Māori health literacy research: Gestational diabetes mellitus

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Acknowledgements

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<tr>
<th>Glossary</th>
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<tr>
<td>Antenatal</td>
<td>The period of a pregnancy before the birth.</td>
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</table>
| Ask-me-3 strategy              | A communication strategy designed to improve communication between patients and health care providers, encourage patients to become active members of their health care team and promote improved health outcomes. The strategy encourages patients to ask their health care providers three questions:  
What is my main problem?  
What do I need to do?  
Why is it important for me to do this? |
<p>| Diabetes                       | When there is too much glucose (sugar) in the blood. This happens because the pancreas cannot make enough insulin. Insulin is a hormone that helps muscles get sugar from the blood and use the sugar for energy. |
| Diabetes in pregnancy (DIP)     | An inclusive term for diabetes first diagnosed during pregnancy including GDM or T2DM. |
| Gestational diabetes mellitus (GDM) | A temporary condition that usually occurs during the last trimester of pregnancy when a woman is unable to process sugar effectively, leading to high blood sugar/glucose that affects her and her baby. Post-pregnancy, women and their babies have an increased risk of developing Type 2 diabetes. |
| Glucose challenge test (GCT)   | Also known as a polycose test. The test involves drinking a sugary solution then waiting an hour before having a blood test to see the level of sugar/glucose still in the blood. A high test result shows that someone may have problems processing sugar (an indicator of GDM). If the test result is high, a second test, called an oral glucose tolerance test, will be carried out to confirm GDM. |
| HbA1c test                     | Also known as the glycated haemoglobin test. This is a blood test used to diagnose diabetes by identifying the average level of sugar/glucose in the blood in the three months prior to the test. This test can also be used in early pregnancy to diagnose women who have had elevated sugar/glucose levels when they enter pregnancy. The test is not used to diagnose GDM because GDM starts later in pregnancy (so looking at the previous three months of blood glucose is unlikely to identify the condition). |
| Health literacy                | The degree to which individuals have the capacity to get, process and understand basic health information and services needed to make good health decisions, which is influenced by health practitioners, health care organisations and the health system. |
| Hyperglycaemia in pregnancy (HIP) | High blood sugar/glucose, which increases the risk of complications during pregnancy, labour and after childbirth. High blood sugar may be due to pre-existing diabetes or GDM. |
| Hypoglycaemia                  | Otherwise known as low blood sugar/glucose. It is a condition in which the level of sugar/glucose in the blood drops below a certain point (about 2.5 mmol/L). |
| Intrauterine foetal death      | Loss of a foetus or stillbirth. Stillbirth happens when the mother is 20 or more weeks pregnant. |</p>
<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jaundice</td>
<td>In newborn babies, this condition refers to the yellow colour of the skin and whites of the eyes, caused by excess bilirubin in the blood. Jaundice occurs when bilirubin builds up faster than the newborn’s liver can break it down and pass it from the body.</td>
</tr>
<tr>
<td>Metabolic syndrome</td>
<td>A name for a group of risk factors that occur together and increase the risk for coronary artery disease, stroke and diabetes.</td>
</tr>
<tr>
<td>Oral glucose tolerance test (OGTT)</td>
<td>A laboratory test to check how the body breaks down sugar. A person must not eat for at least eight hours before the test. A blood test is taken at a laboratory to get starting blood sugar levels. A person then drinks a sugary solution, and blood samples are taken after one and two hours to see how quickly the glucose is cleared from the blood. The results will show whether a woman has GDM.</td>
</tr>
<tr>
<td>Perineal trauma</td>
<td>Any damage to the genitals of a woman during birth of a baby. Tears can also occur inside the vagina and in the labia.</td>
</tr>
<tr>
<td>Polycose test</td>
<td>Also known as glucose challenge test (GCT). The test involves drinking a sugary solution then waiting an hour before having a blood test to see the level of sugar/glucose still in the blood. A high test result shows that someone may have problems processing sugar (an indicator of GDM). If the test result is high, a second test, called an oral glucose tolerance test, will be carried out to confirm (or not) GDM.</td>
</tr>
<tr>
<td>Post-partum</td>
<td>Following childbirth.</td>
</tr>
<tr>
<td>Pre-eclampsia</td>
<td>A condition of pregnancy where a woman has high blood pressure and other symptoms that could lead to convulsions and coma.</td>
</tr>
<tr>
<td>Respiratory distress syndrome</td>
<td>A breathing disorder that affects newborns where the lungs collapse and the baby has to work hard to breathe. The baby might not be able to breathe in enough oxygen to support the body’s organs. The lack of oxygen can damage the baby’s brain and other organs if proper treatment is not given.</td>
</tr>
<tr>
<td>Schema</td>
<td>Pre-existing beliefs and knowledge.</td>
</tr>
<tr>
<td>Type 1 diabetes mellitus (T1DM)</td>
<td>A condition where the body stops making insulin and the blood sugar/glucose level is very high. Treatment to control the blood glucose level is with insulin injections and a healthy diet.</td>
</tr>
<tr>
<td>Type 2 diabetes mellitus (T2DM)</td>
<td>Where the production of insulin is slow or the body is resistant to insulin, causing high blood sugar/glucose levels. This type of diabetes can be treated with weight loss, regular physical activity and medication.</td>
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Executive summary

Gestational diabetes mellitus (GDM) is a temporary condition that usually occurs during the last trimester of pregnancy when a woman is unable to process sugar effectively, leading to high blood sugar that affects her and her baby. GDM is associated with adverse pregnancy outcomes for women and babies, but it can be detected and treated so that these risks are reduced. Women’s blood sugar levels return to normal post-pregnancy, however both women and babies have an increased risk of developing Type 2 diabetes mellitus (T2DM) following GDM.

Screening for GDM is recommended for all pregnant women, unless an earlier diagnosis of diabetes has been made (Simmons et al 2008). However, screening rates are very low among Māori women, despite Māori women being at higher risk of GDM. The incidence of GDM in the National Women’s Hospital annual report was 3.7 percent for New Zealand European women, 5 percent for Māori women, 10.3 percent for Pacific women, 11.3 percent for Asian women, and 16 percent for Indian women (Auckland District Health Board 2010).

Managing GDM requires women to come to grips with diabetes in a short timeframe of approximately 12 weeks. Building the health literacy skills and knowledge required to understand and consent to screening processes for GDM as well as manage the condition is therefore challenging. The main opportunity for women to build an understanding of GDM and the importance of screening is just before or during pregnancy, with information most often being provided by a lead maternity carer (LMC) such as a midwife, general practitioner or obstetrician. In 2010, 83 percent of pregnant Māori women registered with an LMC compared to 92 percent of pregnant European women (Ministry of Health 2011).

Health literacy involves health organisations, health practitioners, and patients and their families. It is described as ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’ (Institute of Medicine 2004, p.2, Ministry of Health 2010). For health practitioners, health literacy is about the ability to effectively communicate health information, and for health organisations it is about the appropriateness of the health information and services they provide for patients and their families. There is a strong relationship between a person’s health literacy and their health status (Ministry of Health 2012).

Workbase was contracted by the Ministry of Health to undertake research about health literacy and GDM. The project team was supported by a clinical Reference Group comprised of experts in diabetes, pregnancy and Māori health. The focus of the project was on young, pregnant Māori women (less than 25 years of age) and GDM. The objectives of the research were to:

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1 The most recent study reporting the national GDM screening rates for Māori women was published in 2000 (Yapa and Simmons). The study identified that approximately 70% of Māori women were not being screened at this time. While this data is now dated there is no more recent data available. The collection of data in order to provide more current information is recommended within this report.
1. identify health literacy barriers and facilitators in understanding and management of GDM

2. highlight any interventions or approaches that may be effective in strengthening health literacy to allow better understanding and management of GDM in New Zealand

3. demonstrate ways to increase health literacy in order to improve outcomes associated with GDM.

Method

The research was undertaken in four phases:

1. Literature reviews for GDM and health literacy were completed. A stocktake of resources available in New Zealand about GDM was completed and a health literacy profile, describing the literacy skills and knowledge required to manage GDM, was prepared.

2. Consultation was carried out with women and health practitioners. Information was gathered from three groups of stakeholders: Māori women, who were sometimes accompanied by family members; health practitioners and providers; and health system managers and representatives. Focus groups, interviews and surveys were used to explore perceptions of antenatal services, knowledge of GDM and reasons for low screening rates. Information gaps and health literacy needs were identified.

3. Resources about GDM and screening were developed. Talking Points (suggested scripts) were developed for LMCs to guide their approach to providing clear and relevant information about GDM, along with an explanation of the consequences of GDM and the screening process. A booklet that LMCs could give to women and discuss (using the approaches in the Talking Points) was also provided.

4. The Talking Points for LMCs and booklet were given to 20 health practitioners (midwives, practice nurses, general practitioners in shared care, consultants and midwifery managers) to share within their services and use with the women and families with whom they work.

Findings

a) Health literacy barriers

Complexity of GDM and screening processes

- GDM is a complex condition to manage requiring women to build significant knowledge and skills (to manage diabetes) in a short timeframe during pregnancy and to make major lifestyle changes.

- The words and acronyms used to describe GDM and screening are unfamiliar to most women, and these are used inconsistently by health practitioners, for
example, gestational diabetes, GDM, DIP, HIP, hyperglycaemia, polycose, GCT, OGGT, fasting, non-fasting, nil by mouth.

- Unlike a standard blood test, GDM screening activities are often unfamiliar to women. Screening involves a visit to a laboratory, sometimes having to book a laboratory appointment, drinking a sugary solution and waiting at the laboratory for an hour or two before having a blood test. Sometimes screening requires a woman to fast beforehand, and occasionally women vomit after drinking the solution, which means they cannot continue with screening and need to return another day. Young Māori women are more likely to have low health literacy (Ministry of Health 2010) and be unfamiliar with and face barriers of access to the maternity care pathway (Makowharemahihi et al 2014). Having low health literacy makes it more difficult to access and navigate health services and increases reluctance to participate in unfamiliar health services, such as working with an LMC or completing screening for GDM at a laboratory.

- Lacking confidence in unfamiliar health situations may also lead to irregular visits to an LMC and a reliance on personal advisors over health practitioners for pregnancy advice. However, there is little public awareness and understanding of GDM, making it harder for women to get helpful and accurate advice from family and friends.

- Māori women who are unsure about the importance of screening or the risks of undiagnosed GDM appear less likely to complete the screening process than non-Māori women.

Lead maternity carers and diabetes services

- LMCs have different opinions as to whether they should encourage screening with all women. In this study the women who were screened for GDM did so based on advice from an LMC.

- Some LMCs report consistently high rates of screening amongst the Māori women with whom they work while others have consistently low rates. Those with low rates of screening provide little information, discussion or assistance to women to help them understand GDM and navigate the screening process.

- LMCs report that discussion about GDM and screening during antenatal appointments usually results in women agreeing to be screened, but fewer Māori women complete the screening process (30 percent compared with 75 percent for non-Māori women) (Yapa and Simmons 2000).

- Some LMCs are using risk factors for GDM to assess whether screening for GDM should be encouraged for a woman rather than encouraging screening for all women (universal screening). Along with the possibility of GDM existing for women without any risk factors, this can result in young Māori women thinking that screening is not recommended for them.

- The advice provided by some diabetes services to women with GDM can be impractical for women with young families, for example, that women buy and eat separate food to the rest of the family. This makes management of GDM difficult and creates a reluctance to work with diabetes services.
Access to health care and information

- There are few clear, comprehensive information resources about GDM and screening in New Zealand.
- Some diabetes services are not located in convenient places for pregnant women to access.
- Women report difficulty in finding an LMC, leading to irregular maternity care and less testing during pregnancy. This contributes to the 17 percent of Māori women who do not register with an LMC (Ministry of Health 2011).

b) Facilitators and interventions to strengthen health literacy

LMCs with consistently high rates of screening amongst Māori women use a number of common approaches to support Māori women to decide to be screened and encourage follow-through on this decision.

LMCs with high rates of GDM screening described high-trust relationships and regular contact with women, often looking after the same women during subsequent pregnancies. These LMCs considered that screening for GDM was relevant for all women and that they were responsible for ensuring women had all the information needed to make an informed choice about being screened, as well as any support needed to complete screening processes and manage GDM.

These LMCs described very similar approaches to working with women. The common elements included:

- offering and encouraging screening with every woman
- discussing GDM and its consequences
- discussing what happens during the screening process
- checking that women understand GDM and what they need to do for screening.
- involving family or other support people in discussions with women about GDM and screening to answer their questions and enlist their support
- helping women organise screening if needed
- regular follow-up and discussion of any issues with screening (including if it has not been completed before the next antenatal visit)
- organising a blood test for screening during an antenatal visit if it has not happened by 28 weeks (where possible).

Should women be diagnosed with GDM, these LMCs continued to provide antenatal care in cooperation with diabetes services, thereby ensuring the continuity of care for women.

The draft resources produced in the project for LMCs reflect the practice of LMCs with high rates of screening for GDM. The resources were:

- a booklet describing GDM, its consequences and the screening process.
- Talking Points (possible scripts) for LMCs describing the approaches to use with women and their families to work through the GDM booklet.
- a video script describing a woman’s visit to a laboratory for GDM screening.
Feedback from a trial with stakeholders identified that the booklet was helpful in supporting discussion about GDM and screening. Feedback also highlighted the need for New Zealand photography and reduced text in the booklet.

