

NDSS Diabetes in Pregnancy National Development Program

Contraception, Pregnancy & Women's Health Survey

Summary report

August 2015

Acknowledgments

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NDSS Diabetes in Pregnancy National Development Program

The NDSS Diabetes in Pregnancy National Development Program (NDP) aims to address the need for pre-pregnancy planning and care in women with diabetes and promote optimal diabetes management during pregnancy.

To identify strategies for the NDSS Diabetes in Pregnancy NDP and guide the development of project activities, a needs assessment was undertaken with women with type 1 and type 2 diabetes

The Contraception, Pregnancy & Women's Health Survey

The *NDSS Contraception, Pregnancy & Women's Health Survey* was a national survey of women with type 1 or type 2 diabetes undertaken to better understand awareness, knowledge and beliefs regarding pregnancy as well as the information and support needs of women.

This report summarises some of the key findings of this survey and makes recommendations for strategies to address the information and support needs of Australian women with diabetes in relation to preconception counselling and pre-pregnancy care.

The aims of this survey were to:

1. Determine recall of preconception counselling among Australian women with diabetes;
2. Describe women's experiences with preconception counselling and identify factors associated with provision of preconception counselling;
3. Determine the current level of knowledge about contraception, pregnancy and diabetes among women with diabetes;
4. Describe attitudes and beliefs of women with diabetes in relation to pregnancy, contraception and family planning;
5. Determine awareness of the need for pre-pregnancy care and intention to seek pre-pregnancy care among women with diabetes;
6. Describe women's experiences with pre-pregnancy care and factors associated with the uptake of pre-pregnancy care among women with prior pregnancies;
7. Identify the information needs of women in relation to pregnancy and diabetes and preferred format for receiving information; and
8. Identify appropriate strategies for reminding women of the need to plan and prepare for pregnancy and determine perceptions of an NDSS delivered pregnancy reminder system.

About the survey

The self-administered survey was available available online or as a written postal survey. The project was approved by Deakin University Human Research Ethics Committee.

The survey questions

The survey questions were based on diabetes and pregnancy guidelines,^{1,2,3} the findings from a project literature review and consultation with experts in pregnancy and diabetes, as well as survey design.

The survey included 66 questions to collect information on demographics (13 questions), diabetes management (8 questions), pregnancy and contraception information (17 questions), diabetes and pregnancy care (11 questions), knowledge and beliefs (7 questions) as well as pregnancy information needs and pre-pregnancy reminders (10 questions). Knowledge and beliefs questions were adapted with permission from published questionnaires.^{4,5} The survey was pilot tested with seven women with diabetes and feedback provided by telephone interview.

Who was invited to take part?

Women registered on the NDSS were invited to complete the survey. Postal invitations were sent to 6000 Australian women randomly selected from the NDSS database who had type 1 diabetes or type 2 diabetes, had consented to be contacted for research and were aged 18-50 years.

Women were sent a letter explaining the purpose of the survey, a plain language statement and a flyer promoting the online survey (with the option of requesting a paper copy). A reminder postcard was sent three weeks after the initial invitation.

To promote the survey, flyers were provided to Diabetes Australia agents for display in retail outlets, and were sent to health professional contacts who specialised in pregnancy and diabetes.

The survey was promoted on social media and online diabetes networks including Facebook pages of NDSS and Diabetes Australia agents, the Type 1 Diabetes Network Facebook page and website, and the Australian Centre for Behavioural Research in Diabetes newsletter and website.

About the results

Of the 6000 women from the NDSS database invited to participate, a total of 967 women with type 1 or type 2 diabetes participated.

Who completed the survey?

Women who completed the survey were an average age of 34 years. Most women were living with type 1 diabetes (77%), were born in Australian (81%) and spoke English as their main

language at home (96%). Women from all states and a variety of different geographic areas completed the survey. These results are shown in Table 1.

Table 1: Characteristics of women who completed the survey (n=967)

	n (%)
Type of diabetes	
Type 1	741 (77%)
Type 2	226 (23%)
Age group	
18-24 years	142 (15%)
25-34 years	359 (37%)
35-44 years	315 (33%)
45 -50 years	150 (16%)
State/territory	
New South Wales	293 (30%)
Queensland	217 (22%)
Victoria	211 (22%)
Western Australia	117 (12%)
South Australia	79 (8%)
Tasmania	23 (2%)
Australian Capital Territory	22 (2%)
Northern Territory	5 (<1%)
Geographic location	
Metropolitan	539 (56%)
Regional	294 (30%)
Rural/Remote	132 (14%)
Country of birth	
Australia	785 (81%)
Other	181 (19%)
Level of education	
No formal qualifications	18 (2%)
Year 10/11 or equivalent	94 (10%)
Year 12 or equivalent	154 (16%)
Certificate, diploma or trade qualification	301 (31%)
University degree or higher	399 (41%)
Employment	
Working full time	340 (35%)
Working part time or casual	284 (29%)
Maternity leave from paid work	39 (4%)
Full time home duties	127 (13%)
Unemployed	61 (6%)
Retired	2 (<1%)
Student	66 (7%)

1. Diabetes management and health care

Diabetes treatment

Most women with type 1 diabetes indicated that they managed their diabetes using insulin injections (53%) with the remaining (47%) using an insulin pump. Just over one quarter (26%) of women with type 2 diabetes managed their diabetes with insulin injections, 76% with diabetes medication and 63% with diet and lifestyle.

Height and weight

Height and weight was self-reported and body mass index (BMI) calculated (weight/height (m²)). The average BMI of (non-pregnant) respondents was 28.7 and 62% of women were in the overweight or obese categories (BMI 25 or above).

