ndss
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diabetes australia

Diabetes peer support in Australia:
A NATIONAL SURVEY

The Australian Centre for Behavioural Research in Diabetes

The Mental Health and Diabetes National Development Programme is funded as part of the National Diabetes Services Scheme which is an initiative of the Australian Government administered with the assistance of Diabetes Australia. This report was developed in collaboration with The Australian Centre for Behavioural Research in Diabetes, a partnership for better health between Diabetes Victoria and Deakin University. If you require further information about this resource, please contact Diabetes Australia on (02) 6232 3800. Please refer people with diabetes to the NDSS Helpline 1300 136 588 for information and self-management support.

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FOREWORD

Peer support provides the opportunity for people with diabetes to share their knowledge, experience, emotions, ideas and concerns with one another. Peer support can effectively supplement the knowledge and expertise offered by health professionals and offer assistance in daily management, social and emotional support, and linkages to formal health care or community resources. Research has demonstrated that diabetes peer support programs can lead to improvements in self-management and reduced healthcare utilisation. Peer support can also increase confidence in diabetes management, reduce emotional distress, and ultimately lead to better health outcomes. Peer support can take many forms, including one-on-one mentoring, support groups and online forums, making it a flexible option for many people living with diabetes.

This report summarises the findings of the Diabetes Peer Support in Australia Study, a national survey about the perceptions, preferences and experiences of diabetes peer support from the perspective of adults with type 1 or type 2 diabetes. This study is the first to collect national data on this issue, and has made a unique and important contribution to our understanding of the current state-of-play of diabetes peer support in Australia.

The study was undertaken in 2015 as part of the National Diabetes Services Scheme (NDSS) Mental Health and Diabetes National Development Programme, an initiative of the Australian Government administered with the assistance of Diabetes Australia. The survey was conducted by The Australian Centre for Behavioural Research in Diabetes (ACBRD), a partnership for better health between Diabetes Victoria and Deakin University. All involved are to be congratulated for their efforts in bringing to fruition this important piece of work that can now inform policy and practice relevant to peer support for people living with diabetes in Australia.

Prof Prasuna Reddy and A/Prof Roger Chen

Chair and Deputy Chair

NDSS Mental Health and Diabetes
National Development Programme Expert Reference Group.

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Executive Summary

The Diabetes Peer Support in Australia Study was a national survey of Australian adults living with type 1 or type 2 diabetes. It was conducted in 2015, as an activity of the National Diabetes Services Scheme (NDSS) Mental Health and Diabetes National Development Programme. The aim was to assess respondents' perceptions and experiences of, and preferences for, diabetes peer support. In doing so, the goal was to generate evidence that would lead to recommendations about the implementation of models of peer support for NDSS registrants.

Method

For this nationwide, primarily online survey, eligible participants were English-speaking Australian adults with type 1 or type 2 diabetes, aged 18-75. A letter of invitation was mailed to a random sample of 20,000 NDSS registrants (stratified: 40% with type 1 diabetes; 30% with insulin-treated type 2 diabetes; 30% with non-insulin-treated type 2 diabetes). In addition, a study invitation was emailed or mailed to 2065 participants of previous research who had consented to being contacted for future opportunities. Finally, the study was also advertised nationwide in diabetes-related media (e.g. e-newsletters, social media). Those who were interested, accessed a website via a URL provided in the invitation letter, provided informed consent and completed eligibility questions. A small number of people requested and completed hard copy version of the survey.

Sample

In total, 2342 eligible respondents were included in the survey sample.

46% (n=1078) had type 1 diabetes:

- Gender: 40% were men, 59% were women and 1% preferred not to say
- Mean age: 44 years. Mean age at diagnosis: 25 years
- Primary diabetes management: 65% insulin injections, 35% insulin pump

54% (n=1263) of respondents had type 2 diabetes:

- Gender: 57% were men, 43% were women and <1% preferred not to say
- Mean age: 61 years. Mean age at diagnosis: 50 years
- Primary diabetes management: 42% insulin therapy, 40% tablets, 14% diet/exercise

Overall, 61% of respondents were living in metropolitan areas of Australia; 80% had completed high school and 39% had a university degree; 53% were employed; 68% were married or in a de-facto relationship; 26% were born outside of Australia; and 97% reported being registered with the NDSS. Relative to the broader Australian population, this study sample was more highly educated and had a higher household income; more likely to live in rural or regional areas and were slightly less likely to be married or in a de-facto relationship. NSW and QLD residents were slightly under represented in the current sample, while residents of TAS and the ACT were slightly over represented.

Diabetes Peer Support Participation

- 11% currently participate in a diabetes peer support group, program or online community (72% of whom had type 1 diabetes).
- 9% have participated in diabetes peer support in the past (69% of whom had type 1 diabetes).
- 38% wish to participate in diabetes peer support in the future (52% of whom have type 1 diabetes).
- The most common form of peer support accessed by people with type 1 diabetes was online forums (26%) closely followed by *Facebook* groups (25%). The most common form of peer support accessed by people with type 2 diabetes was a support group run by their diabetes state/territory member organisation (44%).

Diabetes Peer Support Preferences

- The most commonly preferred mode of peer support was online (38%), followed by group support (26%). This was true for both diabetes types and genders, and for most age groups and diabetes durations.
- This pattern of preference was largely consistent regardless of whether the respondent was currently participating in peer support or whether they wished to participate in the future.

Subjective Experiences of Peer Support

- Of the 215 respondents currently accessing diabetes peer support, 64% rated it as 'enjoyable' or 'very enjoyable'.
- Most respondents indicated that their current diabetes peer support was 'helpful' or 'very helpful' across three domains: connecting with healthcare services (67%), self-management (66%) and emotional well-being (69%).
- 65% reported that they were 'satisfied' or 'very satisfied' with peer support.

Benefits and Disadvantages of Peer Support

- For adults with type 1 diabetes, the most frequently endorsed benefit was that peer support helps to 'make me feel like I'm not alone' (20%).
- For adults with type 2 diabetes, the most frequently endorsed benefit was tied between access to diabetes information and resources and motivation to manage diabetes (both 27%).
- The most commonly reported disadvantage, both for people with type 1 and type 2 diabetes, was that the discussions among peers were not relevant to them (collectively, 41%).

Who is Not Accessing Peer Support and Why?

- Among respondents who had previously participated in peer support but were no longer doing so, the main reasons for non-participation were: being too busy (21% of those with type 1 diabetes) and preferring to manage diabetes on their own (22% of people with type 2 diabetes).
- Among respondents who had not previously participated in peer support, the most common reason for non-participation was the perception that there were no programs relevant to their type of diabetes. Interestingly, this was the most common reason given by both respondents with type 1 and type 2 diabetes (collectively, 27%).

Perceived Social Support

- Perceived social support was assessed using the Diabetes Support Scale, a reliable and valid self-report questionnaire.
- Respondents who were currently participating in diabetes peer support perceived the social support available to them was significantly higher ($p<0.01$) than did those who were not participating in peer support.

Health Professional Support

- People with type 2 diabetes were more likely than those with type 1 diabetes to report that their health professionals were 'supportive' or 'very supportive' about their participation in peer support (56% versus 36%).
- Regardless of diabetes type, less than 10% of respondents believed their health professionals to be 'very unsupportive' or 'unsupportive' of their participation in peer support.
- People with type 1 diabetes were more likely to indicate that they had not discussed peer support with their health professional(s) compared with people with type 2 diabetes (34% versus 22%).

Reflections on Ways to Improve Diabetes Peer Support

All respondents were asked to comment (using free-text boxes) on what changes could be made to improve their peer support experiences (current participants) or what would make peer support groups more appealing to them (those not participating). Responses were similar regardless of diabetes type, and suggestions included:

- Making peer support groups and forums more specific to diabetes type, age, and life-stage.
- Skilled/expert moderation or facilitation to ensure inaccurate advice is not given and to encourage participation from all members.
- More informative or educational material about diabetes management and the latest developments in the field.
- More local and accessible groups and initiatives run during more flexible days/times.
- Peer support groups need to be more positive and more social in nature.
- Better promotion of the available peer support initiatives, both to people with diabetes and healthcare professionals.

Study Strengths and Limitations

People of both genders, and all ages and diabetes durations participated in the study. While the sample was large (N=2342), the response rate was relatively low (11%). Participation was voluntary and thus the sample was self-selected. Further, all data were self-reported and no clinical data were collected.

Recommendations

There are five key recommendations arising from this study:

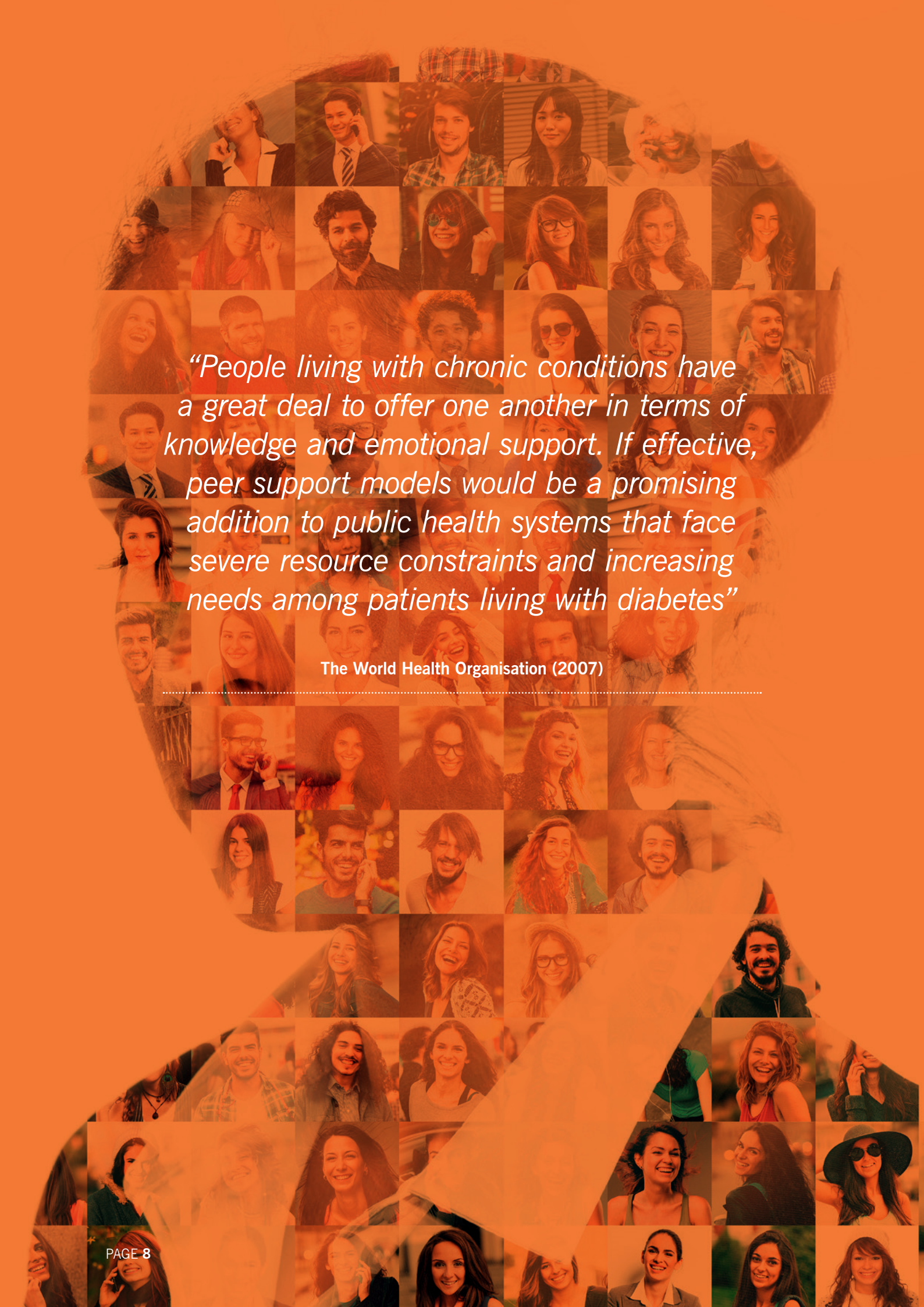
1 Provide online diabetes peer support initiatives.

2 Increase engagement of men, people with less education, and people with type 2 diabetes in peer support.

3 Provide well-structured, expertly moderated/facilitated peer support initiatives.

4 Increase promotion of existing diabetes peer support programs to improve awareness of, access to and reach of programs.

5 Improve awareness and understanding of diabetes peer support among health professionals.



"People living with chronic conditions have a great deal to offer one another in terms of knowledge and emotional support. If effective, peer support models would be a promising addition to public health systems that face severe resource constraints and increasing needs among patients living with diabetes"

The World Health Organisation (2007)

Introduction

Diabetes and Peer Support

Diabetes is widespread, serious and costly, predicted to be the largest health burden in Australia by 2023.[1] Diabetes-related complications, e.g. blindness, kidney damage, amputation, and stroke, account for over half the total diabetes healthcare costs in Australia.[2] However, landmark studies have shown that such complications can be prevented by optimising blood glucose levels.[3 4] Self-management is all-important for achieving this,[5] but the self-management regimen may be complex and unrelenting. It comprises healthy eating, physical activity, taking medication/insulin, checking blood glucose, problem-solving, risk reduction and attending healthcare appointments. Support (from health professionals, family/friends and others) for self-management can be beneficial for initiating and maintaining these behaviours.

Peer support is defined as the help, assistance and encouragement that people with lived experience of a condition (e.g. diabetes) can offer to one another. It is based on the sharing of mutual experiences and supporting the person to make their own decisions about how to integrate optimal self-management into their lifestyle.

Systematic reviews have highlighted the benefits of peer support interventions for people with chronic conditions.[6 7] Randomised controlled trials (RCTs) of peer support programs for people with diabetes[8-15] have demonstrated improvements in:

i. behavioural outcomes, e.g. self-management and healthcare utilisation;
ii. psychosocial outcomes, e.g. diabetes knowledge, self-efficacy, and emotional well-being; and, ultimately
iii. health outcomes, e.g. blood glucose, blood pressure and body mass index (BMI).

Yet, according to the World Health Organization, there is much we still need to learn about how to organise and deliver peer support for those living with chronic conditions such as diabetes.[16]

Diabetes Peer Support in Australia Study

The Diabetes Peer Support in Australia Study was conducted by The Australian Centre for Behavioural Research in Diabetes in 2015, as part of the National Diabetes Services Scheme (NDSS) Mental Health and Diabetes National Development Programme. It was a national survey of Australian adults living with type 1 or type 2 diabetes. The aim was to assess respondents' perceptions and experiences of, and preferences for, diabetes peer support. In doing so, the goal was to generate evidence that would lead to recommendations about the implementation of models of peer support for NDSS registrants.

This report provides a summary of the methods and key findings of the survey, and is a deliverable of the NDSS Mental Health and Diabetes National Development Programme.

Methods

Procedure

A nationwide online survey was conducted to explore the peer support experiences and preferences of Australians with type 1 or type 2 diabetes. The study website featured a plain language description of the study, a consent form, and the online survey (securely hosted by Qualtrics, Copyright © 2015, Provo, UT). After indicating consent and answering eligibility screening questions, participants proceeded to the survey proper. A total of 27 people requested and completed a hard copy version of the survey (and therefore provided written informed consent). The study received ethics approval from Deakin University Human Research Ethics Committee (reference 2011-46).

Participants and Recruitment

Eligible participants were English-speaking Australian adults with type 1 or type 2 diabetes, aged 18-75. Children, elderly adults and those with other types of diabetes were excluded. A random sample of 20,000 NDSS registrants (stratified as follows: 40% type 1 diabetes; 60% type 2 diabetes of whom 50% were insulin-treated) were mailed a letter of invitation that introduced the study, and directed interested persons to the study website. In addition, a study invitation was emailed or mailed to volunteers who had previously participated in ACBRD research and had consented to being contacted for future opportunities (N=2065). Finally, the study was also advertised nationwide in diabetes-related media (e.g. e-newsletters, social media).

