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Cohort profiles of the cross-sectional and prospective participant groups in the second Diabetes MILES—Australia (MILES-2) study

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ABSTRACT

Purpose: More research into the psychosocial aspects of diabetes is needed so that the health and quality of life of people with the condition can be improved. To fill this gap, we conducted the second Diabetes MILES—Australia study (MILES-2), a survey focused on psychological, behavioural and social aspects of diabetes. The aim of the MILES-2 study was to provide a (1) longitudinal follow-up of the original MILES 2011 study cohort; (2) cross-sectional assessment of a new cohort.

Participants: Eligible participants were English-speaking Australians with type 1 or type 2 diabetes, aged 18–75 years. Longitudinal cohort participants were mailed/emailed study invitations directly by researchers. Random sampling (stratified by diabetes type, insulin use, state) of the National Diabetes Services Scheme (NDSS) database and nationwide advertisements were used to recruit new cohort participants. The final sample included N=2342 eligible respondents (longitudinal cohort: n=504; 2015 new cohort: n=1838); 54% had type 2 diabetes.

Findings to date: Survey respondents were from an advantaged socioeconomic background compared to the general population. Respondents with type 1 diabetes were over-represented in the new cohort (45%) relative to the planned stratification (40% type 1 diabetes, 60% type 2 diabetes). Respondents with insulin-treated type 2 diabetes were under-represented in the new cohort relative to the stratified sampling (42% invited vs 50% response). Participants who completed both the 2011 and 2015 surveys were more likely than those completing the 2011 survey only to have type 1 diabetes, report a higher education and annual income, and live in metropolitan areas. Participant feedback indicated that the survey was perceived as relevant and valuable.

Future plans: The depth and breadth of the data available in this large sample will highlight unmet needs and priority areas for future investigation and, crucially, will inform policy, programme and intervention development and evaluation in Australia.

Strengths and limitations of this study

- Key strengths of MILES-2 are the breadth and depth of quantitative data and the large, population-based sample size, which provides sufficient power for various statistical analyses.
- The emerging longitudinal data set enables investigation of predictors and consequences of psychological distress and suboptimal self-management, for the first time, in a non-clinical, population-based sample.
- The response rates for both the longitudinal (26%) and the new cohorts (8%) in the MILES-2 survey were low.
- In the longitudinal cohort, substantial attrition was evident between the 2011 and 2015 surveys.
- Participants were from a relatively advantaged background, which may result in the under-estimation of social and emotional problems, and problems of healthcare access.

INTRODUCTION

Diabetes is one of the most challenging public health issues faced today. The number of people with diabetes has doubled globally in recent decades,[1] and it is predicted that by 2040, 642 million people will have diabetes.[2] Australia is no exception to the global trend, where diabetes is the fastest growing chronic condition, and type 2 diabetes expected to be the largest health burden by 2023.[3] While the majority of Australians with diabetes have type 2 diabetes, the prevalence of both type 1 and type 2 diabetes is increasing.[4]

There have been many developments in recent years to improve the management of diabetes: medications (eg, insulin analogues, GLP-1 agonists and sodium-glucose cotransporter 2 (SGLT2) inhibitors), technologies (eg, wearable glucose monitoring devices, 'artificial pancreas', smartphone apps to

support self-management), education (eg, structured group training programmes, online self-directed interventions) and healthcare access (eg, multidisciplinary single-site care, subsidies for devices and consumables). Despite this, many people with diabetes still experience the condition as burdensome and unrelenting.[5] Achieving recommended treatment targets remains a significant challenge for many people with diabetes. Data from the National Health and Nutrition Examination Surveys (NHANES) in the USA indicate that <20% of people with diabetes have in-target glycated haemoglobin, blood pressure and cholesterol,[6] and that this proportion of people meeting the recommended treatment goals has improved only slightly over time.[7] Australian data from 2013 to 2014 indicate that <50% of people with diabetes in primary care are meeting glycaemic targets, and only 20% are meeting all glycaemic and cardiovascular outcome targets.[8] In addition, severe hypoglycaemia remains all too common, with around 20% of adults with diabetes reporting severe hypoglycaemia in the past 3–6 months.[9–11] Systematic reviews demonstrate that psychological problems are prevalent,[12–16] including clinically significant depressive symptoms (reported by 8–29% of adults with diabetes; though concerns about over-diagnosis have been raised[17]),[12 13 18 19] anxiety (among 7–14%)[14 19 20] and diabetes distress (among 18–39%).[19 21 22]

Impaired psychological well-being is associated with poorer quality of life, as well as with less optimal self-care behaviours, hyperglycaemia, a higher risk of developing microvascular and macrovascular complications of diabetes, and higher mortality rates.[23–26] This suggests that more research into the behavioural and psychological aspects of diabetes is needed to generate further insights into how both health and quality of life outcomes can be improved. Indeed, there have recently been calls for the prioritisation of research that seeks to understand and address the psychological well-being of people with diabetes.[27 28]

In 2011, we conducted the Diabetes MILES (Management and Impact for Long-term Empowerment and Success)—Australia study.[29] The aim of this national survey of Australian adults living with type 1 or type 2 diabetes was to assess the psychosocial aspects of living with diabetes. The 2011 survey was funded primarily by the National Diabetes Services Scheme (NDSS), an initiative of the Australian Government administered with the assistance of Diabetes Australia. The NDSS provides subsidised products, information and support services for Australians with diabetes, and funds strategic initiatives that align with national priorities. Most Australians diagnosed with diabetes are registered with the scheme, and most participants from the first Diabetes MILES—Australia study were recruited from the NDSS registrant database.

Diabetes MILES—Australia represented a major achievement in the study of diabetes in Australia, as it was the first time that the psychological health,

behavioural diabetes management, social impacts and unmet needs of a large and diverse national sample were assessed, providing a baseline against which the results of future studies can be compared.

