The Australian Centre for Behavioural Research in Diabetes

5 YEARS OF INNOVATIVE RESEARCH

Partners for better health



More than 1.1 million Australians have diabetes.¹ With 275 new cases diagnosed every day,¹ diabetes is the fastest growing chronic condition in Australia.²



1 in 4 adults with diabetes experience severe diabetesrelated distress³

1 in 5 adults with diabetes report that they infrequently or never eat a healthy diet³

2 in 3 adults with diabetes report that they do not engage in the recommended levels of physical activity³



1 in 3 adults with diabetes do not know their most recent HbA1c value³

1 in 3 adults with diabetes are interested in joining a peer support group³

1. National Diabetes Services Scheme. Statistical snapshot: December 2014. NDSS: Canberra. http://bit.ly/1BGKzMv. Downloaded 31 March 2015.

- 2. Australian Institute of Health and Welfare. Australia's health 2010. Canberra: AIHW, 2010.
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Foreword

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Acknowledgements

"The evidence that behaviour is the dominant element in successful management of diabetes is so overwhelming that we tend to ignore it." **Professor Edwin Gale**

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FOREWORD

The Australian Centre for Behavioural Research in Diabetes is an important and innovative undertaking, which has helped to reframe the way we think about diabetes.

Diabetes is not just a condition defined by numbers and biomedical risk factors – it places a high self-care and emotional burden on the individual. Through the ACBRD's work the emotional wellbeing of people with diabetes is being considered more widely, as is the need to support people with diabetes to develop their self-management skills. Importantly, the quality of life of people with diabetes is now higher on the research agenda.

While many researchers around Australia focus on how to prevent diabetes or on the psychosocial aspects of other chronic conditions, until the ACBRD was established there was no national research centre focused solely on the behavioural and psychosocial challenges of living with diabetes. For establishing the ACBRD in 2010 as a collaboration between our organisations, we acknowledge the vision and commitment of Professor Greg Johnson (former CEO of Diabetes Australia -Vic, now CEO of Diabetes Australia) and Professor John Catford (former Dean of the Faculty of Health at Deakin University). The creation of the Centre and a Chair of Behavioural and Social Research in Diabetes was unprecedented and a testament to the growing importance of this type of research in Australia. Embedding the ACBRD in the offices of Diabetes Australia – Vic has enabled research to influence programs, services, policies, practices and even the language we use to support people with diabetes; and conversely for real world problems to inform the Centre's research agenda.

Diabetes Australia – Vic is committed to reducing the impact of diabetes in the Victorian community, while Deakin University is committed to strengthening the communities it serves through research that

Diabetes Australia - Vic is the leading charity and peak consumer

community. DA–Vic provides education, information and support

types of diabetes – type 1, type 2, and gestational diabetes – as

well as programs for those at risk of type 2 diabetes. DA-Vic is

diabetes

australiavic

body working to reduce the impact of diabetes in the Victorian

to promote and empower self-management for people with all

Croig Smeth

Professor Craig Bennett

Chief Executive Officer

Diabetes Australia – Vic

committed to funding research

to improve the lives of all

those affected by diabetes



makes a difference. In just five years the ACBRD has strengthened the profile of both founding partners by becoming a nationally and internationallyrecognised research centre, a national voice and a national resource.

Through strategic and effective collaborations the ACBRD has attracted funding, published widely and informed policies and practices to reduce the impact of diabetes. The ACBRD's commitment to excellence has been acknowledged repeatedly over the past five years, most recently through the Council of Academic Public Health Institutions of Australia's inaugural team award for excellence in public health research in 2014.

We are delighted that the ACBRD has made such significant progress in just five years to promote holistic support to improve the quality of life of people with diabetes. We are immensely proud of the Centre's achievements and wish the Foundation Director, Professor Jane Speight, and her talented team further success in the future.

Professor Brendan Crotty Pro Vice Chancellor, Faculty of Health Deakin University

Deakin University is Australia's eighth largest university, with more than 50,000 students. Deakin combines excellent research and teaching with a strong commitment to the communities it serves through strong partnerships, which are relevant, innovative and responsive. Deakin's Faculty of Health is

one of Australia's largest multidisciplinary health faculties with five schools, including the School of Psychology, one of the largest and most research active psychology schools in Australia.



OUR MISSION

To provide a strong national focus



Professor Jane Speight PhD CPsychol AFBPsS Foundation Director, The Australian Centre for Behavioural Research in Diabetes

In 2011, the inaugural Diabetes MILES - Australia Study set the scene: a nationwide survey establishing the unmet psychosocial needs of 3,338 adults with type 1 or type 2 diabetes. This influenced the Centre's research agenda and led to numerous collaborations and publications. More recently, the Diabetes MILES Youth Study has established a new cohort of \sim 800 young people and \sim 800 parents, while MILES-2 is following up the original adult cohort and investigating new areas of interest.

The Centre is conducting world-leading research, e.g. investigating the social stigma surrounding diabetes; and the psychosocial and cognitive impact of cuttingedge 'closed loop' technology (the so-called 'artificial pancreas'). It is also conducting translational research, with a major program focussing on mental health and diabetes: developing resources for people with diabetes as well as for diabetes health professionals. The Centre's diverse research program involves: type 1 and type 2 diabetes, at all ages and stages; improving emotional well-being and self-care; preventing complications, both acute (e.g. severe hypoglycaemia) and long-term (e.g. retinopathy).

The Centre is also a national voice and a national resource. Through our work, we aim to influence policy and practice, with a focus on community engagement and communication. In 2011, we led the development of a Diabetes Australia position statement 'A New Language for Diabetes', highlighting the potentially detrimental impact of certain phrases (e.g. 'non-compliant',

INTRODUCTION

OUR OBJECTIVES

To be a national research

The first five years of The Australian Centre for Behavioural Research in Diabetes have been busy and exciting, with many highlights, which I hope you will enjoy reading.

'poorly controlled') on the well-being, motivation and self-care of people with diabetes. This work has ignited international debate and is literally changing the way people talk and think about diabetes.