Further feedback from some LMCs identified that the booklet was too complex for women to use independently. This demonstrated that LMCs were not clear that the booklet needed to be accompanied by discussion as described in the Talking Points and, therefore, that the Talking Points were not being used. Feedback from the trial was incorporated into both the redesigned booklet and Talking Points.

**Conclusion**

The decision of Māori women to be screened for GDM is influenced by the advice they receive from their LMC and their personal advisors as well as their previous pregnancy experiences. Unless women have experienced GDM it is unlikely they will know much about GDM. Approximately 70 percent of Māori women are not being screened for GDM despite this being recommended for all women during pregnancy (Yapa and Simmons 2000).

Where Māori women are not being screened, they describe the main information they receive from LMCs about GDM as being about the timing of screening, that is screening needs to happen at between 24 and 28 weeks of pregnancy. While women may agree to be screened at this time, the discussion is often insufficient to convince them of the importance of completing screening at a laboratory.

LMCs with high rates of GDM screening among young Māori women use approaches and practice that build women’s health literacy skills and understanding of GDM and screening. In particular, these LMCs ensure women understand the consequences of GDM and why screening is important as well as helping women to become familiar with the screening process. These LMCs also provide regular encouragement to complete the process. The present project developed and trialled Talking Points (a suggested script) and booklet for LMCs which reflect the practice of LMCs with high screening rates.

For women diagnosed with GDM, the significant health literacy demands of managing the condition require regular, relevant and practical support from health practitioners for the duration of the condition. These women are managing two significant health events – pregnancy and diabetes – and are likely to benefit from intensive support. Assisting women with the management of GDM needs to be a partnership between diabetes services and LMCs along with women and their families.
Part 1. Introduction

This section provides a brief overview of health literacy and GDM. This will be expanded upon in Parts 3–5 of the report.

GDM is a temporary condition that usually occurs during the last trimester of pregnancy when a pregnant woman is unable to process sugar effectively, leading to high blood sugar affecting her and her baby. The incidence of GDM at National Women’s Hospital in 2010 was 3.7 percent for New Zealand European women, 5 percent for Māori women, 10.3 percent for Pacific women, 11.3 percent for Asian women and 16 percent for Indian women (Auckland District Health Board 2010).

While GDM is associated with adverse pregnancy outcomes for women and their babies, once detected, GDM can be treated and these risks reduced. Although blood sugar levels return to normal post-pregnancy, women and their babies have an increased risk of developing T2DM. Understanding and managing GDM, including the screening and diagnostic processes, requires good health literacy.

1.1 Gestational diabetes mellitus

There are a variety of terms used to refer to diabetes that is present during pregnancy. GDM, diabetes in pregnancy (DIP), hyperglycaemia in pregnancy (HIP) and high blood sugar in pregnancy are all referred to in New Zealand publications and websites. Although GDM is not interchangeable with these other terms, there is a lack of consistency in how GDM and other terms are used across the health sector. For the purposes of this project, we distinguish between GDM, DIP, HIP and high blood sugar in pregnancy in the following ways:

- GDM is a temporary condition caused by pregnancy that occurs from 24–28 weeks’ gestation and resolves after birth.
- DIP, HIP and high blood sugar in pregnancy are more inclusive terms and relate to any diabetic condition that is present during pregnancy, including diagnosed or undiagnosed Type 1 diabetes mellitus (T1DM) or T2DM and GDM.

Early detection is critical to the successful management of GDM because, unrecognised and untreated, GDM can lead to a variety of adverse maternal outcomes including pre-eclampsia, increased risk of caesarean section and perineal trauma. For the foetus, exposure to high glucose levels may result in a large baby and birth injury. Following birth, there is increased risk of neonatal unit admission, hypoglycaemia, respiratory distress syndrome and jaundice. In women who entered pregnancy with previously unrecognised diabetes, there are additional risks of a baby having birth defects as well as risks of pre-term birth or intrauterine foetal death. GDM is also associated with an increased risk of future T2DM for the woman and increased risks of obesity, metabolic syndrome and T2DM for the child. Treating GDM has been shown to improve pregnancy outcomes.
1.1.1 Screening for GDM

Although there are no nationally agreed screening guidelines for GDM, the diagnosis of GDM in New Zealand is usually made using a two-step approach.

An initial screening test is carried out at 24–28 weeks’ gestation, known as a glucose challenge test (GCT) or polycose test. If the test returns a positive result, a second diagnostic test is carried out, known as an oral glucose tolerance test (OGTT), to confirm GDM. It is also appropriate for a woman at high risk of GDM to go straight to an OGTT at 24–28 weeks. A post-partum OGTT is also required approximately six weeks after birth to confirm that a woman’s blood sugar levels have returned to normal.

From a woman’s perspective, screening for GDM is not like other blood tests during pregnancy. A GCT takes at least an hour, and an OGTT requires fasting and takes at least two hours. Both tests require a woman to drink a sugary solution and rest until a blood test is completed. The tests are both unfamiliar and, for some women, unpleasant (causing nausea and vomiting).

Initially, women need enough of an understanding of GDM and screening to make an informed decision about being screened. This is likely to require building new health knowledge of how the body functions during pregnancy. Women then need to participate in the process of screening. If they have not been screened before or lack confidence in unfamiliar health settings, women need assistance to understand what they will be expected to do. A woman is then presented with her results, usually by an LMC, and may need assistance to understand these results. Finally, if a woman is diagnosed with GDM, there are significant health literacy demands involved in managing and monitoring nutrition, exercise, medication and equipment (see Appendix 3).

A 2008 technical report from the National GDM Technical Working Party recommended a universal offer of screening for GDM whereby all pregnant women are offered screening for GDM at 24–28 weeks gestation (Simmons et al 2008). Prior to this report, screening for GDM had been offered based on the presence of risk factors. The risk factors for GDM are complex and multi-faceted, and GDM can develop in women who have none of the risk factors. It was found that this risk-based approach missed identifying a sizeable proportion of women with GDM (Simmons et al 2008). Since the Working Party’s report, most DHBs and the New Zealand College of Midwives have adopted a universal offer of screening for GDM. Screening advice and the offer of screening are usually provided to pregnant women by their LMC.

In addition to recommending universal screening for GDM at 24–28 weeks’ gestation, the 2008 National GDM Technical Working Party recommended that, in early pregnancy, screening for unrecognised pre-existing diabetes should be considered in women who have risk factors (Simmons et al 2008). This requires LMCs to have a comprehensive understanding about all types of diabetes and the
screening and testing processes recommended for these, how the processes vary and why.\(^2\)

The incidence of GDM is on the increase, with Māori, Pacific and Asian women at significantly greater risk (Bristow et al 2009; Auckland District Health Board 2010). Screening rates are proportionally low in Māori and Pacific populations, suggesting systematic flaws in the way women are approached, advised and managed (Yapa and Simmons 2000).

1.1.2 Managing GDM

GDM is a complicated health condition that requires a person to develop new knowledge and skills in a very short timeframe. In addition to accepting their pregnancy status, women newly diagnosed with GDM also need to accept that they and their baby have a health condition. This may be helped somewhat by GDM occurring at a time when many women feel motivated to make lifestyle changes for the sake of their baby (Bennett et al 2008).

1.2 Health literacy

1.2.1 The concept of health literacy

Health literacy is described as ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’ (Institute of Medicine 2004, p. 2; Ministry of Health 2010).

People are often reliant on the communication skills of the health practitioners they are interacting with and the ability of other stakeholders, such as health organisations and media, to provide health information and services in ways that are appropriate (Institute of Medicine 2004). The more complex health information, services and systems become, the more support people need to access and understand these services and information.

The Institute of Medicine (2004, p. 2) notes that health literacy ‘emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing the information and services’. Health dialogue has now replaced monologue (Zarcadoolas et al 2006). The solution to low health literacy therefore lies in a concerted effort from all sectors, including schools, government agencies and the health care system (Ministry of Health 2010).

\(^2\) The Auckland District Health Board guideline recommends adding an HbA1c test to ‘booking bloods’ for women at high risk of undiagnosed pre-existing diabetes. This is because HbA1c is the test used to diagnose diabetes outside pregnancy. HbA1c is a measurement that reflects whether glucose levels have been elevated over several weeks. It is reasonable to also use this test in early pregnancy to diagnose women who have had elevated glucose levels when they enter pregnancy (as opposed to women with true GDM who will have normal sugar levels when they enter pregnancy). However, other centres recommend using different tests, such as an early OGTT. An HbA1c test is not recommended to diagnose GDM but may occasionally be used with women later in pregnancy.
Zarcadoolas et al (2006) identify the role of culture in health literacy, stating that cultural literacy (i.e. the ability to understand and use culture and social identity to interpret and act on information) is clearly needed by all stakeholders in order to improve health care and health outcomes. Kickbusch et al (2005) mirror this sentiment and state that culture, including the culture of the health system, affects attitudes, perceptions and behaviours at both the patient and provider end or for both those receiving and delivering health services, information, messages, treatment, decisions and actions. As the Institute of Medicine (2004, p. 9) states, ‘these culturally influenced perceptions, definitions and barriers can affect how people interact with the health care system and help determine the adequacy of health literacy skills in different settings’.

There are a number of behaviours that may indicate someone has low literacy, although these alone do not constitute evidence of low health literacy. These indicators include regularly missing medical appointments, ignoring or misunderstanding health instructions or advice, asking a number of questions or asking no questions, arriving with incomplete forms, avoiding filling in forms or taking additional spare copies and making excuses about forgetting reading glasses and needing to read the information at home (Weiss 2007). In addition ‘patients rarely identify themselves as struggling with literacy issues’, and they also seldom ask for assistance in reading health-related materials (Rudd et al 1999, p. 183).

1.2.2 Health literacy in New Zealand

Kōrero Mārama (Ministry of Health 2010) reports on the health literacy of New Zealand adults based on data from the 2006 Adult Literacy and Life Skills Survey. Results from this survey showed that more than half (56.2 percent) of adult New Zealanders have poor health literacy skills (Ministry of Health 2010). Groups with poor health literacy include older people, Māori, people in Pacific and other ethnic minority groups and people on low incomes. Māori have poorer health literacy than non-Māori regardless of age, gender, income, employment status, education level or location. There is a strong relationship between a person’s health literacy and their health status (Ministry of Health 2012).

While Kōrero Mārama does not offer specific insight into the health literacy levels of young (under 25 years of age) Māori women, it does provide information about Māori women and health literacy and Māori youth and health literacy. Māori females have significantly poorer health literacy skills than non-Māori females. Analysis shows that ‘three out of four Māori females have poor health literacy’ (Ministry of Health 2010, p. 7), compared with just over half of non-Māori females. For Māori aged 16–18 years, 87 percent have poor health literacy compared to 69 percent for non-Māori, and for Māori aged 19–24 years, 84 percent (compared to 56 percent for non-Māori) have poor health literacy.
1.2.3 Health literacy and pregnancy

Renkert and Nutbeam (2001, p. 382) define maternal health literacy as ‘the cognitive and social skills which determine the motivation and ability of women to gain access to, understand, and use information in ways that promote and maintain their health and that of their children’. Healthy pregnancy outcomes require the knowledge and skills to detect risk factors and take appropriate actions during pregnancy. In situations where women cannot read the information they receive, complete calculations, understand medical instructions or prescriptions, interact effectively with a health care practitioner or understand what action needs to be taken, they will not be able to fully participate in the health care system and will miss out on key aspects of care (Mojoyinola 2011).

From research carried out in the Counties Manukau District Health Board (CMDHB) area, Corbett and Okesene-Gafa (2012, p. 2) state that ‘women’s beliefs about the value of antenatal care, knowledge of how to access an LMC, social factors and service provider factors are all barriers to early initiation of antenatal care amongst pregnant women residing in the CMDHB catchment area’. A lack of understanding of the maternity system and how it works is a barrier, with women reporting that they wanted better information so they could understand the different types of care available in pregnancy. Many women were also unaware that early antenatal care is important for a successful pregnancy outcome.

The women interviewed by Corbett and Okesene-Gafa emphasised the importance of information that is detailed, up to date and accurate, particularly in relation to the location of LMCs and services. In regards to the quality of antenatal care, women who were unhappy with their care identified issues with LMCs being too judgemental, not providing enough information and not taking the women’s concerns seriously. The women who were most satisfied with the maternity care they received had continuity of care (from one LMC) throughout their pregnancy (Corbett and Okesene-Gafa 2012).

1.2.4 Health literacy and GDM

Literacy (reading, writing, speaking and listening) and numeracy skills and knowledge are central to health literacy. However, the term also encompasses skills and knowledge unique to health, such as a conceptual understanding of nutrition and how the body works, knowing when and where to seek health advice, being able to evaluate the credibility of health advice, being able to interpret and describe symptoms, acting with confidence in health settings and understanding the complex health system (Koh et al 2012). A full description of the health literacy (knowledge and skills) required to manage GDM is provided in the health literacy demands in Appendix 3 of this report.

For some young women, pregnancy is full of unfamiliar activities and information. A woman who has poor health literacy is more likely to lack confidence operating in unfamiliar health environments. Understanding and making decisions about GDM is particularly challenging. A woman with low health literacy may be reliant upon her LMC to help her engage with the health system. She may also need her LMC to
guide her through decision-making processes. This requires an LMC to discuss all new information and describe new processes in clear, well structured ways as well as using multiple methods to check a woman’s understanding (Stang 2000).