The findings of the 2011 Diabetes MILES—Australia study have been disseminated widely in journal articles, at national and international conferences, and at health professional training days and community seminars. Publications have addressed a diverse range of topics including psychological insulin resistance among adults with type 2 diabetes;[30–32] subjective well-being[33] and suicidal ideation[34] among adults with type 1 or type 2 diabetes; measurement of diabetes distress;[35] the relationships between healthcare access and self-management and self-efficacy,[36] economic hardship,[37] and rural/regional living;[38] and the challenges faced by specific groups such as young adults with type 2 diabetes[39] and severely obese adults with type 2 diabetes.[40–42] Collectively, the findings from the 2011 Diabetes MILES—Australia survey have provided crucial evidence to inform policy, practice and service delivery for adults with type 1 and type 2 diabetes in Australia. For example, the 2011 Diabetes MILES—Australia survey indicated that emotional distress is common among Australian adults with diabetes, and subjective well-being is lower in this group than in the general Australian population.[33–35 43] In response to this evidence, the NDSS initiated the Diabetes and Mental Health National Development Programme, which was led by JS with contributions from CH, JLB and ADV. This Programme constituted a multipronged approach to further understanding the psychological needs of adults with diabetes, and developing resources (eg, the Diabetes and Emotional Health Handbook,[44] and related leaflets for people with diabetes) to aid diabetes health professionals to integrate into routine care psychologically sensitive practices (eg, being alert to and identifying, assessing and addressing diabetes distress). Further, using the 2011 survey evidence about the impaired well-being of Australians with diabetes, CH and JS consulted the 2016–2018 revision of the Royal Australian College of General Practitioners Guidelines for General Practice Management of Type 2 Diabetes, which consequently includes a recommendation to screen adults with type 2 diabetes for diabetes distress and depressive symptoms annually. Another key finding from the 2011 survey was that negative insulin appraisals among adults with type 2 diabetes can persist beyond insulin initiation, and that these negative appraisals were associated with impaired emotional well-being.[31] This result highlighted the need for ongoing assessment of attitudes towards insulin, and holistic, continuing support for this group. In response, the research team is currently working with diabetes organisations (eg, Diabetes Victoria) to develop plans for further support, education and intervention for adults with type 2 diabetes using insulin.

The Diabetes MILES Study is now an international collaborative, with a similar survey having been conducted

in the Netherlands.[45] Diabetes MILES—Youth, a national survey of Australian adolescents with diabetes (aged 12–18 years) and their parents, was conducted in 2014.[46]

While the 2011 Diabetes MILES—Australia study provided a valuable 'snapshot', this cross-sectional survey does not allow assessment of change over time, or associations between exposure to a new condition (eg, initiation of insulin therapy) and key outcomes (eg, emotional well-being and treatment self-efficacy). Diabetes treatments, programmes and services are continually developing and advancing,[47] and ongoing survey research at a national level will enable us to track psychosocial well-being and self-management behaviour in parallel with these changes. Further, as psychosocial research in diabetes gains traction and the field expands, new avenues of investigation have been identified and novel topics of interest have emerged. Examples include stigmatisation of, and discrimination against, people with diabetes,[5 48 49] memory and cognition,[50] and self-compassion.[51] Until now, there is little to no population-based data on these important topics in relation to diabetes.

To fill these gaps, we conducted the second Diabetes MILES—Australia (MILES-2) study. In this paper, we detail the methods and cohort profiles of the MILES-2 survey participants. This study had two elements, each with different aims:

1. Longitudinal cohort: a follow-up survey of the 2011 Diabetes MILES—Australia participants to allow assessment of change over time in, and prospective investigation of, key psychological and behavioural outcomes. The longitudinal data will enable exploration of key topics, such as:
   A. Potential impact of changes in treatment (eg, initiation of insulin therapy) and/or self-care regimen (eg, changes in glucose monitoring behaviours) on diabetes-specific distress;
   B. The psychological (eg, illness beliefs, anxiety, depression) and behavioural (eg, healthcare visits, diabetes self-care) antecedents of diabetes complications (eg, diabetic retinopathy);
   C. Prospective predictors of the development of psychological problems (eg, depressive or anxiety symptoms) or diabetes complications.
2. 2015 new cohort: a cross-sectional survey of a new national sample of adults with type 1 or type 2 diabetes to introduce novel, emerging topics of investigation. These new cross-sectional data will enable exploration of novel topics, such as:
   A. Perceived and experienced diabetes stigma and weight stigma, and their associations with key psychological problems (eg, depressive symptoms) and behavioural issues (eg, medication-taking and blood glucose monitoring);
   B. The relationship between prospective memory (ie, remembering to perform a planned action) and diabetes self-care behaviours;
   C. The relationship between self-compassion and the experienced emotional burden of diabetes (eg, diabetes-specific distress).

The reasons for the 4-year intervening period between the first and second MILES surveys were both academic and pragmatic. First, an a priori decision was taken in 2011 to follow-up the initial cohort of participants within 5 years (pending funding, which became available in early 2015); and 2011 participants who agreed to join the longitudinal cohort consented expressly to being contacted within this time frame. Second, as alluded to above, new priority research areas had emerged in the intervening time, and any further lag in collecting new data would have unnecessarily delayed the advancement of knowledge on important topics. Finally, many of the core measures administered to participants in the 2011 and 2015 surveys assess individual-level variables (eg, depressive symptoms) that can reasonably be expected to change in a period of 4 years.

COHORT DESCRIPTIONS
Study design and setting
The MILES-2 survey (both for the longitudinal cohort and the 2015 new cohort) was conducted primarily online, although a hard copy version was made available for those who requested it (eg, due to not having access to, or not knowing how to use, the internet). The study was conducted and is reported according to the Checklist for Reporting Results of Internet E-Survey (CHERRIES, see online supplementary appendix 1).[52]

The survey content and procedure used for the longitudinal and new cohorts were near identical. The methods described below refer to both cohorts unless specified otherwise.

