes* (2024) 22:70
https://doi.org/10.1186/s12955-024-02285-4

Health and Quality of Life
Outcomes

**RESEARCH** **Open Access**

## Perceptions of adults with type 1 diabetes toward diabetes-specific quality of life measures: a survey-based qualitative exploration

Elizabeth Holmes-Truscott[1,2,3*], Jasmine Schipp[1,2,3,4], Debbie D. Cooke[5,6], Christel Hendrieckx[1,2,3], Elizabeth J. Coates[7], Simon R. Heller[8] and Jane Speight[1,2,3]

### Abstract

**Background** Diabetes-specific quality of life (QoL) questionnaires are commonly used to assess the impact of diabetes and its management on an individual's quality of life. While several valid and reliable measures of diabetes-specific QoL exist, there is no consensus on which to use and in what setting. Furthermore, there is limited evidence of their acceptability to people with diabetes. Our aim was to explore perceptions of adults with type 1 diabetes (T1D) toward five diabetes-specific QoL measures.

**Methods** Adults (aged 18 + years) with T1D living in Australia or the United Kingdom (UK) were eligible to take part in 'YourSAY: QoL', an online cross-sectional survey. Recruitment involved study promotion on diabetes-related websites and social media, as well as direct invitation of people with T1D via a hospital client list (UK only). In random order, participants completed five diabetes-specific QoL measures: Audit of Diabetes-Dependent Quality of Life (ADDQoL-19); Diabetes Care Profile: Social and Personal Factors subscale (DCP); DAWN Impact of Diabetes Profile (DIDP); Diabetes-Specific Quality of Life Scale: Burden Subscale (DSQoLS); Diabetes Quality of Life Questionnaire (Diabetes QOL-Q). They were invited to provide feedback on each questionnaire in the form of a brief free-text response. Responses were analysed using inductive, thematic template analysis.

**Results** Of the $N = 1{,}946$ adults with T1D who completed the survey, 20% (UK: $n = 216$, Australia: $n = 168$) provided qualitative responses about ≥ 1 measure. All measures received both positive and negative feedback, across four themes: (1) clarity and ease of completion, e.g., difficulty isolating impact of diabetes, dislike of hypothetical questions,

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This article includes data presented at a scientific meeting: Schipp J, Holmes-Truscott E, Hendrieckx C, Coates E, Heller S, Cooke D, Speight J. A qualitative investigation of the acceptability to adults with type 1 diabetes of five diabetes-specific quality of life measures. Findings of the YourSAY: Quality of Life study. Australasian Diabetes Congress (ADC) 2019, Sydney, Australia, 21-23 August 2019

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BMC

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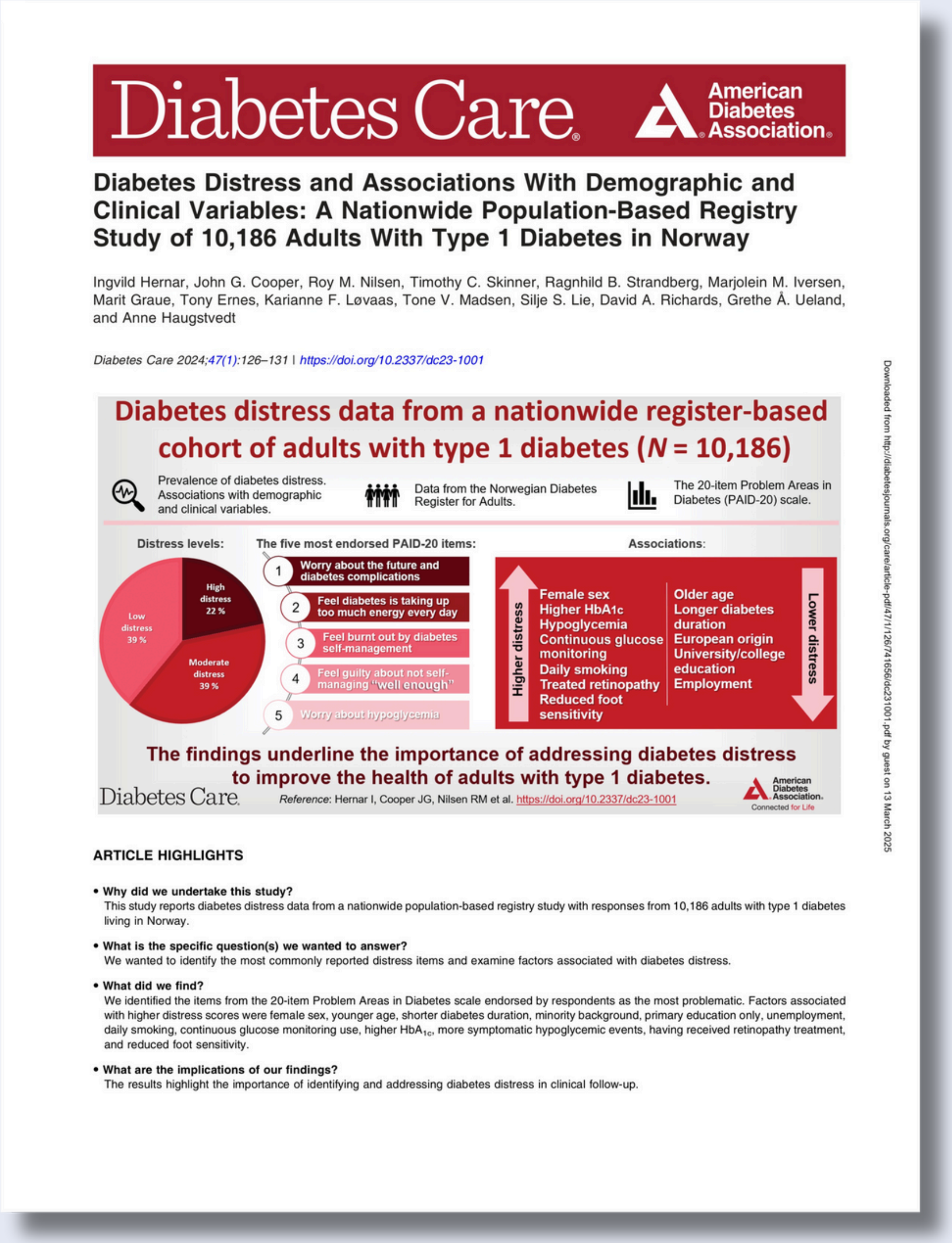
# 3 Examples of International Research Collaborations



Diabetes Care® American Diabetes Association®

## Diabetes Distress and Associations With Demographic and Clinical Variables: A Nationwide Population-Based Registry Study of 10,186 Adults With Type 1 Diabetes in Norway

Ingvild Hernar, John G. Cooper, Roy M. Nilsen, Timothy C. Skinner, Ragnhild B. Strandberg, Marjolein M. Iversen, Marit Graue, Tony Ernes, Karianne F. Løvaas, Tone V. Madsen, Silje S. Lie, David A. Richards, Grethe Å. Ueland, and Anne Haugstvedt

*Diabetes Care* 2024;47(1):126–131 | https://doi.org/10.2337/dc23-1001

**Diabetes distress data from a nationwide register-based cohort of adults with type 1 diabetes (*N* = 10,186)**

Prevalence of diabetes distress. Associations with demographic and clinical variables.

Data from the Norwegian Diabetes Register for Adults.

The 20-item Problem Areas in Diabetes (PAID-20) scale.

Distress levels:

The five most endorsed PAID-20 items:

1. Worry about the future and diabetes complications
2. Feel diabetes is taking up too much energy every day
3. Feel burnt out by diabetes self-management
4. Feel guilty about not self-managing "well enough"
5. Worry about hypoglycemia

Associations:

| Higher distress | Lower distress |
|---|---|
| Female sex<br>Higher HbA1c<br>Hypoglycemia<br>Continuous glucose monitoring<br>Daily smoking<br>Treated retinopathy<br>Reduced foot sensitivity | Older age<br>Longer diabetes duration<br>European origin<br>University/college education<br>Employment |

**The findings underline the importance of addressing diabetes distress to improve the health of adults with type 1 diabetes.**

Diabetes Care *Reference*: Hernar I, Cooper JG, Nilsen RM et al. https://doi.org/10.2337/dc23-1001 American Diabetes Association. Connected for Life

### ARTICLE HIGHLIGHTS

- **Why did we undertake this study?**
  This study reports diabetes distress data from a nationwide population-based registry study with responses from 10,186 adults with type 1 diabetes living in Norway.
- **What is the specific question(s) we wanted to answer?**
  We wanted to identify the most commonly reported distress items and examine factors associated with diabetes distress.
- **What did we find?**
  We identified the items from the 20-item Problem Areas in Diabetes scale endorsed by respondents as the most problematic. Factors associated with higher distress scores were female sex, younger age, shorter diabetes duration, minority background, primary education only, unemployment, daily smoking, continuous glucose monitoring use, higher $HbA_{1c}$, more symptomatic hypoglycemic events, having received retinopathy treatment, and reduced foot sensitivity.
- **What are the implications of our findings?**
  The results highlight the importance of identifying and addressing diabetes distress in clinical follow-up.

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Diabetologia (2024) 67:2160–2174
https://doi.org/10.1007/s00125-024-06233-1

ARTICLE

Check for updates

## The impact of hypoglycaemia on daily functioning among adults with diabetes: a prospective observational study using the Hypo-METRICS app

Uffe Søholm[1,2,3] · Melanie Broadley[2] · Natalie Zaremba[3] · Patrick Divilly[3] · Petra Martina Baumann[4] · Zeinab Mahmoudi[5] · Gilberte Martine-Edith[3] · Julia K. Mader[6] · Monika Cigler[6] · Julie Maria Bøggild Brøsen[7] · Allan Vaag[8,9,10] · Simon Heller[11] · Ulrik Pedersen-Bjergaard[7,12] · Rory J. McCrimmon[13] · Eric Renard[14,15] · Mark Evans[16] · Bastiaan de Galan[17,18,19] · Evertine Abbink[17] · Stephanie A. Amiel[3] · Christel Hendrieckx[20,21] · Jane Speight[2,20,21] · Pratik Choudhary[3,22] · Frans Pouwer[2,23] · on behalf of the Hypo-RESOLVE consortium

Received: 22 February 2024 / Accepted: 29 April 2024 / Published online: 30 July 2024

### Abstract

**Aims/hypothesis** The aim of this work was to examine the impact of hypoglycaemia on daily functioning among adults with type 1 diabetes or insulin-treated type 2 diabetes, using the novel Hypo-METRICS app.

**Methods** For 70 consecutive days, 594 adults (type 1 diabetes, $n$=274; type 2 diabetes, $n$=320) completed brief morning and evening Hypo-METRICS 'check-ins' about their experienced hypoglycaemia and daily functioning. Participants wore a blinded glucose sensor (i.e. data unavailable to the participants) for the study duration. Days and nights with or without person-reported hypoglycaemia (PRH) and/or sensor-detected hypoglycaemia (SDH) were compared using multilevel regression models.

**Results** Participants submitted a mean ± SD of 86.3±12.5% morning and 90.8±10.7% evening check-ins. For both types of diabetes, SDH alone had no significant associations with the changes in daily functioning scores. However, daytime and night-time PRH (with or without SDH) were significantly associated with worsening of energy levels, mood, cognitive functioning, negative affect and fear of hypoglycaemia later that day or while asleep. In addition, night-time PRH (with or without SDH) was significantly associated with worsening of sleep quality (type 1 and type 2 diabetes) and memory (type 2 diabetes). Further, daytime PRH (with or without SDH), was associated with worsening of fear of hyperglycaemia while asleep (type 1 diabetes), memory (type 1 and type 2 diabetes) and social functioning (type 2 diabetes).

**Conclusions/interpretation** This prospective, real-world study reveals impact on several domains of daily functioning following PRH but not following SDH alone. These data suggest that the observed negative impact is mainly driven by subjective awareness of hypoglycaemia (i.e. PRH), through either symptoms or sensor alerts/readings and/or the need to take action to prevent or treat episodes.

