The Gestational Diabetes Mellitus (GDM) Recall Register Pilot Project Evaluation Report

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# Table of Contents

EXECUTIVE SUMMARY ........................................................................................................... 7

CHAPTER 1: BACKGROUND AND RATIONALE................................................................. 11
  1.1 Definition of gestational diabetes mellitus (GDM) .................................................. 12
  1.2 Diagnosis of GDM ...................................................................................................... 12
  1.3 Prevalence of GDM .................................................................................................... 12
  1.4 Post-GDM risk of diabetes .......................................................................................... 13
    1.4.1 Guidelines for screening and management of GDM .............................................. 13
    1.4.2 Rates of development of diabetes and the population attributable risk of GDM .......................................................................................................................... 14
    1.4.3 Ethnic differences in the rates of development of diabetes ................................... 15
    1.4.4 Significance of GDM in preventing or delaying diabetes ........................................ 15
  1.5 Why is a long term GDM recall system required? ....................................................... 16
    1.5.1 Knowledge and compliance of medical practitioners and women with prior GDM with GDM follow up guidelines ................................................................. 17
  1.6 References .................................................................................................................. 18

CHAPTER 2: AIMS ................................................................................................................ 21
  2.1 Aims of the GDM Recall Register Pilot Project ......................................................... 22

CHAPTER 3: METHODOLOGY .......................................................................................... 23
  3.1 Recruitment to the GDM Recall Register Pilot Project .......................................... 24
  3.2 Maintenance of the GDM Recall Register Pilot Project ........................................ 24
  3.3 Recall function of the GDM Recall Register Pilot Project ..................................... 25
  3.4 Information to general practitioners ........................................................................ 25
  3.5 Data sources for evaluation of the GDM Recall Register Pilot Project.................... 26
    3.5.1 Consent forms and Register update forms ......................................................... 26
    3.5.2 Pregnancy Outcome Unit Data .......................................................................... 26
    3.5.3 Telephone questionnaire survey ....................................................................... 26
    3.5.4 Feedback from diabetes centre staff .................................................................. 28
  3.6 Types of evaluation .................................................................................................... 29
    3.6.1 Recruitment evaluation ...................................................................................... 29
    3.6.2 Retention evaluation ......................................................................................... 29
    3.6.3 Return of Register update forms evaluation ..................................................... 29
    3.6.4 Blood glucose test evaluation .......................................................................... 30
    3.6.5 Registrant evaluation ....................................................................................... 30
    3.6.6 Site evaluation .................................................................................................. 30

CHAPTER 4: RESULTS ........................................................................................................ 31
  4.1 Recruitment to the Register ...................................................................................... 32
  4.2 Retention on the Register ......................................................................................... 33
4.3 Return of the Register update form .......................................................... 33
4.3.1 Blood glucose tests................................................................. 33
4.4 Registrants’ evaluation of the Register ..................................................... 37
4.5 Site evaluation .................................................................................. 38
4.5.1 The Register overall ................................................................. 38
4.5.2 Acceptability of the Register to women with GDM ......................... 38
4.5.3 Problems, issues and improvements to the Register ......................... 38
4.5.4 Support for an ongoing Register .................................................. 39
4.5.5 Broadening the aims of the Register to include health education and
promotion ....................................................................................... 40

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS ................. 41
5.1 Effectiveness of the GDM Recall Register ........................................... 42
5.2 Future recommendations .................................................................... 42
5.2.1 Continuation of the GDM Recall Register ...................................... 42
5.2.2 Expansion of the GDM Recall Register ........................................ 43
5.2.3 Translation of the Register literature to other languages ................ 43
5.2.4 Changes to the information sheets and consent forms .................... 44
5.2.5 Expansion of the health promotion function of the GDM Recall Register.. 44
5.2.6 Research function of the GDM Recall Register ............................ 45

Appendix 1: Information sheets ............................................................... 47
Appendix 2: Consent forms ....................................................................... 51
Appendix 3: Wallet card ........................................................................... 57
Appendix 4: Reminder letter and Register update form ............................... 59
Appendix 5: General Practitioner letter ..................................................... 63
Appendix 6: Approach letter for telephone survey .................................... 65
Appendix 7: Telephone survey questionnaire ........................................... 67
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EXECUTIVE SUMMARY
Introduction

The Gestational Diabetes Mellitus (GDM) Recall Register was established as a pilot project in July 2002 in response to the lack of a systematic, centralised long term follow up of women who have had GDM. The GDM Recall Register Pilot Project was a collaboration between the Diabetes Clearing House, Department of Health and the diabetes centres at the Adelaide Community Healthcare Alliance (ACHA) Ashford Hospital and The Queen Elizabeth Hospital and Health Service (TQEH).

Aims

The purpose of the GDM Recall Register is to follow up women who have had GDM over the long term to regularly remind them that they should have their diabetes status checked because they are at increased risk of developing type 2 diabetes.

The aim of the pilot project was to determine if establishment of the GDM Recall Register was feasible, particularly in terms of recruiting women to the Register, retaining women on the Register over time, and encouraging women on the Register to have a blood glucose test to check their diabetes status.

Methods

Women were recruited to the GDM Recall Register at their appointment with the diabetes nurse educator at the diabetes centre. Registrants were sent a letter approximately 15 months after their expected delivery date to remind them to have their diabetes status checked. Included with this reminder was a form to return to the Register with any change of details and to inform the Register of the results of any blood glucose test that they had in the past year.

In addition to recruitment data, returned Register update forms, and information supplied by the Pregnancy Outcome Unit, Department of Health, a telephone survey was conducted among women who had been sent a reminder letter as at 30 June 2004.

Results

As at 30 June 2004, 107 women were enrolled on the Register. External validation analysis using Pregnancy Outcome Unit data indicate that this represented 76.9% of all women diagnosed with GDM at the two hospital sites.
Evaluation of Register Update forms (n=53 as at 30 June 2004), and results of the telephone survey indicated that approximately half of the registrants were actively responding to the GDM Recall Register by returning their Register update form (49.1%) and/or having a long term follow up blood glucose test (47.2%). No registrants had reported being told by a doctor that they had developed diabetes.

**Future recommendations**

It is recommended that the GDM Recall Register continue beyond the pilot project phase for women already recruited, and also be expanded to include other sites within South Australia. The GDM Recall Register has the potential to recruit a high proportion of women with GDM, and encourage a large number of women with GDM to actively respond to the Register by having their diabetes status checked over the long term. Applying the recruitment rate of the pilot project at TQE and Ashford to the total number of women with GDM in South Australia during the period 1 July 2002 to 31 December 2003 (n=912), means that approximately 700 women would have been recruited to the Register during this period. Of these, approximately 330 women would have had a long term follow up blood glucose test. Expanding the Register to recruit women from more sites in South Australia will result in a large number of women having their diabetes status checked over the long term. This, in turn, has the potential for diabetes to be detected early among these women, and related costly complications to be prevented or delayed.

To further improve the recruitment and retention rates and broaden the functions of the GDM Recall Register, it is recommended that:

- The Register information sheets are revised and re-formatted to be more reader-friendly, for example spreading the text over a double-sided page, so that the font size can be enlarged;
- The Register consent forms, information sheets, and reminder letters be translated into other languages, Vietnamese in the first instance, to enable women of non-English speaking backgrounds to participate in the Register;
- Consideration is given to collecting additional information, such as parity and previous history of GDM, on the consent form, and;
- Consideration is given to expansion of the health promotion function of the Register to provide information to women on how to reduce their risk of developing diabetes.
CHAPTER 1: BACKGROUND AND RATIONALE
1.1 Definition of gestational diabetes mellitus (GDM)

Gestational diabetes mellitus (GDM) has been defined as any degree of glucose intolerance in which onset or first recognition occurs during pregnancy, irrespective of the treatment regime, and whether or not the condition persists after pregnancy [1]. GDM is a common medical complication in pregnancy, usually becoming apparent between 24 and 28 weeks gestation and resolving after delivery. Women with GDM are a heterogeneous group that includes unrecognised pre-existing type 2 diabetes and a small number with type 1 diabetes [2]. Complications associated with GDM include infection, hypertension, and an increased risk of caesarean section, pre-eclampsia, infant complications and perinatal morbidity and mortality. GDM requires careful monitoring and is generally managed by diet and, if necessary, the administration of insulin.

1.2 Diagnosis of GDM

No uniform international criteria for the diagnosis of GDM currently exist, however the Australasian Diabetes in Pregnancy Society (ADIPS) currently endorses the diagnostic criteria developed from the WHO criteria in 1991. According to these guidelines, if GDM is suspected, a diagnostic OGGT is indicated irrespective of the stage of pregnancy, however if the test is normal in the early stages of pregnancy, a repeat test is recommended at 26 to 30 weeks gestation [3].