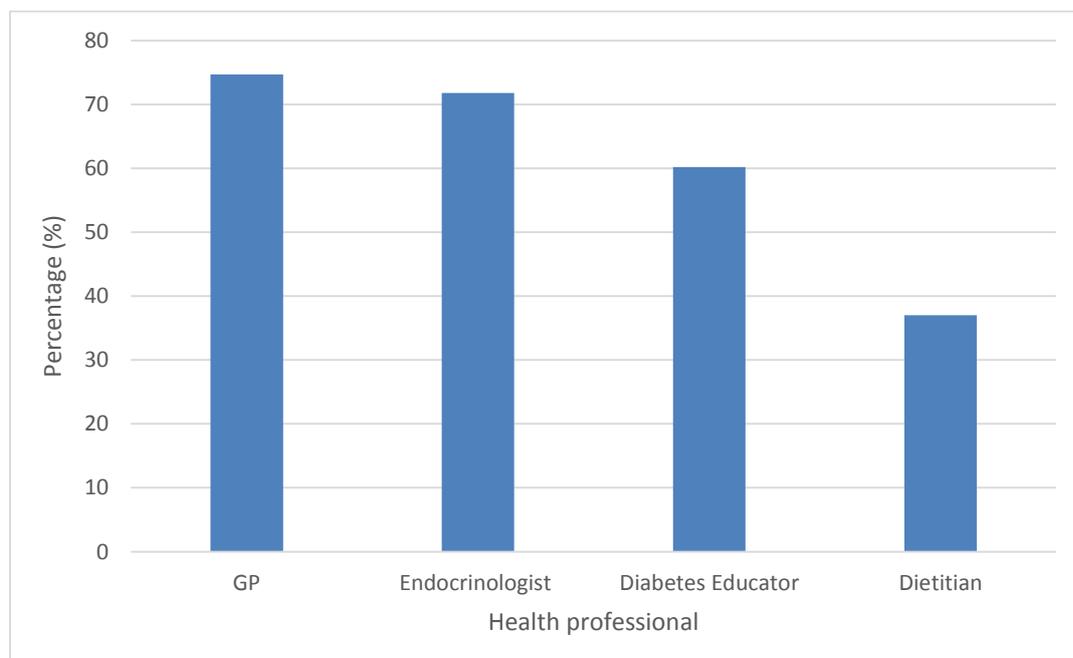
Diabetes complications and other conditions

54% of women reported having one or more diabetes complication or related health condition.

Health care

Respondents indicated the health professionals they had seen in the past 12 months for diabetes management including the frequency of visits. They also indicated the number of visits to their General Practitioner (GP) which were predominately for diabetes management. Figure 1 shows the different health professionals seen by women with diabetes in the past 12 months for diabetes management.

Figure 1: Health professionals seen in the past 12 months for diabetes management (n=967)



The average number of visits to a GP in the past 12 months was 7 visits (range 0-20), with an average of 3 visits being mainly for diabetes. Women with type 2 diabetes reported seeing a GP for diabetes management more often (4 visits) than women living with type 1 diabetes (2 visits).

2. Pregnancy and contraception information

Preconception counselling

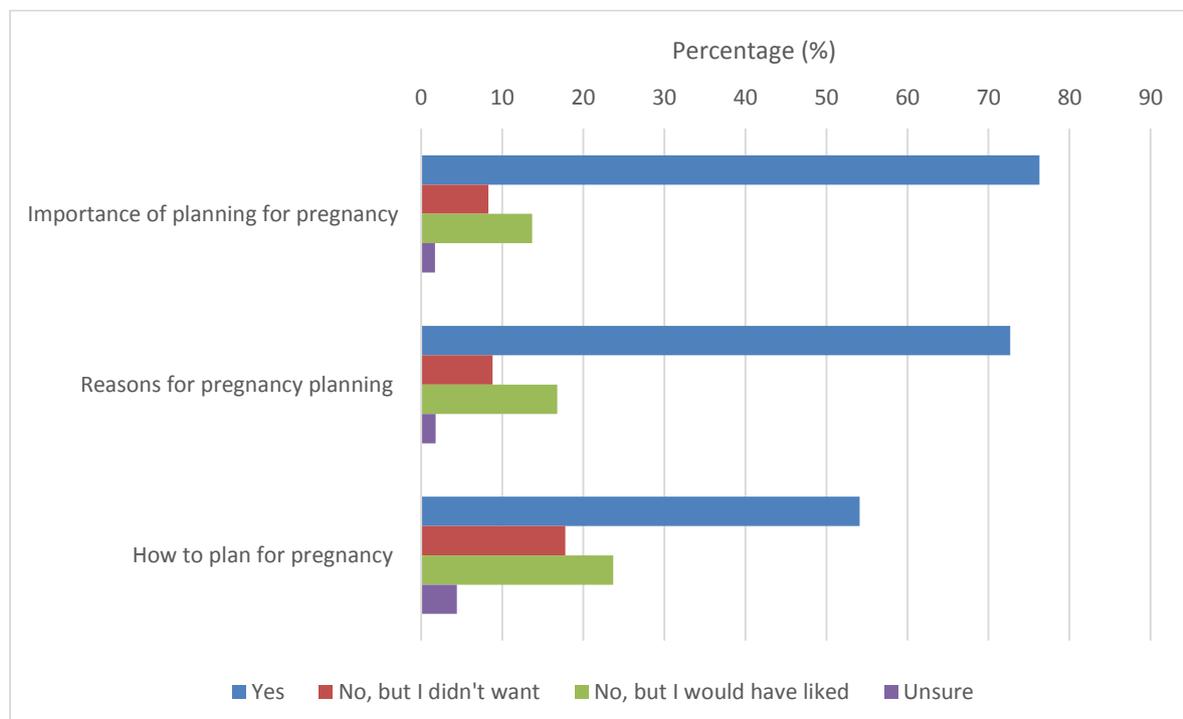
Since being diagnosed with diabetes 70% of women reported talking to a health professional about pregnancy; 79% of women with type 1 diabetes and 44% of women with type 2 diabetes could recall having this conversation with a health professional.

Women talked to a number of different health professionals about pregnancy and diabetes including an Endocrinologist (77%), GP (71%), Diabetes Educator (53%), Obstetrician (45%), Midwife (21%) and Dietitian (16%).

Of women who spoke to more than one health professional, 76% stated that consistent information and advice was provided about pregnancy and diabetes. Fifty nine percent of women said they started the conversation about pregnancy and diabetes with a health professional.

The type of information provided by health professionals during these conversations is shown in Figure 2, including whether or not women would have liked this information (if not provided).

Figure 2: Pregnancy information provided by health professionals to women with diabetes (n=967)