The Centre has published over 60 peer-reviewed articles in leading academic journals, delivered numerous invited lectures at local, national and international meetings, and had major successes in competitive grants. Underpinning these achievements are the Centre's profile and reputation, reflected in successful ongoing collaborations, enabling large multidisciplinary projects and greatly expanding our capacity.

Having set the scene and established key priority areas, our work in the next five years will have a greater focus on developing and evaluating interventions to improve the health and quality of life of Australians living with diabetes.

Being Foundation Director of the ACBRD is a privilege and a wonderful experience. I am supported by an outstanding team, all of whom are passionate about conducting applied, high quality and impactful research – and creating a collegial and fun research environment. I thank my team, our collaborators, our research participants, our funders, and especially our founding partners, Diabetes Australia – Vic and Deakin University, for their support and commitment to enabling our research dedicated to achieving the very best for people living with diabetes.

1 OUR TEAM

RESEARCH STAFF AND STUDENTS

Foundation Director

Professor Jane Speight PhD CPsychol AFBPsS

Research Fellows

Dr Jessica Browne PhD Dr Christel Hendrieckx MSc PhD Dr Steve Trawley PhD

Associate Research Fellows

Jennifer Halliday BHSc(Hons) (not pictured) Dr Adriana Ventura DPsych(Health)

PhD Candidates

Virginia Hagger RN GDipVET MPH Elizabeth Holmes-Truscott BSSc BPsyc(Hons) Amelia Lake BA(Psych), Grad Dip (Psych)

Research Assistant

Lucinda Poole BAppSc(Hons) (not pictured)

Administrator

Anna Edwards

Profiles of current staff and PhD candidates can be found on www.acbrd.org.au

GOVERNANCE

The ACBRD management committee meets quarterly to oversee the work of the ACBRD and ensure its activities are directed towards its stated objectives. The committee comprises:

- Professor Craig Bennett, CEO, Diabetes Australia
 Vic
- Professor Brendan Crotty, Pro Vice Chancellor, Faculty of Health, Deakin University
- Professor Greg Johnson, CEO, Diabetes Australia
- Professor Greg Tooley, Head, School of Psychology, Deakin University

We acknowledge the valuable contributions of past staff

Dianna McDonald, Shaira Baptista, Claudia Gasch, Rachel Isaacs, Beth Martin, Lucy Morrish, Jasmin Schabert, Anna Scovelle, Laura Smith.

TRAINING THE NEXT GENERATION

Our trainees are our future. If we are to meet the challenges and opportunities presented by a condition such as diabetes, we need to focus our attention on developing the next generation of researchers and health professionals. Capacity building is integral to our work.

The Centre has a strong focus on training and mentorship, offering a supportive environment for the academic development of PhD, Doctoral, Masters and Honours students. The Centre's PhD candidates come from a range of academic and vocational backgrounds.

Associate Research Fellow and PhD candidate, Amelia Lake, coordinates the Diabetes and Eye Health project, focusing on prevention of a common complication of diabetes. She came to the Centre with a research background but wanted to stretch herself further. "I began my PhD as an experienced project manager, having worked on several intervention studies and health service evaluations. I greatly appreciate my supervisors, who provide guidance in health psychology principles, whilst enabling me to develop as an independent researcher."

PhD candidate Virginia Hagger manages Diabetes Australia – Vic's TEAM T1 program, a structured education program for adolescents with type 1 diabetes and their parents. Her PhD work is investigating diabetes distress in adolescents. "After many years working as a diabetes nurse educator and program manager, I wanted to build research capacity in my profession and help to connect the art and the science. The ACBRD was the natural place to undertake my PhD, because of the Centre's strong focus on the perspective of the person living with diabetes." Virginia benefits from the applied research environment offered by the Centre, while the Centre's staff and students benefit from her clinical expertise.

The ACBRD also supports staff that wish to develop their research careers. PhD candidate Elizabeth Holmes-Truscott says "I've been with the Centre since 2010, starting as a research assistant fresh from my psychology Honours degree. The passion and energy of the Centre's senior researchers was infectious and I became keen to develop my skills to pursue a research career in behavioural diabetes. When I complete my PhD, I am hoping for the opportunity to continue my research as a postdoctoral fellow, focusing on attitudes to insulin therapy uptake among people with type 2 diabetes. Over my time with the ACBRD, I've worked on a variety of projects. This has given me opportunity to widen my skill set and develop a broad appreciation of the Centre's work and its impact."

The Centre also provides supervision to Deakin University's health psychology doctoral students. Previous doctoral candidate, Dr Adriana Ventura says "completing a health promotion placement with the ACBRD was extremely rewarding. Before this experience, I had never envisioned a career in research for myself but after the mentorship I received from staff and fellow students, I can't imagine not being a part of this community. I have the Centre to thank for this." Following her placement, Adriana continued with the Centre as a part-time research assistant while completing her Doctorate, and is now an Associate Research Fellow.

2 A NATIONAL RESEARCH CENTRE

The Centre has a wide-ranging portfolio of research on which it leads and collaborates, nationally and internationally. All our projects are applied, creating new knowledge and/or translating research into practice.

Here, we highlight a selection of our key research areas. The full range of research projects can be found on www.acbrd.org.au.

DIABETES DISTRESS AND DEPRESSION

A key focus for the Centre over the past five years (in terms of both research and advocacy) has been the mental health and emotional well-being of Australians with diabetes.

The Centre's work in this area began in 2011 with **Diabetes MILES (Management and Impact for Long-Term Empowerment and Success) – Australia Study.**¹ This national survey was the first of its kind in Australia, focused on the psychological well-being of Australian adults with type 1 or type 2 diabetes, attracting 3,338 participants. The results confirmed that emotional problems are common and provided strong rationale for the Centre to undertake further work in this area.

In 2011-2012, we conducted an **Audit of Emotional Well-being** among adults attending the diabetes clinics at the Royal Melbourne Hospital, St Vincent's Hospital, and Baker IDI Heart and Diabetes Institute.² Approximately one third of the participants were identified as having impaired well-being and one in five had severe diabetes distress. Almost half wanted to talk with their health professional about their feelings about diabetes and the idea of routine monitoring was well-received.