**Keywords** Daily functioning · Ecological momentary assessment · Hypoglycaemia · Quality of life

**Abbreviations**

| | |
|---|---|
| CGM | Continuous glucose monitoring |
| EMA | Ecological momentary assessment |
| Hypo-METRICS | Hypoglycaemia MEasurement, ThResholds and ImpaCtS |
| Hypo-RESOLVE | Hypoglycaemia – Redefining SOLutions for better liVEs |
| PRH | Person-reported hypoglycaemia |
| QoL | Quality of life |
| SDH | Sensor-detected hypoglycaemia |

### Introduction

Despite advances in insulin pharmacology, delivery systems and glucose monitoring technologies, hypoglycaemia remains a substantial challenge for people with insulin-treated diabetes. Adults with type 1 diabetes experience

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A list of Hypo-RESOLVE consortium members is included in the electronic supplementary material (ESM).

Extended author information available on the last page of the article

Springer

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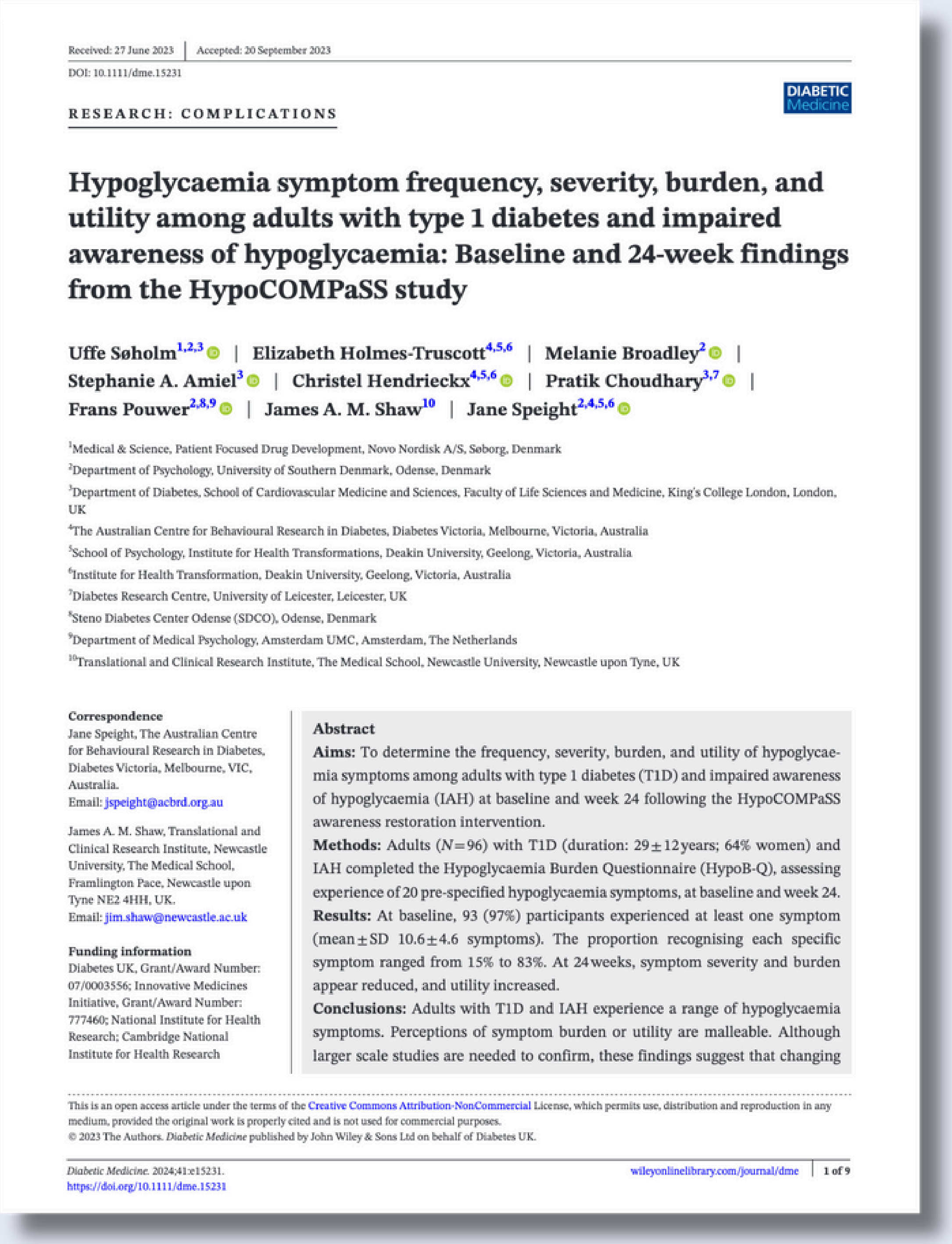

Received: 27 June 2023 | Accepted: 20 September 2023
DOI: 10.1111/dme.15231

RESEARCH: COMPLICATIONS

DIABETIC Medicine

## Hypoglycaemia symptom frequency, severity, burden, and utility among adults with type 1 diabetes and impaired awareness of hypoglycaemia: Baseline and 24-week findings from the HypoCOMPaSS study

**Uffe Søholm**[1,2,3] | **Elizabeth Holmes-Truscott**[4,5,6] | **Melanie Broadley**[2] | **Stephanie A. Amiel**[3] | **Christel Hendrieckx**[4,5,6] | **Pratik Choudhary**[3,7] | **Frans Pouwer**[2,8,9] | **James A. M. Shaw**[10] | **Jane Speight**[2,4,5,6]

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**Funding information**
Diabetes UK, Grant/Award Number: 07/0003556; Innovative Medicines Initiative, Grant/Award Number: 777460; National Institute for Health Research; Cambridge National Institute for Health Research

### Abstract

**Aims:** To determine the frequency, severity, burden, and utility of hypoglycaemia symptoms among adults with type 1 diabetes (T1D) and impaired awareness of hypoglycaemia (IAH) at baseline and week 24 following the HypoCOMPaSS awareness restoration intervention.

**Methods:** Adults ($N$=96) with T1D (duration: 29±12 years; 64% women) and IAH completed the Hypoglycaemia Burden Questionnaire (HypoB-Q), assessing experience of 20 pre-specified hypoglycaemia symptoms, at baseline and week 24.

**Results:** At baseline, 93 (97%) participants experienced at least one symptom (mean ± SD 10.6 ± 4.6 symptoms). The proportion recognising each specific symptom ranged from 15% to 83%. At 24 weeks, symptom severity and burden appear reduced, and utility increased.

**Conclusions:** Adults with T1D and IAH experience a range of hypoglycaemia symptoms. Perceptions of symptom burden or utility are malleable. Although larger scale studies are needed to confirm, these findings suggest that changing

*Diabetic Medicine*. 2024;41:e15231.
https://doi.org/10.1111/dme.15231 wileyonlinelibrary.com/journal/dme | 1 of 9

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DEAKIN UNIVERSITY

# 3 Examples of National Research Collaborations

Research

## Sensitivity and specificity of Aboriginal-developed items to supplement the adapted PHQ-9 screening measure for depression: results from the Getting it Right study

Timothy Skinner[1,2], Alex Brown[3,4], Armando Teixeira-Pinto[5,6], Sara F Farnbach[7], Nicholas Glozier[5], Deborah A Askew[8], Graham Gee[9,10], Alan Cass[11], Maree L Hackett[12,13]

**The known:** Only a small number of validated measures are available to assess depressive symptoms in Aboriginal and Torres Strait Islander people. Few consist of wording derived by and for Aboriginal and Torres Strait Islander peoples.

**The new:** The Aboriginal and Torres Strait Islander-developed depressive symptom screening scale that we studied is reliable and valid, and it performs well across multiple Aboriginal and Torres Strait Islander primary care settings. Items assessing worry, spirit and anger evidenced good sensitivity and specificity as a screening tool to assist with diagnosing major depressive episodes.

**The implications:** Both seven-item and three-item versions of the scale provide brief, validated and culturally appropriate screening tools for depression.

**Abstract**

**Objective**: To determine the psychometric properties of an Aboriginal and Torres Strait Islander-developed depressive symptom screening scale.

**Design**: Prospective diagnostic accuracy study.

**Setting**: Ten primary health care services or residential alcohol and other drug rehabilitation services in Australia that predominantly serve Aboriginal and Torres Strait Islander peoples.

**Participants**: 500 adults (18 years or older) who identified as Aboriginal and/or Torres Strait Islander and were able to communicate sufficiently to respond to questionnaire and interview questions. Recruitment occurred between 25 March 2015 and 2 November 2016.

**Main outcome measure**: Criterion validity of seven Aboriginal and Torres Strait Islander-developed items, using the adapted Patient Health Questionnaire 9 (aPHQ-9) and depression module of the Mini International Neuropsychiatric Interview (MINI) 6.0.0 as the criterion standards.

**Results**: The seven-item scale had good internal consistency ($\alpha = 0.83$) and correlated highly with the aPHQ-9 ($\rho = 0.76$). All items were significantly associated with diagnosis of a current major depressive episode. Discriminant function and decision tree analysis identified three items forming a summed scale that classified 85% of participants correctly. These three items showed equivalent sensitivity and specificity to the aPHQ-9 when compared with the MINI-identified diagnosis of a current major depressive episode.

**Conclusion**: Three items developed by and for Aboriginal and Torres Strait Islander people may provide effective, efficient and culturally appropriate screening for depression in Aboriginal and Torres Strait Islander health care contexts.

Depression is a syndrome diagnosed after a particular constellation of signs and symptoms has been elicited through a semi-structured interview. These assessments focus on two cardinal and seven associated symptoms of depression as identified in diagnostic manuals.[1,2] It is possible to meet the diagnostic criteria for depression through a diverse combination of symptoms. One study of more than 3700 individuals found 1030 distinct depression symptom profiles.[3] Similarly, there is substantial diversity in the symptoms and signs used to indicate the degree of depressed affect being experienced,[4] making it challenging to compare prevalence estimates across studies.[5]

Different cultures have common and culturally specific components of the aetiology, meaning, experience and expression of depression. The World Health Organization's International Study of Psychological Problems in Primary Care demonstrated that the same measurement tool has variable measurement properties and discriminant thresholds for depressive disorder across cultures.[6] This is generally ignored in large surveys, where one measure and one threshold are applied, regardless of cultural background. Consistent with this perspective, research that was initiated and led by an Aboriginal man, and involved men from five Aboriginal language groups in Central Australia, identified the Patient Health Questionnaire 9 (PHQ-9) as potentially useful but requiring modification for use in their communities. The PHQ-9 was adapted and expressed in simplified English for use across Aboriginal languages in Central Australia with Aboriginal community members.[7,8] The adaptations used agreed and consistent local language and expressions of distress; two bidirectional items (poor appetite or overeating; moving slowly or restless) were separated but sleep disturbance remained a single item. This adapted Patient Health Questionnaire 9 (aPHQ-9) version was first tested with 186 Aboriginal men from Central Australia and was found to be acceptable and appropriate. It was then compared with a semi-structured diagnostic interview in a community sample of 78 Aboriginal men,[8] and this indicated that the aPHQ-9 had promising psychometrics.