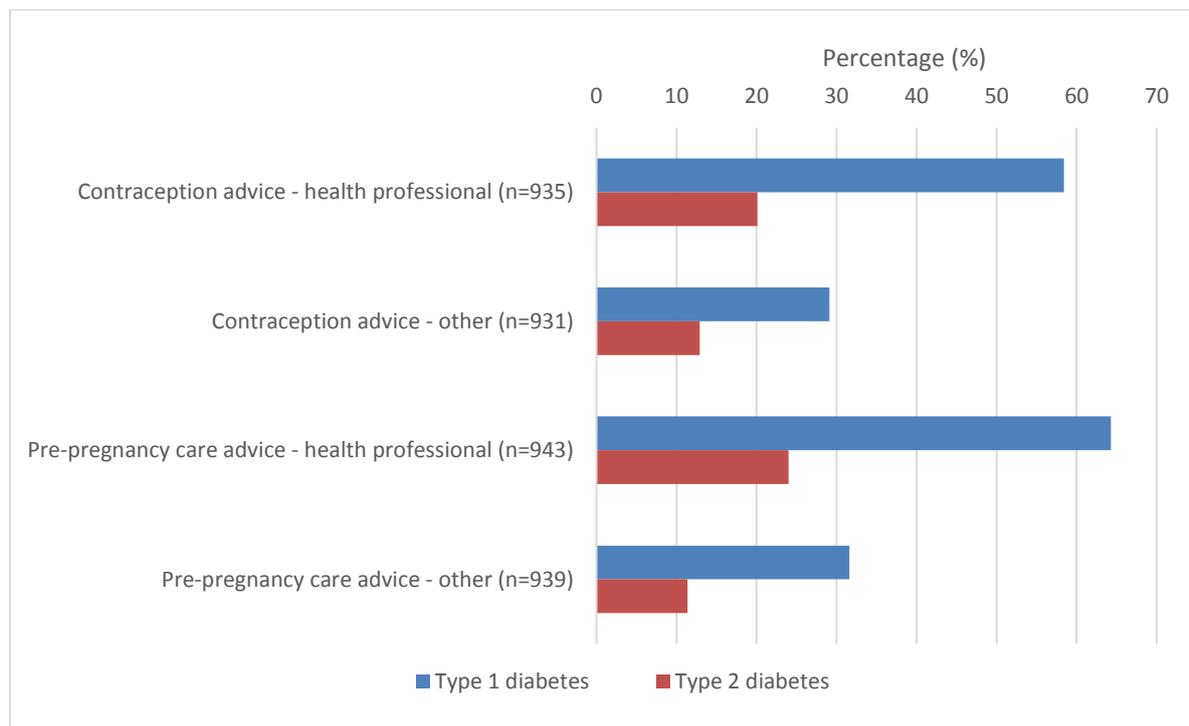


Contraception and pre-pregnancy planning advice

Forty nine percent of women could recall being advised by a health professional to *use some form of contraception to prevent an unplanned pregnancy*, and 25% reported being told this by a partner, family member or friend.

Fifty five percent of women could recall being advised by a health professional that they should get *diabetes specific pre-pregnancy care before falling pregnant or planning a pregnancy*, and 27% reported being told this by a partner, family member or friend. These results differed by type of diabetes, as shown in Figure 3.

Figure 3: Contraception and pre-pregnancy care advice by type of diabetes



Women rated their confidence in discussing pregnancy and diabetes with a health professional on a scale of one (not confident at all) to ten (very confident). The average confidence rating was 8 out of 10.

Pregnancy and diabetes knowledge

There were 13 pregnancy and diabetes knowledge questions asked of all women, with one additional question for women with type 2 diabetes. Three possible answers were included – true, false and not sure. The results of the knowledge questions are shown in the table below.

Table 2: Knowledge about pregnancy and diabetes among women with diabetes

Knowledge question	True or false	Answered Correctly*
Women with diabetes cannot take the oral contraceptive pill	False	89%
Women with diabetes have very limited (few) choices of contraception ^(a)	False	81%
Women with diabetes can have a healthy baby	True	96%
Women with diabetes should get diabetes-specific advice from a health professional before falling pregnant	True	93%
Women with diabetes should take the same amount of folate as all other women during pregnancy ^(b)	False	24%
Blood glucose levels around the time you fall pregnant can affect the health of the baby ^(a)	True	72%
High blood glucose levels early in pregnancy do not increase the risk of birth defects ^(a)	False	61%
High blood glucose levels early in pregnancy increase the risk of miscarriage ^(a)	True	60%
High blood glucose levels early in pregnancy do not increase the risk of problems for mother ^(a)	False	81%
High blood glucose levels early in pregnancy do not increase the risk of problems for baby ^(a)	False	78%
Women with diabetes have an increased risk of having a large baby, making delivery more difficult	True	82%
Women with diabetes are recommended to breastfeed	True	48%

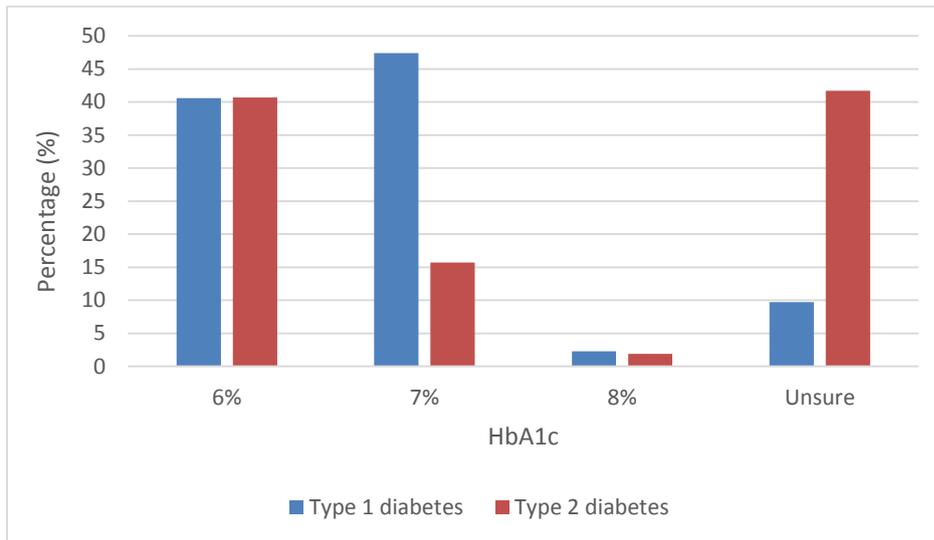
* Remaining responses were either incorrect or unsure

(a) Question adapted from Charron-Prochownik et al. 2006; (b) Question adapted from Holmes et al. 2012. Bold answers are correct.

Women with type 2 diabetes were asked an additional knowledge question about whether or not they may need to change to insulin when planning a pregnancy. Thirty eight percent (38%) of women answered this question correctly.

Women were asked about the recommended HbA1c level before pregnancy in a separate question. These results are shown below.

Figure 4: HbA1c targets for pregnancy in women with diabetes (n=927)



Women were asked to rate their understanding about how diabetes and pregnancy affect as score out of 10 (poor to excellent). 38% percent of women rated their knowledge as high (scores 8 out of 10 and above).

3. Pregnancy and diabetes

Six percent of women were pregnant at the time of completing the survey. Of women who were not currently pregnant 19% were thinking about planning a pregnancy, 8% were trying to fall pregnant and 73% were not planning a pregnancy or trying to fall pregnant.