From 2012-2016, the Centre has a leadership role for the **National Diabetes Services Scheme's National Development Program for Mental Health and Diabetes.**³ Our needs analysis demonstrated that, although guidelines exist, routine monitoring of mental health in diabetes care rarely occurs in practice. Furthermore, many health professionals avoid talking about mental health due to their perceived lack of skills and confidence to have the conversation.⁴ Thus, the Centre is working to translate research into practice.⁵ Key deliverables for this program are:

- Health professional 'Handbook for mental health assessment and communication in diabetes care'
- Establishment of the Diabetes and Mental Health Professional Networks across Australia
- A suite of fact sheets for people with diabetes about common mental health problems
- A report on the value and models of diabetes peer support in Australia

Project team

Prof Jane Speight, Dr Christel Hendrieckx, Jennifer Halliday, Dr Jessica Browne, and Dr Adriana Ventura

Acknowledgements

The Diabetes MILES - Australia 2011 survey was funded by a National Diabetes Services Scheme (NDSS) Strategic Development Grant. The National Development Program for Mental Health and Diabetes is funded by the NDSS. The NDSS is an initiative of the Australian Government administered by Diabetes Australia. In addition, the Diabetes MILES-Australia study received an unrestricted educational grant from Sanofi to support the development of the study website (www. diabetesMILES.org) and miscellaneous activities. The Audit project was funded by Diabetes Australia – Vic and Deakin University. We acknowledge the valuable contributions of Lucy Morrish and Shaira Baptista (formerly of ACBRD) and Dr Linda Beeney (University of Sydney) to this work.

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SOCIAL STIGMA IN DIABETES

There is limited but growing awareness that people with diabetes face stigmatisation and discrimination as a result of their condition. The International Diabetes Federation (IDF) has identified diabetesrelated stigma as a problem that needs urgent attention, and one of its key priorities is to 'champion a world free from discrimination and stigma for people with diabetes' (IDF Strategic Plan 2013– 2015 p.10).

Our world-first program of research investigating the social stigma of diabetes has made a huge contribution to knowledge, informing healthcare communication and practice, and attracting international attention.

Our review of diabetes-related stigma research revealed that while people without diabetes do not perceive the condition to be stigmatised, people with diabetes feel judged, blamed, and monitored.¹ However, the review also highlights a distinct lack of systematic research into diabetes stigma. To examine the issue further, we conducted in-depth interview studies with people with type 1 and type 2 diabetes to explore their perceptions and experiences of diabetes-related stigma.^{2, 3} Our findings indicate that both groups perceive and/or experience stigmatisation as a result of their condition. For people with type 2 diabetes, the stigmatisation is characterised by feeling blamed by others for 'bringing the condition on themselves', being subject to negative stereotyping, being discriminated against, and having restricted opportunities in life. In contrast, people with type 1 diabetes report that they primarily feel stigmatised as a result of association with people with type 2 diabetes. However, they also experience some type 1-specific stigmatisation, including negative social judgement, stereotyping, exclusion, rejection and discrimination. People with type 1 and type 2 diabetes reported being stigmatised by friends and family, employers/ colleagues, health professionals, and most notably, by the media.

The next step in this program of research is to quantify the extent of the problem. Using the qualitative data as a basis, we have developed selfreport questionnaires (tailored for diabetes type) designed to assess perceptions and experiences of social stigma in diabetes. A large-scale, national validation study of these new questionnaires is currently underway.

Project team

Dr Jessica Browne, Dr Adriana Ventura, and Prof Jane Speight

Acknowledgements

We acknowledge Professor Peter Colman and A/Prof David O'Neal (University of Melbourne) and A/Prof Neale Cohen (Baker IDI Heart and Diabetes Institute) for their collaboration on the Audit project, funded by Diabetes Australia – Vic and Deakin University. We acknowledge the valuable contributions of Jasmin Schabert (formerly of ACBRD) and A/Prof Kylie Mosely (Australian Catholic University) to this work. This program of research has been funded by the Diabetes Australia – Vic, the Centre for Mental Health and Wellbeing Research at Deakin University, a Pozible campaign and a Diabetes Australia Research Program grant.

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OPTIMISING SELF-CARE THROUGH STRUCTURED DIABETES EDUCATION

The Diabetes MILES – Australia Study demonstrated that 49% of adults with diabetes had never been offered structured diabetes self-management education (DSME) – and most had only been offered it soon after diagnosis. This is despite a wealth of evidence demonstrating the benefits of structured DSME, not only in terms of improving HbA1c (average blood glucose) but also in terms of reducing severe hypoglycaemia, diabetic ketoacidosis, diabetes-related distress, and improving quality of life.^{1, 2} Programs such as DAFNE^{1, 2} and DESMOND³ are widely available in the UK but are less accessible in Australia, where distance and costs can be barriers to delivery. The Centre is committed to advocating for structured DSME and continuing research to support its implementation and enhance its benefits for people with diabetes.

There is considerable debate in the literature about the value of self-monitoring of blood glucose (SMBG) among adults with type 2 diabetes who do not use insulin. Several systematic reviews have concluded that SMBG does not have any clinical benefit for this group. Furthermore, the pressure to rationalise healthcare to ensure that services, treatments and interventions are cost-effective has never been greater. We critically appraised this evidence and found considerable heterogeneity in the literature, with variations in methodology confounding the results of these studies.⁴ Recent evidence demonstrates that when SMBG is 'structured', incorporated as part of a complex intervention and embedded within education and collaborative care, improvements in average blood glucose levels result. Furthermore, psychosocial outcomes, such as selfefficacy and diabetes-related distress, and other clinical outcomes (e.g. hypoglycaemia detection) should also be considered as clinically important outcomes. We conclude that it is the quality, not the quantity, of SMBG that makes a difference. Restricting access by any particular subgroup is not evidence-based, is unjustifiable and inequitable. We will continue to work in this area to ensure that all people with diabetes have access to the skills and equipment to enable them to undertake effective self-management of their condition to prevent longterm complications.