Materials

A series of study-specific items were developed to assess **perceptions** and **experiences** of, and **preferences** for, diabetes peer support. These included items with Likert scale, multiple choice, and free-text response options. In addition, the survey included a validated scale, the **Diabetes Support Scale** (DSS[17]), designed to measure diabetes-specific social support across three domains: emotional support, advice, and information. The DSS asks respondents to rate the diabetes support they have received over the past three months by indicating their agreement (or otherwise) with 12 statements (e.g. 'It was easy for me to find people who could make personal suggestions about what has worked for them in handling their own diabetes') on a 7-point Likert scale (1=strongly disagree, 7=strongly agree). A total score is calculated by taking the mean of individual item scores (possible range: 1-7). Higher scores indicate more diabetes support. The survey also included questions about demographic characteristics (e.g. age, gender, education) and clinical characteristics (e.g. diabetes type, duration and treatment).

Interpreting Data, Tables and Figures in this Report

Data are presented as percentage (number) or mean ± standard deviation, unless stated otherwise. The number of people who responded to each survey question varies (respondents could choose to skip questions). Where relevant, the tables and figures in this report are accompanied by an indication of the size of the sample (e.g. n=221) upon which the calculations are based. Percentages are reported as 'valid percent' (i.e. based only on the number of participants who responded to the question) and are generally rounded to the nearest whole number, meaning they do not always add to 100.

Participant Characteristics

Sample Size and Response Rate

A total of 2503 unique consenting respondents (eligible or otherwise) took part in this survey about peer support.

Of the 2503 unique respondents, 139 were automatically screened out due to ineligibility and a further 23 were excluded by the authors due to further eligibility checks. The final cross sectional sample included 2342 eligible participants.

The response rates for the two primary modes of recruitment (through the NDSS and previous study volunteers databases) are presented separately below:

- 1497 of eligible survey respondents indicated that they heard about the survey as a result of receiving an invitation from the NDSS. The study invitation was sent to 20,000 NDSS registrants, and thus the response rate is 7.3%. Extrapolating this rate to also include those screened out due to ineligibility, the estimated total response rate is 7.8%.
- 533 of the survey respondents took part in the survey as a result of receiving a study invitation directly from the ACBRD. The study invitation was emailed/mailed to 2065 people on the database of previous research participants and thus the response rate is 25.8%.

Diabetes Type

People with type 1 and type 2 diabetes were almost equally represented in the study sample: 46% (n=1078) of respondents had type 1 diabetes; the remaining 54% (n=1263) had type 2 diabetes.

Gender

Men and women were equally represented in the study sample (women: n=1178, 50%). Respondents with type 1 diabetes were more likely to be women, while respondents with type 2 diabetes were more likely to be men (Table 1).

Table 1. Participant gender by diabetes type

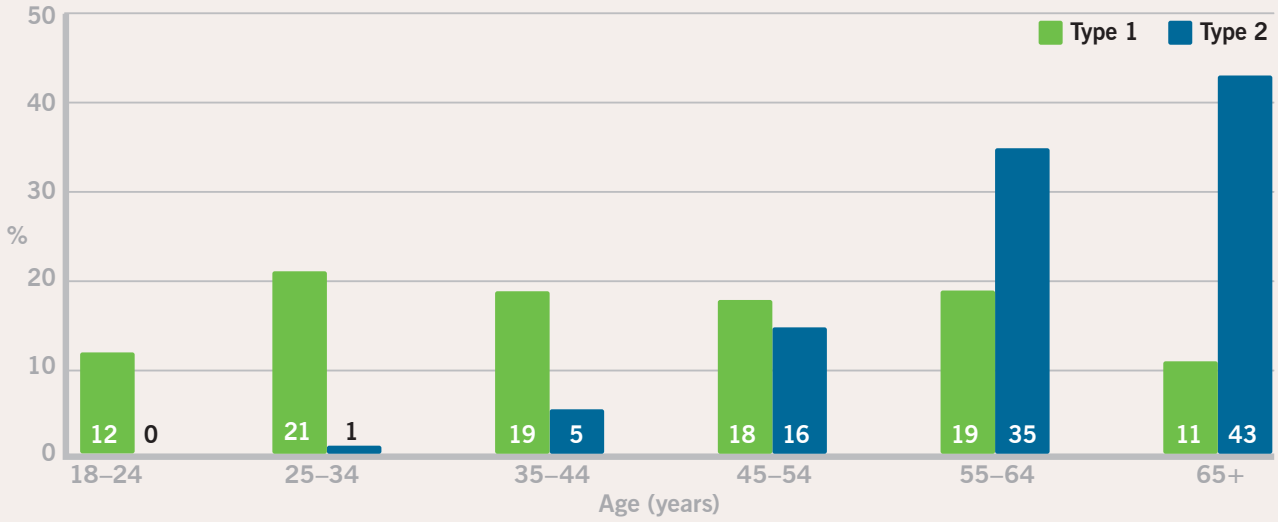
Gender	Type 1	Type 2	Total
Women	639 (54)	539 (46)	1178 (50)
Men	436 (38)	722 (62)	1158 (49)
Prefer not to say	3 (60)	2 (40)	5 (1)

Data are n (%)

Age

As expected, respondents with type 1 diabetes were younger (mean: 44±15 years) than those with type 2 diabetes (mean: 61±9 years). The majority of respondents with type 2 diabetes were 55 years and older, while those with type 1 diabetes were more evenly distributed across the age groups (Figure 1).

Figure 1. Age (years) by diabetes type (n=2342)



Diagnosis Age and Diabetes Duration

As expected, those with type 2 diabetes were diagnosed much later in life than those with type 1 diabetes. On average, respondents with type 1 diabetes were diagnosed with the condition at 25±15 years of age (range: 1-67). Respondents with type 2 diabetes were diagnosed with the condition at 50±10 years of age (range: 13-75).

Respondents with type 1 diabetes reported a longer diabetes duration (19±14 years, range: 0-68), than those with type 2 diabetes (11±7 years, range: 0-44). A total of 2.5% (n=59) reported being diagnosed with diabetes within the past year.

Diabetes Management

Of the respondents with type 1 diabetes, most (65%, n=698) used insulin injections. The majority of respondents with type 2 diabetes used insulin therapy (42%, n=531), or oral hypoglycaemic agents (40%, n=510) (Table 2).

Table 2. Primary method of diabetes management by diabetes type

Diabetes treatment	Type 1	Type 2
Insulin pump	380 (35)	2 (0.2)
Insulin injections	698 (65)	529 (42)
Exenatide (non-insulin injectable)	-	47 (4)
Oral hypoglycaemic agents (tablets)	-	510 (40)
Diet/exercise	-	176 (14)

Data are n (%)

Locality of Respondents

People from all states and territories were represented in this study. Half of all respondents were from New South Wales or Victoria (Figure 2). The smallest proportion (2%) of respondents was from the Northern Territory. Almost two thirds (61%, n=1433) of respondents were from metropolitan areas of Australia (Figure 3).

Figure 2. Percentage of respondents by state/ territory (n=2340)

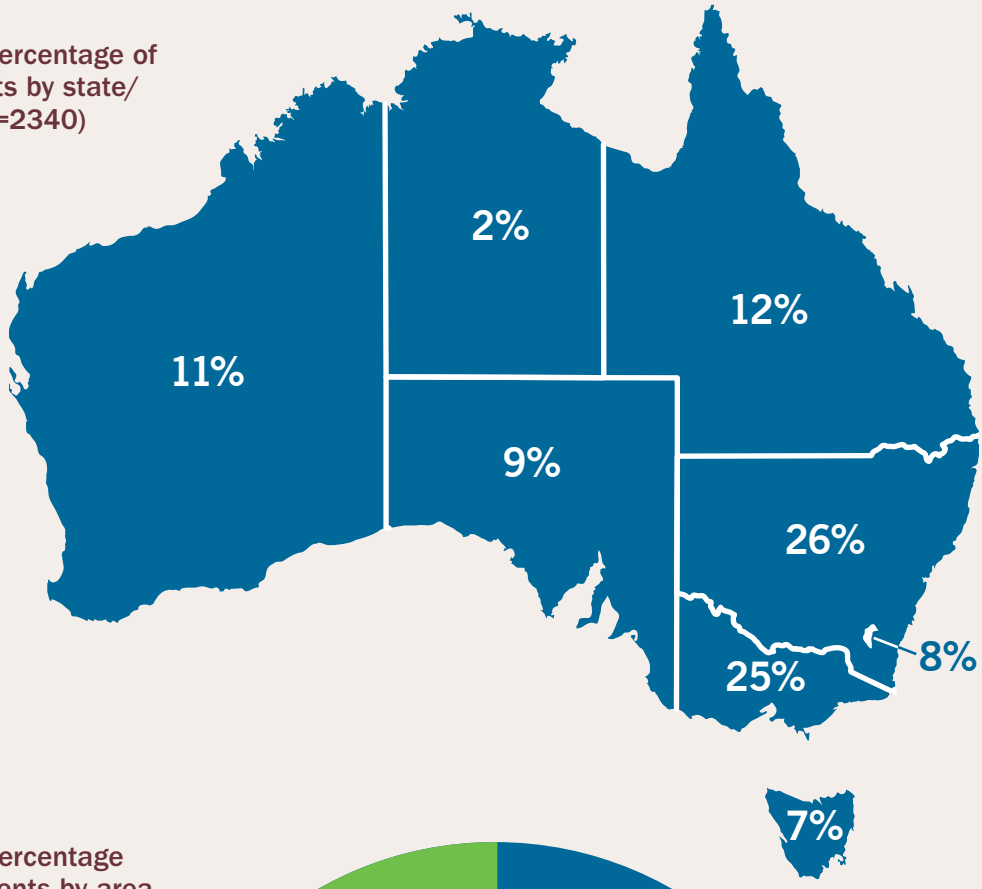
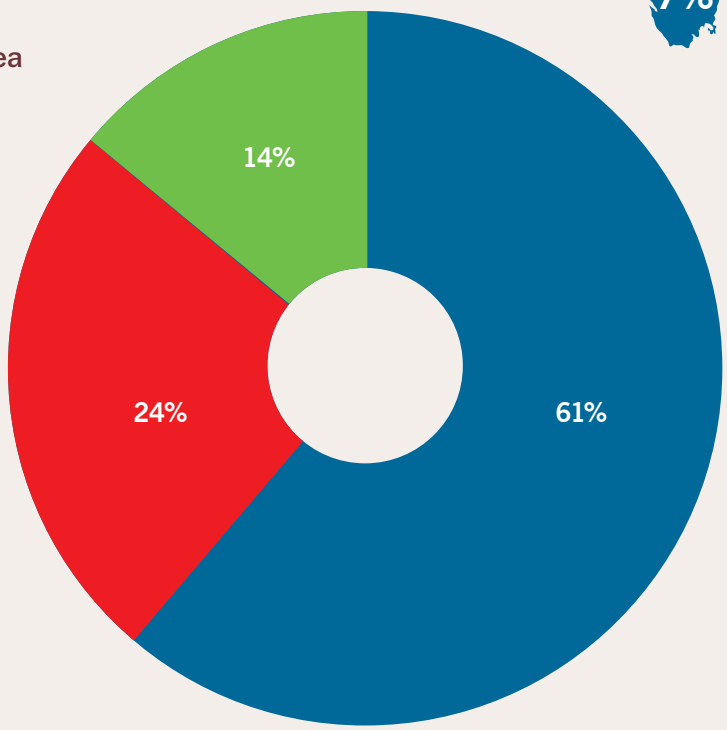


Figure 3. Percentage of respondents by area (n=2336)



Education

A total of 80% (n=1868) of respondents had completed high school and 39% (n=913) of respondents had completed a university degree.

Employment

Around half of all respondents (53%, n=1247) were employed. Those with type 1 diabetes were more likely to be employed (72%, n=770) than those with type 2 diabetes (38%, n=477). The majority of those who were not in paid employment reported being in retirement (66%). Those with type 1 diabetes (48%, n=146) were less likely to report being retired than those with type 2 diabetes (74%, n=579).

Income

Respondents from all income brackets were well represented in the study sample. Table 3 shows the proportion of participants in each gross annual household income bracket.

Table 3. Respondents' gross annual household income

Income	n (%)
Up to $20,000	355 (15)
$20,001 - $40,000	404 (17)
$40,001 - $60,000	334 (14)
$60,001 - $100,000	415 (18)
$100,001 or more	469 (20)
Don't know/prefer not to say	332 (14)

Marital Status

Most respondents reported being married or in a de-facto relationship (68%, n=1597). People with type 1 (66%, n=706) and type 2 diabetes (70%, n=891) were almost equally likely to be married or in a de-facto relationship. People with type 1 diabetes were more likely to report being single (22%, n=241) than those with type 2 diabetes (9%, n=111), while those with type 2 diabetes (6%, n=71) were more likely to report being widowed than those with type 1 diabetes (<1%, n=8).

Cultural Background and Primary Language

Few respondents (1.5%, n=36) reported being of Aboriginal and/or Torres Strait Islander descent. Around 1 in 4 respondents (26%, n=621) indicated that they were born in a country other than Australia.

Most respondents spoke English as their primary language, with just 3% (n=71) indicating that they mainly spoke a language other than English at home.

Representativeness of Sample

Relative to the broader Australian population,[18] this study sample was more highly educated and had a higher household income. They were half as likely to be Aboriginal and/or Torres Strait Islander compared to the general Australian population, but as likely to be born overseas. New South Wales and Queensland residents were slightly under-represented in the current sample, while residents of Tasmania and the Australian Capital Territory were slightly over-represented. Respondents in the study sample were more likely to live in rural or regional areas and were slightly less likely to be married or be living in a de-facto relationship, compared with the broader Australian population.

Relative to the NDSS registrant database, there were fewer people from an Aboriginal and/or Torres Strait Islander descent in the current sample (1.5% versus 3.8%). People from the Australian Capital Territory (8% versus 1%) and Tasmania (7% versus 5%) were slightly over-represented as compared to the NDSS registrant database, while New South Wales (26% versus 33%) and Queensland (12% versus 19%) were slightly under-represented in the current sample.

NDSS Registration and Membership

Almost all (97%, n=2275) respondents reported being registered with the NDSS.

Around half (49%, n=1152) of respondents reported being a member of their diabetes state or territory based organisation (Table 4). Those with type 2 diabetes were slightly less likely to report being a member of such an organisation than those with type 1 diabetes (45% versus 56% respectively).

Table 4. Membership of diabetes state and territory based organisations

	Type 1	Type 2	Total
Diabetes ACT	32 (59)	56 (42)	88 (47)
Diabetes NSW	178 (52)	93 (36)	271 (45)
Healthy Living NT	4 (44)	26 (63)	30 (60)
Diabetes Queensland	67 (48)	64 (45)	131 (46)
Diabetes SA	63 (73)	65 (54)	128 (62)
Diabetes Tasmania	31 (62)	60 (50)	91 (53)
Diabetes Victoria	183 (65)	142 (48)	325 (56)
Diabetes WA	51 (45)	56 (37)	107 (40)
TOTAL	609 (52)	562 (48)	1171 (50)

Data are n (%)

"If proven successful, peer support interventions may help patients with diabetes self-management more successfully without putting additional strain on the global shortage of health workers. Peer support models are especially promising for resource constrained health systems, as they are much less resource-intensive than interventions requiring concentrated health worker involvements. As such, peer support interventions are a potentially important policy option".