At the same time, a woman with low health literacy may have difficulties finding an LMC and accessing antenatal services. This will contribute to the lower proportion of pregnant Māori women who register with an LMC. In 2010, 83 percent of pregnant Māori women registered with an LMC compared to 92 percent of pregnant European women (Ministry of Health 2011). Women without an LMC first present for antenatal care after the 24–28 weeks gestation period, which is too late to be screened for GDM.

Young Māori women with low health literacy may be more reliant on trusted personal advisors, such as family or friends, to help them understand their pregnancy and guide their decision making. This makes it especially important for an LMC (if involved) to encourage this wider group to participate in antenatal discussions.

1.3 The present project

Improving women’s knowledge of GDM requires health practitioners and health educators to communicate in ways that engage women.

Of particular concern for the present project:

- the screening rates for GDM are extremely low for Māori women, 30 percent nationally compared to 70 percent for non-Māori, despite Māori women being at higher risk of GDM (Yapa and Simmons 2000)
- the health literacy skills and knowledge required to manage diabetes are complex and challenging because of the short amount of time a woman has (approximately 12 weeks) to understand and manage GDM.

The present project focused on Māori women under the age of 25 years, as 49.5 percent of the Māori women having babies are aged 24 years or younger. This age group also has one of the lowest levels of health literacy (Ministry of Health 2010).

The objectives of this project are to:

1. identify health literacy barriers and facilitators in understanding and management of GDM
2. highlight any interventions or approaches that may be effective in strengthening health literacy to allow better understanding and management of GDM in New Zealand
3. demonstrate ways to increase health literacy in order to improve outcomes associated with GDM.

An important background issue for this project is the lack of consensus among health practitioners about how to define, screen and manage GDM. While this project was under way, there was also a Ministry of Health project focused on GDM practice in New Zealand. This initiative impacts on this project in that the resources developed
in this project, aimed at improving health literacy, may need to be modified to ensure consistency with any new GDM guidelines or messages.

1.3.1 Project team
A project team of health literacy researchers and resource developers from Workbase was established. A primary health care nurse specialist from Counties Manukau District Health Board was recruited to assist the project team by providing clinical expertise during interviews with women, reviewing clinical literature and facilitating contact with health practitioners.

1.3.2 Reference Group
A Reference Group was established at the start of the project to provide clinical guidance. The group had five meetings and contributed to the development of the project plan, identified existing data and research to review, provided feedback on the literature review and resources and reviewed the project report. The Reference Group members were Norma Campbell (New Zealand College of Midwives), Caran Barratt-Boyes (Counties Manukau District Health Board), Karen Pickering (Diabetes Project Trust), Dr Janet Rowan (National Women’s Hospital Obstetric Physician Diabetes and Pregnancy) and Dr Elaine Rush (Faculty of Nutrition, Health and Environmental Sciences, AUT). Dr Beverley Lawton (Ngāti Porou, University of Otago) acted as critical friend to the project by providing feedback on the literature review, and Leonie Matoe (Te Hotu Manawa Māori) supported the Reference Group and project team by providing links to Māori communities and health research.

1.4 Report structure
Part 2 of this report describes the research method used in the project.

Part 3 describes the findings related to Objective 1, that is, literature on health literacy and GDM are examined for the insight they offer into the barriers to and facilitators of health literacy in understanding and managing GDM.

Part 4 describes the findings related to Objective 2, that is, interventions or approaches that may be effective in strengthening health literacy to understanding and management of GDM. The development of health literacy resources is also described.

Part 5 describes the assessment of health literacy resources in fulfilment of Objective 3, that is, demonstrating ways to increase health literacy in order to improve outcomes associated with GDM.

Part 6 provides an overall discussion of the research.
Part 2. Method

The research was conducted in four phases. Phase 1 involved the review of relevant literature and health literacy resources. In Phase 2, pregnant women and health practitioners were interviewed, and health practitioners were also surveyed. In Phase 3, health literacy resources were developed based on the findings from Phases 1 and 2. In Phase 4, the resources were distributed to LMCs who reviewed and used the resources with women and provided feedback. The alignment of each phase with the three research objectives is outlined in Table 1 below.

Table 1. Alignment of research objectives with research phases

<table>
<thead>
<tr>
<th>Research objectives</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
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<tbody>
<tr>
<td>1. Identify health literacy barriers and facilitators in understanding and management of GDM</td>
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<tr>
<td>2. Highlight any interventions or approaches that may be effective in strengthening health literacy to allow better understanding and management of GDM in New Zealand</td>
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<td>✔️</td>
<td>✔️</td>
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<tr>
<td>3. Demonstrate ways to increase health literacy in order to improve outcomes associated with GDM</td>
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2.1 Phase 1: Literature and resources

The project began with sourcing and analysing existing information on GDM and health literacy.

National and international literature was reviewed to produce a literature review about health literacy and GDM (Appendix 1 and Appendix 2 respectively). Primary searches were completed using Google Scholar, with secondary searches done on PubMed and BMJ. Search terms for health literacy included health literacy, patient communication and a range of qualifiers (for example, assessment, education, tools and culture). Search terms for GDM included gestational diabetes mellitus risk factors, communication, screening, diagnosis and management.

A stocktake was undertaken of hard copy and online resources about GDM. The health practitioners interviewed during Phase 2 of the project identified further resources to be added to the stocktake (Appendix 4).

Health literacy demands for GDM were prepared describing the health literacy knowledge and skills required to understand and manage GDM (Appendix 3) to help inform the development of GDM screening resources and scripts for LMCs to use with women (Appendix 6).
2.2 Phase 2: Consultation

2.2.1 Interviews with women receiving antenatal care

Twenty-six pregnant or recently pregnant women were interviewed about their experiences of antenatal care, their decision to be screened for GDM, what they knew about GDM and their experiences of managing GDM. These women were contacted through their LMC midwives. Twenty two of the women were Māori and four were Pacific.

2.2.2 Interviews with health practitioners

Interviews were conducted with nine midwife LMCs as well as a maternity service manager, four diabetes specialists and an obstetrician.

The information sought from the health practitioners related to:

- their work with young Māori women
- the information, advice and help they provide about GDM and screening
- checks (if any) they made about the health literacy of patients
- explanations for increasing rates of GDM among pregnant Māori women
- their experiences with women diagnosed with GDM.

2.2.3 Health practitioner surveys

Health practitioners including LMCs, specialist diabetes nurses and nutritionists were surveyed to identify current practice in screening for and managing GDM, along with any barriers to screening. The survey was made available to LMC midwives associated with the New Zealand College of Midwives (approximately 1,000 LMC midwives) via the College website. There were 114 responses from midwife LMCs – a small proportion (approximately 11 percent) of the total number of midwife LMCs associated with the College.

A separate online survey for health system representatives was sent to all 20 District Health Boards (DHBs) and nine responses were received.

2.3 Phase 3: Resource development

Using information gathered during consultation, two resources were generated to guide LMCs’ practice in relation to building the health literacy of pregnant women:

- A booklet describing GDM, the consequences of GDM and the screening process.
- Talking Points (suggested scripts) for LMCs describing the approaches to use with women to work through the GDM booklet, in order to build health literacy in relation to GDM and screening.

In addition, a video script was developed describing a woman’s visit to a laboratory for GDM screening. The script was modelled on similar videos posted online (overseas) by women going through the screening process (for example, www.youtube.com/watch?v=KFgr-elM9Hk). These videos help women become...
familiar with the screening process experience and are likely to include information relevant to women because they are told from the perspective of a pregnant woman. Initial feedback on the resources was provided by the Reference Group.

2.4 Phase 4: Resource review

The resources were given to 20 health practitioners (LMCs, practice nurses, GPs in shared care, consultants and midwifery managers) to share within their services and use with the women and families with whom they work. Feedback on the resources was sought through a series of questions related to whether the resources had been used, the usefulness of the resources, including what women liked and the questions the resources provoked, and anything that might be added to or changed in the resources.
Part 3. Objective 1: Barriers to and facilitators of health literacy

The barriers to and facilitators of health literacy related to understanding and managing GDM were elicited through the literature and resource reviews (Phase 1), resource review and stakeholder consultation (Phase 2). Stakeholders’ feedback encompassed GDM screening decision-making, why some women are screened and others not, screening pathways, and the types of health literacy that support screening.

3.1 Literature reviews

The literature reviews identified barriers to and facilitators of both health literacy and understanding and management of GDM. Low health literacy is known to be directly related to adverse maternal and infant outcomes (Endres et al 2004; Mojoyinola 2011).

3.1.1 Barriers to health literacy

Difficulty in reading materials and difficulty in communicating with healthcare providers are two major health literacy barriers that individuals face when they access and use the healthcare system (Rudd et al, 1999). Kickbusch et al (2005, p. 9) assert that ‘access to good reliable information is the cornerstone of health literacy’ yet most health-related material is written at a level beyond that which most patients can understand (Kickbusch et al 2005; Levandowski et al 2006; Zarcadoolas et al 2006; Rudd et al 1999; Rudd et al 2007).

Patients who have trouble reading may prefer a spoken message. Spoken interactions rely on more than words to communicate information and meaning, with tone, body language and gestures all playing an important part (Zarcadoolas et al 2006). However, once a spoken interaction is over, there is nothing left except the memory of what was said, which may be incomplete (Vandergrift 2006). Zarcadoolas et al (2006, p. 90) acknowledge the fleeting nature of spoken interactions and for this reason recommend that spoken messages ‘contain facilitators such as brevity, narrative structure and repetition’.

Kelly and Haidet (2007) also note that many healthcare providers overestimate the health literacy levels of their patients. This leads to a lack of tailored communication, which results in information being provided that is beyond the understanding of the patient, with the potential outcome of non-adherence to a treatment plan. Koh et al (2012) also write that ‘a wide chasm often separates what providers intend to convey in written and oral communication and what patients understand’ (2012, p. 435).

Another barrier to health literacy is an overload of information. There is a vast amount of health information available to patients from an equally vast number of information sources, which can make finding and understanding the right information difficult (Kickbusch et al 2005; Zarcadoolas et al 2006; Institute of Medicine 2004).

An increase in information also makes it more likely that people will encounter information inconsistencies. It is not uncommon for patients to get conflicting
information from their information sources including their health care practitioners, the health system, the media, and their family and friends.

Low GDM screening rates are found in other indigenous populations, including First Nations women (Dyck et al 2002; National Aboriginal Health Organization 2009). Reasons for these disparities in screening rates are not clear, but potential reasons include a lack of understanding among health care practitioners and women about the importance of screening and women first accessing antenatal health care at 30 weeks’ gestation or later (which is too late for timely GDM screening and diagnosis) (Dyck et al 2002).

3.1.2 Facilitators of health literacy

The literature identified a number of actions that health practitioners could use to facilitate improved health literacy. These include:

- using face-to-face opportunities as much as possible to give health advice
- checking patient understanding, which involves the health practitioner checking on the quality of the communication by asking the patient to explain or demonstrate what they have been told
- reading written materials with patients or supporting written materials with verbal explanations
- supporting one form of information with another, such as reinforcing spoken explanations with written materials or supporting written materials with visuals
- using plain language in spoken and written texts and making materials easier to use through a greater consideration of design, font, layout and pictures (Rudd et al 2007; Weiss 2007).

Although good knowledge of a health condition is essential for good health literacy, improved patient knowledge will not always lead to the desired change in behaviour. Kickbusch et al (2005, p. 9) state that ‘health information alone will not be useful to people who do not feel they have the power to act’. The ultimate goal of improved health literacy is greater independence and empowerment in individuals and communities to effectively manage their health.

Confidence and self-efficacy to act on the information and to help others is central to health literacy, and this requires additional inputs such as community development and education (Nutbeam 2008; Kickbusch et al 2005; Zarcadoolas et al 2006).

Rudd et al (2007) highlight the importance of attention to the broad range of skills involved in health literacy, including a closer examination of patient information-seeking skills. Rudd et al note the importance of patient background, knowledge and experience in health-related activities and paying attention to assumptions that information givers have about these.

To minimise the risk of patients not understanding what they read, it has also been recommended in the United States that all written health care material be graded to the reading age of a 10-year-old (Wilson 2009; Zarcadoolas et al 2006). While using plain language in written material is widely recommended in New Zealand, other aspects affecting comprehension such as sense, logic, familiarity, tone and cohesion
need to be taken into account when writing materials (Ministry of Health 2012; Rudd et al 2007).

Providing patients with the most important information first and the rest at a later point can lessen the cognitive load for all patients and act as a facilitator to improve uptake (Rudd et al 1999).

Most people with low health literacy do not know they have an issue, and if they do, they are unlikely to tell health practitioners that they have a health literacy problem. To work within this context, a universal precautions approach to health literacy is being implemented by health practitioners in the United States (DeWalt et al 2010). In health literacy, ‘universal precautions’ means health practitioners approach interaction with every patient or health consumer as if the patient might have health literacy needs. This means using inquiry at the start of an interaction to establish what a patient already understands and needs to know about their health, adding new health knowledge to this base and checking that new understanding has been gained. This requires clear, relevant communication (both written and spoken) by health practitioners and engaging consumers in health discussions.

3.2 Resource review

3.2.1 Resources about GDM and screening

A search found very few New Zealand resources on GDM. No resources were found to provide a written explanation of the screening process for GDM in New Zealand.

The main Ministry of Health publication on pregnancy Your Pregnancy/Tō Hapūtanga makes mention of GDM but does not describe the screening process. The Ministry of Health’s summary, describing all of the tests carried out during pregnancy, does not include GDM.