Participant eligibility and recruitment
Eligible participants were adults (aged 18–75 years) living in Australia who had type 1 or type 2 diabetes, and were proficient in English for the purposes of reading and completing the survey (as it was available in English only). People with other types of diabetes (eg, gestational, Mature Onset Diabetes of the Young (MODY), Latent Autoimmune Diabetes in Adults (LADA)) were not eligible to take part because the survey content was not tailored to address issues specific to these special groups. Similarly, people under the age of 18 and over the age of 75 years were not eligible for participation because the survey content and format were likely to be inappropriate for these groups; and, in the case of those under 18 years, so as not to duplicate the efforts of the recent Diabetes MILES Youth survey.[46]

Longitudinal cohort recruitment
Of the 3833 respondents to the 2011 Diabetes MILES—Australia survey, 2153 (56%) consented to being invited to take part in future longitudinal cohort studies and

provided complete email or postal addresses to facilitate contact. Invitations were sent by email where possible (n=1643), with postal invitations sent initially to only 510 participants who did not provide an email address. An additional 338 invitations were sent by post after email bounce-backs were received. Overall, 88 participants were not contactable by email or post (invitation returned to sender). Thus, 2065 participants of the 2011 survey received an invitation to take part in the MILES-2 survey; a single reminder email/letter was sent 3 weeks later.

2015 New cohort recruitment

As in the 2011 survey, the NDSS registrant database was used to contact potential participants. Of the 1.2 million NDSS registrants,[53] ~47% have indicated consent to be contacted about research participation opportunities. Of these, a stratified random sample of 20 000 registrants were sent a postal invitation directly by the NDSS (ie, researchers did not have access to the database), which directed them to the online survey website and provided researcher contact details. The sample was stratified according to population in each Australian state, and as follows:

▶ Eight thousand with type 1 diabetes (40% of the total sample)
▶ Twelve thousand with type 2 diabetes (60% of the total sample), 6000 of whom registered as using insulin (50% of the type 2 diabetes sample)

Adults with type 1 diabetes and with type 2 diabetes using insulin were purposefully over-sampled to ensure adequate representation of these subsamples. The sample was not stratified by gender.

To ensure that the sample was indeed a new cohort of participants, registrants who were randomly sampled during recruitment for the 2011 Diabetes MILES—Australia survey were excluded from the 2015 sampling. Finally, the study was also advertised nationwide in diabetes-related media (eg, magazines, e-newsletters, social media).

Data collection and handling procedure

Potential participants were directed to the study website[54] which presented a plain language description of the study and an online consent form. Those who provided informed consent were directed through to the eligibility screening. Ineligible participants were screened out automatically and presented with a message thanking them for their interest and advising them that they were not eligible to take part. Eligible participants were directed through to the survey proper. At the end of the survey, all respondents were invited to provide their email address to facilitate one or more of the following: (1) entry into a prize draw (chance to win one of three iPad minis), (2) to receive a free electronic copy of the study report, (3) to receive notifications about future research opportunities, (4) to withdraw data at a later date. Provision of an email address was voluntary, and participants could select to which of the four options they consented.

The MILES-2 survey was hosted by Qualtrics, a secure online survey platform. The survey was open for participation for 7 weeks (23 March—11 May 2015). As participants progressed through the survey, their data were saved automatically by Qualtrics.

All online survey responses (complete and incomplete) were logged by the Qualtrics survey platform and downloaded at survey close into data files for analysis in Statistical Package for the Social Sciences (SPSS) (IBM SPSS Statistics for Windows, V.22.0. Armonk, New York, USA: IBM Corp). Hard copy survey responses were entered manually into the SPSS data file by one researcher, and checked for accuracy by a second researcher. Contact details were extracted from the main data file and stored separately in a password-protected folder. Longitudinal cohort participants' 2015 data were matched with their existing 2011 data using the unique log-in code provided, and by validating the match against diabetes type, age and gender.

A total of 2651 survey responses were recorded by Qualtrics. However, 148 duplicate cases were identified in the data file (using a combination of IP address and demographic/clinical data such as age, gender, postcode and diabetes type) and deleted. The main reasons for duplicate cases were:

A. Participants who were screened out at the eligibility assessment phase restarted the survey to answer the screening questions in a different way (eg, changing diabetes type response from 'MODY' to 'type 2 diabetes'), allowing them to unlock the full survey. In these instances, their second attempt was deleted and their data were not included in any analysis due to ineligibility.

B. Participants who lost their internet connection or their responses failed to save, and they restarted the survey in order to complete it. In these instances, the most complete entry was retained and the other deleted. If there was no difference in the amount of data available in each case, the first entry was retained.

Response rate

A total of 2503 unique consenting responses (27 hard copy completions) to the MILES-2 survey were identified, including 2015 new cohort (n=1970) and longitudinal cohort (n=533) respondents. The response rates for these separate subsamples are discussed separately below.

The 2015 new cohort participants who passed the eligibility screening (n=1829, 93%) had the opportunity to indicate how they heard about the survey. Seventy-nine per cent (n=1453) of this subsample indicated that they received a letter from the NDSS inviting them to take part, indicating a response rate of 7% of the 20 000 NDSS registrants who received an invitation. Extrapolating this rate to also include those screened out due to ineligibility, the estimated total response rate to the NDSS mail-out is 8%.

Of the 2065 participants of the original 2011 survey, who indicated willingness to be contacted about similar studies in the future, 533 (26%) participated, and are referred to hereafter as the longitudinal cohort. Reasons for non-participation are not known.

Final eligible samples and their characteristics

Of the 2503 unique respondents, 161 were screened out due to ineligibility. The final cross-sectional sample included N=2342 eligible participants, comprising n=1838 2015 new cohort participants and n=504 longitudinal cohort participants. Full sample characteristics are presented in table 1.

In the final sample, 46% had type 1 diabetes and 54% had type 2 diabetes. Overall, men and women were represented equally (50% vs 50%). Unsurprisingly, participants with type 2 diabetes were substantially older than participants with type 1 diabetes (mean difference: 17 years), but reported shorter diabetes duration (mean difference: 8 years). Among those with type 1 diabetes, 35% were managing their diabetes with an insulin pump. Among those with type 2 diabetes, 42% were using insulin. Most respondents spoke English as their main language (97%), were married or in a de facto relationship (68%), had vocational or university qualifications (66%), lived in metropolitan areas (61%), were in paid employment (54%) and had an annual household income of more than $A40 000 per annum (54%).