The World Health Organisation (2007)

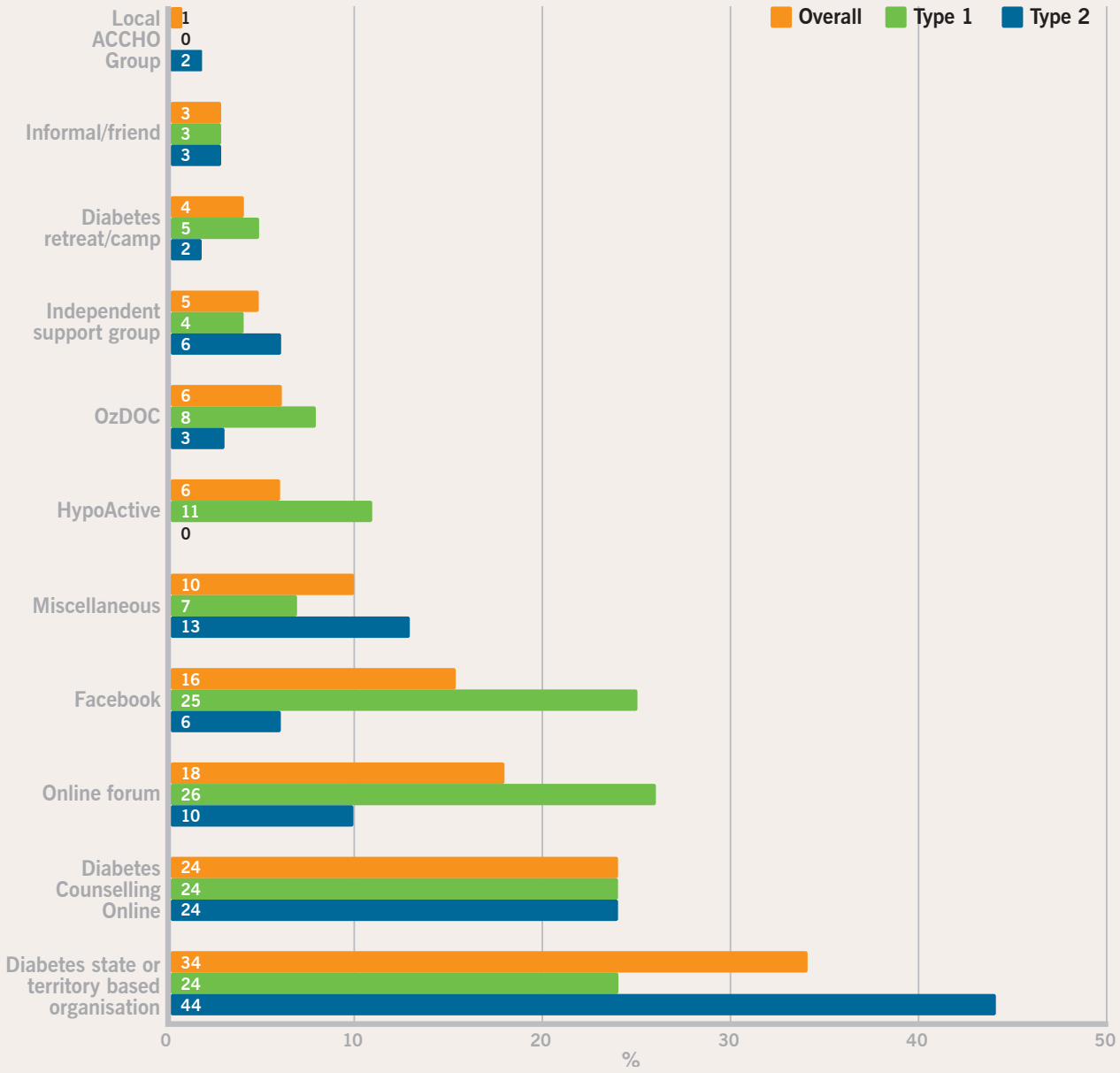
Diabetes Peer Support Participation

- 11% (n=244) of respondents indicated that they currently participate in a diabetes peer support group, program or online community.
  - 72% (n=162) of these had type 1 diabetes.
- 9% (n=167) of respondents reported that they have participated in diabetes peer support in the past.
  - 69% (n=115) of whom had type 1 diabetes.
- 38% (n=718) wish to participate in diabetes peer support in the future.
  - 52% of whom had type 1 diabetes.

A table describing the detailed characteristics of those who are currently participanting, participated in the past, and wished to participate in the future can be found in Appendix II. Key points are summarised here. Regardless of diabetes type, women were more likely than men to indicate current and past participation in peer support, and were more likely to indicate interest in participating in the future. Respondents with type 1 diabetes were more likely than those with type 2 diabetes to indicate current and past participation, and were more likely to indicate interest in participating in the future. Compared with other education levels, more respondents with a university degree had participated in peer support in the past, and showed the highest level of interest in wishing to participate in the future. Respondents who did not complete high school had the lowest current participation rate in peer support, and were the least likely to indicate wishing to participate in peer support in the future.

The respondents currently participating in diabetes peer support were asked to indicate (from a list of eight options) the peer support groups/communities in which they are involved (Figure 4). Multiple responses were possible. Respondents with type 1 diabetes showed a strong trend towards using the internet to access 'virtual' peer support. More specifically, they are most commonly participating in online forums (26%, n=43), in various *Facebook* groups (25%, n=40) and *Diabetes Counselling Online* (24%, n=39). Conversely, respondents with type 2 diabetes were most commonly participating in face-to-face peer support groups run by their diabetes state or territory organisation (44%, n=26), followed by *Diabetes Counselling Online* (24%, n=15). 'Miscellaneous' groups were any groups that did not fit into any of the other group categories listed.

Figure 4. Participation in peer support programs by diabetes type (n=224)



ACCHO: Aboriginal Community Controlled Health Organisation; OzDOC: Australian Diabetes Online Community

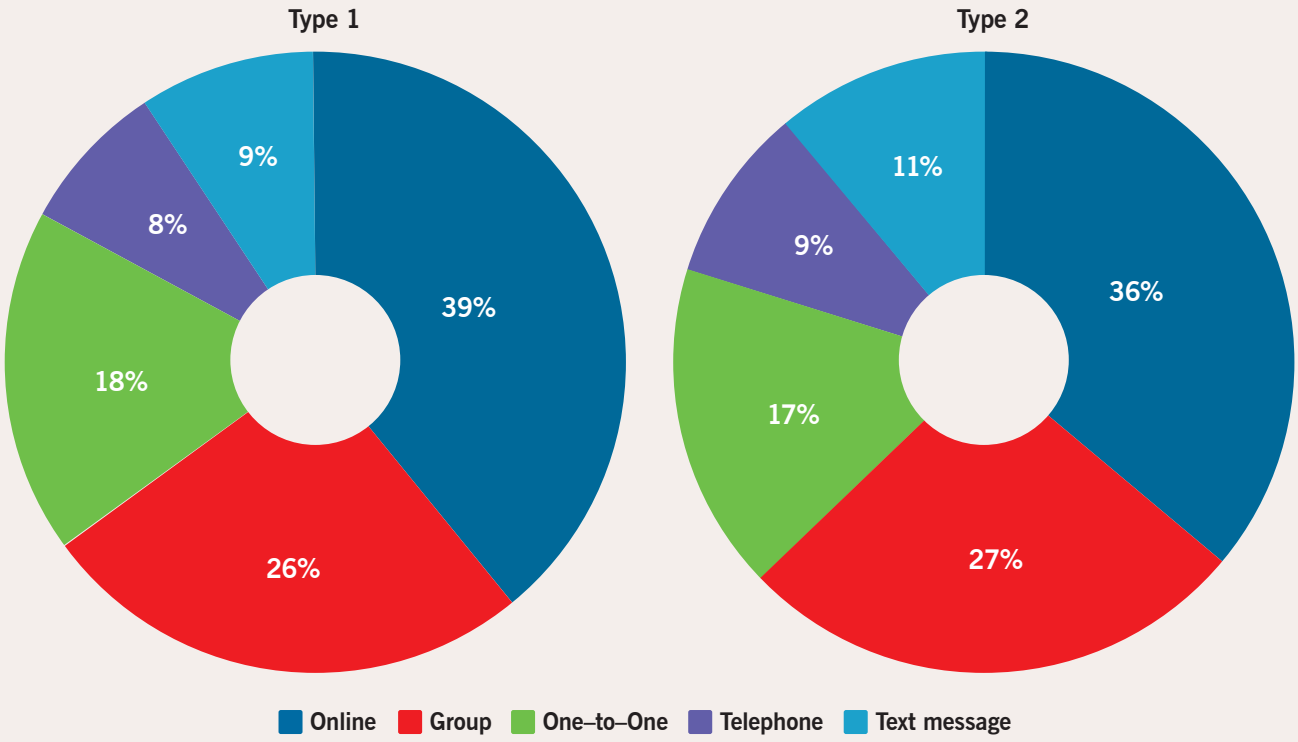
Diabetes Peer Support Preferences

Respondents currently participating in or wishing for future participation in diabetes peer support (n=224 and 718 respectively), were asked what mode of peer support they prefer or would like. Multiple responses were possible (Figure 5). For the purposes of this report:

- 'online' refers to any internet-based peer support, including informal mediums such as *Facebook* groups and forums, and more organised or structured initiatives such OzDOC Tweetchat
- 'group' peer support refers to support groups that meet face-to-face
- 'one-to-one' peer support refers to face-to-face support whereby one person provides support to another person (e.g. mentoring).

Overall, the most commonly endorsed preferred mode of peer support was online (38%, n=658), followed by group support (26%, n=452) and the least preferred modes were via text messaging (10%, n=145) and telephone (8%, n=166). Those with type 1 and type 2 diabetes reported similar preferences. While respondents with type 2 diabetes currently accessing peer support indicated that they were mostly participating in groups (see page 17), most indicated that they would like future participation to involve online peer support.

Figure 5. Preferences for mode of peer support, by diabetes type (n=928)



Preferences of Those Currently Participating in Peer Support

Preferences by Gender

Figure 6 displays the preferences of those who were currently participating in peer support by diabetes type and gender. Online peer support was the preferred method of peer support across gender and diabetes type (58%, n=148), followed by group peer support (44%, n=94), the exception being among men with type 2 diabetes, whose second most preferred option was in-person one-to-one peer support (41%, n=12). The least popular mode of peer support delivery was via text messaging (11%, n=24), with the exception of men with type 2 diabetes, whose least preferred method was via telephone (14%, n=4).

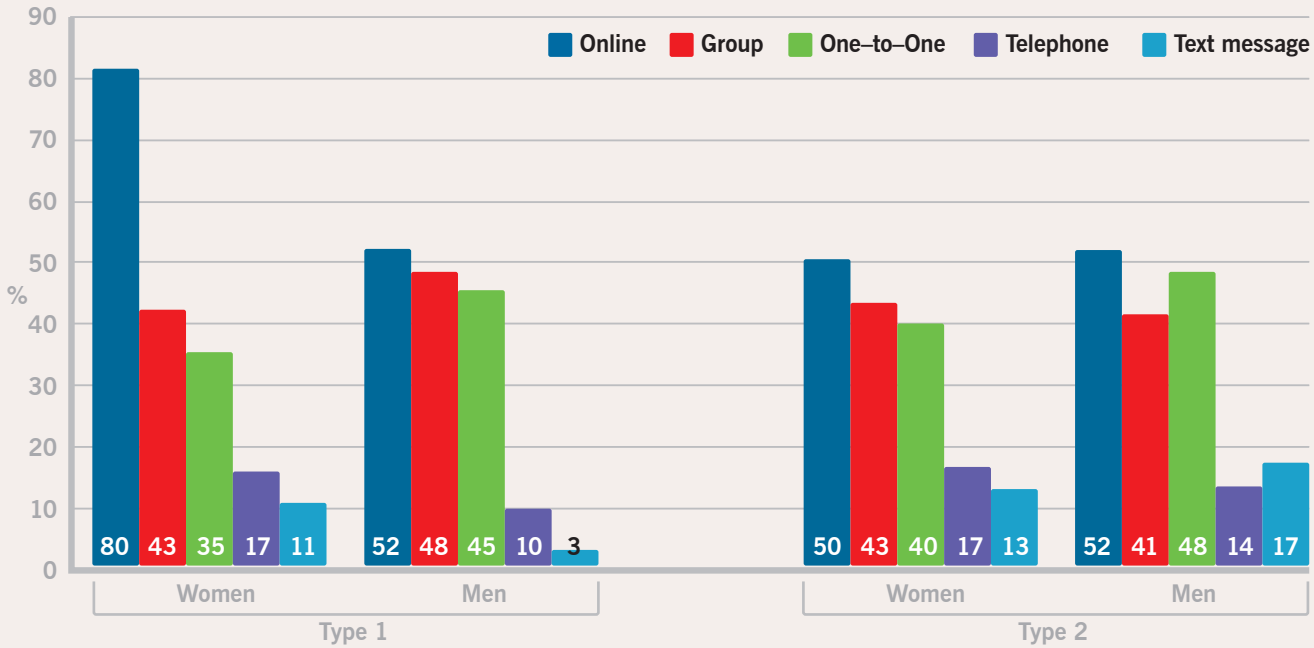
Preferences by Age

The preferences of those currently participating in peer support are shown by age group in Figure 7 for those with type 1 diabetes, and Figure 8 for those with type 2 diabetes.

For the total sample, online peer support was the most preferred method of peer support delivery among all age groups, except those aged 65 years or above - they expressed a preference for group support, followed closely by one-to-one peer support. The preference for online peer support decreased with each age cohort above the age of 45 years.

Among those with type 1 diabetes, preference for face-to-face peer support (group participation and one-to-one) was highest in the older cohorts (≥55 years). Telephone delivery was preferred mostly by those over the age of 55 years, while text messaging was preferred mostly by the youngest cohort, followed by those over the age of 65 years.

Figure 6. Preferences for peer support among those participating currently, by diabetes type and gender (n=217)



There were no respondents with type 2 diabetes aged between 18 and 34 years who indicated currently participating in peer support. Furthermore, there were only three respondents in the 35–44 year age group who completed this section of the study, therefore they were removed from the following analyses. Among the 35–44 year old age group, online, text messaging and one-to-one support were preferred equally, while no-one indicated group and telephone peer support as a preference.

Online peer support was the most preferred form of peer support delivery among those aged 45 - 64 years with type 1 and type 2 diabetes. Those over the age of 65 years with type 1 and type 2 diabetes showed a strong preference for one-to-one peer support, followed by group and then online forms of support.