However, thematic analysis, by an Aboriginal-led team of researchers, of semi-structured interviews with Aboriginal men, Ngangkari Tjuta (traditional healers) and cross-cultural mental health experts, identified several affective and cognitive phenomena indicative of Aboriginal people's distinct experience of depression.[7] These phenomena were developed, discussed

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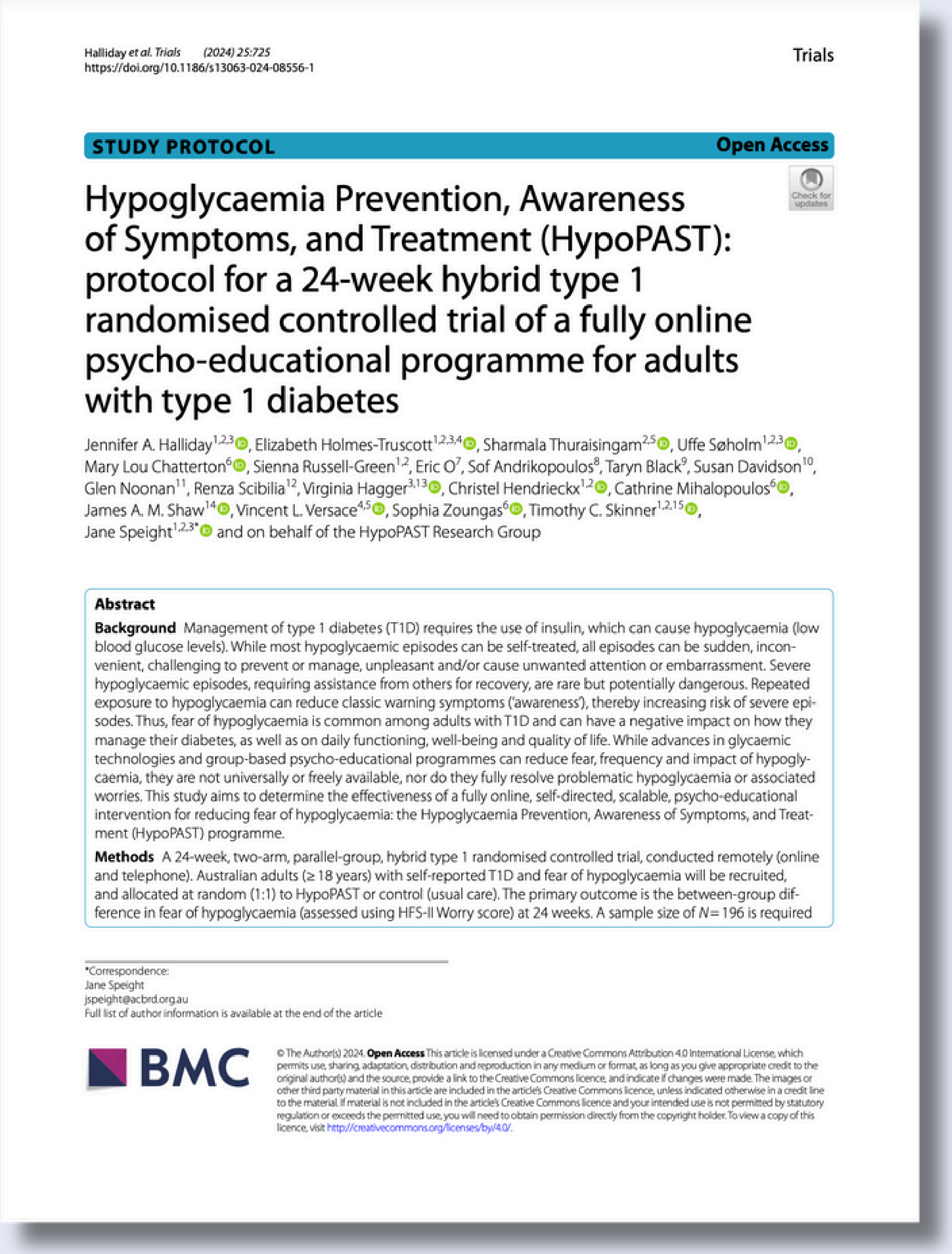

Halliday et al. Trials (2024) 25:725
https://doi.org/10.1186/s13063-024-08556-1

Trials

STUDY PROTOCOL Open Access

## Hypoglycaemia Prevention, Awareness of Symptoms, and Treatment (HypoPAST): protocol for a 24-week hybrid type 1 randomised controlled trial of a fully online psycho-educational programme for adults with type 1 diabetes

Jennifer A. Halliday[1,2,3], Elizabeth Holmes-Truscott[1,2,3,4], Sharmala Thuraisingam[2,5], Uffe Søholm[1,2,3], Mary Lou Chatterton[6], Sienna Russell-Green[1,2], Eric O[7], Sof Andrikopoulos[8], Taryn Black[9], Susan Davidson[10], Glen Noonan[11], Renza Scibilia[12], Virginia Hagger[3,13], Christel Hendrieckx[1,2], Cathrine Mihalopoulos[6], James A. M. Shaw[14], Vincent L. Versace[4,5], Sophia Zoungas[6], Timothy C. Skinner[1,2,15], Jane Speight[1,2,3*] and on behalf of the HypoPAST Research Group

**Abstract**

**Background** Management of type 1 diabetes (T1D) requires the use of insulin, which can cause hypoglycaemia (low blood glucose levels). While most hypoglycaemic episodes can be self-treated, all episodes can be sudden, inconvenient, challenging to prevent or manage, unpleasant and/or cause unwanted attention or embarrassment. Severe hypoglycaemic episodes, requiring assistance from others for recovery, are rare but potentially dangerous. Repeated exposure to hypoglycaemia can reduce classic warning symptoms ('awareness'), thereby increasing risk of severe episodes. Thus, fear of hypoglycaemia is common among adults with T1D and can have a negative impact on how they manage their diabetes, as well as on daily functioning, well-being and quality of life. While advances in glycaemic technologies and group-based psycho-educational programmes can reduce fear, frequency and impact of hypoglycaemia, they are not universally or freely available, nor do they fully resolve problematic hypoglycaemia or associated worries. This study aims to determine the effectiveness of a fully online, self-directed, scalable, psycho-educational intervention for reducing fear of hypoglycaemia: the Hypoglycaemia Prevention, Awareness of Symptoms, and Treatment (HypoPAST) programme.

**Methods** A 24-week, two-arm, parallel-group, hybrid type 1 randomised controlled trial, conducted remotely (online and telephone). Australian adults (≥ 18 years) with self-reported T1D and fear of hypoglycaemia will be recruited, and allocated at random (1:1) to HypoPAST or control (usual care). The primary outcome is the between-group difference in fear of hypoglycaemia (assessed using HFS-II Worry score) at 24 weeks. A sample size of $N = 196$ is required

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DOI: 10.1111/dme.15399

DIABETIC Medicine

RESEARCH ARTICLE

Educational and Psychological Aspects

## Diabetes misconceptions, seriousness, motivation, self-efficacy and stigma: A cross-sectional comparison of eight Australian diabetes communication campaign videos

Elizabeth Holmes-Truscott[1,2,3] | Jessica L. Hateley-Browne[1,2] | Elizabeth Charalambakis[1] | Adriana D. Ventura[1,2] | Annette Ripper[4] | Renza Scibilia[5] | Jane Speight[1,2,3]

[1] School of Psychology, Deakin University, Geelong, Victoria, Australia
[2] The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Melbourne, Victoria, Australia
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**Correspondence**
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**Abstract**

**Aim:** This study examines potential intended (attitudes, motivation and self-efficacy) and unintended (stigmatisation of diabetes) consequences of past Australian National Diabetes Week campaign videos. Further, outcomes are compared by the extent to which participants perceived their allocated video as stigmatising diabetes.

**Methods:** In this cross-sectional, ten-arm study, participants (adults with or without diabetes; 1:2 ratio) were randomly allocated to view one of eight archival diabetes campaign videos (intervention), or either an active or passive control group. Post-exposure, study-specific scales measured diabetes Misconceptions and Seriousness, General and Diabetes Risk-Reduction Motivation and Self-efficacy, and perceptions of video Stigmatisation of diabetes. Scores were compared by condition (intervention vs. control) and by campaign Stigma (highest vs. lowest tertile score), separately by cohort (with or without diabetes).

**Results:** The sample included $n = 1023$ without diabetes; and $n = 510$ with diabetes (79% type 2 diabetes). No significant differences in outcomes were observed between conditions (intervention vs. control), with one exception: a modest effect on General Self-efficacy among those without diabetes only. Those perceiving high campaign Stigma (15%), relative to low Stigma (60%), reported significantly greater diabetes Misconceptions, lower perceived Seriousness and (among those without diabetes only) lower General Motivation but higher Diabetes Risk Reduction Motivation.

**Conclusion:** Though limited to a single-exposure, we found little meaningful positive influence of past diabetes campaign videos on diabetes attitudes, behavioural intentions or self-efficacy. Further, campaign videos were perceived as stigmatising by a minority—a potential harmful impact. This novel study has

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# New external research income in 2024

NHMRC

### Improving mental health among Australian adults with diabetes through population-level monitoring

Holloway E

**$590k**

from the National Health and Medical Research Council (NHMRC): Emerging Leader (EL1) Investigator Grant

diabetes vic

### *Life!* curriculum: behaviour change content review

Holmes-Truscott E, Geerling R, Skinner TC, Speight J
(via funding to Diabetes Victoria from the Victorian Department of Health)

**$181k**

from Diabetes Victoria

NDSS
National Diabetes Services Scheme
An Australian Government Initiative

### Review of NDSS resources on 'Diabetes & Emotional Health' and 'Starting Insulin'

Halliday J, Holmes-Truscott E, Skinner TC, Speight J

**$49.2k**

from the National Diabetes Services Scheme (NDSS)*

VIC

### Understanding, identifying and addressing diabetes distress: Upskilling the Diabetes CONNECT workforce with Diabetes Distress eLearning

Halliday J, Holmes-Truscott E, Speight J

**$34.5k**

from the Victorian Department of Health

Breakthrough T1D™
Formerly JDRF

### Moving the field forward: A landscape review of psychosocial, behavioural and mental health in type 1 diabetes

Stuckey H^, Skinner TC, Cooke D
^Penn State University, USA

**$21.9k**

from Breakthrough T1D
(formerly JDRF International)

* NDSS is an initiative of the Australian Government, administered with the assistance of Diabetes Australia

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# New internal research grants in 2024

**$13K**

Deakin University:
Institute for Health Transformation
Category 1 Seed Funding Grant

**Supporting type 2 diabetes risk reduction for women and their children following gestational diabetes: a qualitative study of health promotion professionals**

Litterbach E, Holmes-Truscott E

**$10K**

Baker-Deakin University:
Early Career Researcher
Seed Funding

**Applying co-design principles to develop a lay description of the behaviour change taxonomy to target health behaviours in type 2 diabetes**

Geerling R, Holmes-Truscott E, Speight J

**$3K**

Deakin University: Faculty of Health
Higher Degree by Research
Conference Grant

**Attending the PsychoSocial Aspects of Diabetes (PSAD) Study Group annual scientific meeting (Würzburg, Germany) and the D-Stress Study investigators meeting (UK)**

Halliday J

# Awards

## World's Top 2% Scientists

**Prof Jane Speight & Prof Timothy Skinner**

Based on Stanford and Elsevier data, this list identifies the most-cited scholars in each discipline.

## Travel Fellowship Award

**Dr Eloise Litterbach**

by the international PsychoSocial Aspects of Diabetes (PSAD) Study Group, to attend the 28th Annual Scientific Meeting in Würzburg, Germany (24-26 April).

## Significant Publication Award

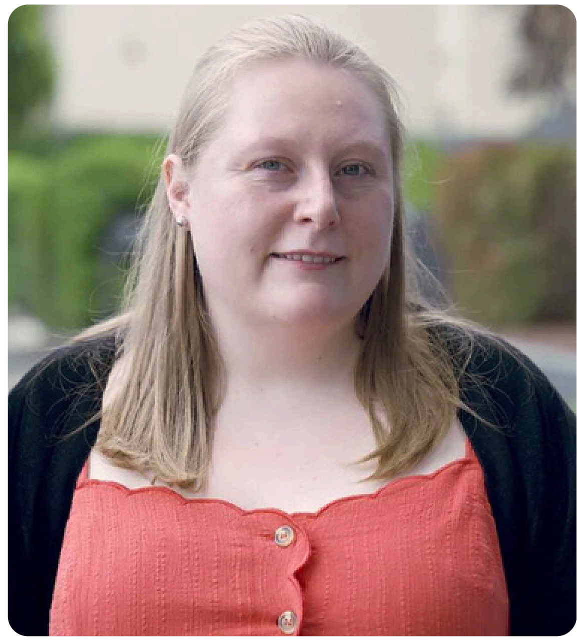
**Prof Jane Speight**

by Deakin University's School of Psychology, for her impactful publications as the lead/senior author and lead of a research group.