Tight CIs of 2.02 were evident (calculated using a worst-case scenario proportion of 50%, a 95% confidence level and sample size of 2342), providing evidence of sample adequacy.

Table 2 compares the sample characteristics of the longitudinal and 2015 new cohorts. With few exceptions, the longitudinal and new cohorts were equivalent on key sociodemographic and clinical characteristics, indicating that the cohorts may be pooled for future analyses. On average, participants with type 1 diabetes in the longitudinal cohort were older and had a longer diabetes duration than those in the new cohort, but while the difference was significant, it was not notable (<5-year mean difference in both instances). Respondents with type 1 diabetes in the longitudinal cohort were more likely to be using an insulin pump than those in the new cohort. Regardless of diabetes type, compared with respondents in the new cohort, those in the longitudinal cohort were more likely to have a university education, less likely to have no qualifications, and more likely to reside in the state of Victoria.

Depth and breadth of available data

Consistent with the aims of the Diabetes MILES Study initiative, the data available primarily relate to the psychological (eg, emotional well-being), behavioural (eg, self-management) and social (eg, diabetes stigma) aspects of living with diabetes. These data make possible the assessment of prevalence, relationships between key variables and (in the longitudinal cohort), change over

time and associations between exposure to a new condition and key outcomes.

The survey included validated scales, study-specific individual items and newly developed measures (for validation). For 'core' constructs (eg, general and diabetes-specific emotional well-being), the measures used in 2011 were included in the 2015 survey. This was important in order to generate a longitudinal data set for assessing within-group change over time, as well as to enable comparison on key issues of the full 2011 and 2015 study samples as representative 'snapshots' of the Australian population of adults with diabetes.

While the 2011 and 2015 surveys had similar content, they were not identical. Some measures (eg, Resources and Support for diabetes Self-Management questionnaire) were not repeated in 2015 because ongoing data collection on the topic was not considered a key priority. Some measures were replaced with another measure of the same construct (eg, the Diabetes Self-Care Inventory—Revised was replaced with the Summary of Diabetes Self-Care Activities[55]). Some measures were replaced with a shorter version to reduce respondent burden (eg, the Quality of Life Questionnaire was replaced with the DAWN Impact of Diabetes Profile[5]). Finally, some measures were replaced with measures tailored to diabetes type and/or treatment (eg, the Diabetes Empowerment Scale Short-Form[56] was replaced with the Confidence in Diabetes Self-care scale, with insulin-using[57] and non-insulin using[58] versions.

In the original (2011) Diabetes MILES study, two alternate survey versions (A and B) were used. To ensure that all longitudinal cohort participants had complete data sets for key variables (eg, diabetes-specific distress), their 2015 survey content was tailored automatically (based on the unique code they entered) to match the survey version they completed in 2011. However, this automatic tailoring was not possible for those completing the hard copy surveys (n=27) and thus they were treated as new cohort participants.

Survey content was grouped by theme into eight sections: (1) Demographics, (2) My general well-being, (3) My feelings about diabetes, (4) My general health, (5) Support from health professionals, family and friends, (6) My diabetes, (7) My blood glucose levels, (8) My thoughts and beliefs. It was also tailored to diabetes type and treatment (based on information provided in the Demographics section of the survey) and, as such, not all measures were presented to every participant. Table 3 summarises the topics/constructs, variables and measures used in the 2015 MILES-2 survey (for both the new and longitudinal cohorts separately) and also indicates which of the same content was included in the 2011 survey.

FINDINGS TO DATE
Sample stratification

The success of the stratified sampling approach was assessed by comparing the subsample of new cohort

Table 1 Sample characteristics for the 2015 Diabetes MILES—Australia survey, by diabetes type*

	Type 1 diabetes n=1078 (46)	Type 2 diabetes n=1264 (54)	Total sample N=2342 (100)
Gender—female	639 (59)	539 (43)	1178 (50)
Age—years	44±15 (18–75)	61±9 (22–75)	53±15 (18–75)
Diabetes duration—years	19±14 (0–68)	11±7 (0–44)	15±12 (0–68)
Primary diabetes management			
Insulin pump therapy	380 (35)	2 (0.2)	382 (16)
Insulin injections	698 (65)	529 (42)	1227 (52)
Non-insulin injectables	–	47 (4)	47 (2)
Blood glucose-lowering tablets	–	510 (40)	510 (22)
Diet and/or exercise alone	–	176 (14)	176 (8)
Aboriginal or Torres Strait Islander	14 (1)	22 (2)	36 (2)
Main language spoken at home—English	1054 (98)	1214 (96)	2268 (97)
Country of birth—Australia	831 (77)	889 (70)	1720 (73)
Relationship status			
Single	241 (22)	111 (9)	352 (15)
In a steady relationship	52 (5)	21 (2)	73 (3)
Married or De Facto	706 (66)	891 (71)	1597 (68)
Separated	18 (2)	36 (3)	54 (2)
Divorced	48 (4)	130 (10)	178 (8)
Widowed	8 (1)	71 (6)	79 (3)
Education			
No qualifications	30 (3)	125 (10)	155 (7)
School/intermediate certificate	105 (10)	205 (16)	310 (13)
High school/leaving certificate	181 (17)	140 (11)	321 (14)
Trade training or diploma(s)	252 (23)	382 (30)	634 (27)
University undergraduate degree	269 (25)	223 (18)	492 (21)
Higher university degree	236 (22)	185 (15)	421 (18)
(Un)Employment details			
Paid employment	770 (72)	477 (38)	1247 (54)
Retired	146 (14)	579 (46)	725 (31)
Full-time student	26 (2)	8 (1)	34 (2)
Unpaid household duties	40 (4)	49 (4)	69 (3)
Unemployed	86 (8)	146 (12)	232 (10)
Other	8 (1)	4 (0.3)	12 (1)
Annual household income ($A)			
≤20 000	130 (12)	225 (18)	355 (15)
20 001–40 000	123 (12)	281 (23)	404 (17)
40 001–60 000	135 (13)	199 (16)	334 (14)
60 001–100 000	240 (23)	175 (14)	415 (18)
100 001–150 000	158 (15)	113 (9)	271 (12)
>150 000	123 (12)	75 (6)	198 (9)
Do not know/prefer not to say	155 (15)	177 (14)	332 (14)
State			
Australian Capital Territory	54 (5)	132 (10)	186 (8)
New South Wales	345 (32)	258 (20)	603 (26)
Northern Territory	9 (0.8)	41 (3)	50 (2)
Queensland	140 (13)	143 (11)	283 (12)
South Australia	86 (8)	120 (10)	206 (9)
Tasmania	50 (5)	120 (10)	170 (7)
Victoria	281 (26)	297 (24)	578 (25)
Western Australia	113 (10)	151 (12)	264 (11)
Geographical location			
Metropolitan	483 (63)	750 (60)	1433 (61)
Regional	272 (25)	303 (24)	575 (25)
Rural	122 (11)	206 (16)	328 (14)