The differing methods of glucose tolerance testing have continued to hinder the development of uniform GDM diagnostic criteria and increased the variability of GDM estimates amongst populations of women.

1.3 Prevalence of GDM

According to the American Diabetes Association (ADA) approximately 7% of all pregnancies are complicated by GDM, however this may range from 1 to 14% depending on the population and diagnostic criteria used [4]. In Australia, most centres report a GDM incidence of 5.5% to 8.8% [3].
In South Australia, the prevalence of GDM amongst women who gave birth between 1 July 2002 and 31 December 2003, was 3.5% (95% CI 3.3 – 3.7) (Pregnancy Outcome Unit, South Australian Department of Health). This prevalence of GDM, however, statistically significantly increased with age ($\chi^2$ trend = 166.98, p<0.001). Women of Asian (7.7%, 95% CI 6.3 – 9.3) and Aboriginal (4.9%, 95% CI 3.4 – 6.7) origin also had statistically significantly higher prevalence of GDM than women of Caucasian background (3.2%, 95% CI 3.0 – 3.4) (Pregnancy Outcome Unit, South Australian Department of Health).

1.4 Post-GDM risk of diabetes

1.4.1 Guidelines for screening and management of GDM

The ADA guidelines recommend reclassification of maternal blood glucose status at least six weeks after delivery, with follow up testing every three years if blood glucose is normal in the post-partum period. Women with impaired fasting glucose (IFG) or impaired glucose tolerance (IGT) should be retested annually, and receive intensive nutrition therapy and an individualised exercise programs because of their very high risk of developing diabetes [4].

The current ADIPS guidelines recommend that an OGTT be performed at six to eight weeks postpartum using the WHO criteria for the non-pregnant population, with a repeat OGTT performed at least every two years. If IGT is detected careful follow-up is warranted, including twice-yearly blood glucose testing for diabetes and assessment of other risk factors for macro-vascular disease [3].

Further to these blood glucose testing regimes, women with prior GDM should be counselled about their increased risk of developing permanent diabetes and be made aware of the symptoms of hyperglycaemia [3]. They should be educated in lifestyle modifications that reduce insulin resistance, including maintaining normal body weight through dietary modification and adequate physical activity levels [3, 4]. Family planning and contraceptive advice should be given in the puerperium to ensure optimal glycaemic control in any subsequent pregnancy [3, 4]. They should also be reviewed by a general practitioner prior to conception, and a pre-conception OGTT should be considered [3].
1.4.2 Rates of development of diabetes and the population attributable risk of GDM

Many studies of diabetes risk in women with prior GDM indicate an increased risk of impaired glucose tolerance and diabetes at mid term and long term follow up, compared to women with no history of GDM [5-15]. A systematic review of studies published from 1965 to 2001 found that although the conversion rates of women with prior GDM to type 2 diabetes ranged widely between studies from 2.6% over 6 weeks to 70% over 28 years [16], this variation was largely accounted for by differences in length of follow up from 6 to 28 weeks and the retention of participants, and to a lesser extent, by differences in diagnostic criteria and non-randomised population selection [16-18]. Most women with prior GDM who develop diabetes have type 2 diabetes, although type 1 is also possible [10, 19, 20].

In a recent Danish study involving long term follow up of women with previous diet-treated GDM, a doubling in the incidence of diabetes and impaired glucose tolerance/impaired fasting glucose over a 10-year period from 1990 was reported. This increasing incidence was associated with substantial increases in BMI in women with GDM [21]. Other factors that appear to enhance the risk of type 2 diabetes post-GDM include early gestational age at diagnosis, elevated fasting glucose level, need for insulin therapy, and history of GDM, as well as obesity and other factors that promote insulin resistance [4, 17].
1.4.3 Ethnic differences in the rates of development of diabetes

Rates of development of diabetes in women with prior GDM are much higher in several non-European ethnic groups. For example, in Polynesian women who had had a postpartum OGTT, prevalence of type 2 diabetes has been reported to be as high as 30% [22]. In Latino women, a 47% cumulative incidence of type 2 diabetes has been reported using life-table analysis over five years [23], whilst in another study of women in Trinidad, 62% developed type 2 diabetes after follow up of only 3.6 to 6.5 years [24]. Correspondingly, recommendation has been made for follow up OGTT more frequently than once every two years in these high risk groups [3].

1.4.4 Significance of GDM in preventing or delaying diabetes

GDM is considered by some researchers to be a transient unmasking of an underlying disposition to diabetes, induced by the metabolic changes of pregnancy [25]. Recognition of this predisposition to diabetes and the significant population attributable risk of GDM may provide opportunity and incentive to women with prior GDM to undertake lifestyle measures to reduce their diabetes risk. Regular screening for diabetes should also occur among these women to allow intervention before the harmful end-organ effects of diabetes have been incurred [26].

Substantial population health impact is possible through preventative strategies directed at women with prior GDM, especially in populations in which prior GDM accounts for a large proportion of the women with diabetes. Greatest effect is likely in regions such as Australasia, where studies consistently demonstrate a high incidence of GDM, and where approximately one-third of women with diabetes may have been identified earlier via a GDM pregnancy [26].

Results of the Diabetes Prevention Program [27] and the Finnish Diabetes Prevention study [28] in which intensive lifestyle intervention reduced diabetes rates in people with impaired glucose tolerance by 58% over 3-4 years, indicates that diabetes can be prevented or delayed in high risk individuals. Optimism that similar effects could be achieved in the GDM population is plausible, and in fact, 15% of participants in the Diabetes Prevention Program and the Finnish Diabetes Prevention study had a history of GDM [26].
The prevention and delay of diabetes, irrespective of the substantial individual, societal and health care benefits, may also have profound economic benefits as demonstrated in a US study conducted in 1993, in which a 50% reduction of type 2 diabetes amongst women who had had previous GDM over a 10 year period was estimated to save US$331 million [29].

1.5 Why is a long term GDM recall system required?

A recall system to remind women who have had GDM to get their diabetes status checked is required over the long term for early detection of diabetes. The individual, societal and health care costs of diabetes are significant. Diabetes is a major cause of chronic disability and premature death, according to disability-adjusted life years, years lost due to disability and years of life lost [30] and is a costly condition [31]. As intervention in high risk groups, such as women with GDM, may delay the onset of type 2 diabetes and its complications (with advice on diet, exercise and weight control), any opportunities for such intervention should not be missed [1]. Recall registers facilitating earlier detection of impaired glucose tolerance and diabetes, and allowing for earlier lifestyle and medical intervention, will substantially reduce diabetes-related complications.

Although cases of GDM have been recorded since 1823, and the term itself has appeared in medical literature since the 1960’s [32], it was not widely accepted as a risk factor for Type 2 diabetes in Australia until the mid 1990’s [1]. Women with GDM now need to be made aware of their increased risk for development of Type 2 diabetes, and encouraged to monitor their risk status and detect symptoms of diabetes [4, 33, 34]. Since the risk of later diabetes mellitus in women with GDM is now well recognised, failure to institute a formal follow-up program may be considered an inadequate standard of care [35]. For example, women with previous GDM may present with vascular complications and then have diabetes diagnosed, when follow-up may have led to earlier diagnosis and prevention of complications.

Preventing or delaying the development of Type 2 diabetes, and achieving maternal and child outcomes for women with gestational diabetes equivalent to those of non-diabetic pregnancies are goals of the National Diabetes Strategy [36]. A specific activity to achieve these goals is the development and establishment of appropriate recall systems, including for women with past gestational diabetes. Long-term
monitoring of women with GDM is also a recommendation of The Strategic Plan for Diabetes in South Australia [37]. The Australian Diabetes in Pregnancy Society (ADIPS) Gestational Diabetes Management Guidelines recommend that women with GDM be followed up with an oral glucose tolerance test at 6-8 weeks post-partum, then at least every two years, because of the increased risk of developing permanent diabetes [3]. Similarly, the American Diabetes Association recommends that reclassification of maternal glycaemic status be performed at least six weeks after delivery and if normal, reassessment of glycaemia should be undertaken at a minimum of three year intervals [4].

In South Australia, women with GDM are currently followed up at 3-months post-partum to ensure GDM has resolved, and some diabetes centres do a longer 1-year follow up, but there is no systematic longer term follow up of women with GDM in place.