Some international resources were identified, and the nine LMCs interviewed provided copies of the (few) publications and websites they use to explain GDM and how this affects pregnancy. A full list of resources is provided in Appendix 4.

The resources about GDM include a range of technical terminology, such as gestational diabetes mellitus, diabetes in pregnancy, hyperglycaemia in pregnancy, polycose test, glucose challenge test, GCT, glucose tolerance test, GTT, Type 2 diabetes and HbA1c.

Te Hauora o Hine Te Iwaiwa/Keeping Healthy in Pregnancy and Gestational Diabetes – a pamphlet for Māori women, produced by Nga Maia with support from the Ministry of Health – was the most clear and comprehensive of the GDM resources, with LMCs describing women as liking and using this resource. The resource uses personal stories to demonstrate what managing GDM involves. The resource also provides a timeline of GDM activities during pregnancy and has graphics and design which emphasis Māori culture. More information about the screening process could be added to this resource. The resource and a health literacy review of the resource are provided in Appendix 5.
3.3 Stakeholder consultation

3.3.1 Interviews with women receiving antenatal care

Twenty two Māori women were interviewed, with 20 of them being under 25 years of age. This included a small group of young Māori women at a teen parent centre. Four Pacific women under 25 years of age were also interviewed. Of the 26 women, 21 had completed a GCT and five of them had also completed an OGTT, with four being confirmed as having GDM. Five women had not been screened. The women who had not been screened included women who had consented to screening but had not gone ahead with screening and a woman who had declined screening in her current pregnancy but had been screened in earlier pregnancies.

A. Barriers to health literacy

Women discussed their reasons for not being tested for GDM and their attitudes towards testing and pregnancy. Two women reported avoiding or declining every test during pregnancy because they considered tests to be largely unnecessary. Both of these women had experienced healthy pregnancies before and considered their current pregnancies to be progressing similarly. These women did not complete other second trimester blood tests. Each woman was monitoring the size and growth of their baby with an LMC to check if their baby was growing appropriately.

One woman reported not being offered screening by her LMC during her pregnancy, despite experiencing GDM in a previous pregnancy.

The teenage women who consented to screening but did not complete the screening process were not from the teen parent centre and did not have an understanding of GDM or why screening might be important. For these young women, it was not an explicit decision not to be tested but rather that testing never became a priority. One young woman did not have the test because her mother told her she did not need it. This young woman lacked confidence in communicating with health practitioners and had little knowledge of the health system or maternity services. None of the women interviewed reported declining or avoiding a GCT because they were afraid of a positive diagnosis of GDM, disliked the unpleasant drink or disliked needles.

B. Facilitators of health literacy

The 21 women who were screened for GDM did so based on advice from an LMC (including the LMC at the teen parent centre). They described very positive relationships with an LMC, placing trust in their opinions and appreciating the way LMCS worked with them. The advice they received gave the women some understanding of the consequences of untreated GDM and that they might be at risk of GDM for a variety of reasons, such as a family history of diabetes (even though these factors do not need to be present for screening to be recommended). Women felt they had been encouraged to be screened by an LMC and knew what to expect during the screening process. Those who had been screened and had negative test results did not want more information about GDM as they did not consider it relevant to them.
The women attending the teen parent centre described having no prior knowledge about pregnancy, the health system or GDM. They received substantial daily support from an LMC and teaching staff to participate in new and unfamiliar situations (such as screening).

### 3.3.2 Interviews with health practitioners

The 15 health practitioners interviewed agreed that there was poor awareness of GDM within the general population and amongst pregnant women, including those who had been screened during previous pregnancies, the exception being women who had experienced GDM in a previous pregnancy.

**Professional practice can facilitate or be a barrier to health literacy**

Varying advice with regard to screening was given by LMCs. LMCs have different opinions as to whether they should encourage screening with all women. Some LMCs encourage screening for all or most women, as they view screening as an important step in the pregnancy journey and because women without symptoms or risk factors are still at risk of GDM.

Overall, LMCs identified three main approaches in relation to GDM screening. The first approach reflects good practice as it facilitates improved understanding of GDM and screening and results in high rates of screening:

1. Women are given an explanation of the health consequences of GDM, the importance of screening and the screening process, and their questions and opinions are discussed. Women are asked whether they agree to be screened. Women are contacted if they are not screened before their next LMC appointment to see if there is anything the LMC can do to assist women to complete screening. This approach encouraged agreement to be screened and the follow-through behaviour of completing screening.

The other two approaches were much less effective in building understanding of GDM and screening and were less likely to result in screening for GDM:

2. Women are told that they are at the stage where they could be screened for GDM with a short explanation of GDM and are asked if they agree to be screened. This approach encouraged agreement to be screened but did not always result in follow-through (completing screening).

3. Women are given an explanation of the risk factors that indicate the likelihood of GDM and are asked whether they want to be screened or not. This approach made it unlikely that Māori women would agree to screening unless they had multiple risk factors.

One midwifery centre reported using HbA1c tests for every woman, at each trimester, as an indicator of undiagnosed diabetes and GDM. Unless indicated by abnormal HbA1c test results, LMCs would not generally recommend a GCT or OGTT. At the same centre, LMCs encouraged an early GCT or OGTT if a woman had a history of GDM or diabetes mellitus.

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3 Note that the use of HbA1c testing is not effective for indicating or diagnosing GDM.
Conflicting beliefs about GDM, both within and between antenatal centres, were reported by health practitioners. Two LMCs had encountered problems with the specialist diabetes services for Māori women with GDM. These LMCs reported that, once diagnosed with GDM, women lose contact with their LMC, compromising their continuity of care, and that women feel forced down a pathway that is not of their choosing, such as being encouraged to have a caesarean delivery.

Where LMCs continued to be involved with a woman with GDM, some reported that the regional diabetes services were very poor at keeping LMCs in the ‘information loop’. Some diabetes specialists also described a failure of some diabetes services to provide a supportive environment for pregnant women.

Conversely, other LMCs described continued and strong relationships with diabetes services and women with GDM as well as good information sharing by diabetes services. Where these LMCs continued to support women, in cooperation with diabetes services, women received intensive support before and after meetings with diabetes specialists to ensure they understood how to manage GDM. This model was particularly encouraged where women were managing GDM through diet and lifestyle. Diabetes services also reported good coordination with LMCs, particularly in remote areas.

All health practitioners identified that the GCT and OGTT were time consuming and as such were not a ‘preferred’ part of the pregnancy process for women who had experienced screening before. However, none reported that this strongly affected whether women went through with screening in subsequent pregnancies (although time and looking after other small children were always a consideration).

3.3.3 Surveys of health practitioners and DHBs

A. Barriers to health literacy

When focusing on why women at risk of GDM are not being screened, half of the 114 midwife LMC survey respondents identified time and cost as major contributors, along with difficulty accessing screening services. Fifty-nine percent also identified that women are presenting too late in their pregnancy for screening or have irregular contact with an LMC. Other responses suggest low health literacy in relation to GDM, with 35 percent reporting GDM as not being understood or women and families thinking screening is unimportant (40 percent).

DHB respondents similarly identified the time for screening (five out of nine responses) and late presentation (four out of nine responses) as common reasons for low GDM screening rates. DHB respondents also identified that both women and health providers may perceive screening to be unimportant or unnecessary.

B. Facilitators of health literacy

Fifty-five percent of the midwife LMCs identified that providing better information resources about GDM and raising awareness of GDM pre-pregnancy would help. Twenty-five percent of midwife LMC respondents thought that spending more time on GDM during a consultation could improve screening rates. Over 50 percent also
identified that practical assistance such as childcare, transport and similar supports would improve screening rates.

### 3.4 Discussion

#### 3.4.1 Barriers to building health literacy in relation to GDM

Literature and resource reviews as well as interviews with health practitioners and women helped define the considerable health knowledge and skills required of women at each stage of diagnosing and managing GDM. Many Māori women are unfamiliar with GDM and the screening process (if pregnant for the first time or unscreened in previous pregnancies).

As described in section 3.3.2, practice variations in discussing GDM and the universal offer of screening have a significant impact on whether Maori women complete screening for GDM. While screening for GDM may be offered to most pregnant women and verbal agreement to screening may be high for Maori women, this alone is not sufficient to ensure screening is completed. If the risks of GDM are not discussed or understood, or screening is not fully explained or encouraged, it is unlikely that Maori women will complete screening.

A minority of LMCs were not concerned with low screening rates for Māori women, as they considered a risk-based approach to screening to be more appropriate than universal screening (screening all women) despite research showing this approach to screening misses diagnosing a significant portion of women with GDM.

In some situations, a pregnant woman may encounter pressure not to be screened from family or peers more experienced in pregnancy. Young women in particular may be dependent on their family for pregnancy advice or transport to maternity care and screening.

#### 3.4.2 Facilitators of health literacy in relation to GDM

Women are most interested in learning about GDM when they are pregnant or trying to get pregnant. As such, LMCs are likely to be the main source of information about GDM during pregnancy and can approach the discussion about GDM and screening in ways that increase the likelihood of a woman completing screening for GDM.

LMCs who encourage women to discuss all aspects of their pregnancy and GDM, involve family members in discussions and questions, and help women to build new knowledge and practise new skills, are building health literacy.

The LMCs surveyed identified that they would appreciate more written resources about GDM and screening as there are few resources available which provide clear information on GDM and no New Zealand resources which describe the screening process.

Those LMCs with consistently high rates of screening for GDM amongst the Māori women with whom they work follow a common approach in relation to discussing screening. These LMCs discuss GDM and the risks associated with GDM with women and their families. They also help women to understand what will be expected of them during the screening process and assist them to go through the
process. These LMCs also contact women if they are not screened before their next appointment remind them about screening and see if there is anything they can do to further assist women to complete screening.
Part 4. Objective 2: Interventions to strengthen health literacy

The research into interventions to strengthen health literacy spanned the literature reviews (Phase 1), stakeholder consultation (Phase 2) and resource development (Phase 3). The development of resources was in response to the findings from Phases 1 and 2.

4.1 Literature review

The literature was examined for interventions that successfully strengthened health literacy.

4.1.1 Health literacy interventions

Sudore and Schillinger (2009) developed a framework and description for best practice interventions to improve care for patients with low health literacy. The framework and description are the result of a literature review to identify feasible health literacy interventions at the practitioner-patient level, at the system-patient level and at the community-patient level.

Key messages from interventions focused on the interaction between health practitioners and patients that are relevant to GDM and screening include:

- patient-centred communication, where existing patient knowledge and experiences are identified and built on
- clear health communication, including use of plain language
- confirmation of patient understanding, including use of the teach-back method
- reinforcement of information, including using multiple modalities and involving the patient’s support network
- clear numeracy and risk information, including providing absolute risks instead of relative risks
- medication reconciliation, including simplifying regimens as much as possible and confirming dosage.

Key messages from interventions focused on the interaction between the health system and patients that are relevant to GDM and screening include:

- clinician training, including health literacy education
- creating health education materials, with the audience being involved in the design of the materials
- disease self-management support systems, which need to be proactive and disease-specific
- creating an empowering environment, including making signs and forms easy to read and encouraging patients to ask questions. (Sudore and Schillinger 2009).

Kickbusch et al (2005, p. 18) note the importance of cultural relevance and claim that ‘health messages and solutions must be placed within settings relevant to their target audiences and encompass both a social and health dimension’. This reinforces the need for LMCs to sensitively explore what women know and believe about their
health and pregnancy and use this as the basis for building new knowledge and understanding of GDM. Similarly, McLaughlin identifies as important: effective communication; the culturally competent use of resources; culturally appropriate resources and improved health care access for all women with GDM (McLaughlin 2009).

McLaughlin (2009) adds that personal empowerment is critical to lifting individual health literacy levels and improving GDM outcomes, as it enables each woman to take control of her GDM status and self-manage her condition effectively.

Stang (2000) states that literacy and numeracy as well as comprehension are key to helping adolescents understand complex information and situations. Pregnant adolescents with poor literacy cite family and friends as their primary source of health and nutrition-related information (Stang 2000). Involving a wider support group in maternity care discussions may be a useful strategy to build an understanding of what is relevant to a pregnant adolescent and for building health literacy. Stang also highlights the importance of listening, group discussion and hands-on activities in the nutrition education of pregnant adolescents.

4.2 Stakeholder interventions

4.2.1 Interventions described in interviews

LMCs with high rates of GDM screening amongst their Māori clients considered that screening for GDM was relevant for all women and that they were responsible for ensuring women had the information they needed to make an informed choice about being screened, as well as any support needed to complete screening processes and manage GDM.

These LMCs described very similar approaches to working with women. The common elements included:

- offering and encouraging screening with every woman
- explaining and discussing GDM and its consequences
- discussing what happens during the screening process
- checking that women understand GDM and what they need to do for screening
- involving family or other support people in discussions with women about GDM and screening to answer their questions and enlist their support
- helping women organise screening if needed
- regular follow-up and discussion of any issues with screening (including if it has not been completed before the next antenatal visit)
- organising a blood test for screening during an antenatal visit if it has not happened by 28 weeks’ gestation (where possible).