Data are n (%) or mean±SD (range).
*Total N reported is not always consistent with total sample size due to missing data for some variables. Percentages do not always sum to 100 due to rounding.

Table 2 Sample characteristics by cohort*

	Longitudinal Cohort	2015 new Cohort	Significance
Total eligible sample	504 (22)†	1838 (79)	
Gender—female	261 (52)	917 (50)	NS
Diabetes type			NS
Type 1 diabetes	236 (47)	842 (46)	
Type 2 diabetes	268 (53)	996 (54)	
Age—years			
Type 1 diabetes	47±14	43±16	<0.001
Type 2 diabetes	62±8	61±10	NS
Diabetes duration—years			
Type 1 diabetes	22±14	18±14	<0.001
Type 2 diabetes	12±7	11±8	NS
Primary treatment for type 1 diabetes			<0.001
Insulin pump therapy	106 (45)	274 (33)	
Insulin injections	130 (55)	568 (67)	
Primary treatment for type 2 diabetes			NS
Insulin pump therapy	0 (0)	2 (0.2)	
Insulin injections	95 (35)	434 (44)	
Non-insulin injectables	11 (4)	36 (4)	
Blood glucose-lowering tablets	119 (44)	391 (39)	
Diet and/or exercise alone	43 (16)	133 (13)	
Aboriginal or Torres Strait Islander origin	5 (1)	31 (2)	NS
Main language spoken at home—English	494 (98)	1774 (97)	NS
Country of birth—Australia	387 (77)	1333 (73)	NS
Relationship status			NS
Single	64 (13)	288 (16)	
In a steady relationship	12 (2)	61 (3)	
Married or De Facto	356 (71)	1241 (68)	
Separated	12 (2)	42 (2)	
Divorced	44 (9)	134 (7)	
Widowed	15 (3)	64 (3)	
Education			<0.001
No qualifications	15 (3)	140 (8)	
School/intermediate certificate	68 (14)	242 (13)	
High school/leaving certificate	58 (12)	263 (14)	
Trade training or diploma(s)	132 (26)	502 (28)	
University undergraduate degree	123 (25)	369 (20)	
Higher university degree	106 (21)	315 (17)	
(Un)Employment details			NS
Paid employment	280 (56)	967 (53)	
Retired	155 (31)	570 (31)	
Full-time student	6 (1)	28 (2)	
Unpaid household duties	26 (5)	63 (3)	
Unemployed	35 (7)	197 (11)	
Other	2 (0.4)	10 (1)	
Annual household income ($A)			NS
≤20 000	67 (13)	288 (16)	
20 001–40 000	79 (16)	325 (18)	
40 001–60 000	80 (16)	254 (14)	
60 001–100 000	94 (19)	321 (18)	
100 001–150 000	61 (12)	210 (12)	
>150 000	57 (11)	141 (8)	
Do not know/prefer not to say	65 (13)	267 (15)	
State			<0.001
Australian Capital Territory	17 (3)	169 (9)	
New South Wales	105 (21)	498 (27)	
Northern Territory	1 (0.2)	49 (3)	
Queensland	81 (16)	202 (11)	
South Australia	25 (5)	181 (10)	

Table 2 Continued

	Longitudinal Cohort	2015 new Cohort	Significance
Tasmania	12 (2)	158 (9)	
Victoria	215 (43)	363 (20)	
Western Australia	47 (9)	217 (12)	
Geographical location			NS
Metropolitan	312 (63)	1121 (61)	
Regional	127 (25)	448 (24)	
Rural	63 (13)	265 (14)	

Data are n (%) or mean±SD (range).
*Table refers only to eligible participants. Total N reported is not always consistent with total sample size due to missing data on some items. Percentages do not always sum to 100 due to rounding.
†Of the 504 longitudinal cohort participants, 459 could be matched with 2011 data.
NS, not significant.

respondents who indicated that they received an invitation direct from the NDSS against the planned stratification (described in Methods). Respondents with type 1 diabetes were slightly over-represented in the new cohort (45%) relative to the planned stratification (40% type 1 diabetes, 60% type 2 diabetes). Relative to the planned stratification for state (designed to reflect the proportion of NDSS registrants per state), there was evidence of over-sampling of participants in the Australian Capital Territory (3% invited vs 11% response), New South Wales (21% vs 26%), the Northern Territory (1% vs 3%) and Tasmania (3% vs 10%). Under-sampling of participants was evident in Queensland (19% invited vs 12% response), South Australia (16% vs 11%), Victoria (20% vs 15%) and Western Australia (17% vs 12%). Respondents with insulin-treated type 2 diabetes were under-represented in the new cohort relative to the stratified sampling (50% invited vs 44% response).

Longitudinal cohort data matching
Of the 504 eligible participants who completed the longitudinal cohort survey, 459 (91%) were matched with their original 2011 data. The representativeness of the longitudinal data set compared to the original 2011 sample can be assessed by comparing the sample characteristics of those who took part in 2011 and 2015 with those who took part in 2011 only. As shown in table 4, participants who completed both the 2011 and 2015 surveys were slightly more likely than those completing the 2011 survey only to have type 1 diabetes, report a higher education and annual income, and live in metropolitan regions of Australia. For those with type 1 diabetes, those who participated in the 2011 and 2015 surveys had a longer mean diabetes duration relative to those who took part in 2011 only. Among those with type 2 diabetes, the reverse was true: participants of both the 2011 and 2015 surveys had a shorter mean diabetes duration compared to those who took part in 2011 only.