**1.5.1 Knowledge and compliance of medical practitioners and women with prior GDM with GDM follow up guidelines**

Knowledge and compliance of medical practitioners with clinical practice guidelines for postpartum glucose testing following GDM, and knowledge of the risk of diabetes (type 1 and type 2) and recurrent GDM may be highly variable and dependent on individual practitioner factors. In a recent study of medical residents in the United States, only 5.2% recognised the risk of diabetes associated with GDM, and although 53.1% were aware that some form of post-partum glucose testing was recommended, only 32.9% reported having provided continuity of care or longer term follow-up [38]. Although no comparable studies have been done in Australia, results of the American study are likely to be similar, and serves to highlight the need for systematic, long term follow up of women with prior GDM independently of follow up provided by medical professionals.
# 1.6 References


CHAPTER 2: AIMS
2.1 Aims of the GDM Recall Register Pilot Project

The purpose of the GDM Recall Register is to enhance earlier detection of pre-diabetes and diabetes in women who have been diagnosed with GDM because they are at increased risk of developing type 2 diabetes. Encouraging women who have had GDM to have regular blood glucose screening tests, and maintaining this regular screening over the long term allows changes in blood glucose status and the development of diabetes to be detected earlier. This earlier detection in turn allows for earlier intervention and treatment of pre-diabetes and diabetes to prevent or reduce serious, costly diabetes-related complications.

The Register also seeks to raise awareness among women who have had GDM of their risk of developing diabetes in the future, and the importance of regular blood glucose testing for earlier detection of diabetes and reduction of diabetes-related complications.

The aim of the GDM Recall Register Pilot Project was to determine the effectiveness of establishing a centralised register and long term recall system of women who have had GDM.

Effectiveness of the GDM Recall Register Pilot Project was evaluated in terms of:

- Recruitment to the Register.
- Retention of women on the Register over time.
- Proportion of women returning the Register Update form.
- Proportion of women on the Register having a long term follow up blood glucose test.
- Opinions of the Register among women on the Register.
- Opinions of the Register among staff at each site of recruitment.
CHAPTER 3: METHODOLOGY
3.1 Recruitment to the GDM Recall Register Pilot Project

Recruitment to The GDM Recall Register Pilot Project occurred at the diabetes centres of The Queen Elizabeth Hospital and the Adelaide Community Healthcare Alliance (ACHA), Ashford Hospital campus from 1 July 2002. These hospitals were chosen as they had obstetric and diabetes services, and represented public and private health sector services in differing geographical and socioeconomic regions of Adelaide. The Queen Elizabeth Hospital is a public sector hospital in north-west Adelaide. Ashford Hospital is a private sector hospital in the southern region of Adelaide.

Recruitment of participants to the Register occurred through the hospital diabetes centres, where women diagnosed with GDM were invited to enrol on the Register at the time of their first appointment with the diabetes nurse educator. At this time, the women were given an information sheet (Appendix 1), a consent form (Appendix 2) and a wallet card (Appendix 3). Information sheets used at each hospital differed in information and contact details for the respective hospital research and ethics committees.

The consent form, in addition to obtaining consent from the women for their details to be entered on the Register, requested personal contact information and other personal details, including date of birth and the expected delivery date, their general practitioner’s name and contact details, and for follow-up contact, the contact details of a secondary contact not living with them. Consent was also given, on this form, for their general practitioner to be informed of their enrolment on the Register. Completed and signed consent forms were then sent to The Diabetes Clearing House, Department of Health from the diabetes centres.

The wallet card, given to those who consented to go on the Register, reminded them that they were due to have a diabetes test in the future.

3.2 Maintenance of the GDM Recall Register Pilot Project

The GDM Recall Register Pilot Project was maintained on a password secured Access database at The Diabetes Clearing House, Department of Health. Registrants’ information from the consent form was entered onto the database and the consent
forms were secured in a locked cabinet to which only authorised study personnel had access.

### 3.3 Recall function of the GDM Recall Register Pilot Project

The recall function of the GDM Recall Register Pilot Project was achieved by sending a reminder letter and enclosed Register update form to registrants for whom fifteen months had passed since their expected delivery date (Appendix 4).

The reminder letter requested registrants to visit their general practitioner for a screening blood glucose test to check for the development of diabetes, and recounted the importance of having regular blood glucose tests for earlier diabetes detection and reduction of diabetes-related complications.

The Register update form asked registrants about their current diabetes status and requested them to update their personal information held on the Register. A reply-paid addressed envelope was enclosed for return of the completed form to the Register.

### 3.4 Information to general practitioners

At the time registrants were sent their first reminder letter and Register update form, the registrants’ general practitioners were sent a letter to inform them of their patient’s involvement with the Register (Appendix 5). An information brochure about the GDM Recall Register was enclosed with this letter. General practitioners were otherwise not involved with the Register.
3.5 Data sources for evaluation of the GDM Recall Register Pilot Project

3.5.1 Consent forms and Register update forms

Consent forms received by the Register between 1 July 2002 and 30 June 2004 and Register update forms received by the Register that had been sent to registrants between 1 July 2002 and 30 June 2004 were used to evaluate of the pilot phase of the Register. Diabetes status and updated personal information from the forms were recorded on the Register as they were received. The forms were then filed in a secure and access-restricted cabinet in the Diabetes Clearing House.

3.5.2 Pregnancy Outcome Unit Data

Hospital-specific data from the Pregnancy Outcome Unit, Department of Health was used to provide estimates of the total number of women diagnosed with GDM at each hospital.

3.5.3 Telephone questionnaire survey

3.5.3.1 Methods

All registrants who had been sent a reminder letter between 1 July 2002 and 30 June 2004 were eligible to participate in the telephone survey. An approach letter was sent to all eligible registrants prior to conducting the survey in September 2004 (Appendix 6). The questionnaire was pilot tested with seven registrants. The final questionnaire is listed in Appendix 7.

The telephone survey was conducted by a privately contracted and accredited survey company under supervision of the Diabetes Clearing House study personnel. Trained professional interviewers telephoned the households, identified themselves, and requested to speak with the study participant. The purpose of the survey was not revealed to anyone other than the registrant, in order to maintain privacy and confidentiality. Appointments were made to call back at a more convenient time, or at a time when they were more likely to be available.
Telephone interviews were undertaken between 9.30am and 8.00pm. At least six callbacks were made, at different times of day or evening, before a non-contact was recorded. Any refusals to participate were recorded.

Participants’ responses were recorded onto a paper-version of the questionnaire at the time of interviewing. Completed questionnaires were only identifiable by the unique GDM Recall Register identification number assigned to each registrant at the time of enrolling onto the Register. On completion of the survey, questionnaires were sent to the Diabetes Clearing House and raw data was entered onto an Access database using an electronic data entry form and imported into SPSS for Windows (Version 12.0) for analysis.

3.5.3.2 Response rate

Of the 107 women on the Register at the end of the pilot phase on 30 June 2004, 53 registrants had been sent a reminder letter and Register Update form at 30 June 2004, and were eligible to participate in the telephone survey. At the completion of the survey 47 registrants had been interviewed, resulting in a response rate of 88.7%.

Of the six eligible registrants who were unable to be interviewed, two had disconnected phone numbers, one had moved address with no forwarding address, one was absent overseas, and two were unavailable for interview after six call-back attempts.

3.5.3.3 Demographic profile

The demographic profile of registrants who participated in the telephone survey (n=47) is shown in Table 3.1.
Table 3.1: Demographic profile of telephone survey participants

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hospital</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ashford</td>
<td>42</td>
<td>89.4</td>
</tr>
<tr>
<td>TQEH</td>
<td>5</td>
<td>10.6</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 29 years</td>
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<td>17.0</td>
</tr>
<tr>
<td>30 – 34 years</td>
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</tr>
<tr>
<td>≥ 35 years</td>
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<td>38.3</td>
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<tr>
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<tr>
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</tr>
<tr>
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<tr>
<td>English</td>
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<td><strong>Highest level of education</strong></td>
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<td>Some high school</td>
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</tr>
<tr>
<td>Completed high school</td>
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<td>TAFE, or trade certificate or diploma</td>
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</tr>
<tr>
<td>University, CAE or some other tertiary institute degree</td>
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<td>34.0</td>
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<td><strong>Household income</strong></td>
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<td>More than $100,000</td>
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<td>17.0</td>
</tr>
<tr>
<td>Not stated / Refused / Don’t Know</td>
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<td>12.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>47</td>
<td>100.0</td>
</tr>
</tbody>
</table>

3.5.4 Feedback from diabetes centre staff

Site evaluations were undertaken at the diabetes centres in November 2004. A schedule of questions was emailed to the diabetes centre staff prior to visiting each hospital site to provide a guideline for evaluation of the Register. Feedback received from the diabetes centre staff was scribed at the time of the visits and summated on separate interviewer record sheets for each site.
3.6 Types of evaluation

3.6.1 Recruitment evaluation

The effectiveness of the GDM Recall Register in terms of recruitment was evaluated by calculating the proportion of women consenting to go on the Register, out of the total number of women diagnosed with GDM, at each hospital during the period 1 July 2002 to 31 December 2003. The total number of women diagnosed with GDM at each hospital was obtained from the Pregnancy Outcome Unit, Department of Health. This data was only available from 1 July 2002 to 31 December 2003, hence recruitment rates were evaluated for this period rather than the total duration of the pilot project to 30 June 2004.