## Individual Award for Research Excellence (PhD)

**Jennifer Halliday**

by Deakin University, Institute for Health Transformation (IHT), as part of the Early and Mid-Career Researchers Award Program.



Social Experiences of Gestational Diabetes

"Almost seems like a finger-pointing type thing": Exploring the Social Experiences of Women with Gestational Diabetes and Co-Designing a Measure of Gestational Diabetes Stigma

Dr Eloise Litterbach, Prof Jane Speight, Christina Arampatri, Cobi Calyx, Jane-Elise Cherry, A Prof Matthew Fuller-Tyszkiewicz, Dr Amelia Williams, Prof Helena Teede, Dr Elizabeth Holmes-Truscott (CI)

Dr Eloise Litterbach
e.litterbach@acbrd.org

# Key Research
# Projects

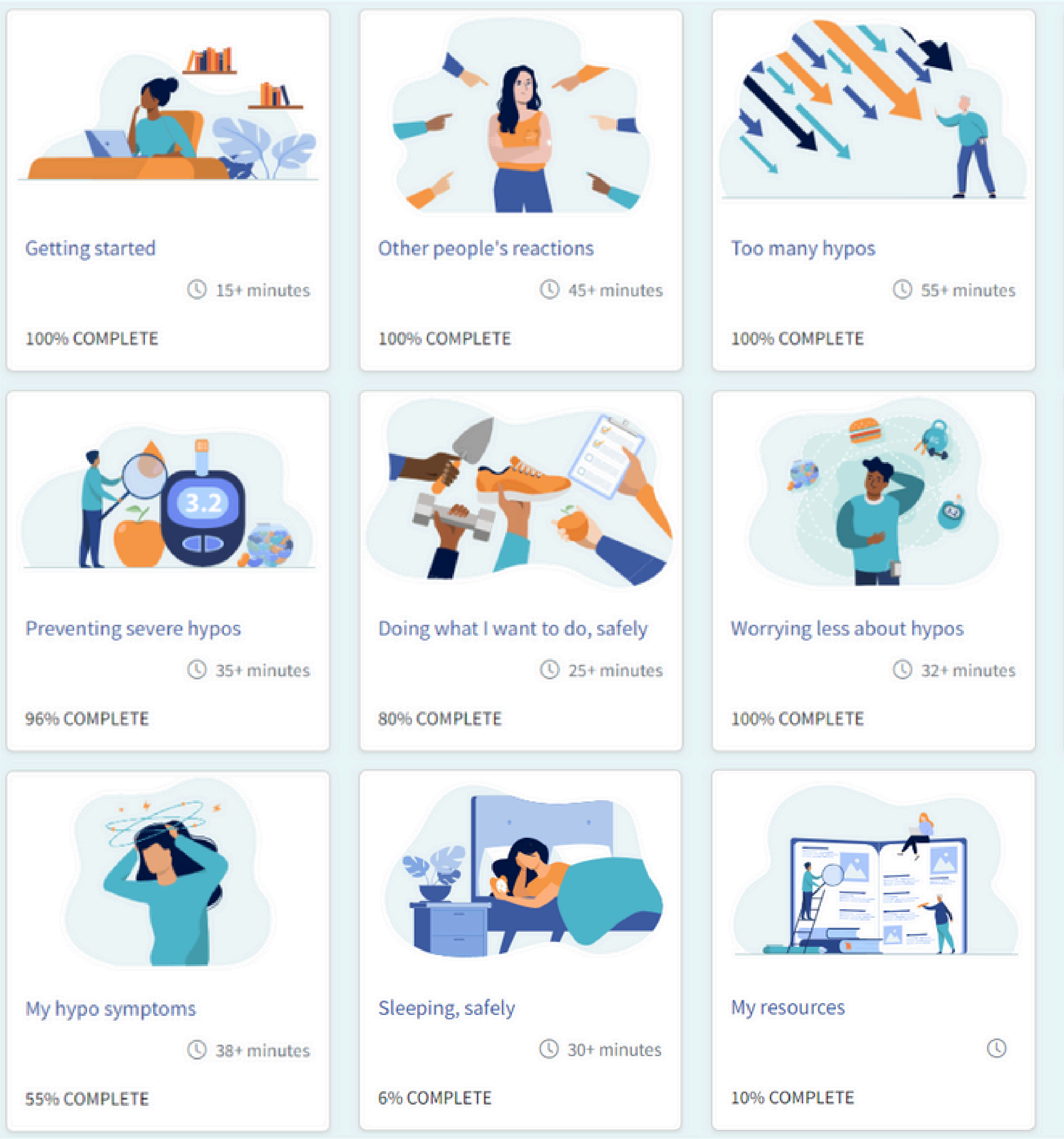
# HypoPAST Hypoglycaemia Prevention, Awareness of Symptoms and Treatment

HypoPAST
An online program for Hypoglycaemia Prevention, Awareness of Symptoms and Treatment

**HypoPAST is a novel, self-guided, online psycho-educational program for adults with type 1 diabetes, designed to support them with preventing hypoglycaemia (low glucose), regaining awareness of symptoms, optimising treatment of hypoglycaemia and managing fear of hypoglycaemia.**

In 2023, we developed the program materials in collaboration with an expert advisory group of adults with type 1 diabetes. In 2024, we:

- began a national randomised controlled trial to examine the effect of the program
- recruited 218 adults with type 1 diabetes experiencing hypoglycaemia-related anxiety (aka fear of hypoglycaemia)
- completed baseline and mid-trial (3-month follow-up) data collection
- commenced end-trial (6-month follow-up) data collection
- gave three conference presentations (one international, two national)
- published the study protocol in *Trials.*



TTRA
DIABETES + CARDIOVASCULAR DISEASE
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diabetes vic
LA TROBE UNIVERSITY
MONASH University
Newcastle University
ADEA
ads Australian Diabetes Society
diabetes australia
umotif.

# LISTEN Low-Intensity mental health Support via a Telehealth Enabled Network

The **aim of the LISTEN** program is to provide evidence-based, early intervention to support adults with type 1 and type 2 diabetes experiencing diabetes distress.

LISTEN is facilitated by diabetes health professionals (including credentialled diabetes educators, nurses, and dietitians) via telehealth.

In 2023, we completed a randomised controlled trial of the **LISTEN** program.

429 adults with T1D and T2D randomised to:

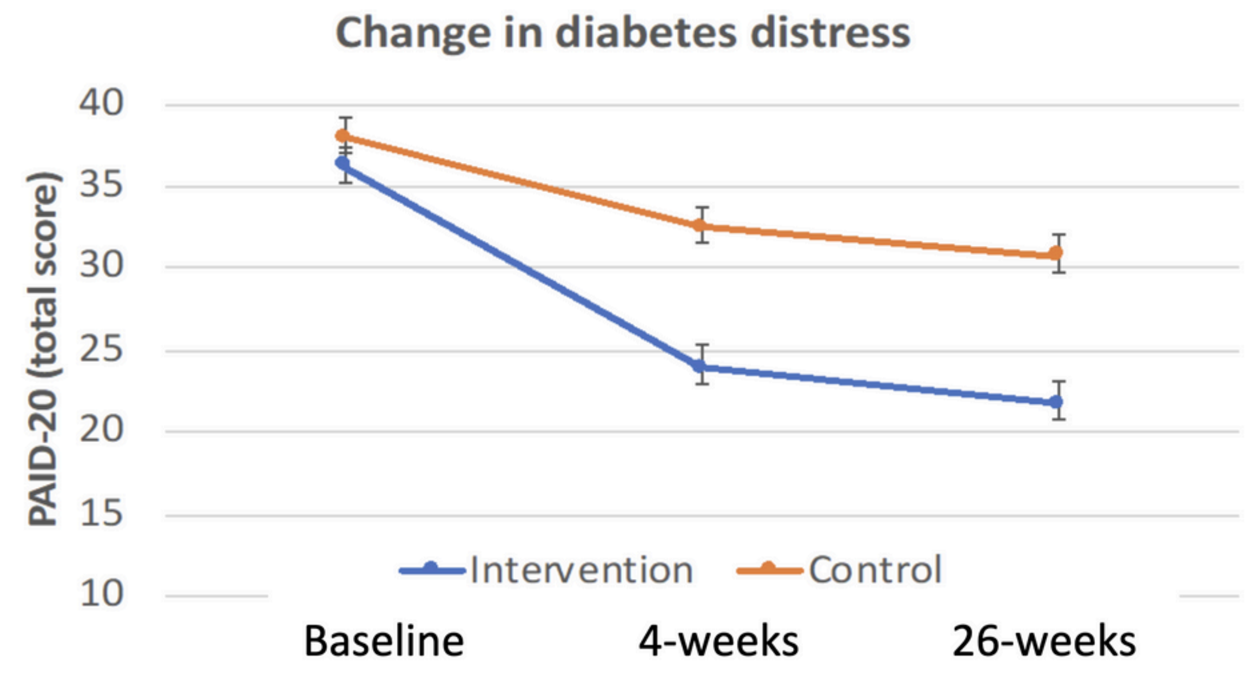
**LISTEN** Intervention (n=216)

Up to 4 weekly telehealth sessions with a LISTEN-trained diabetes educator

**Usual care** Control (n=213)

Resources about diabetes and emotional health

**Results**: At 26 weeks, compared to control, LISTEN had reduced diabetes distress (see Figure below), improved general emotional well-being and coping self-efficacy among adults with type 1 and type 2 diabetes.



*PAID=20-item Problem Areas in Diabetes

Upskilling diabetes health professionals to deliver LISTEN has the potential to address the unmet needs of adults experiencing diabetes distress.

The Australian Centre
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in Diabetes

Partners for better health

# ACADI

## Partnering to lead the Behavioural Platform for the Australian Centre for Accelerating Diabetes Innovations

ACADI

The ACBRD's Deputy Director, Dr Liz Holmes-Truscott, leads ACADI's Behavioural Platform. Liz collaborates with ACADI's researchers, other platform leads and partners, bringing unique expertise in the psychosocial and behavioural aspects of diabetes, essential for all research involving human participants. In 2024, a key focus for the platform was understanding barriers to, and enablers of, community involvement in diabetes research.

### Focusing on rural health disparities: how can we improve diabetes research participation for people with type 2 diabetes (T2D) living in Australian rural communities?

This project involved listening to 21 adults with T2D living in rural communities across all six Australian states to understand their barriers to, enablers of, and motivators to take part in diabetes research. Findings will be published in 2025.

### How do we increase T2D community involvement in research and health service improvement?

This project involves a rapid literature review to identify barriers to, and enablers of, community involvement in research and health services improvement among people living with T2D. This review will document strategies that have increased community involvement with diverse or under-represented T2D communities. Findings will be published in 2025.

ACADI is a national, collaborative interdisciplinary diabetes research centre uniting over 70 partners, including academic, advocacy, health service, industry and community partners

### **2024 publication:** Recommendations for improved community involvement in diabetes research

> Lancet Diabetes Endocrinol. 2024 Mar;12(3):155-157. doi: 10.1016/S2213-8587(24)00032-9.