Pre-pregnancy care

Of women who had been pregnant since being diagnosed with type 1 or type 2 diabetes, were currently pregnant or trying to fall pregnant 54% reported having attended pre-pregnancy care. The reasons reported for not attending pre-pregnancy care are shown in the table below.

Table 3: Reasons for not attending pre-pregnancy care

Reason	
I didn't know pre-pregnancy care was available	48%
My pregnancy was not planned	47%
I already knew what I needed to do	19%
I fell pregnant sooner than expected	18%
Practical barriers (e.g. time, cost, childcare)	10%
No services were available in my area	8%
Didn't have access to diabetes health professionals I felt comfortable with	6%
Didn't want a pregnancy that was different from women without diabetes	6%
Negative experiences when discussing this topic with health professionals	6%
Too difficult to get my BGLs into target range for pregnancy	4%
Worried or afraid of what I might learn about pregnancy and diabetes	3%

Does not tally to 100% due to multiple response categories

Women who had previously attended pre-pregnancy care were asked to rate how helpful this was on a scale of one (not helpful at all) to ten (extremely helpful). The average rating was 8, with 68% of women rating the helpfulness of pre-pregnancy care as 8 out of 10 or above.

Women were asked if they would be likely to discuss any future pregnancy plans with a health professional before trying to fall pregnant. Sixty three percent (63%) said they would discuss these plans with a health professional, 3% said that they would not discuss and 3% were unsure. The remaining 31% of women said that this did not apply to them as they were not planning any pregnancies in the future.

Women with type 1 diabetes were most likely to discuss pregnancy plans with an endocrinologist (65%), while women with type 2 diabetes would be more likely have these discussions with a General Practitioner (44%).

Confidence in the knowledge of the health professional they would be most likely to speak with about pregnancy was rated from one (not confident at all) to ten (extremely confident). The average rating of confidence in health professionals was 8 out of 10.

Women were asked if pre-pregnancy care was available through their local diabetes service, community health centre, hospital or endocrinologist. One third of women (33%) said that diabetes pre-pregnancy care was available, 5% said that this was not available and 61% were unsure if this was available. 89% of women said they would attend their local service if pre-pregnancy care was available, 4% said they would not attend and 7% were unsure if they would attend.

Reasons why women would not attend pre-pregnancy care included already knowing what they need to do (44%), not having a health professional at their local service that they feel comfortable with (16%) and other reasons (33%) the main one being that they had previously attended another service and would access this care again rather than seek out local services.

4. Beliefs about pregnancy and contraception

Women's views and beliefs about pregnancy and diabetes were examined in a series of questions which included measures of preconception planning behaviours adapted with permission from the RHAB questionnaire [10]. Risk perceptions were also examined in two separate questions in this section of the survey. Selected results are presented in this report.

Women were asked to rate how much they worry about the potential for health problems using a scale from one (not at all) to five (a lot). These results are shown by type of diabetes in Figures 5 and 6.

Figure 5: How much do you worry that you could develop health problems during pregnancy? (n=625)

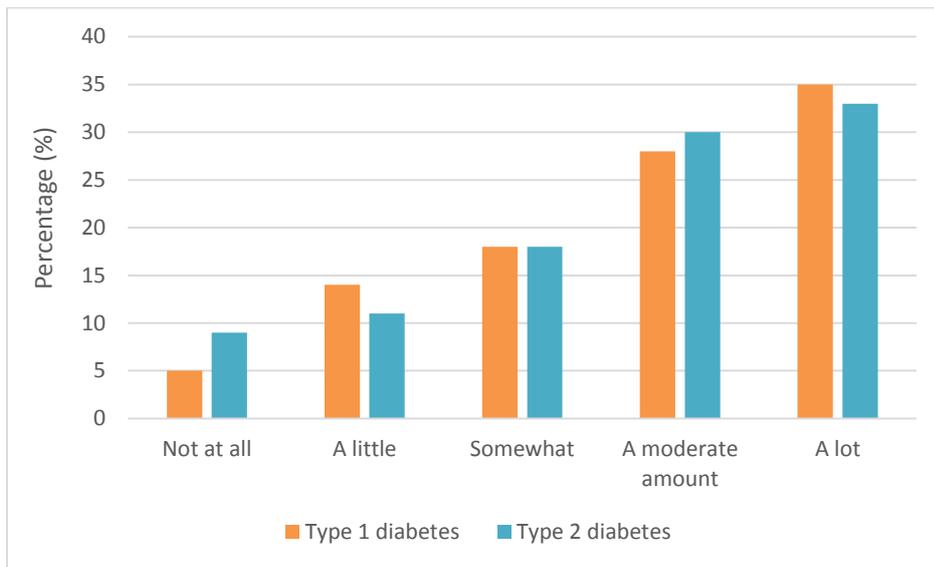
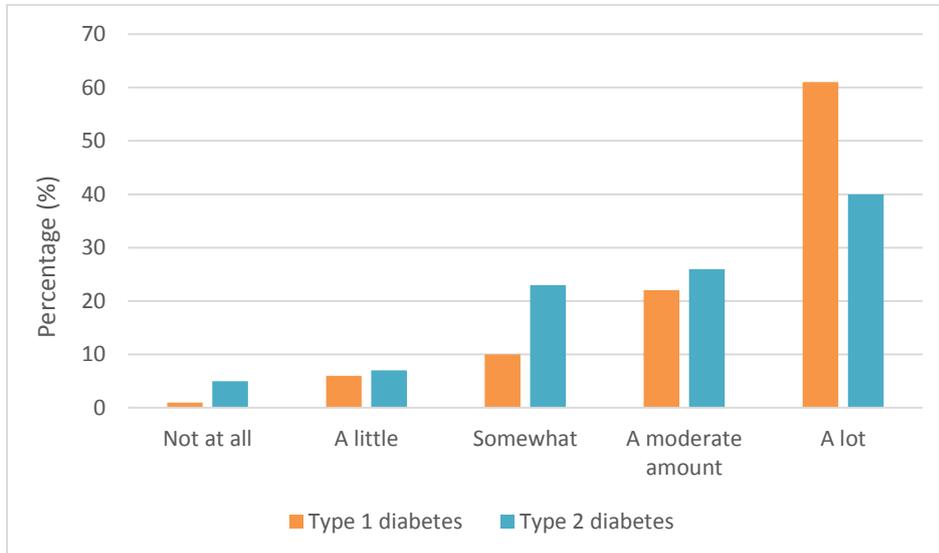


Figure 6: How much do you worry that your baby could develop health problems during your pregnancy? (n=623)



Women were asked to rate the seriousness of health problems using a scale from one (not serious at all) to five (very serious). These results are shown by type of diabetes in Figures 7, 8 and 9.