Figure 7. Preferences for peer support by age group of adults with type 1 diabetes currently participating (n=158)

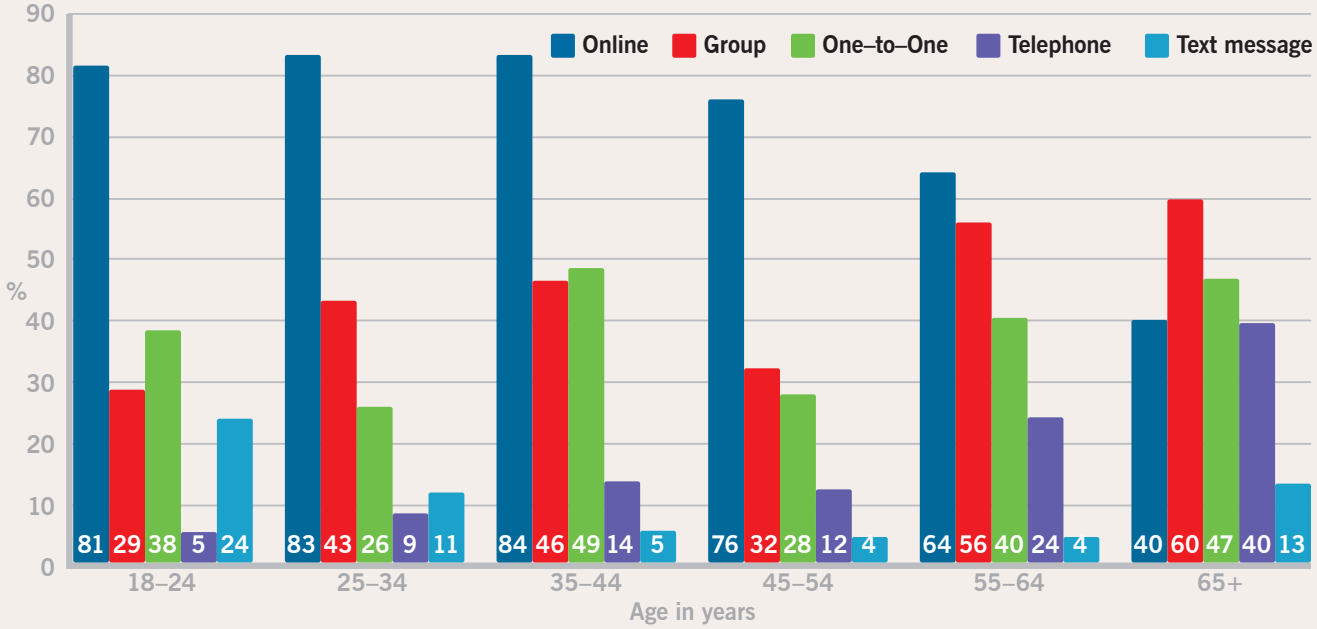
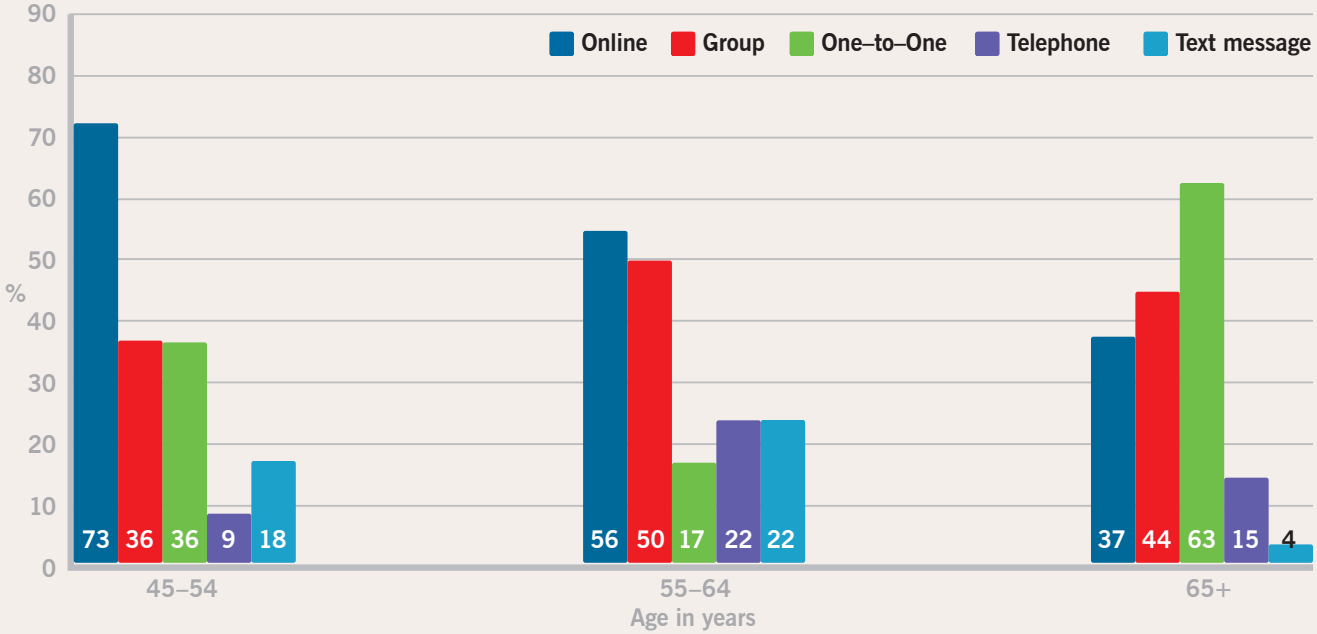


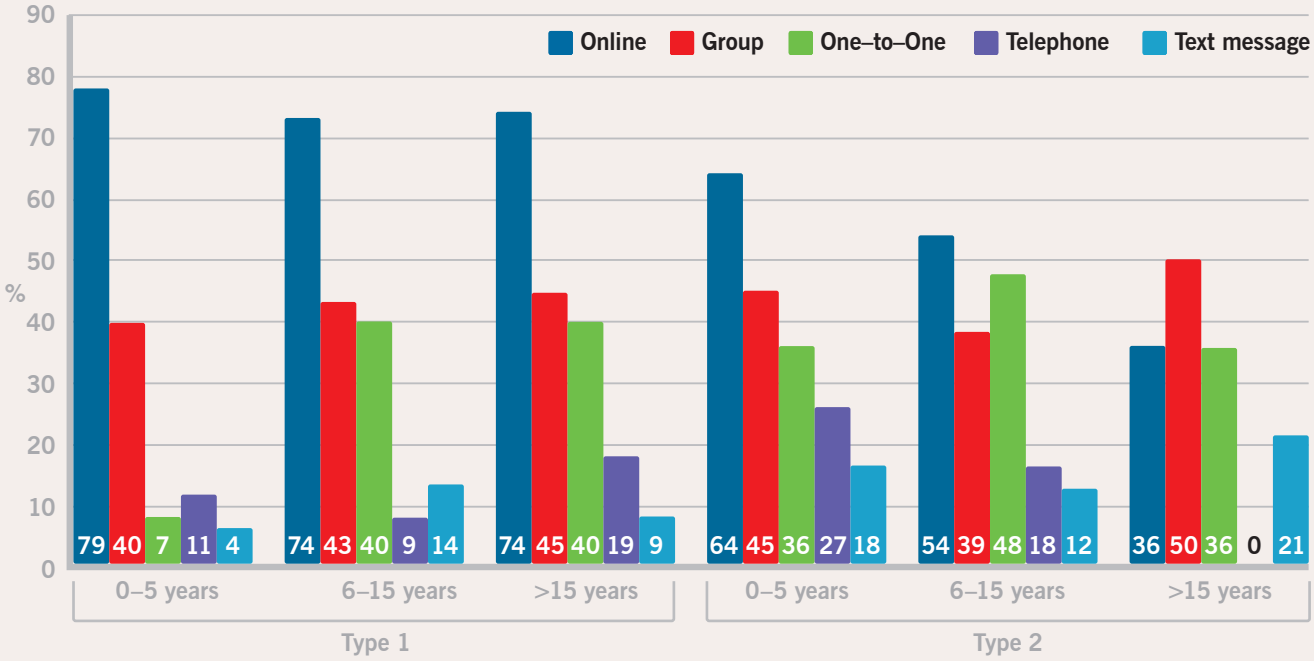
Figure 8. Preferences for peer support by age group of adults with type 2 diabetes currently participating (n=56)



Preferences by Diabetes Duration

Figure 9 displays the preferences of those who were currently participating in peer support by diabetes type and diabetes duration. Preference for online peer support remained relatively stable across diabetes durations for those with type 1 diabetes. In contrast, preference for online peer support decreased markedly as diabetes duration increased among respondents with type 2 diabetes. Preferences for face-to-face forms of support increased with diabetes duration for respondents with type 1 diabetes. For respondents with type 2 diabetes, a clear trend was less obvious. However, those with a diabetes duration of >15 years had a clear preference for group support. Preferences for telephone or text-based support were relatively low across all diabetes duration categories.

Figure 9. Preferences for peer support among those participating currently, by diabetes type and duration (n=217)

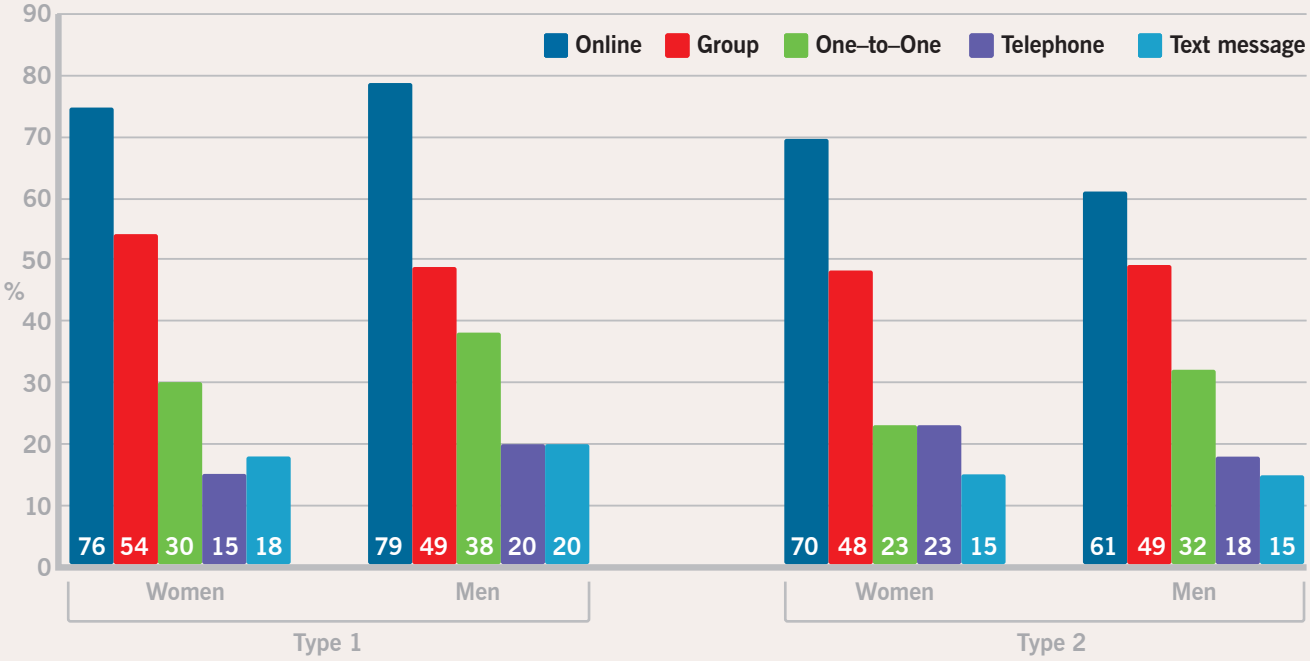


Preferences of Those Who Wish for Future Participation in Peer Support

Preferences by Gender

Figure 10 displays the preferences of those who wish to participate in peer support in the future, by diabetes type and gender. These preferences were not markedly different from the preferences of those who participate currently. Online delivery was, again, the most popular preference across diabetes type and gender (71%, n=509) with group peer support being the second most popular option (50%, n=357) and text messaging being the least favoured (17%, n=120). There were no notable gender differences in preferences for future peer support.

Figure 10. Preferences of those who wish for future participation in peer support, by diabetes type and gender (n=711)



Preferences by Age

The preferences of those wishing to participate in peer support in the future are shown by age group in Figure 11 for respondents with type 1 diabetes and Figure 12 for respondents with type 2 diabetes.

Among those with type 1 diabetes, online peer support was most popular with those under the age of 44 years. Although popularity of this delivery mode decreased gradually with age, it remained the most preferred delivery method across all age groups (Figure 11). Group peer support was the second most preferred option across all age cohorts with type 1 diabetes, and text messaging was the least preferred, with the exception of the 25-34 year age group.

Similar trends were found among those with type 2 diabetes (Figure 12). Online peer support was the most preferred option across all age groups, followed by group peer support and one-on-one peer support. Text messaging was least preferred as a mode of delivery by those over the age of 35 years, while telephone was the least preferred by those aged 34 years or younger.

Figure 11. Preferences of adults with type 1 diabetes wishing for future participation in peer support, by age group (n=374)

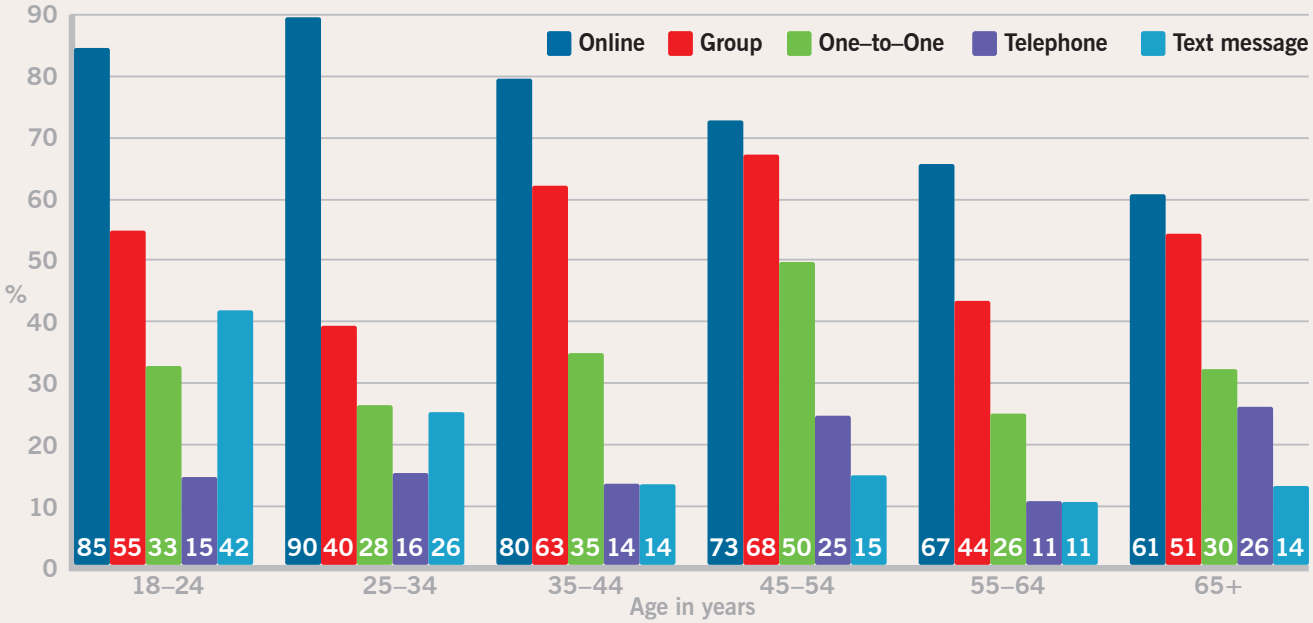
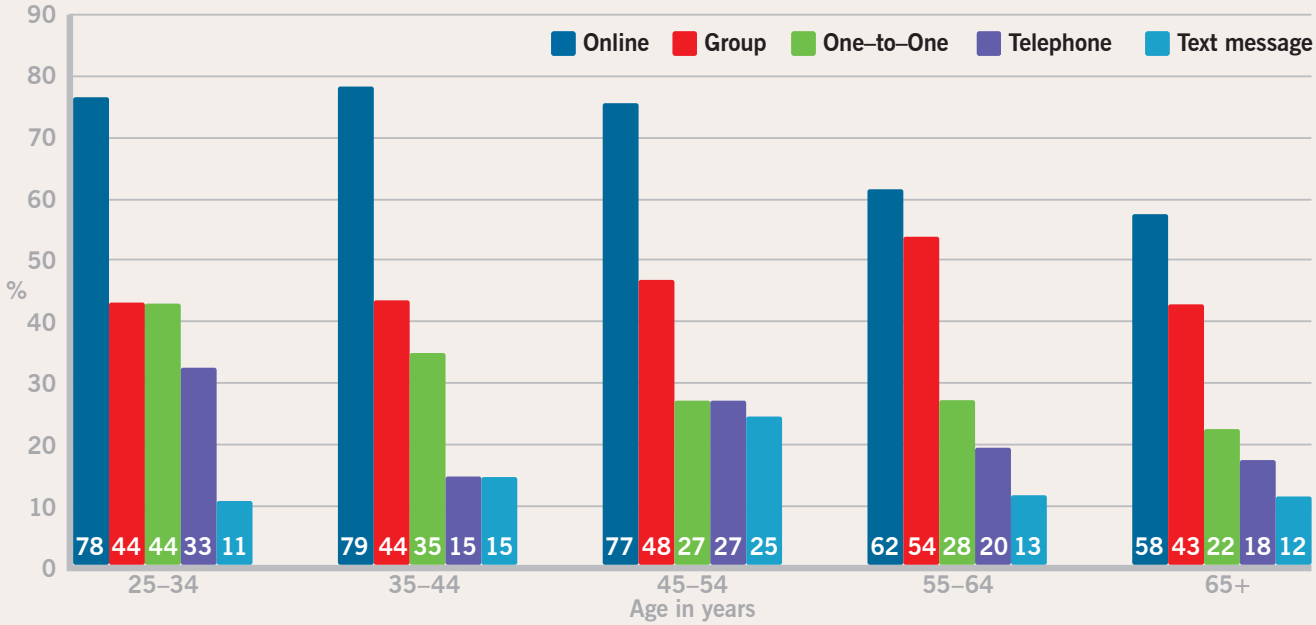