Should women be diagnosed with GDM, these LMCs continued to provide antenatal care in cooperation with diabetes services, thereby ensuring the continuity of care for women. This model was particularly effective where women were managing GDM through diet and lifestyle.
4.2.2 Interventions described in the surveys

Of the 114 respondents to the midwife LMC survey, 109 described face-to-face discussion of GDM as the primary way they encouraged screening. The majority checked women’s understanding of GDM (63 percent) and provided the laboratory form and the location of screening services (60 percent). Twenty-three percent of respondents included support people in the screening and GDM discussion, and 20 percent provided written or web-based information to women. Just under 40 percent of the midwife LMC respondents made contact with a woman if she did not undergo screening and did not keep her next appointment.

Midwife LMC respondents reported using a wide range of strategies to check whether a woman has understood what has been discussed about GDM during her consultation. Midwife LMCs and diabetes nurses identified that discussion and reviewing pregnancy experiences were the best way to gain an indication of a woman’s literacy and health literacy in relation to pregnancy.

Eighty-two percent of midwife LMCs identified patient-focused written resources as a way they could help women better understand GDM. Sixty-eight percent thought that continuing education for midwife LMCs would also be helpful. This was reinforced in qualitative comments from midwife LMCs who identified health practitioners’ (including LMCs) understanding of GDM as needing improvement, especially understanding the need for screening. A further 38 percent were interested in gaining a better understanding of how to work with audiences with poor health literacy.

All of the nine DHB respondents thought that raising awareness of GDM amongst women and families (pre-pregnancy) would help improve the understanding and management of GDM. Seven DHB respondents also considered better information and resources for pregnant women and education for LMCs and health providers would be valuable. Six DHBs identified that practical support with organising screening and access to services was likely to improve management of GDM.

4.3 Resources to support health literacy in relation to GDM

As noted in section 3, very few clear resources on GDM or the screening process in New Zealand are available. Resources about GDM and the screening process were developed for trial within the present project.

The main resource developed was for LMCs and other health practitioners, called Talking Points. The resource was designed to reflect the practice of LMCs with high screening rates amongst Māori women and the things women identified as relevant to their decision making (during interviews).

The Talking Points provide an adaptable script, with discussion guidance and questions, for LMCs to use with women and their families to discuss GDM and the screening process. The Talking Points are based on the best practice interventions for health literacy described by Sudore and Schillinger (2009) for interactions

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4 The survey was made available to approximately 1,000 LMC midwives via the New Zealand College of Midwives website – 114 responses were received to this survey.
between health practitioners and patients (in this case LMCs and pregnant women). Specifically the Talking Points demonstrate the universal precautions approach to health literacy (DeWalt et al 2010), encouraging LMCs to:

- ask questions to find out about women’s past screening experiences and understanding of GDM and pregnancy (known as existing knowledge and skills)
- build new knowledge about GDM and screening with women and families by connecting to what women already know
- confirm understanding of new knowledge and skills in multiple ways.

The Talking Points are accompanied by a second resource, a booklet about GDM and screening, which can be used with women and families during the discussion about screening with an LMC. The booklet provides women and families with information they can take away and refer back to as needed.

Other resource ideas were partially developed. A video script for a woman going through the GDM screening process was developed following discussion with the Reference Group and viewing similar videos available on YouTube (from the United States). The video was not produced, but the script is provided in Appendix 7. The video is a possible alternative or addition to the booklet, to help women understand what to expect during the screening process. However, as with the booklet, it is important that an LMC discusses a video with a woman to ensure she understands the content and has her questions answered.
Part 5. Objective 3: Demonstrate ways to increase health literacy

This section describes the testing of health literacy resources developed to improve the understanding and management of GDM and screening.

5.1 Resource trialling

5.1.1 Reference Group

The Talking Points for health practitioners, booklet and video script were initially provided to the Reference Group for feedback on technical accuracy and completeness.

5.1.2 Health practitioners

The booklet and Talking Points were trialled with 20 health practitioners including LMCs, practice nurses, GPs in shared care, midwifery managers and consultants, as well as the women and families with whom they work.

The feedback received confirmed that it was useful to have a booklet describing GDM and the screening process. However, it needed to be less wordy and complex. Poor photography was also an issue, as stock photography had been used.

No mention was made of the Talking Points in the feedback received, suggesting that this resource was not used to guide health professionals as they worked through the booklet. Examples of the feedback received from health practitioners are provided below.

a) LMC and practice nurse feedback

There was positive feedback about the content of the booklet and useful suggestions for revision from LMCs and practice nurses who had used it in discussions with pregnant women:

‘I think the information pamphlet is good. Simple, easy to read and understand, factual yet not overbearing. It would be an easy tool to use when referring people for a polycose or GTT. As I only deal with primary care, it is very rarely that we use GTT referrals, more so polycose. The only question I got from my women for the few I was able to use this tool with was the concern that, because they were getting the information for both tests, they were assuming they required both tests. That was easily remedied with a quick explanation.’

‘Did a feedback form yesterday and patient found the booklet simple to understand. Downside, it is more aimed at LMC/midwives. Majority of our patients see the GP under a shared-care model.’

‘Used the resource with patients to explain GDM and associated problems. Used to explain the two tests, what to do if diagnosed and actions to take that help with a healthy pregnancy. I would change the order of the testing especially if an MSU is required as this must be done first. Great resource. Where it says the
good news, maybe something like a warning bell to alert that changes in diet and exercise may avoid the risks of developing diabetes in your middle years.'

Some of the feedback related to how health practitioners would use the information in a consultation, including prefacing the introduction of the booklet with a verbal explanation:

‘Yes, I will use it, however would verbally discuss with the patient and then give instructions for the (polycose) test alone. Too much information on leaflet – not sure if my patients would read it.’

Other feedback from these health practitioners provided suggestions for revision. The main theme of their feedback was that there was too much information contained in the booklet:

‘I liked the information about the process of polycose and OGTT testing. The photos did not feel ‘NZ’, e.g. doctor in a white coat, also wine and yoga picture examples are not relevant to the demographics I work with. Very Americanised.’

‘Has some good information points in it, but I feel there is too much information and probably too hard to follow for many of our patients. Better to simplify into a single page info sheet. Could include polycose on one sheet and have a second sheet if they need to have a GTT.’

‘I think there is too much written explanation. A4 is too big, A5 sheet appears overloaded. Needs to be simplified.’

b) GP, consultant, midwifery manager feedback

Positive feedback was received from GPs, consultants and the midwifery manager, with one making a suggestion for revision:

‘I do talk about each blood test to all my antenatal patients anyway, but it is good to have, especially for gestational diabetes screening. I would definitely use it to back up the verbal information with patients.’

‘Page 4, exercise image – suggest more active one rather than stretching/yoga. Very good resource.’

5.2 Resource revision

The resources were revised following feedback and are attached in Appendix 6. The main change to the booklet involved removing the process for OGTT, as this was seen as overwhelming and unnecessary information for the majority of women who only go through the first step of the screening process. It was suggested that limiting the resource to GDM information and the GCT/polycose testing process was more focused and relevant for all women, and the same information could be adapted for a discussion about OGTT should it be required.

A lack of feedback on the Talking Points suggested that the purpose of the Talking Points was unclear (and hence they were not used to guide discussions with women). This led to a redesign of the Talking Points and booklet to make them look
more like a set of resources that are to be used together. The purpose of the Talking Points was also made more explicit in the introduction to the resource.
Part 6. Implications

6.1 Policy and practice

Improved health literacy or understanding of GDM and increased screening rates would be supported by the following:

1. Consistent guidance to LMCs regarding the intent of ‘the universal offer of screening’ for GDM. In particular, that screening should be encouraged for all women.

2. Producing resources for LMCs to use with women, particularly Māori women, to guide LMCs through an explanation of GDM and the screening process and show LMCs how to check women’s information and support needs. The resources describe a universal precautions approach to health literacy where LMCs approach discussions with each woman as if they may have health literacy needs. The resources include:
   - a short booklet or handout explaining GDM and the screening process for LMCs to discuss with women when seeking screening consent
   - guidance for LMCs about how to talk about GDM and screening and use the booklet with women and families to build and check their understanding
   - a video showing a woman going through the screening processes, preferably narrated from the woman’s perspective, to help women become familiar with the processes of the GCT and OGTT.

3. Improved cooperation (where needed) between LMCs and diabetes services to help ensure women receive sufficient and consistent information and continuity of care when managing GDM and pregnancy.

4. Consistent use within the health sector of the terms for GDM and other types of diabetes (in pregnant women) as well as the terms for screening procedures.

5. Consistent practice in the diagnosis of GDM and other diabetes during pregnancy (supported by a national guideline or clinical pathway regarding the screening process for GDM and undiagnosed diabetes mellitus in order to encourage consistent practice in diagnosis).

6. Other approaches to improving GDM screening rates for Māori women and the management of diabetes in pregnancy that are not health literacy interventions were identified:
   - Improved access to antenatal care that meets the needs of Māori women would reduce the numbers of women missing antenatal tests, including screening for GDM. Improved access may involve general practices supporting women to find a suitable LMC, more LMCs and cultural competency training for LMCs.
   - Other types of diabetes could be subject to a universal offer of screening for pregnant women particularly to support the early detection of recognised
T2DM during pregnancy. This would be assisted by ensuring laboratory forms provided to LMCs include HbA1c testing as a standard option.

- Developing less intensive and time-consuming testing processes for GDM might improve screening rates.
- Improved information-sharing systems between health providers in order to improve post-partum testing rates (and long-term diabetes management).
- National collation and monitoring by the Ministry of Health of the rates of screening for GDM within each District Health Board, particularly for high-risk groups, including Māori women. The main indicator of screening rates (laboratory requests for polycose or glucose tolerance tests) is already recorded by laboratories. Numbers of glucose tolerance tests are already supplied to the Ministry by laboratories for funding purposes.

6.2 Findings outside the scope of the project

Some women are not accessing maternity care or are accessing care too late for screening for GDM to occur.

More targeted public information about pregnancy may be helpful to engage women who do not normally make contact with an LMC until late in their pregnancy, if at all. Improved public awareness of GDM and a greater focus on the prevention of GDM could also be part of a wider public health discussion about obesity and diabetes.

The researchers regularly heard stories of it being difficult for women to find an LMC as there was a shortage in some locations, particularly of Māori and Pacific LMCs, and an unwillingness by some LMCs to take on women with potentially difficult pregnancies (such as those presenting late for maternity care). Similarly, maternity care and GDM services are difficult to access for women in remote locations.

In response to a lack of a national guideline for diagnosing GDM, local guidelines have been created. This may be contributing to inconsistent screening practice, language and advice amongst LMCs.

GPs are responsible for long-term follow-up with women who have had GDM. It was identified that there is often poor communication and follow-up between LMCs, diabetes services and GPs, all of which affect the continuity of care. The lack of a national tracking system may also be a systemic barrier to effective follow-up. Other barriers to long-term follow-up include women having competing responsibilities and a lack of time, a lack of childcare and transport and a lack of understanding of the long-term risks of T2DM (Corbett and Okesene-Gafa 2012). In addition, young women are an especially mobile population, which makes it harder to sustain contact and continuity of care.

6.3 Limitations of the present research

It should be noted that the findings of this project are based on a small number of interviews carried out with 26 recently pregnant women, nine midwife LMCs, a maternity service manager, four diabetes specialists and an obstetrician. Survey responses were also collected from nine DHBs and 114 midwife LMCs.
(approximately 11 percent of LMCs) associated with the New Zealand College of Midwives.
Part 7. References


Part 8. Appendices
Appendix 1: Literature review: Health literacy

Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Adult Literacy and Life Skills Survey (ALLS)</td>
<td>A second literacy survey undertaken by the Organisation for Economic Co-operation and Development (OECD) in a number of countries which measured health literacy. The ALL Survey was undertaken in New Zealand in 2006.</td>
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<tr>
<td>Anticoagulation therapy</td>
<td>Therapy which stops the blood thickening and clotting.</td>
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<td>Ask-Me-3</td>
<td>A framework of 3 questions that patients are encouraged to ask their health practitioner to build the patient’s health literacy: <a href="http://www.minuteclinic.com/ask_me_3">www.minuteclinic.com/ask_me_3</a></td>
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<tr>
<td>Chronic disease</td>
<td>A disease that develops over a long period of time and is the leading cause of deaths in New Zealand.</td>
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<tr>
<td>Conceptual knowledge</td>
<td>Understanding what something is.</td>
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<tr>
<td>Critical thinking</td>
<td>Thinking that involves judgement, analysis and questioning.</td>
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<tr>
<td>Glycemic control</td>
<td>Controlling blood sugar levels.</td>
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<tr>
<td>Health literacy</td>
<td>The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions which is influenced by health practitioners, health care organisations and the health system.</td>
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<tr>
<td>International Adult Literacy Survey (IALS)</td>
<td>A first literacy survey undertaken by the Organisation for Economic Co-operation and Development (OECD) in a number of countries. The IAL Survey was undertaken in New Zealand in 1996.</td>
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<tr>
<td>Māori</td>
<td>The indigenous people of New Zealand.</td>
</tr>
<tr>
<td>Numeracy</td>
<td>The ability to apply knowledge of numbers to everyday tasks</td>
</tr>
<tr>
<td>Pākehā</td>
<td>New Zealanders of Caucasian descent.</td>
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The Changing Face of Health Care

The sphere of health has extended far beyond its traditional confines and has become a much broader, complex concept. Health is no longer confined to clinical settings but is now a regular feature in print and social media, television and radio (Kickbusch et al 2005). Health now includes what we eat and drink, how much we sleep and exercise, and how we manage stress and emotions.