**Living between two worlds: lessons for community involvement**

Ashley H Ng [1], Matthew Quigley [2], Tim Benson [3], Lauren Cusack [4], Rachel Hicks [5], Ben Nash [6], Meaghan Read [7], Renza Scibilia [8], Cheryl Steele [9], Leon Tribe [10], Elizabeth Holmes-Truscott [11]

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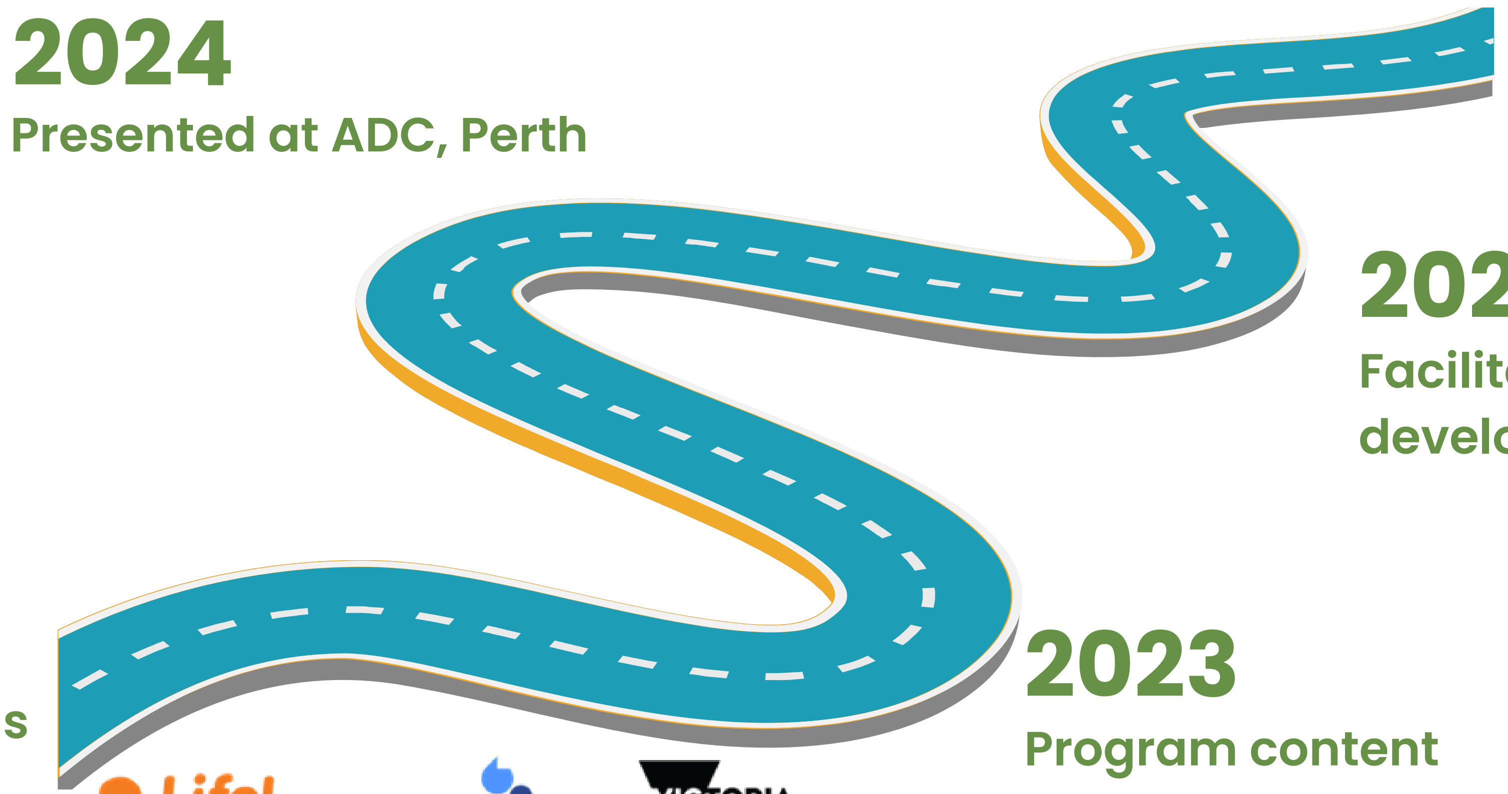
# Life! Partnering with Diabetes Victoria on the *Life!* program redevelopment project



**2022**
**Review begins**

**2023**
**Program content development**

**2024**
**Presented at ADC, Perth**

**2025**
**Facilitator training development**

**2026**
**Relaunch**

The *Life!* program is supported by the Victorian Government

## ACBRD activities and achievements:

- Rapid literature review of effective behaviour change techniques and program gap analysis
- Redevelopment of Life! program workbooks for participants and facilitators
- Presentation of activities at the Australasian Diabetes Congress, Perth, Aug 2024
- Recommendations for revised facilitator training materials and assessment.

The Life! program is a 12-month behaviour change program available to adults in Victoria at risk of type 2 diabetes, heart disease and stroke. Funded by the Victorian Government and managed by Diabetes Victoria, Life! is the largest type 2 diabetes and cardiovascular disease (CVD) prevention program in Australia. Since its inception in 2007, over 75,000 Victorian adults have taken part in the program..

Since 2023, the ACBRD has been engaged to bring its expertise in behavioural science and the psychosocial aspects of diabetes to ensure the curriculum incorporates state-of-the-art behaviour change techniques and related contemporary evidence to improve the program. The ACBRD received a contract renewal for 2024-25 to lead the work on redeveloping the program's facilitator training, bringing it into line with best practice to enable participants to achieve beneficial health outcomes.

# Reach and Impact

# A National Voice & A National Resource

**723**
Facebook followers

**8**
Advisory panels

**1**
International policies / guidelines citing ACBRD research

**11**
Issues of Research Round-Up*

**634**
LinkedIn Followers

**1**
Published commentary

**25**
ACBRD blogs

**1,211**
Research Round-Up* subscribers

**79**
Instagram followers (launched Aug 2024)

**3**
Guidelines and Consensus Statements

**48**
Media appearances

**47%**
Average open rate^

The ACBRD website includes media mentions, e-newsletters, blogs and the ACBRD webinar series.
*The ACBRD's free monthly e-newsletter. ^Industry average for open rate = 25%

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for Behavioural Research
in Diabetes

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# #EndDiabetesStigma

# EndDiabetesStigma.org

WE TOOK THE PLEDGE TO END DIABETES STIGMA

**10**

Invited presentations by the ACBRD on the International Consensus & Pledge to End Diabetes Stigma

**15**

In 2024, the Pledge was translated into 3 new languages: Dutch, German and Sinhalese.

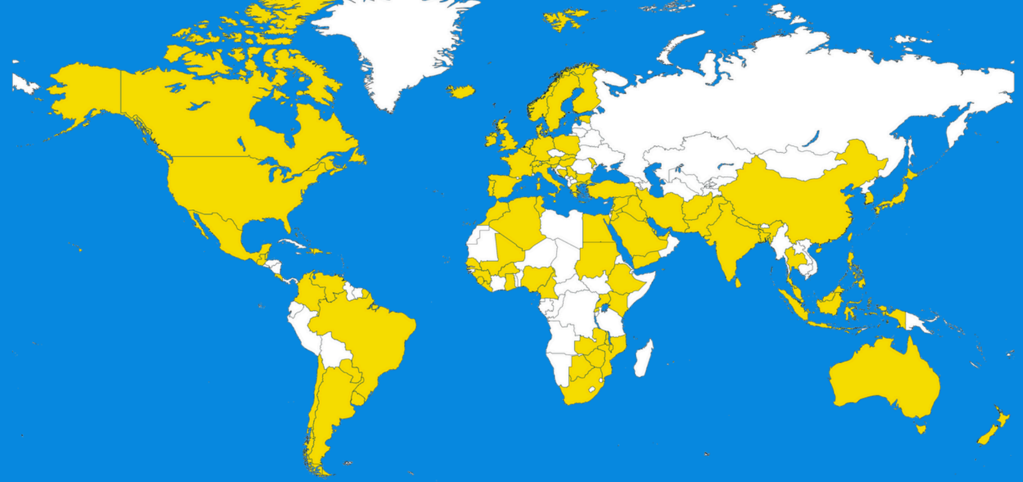
This brought the total to 15 languages, including the original English version.

By the end of 2024, the Pledge had been taken by

**3,000+** Individuals

**330** Organisations

**in 109** Countries



The Pledge is based upon the International Consensus to bring an end to diabetes stigma and discrimination, published in *The Lancet Diabetes & Endocrinology* (Jan 2024), co-led by Speight and Holmes-Truscott.

At the Australasian Diabetes Congress (Perth, Aug 2024), the ACBRD stand in the exhibition hall was themed to promote this important international movement.

In September 2024, Professor Chantal Mathieu spoke about the Pledge during her Presidential Address, opening the 60th annual meeting of the European Association for the Study of Diabetes (EASD, Madrid).

Spotlight on Diabetes Stigma in Australia

A UNSW Centre for Social Research in Health Seminar
Presented by Dr Elizabeth Holmes-Truscott, Meaghan Read and Alison Robinson

The Australian Centre for Behavioural Research in Diabetes

Partners for better health

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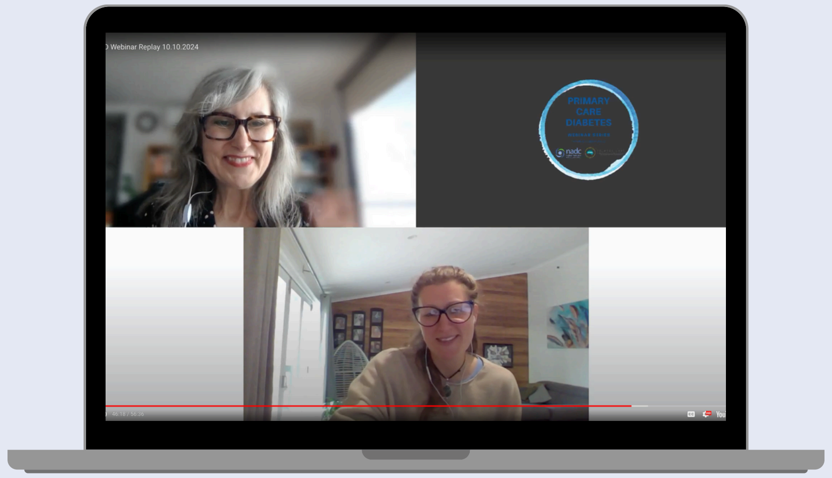
# Our Language Matters

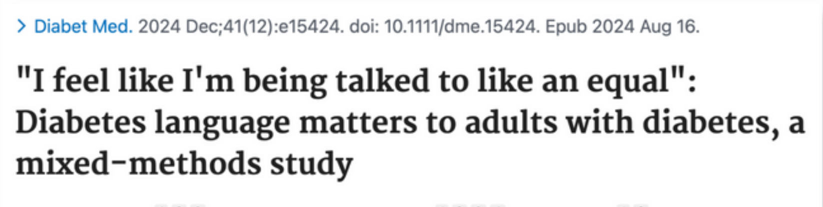
New Language Matters statements were published in:
**Ireland**, **the Netherlands** and **South Africa**.

**There are now 20+ similar statements published across the world, inspired by the position statements by Speight et al. (2011, 2021).**

A new international guide *by women with diabetes for women with diabetes* was launched:
**Language MattHERs**:
A guide to using inclusive and empathetic language for Women with Diabetes



Dr Eloise Litterbach spoke at a webinar hosted by the *Primary Care Diabetes Society of Australia* **— Language Matters: How we speak to and about people with diabetes can have profound impacts.**



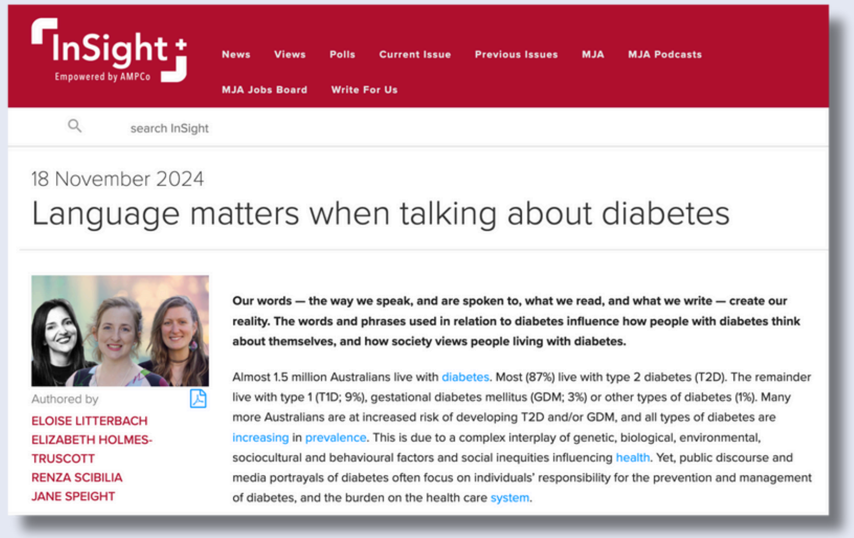
> Diabet Med. 2024 Dec;41(12):e15424. doi: 10.1111/dme.15424. Epub 2024 Aug 16.