3.6.2 Retention evaluation

Retention on the Register was evaluated by assessing the number of registrants who had requested to be removed from the Register, together with the number of women who were lost to the Register, against those who remained on the Register who had been sent a reminder letter before 30 June 2004.

The number of women lost to the Register was calculated from the number of reminder letters returned as ‘unknown address’ that were not able to be readdressed through information gained from their secondary contact, together with the number of women unable to be contacted in the telephone survey because of disconnected phone numbers or having moved with no forwarding address.

3.6.3 Return of Register update forms evaluation

Participation in the Register was assessed by the proportion of women who returned their Register update form. This form was sent to women 15 months after their expected delivery date with the reminder to have a blood glucose test (Appendix 4).
3.6.4 Blood glucose test evaluation

The proportion of women who had had a blood glucose test was determined using data from the Register update forms and the telephone survey. Registrants indicated on their Register update form whether they had had a long term follow up blood glucose test. This question was also included in the telephone survey to account for registrants who had had a blood glucose test, but had not returned the Register update form. The telephone questionnaire was also used to determine whether women had the blood glucose test in response to the reminder letter prompt.

3.6.5 Registrant evaluation

Women participating in the telephone survey were also asked comment on the Register. These comments were useful in evaluating their attitude to the Register protocol and their evaluation of its usefulness to them as recall and reminder system.

3.6.6 Site evaluation

Feedback about the Register from the diabetes centre staff was useful in evaluating the feasibility of continuing the Register at these sites, and the potential for roll-out to other hospital sites, as well as indicating any important changes and improvements required in the Register protocol.
CHAPTER 4: RESULTS
4.1 Recruitment to the Register

During the pilot phase from 1 July 2002 to 30 June 2004, 107 women with GDM were recruited to the GDM Recall Register. The profile of registrants by hospital and age group is shown in Table 4.1.

Table 4.1: Profile of women on the GDM Recall Register at 30 June 2004

<table>
<thead>
<tr>
<th>Hospital</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ashford</td>
<td>86</td>
<td>80.4</td>
</tr>
<tr>
<td>TQEH</td>
<td>21</td>
<td>19.6</td>
</tr>
<tr>
<td>Age group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 29 years</td>
<td>23</td>
<td>21.5</td>
</tr>
<tr>
<td>30 - 34 years</td>
<td>45</td>
<td>42.1</td>
</tr>
<tr>
<td>≥ 35 years</td>
<td>39</td>
<td>36.4</td>
</tr>
<tr>
<td>Total Registrants</td>
<td>107</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 4.2 shows the proportion of women with GDM who were recruited to the Register from the total number of women diagnosed with gestational diabetes mellitus at each hospital from 1 July 2002 to 31 December 2003. Overall recruitment to the Register for this period was 76.9%.

Table 4.2: Recruitment of the GDM Recall Register 1 July 2002 to 31 December 2003

<table>
<thead>
<tr>
<th></th>
<th>Ashford</th>
<th>TQEH</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women diagnosed with GDM</td>
<td>93</td>
<td>24</td>
<td>117</td>
</tr>
<tr>
<td>Women with GDM recruited to the Register</td>
<td>75</td>
<td>15</td>
<td>90</td>
</tr>
<tr>
<td>Register Recruitment Rate (%)</td>
<td>80.6</td>
<td>62.5</td>
<td>76.9</td>
</tr>
</tbody>
</table>

*Pregnancy Outcome Unit data*
4.2 Retention on the Register

During the pilot phase of the Register there were no requests to withdraw from the Register and only one reminder letter and register update form was returned to the Register as “unknown address” of the 53 that were sent. This registrant was subsequently contacted through their secondary contact, and retained on the Register. Register retention at 30 June 2004 was 100%, based on returned reminder letters and register update forms and those who remained lost to the Register after follow up using the secondary contacts.

Using the telephone survey contact attempts, of the 53 registrants that were eligible to participate in the telephone survey, three were unable to be contacted at the time of the survey – two had disconnected telephone numbers, and one had moved address. After attempting to contact these registrants using their secondary contacts, only two remained lost to the Register. The Register retention based on the telephone survey participants was thus 92.5%.

4.3 Return of the Register update form

At the end of the pilot phase, 53 registrants had been sent the reminder letter and register update form, of which twenty six (49.1%) completed and returned the form to the Register (Table 4.3).

4.3.1 Blood glucose tests

Data from the Register update forms and the telephone survey showed that 47.2% of registrants had had a long term follow up blood glucose test after being sent a reminder letter (Table 4.3).
Table 4.3: Proportion of Register update forms returned and blood glucose tests performed among women who had been sent a reminder letter as at 30 June 2004

<table>
<thead>
<tr>
<th>Recruited</th>
<th>107</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reminder letter sent</td>
<td>53</td>
</tr>
<tr>
<td>Register update form returned</td>
<td>26</td>
</tr>
<tr>
<td>Had long term follow up blood glucose test*</td>
<td>25</td>
</tr>
<tr>
<td>Been told by a doctor have diabetes</td>
<td>0</td>
</tr>
</tbody>
</table>

* Data from Register update form and telephone survey

In the telephone survey, women who had had a blood glucose test (n=24) were asked what prompted them to have the test. Table 4.4 shows 62.5% of women who had had a blood glucose test were prompted by the reminder letter, either alone or in combination with another prompt.

Table 4.4: Proportion of blood glucose prompts amongst women who had had a blood glucose test in the telephone survey

<table>
<thead>
<tr>
<th>Blood glucose test prompt</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reminder letter alone</td>
<td>12</td>
<td>50.0</td>
</tr>
<tr>
<td>Reminder letter and other prompt</td>
<td>3</td>
<td>12.5</td>
</tr>
<tr>
<td>Other prompt alone</td>
<td>9</td>
<td>37.5</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>24</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Prompts other than the reminder letter that were reported by women who had had a blood glucose test included:

- Endocrinologist recommended it soon after the baby was born.
- Obstetrician recommended a test at six weeks.
- Because I was pregnant and my obstetrician recommended the test.
- Pregnant and had the test just before received the reminder letter.
- Second pregnancy.
- Subsequent pregnancy.
- Family doctor said I need a follow up test. Family doctor aware of gestational diabetes.
- Going to the doctor anyway.
- General practitioner wanted me to.
- Thought I was developing symptoms so wanted to have the test.
- Wanted to have test done earlier as I was feeling unwell.
- Worried about symptoms (thirsty), so had already had a test earlier.
Women in the telephone survey who had not had a blood glucose test (n=23) were asked to indicate their reasons for not having a test. Responses are listed in Table 4.5.

**Table 4.5: Reasons for not having a blood glucose test amongst telephone survey participants who had not had a blood glucose test**

<table>
<thead>
<tr>
<th>What are the reasons why you haven’t had a blood glucose test?*</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haven’t had time</td>
<td>12</td>
<td>54.5</td>
</tr>
<tr>
<td>Don’t think I need a test</td>
<td>6</td>
<td>27.3</td>
</tr>
<tr>
<td>Intend to have the test, but haven’t done so yet</td>
<td>3</td>
<td>13.6</td>
</tr>
<tr>
<td>Forgot about having the test done</td>
<td>2</td>
<td>9.1</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>36.4</td>
</tr>
</tbody>
</table>

* Multiple responses possible

Other reported reasons for not having a blood glucose test included:
- Child unwell.
- Didn’t know where to go or if referral was required.
- Have been testing myself and results were normal.
- Have used a monitor to check levels and they have been normal, so didn’t think I needed the test.
- Just had a blood test and glucose normal, so doctor said I didn’t need a test.
- Need babysitter for child, because test takes two hours.
- Pregnant again and just waiting to see how things go.
- Test in hospital was normal, so didn’t think another test was necessary.

Women who had not had a blood glucose test (n=23), were also asked what factors, apart from the reminder letter, that would make them more likely to have a blood glucose test (Table 4.6).

**Table 4.6: Factors other than the reminder letter that would make women more likely to have a blood glucose test, amongst women in the telephone survey who had not had a blood glucose test**

<table>
<thead>
<tr>
<th>Other than the reminder letter, is there anything else that would make you more likely to have a blood glucose test?*</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>15</td>
<td>65.2</td>
</tr>
<tr>
<td>Yes – If I had more time</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td>Yes - Other</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>4.3</td>
</tr>
</tbody>
</table>

* Multiple responses possible
Other factors that would make these women more likely to have a test included:

- If they send me a referral through the mail to the pathologist to save me a trip to the GP.
- Ill health or weight gain.
- More information about where to go for the test.
- A phone call.