Qualitative findings
The qualitative data provided by participants in the free-text boxes indicated that, in general, the survey was

highly acceptable to participants. While some participants felt the survey was *too long*, others were appreciative of the *comprehensive* and *thoughtful* nature of this research. For many, it promoted further learning about diabetes, and a chance to reflect on their attitudes to living with diabetes:

> Doing this survey makes me realise that I could access support networks/forums/healthcare practitioners more than I actually do (woman, 31 years, type 1 diabetes)

Some participants perceived that *psychological support doesn't exist* (woman, 25 years, type 1 diabetes) for their diabetes-related concerns, and therefore were pleased that this work was being conducted:

> I would like to say thank you for this survey, as it's good to know that there are people concerned with diabetes and the issues we may have (man, 67 years, type 2 diabetes)

STRENGTHS AND LIMITATIONS
Strengths
Key strengths of MILES-2 are the breadth and depth of quantitative data and the large population-based sample size that will afford the necessary statistical power to investigate subgroups and conduct multivariate analyses. Our CI calculations confirm that this sample size is adequate to facilitate relatively accurate estimations of population-level statistics. While clinical and biomedical research abounds in the field of diabetes, there is a pressing need for an increased research focus on the psychosocial aspects of the condition.[27] MILES-2 contributes to this gap in our knowledge by providing a rich data set that combines cross-sectional and longitudinal assessment of key topics such as emotional well-being, self-management and healthcare access, as well as introducing novel topics of investigation such as social stigma, cognition and memory, and self-compassion. The qualitative feedback from participants indicated that the topics included in the survey were relevant to them, and the survey was generally very well received.

Table 3 Survey content for the 2015 Diabetes MILES–Australia survey

Concept/topic	Measure or variable	2015 new cohort	Longitudinal cohort	2011 survey
Demographics				
Eligibility screen	Diabetes type, age, live in Australia			
Demographic and socioeconomic details	Gender, state, postcode, country of birth, language, marital status, living situation, income, employment, education	✓	✓	✓
Diabetes details	Diabetes duration, diabetes treatment			
Other	Diabetes organisation membership, how they heard about survey			
My general well-being				
General emotional well-being	World Health Organisation Well-being Index (WHO-5)[59]			
	General life satisfaction (single item)[60]	✓	✓	✓
Depressive symptoms	Patient Health Questionnaire (PHQ-8)[61]			
Anxiety symptoms	Generalised Anxiety Disorder scale (GAD-7)[62]			
My feelings about diabetes				
Diabetes-specific distress	Problem Areas In Diabetes Scale (PAID)[63]	✓	✓*	✓*
	Diabetes Distress Scale (DDS)[64]		✓†	✓†
	Type 1 Diabetes Distress Scale (T1-DDS)[65]		✓†‡	
Diabetes-related and generic stigma	Type 1 and Type 2 Diabetes Stigma Assessment Scales (DSAS-1[66]; DSAS-2 [67])	✓	✓*	
	Stigma Scale for Chronic Illnesses-8 item version (SSCI-8)[68]	✓	✓*	
	6 study-specific items about portrayal of diabetes in the media	✓	✓	
Quality of life	DAWN Impact of Diabetes Profile (DIDP)[5]	✓	✓	
Illness centrality	Centrality Scale[69]	✓	✓	
My general health				
Health background	Physical and mental health comorbidities and complications, height and weight, smoking status, health insurance and pension	✓	✓	✓
Weight stigma	Weight Self-Stigma Questionnaire (WSSQ)[70]	✓	✓	
Memory	Prospective and Retrospective Memory Questionnaire (PRMQ)[71]	✓	✓	
Support from health professionals, family and friends				
Healthcare	Access to providers in past 12 months, main provider, group structured education	✓	✓	✓
Social support	Diabetes Support Scale (DSS)[72]	✓	✓	
	Social Support subscale of Diabetes Care Profile (DCP)[73]	✓	✓	
Peer support	Study-specific items	✓	✓	
My diabetes				
Self-care	Diet and physical activity subscales of the Summary of Diabetes Self-Care Activities (SDSCA)[55]	✓	✓	
	Study-specific items: dietary behaviours	✓	✓	
	Study-specific items: physical activity behaviours	✓	✓	
	Study-specific items: blood glucose monitoring	✓	✓	
	Modified importance and burden items (for diet, physical activity, blood glucose monitoring) from the Summary of Diabetes Self-Care Inventory-Revised (unpublished)	✓	✓	
Diabetes treatment	Study-specific items assessing frequency/time of day for injections/bolusing, frequency of forgetting and skipping injections/bolus/medication dose, reasons for forgetting/skipping	✓	✓	

Continued

Table 3 Continued

Concept/topic	Measure or variable	2015 new cohort	Longitudinal cohort	2011 survey
HbA1c	Study-specific items	✓	✓	✓
App use for self-management support	Study-specific items	✓	✓	
Diabetes-specific self-efficacy	Confidence In Diabetes Self-Care (CIDS) (insulin-using [57] and non-insulin-using versions [58])	✓	✓	
Psychological insulin resistance	Insulin Treatment Appraisal Scale (ITAS)[74]	✓§	✓§	✓§
	'Willingness to begin insulin' single item[75]	✓§	✓§	
My blood glucose levels				
Hyperglycaemia	Two items adapted from the Hyperglycaemia Avoidance Scale (HAS)[76]	✓‡	✓‡	
Hypoglycaemia	Study-specific items (some based on the Hypoglycaemia Awareness Questionnaire [77]) to assess frequency, hospitalisation, insulin adjustment in response to hypoglycaemia, impaired awareness of hypoglycaemia	✓	✓	✓
	Edinburgh Hypoglycaemia Survey (EHS)[78]	✓	✓	
	Gold Score[79]	✓	✓	✓
My thoughts and beliefs				
Self-esteem	Rosenberg Self-Esteem Scale (RSE)[80]	✓	✓	
Self-compassion	Self-Compassion Scale Short Form (SCS-SF)[81]	✓	✓	
Other	Free-text box inviting participants to make any other comments	✓	✓	✓

*Participants who completed survey B version in 2011 only.
†Participants who completed survey A version in 2011 only.
‡Participants with type 1 diabetes only.
§Participants with type 2 diabetes only.
HbA1c, glycated haemoglobin.