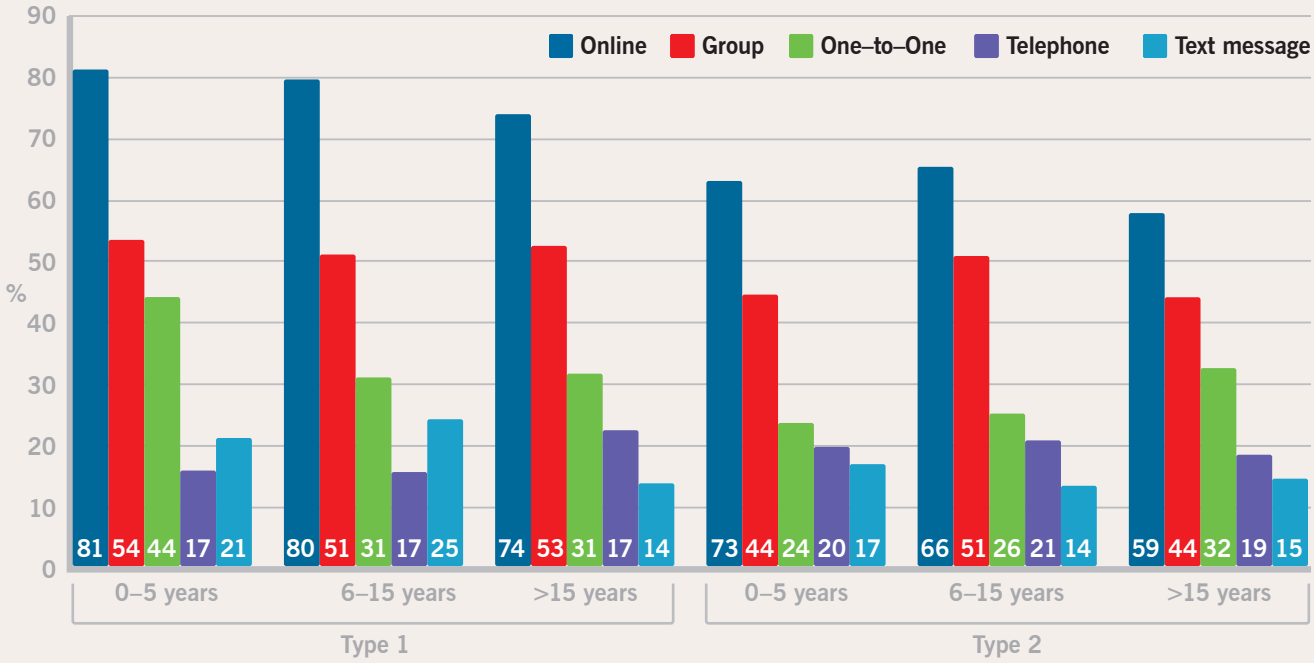
Figure 12. Preferences of adults with type 2 diabetes wishing for future participation in peer support, by age group (n=337)



Preferences by Diabetes Duration

There was a trend for preferences for online, support to decrease as diabetes duration increased, though more notably among the type 2 respondents as compared to the type 1 respondents (Figure 13). A preference for group support remained relatively stable across diabetes duration categories for both groups. Preferences for one-to-one support were higher among those with a lower diabetes duration (0-5 years) for type 1 respondents, but the opposite pattern was evident among the type 2 respondents, such that preferences for one-to-one support increased with duration. Preferences for telephone and text message support remained relatively stable across diabetes duration categories, though were relatively low throughout.

Figure 13. Preferences for peer support among those wishing for future participation, by diabetes type and diabetes duration (n=711)



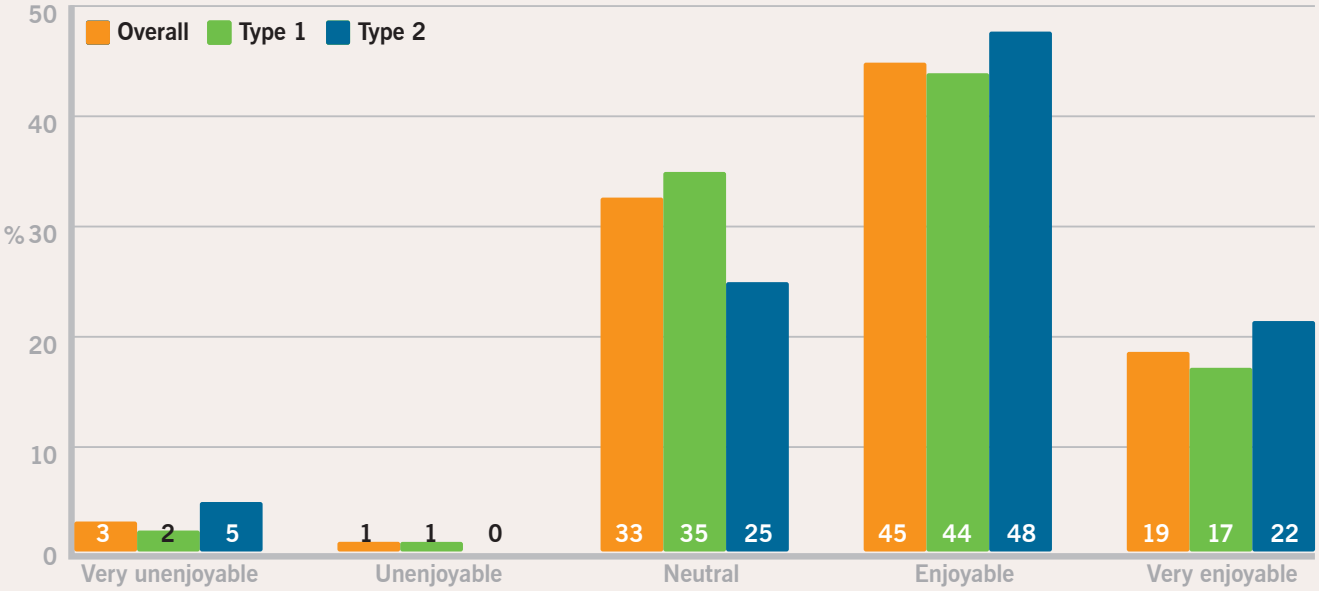
Subjective Experiences of Current Peer Support

Respondents participating currently in diabetes peer support were asked to evaluate their experiences in terms of enjoyment, helpfulness, and satisfaction.

Enjoyment

Respondents rated their enjoyment of diabetes peer support on a 5-point scale, ('very unenjoyable' to 'very enjoyable'). Overall, 64% (n=137) of respondents rated their current diabetes peer support as 'enjoyable' or 'very enjoyable'; only 4% (n=8) rated their peer support experiences as 'unenjoyable' or 'very unenjoyable' (Figure 14). Respondents with type 2 diabetes were slightly more likely to rate their peer support as 'enjoyable' or 'very enjoyable', compared with respondents with type 1 diabetes (70% versus 61%).

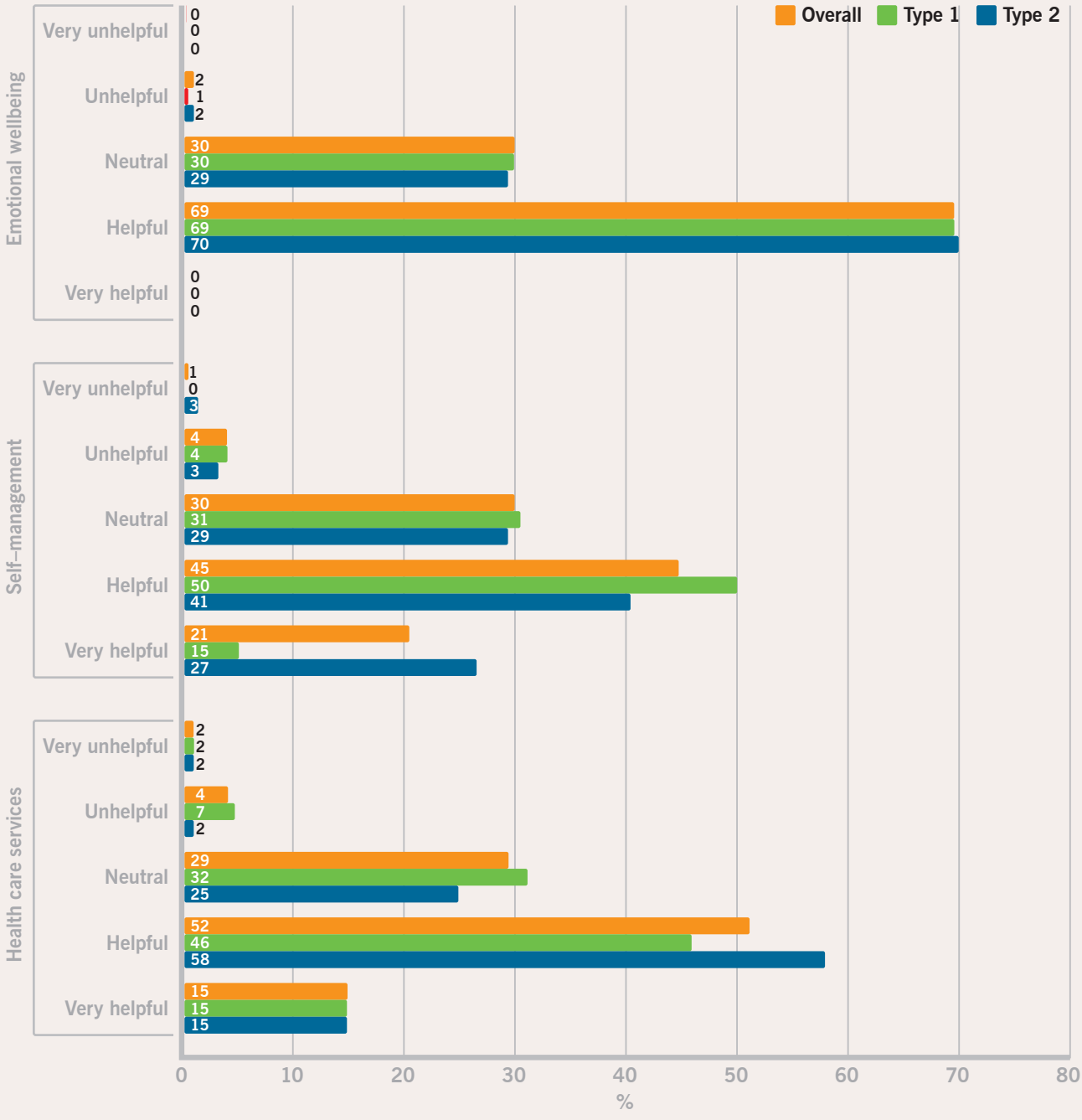
Figure 14. Enjoyment of current diabetes peer support by diabetes type (n=215)



Helpfulness

Respondents rated the helpfulness of their current diabetes peer support on a 5-point scale ('very unhelpful' to 'very helpful') on three support domains: 'emotional well-being', 'self-management', and 'connecting with healthcare services and resources' (Figure 15). Around two thirds of respondents indicated that their current diabetes peer support was 'helpful' or 'very helpful' on all three domains. The reported level of helpfulness of peer support for 'emotional well-being' and 'self-management' did not differ substantially by diabetes type. However, people with type 2 diabetes were more likely to report their peer support as 'helpful' or 'very helpful' for 'connecting with healthcare services and resources' than people with type 1 diabetes (73% versus 61%) (Figure 15).

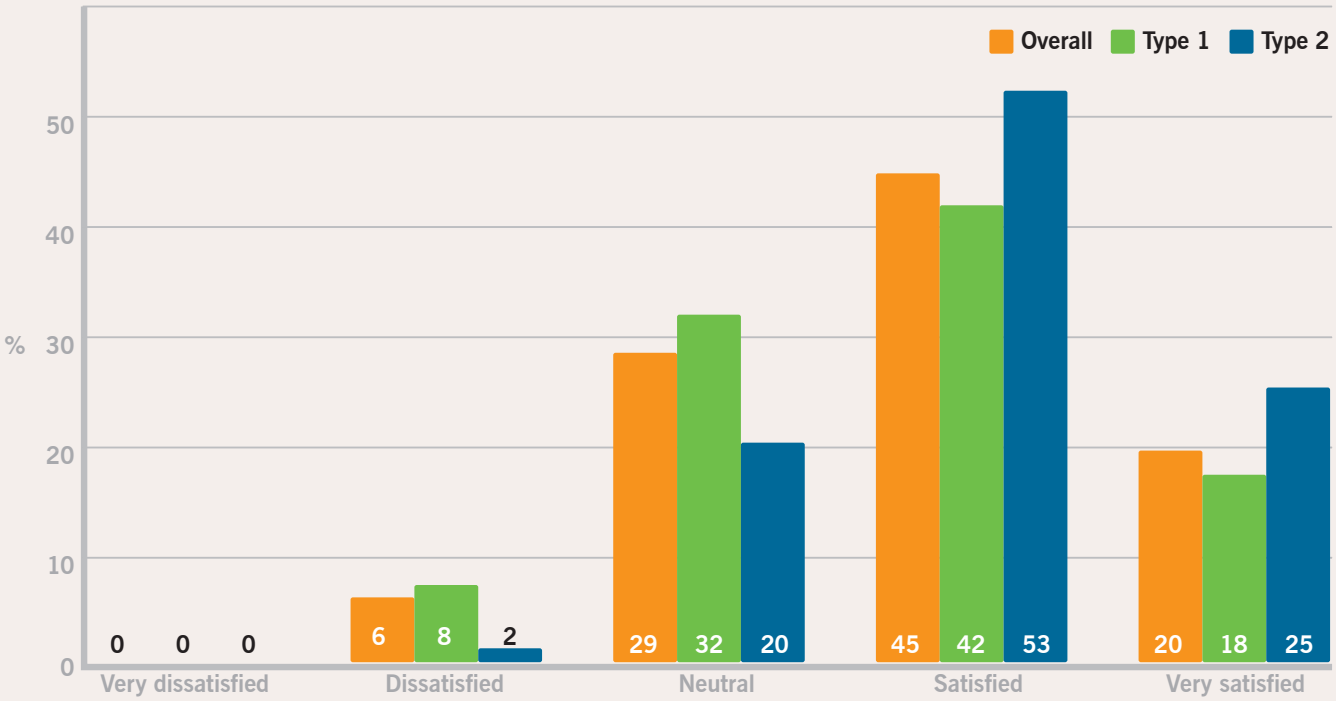
Figure 15. Perceived helpfulness of current diabetes peer support for a) emotional well-being, b) self-management and c) connecting with healthcare services, by diabetes type (n=217)



Satisfaction

Respondents rated their satisfaction with their current peer support on a 5-point scale ('very dissatisfied' to 'very satisfied'). Overall, 65% (n=141) reported that they were 'satisfied' or 'very satisfied', and those with type 2 diabetes reported higher satisfaction than those with type 1 diabetes (78% versus 60%; Figure 16). No-one reported being very dissatisfied.

Figure 16. Satisfaction with current diabetes peer support, by diabetes type (n=217)



69% of people currently participating in peer support, found that it was helpful to their emotional well-being, 66% helpful or very helpful to their self-management of diabetes, and 67% found that it was helpful or very helpful in connecting them with health-care services.

Benefits and Disadvantages of Peer Support

Respondents participating currently in diabetes peer support were asked to indicate what benefits and disadvantages they experienced from it. Respondents were asked to select up to three responses from a list of 10 possible benefits and three from a list of 10 possible disadvantages. They were then asked to rank their responses in order of importance.