As the sphere of health continues to grow and become more complex, the relationship between the health system and the health consumer also continues to change and evolve. According to Zarcadoolas et al (2006) examples of this new dynamic include health instructions no longer going unchallenged, and dialogue replacing monologue as the typical pattern of communication between health provider and patient. One of the drivers for this change is the growth of chronic diseases. Zarcadoolas et al (2006, p 40) state that individual health behaviour is a far greater factor in rates of death and disability in the United States than biomedical advances, and that the ‘21st century will likely see a dramatic increase in death and disability from chronic diseases related to lifestyle’. The combination of increasing rates of chronic disease and an ageing population means that the cost of health care is becoming increasingly expensive. Increased rates of chronic disease result in increased and recurring hospital admissions and the necessity of on-going care, all of which are a huge drain on scarce resources. This rise in rates of chronic disease coupled with the rising cost of health care provision means that doing more with less has become the norm in most health settings. There is an ever increasing amount of health information available to patients and more choice in treatment options. Health care systems are now far more complex than before and encompass a broader range of providers.

As part of doing more with fewer resources, patients now find themselves having to do more self-management of their conditions and being increasingly responsible for adherence to long-term health goals and self care in a complex health system (Pignone et al 2005; Koh et al 2012). As the need to self manage conditions increases, patients are required to develop new skills to find and manage information, understand and manage their rights and responsibilities and make health decisions for themselves and others (Institute of Medicine 2004).

The need to become informed, engaged and active consumers of health means that there are far greater demands being placed on patients (Kickbusch et al 2005). The Institute of Medicine (2004, p 3) states that ‘underlying these demands are assumptions about people’s knowledge and skills’. A host of national and international research shows these assumptions to be faulty as evidence from around the world shows that patients’ knowledge and skills are usually below those demanded of them by their health system (Rudd et al 1999; Rudd et al 2007). As Koh et al (2012, p 435) state ‘a wide chasm often separates what providers intend to convey in written and oral communication and what patients understand.’
a. Defining health literacy

It is now commonly accepted that literacy is a major determinant of health status (Nutbeam 2008; Institute of Medicine 2004; Zarcadoolas et al 2006; Kickbusch et al 2005; Rudd et al 1999; Rudd et al 2007). To be able to understand, interpret and analyse health information a patient needs to draw on their general literacy and numeracy skills. These include basic print literacy (the ability to read, write and understand printed language), oral literacy (using speaking and listening skills) to communicate with health providers, and numeracy (the ability to apply numerical knowledge to everyday tasks) (Weiss 2007; Institute of Medicine 2004).

Having the ability to make the right decisions about health in the context of everyday life, or having good health literacy, goes far beyond general literacy skills because it requires advanced skills needed to interpret, evaluate and act on health information (Kerka 2000; Zarcadoolas et al 2006). Although literacy and numeracy skills play a significant role in health literacy, health literacy is influenced by many factors, making it a more complex construct than literacy (Speros 2005; Zarcadoolas et al 2006).

The US Department of Health and Human Services (2000, p 11) defines health literacy as ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’. The essence of this definition lies with the ability of the individual to obtain information (Rudd et al 2007). However, health literacy goes beyond this and ‘emerges when the expectations, preferences and skills of individuals seeking health information and services meet the expectations, preferences and skills of those providing the information and services’ (Institute of Medicine 2004, p 2). In Kōrero Mārama: Health Literacy and Māori, the authors of that report acknowledge that the term health literacy is widely used and encompasses a variety of definitions and ideas. The report refers to the earlier definition from the US Department of Health and Human Services (see above) and states that ‘Health literacy is essentially the skills people need to find their way to the right place in hospital, fill out medical and insurance forms and communicate with their health providers’ (Ministry of Health 2010, p 1).

Health literacy is an outcome of both individual and social factors (Kickbusch et al 2005; Zarcadoolas et al 2006). An individual’s health literacy status is mediated by a range of factors, including literacy levels, socio-economic status, and cultural beliefs and attitudes. Of equal significance are the communication skills of the health practitioners the individual is interacting with, and the ability of various other stakeholders, including the health system, the media and the marketplace to provide health information and services in a way that is appropriate for that individual (Institute of Medicine 2004).

Kickbusch et al (2005, p 9) emphasise that health literacy is both an active and dynamic construct and claim that individuals with high levels of health literacy are in ‘continuous exchange and dialogue with their environment’. As society changes, so too must individuals learn new information and discard outdated information in order to successfully navigate the health system and make sound health decisions.
Similarly, Edwards et al (2012, p151) emphasise the complex social and changing nature of health literacy by defining it as a ‘multi-dimensional construct that develops over time, across different health contexts and through social interactions’. The authors see health literacy as developing along a continuum towards greater knowledge, greater self-management and greater participation in decision making, and existing as both a process and an outcome. Zarcadoolas et al (2006) also see health literacy as operating on a continuum with health literacy levels evolving over a lifetime affected by health status and demographic, socio economic and cultural factors.

b. Consequences of low health literacy

Health literacy is likely to be a key factor in health disparity (Kickbusch et al 2005; Baker et al 1998; Nutbeam 2008; Zarcadoolas et al 2006; Institute of Medicine 2004; Ministry of Health 2010). Poor communication between the patient, the health provider and the health system is likely to contribute to disparities in patient understanding of their health status, their health condition, the procedures for prevention and treatment of their condition, and utilisation of health services (Rudd et al 1999). Highlighting this correlation, the American Medical Association (1999, p 554) found health literacy to be ‘a stronger correlate of health status than education level and other socio-demographic correlates’. Similarly, the Institute of Medicine (2004) claims that any reduction in health disparities requires a simultaneous improvement in health literacy levels. Kickbusch et al (2005) refer to health literacy as a building block or pathway to health, with low health literacy levels being a strong factor in health disparities. Just as low literacy is seen to contribute to low health status, so too is low health literacy seen to contribute to socio-economic disadvantage, and an inability to engage with and achieve health and wider life goals (Kickbusch et al 2005).

There is a large and growing body of research linking low health literacy levels to low health knowledge and adverse health behaviours and outcomes (Koh et al 2012). In addition to higher health care costs these outcomes include a decreased likelihood of using screening or preventative measures, a decreased likelihood of being compliant with medication, a decreased likelihood of successful self-management of chronic conditions, a decreased likelihood of involvement in consultation and decision making, and an increased likelihood of using emergency services (Ministry of Health 2010; Kickbusch et al 2005; Fetter 2009; Zarcadoolas et al 2006; Nutbeam 2008; Edwards et al 2012). Zarcadoolas et al (2006) refer to health policy reports such as Healthy People 2010 which show a strong link between low education, low literacy and poor health, and list the consequences of low health literacy as including financial costs to both individuals and the health system, lack of social empowerment and self efficacy, and an increased risk in emergency situations. More specifically they claim that ‘people with low or inadequate health literacy find it difficult, if not impossible, to accurately read instructions for taking medications, understand their health plan restrictions, understand and act on public health warnings, or accurately read evacuation plans and other emergency information’ (Zarcadoolas et al 2006, p xv).
Nutbeam (2008) highlights growing evidence of a robust relationship between low literacy levels and a declining use of health information and services. The Institute of Medicine (2004, p 7) highlights studies which show a clear relationship between low health literacy and a number of adverse health behaviours, including ‘decreased ability to share in decision making about prostate cancer, lower adherence to anticoagulation therapy, higher likelihood of poorer glycemic control, and lower self-reported health status’. These relationships are reinforced by additional studies which link low literacy to poorer adherence to medication regimes (such as with anticoagulant therapy), decreased ability to identify medications, higher rates of misunderstanding of instructions on prescription drug labels and an increase in medication error rate. In addition, a patient with low health literacy is not likely to access medical care in a timely manner, which in turn can lead to a negative health outcome (Estrada et al 2004; Kripalani et al 2006).

Low health literacy is often referred to as ‘a silent killer’ or ‘a silent epidemic’ as it is less diagnosed and treated than more visible medical conditions. Instead of referring to low health literacy, terms such as ‘decreased compliance’, ‘non adherence’ or ‘DNA - did not attend’ have been used to describe a patient’s inability to follow a prescribed health process, appointment or regime. These terms may mask an underlying health literacy issue (Zarcadoolas et al 2006; Institute of Medicine 2004).

Without improvements in the field of health literacy and the growth of a health literate society, advancements in the field of medical science risk being diminished (Institute of Medicine 2004). Similarly, Kickbusch et al (2005) highlight the significance of health literacy in today’s society by stating that health literacy is simultaneously an essential life skill, an urgent matter for public health, a critical economic issue and an important part of social capital.

c. Who is affected by low health literacy?

Studies have shown that while low health literacy can occur in a range of populations it is most likely to occur in those comprising the elderly, those with limited education, those with limited income and those with limited language proficiency (Institute of Medicine 2004). Zarcadoolas et al (2006) highlight the fact that education levels are often used as a proxy for literacy levels, and refer to the 2003 Canadian report from the International Adult Literacy Survey (IALS) which claims that, while there is a strong correlation between education and literacy levels, this correlation is not exclusive.

New Zealand took part in the 2006 Adult Literacy and Life Skills Survey (ALLS). This survey found that the majority of New Zealand adults do not have the minimum levels of literacy to meet the demands of everyday life and work (Ministry of Health 2010). Data from the health-related items (linked to health promotion, health protection, disease prevention, health care maintenance and system navigation) in the 2006 ALL survey shows that ‘overall the majority of New Zealanders are limited in their ability to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions’. (Ministry of Health 2010, p iii). In addition, data from the ALL survey found Māori to have much
lower health literacy levels that non Māori, regardless of other demographic factors such as age, gender, income, and educational status, and that Māori in the 50-60 and 19-24 years age groups had the lowest levels of health literacy (Ministry of Health 2010).

Although Māori have the worst lowest level of health literacy in New Zealand, it is important not to view this problem as one pertaining solely to the Māori population. In fact Pākehā comprise the largest group with low literacy (Ministry of Education 2008; Ministry of Health 2012). This situation is reflected internationally, including in the United States where a study by Vernon et al (2007) found the majority of adults with low literacy levels to be white, native born Americans, as this group represents the largest section of the overall population.

There are a number of behaviours that may indicate a person has low literacy but these are just indicators and, on their own, do not constitute evidence of low health literacy. These indicators are numerous and include: regularly missing medical appointments; ignoring or misunderstanding health instructions or advice; asking a number of or alternatively no questions; arriving with incomplete forms; avoiding filling in forms or taking additional spare copies; and making excuses about forgetting their glasses and needing to read the information at home (Weiss 2007).

The challenge of communicating effectively with patients who have low health literacy is highlighted in Rudd et al (1999, p 183), which states that in addition to the fact that ‘patients rarely identify themselves as struggling with literacy issues’, they also seldom ask for assistance in reading health related materials.

It is also important to distinguish between patients who have on-going health literacy problems from those who have episodic health literacy problems. Patients who have low health literacy will have on-going difficulties in making informed health decisions, but most people will at some point in their lives experience an episode of low health literacy. As mentioned earlier, although general literacy skills are the strongest factor in health literacy levels, these skills are not the only factor that affect our ‘capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions’. The Institute of Medicine (2004, p 11) illustrates this point well, claiming that ‘even highly skilled individuals may find the systems too complicated to understand, especially when these individuals are made more vulnerable by poor health’.

d. Causes of low health literacy

There is on-going research into the causes of low health literacy. Fetter (2009) identifies, among other factors, low education levels, poverty, aging, limited English language proficiency, physical, mental and learning disabilities, poor communication, overuse of medical jargon in patient documents and cultural insensitivity.

At the level of each individual patient, factors such as linguistic, cognitive, visual and aural impairment clearly affect health and literacy levels. However the Institute of Medicine (2004) warns against viewing health literacy as a concept that begins and ends with the capacity of an individual, and instead argues for it to be viewed as
arising from a convergence of socio-cultural factors, health care and education systems and the barriers contained in those systems.

e. Culture and health literacy

The role of culture in health literacy is widely accepted. Zarcadoolas et al (2006) state that as a component of health literacy, cultural literacy (the ability to understand and use culture and social identity to interpret and act on information) is clearly needed by all stakeholders in order to improve health care and health outcomes. Kickbusch et al (2005) mirror this sentiment and state that culture (including the culture of the health system) affects attitudes, perceptions and behaviours at both the patient and provider end, or for both those receiving and delivering health services. Apart from their role in shaping individual attitudes, behaviours and interactions, socio-cultural factors are also of great importance when shaping public health campaigns and messages. Kickbusch et al (2005, p18) argue the importance of cultural relevance and claim that ‘health messages and solutions must be placed within settings relevant to their target audiences and encompass both a social and health dimension’. Tailoring health messages so that they are culturally and socially relevant is crucial, especially when targeting vulnerable groups. A one-size-fits-all health campaign may be cost effective in the short term, but not in the long-term, as it will rarely reach its target audience (Kickbusch et al 2005; Zarcadoolas et al 2006).

The socio-cultural aspects of health literacy are not just limited to public health campaigns. Culture shapes language, perceptions, beliefs and behaviours, so it follows that culture also shapes perceptions, beliefs and behaviours around health, including health information, messages, treatment, decisions and actions. Culture is constantly changing and evolving so health care encounters are a mix of differing and evolving perceptions, beliefs and behaviours. This point is highlighted by the Institute of Medicine (2004, p 9) which states that ‘these culturally influenced perceptions, definitions and barriers can affect how people interact with the health care system and help determine the adequacy of health literacy skills in different settings’. Furthermore, the Institute claims that health literacy is not just shaped by cultural differences between patients and providers but also between those who create the health messages and those who use them.

f. Who is responsible for developing health literacy?