2

Project team

Prof Jane Speight and Dr Jessica Browne

Acknowledgements

We acknowledge funding received by the DAFNE and DESMOND programs in the UK from Diabetes UK and the NIHR. We acknowledge Prof Simon Heller (University of Sheffield), Prof Stephanie Amiel (King's College London), Prof Melanie Davies and Prof Kamlesh Khunti (University of Leicester), and the numerous collaborators on this research, many of whom are authors in the references cited below. We declare that Prof Speight is a member of the Accu-Chek Advisory Board (Roche Diagnostics Australia).

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HYPOGLYCAEMIA: IMPACT AND PREVENTION

The discovery of insulin in 1922 was a life-saving breakthrough for people with type 1 diabetes. Ninety years later, exogenous insulin (by injection or pump) cannot mimic the body's natural insulin supply, and hypoglycaemia (low blood glucose) is an inevitable side effect.¹

We have conducted the first Australian studies into the prevalence of severe hypoglycaemia and impaired awareness of hypoglycaemic symptoms.² Among 422 adults with type 1 diabetes attending three diabetes clinics in Melbourne, one in five had experienced at least one severe hypoglycaemic event in the past six months.² Those with impaired awareness of hypoglycaemic symptoms were 10 times more likely to experience severe hypoglycaemia. Severe hypoglycaemia was associated with greater fear of hypoglycaemia, diabetes-related distress and impaired emotional well-being.² Building on these findings, we are investigating behavioural, educational and technological approaches for preventing severe hypoglycaemia.

Currently, we are developing an online psychoeducational training program for people with type 1 diabetes, which is designed to help them prevent severe hypoglycaemia. If successful (as we expect it to be), this program will be made available to all Australian adults with type 1 diabetes via Diabetes Australia – Vic.

An 'artificial pancreas' or 'closed loop' system has great potential to prevent hypoglycaemia. This new technology determines insulin requirements based on a computerised algorithm reviewing continuous glucose information. A clinical trial (led by colleagues at University of Melbourne) is evaluating the use of overnight 'closed loop' for the first time in the home setting in Australia. We are interviewing participants about their expectations and experiences with overnight 'closed loop', and assessing its effect on daytime cognitive functioning (attention and concentration). Prof Speight's UK-based work, including a definitive review of severe hypoglycaemia,¹ also contributes important new knowledge to this field. The HypoCOMPaSS interview study demonstrates the individual's psychological, behavioural and cognitive barriers to preventing severe hypoglycaemia.³ The HypoCOMPaSS trial demonstrates recovery of hypoglycaemia awareness and prevention of severe hypoglycaemia among adults with long-standing type 1 diabetes can be achieved via insulin adjustment, education and support.⁴

Project team

Dr Christel Hendrieckx, Dr Steve Trawley and Prof Jane Speight.

Acknowledgements

We acknowledge Prof Peter Colman and A/Prof David O'Neal (University of Melbourne) and A/Prof Neale Cohen (Baker IDI Heart and Diabetes Institute) for their collaboration on the Audit project, funded by Diabetes Australia – Vic and Deakin University. We acknowledge Prof Tim Skinner, Prof Frank Snoek, A/Prof David Austin and other colleagues on the development of our online program for prevention of severe hypoglycaemia. We acknowledge A/Prof David O'Neal and the 'Closed Loop' study team and the funding from JDRF International. We acknowledge Professor James Shaw (Newcastle University, UK) and the HypoCOMPaSS Study team, and the funding from Diabetes UK.

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DIABETIC RETINOPATHY: EFFECTIVE COMMUNICATION TO PREVENT EYE COMPLICATIONS

People with diabetes are vulnerable to diabetic retinopathy (DR), a common complication that progressively damages the blood vessels at the back of the eye. As the early stages of DR are without symptoms, early detection via eye examination and timely treatment are essential to reduce the risk of vision loss or blindness. Australian guidelines recommend eye examinations at diabetes diagnosis and a minimum of every two years thereafter. Eye examination rates are known to be lower than average among adults with young-onset type 2 diabetes (T2DM, aged 18-39 years) and people from rural/regional locations (estimated to be 50% and 65% respectively).

The Diabetes and Eye Health project is a collaboration between Vision 2020 Australia, Diabetes Australia – Vic, The Centre for Eye Research Australia and ACBRD. The aim of this project is to develop communication messages designed to increase eye examination rates for people recently diagnosed with type 2 diabetes in the two at-risk groups identified above. Secondary aims include raising the awareness of the steps an individual can take to prevent development or slow progression of DR, such as maintaining optimal blood glucose and blood pressure levels.

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We have used in-depth interviews and surveys to explore individual factors influencing eye examination behaviour, and to develop evidence-based messages designed to educate and motivate people in these target groups. Presented in leaflet format and tailored to each cohort (i.e. young adults or those from rural/regional locations), the messages are currently being tested in a nationwide randomised controlled trial. This project is an example of successful inter-agency collaboration between numerous stakeholder organisations and of the value of an evidence-based, person-centred focus in developing health promotion resources. Publications from this research are in preparation. Amelia Lake is focusing in-depth on the young adult cohort for her PhD research.

In related work, Prof Jane Speight is working with Dr Gwyn Rees and colleagues from the Centre for Eye Research Australia, to examine the effectiveness of 'personalised eye consultations'. This involves an eye health specialist showing people with DR their own retinal images and guiding them through the images using scripted information to communicate the links between self-care behaviours, HbA1c (average blood glucose) and DR. In a pilot study involving 25 participants, the intervention group showed significantly greater improvements in HbA1c than the usual care group, as well as increased knowledge, motivation and intentions to change their diabetes self-care.¹ Having shown considerable potential and feasibility in a small study, this intervention is now being tested in a fully powered randomised controlled trial.

Project team

Amelia Lake, Prof Jane Speight and Dr Jessica Browne

Acknowledgements

The Diabetes and Eye Health project is a Vision Initiative project funded by the Victorian Government and managed by Vision 2020 Australia. We acknowledge the collaboration of Dr Gwyn Rees and colleagues (Centre for Eye Research Australia), and funding from the Diabetes Australia Research Program (*Millennium Type 2 Grant*) to support the ongoing 'personalised eye consultations' trial.