Figure 7: If you developed health problems during pregnancy, how serious do you think those health problems would be? (n=610)

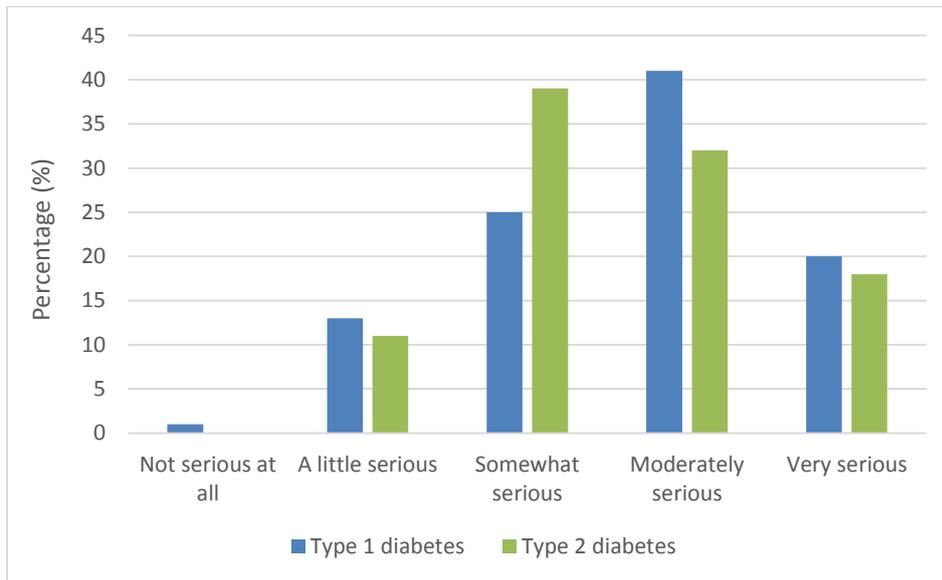


Figure 8: If your baby developed health problems during pregnancy, how serious do you think those health problems would be? (n=618)

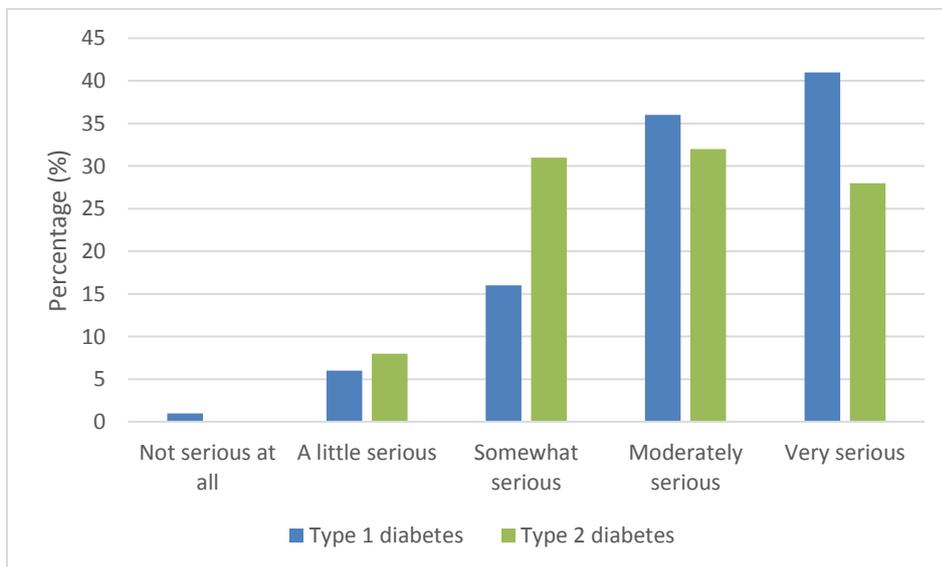
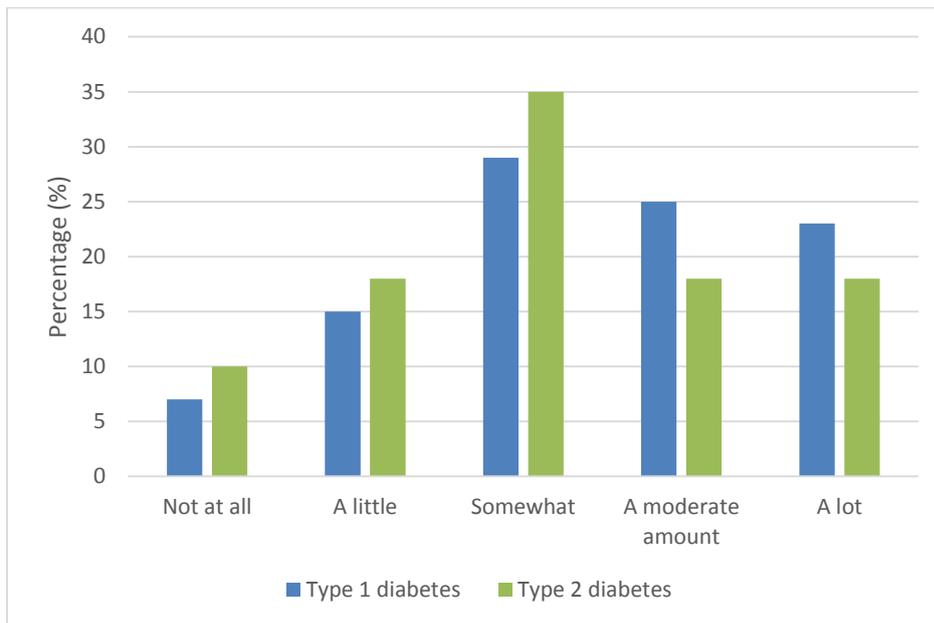


Figure 9: If you had an unplanned pregnancy, do you think this could cause health problems for you or the baby? (n=624)



Women were asked to rate using a scale from one (not at all) to five (a lot) how much they believed these preventive health measures would improve pregnancy outcomes. These results are shown by type of diabetes in Figures 10, 11 and 12.