Of those who had had a blood glucose test (n=24), no respondents had been told by a doctor that they had diabetes.
4.4 Registrants’ evaluation of the Register

On completion of the telephone questionnaire respondents were given an opportunity to comment on the GDM Recall Register. Twenty one respondents (44.7%) elected to comment. All comments received were positive, as follows:

- Good or great idea. (10)
- Terrific service.
- Beneficial. Makes people more aware of the need for follow up.
- Good idea for reminder to be sent out.
- Good idea. Encourages people to be responsible for their health.
- Good idea. Phone call has prompted me to have a test as soon as I can.
- Good idea. Should be more information about where to go for the test in the recall letters.
- Good idea. The follow up phone call about the Register is a good idea as another reminder.
- Good to have a reminder.
- Reminder good. Further tests by Endocrinologist revealed I did not have gestational diabetes, but was on the borderline. Still want to remain on the Register for the time being.
- Very educational. I am looking after myself a lot better now than ever before.
- Very well organised. Fantastic help and support from the service. Helped me to understand my diabetes.
4.5 Site evaluation

4.5.1 The Register overall

Diabetes Centre staff at both hospital sites were very supportive of the Register and felt it fulfilled a necessary role of regular long term follow-up reminding women to have a screening blood glucose test. Both sites had integrated Register recruitment into the gestational diabetes appointment process and commented that the Register was a good idea and well received by the women. The diabetes educators felt that a twelve-monthly reminder was very important as the women tended to forget, especially after having had a new baby.

4.5.2 Acceptability of the Register to women with GDM

The diabetes educators commented that overall the women were happy to go on the Register, especially once they knew they were at risk of developing diabetes in the future. Women with a family history of diabetes tended to better understand the implications of developing diabetes, and tended to require no encouragement to go on the Register. Staff at TQEH Diabetes Centre also commented that none of the women that were asked to go on the Register refused to be involved.

4.5.3 Problems, issues and improvements to the Register

When asked about any problems or issues encountered with the Register, staff at TQEH commented that reading the information sheet and filling out the consent form was reasonably time consuming, and the appointment time had been increased to accommodate this. At the Ashford hospital, on occasions when there had been time constraints on the appointment, the information sheet, consent form and wallet card had been given to the women to read and complete at home. These women were also given reply-paid envelopes for returning the signed consent form either to the hospital, or direct to the Diabetes Clearing House.

TQEH staff commented that if the information sheet was not easily understood by the women on first reading while waiting for their appointment, areas requiring clarification were then dealt with during their appointment. Ashford staff suggested
Results

that a dot-point information sheet may be less time consuming, easier to assimilate, and more acceptable to the women.

TQEH Diabetes Centre staff specifically requested translation into Vietnamese in order to increase the recruitment of these women to the Register, especially as these women represent a high risk group and constitute a reasonably high proportion of women with GDM at TQEH. Italian and Greek translation may also be required by TQEH Diabetes Centre.

According to Pregnancy Outcome Unit data, both hospitals recruited women with GDM who were of Asian origin. The difference in GDM prevalence between Caucasian (4.1%, 95% CI 3.34 – 5.04) and Asian (10.3%, 95% CI 4.30 – 20.28) women at the Ashford hospital did not reach statistical significance, however TQEH showed a statistically significant difference ($\chi^2 = 8.80$, $p<0.01$) in GDM prevalence between Caucasian (1.8%, 95% CI 1.01 – 2.98) and Asian women (5.6%, 95% CI 2.99 – 9.54). The proportion of Asian women with GDM attending each hospital also differed significantly ($\chi^2 = 7.40$, $p<0.01$) from 1 July 2002 to 31 December 2003 with TQEH having a higher proportion (1.1%, 95% CI 0.58 – 1.91) than the Ashford hospital (0.3%, 95% CI 0.11 – 0.57). A higher GDM prevalence in Asian women overall, and a higher proportion of Asian women with GDM at TQEH, is a potentially significant factor that may reduce recruitment of women to the GDM Recall Register who are unable to understand English.

Apart from these suggested changes, there were no other improvements to the Register that were thought to be necessary. In general, both sites were happy with the acceptability of the Register to the women, the level of communication with Diabetes Clearing House staff, and the Register protocol and administration.

4.5.4 Support for an ongoing Register

Both sites were supportive of an ongoing Register and indicated that they felt the hospital administration would also be supportive. TQEH staff commented that the Register provided a more cost-effective follow-up, than if the same follow-up was to be provided by the diabetes educators.
4.5.5 Broadening the aims of the Register to include health education and promotion

When asked about their views on broadening the aims of the Register to include health education and promotion, both sites thought this would be a good idea. However, concern was also raised that the original consent, given by the women at the time of going on the Register, may not cover extensive health promotion interventions or activities. Specific ideas for health promotion and education suggested by the diabetes educators were fridge magnets or information flyers about the symptoms of high blood glucose, epidemiological information about gestational diabetes and the risk of developing diabetes, and reminders about healthy weight, diet and physical activity levels. Suggestion was also made to send out information about upcoming Diabetes SA diabetes prevention seminars, with the proviso that a tick box be included on the consent form, allowing registrants to choose to have this information sent to them or not.
CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS
5.1 Effectiveness of the GDM Recall Register

The pilot phase of the GDM Recall Register has shown this systematic, centralised Register to be an effective method of long term follow up women who have had GDM to remind them that they should continue to have their diabetes status checked because they are at increased risk of developing type 2 diabetes.

The effectiveness of the GDM Recall Register is evident in a number of measures. First, the Register has an overall recruitment rate of 77% of all women diagnosed with GDM at Ashford and TQEH. Second, retention of women on the Register over the first twelve months was 93%. Third, a high response rate (88.7%) to the telephone survey was obtained. Fourth, almost half (47%) of the women reported having had a long term follow up blood glucose test, and the majority of these had the test in response to receiving the reminder letter.

In addition, the administration of the GDM Recall Register is not considered a burden by staff at the diabetes centres involved. Women enrolled on the Register also provided positive feedback about the value of the Register to them.

5.2 Future recommendations

5.2.1 Continuation of the GDM Recall Register

It is recommended that the GDM Recall Register continue beyond the pilot project phase so that current registrants continue to receive reminders about getting their diabetes status checked. The ongoing recall of registrants could occur by sending reminder letters and Register update forms to registrants on an annual basis. Sending reminder letters less frequently than this is likely to result in a higher proportion of women being lost to follow up. If a diagnosis of diabetes is made registrants will no longer be sent reminder letters, but will remain on the Register.
5.2.2 Expansion of the GDM Recall Register

It is recommended that the GDM Recall Register expands to include other sites within South Australia. The GDM Recall Register has the potential to recruit a high proportion of women with GDM, and encourage a large number of women with GDM to actively respond to the Register by having their diabetes status checked over the long term. Applying the recruitment rate of the pilot project at TQEH and Ashford to the total number of women with GDM in South Australia during the period 1 July 2002 to 31 December 2003 (n=912), means that approximately 700 women would have been recruited to the Register during this period. Of these, approximately 330 women would have had a long term follow up blood glucose test. Expanding the Register to recruit women from more sites in South Australia will result in a large number of women having their diabetes status checked over the long term. This, in turn, has the potential for diabetes to be detected early among these women, and related costly complications to be prevented or delayed.

Modification of the current Register protocol may be required for use in other hospitals or sites, although these changes are not expected to be major.

Other methods of recruitment, such as via pathology laboratories notifications of GDM, such as that used for recruitment to the Cervical Cancer registry, could also be considered.

5.2.3 Translation of the Register literature to other languages

Translation of the information sheet, consent form, reminder letter, wallet card, and Register update form into other languages is essential for capturing those women with GDM who do not speak English. TQEH Diabetes Centre specifically requested translation into Vietnamese in order to increase the recruitment of these women to the Register, especially as these women represent a high risk group and constitute a reasonably high proportion of women with GDM at TQEH. Italian and Greek translation may also be required by TQEH Diabetes Centre.
5.2.4 Changes to the information sheets and consent forms

Revision and re-formatting of the Register information sheets to make them more reader-friendly (for example spreading the text over a double-sided page, so that the font size can be enlarged, more use of dot points, etc.) will improve clarity of information and speed up the informed consent process.

Data to be considered for future collection from women include parity and whether they have previously had gestational diabetes mellitus as these factors are associated with increased risk of developing type 2 diabetes. Such questions could be included on the consent form.

The Register consent forms sent to each hospital need to be clearly labelled with the hospital name, so the source hospital can be easily identified for each registrant when the form is returned to the Register. This will be especially important if the Register is expanded to include more than the current two hospitals.