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ATTITUDES TO INSULIN USE IN ADULTS WITH TYPE 2 DIABETES

In Australia, around 23% of adults with type 2 diabetes are currently using insulin – this is about twice the number of people with type 1 diabetes using insulin. Based on the discrepancy between actual and target HbA1c (average blood glucose) levels, national and international data suggest that many more adults with type 2 diabetes may benefit from using insulin therapy. Prolonged hyperglycaemia (high blood glucose) significantly increases the risk of developing or worsening long-term diabetes complications. Therefore, timely intensification of medications is critical but insulin initiation is frequently delayed.

Few studies have explored attitudes to insulin therapy among adults with type 2 diabetes in the Australian context. PhD candidate, Elizabeth Holmes-Truscott, is conducting a series of research projects focused on insulin therapy appraisals, as well as investigating interventions to improve receptiveness to insulin among adults with type 2 diabetes in primary care.

Our research has demonstrated that people with type 2 diabetes delay insulin for a number of reasons, ranging from concerns about the perceived complexity of insulin therapy, to the belief that they have failed if insulin needs to be prescribed.^{1,2} This negative appraisal of insulin, known as 'psychological insulin resistance', may act a barrier to insulin initiation or the optimal use of insulin therapy. International data show that approximately one guarter of people with type 2 diabetes report being unwilling to begin insulin therapy. Further, negative insulin therapy appraisals can persist beyond insulin initiation, and may compromise optimal use of insulin therapy. Our work also shows that those with more negative insulin therapy appraisals commonly report increased diabetes-related distress and general emotional impairment.²

While the majority of healthcare provision for people with type 2 diabetes takes places within the primary care setting, referral to specialist diabetes services for insulin initiation is common in Australia. This delays treatment intensification, is costly, and affects continuity of care. We are collaborating with researchers at the University of Melbourne on the Stepping Up trial, examining the effectiveness of a general practitioner and practice nurse led model of care (education and local practice system change) for timely initiation and up-titration of insulin, compared to usual care.³ Our focus is on how attitudes towards insulin may change over time (with or without intervention), the facilitators of, or barriers to, insulin therapy initiation within general practice, and the impact of insulin initiation on emotional well-being.

Project team

Elizabeth Holmes-Truscott and Prof Jane Speight

Acknowledgements

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MEETING THE NEEDS OF ADOLESCENTS WITH TYPE 1 DIABETES

Every year, 2,100 new cases of type 1 diabetes are diagnosed in Australia, half of which are in those under 15 years of age. The biological and physiological changes that accompany puberty have a direct impact on HbA1c (average blood glucose). Adolescence is typically a period of experimentation and risk-taking, erratic meal and physical activity patterns, and at this stage of life, young people will typically prioritise socialising and 'fitting in' rather than engaging with strict diabetes management regimens.

Our work in this area aims to better understand the needs, behaviours and psychological well-being of young people with diabetes, and their parents, to inform self-management services and support.

Among adults, the significance of diabetes-related distress is well-established. However, its relevance among adolescents is unclear. Therefore, we have undertaken the first systematic literature review to examine the prevalence and consequences of diabetes distress among adolescents with type 1 diabetes, and identify interventions targeting diabetes distress to determine common characteristics of successful interventions. The review will be submitted for publication in 2015.

Building on the successes of the Diabetes MILES Study, we have invited adolescents with diabetes and their parents across Australia to complete the Diabetes MILES Youth Study – the first large-scale survey in Australia investigating diabetes selfmanagement, healthcare access and psychosocial outcomes (e.g. social support, quality of life, general emotional well-being, and diabetes-related distress). This national online survey was completed in September 2014 by 781 adolescents with type 1 diabetes aged 10 to 19 years and 826 parents, recruited via the National Diabetes Services Scheme register. Analyses are underway, and the NDSS plans a public launch of the survey report in July 2015. Initial peer-reviewed publications will focus on diabetes-related distress, fear of hypoglycaemia and disordered eating.

Finally, our work in this area also includes the development and evaluation of TEAM T1 (Teens Empowered to Actively Manage Type 1 Diabetes) – a structured diabetes education program for adolescents with type 1 diabetes aged 14-18 years, with a parallel program for parents. TEAM T1 is adapted from the DAFNE (Dose Adjustment for Normal Eating) program for adults with type 1 diabetes. The ACBRD is leading the evaluation, which will assess the impact of the TEAM T1 program on a range of psychological, behavioural and clinical outcomes among adolescents and their parents. A qualitative sub-study is investigating the experiences of health professionals in delivering the program. The study will be completed by mid 2016.

Project team

Virginia Hagger, Dr Christel Hendrieckx, Dr Steve Trawley and Prof Jane Speight

Acknowledgements

We acknowledge Prof Tim Skinner (Charles Darwin University) and Prof Jackie Sturt (King's College London) for their contributions to the literature review. The Diabetes MILES *Youth* Study is funded by the National Diabetes Services Scheme, an initiative of the Australian Government administered by Diabetes Australia, via the National Development Program for Young People with Diabetes. We acknowledge the contributions of Prof Tim Skinner, Prof Fergus Cameron (Royal Children's Hospital, Melbourne) and our expert reference groups. TEAM T1 is funded by the Department of Health and Ageing (*Chronic Disease Service Improvement Fund*).

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Publications are in preparation.

MEETING THE NEEDS OF YOUNGER ADULTS WITH **TYPE 2 DIABETES**

Type 2 diabetes was once thought of as a condition of older age but the average age of onset has declined in recent years. Population-based studies in Australia and elsewhere in the world have found increasing numbers of younger adults with type 2 diabetes. Recent clinical research demonstrates that adults with early onset type 2 diabetes often have sub-optimal biomedical outcomes compared to older adults with type 2 diabetes, and age-matched adults with type 1 diabetes. However, less is known about the psychological and behavioural challenges faced by young adults with type 2 diabetes.