**"I feel like I'm being talked to like an equal": Diabetes language matters to adults with diabetes, a mixed-methods study**

Eloise Litterbach [1 2 3], Elizabeth Holmes-Truscott [1 2 3 4], Shikha Gray [1 2], Jennifer Halliday [1 2 3], Renza Scibilia [5], Timothy Skinner [1 2 6], Jane Speight [1 2 3]

Dr Litterbach also led a paper published in *Diabetic Medicine*:

[“I feel like I'm being talked to like an equal”: Diabetes language matters to adults with diabetes, a mixed-methods study]



18 November 2024

Language matters when talking about diabetes

Authored by
ELOISE LITTERBACH
ELIZABETH HOLMES-TRUSCOTT
RENZA SCIBILIA
JANE SPEIGHT

**Our words — the way we speak, and are spoken to, what we read, and what we write — create our reality. The words and phrases used in relation to diabetes influence how people with diabetes think about themselves, and how society views people living with diabetes.**

Almost 1.5 million Australians live with diabetes. Most (87%) live with type 2 diabetes (T2D). The remainder live with type 1 (T1D; 9%), gestational diabetes mellitus (GDM; 3%) or other types of diabetes (1%). Many more Australians are at increased risk of developing T2D and/or GDM, and all types of diabetes are increasing in prevalence. This is due to a complex interplay of genetic, biological, environmental, sociocultural and behavioural factors and social inequities influencing health. Yet, public discourse and media portrayals of diabetes often focus on individuals' responsibility for the prevention and management of diabetes, and the burden on the health care system.

It was featured in MJA InSight +

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for Behavioural Research
in Diabetes

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# World Diabetes Day Lecture Series

In 2024, we launched a new World Diabetes Day lecture series, in honour and memory of Emeritus Professor Trisha Dunning AM.

Diabetes Victoria hosted the event, which will be held annually in partnership with the Institute for Health Transformation, Deakin University.

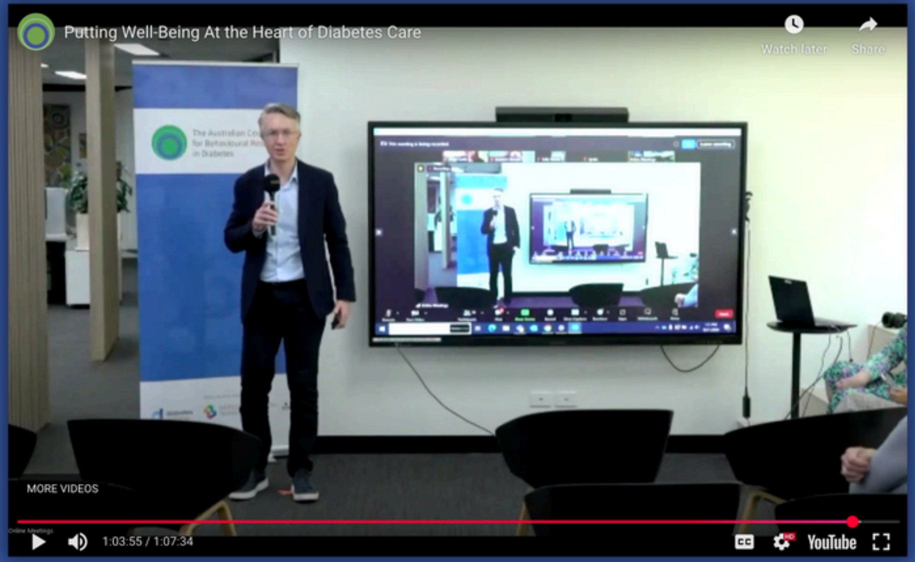
Professor Jane Speight gave the inaugural lecture:

## Putting Well-Being at the Heart of Diabetes Care

Her presentation focused on the progress made over the past 30 years to protect and maintain the well-being of people with diabetes. She also spoke about remaining challenges and opportunities in this area. The presentation can be viewed by clicking on the link above.


Putting well-being at the heart of diabetes care

Professor Jane Speight



# International Leadership: The PSAD Study Group

Since 2020, Prof Jane Speight has been the Chair of the PsychoSocial Aspects of Diabetes (PSAD) Study Group. She was returned to the role for a second term in 2024.

The PSAD Study Group is a reference group to the European Association for the Study of Diabetes (EASD), providing guidance on all matters related to the psychological, social and behavioural aspects of diabetes. The PSAD is an international network of 150+ members around the world, including Europe, Canada, USA, South America, Asia and Australia.

Through research, collaboration and advocacy, the PSAD Study Group aims to stimulate communication about and improve the quality of psychosocial research in diabetes.

## 28th PSAD Annual Scientific Meeting

Wurzburg, Germany | 24-26 April 2024

PSAD
PsychoSocial Aspects of Diabetes

**4**
ACBRD team members attended

**16**
countries were represented at the conference

**71**
people attended, including researchers, health professionals and people living with diabetes

## Three members of the ACBRD serve on the Executive Committee of the PSAD Study Group:

**Prof Jane Speight**
Chair of the
PSAD Study Group

**Dr Eloise Litterbach**
Early Career Researcher
Working Group Co-Lead

**Karen Pearce**
Website Content &
Development Lead

Prof Jane Speight and Jennifer Halliday led a workshop on the International Consensus and Pledge to #EndDiabetesStigma. Dr Eloise Litterbach presented ACBRD's work on the social experiences of gestational diabetes.

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# In the Media

**48**

Media Appearances in 2024

**58%**

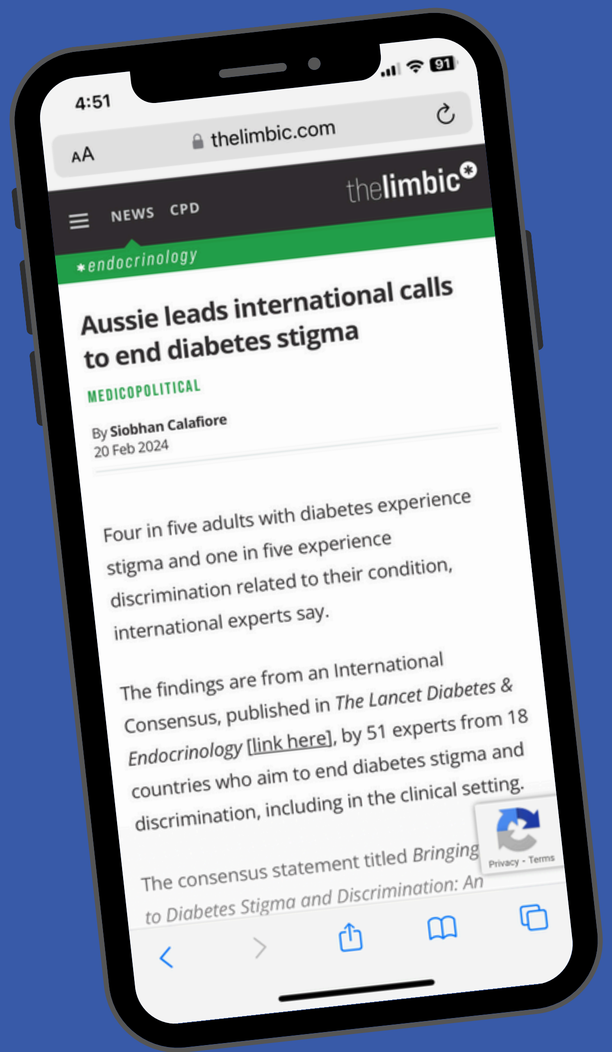
were in international media outlets*

*These included Argentina, Belgium, Canada, Denmark, Ireland, Italy, Netherlands, South Africa, Spain, Sweden, Switzerland, UK, and USA.

EXPERTS CALL FOR AN END TO DIABETES STIGMA

2024-01-23

A group of 51 experts from across the globe have come together to



Aussie leads international calls to end diabetes stigma

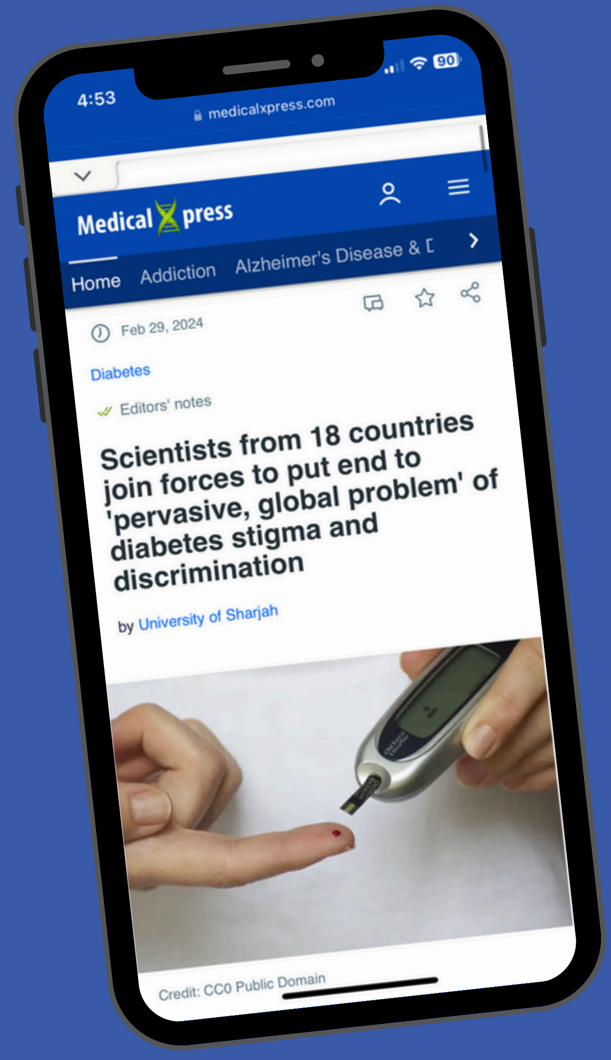
MEDICOPOLITICAL

By Siobhan Calafiore
20 Feb 2024

Four in five adults with diabetes experience stigma and one in five experience discrimination related to their condition, international experts say.

The findings are from an International Consensus, published in *The Lancet Diabetes & Endocrinology* [link here], by 51 experts from 18 countries who aim to end diabetes stigma and discrimination, including in the clinical setting.

The consensus statement titled *Bringing* ... *to Diabetes Stigma and Discrimination: An*



Feb 29, 2024

Diabetes

Editors' notes

Scientists from 18 countries join forces to put end to 'pervasive, global problem' of diabetes stigma and discrimination

by University of Sharjah

Credit: CC0 Public Domain

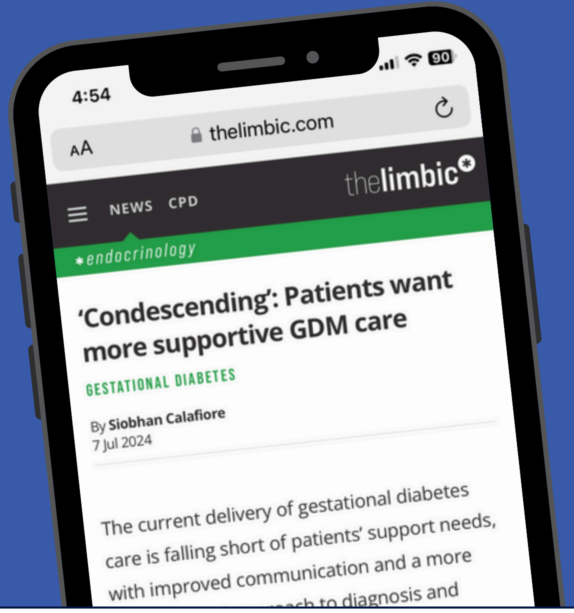
Medscape Medical News

Pledging to End Diabetes Stigma and Discrimination

Miriam E. Tucker
DISCLOSURES | January 19, 2024

An international effort aims to end diabetes stigma and discrimination in all its forms, including that experienced by people with the condition in clinical settings.