Figure 10: Would using contraception prevent an unplanned pregnancy? (n=623)

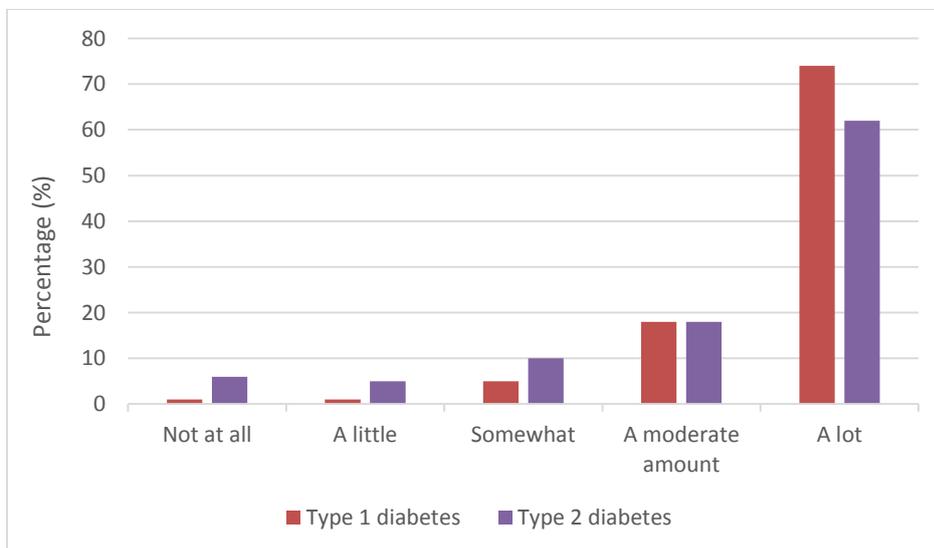


Figure 11: Would getting pre-pregnancy care (specialist diabetes medical care and advice) when planning a pregnancy improve your chances of having a healthy baby? (n=623)

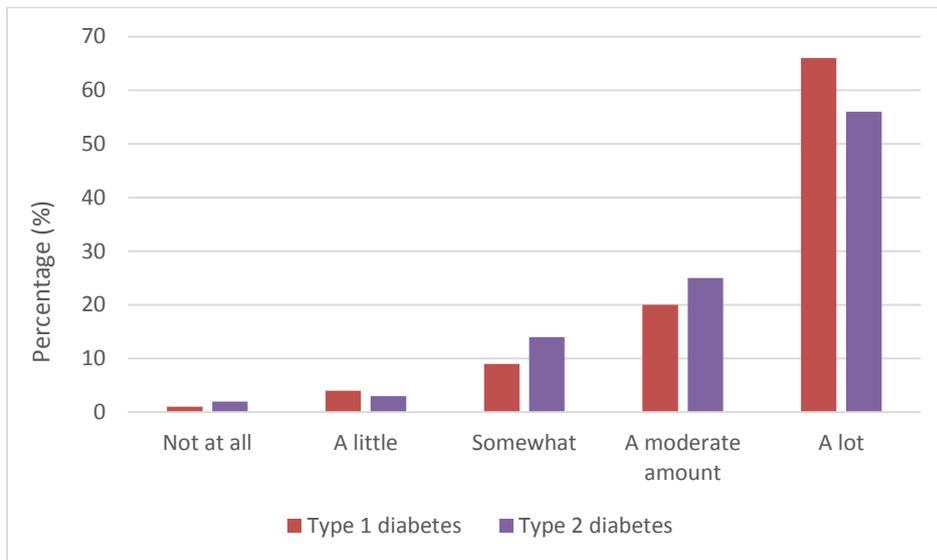
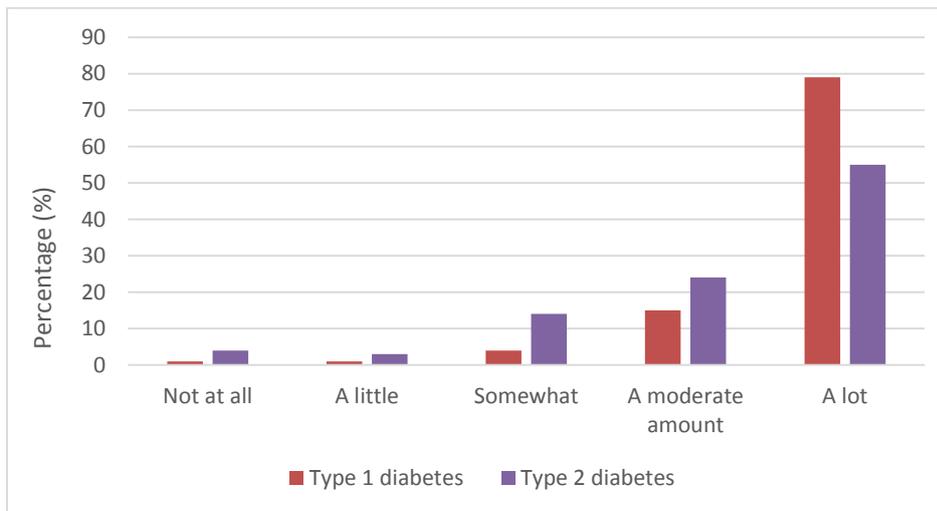
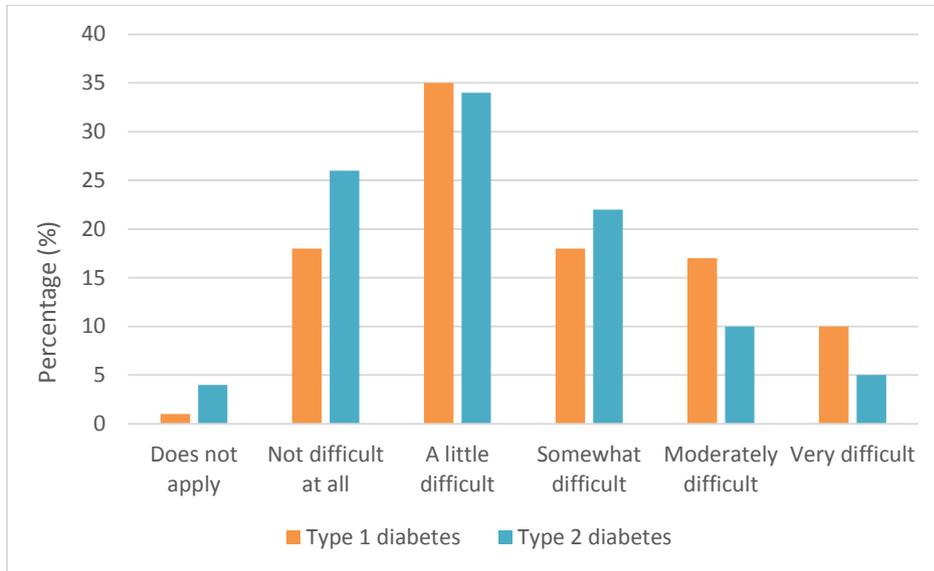


Figure 12: Would having blood glucose levels in the target range before becoming pregnant improve your chances of having a healthy baby? (n=623)