The ACBRD has conducted some of the first studies in the world about the mental health and behavioural management of diabetes among this emerging group. These studies have included:

1) a collaborative project with Diabetes Australia - Vic surveying the needs, concerns, and

characteristics of Victorian adults with early onset type 2 diabetes.¹ Results were used to inform and shape programs and services at Diabetes Australia -Vic.

2) A multi-national case-controlled study that assessed depression, anxiety and self-care amongst young adults with type 2 diabetes using two matched case control groups (a sample of older adults with type 2 diabetes, and a sample of young adults with type 1 diabetes).² Using data from the international Diabetes MILES study (combining samples from Australia and The Netherlands), we found that young adults with type 2 diabetes have more symptoms of depression than their older counterparts, are more likely to deviate from their recommended insulin therapy regimen than other groups, and are less likely to eat a healthy diet and engage in physical activity than older adults with type 2 diabetes and young adults with type 1 diabetes, respectively. These findings highlight the fact that young adults with type 2 diabetes are a unique group, and may require tailored, specialised diabetes healthcare and support services.

Project team

Dr Jessica Browne and Prof Jane Speight

Acknowledgements

The Diabetes MILES-Australia 2011 survey was funded by a National Diabetes Services Scheme (NDSS) Strategic Development Grant. The NDSS is an initiative of the Australian Government administered by Diabetes Australia. In addition, the Diabetes MILES-Australia study received an unrestricted educational grant from Sanofi to support the development of the study website (www.diabetesMILES.org) and miscellaneous activities. The Diabetes MILES-The Netherlands study was supported by the Prof Dr J Terpstra Young Investigator Award 2010 from the Dutch Association for Diabetes Research (Nederlandse Vereniging voor Diabetes Onderzoek)/Lilly Diabetes awarded to Dr Giesje Nefs.

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ACADEMIC COLLABORATIONS

We have strong collaborations with numerous researchers across Australia and around the world. We acknowledge the support and collegiality of the following academics and their research teams.

Australian Catholic University, Sydney -A/Prof Kylie Mosely

Baker IDI Heart and Diabetes Institute, Melbourne - A/Prof Neale Cohen, A/Prof John Dixon, A/Prof Jonathan Shaw, Prof Paul Zimmet

Centre for Eye Research Australia, Melbourne – Prof Ecosse Lamoureux, Dr Gwyn Rees

Charles Darwin University, Darwin -Prof Tim Skinner

Deakin University, Melbourne -

A/Prof David Austin, Prof Rob Carter, Prof Trisha Dunning, A/Prof Bodil Rasmussen

Eastern Health, Melbourne – Prof Chris Gilfillan

King's College London. UK – Prof Stephanie Amiel. Prof Jackie Sturt, Dr Pratik Chaudhury

Monash University, Victoria – Prof Helena Teede, Dr Katharine Kibbev

Newcastle University, UK – Prof James Shaw, Dr Stuart Little

St Vincent's Institute, Melbourne - Prof Tom Kay, Dr Anne Thorburn

Tilburg University, The Netherlands – Prof Frans Pouwer, Dr Giesje Nefs

University of Edinburgh, UK - Prof Brian Frier

University of Leicester, UK - Prof Melanie Davies, Prof Kamlesh Khunti

University of Manchester, UK - Dr Martin Rutter

University of Melbourne – Prof Peter Colman. Dr Jennifer Conn, A/Prof John Furler, Prof Brian Oldenburg, A/Prof David O'Neal

University of Sheffield, UK - Prof Simon Heller, Dr Jackie Elliott

University of Surrey, UK - Dr Debbie Cooke

University of Sydney - Prof Alicia Jenkins, Dr Linda Beeney, Dr Jane Holmes-Walker

University of Virginia, USA - Dr Harsimran Singh

Vrije Universiteit, The Netherlands -Prof Frank Snoek

ACADEMIC VISITORS

We acknowledge the following international academic visitors who have spent time with ACBRD researchers over the past five years, generously sharing their valuable insights and offering guest lectures:

- Prof Charles Abraham, University of Exeter (UK)
- Dr Molly Byrne, National University of Ireland Galway (Ireland)
- Prof Lawrence Fisher, University of California (USA)
- Ms Martha Funnell, Michigan Diabetes Centre (USA)
- Prof Julia Lawton, University of Edinburgh (UK)
- Prof Colin Martin, Bucks New University (UK)
- Dr Giesje Nefs, Tilburg University (The Netherlands)
- Prof Frans Pouwer, Tilburg University (The Netherlands)
- Ms Rosemary Walker, Successful Diabetes (UK)

CENTRE

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3 A NATIONAL VOICE

An important aspect of the Centre's work is to act as a national voice for the behavioural, psychological and social aspects of living with diabetes.

ity Adherence Diabetic Ty Monitoring Correction Care Correction Care Construction Care Construction Co

TRAINING HEALTH PROFESSIONALS

Sufferer

Responsibility Non-Compliance

Self-management

In 2011, Prof Jane Speight led a position statement

implications of the language used in communications with and about people with diabetes. It recognises

that careless, negative language can be harmful to

the well-being, motivation, self-care and, ultimately,

the health of people with diabetes. The aim of the

statement was to raise awareness of the impact

of language, and support conscious efforts to use

more effective and positive language. This work has

captured global interest and continues to be a hot

numerous tweets and blogs by people with

peer-reviewed articles focused on language

We acknowledge Prof Trisha Dunning (Deakin

University), Dr Jennifer Conn (University of

• an invited workshop at Diabetes UK on the use

Melbourne) and Prof Tim Skinner (Charles Darwin University) for their valuable contributions to this position statement, a copy of which can be found at:

diabetes, researchers and clinicians

of language in written research

on behalf of Diabetes Australia highlighting the

Illness

Normal heat

Patient

FOR DIABETES

topic. It has spawned:

http://bit.ly/1vDGefJ.

A NEW LANGUAGE

In February 2014, the National Diabetes Services Scheme and Australian Diabetes Society launched 'Enhancing your consulting skills - supporting self-management and optimising mental health in people with type 1 diabetes'. Led by Dr Jennifer Conn (University of Melbourne), with considerable input from the ACBRD's clinical psychologist Dr Christel Hendrieckx, this NDSS/ADS educational resource was developed specifically for endocrinology trainees.