Figure 17 shows the percentage of respondents who ranked each benefit as most important for them, by diabetes type. For adults with type 1 diabetes, the most frequently endorsed top-priority (ranked number 1) benefits were that peer support helps to 'make me feel like I'm not alone' (20%, n=32), and information and resource provision (19%, n=31). For adults with type 2 diabetes, the most frequently endorsed top-priority benefits were tied between access to diabetes information and resources (27%, n=15) and motivation to manage diabetes well (27%, n=15).

Figure 17. Top priority benefits of current diabetes peer support, by diabetes type (n=210)

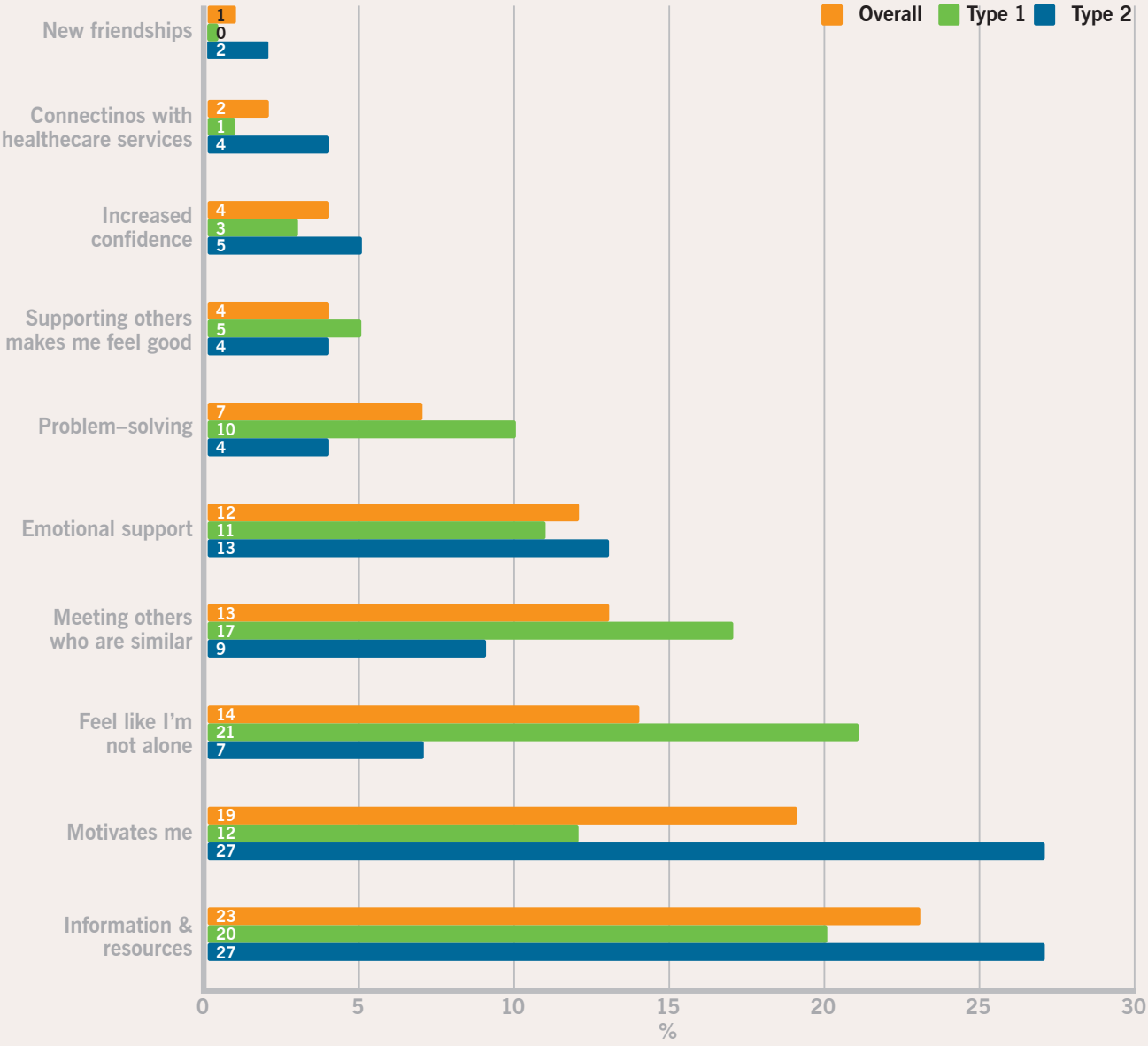
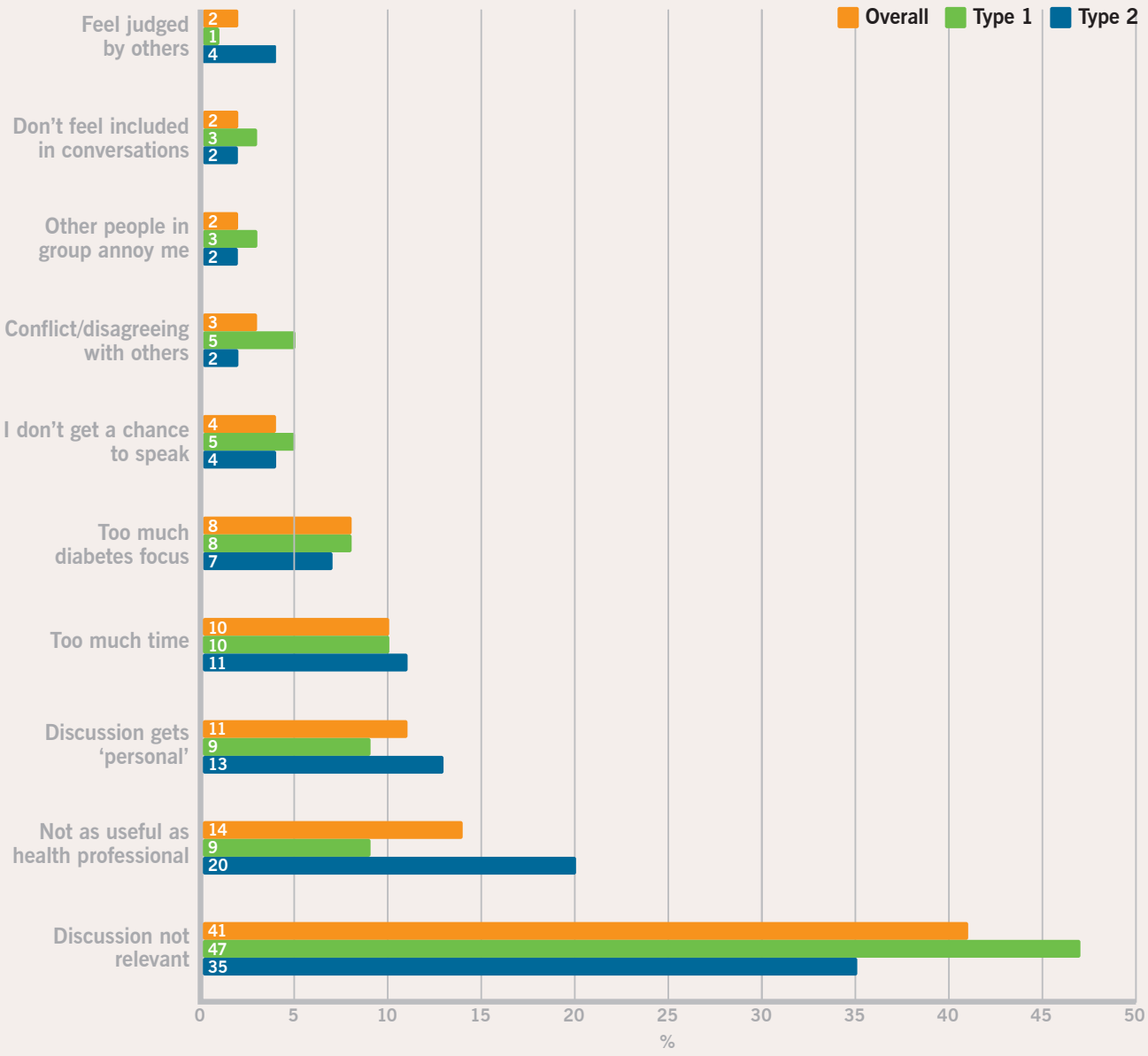


Figure 18 shows the percentage of respondents indicating each potential disadvantage of current diabetes peer support as the most important for them, by diabetes type. The most commonly reported disadvantage both for people with type 1 and type 2 diabetes was that the discussion was not relevant to them (collectively, 41%, n=87).

For respondents with type 1 diabetes, the second most commonly reported disadvantage was that peer support takes up too much time (10%, n=14), while for those with type 2 diabetes, the second greatest disadvantage was that it is 'not as useful as speaking to a health professional' (20%, n=19).

Figure 18. Top disadvantage of current diabetes peer support, by diabetes type (n=224)



Who is Not Accessing Peer Support and Why?

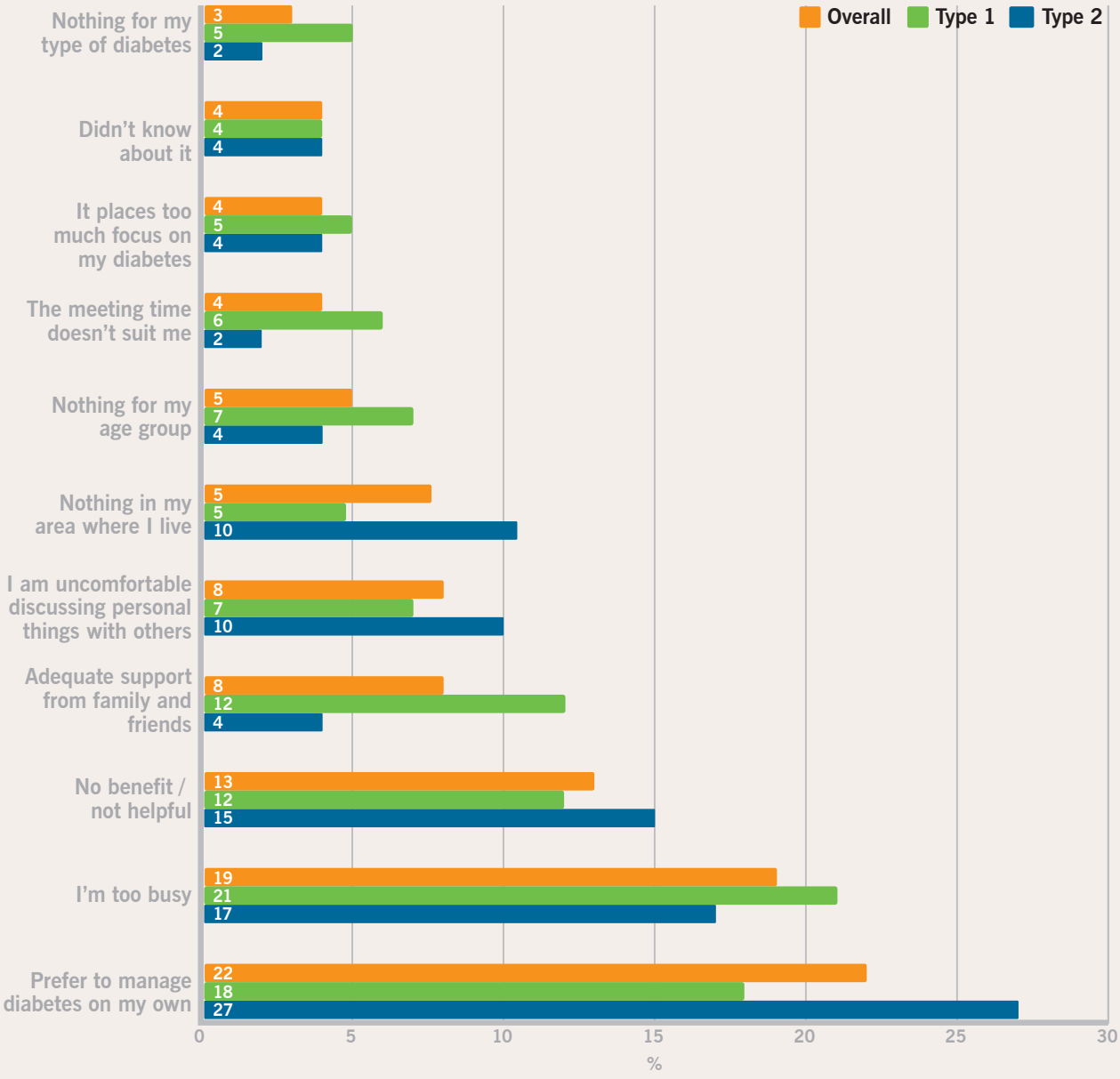
Reasons for not attending peer support

The majority of respondents (90%, n=2113) reported no current involvement in peer support and were asked to indicate their main reason for not participating, from a list of 11 options. The responses of those who indicated that they have previously participated (but are no longer participating) in peer support were analysed separately from the responses of those who had never participated in peer support.

People who have previously participated in peer support

A small minority of respondents had previously participated in peer support activities but were no longer doing so (9%, n=167; type 1 n=115, type 2 n=52). Among this group, the most frequently endorsed reason for not being involved currently was preferring to manage diabetes on their own (22%, n=32; Figure 19). This was also the most commonly selected reason among people with type 2 diabetes (27%, n=13), while for those with type 1 diabetes the most common reason for not participating in peer support was being too busy (21%, n=23).

Figure 19. The most frequently endorsed reason for no longer participating in diabetes peer support among those who have previously participated, by diabetes type (n=152)

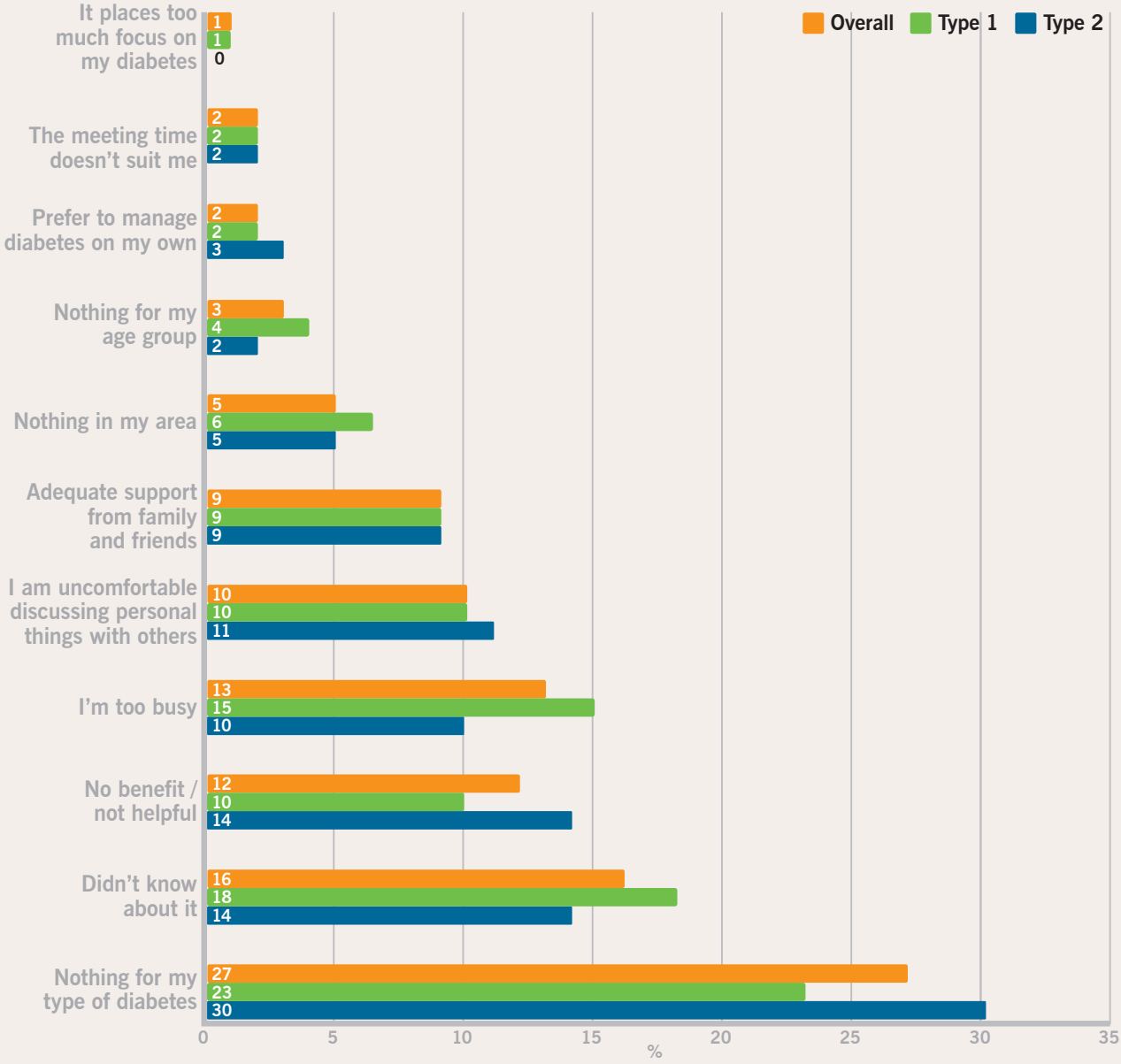


People Who Have Not Participated in Peer Support

Figure 20 shows the reasons for not participating in peer support among respondents who have never participated in peer support (93%, n=1563; type 1 n=657, type 2 n=942). Overall, the most common reason given was that there is 'nothing for my type of diabetes' (27%, n= 400).