The survey was conducted primarily online, with only 27 of the 2342 respondents (1%) asking to complete a hard copy version. The online survey methods were successful in generating a sample with gender balance, a wide age range, diverse socioeconomic backgrounds and a representative mix of people living in metropolitan, regional and rural areas in all states and territories of Australia. The online survey was a successful and economical approach to surveying a wide range of Australian adults with diabetes, all within a relatively short time period (7 weeks).

The significance of the emerging longitudinal data set is particularly noteworthy. For the first time, it will be possible to explore predictors and consequences of psychological distress and suboptimal behavioural diabetes management in a non-clinical, population-based sample. It represents the first attempt to track the natural trajectory of emotional problems in people with diabetes (eg, diabetes distress) and to investigate any social, economic and/or demographic factors that may contribute to variation in psychological experiences. This in turn will enable better tailoring of interventions to meet those with the greatest need. It is our intention to conduct further surveys in the future to continue to follow all respondents who have indicated their willingness to continue their participation. This will enable us to build on the existing longitudinal data set using a third wave of data collection, and to increase the sample size and breadth of survey topics available in the longitudinal cohort.

Limitations
Response rates

The response rates for both the longitudinal and the new cohorts in the MILES-2 survey were low; the longitudinal cohort had a markedly better response rate (26%) than the 2015 new cohort (8%). It is possible that respondents who agreed to take part in future surveys in 2011 had a higher level of commitment to and interest in the Diabetes MILES Study due to their previous participation.

In the longitudinal cohort, substantial attrition was evident between the 2011 and 2015 surveys, and the response rate is notably lower than other health-related longitudinal Australian surveys.[82 83] However, these other initiatives were very well resourced, enabling many repeat attempts at contact using various methods. For MILES-2, only two contacts were possible (invitation plus one reminder). Further, MILES-2 focused specifically on adults with type 1 or type 2 diabetes aged 18–75 years, whereas, in contrast, the other initiatives sampled the general population

Table 4 Baseline characteristics of longitudinal survey completers (2015 and 2011) versus non-completers (2011 only)*

	2011 only (cross-sectional) cohort	2011 and 2015 (longitudinal) cohort	Significance
TOTAL	2879 (86)	459 (14)	
Gender—female	1538 (54)	240 (53)	NS
Diabetes type			0.002
Type 1 diabetes	1157 (40)	219 (48)	
Type 2 diabetes	1722 (60)	240 (52)	
Age—years			
Type 1 diabetes	42±14	43±13	NS
Type 2 diabetes	59±9	57±8	0.016
Diabetes duration—years			
Type 1 diabetes	15±13	18±14	0.001
Type 2 diabetes	9±7	8±6	0.030
Primary treatment for type 1 diabetes			<0.001
Insulin pump therapy	246 (21)	79 (36)	
Insulin injections	902 (79)	140 (64)	
Primary treatment for type 2 diabetes			0.002
Insulin pump therapy	8 (0)	0 (0)	
Insulin injections	642 (39)	72 (30)	
Non-insulin injectables	15 (1)	7 (3)	
Blood glucose-lowering tablets	767 (45)	109 (45)	
Diet and/or exercise alone	266 (16)	52 (22)	
Aboriginal or Torres Strait Islander origin	47 (2)	2 (0)	0.037
Main language spoken at home—English	2759 (97)	446 (98)	NS
Country of birth—Australia	2119 (74)	354 (77)	NS
Relationship status			NS
Single	391 (14)	59 (139)	
In a steady relationship	105 (4)	20 (4)	
Married or De Facto	1945 (69)	325 (71)	
Separated	77 (3)	6 (1)	
Divorced	216 (8)	39 (9)	
Widowed	89 (3)	7 (2)	
Education			<0.001
No qualifications	254 (9)	12 (3)	
School/intermediate certificate	308 (11)	34 (8)	
High school/leaving certificate	552 (20)	79 (18)	
Trade training/certificate/diploma	848 (31)	135 (30)	
University undergraduate degree	474 (18)	108 (24)	
Higher university degree	271 (10)	81 (18)	
In paid employment	1654 (57)	310 (68)	<0.001
Annual household income ($A)			<0.001
≤20 000	539 (20)	57 (13)	
20 001–40 000	500 (19)	59 (13)	
40 001–60 000	502 (19)	79 (18)	
60 001–100 000	579 (21)	120 (27)	
100 001–150 000	346 (13)	81 (18)	
>150 000	228 (8)	52 (12)	
Geographical location			<0.001
Metropolitan	1425 (51)	275 (61)	
Regional	808 (29)	116 (26)	
Rural	587 (21)	63 (14)	

Data are n (%) or mean±SD (range).
*Data from 2011 Diabetes MILES—Australia.
NS, not significant.

and did not focus on a particular condition. It has been noted that the population being sampled is the most important determining factor for survey response rates,[84] and thus comparison of the MILES-2 response rate with other Australian general population surveys is not necessarily appropriate. People with diabetes are more likely than the general population to have serious physical and mental health comorbidities,[12][13][85][86] impaired general well-being,[33] and those with type 2 diabetes are more likely to be

socioeconomically disadvantaged,[87] making non-response and problematic attrition more likely.[88 89]

Another possible explanation for the relatively high rate of attrition between the 2011 and 2015 surveys is the different methods of recruitment and data collection. In 2011, participants received a hard copy survey; online survey completion was possible but 70% of 2011 survey respondents completed the hard copy version. In contrast, the 2015 survey was online by default, and respondents needed to request a hard copy. This may have created too many barriers to participation for some, leading to non-response.