Dr Hendrieckx contributes to the annual ADS Practical Skills Course for first year advanced trainees in endocrinology and advanced trainees in general medicine. Prof Speight contributes to Deakin University's professional doctorate program for health / clinical psychology.



NAL VOICE | L 5 YEARS (

FRIDAY, NOVEMBER 21, 2014

BY ALISON

The Washington Pos

CONSULTING ON NATIONAL **DEVELOPMENTS IN POLICY** AND PRACTICE

Over the past five years, we have responded to several consultations invited by professional bodies and Government relating to guideline and policy development. These include:

- ADS Position statement: A new blood glucose management algorithm for type 2 diabetes (2014)
- ADS and APEG: National Evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults. Australian Government Department of Health and Ageing, Canberra, (2011)
- beyondblue and Diabetes Australia: Diabetes, anxiety and depression leaflet (2014)

REVIE

ВRО

18

/OICE

- PBAC Review of Products and Medicines used in the Treatment of Diabetes - Phase 1: Review of self-monitoring of blood glucose for people with type 2 diabetes not using insulin (2013)
- PBAC Review of Products and Medicines used in the Treatment of Diabetes - Phase 2: Review of the clinical benefits of insulin pump therapy for type 1 diabetes (2013)
- PBAC Review of Products and Medicines used in the Treatment of Diabetes – Phase 3: Medicines used in the treatment of type 2 diabetes (2013)
- RACGP Guidelines for type 2 diabetes (2013)

Through its close affiliation to Diabetes Australia and its state and territory member organisations, the Centre is in a unique position to work with those organisations to inform their work and advocate on behalf of people with diabetes. Prof Speight has had the privilege of speaking at three Diabetes Australia National Policy Forums (Parliament House, Canberra) to advocate for psychological well-being and structured diabetes self-management education (2011), prevention of complications (2012), and technologies for type 1 diabetes (2014).

The Centre also provides expert advice to industry. Prof Speight has been a member of the Roche Diagnostics Australia Accu-Chek Advisory Board since 2011. Prof Speight and Dr Browne consult to Sanofi on several projects.

NATIONAL AND INTERNATIONAL SYMPOSIA



Since 2011, the ACBRD has convened national symposia to highlight the important role of behavioural and psychological factors in living with diabetes. We acknowledge the collaboration of the Australasian Society for Psychosocial Research in Diabetes (ASPRID) on these events.

In November 2013, we convened our symposium as an official Satellite of the IDF World Diabetes Congress, and over 70 national and international delegates attended. Themes of this 1.5 day symposium included 'imporiving emotional wellbeing', 'attending to the needs of special groups', 'preventing the most feared complications', and 'sustainable solutions to manage the type 2 diabetes epidemic'. We thank our national and international guest speakers.*

In 2011 and 2014, we convened symposia within the ADEA conference ('talking the talk: how to engage people with diabetes' and 'diabetes distress and depression'), each of which was attended by around 200 delegates.

* Prof Lawrence Fisher (University of California), Prof Richard Holt (University of Southampton), Prof David Kavanagh (Queensland University of Technology), Prof Brian Oldenburg (University of Melbourne), Prof Frans Pouwer (Tilburg University), Dr Gwyn Rees (CERA), Prof Laurie Ruggiero (University of Illinois), Prof Tim Skinner (Charles Darwin University), Prof Helen Skouteris (Deakin University), most of whom are pictured above.

Facing not only diabetes, but stigma, too

Those with Type 2 say they often receive judgment and blame from people who aren't educated about the condition



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IN THE MEDIA

Informed media coverage promotes greater awareness of the behavioural and psychological aspects of living with diabetes. It also highlights the Centre's research achievements. In the past five years, the Centre's research has featured regularly in the health professional and general media. Here is a snapshot of our media stories.

DIABETES: A SPECIAL REPORT



feel judged or blamed for having

This attitud

AA3

21 November 2014 The Washington Post

"Mind your language in diabetes discussions.

1 November 2011

observer

"Australian study shows negativity towards insulin."

update

9 March 2015 Endocrinology

"Professor puts focus on psychological well-being."

2 September 2014

DiabetesEducators

4 A NATIONAL RESOURCE

The Centre has embraced the power of social media and online platforms, through which to communicate with various communities, and disseminate.

WEBSITE

We have invested in our website as part of our commitment to being open and accessible to both practitioners and people with diabetes. Our website provides:

- information about ACBRD's purpose and current research projects
- resources, such as publications relating to key topics in behavioural diabetes, forthcoming events, answers to FAQs
- access to ACBRD reports and peer-reviewed publications (a significant portion of which are open-access), presentations and media reports
- a platform for participant recruitment, enabling visitors to make a direct contribution to the Centre's research activities
- access for interested parties to sign up to receive our free monthly e-newsletter
- a platform for visitors to find out how they can support the Centre

SOCIAL MEDIA



Increasingly over the past five years, we have used social media to raise awareness of our Centre and its activities, and to inform and promote behavioural diabetes issues more generally. The @ACBRD Twitter account now has nearly 500 followers, while many of the ACBRD staff and students also actively engage the community via their own accounts. We have created a dynamic online environment with which people with diabetes, researchers, health professionals, and policy makers engage and interact.

E-NEWSLETTER

The first issue of 'Research Round-Up' was distributed in May 2012 and we recently published our 33rd issue. We now circulate it to more than 900 subscribers.

EXHIBITING AT THE NATIONAL CONFERENCE



We have had an exhibition stand at the annual ADS/ ADEA conference since 2011, on which we display copies of the ACBRD brochure, publications, reports and other resources, e.g. the Diabetes Australia position statement 'A New Language for Diabetes'. The stand provides an important annual opportunity to promote the behavioural and psychosocial aspects of diabetes, and for health professionals, researchers and industry to interact with the ACBRD team.

5 PUBLICATIONS AND PRESENTATIONS

The Centre has published more than 60 peerreviewed publications and given more than 50 invited lectures in the past five years.