A new consensus statement *Bringing an End to Diabetes Stigma and Discrimination: An International Consensus Statement on Evidence and Recommendations* was published in the January 2024 issue of *The Lancet Diabetes and Endocrinology*. The authors were a 51-member panel co-led by health psychologist Jane Speight, PhD, director of the Australian Center for Behavioral Research in Diabetes (ACBRD), Diabetes Victoria, Melbourne, Australia, and Elizabeth Holmes-Truscott, PhD, also of ACBRD. The work was in collaboration with the San Francisco–based diaTribe Foundation and other diabetes experts from around the world.



'Condescending': Patients want more supportive GDM care

GESTATIONAL DIABETES

By Siobhan Calafiore
7 Jul 2024

The current delivery of gestational diabetes care is falling short of patients' support needs, with improved communication and a more

Diabete e linguaggio: le parole hanno un peso sul distress psicologico dei pazienti

Novembre 2024 / / da Redazione

Patient-First Care: Reframing the Language of Diabetes

March 11, 2024
By Nicholas Galloway ,BSN, RN, CDCES and UH

Innovations in Diabetes & Metabolic Care | Winter 2024

According to a recent international statement published

Il diabete e il peso dello stigma

Di Chiara Di Lucente

*Lo stigma e la discriminazione nei confronti delle persone con diabete sono un problema diffuso nella nostra società, ma troppo spesso poco considerato: vediamo di cosa si tratta, quali sono gli effetti e come ridurlo*

# Service and Contributions

## TO OUR PARTNER ORGANISATIONS

# Service and Contributions

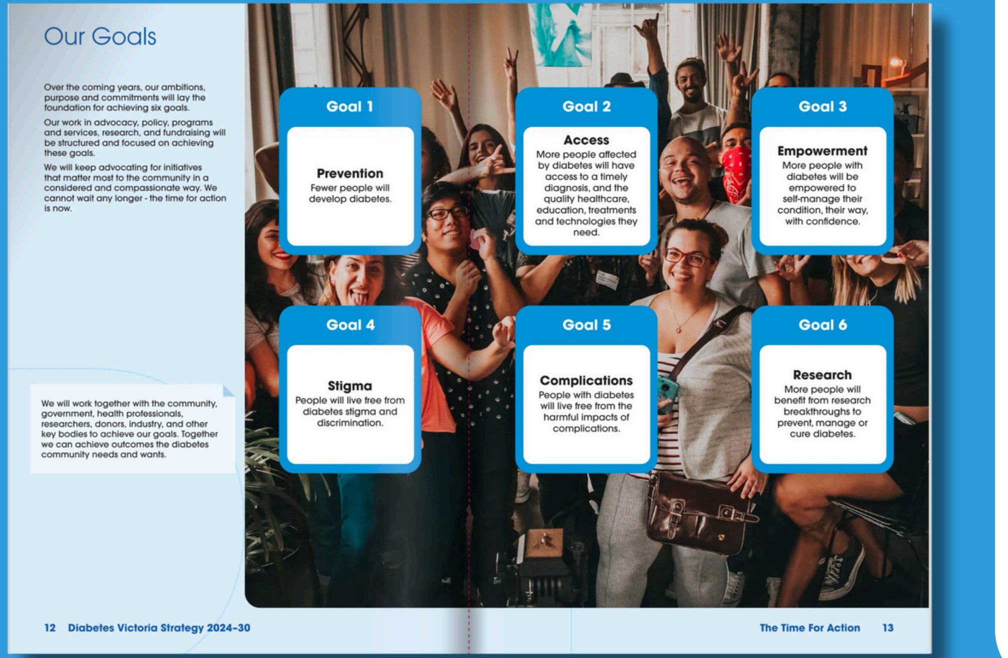
## LEADERSHIP

At Diabetes Victoria, Professor Jane Speight serves on the Leadership Team, and Dr Elizabeth Holmes-Truscott serves on the Extended Leadership Team.

They advise on, contribute to and/or review various materials, resources and events during the year, e.g.:

- Advocacy, strategy, impact
- Campaigns and communications, including National Diabetes Week campaigns and Fundraising campaigns

The Time For Action
Diabetes Victoria Strategy 2024-30
diabetes victoria



## Our Goals

Over the coming years, our ambitions, purpose and commitments will lay the foundation for achieving six goals.

Our work in advocacy, policy, programs and services, research, and fundraising will be structured and focused on achieving these goals.

We will keep advocating for initiatives that matter most to the community in a considered and compassionate way. We cannot wait any longer - the time for action is now.

We will work together with the community, government, health professionals, researchers, donors, industry, and other key bodies to achieve our goals. Together we can achieve outcomes the diabetes community needs and wants.

**Goal 1**
**Prevention**
Fewer people will develop diabetes.

**Goal 2**
**Access**
More people affected by diabetes will have access to a timely diagnosis, and the quality healthcare, education, treatments and technologies they need.

**Goal 3**
**Empowerment**
More people with diabetes will be empowered to self-manage their condition, their way, with confidence.

**Goal 4**
**Stigma**
People will live free from diabetes stigma and discrimination.

**Goal 5**
**Complications**
People with diabetes will live free from the harmful impacts of complications.

**Goal 6**
**Research**
More people will benefit from research breakthroughs to prevent, manage or cure diabetes.

12 Diabetes Victoria Strategy 2024-30
The Time For Action 13

## Diabetes Victoria Strategy 2024–2030

Dr Holmes-Truscott leads
**Goal 4: Stigma**

Prof Speight leads
**Goal 6: Research**

## Journey to a Cure – Tax Appeal Campaign

Dr Holmes-Truscott highlighted the importance of behavioural research

## 2024 Thank You Event

Dr Holmes-Truscott was invited to join the research panel discussion

# Service and Contributions

Several members of the team served on Diabetes Victoria's committees and working groups to support the translation of research into practice

**Access and Equity Committee**

**Health Literacy working group**

**Health Promotion Community of Practice**

**Lived Experience Employee Engagement Group (LEEEG)**

**Weight Inclusive working group**

# Service and Contributions

## PROGRAMS & PROJECTS

### Making Sense

Supporting interpretation and dissemination of this feasibility study, which was an outcome of the ‘Empower Us’ study (2023)

### Life!

Curriculum review to enhance content focused on supporting behaviour change

### OzDAFNE

Advisory Group

# Service and Contributions

## FACULTY OF HEALTH

### Community Research Engagement Network

### Faculty of Health Board

### HEAG-H Ethics Committee

# Service and Contributions

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**Executive Committee**
(inc co-lead of the Sustainability pillar)

**Early- & Mid-Career Researcher Committee**

**Diversity & Inclusion Committee**

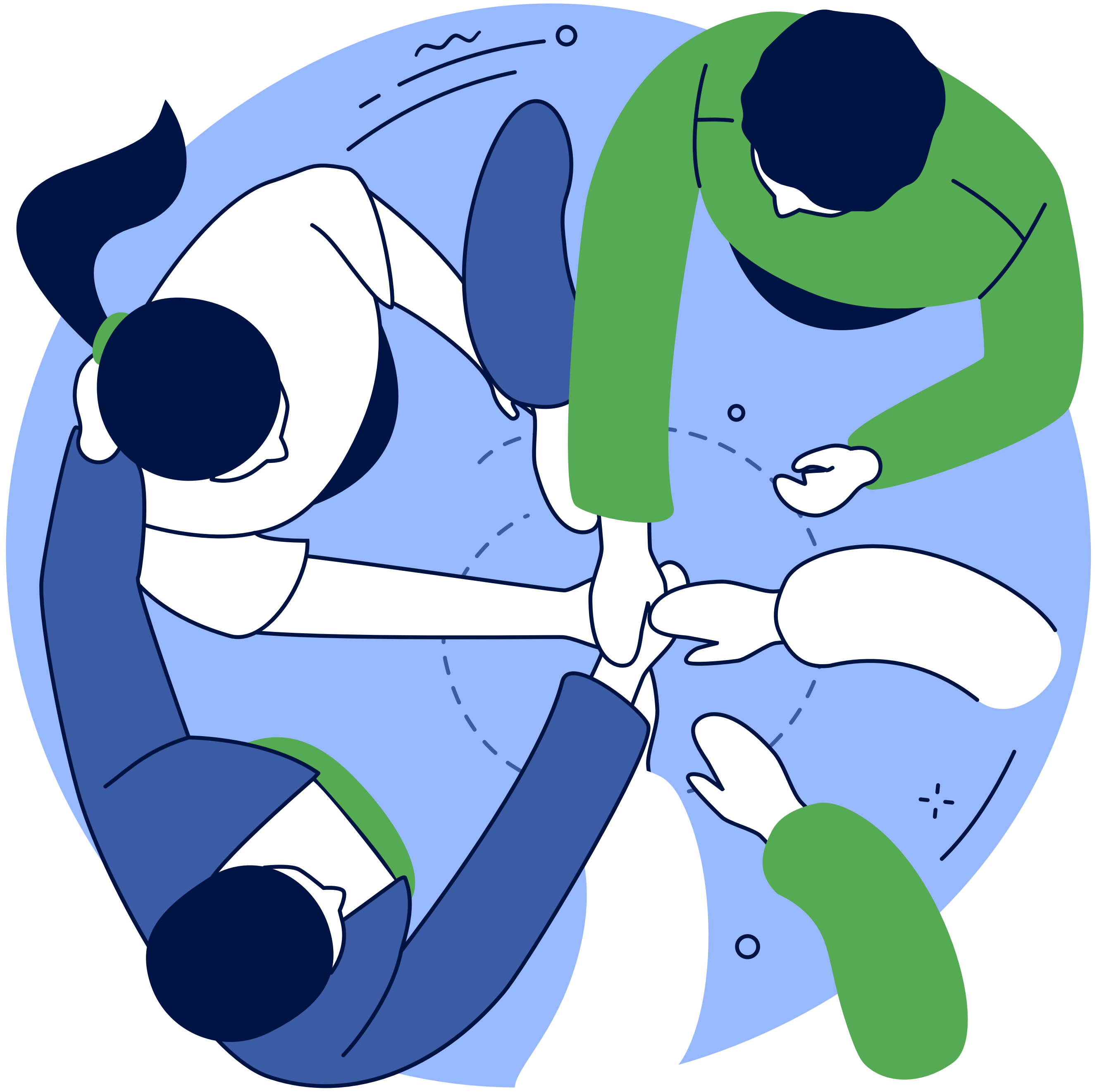
**Communications Community of Practice**

**Research Committee**

## IHT All Members Day – Health Stigma

Dr Holmes-Truscott and Dr Litterbach helped plan this event.
Dr Holmes-Truscott also gave a presentation about the Pledge to End Diabetes Stigma and facilitated a workshop.