5.2.5 Expansion of the health promotion function of the GDM Recall Register

There is potential for the health promotion role of the GDM Recall Register to be increased. Currently, women are informed of their increased risk of developing diabetes during their appointment at the diabetes centre and through the information they receive from the Register. The information they receive on how to go about reducing their risk of developing diabetes and related complications, for example through improvements in diet, reductions in weight and increased physical activity, remain minimal. Such information could also include advertisements for educational and health-promoting events and activities organised through the diabetes centres. In future, the Register may also be used to disseminate new research, policy and program developments in relation to gestational diabetes mellitus, diabetes and its complications, and preventative lifestyle factors to women on the Register. Expansion of this function of the Register will need to consider the ethical implications of providing further information to existing registrants who did not originally consent to receiving such information, and also the increased costs associated with providing more information to registrants.
5.2.6 Research function of the GDM Recall Register

Future functions of the Register may involve use of the Register as a database for research projects. At the time of enrolling on the Register women may be asked to give consent to being contacted in the future by researchers. Data collected by the Register may also be expanded to reflect these possible research interests, such as recording anthropometric measures of height and weight at the time of recruitment at the diabetes centre, or completion of more detailed questionnaires on socio-demographic factors, risk factors, attitudes and beliefs, and health status. Detailed examination of the ethical and budget implications will be required with the future inclusion of such a function in the GDM Recall Register.
Appendix 1: Information sheets
What is the study about?

Gestational diabetes mellitus (GDM) is a form of diabetes that occurs during pregnancy, when certain hormones stop insulin from working properly. It currently affects approximately 1 in every 30 women in South Australia.

Up to half of women with GDM develop Type 2 diabetes within ten years after delivery. Type 2 diabetes occurs because insulin is produced in lesser amounts or is less effective. Symptoms include thirst, frequent passage of urine, increased fatigue, and weight loss. Following a healthy diet, participating in regular physical activity and maintaining a healthy weight may help prevent the development of Type 2 diabetes.

The aim of this project is to determine how effective a register and recall system would be for women who have had GDM by providing them with regular reminders to visit their doctor or clinic to have their blood glucose levels checked for early detection of Type 2 diabetes.

Your involvement in the GDM Recall Register is very important because if your blood glucose levels are checked regularly and you do develop diabetes, there is more chance that it will be detected and managed before your health is affected.

What happens during the project?

The signed consent form agreeing to participate in the project will be sent to the Diabetes Clearing House in the South Australian Department of Human Services and a copy held in your medical file. Contact information for the reminder system will be entered onto a confidential database and the signed consent forms will be stored in a secure environment at the Diabetes Clearing House. After approximately 15 months following registration, a letter will be sent to you, reminding you to visit your general practitioner for a diabetes test. The reminder letter will be sent to you each year (reverting to once every three years if results remain within the normal range for three years running). Participant confidentiality and data security will be maintained at all times.

How can I benefit if I take part?

Through our regular reminder to you and your subsequent visit to the doctor for a diabetes check, Type 2 diabetes is more likely to be detected at a much earlier stage, which will contribute greatly to better management of the condition and its effects on heart, kidney, eye and circulation complications. Your participation in the register may detect early symptoms of Type 2 diabetes which otherwise may have been undetected for a number of years.

You will also receive information about the project and regular health newsletters.

What if I don't want to take part?

Participation in the project is on a voluntary basis and withdrawal from the project can be made at any time by contacting the Diabetes Clearing House at the South Australian Department of Human Services (see contact details below). Your involvement in or withdrawal from the project will not affect the care you receive at the hospital in any way.

What happens with information from the project?

All records will remain confidential and no information that may lead to the identification of any individual will be released. The data will be analysed and the results may be published in a medical journal, but there would be no way of identifying you as a participant.

What if I change my address or would like more information?

If you change your address or would like further information on the GDM Recall Register, please contact Katherine Baldock at the Diabetes Clearing House, South Australian Department of Health, on (tel) 8226 6897, (fax) 8226 6244 or (email) Katherine.Baldock@health.sa.gov.au.


The Ethics of Human Research Committee at The Queen Elizabeth Hospital has reviewed this study. Should you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Executive Officer of the Ethics of Human Research Committee at The Queen Elizabeth Hospital on (tel) (08) 8222 6841 (direct).
PARTICIPANT INFORMATION SHEET

What is the study about?
Gestational diabetes mellitus (GDM) is a form of diabetes that occurs during pregnancy, when certain hormones stop insulin from working properly. It currently affects approximately 1 in every 30 women in South Australia. Up to half of women with GDM develop Type 2 diabetes within ten years after delivery. Type 2 diabetes occurs because insulin is produced in lesser amounts or is less effective. Symptoms include thirst, frequent passage of urine, increased fatigue, and weight loss. Following a healthy diet, participating in regular physical activity and maintaining a healthy weight may help prevent the development of Type 2 diabetes.

The aim of this project is to determine how effective a register and recall system would be for women who have had GDM by providing them with regular reminders to visit their doctor or clinic to have their blood glucose levels checked for early detection of Type 2 diabetes.

Your involvement in the GDM Recall Register is very important because if your blood glucose levels are checked regularly and you do develop diabetes, there is more chance that it will be detected and managed before your health is affected.

What happens during the project?
The signed consent form agreeing to participate in the project will be sent to the Diabetes Clearing House in the South Australian Department of Human Services and a copy held in your medical file. Contact information for the reminder system will be entered onto a confidential database and the signed consent forms will be stored in a secure environment at the Diabetes Clearing House. After approximately 15 months following registration, a letter will be sent to you, reminding you to visit your general practitioner for a diabetes test. The reminder letter will be sent to you each year (reverting to once every three years if results remain within the normal range for three years running). Participant confidentiality and data security will be maintained at all times.

How can I benefit if I take part?
Through our regular reminder to you and your subsequent visit to the doctor for a diabetes check, Type 2 diabetes is more likely to be detected at a much earlier stage, which will contribute greatly to better management of the condition and its effects on heart, kidney, eye and circulation complications. Your participation in the register may detect early symptoms of Type 2 diabetes which otherwise may have been undetected for a number of years. You will also receive information about the project and regular health newsletters.

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All records will remain confidential and no information that may lead to the identification of any individual will be released. The data will be analysed and the results may be published in a medical journal, but there would be no way of identifying you as a participant.

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The Research & Ethics Committee at ACHA has reviewed this study. Should you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the Co-ordinator of the ACHA Research and Ethics Committee on (tel) (08) 8375 5271.
Appendix 2: Consent forms
CONSENT FORM

I, .............................................................................................................., consent to my involvement in the Gestational Diabetes Mellitus Recall Register Pilot Project.

I have been provided with and read the information sheet, and I understand the reasons for this project. The ways in which it will affect me have been explained by the Diabetes Nurse Educator. My questions have been answered to my satisfaction. My consent is given voluntarily.

The details of the project have been explained to me, including the reminder letter and how often it will be sent, depending on the previous result; and the expected time the project will take.

I understand that the purpose of this research project is to improve the quality of medical care, but my involvement may not be of benefit to me.

I have been given the opportunity to have a member of family or a friend present while the project was explained to me.

No information about my medical history will be taken from the hospital. My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.

My involvement in the project will not affect my relationship with my medical advisers. I understand I am free to withdraw from the project at any stage without having to give any reasons, and that if I do withdraw from the project, it will not affect my treatment at this hospital in the future.

I am 18 years of age or over. I consent to my general practitioner being informed of my participation in this study. I also consent to Recall Register staff contacting the person I have named as a secondary contact, if they are experiencing difficulties getting in touch with me.

Signature of Participant: Date:       /       /

Signature of Diabetes Nurse Educator: Date:       /       /

(if applicable, for example if an interpreter is used) I declare that I have been present when the research was explained to the above participant and I believe that the participant has an appreciation and understanding of the explanation given and that the consent was freely given:

Signature of Witness: Date:       /       /

Address of Witness:
<table>
<thead>
<tr>
<th>YOUR DETAILS - please print</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title:</td>
</tr>
<tr>
<td>Family Name:</td>
</tr>
<tr>
<td>First &amp; Second Names:</td>
</tr>
<tr>
<td>Maiden Name:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>Telephone Number:</td>
</tr>
<tr>
<td>Home:</td>
</tr>
<tr>
<td>Work:</td>
</tr>
<tr>
<td>Mobile:</td>
</tr>
<tr>
<td>Email:</td>
</tr>
<tr>
<td>Home:</td>
</tr>
<tr>
<td>Work:</td>
</tr>
<tr>
<td>Date of Birth:</td>
</tr>
<tr>
<td>Expected Delivery Date:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GENERAL PRACTITIONER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please complete this section so we can let your doctor know that you are taking part in the GDM Recall Register</td>
</tr>
<tr>
<td>GP’s Name:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SECONDARY CONTACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please provide details of someone who does not live with you, but will always know where you are if we are having difficulty contacting you.</td>
</tr>
<tr>
<td>Title:</td>
</tr>
<tr>
<td>Family Name:</td>
</tr>
<tr>
<td>First Name:</td>
</tr>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>Telephone Number:</td>
</tr>
<tr>
<td>Home:</td>
</tr>
<tr>
<td>Work:</td>
</tr>
<tr>
<td>Mobile:</td>
</tr>
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<td>Email:</td>
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<tr>
<td>Home:</td>
</tr>
<tr>
<td>Work:</td>
</tr>
<tr>
<td>Relationship to you:</td>
</tr>
</tbody>
</table>
CONSENT FORM

I, .................................................................................................................., consent to my involvement in the Gestational Diabetes Mellitus Recall Register Pilot Project.