PEER-REVIEWED JOURNAL ARTICLES

In press

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Community publications

We have contributed to numerous community magazines for people with diabetes including *Connect, Conquest, Diabetes Matters, Diabetes Today.*

INVITED LECTURES

Our senior team have been invited speakers at the following meetings:

National and international

conferences

- Australian Diabetes In Pregnancy Society (ADIPS)
- Australian Diabetes Educators Association (ADEA)
- Australian Diabetes Society (ADS)
- Australian Disease Management Association (ADMA)
- Australian Practice Nurse Association (APNA)
- Council of Academic Public Health Institutions
 of Australia (CAPHIA)
- Diabetes UK
- Dietitian's Association of Australia (DAA)
- International Diabetes Federation Western Pacific Region (IDF-WPR)
- International Diabetes Federation World Diabetes Congress (IDF-WDC)
- New Zealand Society for the Study of Diabetes (NZSSD)
- Roche Accu-Chek 8th International Network meeting (Malta)
- Roche Educator Day (satellite to ADS/ADEA)

Local and state-based meetings

- Abbott Australia Sales Team meeting
- Albury Wodonga Annual Health Professional Seminar
- Austin Health
- Australian Islet Transplant Consortium
- Ballarat Health
- Baker IDI Heart and Diabetes Institute
- Cancer Council Victoria
- Centre for Rural and Remote Health, NSW
- Chronic Illness Alliance
- Diabetes Australia Vic / Baker IDI: Annual Health Professional Symposium
- Diabetes Care Project Forum, Gold Coast
- Diabetes and Mental Health Professionals
 Network: Melbourne
- Diabetes and Mental Health Professionals Network: Tasmania

- Education in Nutrition
- ISEAL, Victoria University
- Jean Hailes Foundation, Monash Medical Centre
- New South Wales Paediatric Outreach meeting
- OzDAFNE Professional Development Day
- Sanofi Diabetes Educator State Workshop (NSW)
- Southern GP Training, Victoria
- St John of God Hospital, Warrnambool
- Victorian Association of Cardiac Rehabilitation
- Western Metro Diabetes Educators
 Networking Meeting
- Westmead Hospital / University of Sydney

Community Seminars

We present at numerous events for people with diabetes and their families (usually at least 6 events per year):

- Albury Wodonga Support Group
- 'ConnecT-1n': Diabetes Australia Vic weekend retreats for young adults with type 1 diabetes
- Generation T2; Diabetes Australia Vic program for young adults with type 2 diabetes
- 'Living Well with Diabetes': Diabetes Australia Vic half-day seminars for adults with diabetes and their families
- 'Research Revealed': Diabetes Australia Vic / JDRF whole day seminars for people with type 1 diabetes interested in latest research findings
- 'Type 1 in the City': Diabetes Australia Vic lectures for people with type 1 diabetes living in Melbourne
- 'Type 1 out of Town': Diabetes Australia Vic lectures for people with type 1 diabetes living in regional areas
- Women's weekend: Diabetes-Australia Vic weekends for women with type 1 diabetes

CONFERENCE PRESENTATIONS

We have presented over 70 peer-reviewed abstracts (orals and posters) at the following national and international conferences:

- American Diabetes Association (ADA)
- Artificial Insulin Delivery Pancreatic and Islet Transplantation (AIDPIT) Study Group of the EASD
- Australian Diabetes Educators Association (ADEA)
- Australian Diabetes Society (ADS)
- Australia and New Zealand Obesity Society (ANZOS)
- Australian Psychological Society (APS)
- Australasian Society for Behavioural Health and Medicine (ASBHM)
- Australian Society for Psychosocial Obstetrics and Gynaecology (ASPOG)
- Diabetes UK
- European Association for the Study of Diabetes (EASD)
- European Health Psychology Society (EHPS)
- International Diabetes Federation: World Diabetes Congress (WDC)
- Obesity Surgery Society of Australia & New Zealand (OSSANZ)
- Primary Health Care Research Conference
- PsychoSocial Aspects of Diabetes (PSAD) Study Group of the EASD

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- Diabetes Australia Research Program
- Diabetes Australia Vic
- Deakin University's Centre for Mental Health and Well-being Research (CMHWR)
- Juvenile Diabetes Research Foundation (JDRF) International
- Medtronic
- National Diabetes Services Scheme (NDSS)
- National Health and Medical Research Council (NHMRC)
- Novo Nordisk Regional Diabetes Support Scheme
- Royal Australian College of General Practitioners (RACGP)
- Roche Diagnostics Australia
- Sanofi
- Vision 2020 Australia

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For sponsoring our symposia

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YOUR SUPPORT MAKES RESEARCH POSSIBLE!

The achievements of the last five years are made possible through the generous support of countless donors. You have enabled us to reach this wonderful milestone.

With your help we can do so much more. Your support will help us to continue to investigate the behavioural, psychological and social aspects of diabetes; to find ways to improve the lives of all people with diabetes and their families. There are many ways to support us.

Adopt a project

We know that our research means a lot to those affected by diabetes. 'Adopt a project' is designed to enable people to become involved in funding the projects they are most passionate about. Visit our website (www.acbrd.org.au/support-us) or call (03) 8648 1844 to find out more.

Donate money

Diabetes Australia – Vic is a charity, which relies on the generosity of its supporters to continue to fund research. There are many ways to donate. You can become a regular supporter, donate by mail, leave a gift in your will, invite donations in place of gifts for your special occasion, donate in memory of a loved one, or develop a workplace giving program. For more details, visit www.diabetesvic.org.au/get-involved/ways-to-donate.

Donations of \$2 or more are tax deductible in Australia.

Donate clothing

Your donations help fund research. Donate your old or outgrown clothes, unused toys, old and unwanted mobile phones, small household goods, unwanted presents and books to Diabetes Australia – Vic. Book a collection online 24 hours a day 7 days a week or call (03) 9923 8400.

Donate time

We often seek volunteers to take part in our research projects. Most opportunities involve being interviewed or completing a survey. Please call (03) 8648 1844 to find out more or visit www.acbrd.org.au to sign up for our free monthly e-newsletter in which we advertise research opportunities.

XCK

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