# People and Partnerships



Meet

# Our 2024 Team


**Prof Jane Speight**
Foundation Director


**Dr Elizabeth Holmes-Truscott**
Deputy Director


**Danni Bellu**
Administrator


**Dr Ralph Geerling**
Research Fellow


**Jennifer Halliday**
Research Fellow


**Dr Edith Holloway**
Research Fellow


**Dr Joanne Jordan**
Research Fellow


**Dr Eloise Litterbach**
Research Fellow


**Sarah Manallack**
PhD Candidate /
Research Assistant


**Karen Pearce**
PhD Candidate


**Narelle Robertson**
Casual Research Fellow


**Alison Robinson**
Research Fellow


**Sienna Russell-Green**
Research Fellow


**Prof Timothy Skinner**
Professor


**Dr Uffe Søholm**
Research Fellow


**Sharm Thuraisingam**
Research Fellow


**Victoria Yutronich**
Communications Officer

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in Diabetes

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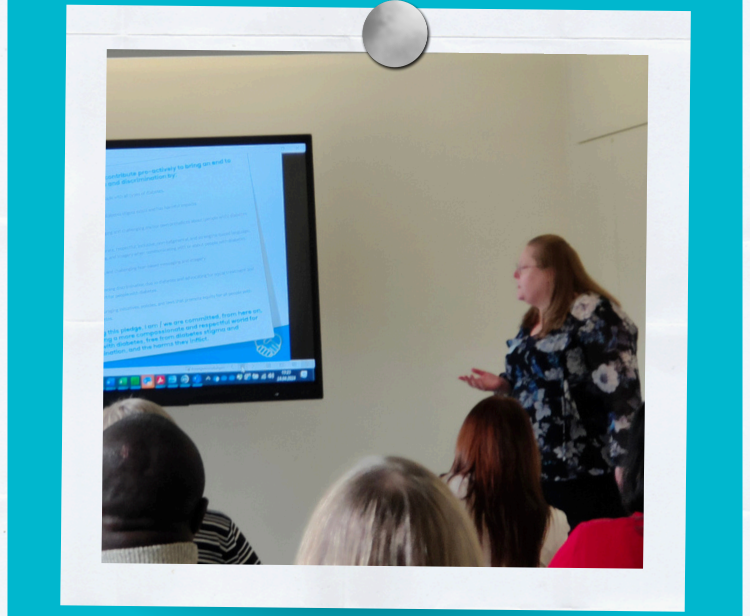
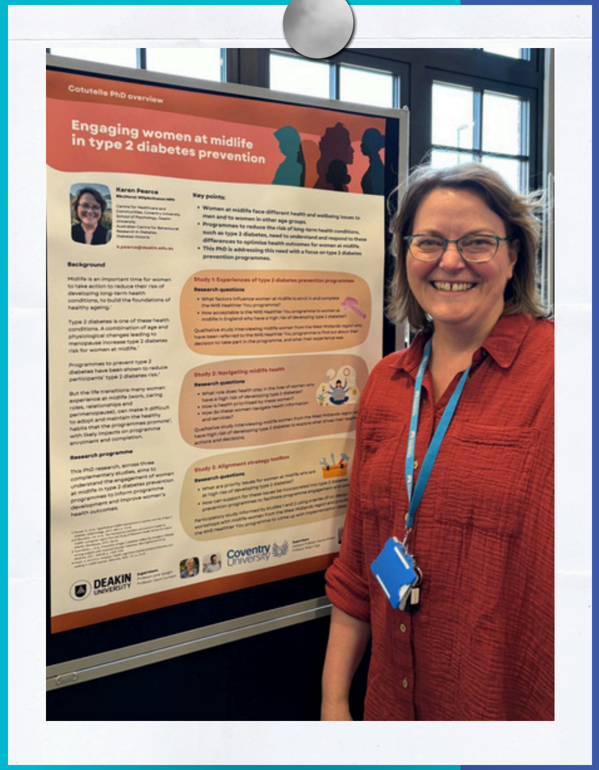
# Our Next Generation

Capacity building is integral to our work. Our PhD candidates are our future leaders.

Our PhD candidates all made excellent progress in 2024, continuing their research and presenting at national and international conferences. We were delighted to welcome Karen Pearce who began her PhD in February, under a Cotutelle arrangement with Coventry University, UK.

Ralph Geerling was awarded his PhD by Deakin University. The title of his thesis was:
**Personality and weight management in adults with type 2 diabetes.**





## Ongoing PhDs – Deakin University

Jennifer Halliday

**Supporting health professionals to provide support for diabetes distress**

Sarah Manallack

**Internalised stigma among women with type 2 diabetes at mid-life**

Karen Pearce
(Joint PhD with Coventry University – UK)

**Tailoring diabetes prevention programs for women in mid-life**

# Local, national and international collaborations

## in Victoria

- Baker Heart & Diabetes Institute
- Centre for Eye Research Australia
- Deakin University
- Diabetes Victoria
- La Trobe University
- Monash Partners Academic Health Sciences Centre
- Monash University
- Murdoch Children's Research Institute
- Royal Melbourne Hospital
- St Vincent's Hospital, Diabetes Technology Group
- St Vincent's Institute of Medical Research
- University of Melbourne

## across Australia

- Australian Catholic University
- Australian Centre for Accelerating Diabetes Innovations (ACADI)
- Australian Centre for Health Services Innovation (AusHSI), Qld
- Australian Diabetes Clinical Quality Registry (ADCQR)
- Australian Diabetes Educators Association (ADEA)
- Australian Diabetes Society (ADS)
- Australian JDRF Closed Loop Research Group
- Australian National University
- Australian T1D Clinical Research Network
- Australian T1D Immunotherapy Collaborative
- Australian T1D National Screening Program
- CSIRO
- Diabetes Australia, including the National Diabetes Services Scheme (NDSS)
- Kids Research Institute Australia, WA
- National Association of Diabetes Centres (NADC)
- OzDAFNE Collaborative
- Perth Children's Hospital, WA
- Primary Care Diabetes Society of Australia (PCDSA)
- The George Institute for Global Health, NSW
- The Obesity Collective
- University of Adelaide, SA
- University of Sydney, NSW
- University of Western Sydney, NSW

## across the world

- Aarhus University, Denmark
- Amsterdam UMC, The Netherlands
- Behavioral Diabetes Institute, USA
- Charite - Universitatsmedizin, Berlin, Germany
- Columbia University, USA
- Coventry University, UK
- #dedoc°, Berlin, Germany
- Dalhousie University, Canada
- Diabesties Foundation, India
- Diabetes Canada
- Diabetes Center Berne, Switzerland
- Diabetes New Zealand
- Diabetes UK
- diaTribe Foundation, USA
- European Association for the Study of Diabetes (EASD)
- EU Hypo-RESOLVE Consortium
- EU OPEN Diabetes Consortium
- FIDAM Research Institute, Germany
- International Hypoglycaemia Study Group (IHSG)
- Jaeb Center for Health Research, USA
- Kaiser Permanente, USA
- Karolinska Institute, Sweden
- King's College London, UK
- Leicester Diabetes Centre, UK
- NIH CLEAR trial consortium: 9 centres (6 in US, 2 in UK and one in Australia)
- National University Singapore
- OpenAPS, USA
- Penn State University, USA
- PsychoSocial Aspects of Diabetes (PSAD) Study Group
- Radboud UMC, The Netherlands
- Ramaiah Medical College, Bengaluru, India
- Staffordshire University, UK
- Stanford University, USA
- Steno Diabetes Center Copenhagen, Denmark
- Syddansk University, Denmark
- University of Alberta, Canada
- University College Dublin, Ireland
- University College London, UK
- University of Connecticut, USA
- University of Copenhagen, Denmark
- University of Dundee, UK
- University of East Anglia, UK
- University of Galway, Ireland
- University of Leeds, UK
- University of Leicester, UK
- University of Michigan, USA
- University of Newcastle, UK
- University of Pennsylvania, USA
- University of Sharjah, UAE
- University of Sheffield, UK
- University of Southampton, UK
- University of Virginia, USA
- Western Norway University

# We thank the following organisations for funding our research in 2024

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The ACBRD is supported via Deakin University's Faculty of Health, School of Psychology, and Institute for Health Transformation

Australian Government
National Health and Medical Research Council

NHMRC

Australian Government
Department of Health

TTRA
TARGETED TRANSLATION RESEARCH ACCELERATOR
DIABETES + CARDIOVASCULAR DISEASE

Powered by
MTPConnect
MedTech and Pharma Growth Centre
In partnership with
ANDHealth
MEDICAL DEVICE PARTNERING PROGRAM
UNIQUEST

ADEA

ads
Australian Diabetes Society

Breakthrough T1D™
Formerly JDRF

diabetes australia

DIABETES CANADA

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## In addition, we acknowledge these organisations, supporting research on which the ACBRD is a partner

Heart Foundation

The Ian Potter Foundation

NIH National Institutes of Health
*Turning Discovery Into Health*

NIHR National Institute for Health Research

VICTORIA State Government
Department of Health

The Australian Centre for Behavioural Research in Diabetes

Partners for better health

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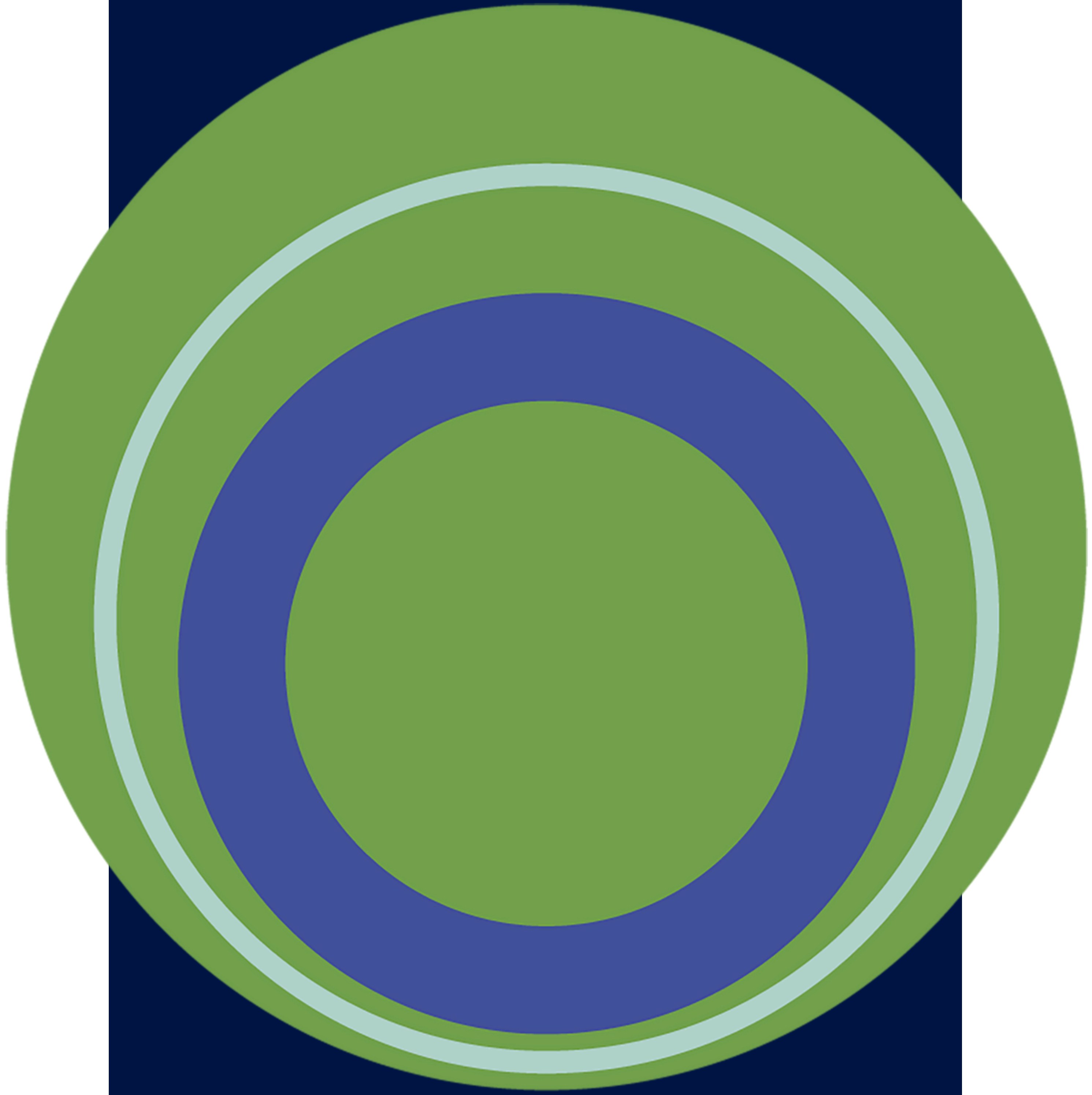

We thank all the people living with, or affected by, diabetes and everyone else who has contributed to or supported our work in 2024

# Connect

ACBRD.org.au

Info@acbrd.org.au

Research Round-Up E-Newsletter

## Socials

Facebook @ACBRD

Instagram @ACBRD_AU

LinkedIn @A-C-B-R-D