I have been provided with and read the information sheet, and I understand the reasons for this project. The ways in which it will affect me have been explained by the Diabetes Nurse Educator. My questions have been answered to my satisfaction. My consent is given voluntarily.

The details of the project have been explained to me, including the reminder letter and how often it will be sent, depending on the previous result; and the expected time the project will take.

I understand that the purpose of this research project is to improve the quality of medical care, but my involvement may not be of benefit to me.

I have been given the opportunity to have a member of family or a friend present while the project was explained to me.

No information about my medical history will be taken from the hospital. My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.

My involvement in the project will not affect my relationship with my medical advisers. I understand I am free to withdraw from the project at any stage without having to give any reasons, and that if I do withdraw from the project, it will not affect my treatment at this hospital in the future.

I am 18 years of age or over. I consent to my general practitioner being informed of my participation in this study. I also consent to Recall Register staff contacting the person I have named as a secondary contact, if they are experiencing difficulties getting in touch with me.

Signature of Participant:          Date:   /  /  
Signature of Diabetes Nurse Educator:   Date:   /  /

(if applicable, for example if an interpreter is used) I declare that I have been present when the research was explained to the above participant and I believe that the participant has an appreciation and understanding of the explanation given and that the consent was freely given:

Signature of Witness:          Date:   /  /  
Address of Witness:

PLEASE COMPLETE YOUR DETAILS
OVER THE PAGE
### YOUR DETAILS - please print

<table>
<thead>
<tr>
<th>Title:</th>
<th>Ms / Mrs / Miss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Name:</td>
<td></td>
</tr>
<tr>
<td>First &amp; Second Names:</td>
<td></td>
</tr>
<tr>
<td>Maiden Name:</td>
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<tr>
<td>Address:</td>
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</tbody>
</table>

<table>
<thead>
<tr>
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<th>Home:</th>
<th>Work:</th>
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<td></td>
<td>Mobile:</td>
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<table>
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<th>Email:</th>
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<table>
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<tr>
<th>Date of Birth:</th>
<th></th>
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</table>

<table>
<thead>
<tr>
<th>Expected Delivery Date:</th>
<th></th>
</tr>
</thead>
</table>

### GENERAL PRACTITIONER

Please complete this section so we can let your doctor know that you are taking part in the GDM Recall Register

<table>
<thead>
<tr>
<th>GP’s Name:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td></td>
</tr>
</tbody>
</table>

### SECONDARY CONTACT

Please provide details of someone who does not live with you, but will always know where you are if we are having difficulty contacting you.

<table>
<thead>
<tr>
<th>Title:</th>
<th>Mr / Ms / Mrs / Miss</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Name:</td>
<td></td>
</tr>
<tr>
<td>First Name:</td>
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<table>
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<tr>
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<th>Work:</th>
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<td></td>
<td>Mobile:</td>
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</table>

<table>
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<tr>
<th>Email:</th>
<th>Home:</th>
<th>Work:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Relationship to you:</th>
<th>Father / Mother / Brother / Sister / Grandfather / Grandmother / Uncle / Aunt / Cousin / Friend / Other (specify)</th>
</tr>
</thead>
</table>
Appendix 3: Wallet card
Gestational Diabetes Mellitus Recall Register

Remember to ...

✓ Visit your General Practitioner for a diabetes test
✓ Exercise at least 20 minutes (ie walking or equivalent) on 4 or more days per week
✓ Eat a nutritious diet that is low in fat

Reminder Card for Diabetes Screening

Screening test result - please ✓ box next to appropriate year below

NORMAL - next test due in 3 years
INCREASED RISK - next test due in 1 year

☐ 2003  ☑ 2004  ☑ 2005  ☑ 2006  ☑ 2007

☐ 2008  ☑ 2009  ☑ 2010  ☑ 2011  ☑ 2012

ENQUIRIES
Diabetes Clearing House, SA Department of Human Services
☎ 8226 6505  ☎ 8226 6244  ✉ Lynda.Caudle@health.sa.gov.au
Level 8/CitiCentre Bldg, PO Box 287/Rundle Mall, Adelaide SA
Appendix 4: Reminder letter and Register update form
1 February 2006

Dear «Title» «Surname»

RE: BLOOD GLUCOSE TEST REMINDER

Thank you for registering on the Gestational Diabetes Mellitus (GDM) Recall Register. As over a year has passed since you were registered, we would like to take this opportunity to remind you to visit your general practitioner for a screening blood glucose test.

Regular blood glucose tests are recommended for women who have had gestational diabetes, as they have an increased risk of developing type 2 diabetes in the future. Earlier detection of type 2 diabetes, through regular blood glucose testing, greatly contributes to better management of this condition, and in turn reduces the effects on the heart, kidneys, eyes and circulation.

Please complete the enclosed form in order for us to keep your information on the Register up to date. Please check the personal information on this form and indicate any changes to your details, your general practitioner details or your secondary contact details, by crossing out the incorrect details and writing the new details within each section. Any personal information provided by you will remain private and confidential. Please return the completed form either by fax on (08) 8226 6244 or by using the printed Reply Paid envelope supplied.

Your continued involvement in the Gestational Diabetes Mellitus Recall Register is important and provides vital information for the future development of strategic policy and planning in the effective management of diabetes and diabetes-related complications. If you have any questions about the study, please contact me by email at lynda.caudle@health.sa.gov.au, by phone (08) 8226 6505, or fax (08) 8226 6244. Thank you for your participation in this project.

Yours sincerely

Lynda Caudle
Epidemiology Research Officer
Gestational Diabetes Mellitus Recall Register
Diabetes Clearing House
Please answer the following questions by ticking the appropriate box:

### DIABETES INFORMATION

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you had a blood glucose test for diabetes in the last 12 months?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>(NB: This does not include when you were diagnosed with GDM)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you ever been told by a doctor that you have diabetes?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>(NB: This is apart from being diagnosed with GDM)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If you have been told you have diabetes, what date were you told?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>(NB: This is apart from being diagnosed with GDM)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please check your personal information below and indicate any changes by crossing out the incorrect details and writing in the new details.

### YOUR DETAILS

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
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<td>«Title»</td>
</tr>
<tr>
<td>Family Name</td>
<td>«Surname»</td>
</tr>
<tr>
<td>First &amp; Second Names</td>
<td>«Othernames»</td>
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<tr>
<td>Maiden Name</td>
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<td>«Address»</td>
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</tr>
<tr>
<td>Email_2</td>
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</tbody>
</table>

### GENERAL PRACTITIONER

<table>
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<th>Field</th>
<th>Details</th>
</tr>
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<tbody>
<tr>
<td>GP’s Name</td>
<td>«GPName»</td>
</tr>
<tr>
<td>Address</td>
<td>«GPAddress1»</td>
</tr>
<tr>
<td></td>
<td>«GPAddress2»</td>
</tr>
</tbody>
</table>

### SECONDARY CONTACT (Other than those you live with )

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title</td>
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</tr>
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<tr>
<td>Relationship to you</td>
<td>«M_2ConRelationship»</td>
</tr>
</tbody>
</table>

GDM = Gestational Diabetes Mellitus
Appendix 5: General Practitioner letter
1 February 2006

«Gpname»
«Gpaddress»
«Gpaddress1»
«Gpaddress2» SA «GPPostcode»

Dear «Gpname»

RE: THE GESTATIONAL DIABETES MELLITUS RECALL REGISTER PILOT PROJECT

We would like to inform you that «Title» «Othernames» «Surname» is a participant in the Gestational Diabetes Mellitus (GDM) Recall Register Pilot Project.

Participants on this register are reminded that they should regularly attend their general practitioner for a screening blood glucose test for early detection of type 2 diabetes.