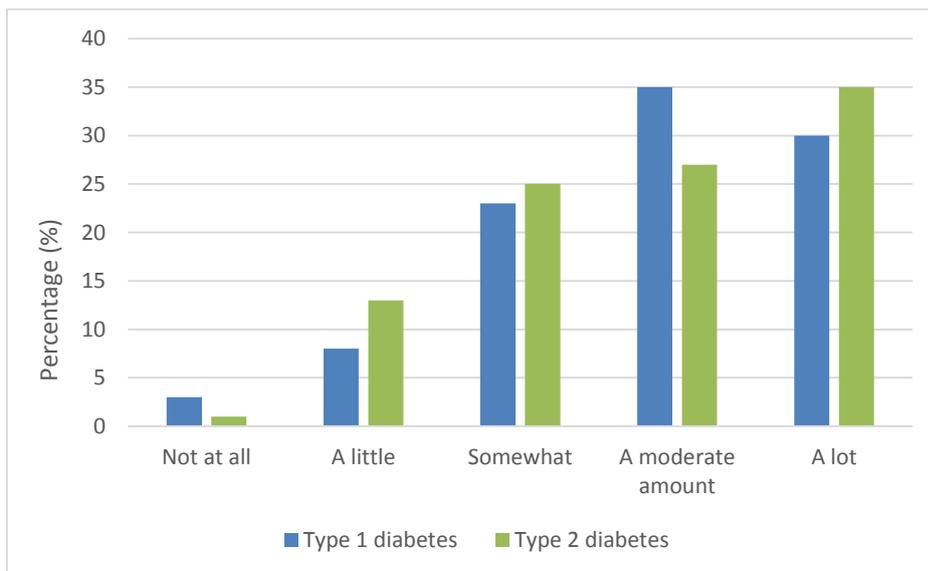
Women were asked to rate the difficulty of getting and following pre-pregnancy care using a scale from one (not difficult at all) to five (very difficult). These results are shown by type of diabetes in Figure 13.

Figure 13: How difficult would it be to follow pre-pregnancy care (specialist diabetes medical care and advice) when planning a pregnancy? (e.g. keeping blood glucose levels within the target range, adjusting insulin doses) (n=617)



Women were asked about what they believed would be the benefits of seeking pre-pregnancy care. Women rated the question on a scale from one (not at all) to five (a lot). These results are shown below.

Figure 14: Would you say that getting pre-pregnancy care would help you get your blood glucose levels in the target range? (n=614)



Seventy seven percent (77%) of women believed that they were at 'moderate' or 'high risk' for developing health problems related to diabetes during pregnancy and 36% believed that their risk of health problems during pregnancy was 'much higher' than women without diabetes as shown in figures 15 and 16.

Figure 15: What do you believe your risk is for developing health problems related to diabetes during pregnancy? (n=627)

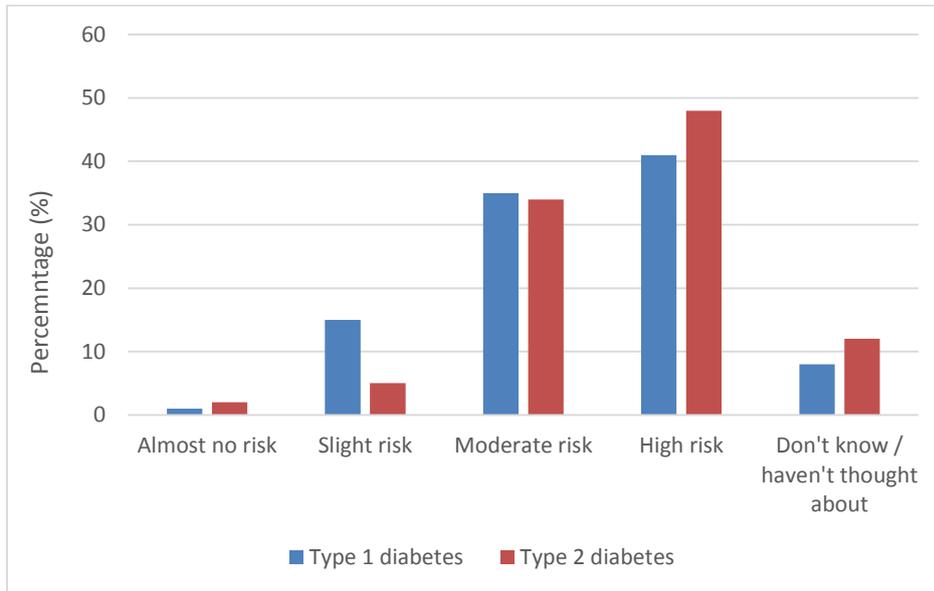
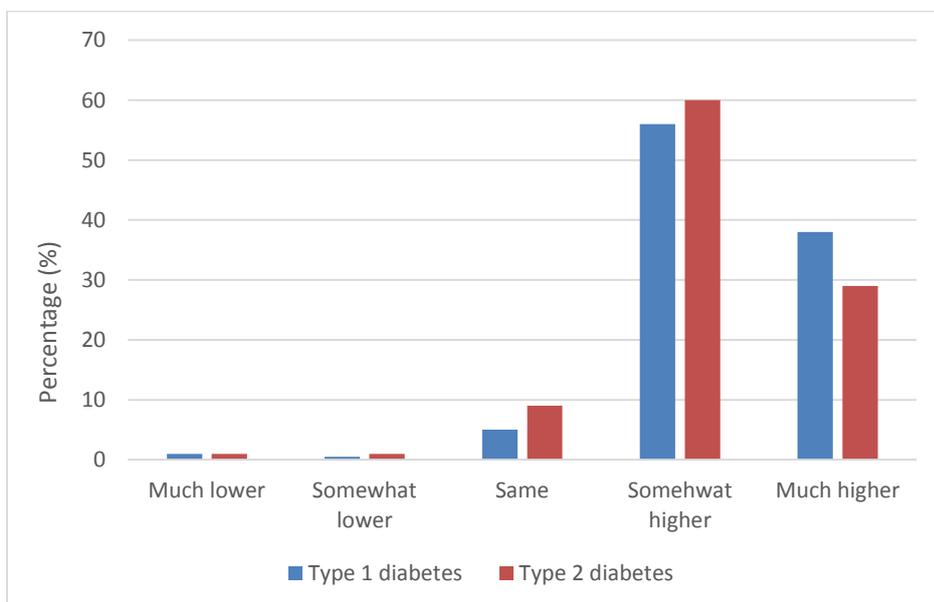


Figure 16: What do you believe your risk of developing health problems during pregnancy is compared to other women of your age who don't have diabetes? (n=570)



5. Pregnancy and diabetes information

Women were asked a series of questions about the type of information they would like about contraception, pregnancy and women's health and how they would like to receive this information. Questions were also asked to determine if women with diabetes believed there would be a benefit in being reminded about planning and preparing for pregnancy, preferred frequency and method for receiving reminders.