Since it is now widely accepted that health literacy reaches beyond the capacity of the individual patient and is a product of the convergence of numerous factors, it follows that the responsibility for improving health literacy levels is shared among the various stakeholder groups in health care. These stakeholders include the individual patients, the health practitioner and the wider health system (Rudd et al 2007; Koh et al 2012).

Bryan (2008) asserts that efforts to curb low health literacy in the United States need to take place at local, regional and national levels, and the United States Institute of Medicine (2004) states that health providers have a key responsibility in this area, suggesting that it is their skills and expectations that actually drive health literacy levels. The central role of health practitioners is reinforced by Edwards et al (2012)
who state that it is the capacity of health practitioners to empower or disempower patients that can either facilitate or limit health literacy. From a New Zealand perspective, Kōrero Mārama includes a statement that instead of viewing health literacy as an issue for the individual patient, where the onus is on the individual to lift their skills, the solution lies in a concerted effort from all sectors including, schools, government agencies and the health care system (Ministry of Health 2010).

The ethical dimensions of health literacy (for example health disparities), are reflected in New Zealand by Right 5 of the Code of Health and Disability Services Consumers’ Rights Regulation 1996, which gives every consumer the right ‘to effective communication in a form, language and manner that enables the consumer to understand the information provided’ (Knight 2006, p 4). Clear and effective health communication is a patient’s right, so addressing poor health literacy is a responsibility for all stakeholders in the health care system.

Health literacy is more than improving access to information, quality of information and information flow between individuals, communities, health practitioners and the health system. More importantly health literacy is about the skills and knowledge of individuals, families and communities, so that they synthesise the information they receive from both the health system and other sources, decide whether they have enough information and if not gather more, and then act on the information. This concept of empowered self care runs alongside the process and outcome of becoming more health literate.

g. Approaches to health literacy

Nutbeam (2008) investigates two different approaches, which conceptualise health literacy either as a risk that needs to be managed or as an asset that needs to be built on. The risk model, which earlier was prevalent in the United States, sees low literacy skills as a potential risk factor that needs to be managed and minimised. The risk model focuses on getting patients to become compliant with recommended clinical care and therefore is mostly applied in clinical settings. The asset model is closely linked to health education and sees health literacy as an outcome of personal empowerment in decision making. Improved health knowledge, along with the competence to put that new knowledge into action, will enable individuals to gain greater self control over their health and the health decisions they need to make. This in turn will make them more health literate.

There are key differences in the way the two models view health education. In the risk model, health education is more goal-directed and the health practitioners are focused on what can be done to minimise the risk of their patients not understanding the information or advice they give them. Nutbeam (2008, p 2073) explains that according to this perspective ‘the effects of poor literacy can be mitigated by improving both the quality of health communications, and a greater sensitivity among health practitioners of the potential impact of low literacy on individuals and in populations’. The risk model requires an assessment of the individual’s literacy levels so that the proper interventions can be put in place. In the United States, health literacy assessment tools such as the Rapid Estimate of Adult Literacy in Medicine
(REALM) or the Test of Functional Health Literacy in Adults (TOFHLA) are frequently used to assess patients for low health literacy. The validity of these tests has been criticised as they only measure health literacy in terms of reading at the individual word level and do not include other critical skills such as conceptual knowledge, listening, speaking, and numeracy, all of which are needed to get a true picture of a patient’s health literacy level (Zarcadoolas et al 2006; Institute of Medicine 2004).

The asset model of health literacy draws on principles of adult education and requires educators to draw on the patient’s prior knowledge and experience. Starting with what the patient knows about their condition opens the door to increased interaction, participation and critical thinking, all of which are positive for health literacy (Nutbeam 2008). The asset model can be applied outside health care settings, including schools and community development programmes and offers great potential for enabling positive health actions. The asset model, while powerful in theory, has not yet been widely implemented. This could be due to the fact that the asset model is not as well tested through systematic research as the risk model (Nutbeam 2008).

h. Barriers and facilitators in health literacy

This section outlines barriers and facilitators to health literacy. Information on each barrier also includes how that barrier could be overcome (or what facilitator could be used), to achieve greater health literacy.

Difficulty in reading materials and difficulty in communicating with health care providers are two major health literacy barriers that individuals face when they access and use the health care system (Rudd et al 1999). Kickbusch et al (2005, p 9) assert that ‘access to good reliable information is the cornerstone of health literacy’ yet most health related material is written at a level beyond what most patients can understand (Kickbusch et al 2005; Levandowski et al 2006; Zarcadoolas et al 2006, Rudd et al 1999; Rudd et al 2007). To minimise the risk of patients not understanding what they read, it is now recommended that all written health care material in the United States be graded to the reading age of a 10 year old (Wilson 2009; Zarcadoolas et al 2006). While using plain language in written material is widely recommended, the validity of this readability approach has been questioned as, apart from the fact that adult patients are not 10 year old children, this approach fails to take account of the important role that sense, logic, familiarity, tone and cohesion play in the comprehension of a text (Ministry of Health 2012; Rudd et al 2007).

Another major barrier to health literacy is an overload of information. There is a vast amount of health information available to patients, from an equally vast number of information sources, which can make finding and understanding the right information difficult (Kickbusch et al 2005; Zarcadoolas et al 2006; Institute of Medicine 2004). Rethinking how information is given to patients, with the most important information being given first and the rest at a later point can really lessen the cognitive load for all patients and act as a facilitator to improve uptake (Rudd et al 1999).
An additional outcome of an increase in information is a decrease in the consistency of the information. These days it is not uncommon for patients to get conflicting information from their information sources including their health care practitioners, the health system, the media and their family and friends. Even though there is not much that can be done about information that is received from sources outside the health system, consistency in health and medication messages is important. This barrier to health literacy is underscored by Eagle et al (2006) who found that consistency of advice between doctors and pharmacists was rated as very important by a sample of patients.

The quality of oral interactions between patients and their health providers is crucial to health literacy. Spoken language is our main form of communication, so patients who have trouble reading may better understand a spoken message. Spoken interactions are also context-rich and rely on more than words to communicate information and meaning, with tone, body language and gestures all playing an important part (Zarcadoolas et al 2006). On the other hand, speech is ephemeral and once the interaction is over there is nothing left except the memory (which may be incomplete) of what was said (Vandergrift 2006). Zarcadoolas et al (2006, p 90) acknowledge the fleeting nature of spoken interactions and for this reason recommend that spoken messages ‘contain facilitators such as brevity, narrative structure and repetition’.

Kelly and Haidet (2007) claim that many health care providers overestimate the health literacy levels of their patients. This leads to a lack of tailored communication which in turn leads to information that is beyond the understanding of the patient, with the potential outcome of non-adherence to a treatment plan. Many experts in the health literacy field now claim that the most effective way to improve patient understanding is to support one form of information with another, i.e. reinforcing spoken explanations with written materials or supporting written materials with visuals (Weiss 2007).

Facilitators for health literacy, which health practitioners can use, include:

- using face to face opportunities to give medical advice as much as possible
- using the teach-back method to check patient understanding, which involves the health practitioner taking responsibility for the clarity of the communication by asking the patient to explain or demonstrate what the health practitioner has said
- reading written materials with patients or supporting the materials with verbal explanations supporting oral explanations with pictorial material or visual aids
- using plain language in spoken and written texts and making materials easier to use through a greater consideration of design, font, layout and pictures (Rudd et al 2007; Weiss 2007).

Rudd (2007, p 183) cites recent medical and public health reports which recommend that future studies in the area of health literacy ‘continue to include – but move beyond the doctor-patient encounter ... and include investigations into health-related activities at home, in the workplace, in the community, and in a range of health systems and care settings’. In addition, Rudd highlights the importance of attention
to the broad range of skills involved in health literacy, including a closer examination of patient information-seeking skills. Other areas which Rudd considers could facilitate better health literacy, and which require closer attention, include:

- considering the importance of patient background, knowledge and experience in health related activities and paying attention to assumptions that information-givers have about these
- considering the value that new technologies can add to the field of health literacy (Rudd et al 2007).

Although good knowledge of a health condition is essential for good health literacy, improved patient knowledge will not always lead to the desired change in behaviour. Kickbusch et al (2005, p 9) state that ‘health information alone will not be useful to people who do not feel they have the power to act’. Confidence and self-efficacy to act on the information and to help others is what counts, and this requires additional inputs such as community development and education (Nutbeam 2008; Kickbusch et al 2005; Zarcadoolas et al 2006). The ultimate goal is greater independence and empowerment in individuals and communities to effectively manage their health. For this to happen a greater understanding is needed around the potential of health education to help focus the health dialogue on the social determinants of health as well (Nutbeam 2008).

Sudore and Schillinger (2009) have developed a framework and description for best practice interventions to improve care for patients with low health literacy in the United States. The framework and description are the result of a comprehensive literature review to identify feasible health literacy interventions at the practitioner-patient level, at the system-patient level and at the community patient level. Although designed to address health literacy in the United States, the framework will provide a useful starting point for analysing and developing effective health literacy interventions in New Zealand.

Key messages from interventions at the health practitioner-patient level include:

- patient-centred communication, where existing patient knowledge and experiences are built on
- clear health communication, including use of plain language
- confirmation of understanding, including use of the teach-back method
- reinforcement of information, including using multiple modalities and using the patient’s support network
- clear numeracy and risk information, including providing absolute risks instead of relative risks
- medication reconciliation, including simplifying regimens as much as possible and confirming regimen dosage.

Key messages from interventions at the system-patient level include:

- health education materials, including incorporating the target audience in the design of the tools
- medication drug labels, including using concrete examples
• disease self-management support systems which need to be proactive and disease-specific
• creating an empowering environment, including making signs and forms easy to read and encouraging the patients to use the Ask-Me-3 strategy
• clinician training, including health literacy education while clinicians are in training.

Key messages from interventions at the community-patient level include:
• referrals to adult literacy classes
• use of lay health educators/navigators
• use of mass media to disseminate health information (Sudore & Schillinger 2009).
References: Literature review - health literacy


Appendix 2: Literature review: Health literacy and Gestational Diabetes Mellitus

Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal</td>
<td>The period of a pregnancy before the birth.</td>
</tr>
<tr>
<td>Gestational diabetes mellitus (GDM)</td>
<td>Usually a temporary condition that usually occurs during the last trimester of pregnancy when a woman is unable to process sugar effectively, leading to high blood sugar that affects her and her baby. Post-pregnancy, both women and their babies have an increased risk of developing Type 2 Diabetes.</td>
</tr>
<tr>
<td>Glucose challenge test (GCT)</td>
<td>Also known as a Polycose test, it will show if someone has any signs of gestational diabetes. If there are signs of gestational diabetes a second test, called a Glucose Tolerance Test, will be carried out.</td>
</tr>
<tr>
<td>Health literacy</td>
<td>The degree to which individuals have the capacity to get, process, and understand basic health information and services needed to make good health decisions which is influenced by health practitioners, health care organisations and the health system.</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>Otherwise known as low blood sugar/glucose. It is a condition in which the level of sugar/glucose in the blood drops below a certain point (about 2.5mmol/l).</td>
</tr>
<tr>
<td>Insulin</td>
<td>A hormone that helps muscles get sugar from the blood and use the sugar for energy.</td>
</tr>
<tr>
<td>Jaundice</td>
<td>In newborn babies, this condition refers to the yellow colour of the skin and whites of the eyes, caused by excess bilirubin in the blood. Bilirubin is produced by the normal breakdown of red blood cells. Jaundice occurs when bilirubin builds up faster than the newborn’s liver can break it down and pass it from the body.</td>
</tr>
<tr>
<td>Macrosomia</td>
<td>A newborn baby with an excessive birth weight.</td>
</tr>
<tr>
<td>Perineal trauma</td>
<td>Any damage to the genitals of a woman during birth of a baby. Tears can also occur inside the vagina and in the labia.</td>
</tr>
<tr>
<td>Polycose Test</td>
<td>Also known as glucose challenge test (GCT). A test to show if someone has any signs of gestational diabetes mellitus. If there are signs of gestational diabetes, a second test, called a Glucose Tolerance Test, will be carried out.</td>
</tr>
<tr>
<td>Psycho-social</td>
<td>Involves aspects of social (human society) and human interactive behaviour.</td>
</tr>
<tr>
<td>Respiratory distress syndrome</td>
<td>A breathing disorder that affects newborns, where the lungs collapse and the baby has to work hard to breathe. The baby might not be able to breathe in enough oxygen to support the body’s organs. The lack of oxygen can damage the baby’s brain and other organs if proper treatment is not given.</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>The belief a person has in their capabilities to achieve a goal or an outcome.</td>
</tr>
<tr>
<td>Condition</td>
<td>Description</td>
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<td>---------------------------------</td>
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<tr>
<td>Shoulder dystocia</td>
<td>Occurs when the baby’s head has been born but one of the shoulders becomes stuck behind the mother’s pelvic bone, preventing the birth of the baby’s body.</td>
</tr>
<tr>
<td>Type 1 diabetes mellitus (T1DM)</td>
<td>A condition where the body stops making insulin and the blood sugar/glucose level is very high. Treatment to control the blood glucose level is with insulin injections and a healthy diet.</td>
</tr>
<tr>
<td>Type 2 diabetes mellitus (T2DM)</td>
<td>Where the production of insulin is slow or the body is resistant to insulin, causing high blood sugar/glucose levels. This type of diabetes can be treated with weight loss, regular physical activity and medication.</td>
</tr>
<tr>
<td>Whānau</td>
<td>An extended family or community of related families</td>
</tr>
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</table>
Overview

The literature review provides an overview of how diabetes in pregnancy, or Gestational Diabetes Mellitus (GDM), is managed in New Zealand and the role of health literacy in the management of GDM. Proxy terms for health literacy, such as communication and understanding were used, as well as the actual term ‘health literacy’. In light of the paucity of literature about health literacy and GDM in New Zealand, the search was broadened to identify what is known about health literacy and general diabetes interventions nationally and internationally. It is recognised that some of the research related to diabetes is not relevant to GDM due to the differences between the conditions. In particular, GDM is a temporary, short term condition requiring urgent management. By contrast, diabetes is a long term disease that can worsen over time and lead to associated health conditions.