This was the most common response for people with type 2 diabetes (30%, n=284) and for those with type 1 diabetes (23%, n=152). The second most common response was not knowing that diabetes peer support existed, endorsed by 18% (n=115) of adults with type 1 diabetes and 14% (n=132) of adults with type 2 diabetes.

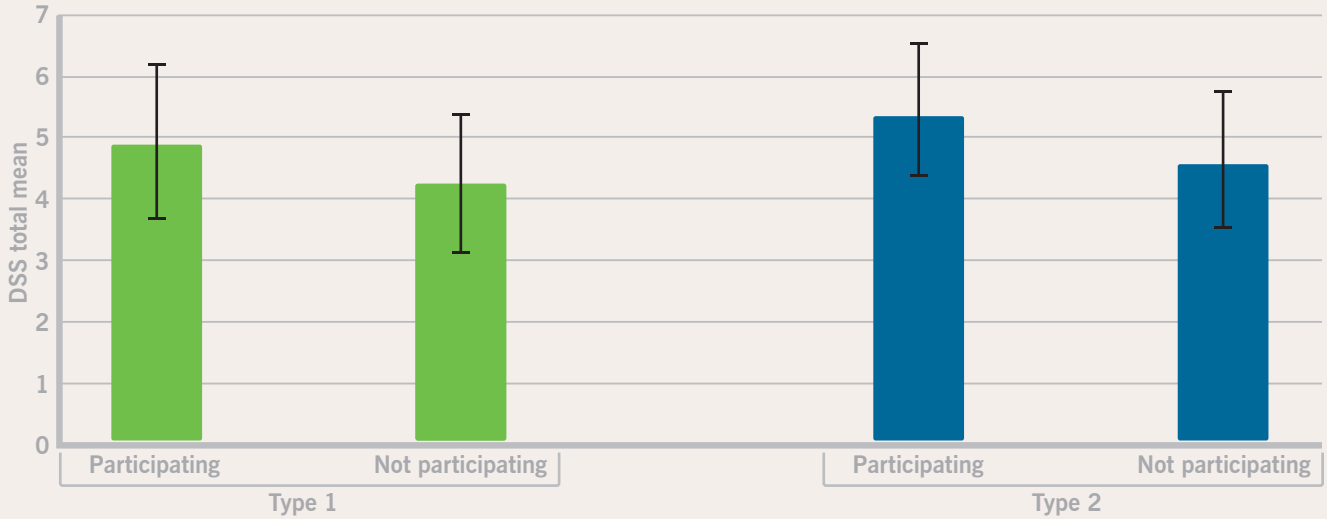
Figure 20. The most frequently endorsed reason for not participating in diabetes peer support among those who have never participated, by diabetes type (n=1599)



Perceived Social Support

The impact of current peer support participation on diabetes support was assessed using the Diabetes Support Scale (DSS) (see Methods). This instrument assesses perceived diabetes support in the forms of emotional support, advice, and information provision. Compared with those not participating in peer support, respondents currently participating had higher mean DSS scores, (Figure 21), suggesting that they perceive that they receive more social support for their diabetes. The difference in perceived social support by participation status was significant, both for respondents with type 1 and those with type 2 diabetes.

Figure 21. Perceived social support by diabetes type and peer support participation



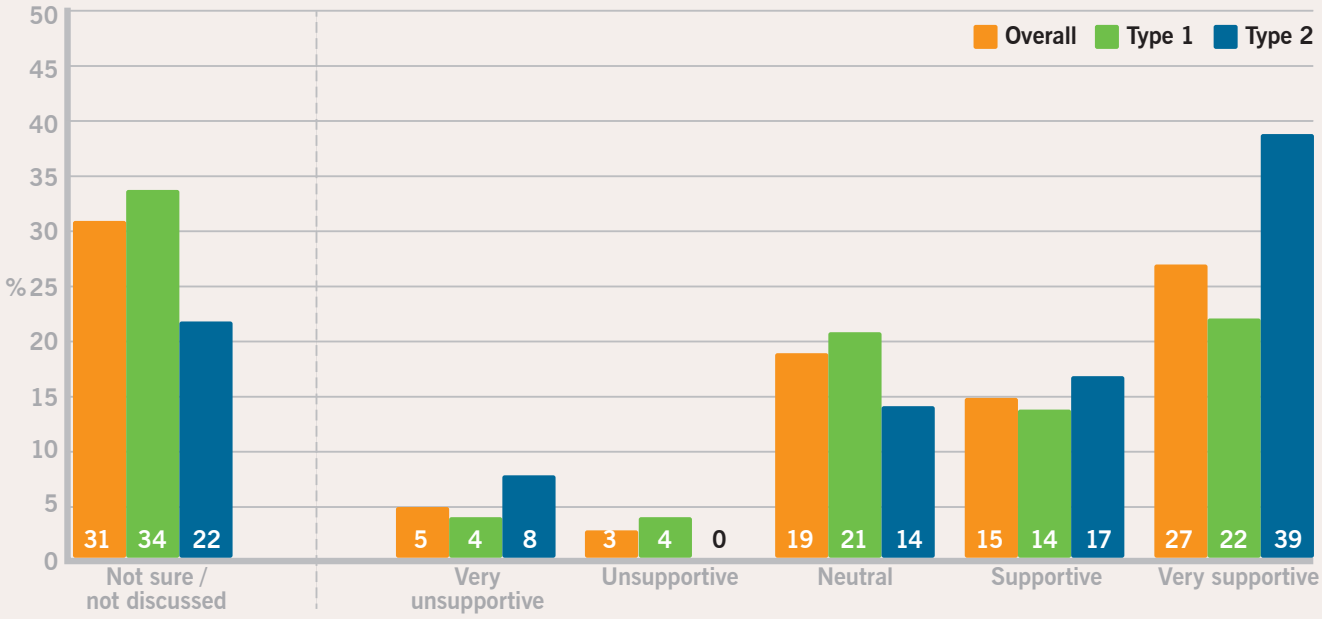
Bars represent mean score and error bars show standard deviation.

Type 1: $F=(1, 960)=44.39$, $p<0.01$ Type 2: $F=(1, 960)=44.39$, $p<0.01$

Health Professional Support

Respondents participating currently in diabetes peer support were asked to rate how supportive their diabetes health professionals were of their participation (Figure 22). Responses were scored on a 5-point scale ('very unsupportive' to 'very supportive') or respondents could indicate 'not sure/haven't discussed it'. Overall, one third of respondents (31%, n=67; type 1=34%, type 2=22%) indicated that they were not sure/ had not discussed the peer support with their health professional. Of those who responded to this question (n=150), people with type 1 diabetes were more likely to indicate that they had not discussed peer support with their health professional compared with people with type 2 diabetes (34% versus 22%). Regardless of diabetes type, less than 10% of respondents believed their health professionals to be 'very unsupportive' or 'unsupportive' of their participation in peer support. People with type 2 diabetes were more likely than those with type 1 diabetes to report that their health professionals were 'supportive' or 'very supportive' about their participation in peer support (56% versus 36%).

Figure 22. Responses to 'How supportive is your health professional about you participating in peer support?' by diabetes type (n=217)



Reflections on Ways to Improve Diabetes Peer Support

The views of those participating currently in diabetes peer support

Respondents who indicated that they were currently participating in diabetes peer support were asked to comment (using free-text boxes) on what changes could be made to improve their peer support experiences, and to enhance the diabetes peer support offerings in Australia. A total of 167 participants provided qualitative comments.

Of those who responded, 21% (n=35) indicated that they did not have any suggestions for improvement because they were happy with the way things were, and the peer support they were participating in was meeting their needs. A further 8% (n=14) respondents reported being unsure about what could be done to improve diabetes peer support.

Thus, suggestions were offered by 71% (n=118) of those who responded to this question. Key suggestions for what could be done to improve diabetes peer support initiatives included:

- Making peer support groups and forums more specific to diabetes type, age, and life-stage, so discussions could be more targeted and relevant, and meeting/activity times could be more suitable.

'If I knew the group was around the same age as me, and having similar thoughts or issues, I would be more inclined to speak up.'

Woman, age 28, type 1 diabetes

- Skilled moderation or facilitation of groups/forums to ensure inaccurate advice is not given and to encourage participation from all members.

'Facilitators that ensure equal participant participation of issues and discussion.'

Man, age 54, type 2 diabetes

- More local and accessible groups and initiatives, including more Australian online groups/forums.

'Most of the [forum] members are American. I would like to connect to more Aussies.'

Woman, age 57, type 1 diabetes

- More support, resources and funding (e.g. from diabetes state/territory member organisations, government, industry) for peer support groups and initiatives.

'Devote resources to facilitating [peer support] groups and help minimise the risks of peer support group leaders getting burnt out.'

Man, age 56, type 1 diabetes

- Better promotion of the available peer support initiatives, both to people with diabetes and healthcare professionals.

'[Organisations] should better promote the benefits of peer support and ensure it is made more accessible to all no matter where they live in Australia nor what their financial circumstances are.'

Woman, age 62, type 1 diabetes

The views of those not participating currently in diabetes peer support

Respondents who indicated that they were not participating currently in diabetes peer support were asked to comment (using free-text boxes) on what would make peer support groups more appealing to them. A total of 1264 participants provided a response.

Of all the respondents, less than three percent (n=33) indicated that they were too busy to engage in peer support, while almost half (47%, n=598) indicated that they did not have any suggestions.

The key suggestions of the 50% (n=631) of respondents who were not currently participating in diabetes peer support were very similar to the suggestions made by those currently participating, and included:

- Peer support groups need to be more specific to diabetes type, age, location, education level and/or stage of diabetes.

'If the demographic was similar to me - similar age range, education level, lifestyle. I don't see any benefit speaking with a 20-year-old who lives at home and is unemployed'.

Woman, age 44, type 1 diabetes

- Diabetes peer support needs to be more informative or educational about diabetes management and the latest developments in the field. This includes being moderated or facilitated by health professionals in order to keep groups 'on track' and dispel and misinformation that other group members may bring, and being more structured/organised.

'Combine with actual medical/specialist information so is not just "peer" mis-information'

Woman, age 41, type 2 diabetes

- Peer support groups need to be more positive. Many respondents reported feeling deterred from participating in peer support because they perceived other participants to be too negative. They suggested that peer support groups could be more social in nature, and not so heavily focused on diabetes.

'The online communities were helpful when I was first diagnosed. However, I found that belonging to the communities reinforced the idea that I was 'sick' or 'damaged' and this did not help me. Diabetes defines a lot of people who belong to online communities and I did not want to become one of those people'.

Woman, age 35, type 1 diabetes

'Lighten Up! I know diabetes isn't funny - but, hey, a little humour, a little fun goes a long way. If the support groups were more interactive, encouraging members to tell the funny stories about their diabetes experiences, send funny pictures, get together on what's working for them, have competitions for slogan-writing (I'd be in this!) - make it more down-to-earth people-friendly. Make it FUN!!!!'

Woman, age 74, type 2 diabetes

REFLECTIONS ON WAYS TO IMPROVE DIABETES PEER SUPPORT

- Face-to-face peer support groups need to accommodate people's work/ family commitments and be more flexible in their scheduled meeting times.

'Have them held outside of work hours as I work full-time all of the peer groups that I have enquired about are held mid-morning on week days'

Woman, age 48, type 1 diabetes

- More online peer support opportunities (e.g. *Facebook*, forums, Instagram, smartphone application etc.).

'Online would be best as I don't have time to travel to groups'

Woman, age 61, type 2 diabetes

- A substantial minority of respondents (15%, n=196) of respondents offered suggestions about the need to raise awareness about the existence of diabetes peer support, as many indicated they did not know that diabetes peer support was available.

'More advertising of them, discussion/notices in diabetes clinics. I just genuinely had no idea such a thing existed'

Woman, age 26, type 1 diabetes

'As I didn't know about these types of groups, I can't say what would make them better – but I would say it would be good if they were more widely known about'.

Woman, age 44, type 2 diabetes.

Discussion

The Diabetes Peer Support in Australia Study was the first large-scale national survey of Australians with type 1 or type 2 diabetes about their perceptions, preferences and experiences of peer support. The study provides significant insights about the current state of diabetes peer support in Australia, what Australians with diabetes want from peer support programs, and how the offerings can be improved nationwide to better meet the needs of people with diabetes.

Peer Support Participation

The survey revealed relatively low rates of diabetes peer support participation, with 11% of respondents indicating they currently participate in some form of peer support, and 9% indicating they used to take part. In contrast, the survey revealed relatively high levels of interest in diabetes peer support, with 38% of respondents indicating that they wished to participate in the future. This figure is consistent with findings from the 2011 Diabetes MILES – Australia survey, which found that 32% wanted to be involved specifically in a face-to-face support group[19]. In the current study, women, people with type 1 diabetes, and those with a higher education were more likely to indicate past, current and interest in future participation.

Overall, face-to-face groups administered by the diabetes state or territory member organisation were the most common form of diabetes peer support currently being accessed. Of those currently participating, almost 1 in 2 respondents with type 2 diabetes indicated they were involved in this kind of group, while 1 in 4 respondents with type 1 diabetes were involved in such a group. Respondents with type 1 diabetes were more likely to be participating in online initiatives, such as forums, *Facebook* groups, and OzDOC.

Among those who previously participated in peer support (but are no longer involved), reasons for not currently participating differed between the type 1 and type 2 diabetes groups. For those with type 1 diabetes, the main reason they were not currently involved with peer support was due to time constraints. This may suggest that peer support becomes less of a priority over time, perhaps because the need for support was less pronounced. For those with type 2 diabetes, the main reason for not being involved was that they preferred to manage their diabetes on their own. Indeed, peer support may not be for everyone: practical factors (e.g. distance from healthcare services) or individual factors (e.g. personality and preferences) are likely to influence one's experiences and perceptions of peer support, perhaps leading some to conclude that it is simply 'not for them'.

Among those who had never participated in peer support, the primary reason for not participating was the perception that there are no programs for 'my type' of diabetes. This was the most common response for both groups, though people with type 2 diabetes were more likely to report this response (around 1 in 3 respondents) than those with type 1 diabetes (around 1 in 4 respondents). The second most common reason for not participating was not being aware of the existence of peer support programs. This points to a key weakness in the system, namely that peer support programs are not reaching their target audience.