The response rate of the 2015 new cohort is low at 8%, and considerably lower than the 18% observed in the 2011 survey.[29] However, a number of factors may explain this. First, as noted above, the default online data collection may have been a barrier to participation. Second, the survey took place at a time when NDSS registrants were being contacted frequently for research purposes, which was not the case in 2011. On the advice of the NDSS, the survey launch date was pushed back from November 2014 to March 2015 in an attempt to avoid survey fatigue. However, the low response rate suggests that this delay was insufficient and that NDSS registrants may have been burdened by too many research participation requests. Finally, online surveys are now prolific, and decreasing response rates have been noted elsewhere.[84] Thus, the low response rate observed in the 2015 new cohort of the MILES-2 survey may be reflective of a broader trend, compounded by the challenges faced by this population as already described.

In spite of the low response rates, as noted above, the sample sizes obtained are more than adequate to facilitate inferential data analyses and to draw conclusions about the unmet needs of Australian adults with type 1 and type 2 diabetes.

Stratification of the new cohort sample

The sampling for the new cohort was stratified by diabetes type, insulin use (type 2 diabetes only) and Australian state of residence. Respondents with type 1 diabetes were slightly over-represented in our sample (45%) relative to the stratification (40%). This may reflect a generally higher level of engagement in diabetes-related activities and advocacy in this group relative to those with type 2 diabetes.

Among respondents with type 2 diabetes, 44% were using insulin, which is almost double the proportion observed on the NDSS database (24%), but less than anticipated given the purposeful sampling stratification (50%). On the basis of our previous research, Australian adults with type 2 diabetes who use insulin (compared with those not using insulin) have a longer diabetes duration,[90] are more likely to have at least one diabetes-related complication,[31 32] and are more likely to have depressive and anxiety symptoms.[43] These factors may make them less likely to engage in research initiatives.[88 89]

Sample representativeness

The NDSS is considered to be one of the best national sources of data about Australians with diabetes,[91] and thus the representativeness of our study sample can best be determined by comparing our sample characteristics with the NDSS registrant database characteristics.

Notwithstanding the purposeful stratification and over-sampling of adults with type 1 diabetes and those with insulin-treated type 2 diabetes, the gender balance was broadly representative of people registered on the NDSS database.[90] Overall, men and women were represented equally in the sample (50% men; 50% women) and the proportions in our sample approximate the NDSS register (52% men vs 48% women).

Among those with type 1 diabetes, 35% were using an insulin pump to manage their diabetes. Since only 10% of adults with type 1 diabetes registered with the NDSS use an insulin pump,[92] it appears that this group is over-represented in our sample. While insulin pump users were intentionally over-sampled in the 2011 survey, this was not the case for the 2015 new cohort, and yet they were over-represented in the sample anyway. The over-representation of pump users is consistent with research participation patterns observed in similar studies.[44 45] Pump users may be more engaged in research because they perceive themselves to benefit from advances in knowledge, or it may be reflective of the fact that pump users tend to be more highly educated and from higher socioeconomic backgrounds relative to non-pump users.[92]

Compared with the Australian general population, our sample was more likely to speak English as their main language,[93] to be married or in a de facto relationship,[94] to be in paid employment[95] and have post-high school qualifications.[96] This indicates that those who took part are a relatively privileged sample with significant social resources who are likely to have better health literacy and access to health services than Australians with diabetes generally. Self-selection bias is commonly observed in web-based studies,[97 98] and may result in the under-estimation of social and emotional problems, and problems of healthcare access. In the context of the MILES-2 study, this bias must be acknowledged as a considerable limitation that may threaten the generalisability of the data to the broader Australian population of adults with diabetes. Weighting of cases may be adopted for future analyses, depending on the subsample and outcome variables being used. Since a key focus of future inferential analyses of the MILES-2 data will be the relationships between variables, the self-selection bias is likely to have minimal impact on this if cases are weighted accordingly. For future MILES studies, consideration will be given to strategies that will address the under-sampling of participants from less advantaged backgrounds such as community outreach through health professionals and diabetes clinics, collaborating with researchers with expertise in working with Aboriginal and Torres Strait Islander communities and stronger promotion of the availability of hard copy versions of the survey.

FUTURE DIRECTIONS AND COLLABORATIONS

Subject to funding availability, we plan ongoing follow-up (approximately every 4 years) of the longitudinal cohort and we expect to be able to grow both the cohort and the depth and breadth of data available by also conducting follow-up MILES surveys with the 2015 new cohort. To maintain participant engagement and therefore aid retention, we are currently writing a report that summarises top-level findings of the study for a lay audience. All MILES-2 participants were given the opportunity to opt to receive a free electronic copy of the report when it becomes available.

One key direction for future data analysis and publication is examination of within-participant changes between 2011 and 2015 on variables such as depressive and anxiety symptoms, diabetes distress and insulin appraisals. Additional priority avenues of enquiry will include identifying the psychological and behavioural correlates of diabetes distress, hypoglycaemia avoidance and depressive symptoms to inform intervention development, exploring associations with diabetes stigma and psychological and behavioural outcomes, characterising the use of technologies (eg, smartphone apps) to aid self-management and psychometric analysis of scales that have not previously been used in an Australian context (eg, DIDP). Findings from MILES-2 will be disseminated through academic publications, conference presentations, health professional training and community symposia over several years.

We encourage collaborations from researchers with relevant expertise in the field. Researchers may gain access to the second Diabetes MILES—Australia survey data set on submission of a proposal detailing the topics of interest, key research questions and hypotheses. Proposals will be evaluated by the Diabetes MILES Study research team on the basis of feasibility, relevance, novelty and expertise of the researchers. Enquires should be directed to Browne JL (first author).

CONCLUSIONS

The second Diabetes MILES—Australia study builds on the previous Diabetes MILES Study initiatives to deliver Australia's first large-scale longitudinal assessment of the psychosocial aspects of type 1 and type 2 diabetes, and to introduce novel topics of investigation at a population level. The depth and breadth of the data available in this large sample will raise further awareness of the psychosocial impact of living with type 1 and type 2 diabetes, will highlight unmet needs and priority areas for future investigation and, crucially, will inform policy, programme and intervention development and evaluation.

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