Information needs

The information that women would like about pregnancy and diabetes either now or in the future are shown in Table 4 below.

Table 4: Pregnancy and diabetes information needs

Topic	
How to manage my diabetes during pregnancy	70%
Risks or complications for my baby	65%
How to manage my diabetes to prepare for pregnancy	64%
Risks or complications related to pregnancy	61%
Medications or insulin changes during pregnancy	59%
Diabetes pre-pregnancy services available in my area	49%
Breastfeeding and diabetes	47%
Diabetes and fertility	45%
How to manage my diabetes after childbirth	44%
Nutrition and exercise during pregnancy	37%
Labour and birth	34%
Moods and emotions related to pregnancy and childbirth	23%
Contraception	22%
Other	3%

When asked how they would like to receive information about pregnancy and diabetes, women indicated their preferred sources of information as shown in Table 5.

Table 5: Preferred source of pregnancy and diabetes information

Source of information	
One-on-one advice from a health professional	79%
A pregnancy and diabetes information seminar or webinar	41%
Pamphlets, booklets or written information from NDSS or agent	40%
Internet/web-based information	40%
Pamphlets, booklets or written information provided by a health professional	34%
Group education sessions with a health professional	26%
DVD	8%
Smart phone app	30%
Other	2%

Eighty one percent of women reported that they would use – or have previously used – the internet to search for information about contraception, pregnancy and diabetes. When these women were asked about preferred format for accessing web based information 92% of preferred downloadable fact sheets, 27% blogs, 26% online forums, 22% social media, 21% online video clips with information from a health professional, 19% online video clips with information from a women with diabetes and 3% other format.

NDSS resources

Women were asked about use of the existing NDSS *Can I have a healthy baby?* Booklet and DVD. Twenty eight percent of women had read the NDSS booklet, 67% had not read the booklet and 6% were unsure. Eight percent of women had watched the DVD, 89% had not seen the DVD and 3% were unsure.

Pregnancy reminders

When asked about whether they would see a benefit in receiving regular reminders about planning and preparing for pregnancy, 36% of women agreed, 14% disagreed and 12% were unsure. Thirty nine said that this would not apply to them as they were not planning any pregnancy in the future.

Of those who wanted to receive reminders, the preferred frequency was annual reminders (73%), with fewer women wanting reminders every second year (19%) and 8% wanting reminders at an ‘other’ time, including quarterly, every six months or every 3-5 years.

Women who wanted to receive reminders were asked to nominate their preferred source for receiving this information. Some differences were noted in the preferred source of pregnancy planning reminders by type of diabetes. Women with type 1 diabetes were more likely to prefer

a reminder from a diabetes health professional than women with type 2 diabetes (53% vs. 30%), while women with type 2 diabetes were more likely to prefer a reminder from a GP (35% vs. 21%) or an electronic reminder from the NDSS (54% vs. 38%).

When asked if they would like to receive general health or women's health information from the NDSS, the majority of women (79%) were happy to receive this type of information, 14% did not want this information from the NDSS and 7% were unsure.

A summary of the results

This is the first Australian survey investigating the knowledge, barriers, attitudes, beliefs and information needs of women with diabetes in relation to contraception and pregnancy.

Key findings from this survey are summarised below:

- The majority of women had discussed pregnancy and diabetes with a health professional. These results varied by type of diabetes, with less women with type 2 diabetes reporting having this conversation with a health professional.
- Diabetes health professionals (Endocrinologists and Diabetes Educators) and GPs were the health professionals with whom pregnancy and diabetes was most frequently discussed.
- Women reported that they were most likely to initiate the conversation about pregnancy and diabetes.
- The importance of planning for pregnancy was discussed most frequently, followed by reasons for planning. How to plan for pregnancy was less likely to be discussed. Approximately half of all women who did not receive information on planning and preparing for pregnancy would have liked this information.
- Approximately one quarter of women reported that the information they received about pregnancy and diabetes differed between health professionals.
- Women with type 2 diabetes were less likely to recall receiving advice about contraception and the need for pre-pregnancy care from a health professional.
- The main gaps in knowledge for women with diabetes were the need for high dose folate, breastfeeding recommendations and understanding of the risks associated with high blood glucose levels in early pregnancy (miscarriage and birth defects).
- Most women identified the target HbA1c prior to pregnancy as 6% or 7% (or less). Many women were unsure of the recommended target HbA1c.
- Women with type 1 and type 2 diabetes were likely to seek advice from different health professionals in regards to pregnancy and diabetes.
- A lack of awareness about pre-pregnancy planning services and unplanned pregnancies were the major reasons given by women for not attending pre-pregnancy care.
- Awareness about the availability of pre-pregnancy care at local services was limited.
- Less than half of all women rated the risk of health problems for the baby associated with unplanned pregnancy as 'moderate' or 'a lot'.
- The majority of women believed that they were 'moderate' or 'high risk' for developing health problems related to diabetes during pregnancy.

- Just over one third believed that their risk of health problems during pregnancy was 'much higher' than women without diabetes.
- The benefit of contraception to prevent unplanned pregnancy, having blood glucose levels in the target range and pre-pregnancy care improving the chances of having a healthy baby were recognised by most women.
- Women reported that they would prefer receiving information one on one from a health professional, in addition to pamphlets and booklets provided by a health professional, NDSS or Diabetes Australia agents, seminars/webinars and the internet.
- The information women with diabetes were most interested in were related to risks during pregnancy and risks for the baby, as well as diabetes management before and during pregnancy.
- The majority of women did not see a benefit in receiving regular reminders about planning and preparing for pregnancy. Of those who did wish to be reminded, a reminder from NDSS or a diabetes health professional were preferred.
- Most women were happy to receive general diabetes management information or women's health information from the NDSS.

Next steps...

Based on the key findings from survey and consultation with health professionals, a number of strategies have been developed for the NDSS Diabetes in Pregnancy NDP to improve access to information about pregnancy and diabetes for women and their health care professionals. These include strategies to plan and develop:

- Resources on pregnancy and diabetes, including a website, booklets and pregnancy planning fact sheets for women with type 1 and type 2 diabetes
- Pregnancy and diabetes seminar/webinar package
- Continuing professional development for health professionals
- Strategies for reminding women with diabetes of the need to plan and prepare for pregnancy

The findings of the *NDSS Contraception, Pregnancy & Women's Health Survey* can also provide further guidance for the development of future NDSS activities.

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