Peer Support Preferences

Online diabetes peer support was the preferred mode both for people who are currently participating, and for those who wish to participate in the future. Among those currently participating, a preference for online support was expressed by people with type 1 and type 2 diabetes, men and women, by all age groups except those aged 65+ years, and for all diabetes durations except those with type 2 diabetes who had been living with the condition for more than 15 years. Among those who wished to participate in the future, the preference for online support was consistent across both diabetes types and genders, and all age groups and diabetes durations.

This strong preference for online diabetes peer support stands in contrast to the pattern of actual participation for people with type 2 diabetes, suggesting that they either are not aware of the available online peer support initiatives, or that the existing online initiatives do not meet their needs.

Peer Support Perceptions and Experiences

Respondents who were currently participating in diabetes peer support indicated that, in general, their experiences were very positive. Around 2 in 3 respondents reported that it is enjoyable, helpful in terms of their self-management, emotional coping, and connecting them with healthcare services/resources, and that they are satisfied with the program(s) in which they are involved. Respondents who were currently participating had significantly higher perceived social support scores as compared to those not participating in peer support (regardless of diabetes type). Very small numbers of respondents rated their peer support experiences negatively, a finding that reflects well on existing programs. Response patterns were largely equivalent across diabetes types.

While respondents with type 1 and type 2 diabetes rated access to information and resources as a key benefit of diabetes peer support, other responses differed notably between the two groups. For people with type 1 diabetes, feeling as though they were not alone in their diabetes journey was a key benefit of peer support, but few people with type 2 diabetes indicated that this was an important benefit for them. Given the relatively small number of Australians living with type 1 diabetes, and the fact that they are more likely to be diagnosed in their youth, it is perhaps unsurprising that our findings suggest they are driven to engage in peer support in order to minimise feelings of isolation and loneliness. For those with type 2 diabetes, motivation for self-management was a key benefit offered by peer support. Management of type 2 diabetes often requires significant lifestyle change that can be difficult to initiate and sustain,[20] after years (perhaps decades) of habitualised behaviours. Previous research has shown that social support generally, and peer support specifically, has a positive impact on health behaviour change,21 and the results of the current study suggest that respondents with type 2 diabetes who participate in peer support are reaping these important benefits.

Respondents with type 1 and type 2 diabetes were in agreement that the main disadvantage of peer support is that the discussions are not always personally relevant. Limited research exists but some studies have identified 'off-topic postings' as common in online peer support forums or groups,[22] and a lack of 'control' over the nature and content of the discussions that take place in peer support groups.[23]

The Role of Health Professionals

Notably, around 1 in 3 respondents who were currently participating in diabetes peer support indicated that they were unsure of their health professionals' view of peer support or had not discussed it with them. While most respondents who were able to answer this question indicated that their health professional was supportive of their participation, almost 1 in 10 reported that their health professional was unsupportive. This points to a lack of connection between peer support programs and the formal healthcare system, which may be operating as a barrier to participation and a reason for the lack of support among some health professionals.

Suggestions for Improvement

Suggestions to make peer support more appealing included making peer support programs more specific (e.g. by diabetes type, location, age groups etc.), more informative, and to involve health professionals as moderators to ensure any myths or misconceptions are dispelled in a timely manner. Respondents also suggested more flexible scheduling of days and times, particularly for those who with work/study or family commitments. Other suggestions included making peer support more positive and less focused on the negative, and making the programs more social. A large portion of those who were not currently involved in peer support programs indicated not being aware that peer support existed and, thus, called for greater advertising / promotion of their existence.

Strengths and Limitations of the Study

The Diabetes Peer Support in Australia Study was unique in its focus, and offers new information for diabetes organisations, health professionals and policy makers to guide decisions about delivery of peer support programs. The large sample (including adults with type 1 and type 2 diabetes) is a key strength of this study.

While the sample was large (N=2342), the response rate was relatively low (11%). Participation was voluntary and thus the sample was self-selected, which may have introduced some bias. While respondents were from all over Australia, the majority of respondents were living in metropolitan areas of New South Wales, Victoria, and Queensland, which reflects the geographic distribution of NDSS registrants. People of both genders, and all ages and diabetes durations participated in the study. Six percent of respondents with type 2 diabetes were aged <45 years (proportional to the 4% registered with NDSS),[24] but the small number precluded further analysis regarding the perceptions, experiences and preferences of this emerging, high-risk group.

Further, all data were self-reported and due to participant anonymity, it was not possible to corroborate their reported peer support participation (or otherwise) with the relevant groups or organisations. In addition, the self-report nature of the study precluded collection of clinical data so we cannot explore relationships with biomedical outcomes such as HbA1c or diabetes complications.

Key Recommendations

The findings of this survey provide an evidence base for making five key recommendations for the future of diabetes peer support in Australia:

1. Provide online diabetes peer support initiatives.

There was a very strong preference for online diabetes peer support across diabetes types, genders, and most age groups and diabetes durations. While the pattern of participation was consistent with reported preferences for respondents with type 1 diabetes (the most commonly accessed peer support initiatives by this group were online), there was a notable disconnect between participation patterns and preferences among those with type 2 diabetes. This suggests that the current online offerings may not be sufficient (in terms of availability or relevance) for people with type 2 diabetes. Previous work conducted as part of the NDSS Mental Health and Diabetes National Development Programme found that most online diabetes peer support groups, forums and initiatives are based overseas, and there are a limited number that cater primarily to Australians with diabetes[25]. This gap needs to be addressed and is a priority area for future program development and delivery.

2. Increase engagement of men, people with less education, and people with type 2 diabetes in peer support.

The survey findings indicate that men, people with lower levels of formal education and people with type 2 diabetes were less likely to be participating currently in peer support, less likely to have participated in the past, and less likely to indicate wanting to participate in the future. It is possible that these people do not perceive and/or have not experienced any benefits of peer support, and thus self-select out of the programs. However, it is also possible that existing peer support offerings are not of a style or format that is appealing or accessible to these demographic groups. New, tailored programs or modifications to existing programs need to be made to reduce the barriers to participation for these groups. Further research is needed to understand exactly how to enhance accessibility and appeal of diabetes peer support.

3. Provide well-structured, expertly moderated/facilitated peer support initiatives.

Respondents expressed a wish for diabetes peer support programs to be more positive in tone and more social in format. However, they also expressed a desire for programs to be tailored to their diabetes type, age and life stage, to be embedded with up-to-date, evidence-based information and resources, and to be facilitated or moderated by either health professionals or trained, 'expert' peers to ensure that discussions are relevant and that participation is encouraged equally from all members. Previous research indicates that peer support combined with structured or semi-structured diabetes education is particularly effective.[21] While informal, unstructured gatherings of people with diabetes have their place and likely serve many positive purposes for those who participate, they can be hard to sustain and difficult for new members to find and access. We recommend moving towards a system that includes options for structured peer support programs that have infrastructure such as peer leader training, curricula, and topic-based discussions to ensure maximum effectiveness and longevity of the program; optional social elements can be incorporated into a structured program.

4. Increase promotion of existing diabetes peer support programs to improve awareness of, access to and reach of programs.

The survey findings indicate that a lack of awareness about the availability of diabetes peer support is a key barrier to participation. This demonstrates that existing diabetes peer support programs do not yet have sufficient reach, so that all people who want to participate can do so. Promotion of existing programs and initiatives (including those that exist online) through the NDSS and diabetes state/territory member organisations may go some way towards solving this problem. Referral into diabetes peer support programs by health professionals would also be advantageous.

5. Improve awareness and understanding of diabetes peer support among health professionals.

The survey findings suggest that as many as 1 in 3 respondents had not discussed diabetes peer support with their health professional, and around 1 in 10 respondents indicated that their health professional was unsupportive of their participation in diabetes peer support. This suggests two areas for future work: a) ensuring health professionals have access to the evidence base for peer support programs and are aware of its potential benefits (e.g. through a Diabetes Australia position paper or articles in the Diabetes Management Journal); b) peer support programs need to be better integrated and linked with the formal healthcare system and health professionals need to be better engaged with existing initiatives. For example, community health centres could host or administer support groups for their patients with diabetes, or health professionals could volunteer to be guest moderators on online forums.

Summary and Conclusions

The Diabetes Peer Support in Australia Study represents the first national survey of adults with type 1 and type 2 diabetes specifically focused on exploring their perceptions and experiences of, and preferences for, diabetes peer support. The study has contributed substantially to our knowledge about what people with diabetes perceive to be the strengths and weaknesses of diabetes peer support today, and how we can strengthen and improve the offerings nationally so that all people with diabetes who want to participate in peer support can do so.

Overall, there was a high level of interest in diabetes peer support, though actual participation rates were relatively low. There was a strong expressed interest in online diabetes peer support, although this was not the most common mode of support currently used by respondents. Those who are participating in peer support appear to be satisfied with it and find it useful, both for emotional and practical support; though the apparent lack of reach of such programs is clearly problematic. A lack of awareness about the existence of diabetes peer support programs was a key barrier to participation; and one that is relatively easily addressed. The findings of this study will be used to inform policy and program design and delivery to strengthen peer support and better meet the needs of Australians living with diabetes.

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APPENDICES

Appendix I: The NDSS Mental Health and Diabetes National Development Programme – Expert Reference Group

Name	Affiliation	State	Position
Prof Prasuna Reddy (Chair)	Flinders University	NSW	Health Psychologist
Assoc/Prof Roger Chen (Deputy Chair)	University of Sydney	NSW	Endocrinologist
Dr Gary Kilov	The Seaport Practice	TAS	General Practitioner
Dr Christine Walker	Chronic Illness Alliance	VIC	Health Sociologist; CEO of Chronic Illness Alliance
Ms Mari Harrison	N/A	ACT	Person with diabetes and dietitian
Ms Elizabeth Cornish	Austin Health: Diabetes Care-management & Assessment Service (DCAS)	VIC	Credentialed Diabetes Educator - Registered Nurse
Ms Kelly Wilson	beyondblue	VIC	Project Manager

Appendix II: Table of demographic characteristics of respondents by diabetes peer support participation

Demographics	Current participation			Past participation			Wish for future participation		
	Type 1 n=162	Type 2 n=62	Total n=224	Type 1 n=115	Type 2 n=52	Total n=167	Type 1 n=375	Type 2 n=343	Total n=718
Diabetes duration:									
0-5 years	29 (17)	12 (4)	31 (14)	11 (8)	6 (2)	17 (5)	53 (40)	67 (26)	120 (33)
6-10 years	18 (54)	14 (4)	32 (29)	16 (14)	14 (5)	30 (10)	59 (52)	107 (39)	166 (45)
11-15 years	25 (13)	21 (7)	46 (10)	26 (16)	14 (6)	40 (11)	81 (46)	88 (30)	169 (38)
>15 years	90 (23)	14 (5)	104 (14)	62 (21)	17 (4)	79 (12)	178 (49)	79 (30)	257 (39)
Age:									
18-24 years	22 (22)	-	22 (10)	15 (19)	-	15 (19)	33 (42)	-	33 (42)
25-34 years	35 (17)	0	35 (16)	23 (13)	0	23 (13)	95 (56)	9 (82)	104 (57)
35-44 years	37 (20)	3 (5)	40 (18)	23 (16)	3 (5)	26 (13)	71 (48)	34 (60)	105 (51)
45-54 years	25 (14)	11 (6)	36 (16)	19 (13)	5 (3)	24 (8)	60 (40)	65 (39)	125 (39)
55-64 years	27 (14)	18 (4)	45 (20)	19 (12)	21 (5)	40 (7)	73 (45)	123 (32)	196 (36)
65+	16 (14)	30 (6)	46 (21)	16 (16)	23 (5)	39 (7)	43 (44)	112 (25)	155 (28)
Gender:									
Women	130 (23)	30 (6)	160 (15)	65 (15)	32 (7)	97 (11)	232 (52)	176 (40)	309 (46)
Men	32 (8)	32 (5)	64 (6)	49 (13)	20 (3)	69 (7)	142 (40)	167 (27)	408 (31)
Prefer not to say	-	-	-	1 (50)	-	1 (50)	1 (50)	-	1 (50)
State/ territory:									
ACT	6 (12)	1 (1)	7 (4)	5 (12	5 (4)	10 (6)	21 (50)	39 (33)	60 (37)
NSW	48 (16)	20 (9)	68 (13)	38 (15)	9 (4)	47 (10)	118 (46)	76 (36)	194 (41)
NT	1 (11)	1 (3)	2 (4)	1 (12)	0	1 (2)	5 (63)	15 (44)	20 (48)
QLD	27 (21)	9 (7)	36 (14)	12 (12)	6 (5)	18 (8)	47 (47)	42 (36)	89 (41)
SA	13 (17)	4 (4)	17 (9)	6 (9)	1 (1)	7 (4)	25 (40)	25 (40)	50 (30)
TAS	2 (5)	7 (6)	9 (6)	6 (16)	6 (6)	12 (9)	22 54)	22 (54)	44 (32)
VIC	54 (21)	14 (5)	68 (13)	35 (17)	16 (6)	51 (11)	94 (47)	88 (34)	182 (40)
WA	11 (10)	6 (4)	17 (7)	12 (13)	9 (7)	21 (9)	43 (25)	36 (27)	79 (35)
Region:									
Metropolitan	92 (15)	41 (6)	133 (10)	79 (15)	30 (5)	109 (9)	235 (45)	200 (31)	435 (38)
Regional	51 (21)	16 (6)	67 (13)	21 (11)	11 (4)	32 (7)	99 (52)	87 (34)	186 (42)
Rural	19 (17)	5 (3)	24 (8)	15 (16)	11 (6)	26 (9)	41 (44)	56 (31)	97 (35)
Australian born:									
No	26 (11)	21 (6)	47 (8)	26 (13)	11 (3)	37 (7)	98 (49)	109 (34)	207 (40)
Yes	136 (18)	41 (5)	177 (11)	89 (15)	40 (5)	129 (10)	277 (46)	234 (31)	511 (38)
Relationship status:									
Single	45(16)	16 (5)	61 (10)	39 (16)	17 (6)	56 (8)	122 (51)	97 (34)	219 (42)
Partnered	115 (17)	46 (5)	161 (11)	76 (13)	35 (4)	111 (8)	253 (45)	246 (31)	499 (38)
Income:									
<$20,000	21 (18)	11 (6)	32 (10)	11 (12)	10 (5)	21 (8)	45 (48)	60 (33)	105 (38)
$20,001- $40,000	22 (20)	14 (5)	36 (10)	17 (20)	15 (6)	32 (10)	41 (47)	78 (32)	119 (36)
$40,001 - $60,000	14 (11)	8 (4)	22 (7)	13 (12)	9 (5)	22 (8)	53 (49)	50 (30)	103 (37)
$60,001- $100,000	39 (18)	10 (4)	49 (13)	18 (10)	2 (1)	20 (6)	96 (53)	53 (36)	149 (46)
>$100,001	45 (17)	7 (3)	52 (26)	35 (15)	5 (2)	40 (8)	86 (40)	58 (34)	144 (37)
Prefer not to say	17 (13)	10 (6)	27 (9)	19 (16)	11 (8)	30 (11)	51 (44)	43 (30)	94 (36)
Education:									
<Year 12	16 (10)	16 (6)	32 (8)	18 (16)	17 (5)	35 (8)	37 (37)	87 (30)	124 (33)
Year 12	24 (15)	10 (8)	34 (12)	13 (10)	3 (3)	16 (7)	64 (48)	37 (33)	101 (41)
Vocational training	29 (13)	21 (6)	50 (9)	22 (11)	16 (5)	38 (7)	97 (49)	106 (32)	203 (38)
University degree	90 (19)	15 (4)	105 (12)	62 (17)	16 (4)	78 (10)	177 (48)	113 (32)	290 (40)
Employed:									
No	61 (21)	44 (6)	105 (10)	33 (14)	31 (5)	34 (7)	106 (46)	194 (30)	300 (34)
Yes	101 (15)	18 (4)	119 (11)	82 (14)	21 (5)	103 (10)	269 (47)	149 (37)	416 (43)

Data are n (%). All reported percentages are the percentage of respondents who indicated 'yes' to each participation type.
NB: Not all participants answered every question.
– indicates that there were no respondents in this category.

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