The GDM Recall Register is a pilot project being conducted by the Diabetes Clearing House, Department of Health, in collaboration with the diabetes centres of the Adelaide Community Healthcare Alliance (ACHA) Inc (Ashford Hospital campus) and The Queen Elizabeth Hospital and Health Service to assess the feasibility of a centrally-based long term follow-up system of women who have had GDM and are at increased risk of developing type 2 diabetes. This GDM Recall Register is the first of its kind in the state, and has the potential to aid in improving the management and health outcomes of women who have previously been diagnosed with gestational diabetes.

Further information regarding the GDM Recall Register Pilot Project is contained in the enclosed information brochure. If you have any further queries, please contact me either by email at catherine.chittleborough@health.sa.gov.au, or by telephone (08) 8226 0788 or fax (08) 8226 6244. Your support of the GDM Recall Register is greatly appreciated.

Yours sincerely

Catherine Chittleborough
Senior Epidemiologist, Diabetes Clearing House
Appendix 6: Approach letter for telephone survey
1 February 2006

Dear «Title» «Surname»

RE: GESTATIONAL DIABETES MELLITUS RECALL REGISTER TELEPHONE SURVEY

Thank you for your participation in the Gestational Diabetes Mellitus (GDM) Recall Register. We are now evaluating the usefulness of the reminder letter used in this register and would appreciate your responses to a brief telephone survey. The reminder letter was sent to you just over a year after you enrolled on the register at the time of your appointment with the Diabetes Nurse Educator. This letter reminded you to visit your general practitioner for a blood glucose test to check for type 2 diabetes.

One of our interviewers will be contacting you by telephone in the next few weeks to complete the survey which will take around 10 minutes. All information provided by you will remain private and confidential.

Your continued involvement in the GDM Recall Register is important as it provides vital information for the future management of diabetes. If you have any questions about the telephone survey or the GDM Recall Register please contact me on phone (08) 82266505, email lynda.caudle@health.sa.gov.au or fax (08) 82266244.

Thank you for your participation in this project.

Yours sincerely

Lynda Caudle
Epidemiological Research Officer
Gestational Diabetes Mellitus Recall Register
Appendix 7: Telephone survey questionnaire
A. INTRODUCTION
Good …………. My name is …………………

[Could I please speak to …………. .…… ...
Continue if correct person is on line.
Or
a) Repeat Introduction once the correct
person is on line.
b) If required person not available ask for a
suitable time to call back. Record first
name and make appointment. (End)
c) If required person not at this phone
number ask for any follow-up details.
1) Phone no. ……… ……… ……… ……. .… ..…..
2) Address ………… ……… ……… ……… …… ….
………… …. …… …… ……… ……… ……… … (End
- Send approach letter to new address)
d) If required person incapable / deaf / ill /
disabled.
1) Note reason ……………… ……… …. . (End)
e) If required person needs an interpreter.
1) Note language required

I’m calling on behalf of the Gestational
Diabetes Recall Register at the South
Australian Department of Health. We are
conducting a survey about this Recall
Register that you were enrolled on at
your appointment with a Diabetes Nurse
Educator.

I can assure you that all information
given in this survey will remain
confidential. The answers from all
people interviewed will be gathered
together and presented in a report. No
individual answers will be passed on.

A.1 We recently sent you a letter about
this telephone survey. Did you receive
the letter?
(Single response)
1. Yes {  }
2. No {  }
3. Don’t know {  }

B. GDM REMINDER LETTER
The following questions relate to the letter
that was sent to you approximately 15
months after the delivery of your baby
reminding you to have a blood glucose test
to screen for the development of type 2
diabetes.

B.1 Could you please tell me... did you
receive this letter [from the Gestational
Diabetes Mellitus Recall Register
reminding you to have a blood glucose
test]
(Single response)
1. Yes {  }
2. No {  }
3. Don’t Know {  }

B.2 Have you had a blood glucose test (a
test to check for diabetes)?
(Single response)
1. Yes {  }
2. No {  } Go to B.6
3. Don’t Know {  } Go to B.7

B.3 What prompted you to have this blood
glucose test?
(Multiple response)
1. The reminder letter {  }
2. Other (specify) {  }
3. Don’t Know {  }
B.4 When did you have this blood glucose
test?
(Record month and year)
1. Month __ __
2. Year __ __ __ __
3. Around the time receiving the letter __ __ __ __
4. Don’t Know __ __ __ __

B.5 What was the result of the blood
glucose test?
(Single response, prompt if necessary)
1. Normal / No Diabetes __ __ __ __
2. Impaired Fasting Glucose __ __ __ __
3. Impaired Glucose Tolerance __ __ __ __
4. Diabetes __ __ __ __
5. Don’t Know __ __ __ __

Sequence guide: Go to B.8

B.6 What are the reasons why you
didn’t have a blood glucose test?
(Multiple response)
1. Haven’t had time __ __ __ __
2. Don’t think I need a test __ __ __ __
3. Told by my doctor I did not need to have the test __ __ __ __
4. Forgot about having the test done __ __ __ __
5. Can’t afford it __ __ __ __
6. Intend to have the test, but haven’t done so yet __ __ __ __
7. Don’t have access to a general practitioner __ __ __ __
8. No reason __ __ __ __
9. Other (specify) __ __ __ __
10. Don’t Know __ __ __ __

B.7 Other than a reminder letter, is there anything else that would make you more likely to have a blood glucose test?
(Multiple responses possible)
1. Yes - if I had more time __ __ __ __
2. Yes - if my doctor told me I needed it __ __ __ __
3. Yes - if it didn’t cost anything to have the test __ __ __ __
4. Yes - Other (please specify) __ __ __ __
5. No __ __ __ __
6. Don’t Know __ __ __ __

B.8 Have you changed your contact details since you enrolled on the Register?
1. Yes (record changes) __ __ __ __
2. No __ __ __ __
C. DEMOGRAPHICS

I am now going to ask you some more general questions ... .

C.1 How would you best describe your family structure? Please listen to the description and then tell me which one is the closest to your family situation.

(Read options. Single response)

1. A family with a child or children living with both biological or adoptive parents
2. A step or blended family
3. A sole parent family
4. Shared care parenting
5. Adult living alone
6. Adult living with partner and no children
7. Related adults living together
8. Unrelated adults living together
9. Other (specify)
10. Refused

C.2 In which country were you born?

(Single response)

1. Australia
2. Austria
3. Bosnia-Herzegovina
4. Canada
5. China
6. Croatia
7. France
8. Germany
9. Greece
10. Holland / Netherlands
11. Hong Kong
12. Iran
13. Italy
14. Japan
15. Malaysia
16. New Zealand
17. Philippines
18. Poland
19. Slovenia
20. Spain
21. UK and Ireland
22. USA
23. Vietnam
24. Former Yugoslav Republic of Macedonia
25. Former Yugoslav Republics of Serbia & Montenegro
26. Other country (specify)
27. Refused
28. Fiji
29. India
30. South Africa

C.3 Are you of Aboriginal or Torres Strait Islander origin?

(Single response)

1. No
2. Aboriginal
3. Torres Strait Islander
4. Both
5. Not stated

C.4 Do you speak a language, other than English, at home?

(Multiple responses possible)

1. Yes - Italian
2. Yes - Greek
3. Yes - Vietnamese
4. Yes - Other (specify)
5. No
6. Not stated
C.5 What is the highest level of education you have completed?
(Single response. Prompt if necessary)
1. Never attended school {  }
2. Some primary school {  }
3. Completed primary school {  }
4. Some high school {  }
5. Completed high school {  }
6. TAFE or trade certificate or diploma {  }
7. University, CAE or some other tertiary institute degree {  }
8. Other (specify) {  }

C.6 What is your current marital status?
(Read options. Single response)
1. Married {  }
2. Living with a partner (De Facto) {  }
3. Divorced {  }
4. Separated {  }
5. Widowed {  }
6. Never Married {  }
7. Not stated {  }

C.7 Can you tell me the approximate annual gross income of your household?
That is, for all people in the household before tax is taken out. I’ll read out some categories and could you please tell me into which one your household’s income falls?
(Read options. Single response)
1. Up to $12,000 {  }
2. $12,001 - $20,000 {  }
3. $20,001 - $40,000 {  }
4. $40,001 - $60,000 {  }
5. $60,001 - $80,000 {  }
6. $80,001 - $100,000 {  }
7. More than $100,000 {  }
8. Not stated / Refused {  }
9. Don’t know {  }

C.8 Are there any comments that you would like to make about the Gestational Diabetes Mellitus Recall Register?
(Encourage comments)
1. No comments {  }
2. Comments (specify) {  }

That concludes the survey. On behalf of the Diabetes Clearing House at the South Australian Department of Health, the Adelaide Community Health Alliance and The Queen Elizabeth Hospital, thank you very much for taking part in this survey.