Section 1. Introduction to Gestational Diabetes Mellitus

The purpose of the literature review is to examine the relationship between health literacy and health outcomes and to highlight effective GDM interventions from a health literacy perspective.

The literature review has two sections. The first section gives an overview of how GDM is currently managed in New Zealand, including information on screening and treatment of GDM and recommendations for better care and outcomes. The second section looks at the role of health literacy in the management of GDM, including information on barriers to effective care, the influence of patient and provider beliefs and attitudes, patient-provider communication, the importance of self-management in GDM and approaches to education.

The information in this literature review is intended to contribute to an increased understanding of the importance of health literacy in effective GDM care and management, and inform the development of effective health literacy-focused interventions for patients with GDM in New Zealand.

The original intention of this review was to keep the search limited to literature on health literacy and GDM in New Zealand. However, there is very little literature which focuses on health literacy and GDM, with the majority of the searches resulting in literature on health literacy and diabetes mellitus. There was also very little literature that relates to the New Zealand context, as most of the studies about health literacy and Type 1 diabetes mellitus (T1DM) or Type 2 diabetes mellitus (T2DM) originate from the United States. In light of the paucity of literature that relates specifically to health literacy and GDM in New Zealand in relation to both Māori and non-Māori, the search was broadened to identify what is known about health literacy and general diabetes interventions nationally and internationally.

Along with the search term ‘health literacy’, proxy terms were used for searching including: communication; (non) adherence or compliance; patient understanding or comprehension; diabetes education or intervention; patient knowledge attitudes and behaviours; and decision making. A number of terms are used to refer to health care practitioners, including health care providers; health care practitioners; lead maternity carers (LMCs) and general practitioners (GPs).
As Māori women are more likely to develop GDM than the non-Māori population (excluding Pacific and Asian populations), and half of the Māori women having children are aged 24 or under, this project is focused on identifying interventions which are effective for this population. As already mentioned, there is little literature available on Māori and GDM, and none specific to this age group. Accordingly, we have looked at literature for all adolescents and all age groups in order to find information that might be relevant for young Māori women.

GDM in New Zealand

GDM is diabetes mellitus that is first diagnosed in pregnancy. It is a fairly common complication of pregnancy, is sometimes symptom-free and is diagnosed during routine screening. It occurs when a pregnant woman cannot produce enough insulin to overcome the effects of increased insulin resistance. This in turn leads to high blood sugar levels. GDM is able to be diagnosed using defined criteria at between 24 and 28 weeks gestation and will most often resolve for the woman after birth at which point it can be diagnosed as true GDM. Women diagnosed with GDM may also have pre-existing but undiagnosed T1DM or T2DM (Diabetes New Zealand 2008; Bristow et al 2009).

Traditionally GDM has occurred in 3 to 10 percent of all pregnancies. Data from the National Women’s Hospital 2010 annual report places the incidence of GDM at 3.7 percent for New Zealand European, 5 percent for Māori, 10.3 percent for Pacific, 11.3 percent for Asian and 16.0 percent for Indian (Auckland District Health Board 2010).

The incidence of GDM is on the increase, with Māori, Pacific and Asian women at significantly greater risk (Yapa and Simmons 2000; Bristow et al 2009; Auckland District Health Board 2010).

Along with belonging to an ethnic group with a higher prevalence of GDM, the following factors are also known to increase the risk of GDM (Diabetes New Zealand 2008; Getahun et al 2010):

- having diabetes in a previous pregnancy
- being older (over 30-35 years)
- having a family history of T2DM
- being obese (based on ethnicity specific criteria)
- rapid and excessive weight gain in pregnancy
- high blood pressure in pregnancy.

The risk factors for GDM are complex and multi-faceted. GDM can also develop in women who have none of the above risk factors, hence the decision to implement the universal offer of screening (where screening for GDM is offered to every pregnant woman by their LMC).

Early detection and treatment of GDM is critical because, unrecognised and untreated, GDM can lead to a variety of adverse maternal and neonatal outcomes including pre-eclampsia, caesarean section, perineal trauma, congenital heart disease in babies, macrosomia, stillbirth, shoulder dystocia, birth injuries,
hypoglycaemia, respiratory distress syndrome and jaundice (Crowther et al 2005). GDM is also associated with an increased risk of future T2DM for both the mother and child (Dyck et al 2002; Simmons et al 2008; Diabetes New Zealand 2008; Bristow et al 2009; Getahun et al 2010; Ministry of Health 2011) and an increased risk of GDM in subsequent pregnancies (Auckland District Health Board 2010; Getahun et al 2010). Langer et al (2005) assert that a GDM diagnosis is associated with a 30-70 percent increased risk of developing GDM in subsequent pregnancies and T2DM in later life.

Screening

Early detection is critical to the successful management of GDM. The screening and management of GDM in New Zealand is guided by the Australasian Diabetes in Pregnancy Society (ADIPS) Guidelines, which recommend universal screening at 24-28 weeks gestation. Historically, health practitioners recommended screening based on the presence of risk factors for GDM, but most have now adopted a policy of a universal offer of screening, as risk-factor based approaches are complex to administer and miss a sizeable portion of women with GDM (Simmons et al 2008). Screening advice and the offer of screening is usually provided to pregnant women by their LMC. Screening is carried out either in a laboratory located within a pregnancy centre or, more often, in an independent facility.

The diagnosis of GDM in New Zealand is generally made using a two-step approach. The initial screening for GDM begins with a non-fasting, 50 gram, glucose challenge test (GCT) at 24-28 gestation which requires a woman to drink a solution and then wait one hour for a blood sample to be taken. If a woman’s glucose concentration is equal to, or higher than, 7.8mmol/L then a woman is referred for a diagnostic, 75 gram, fasting oral glucose tolerance test (OGTT). This test requires the woman to fast for twelve hours, drink a sugary solution and then wait for two hours in the laboratory before a blood sample is taken. Women may have to repeat this latter test as the sugary solution can induce vomiting, which invalidates the test. In New Zealand, GDM is diagnosed when the two-hour blood glucose concentration is more than 9.0 mmol/L (Hoffman et al 1998).

The diagnostic criteria (of 9.0 mmol/L) for GDM has been in use since 1992 and is unique to New Zealand with many other developed countries operating at a lower cut off point. In Australia, the cut off point is 8.0 mmol/L (Simmons et al 2008). Having the cut off point for GDM diagnosis in New Zealand lowered to match the level in Australia would result in approximately double the number of women being diagnosed with GDM. This is a number for which our current health care system cannot provide the necessary specialist services (Simmons et al 2008; Cundy 2012).

New criteria for the diagnosis of GDM have been proposed by the International Association of Diabetes in Pregnancy Groups (IADPG) and adopted by a number of groups including the American Diabetes Association. The new criteria would mean that all pregnant women would have a 75g OGTT at 24-26 weeks gestation with a diagnosis of GDM occurring where at least one of the following values is met or exceeded: fasting at 5.1 mmol/L; one hour post-glucose at 10.0 mmol/L or two hour
post-glucose at 8.5 mmol/L (Ryan 2011). The newly proposed criteria have been criticised on a number of grounds including increased costs and the dangers of diagnosis based on a single abnormal value (Ryan 2011; Cundy 2012; Werner et al 2012).

Although screening plays a critical role in effective GDM care and management, there are significant ethnic disparities in terms of who gets screened. Screening rates are proportionally low in Māori and Pacific populations with Yapa and Simmons (2000, p. 221) stating that such low screening rates ‘suggest major systematic flaws in the way women were approached ... advised ... and managed ... in relation to screening for GDM’. The same study states that 53 percent of Māori and 31 percent of Pacific Island women were not screened for GDM in South Auckland (Yapa and Simmons 2000).

The low screening rates among Māori women are replicated by those for other indigenous populations including First Nations women (Dyck et al 2002; National Aboriginal Health Organization 2009). Reasons for these ethnic disparities in screening rates are not clear, but potential reasons include a lack of understanding among some health care practitioners and women about the importance of offering screening, women not wanting to be screened and/or presenting themselves to their health care practitioner at 30 weeks or later, which is too late for timely GDM screening and diagnosis (Dyck et al 2002).

**Treatment**

In New Zealand, once a GDM diagnosis has been made, treatment usually starts with blood glucose monitoring, and advice around diet and physical activity. Treatment also includes visits to a Diabetes Pregnancy Clinic (if accessible) every two to three weeks during pregnancy to monitor the condition. When glycaemic control exceeds the target levels despite diet modification and exercise, medication is recommended. Women with GDM can stop their medication post delivery, but need to have a 6-8 week post delivery OGTT to ensure they no longer have GDM. A continuation of a high glucose concentration in the blood (past eight weeks post delivery) may suggest a women has previously undiagnosed T2DM rather than GDM. Even though there are many barriers to completing the post partum test, it is nevertheless a crucial step in the early detection of T2DM. Given the high prevalence of T2DM, and the increased likelihood of developing T2DM after a diagnosis of GDM, women who have had GDM are encouraged to have annual screening for T2DM (Diabetes New Zealand 2008; Simmons et al 2008).

Although GPs are not usually providing LMC services, the responsibility for long-term follow up often falls to them in partnership with their patients. Long-term follow up and effective self management can be hindered by women having competing responsibilities and a lack of time, a lack of child care and transport issues (Smith et al 2008). A review by Jones et al (2009) on the health beliefs and behaviours of women with previous GDM highlights that these women do not necessarily perceive themselves to be at increased risk of T2DM, despite their awareness of GDM as a risk factor for future diabetes mellitus.
Section 2 - The role of health literacy in diabetes outcomes and GDM outcomes

The purpose of this section is to highlight connections between health literacy and GDM outcomes. As mentioned earlier, there is a lack of literature specifically on health literacy and GDM, and as a result diabetes mellitus research has been sourced as this may provide ideas which are relevant to GDM. Therefore, this section investigates the role of health literacy in relation to GDM by referring to health literacy research in relation to general pregnancy and diabetes outcomes.

According to McLaughlin (2009, p. 19) low health literacy affects one in three individuals with diabetes, with the majority of literature on health literacy and diabetes focusing on ‘diabetes knowledge, glycemic control, self-efficacy and interventions to correct some problems’. McLaughlin (2009) also claims that there is a lack of published information which explores the associations between health literacy and GDM.

Renkert and Nutbeam (2001, p. 382) define maternal health literacy as ‘the cognitive and social skills which determine the motivation and ability of women to gain access to, understand, and use information in ways that promote and maintain their health and that of their children’. Low health literacy is known to be directly related to adverse maternal and infant outcomes including poorer disease-specific knowledge, higher likelihood of an unplanned pregnancy, poor participation in preventative health care, poor antenatal care utilisation and unreliable self report of glycemic control (Endres et al 2004; Mojoyinola 2011).

Healthy pregnancy outcomes require the knowledge and skills to detect risk factors and take the appropriate actions during pregnancy, including healthy lifestyle choices. In situations where a woman cannot read the information she receives, do simple calculations, understand medical instructions or prescriptions, interact effectively with her health care practitioner, or understand what actions need to be taken, she will not be able to fully participate in the health care system and will miss out on key aspects of care (Mojoyinola 2011).

In addition to managing their pregnancy, newly diagnosed women with GDM also need to accept that they and their child have a health problem. This can be a lot to process, especially for women who are young, on a tight budget, already have busy households to manage or who do not have much support from their immediate or wider family (Bennet et al 2008). In spite of this, GDM occurs at a time when many women are motivated to make lifestyle changes for the sake of their child, which offers a narrow but valuable window of opportunity for improved outcomes (Gabbe and Graves 2003).

Counties Manukau District Health Board

The CMDHB serves one of the most economically deprived areas of New Zealand, has the highest perinatal mortality rate in New Zealand and has a high proportion of young mothers as well as high Māori and Pacific populations.
In a report identifying the barriers to antenatal care in the CMDHB catchment area, Corbett and Okesene-Gafa (2012, p. 2) state that women’s beliefs about the value of antenatal care, knowledge of how to access an LMC, social factors and service provider factors are all barriers to early initiation of antenatal care amongst pregnant women residing in the CMDHB catchment area. The report claims that poverty is a central factor in late booking. Lack of access to a car, a phone or childcare are key barriers to early antenatal care, of which a lack of transport is the strongest predictor of a late booking. Another common issue is difficulty in finding an LMC, with reported difficulties in the step between a pregnancy being confirmed by a general practitioner and finding an LMC. A lack of understanding of the maternity system and how it works is another barrier to access with women reporting that they want greater understanding about the different types of care available in pregnancy. The women interviewed by Corbett and Okesene-Gafa emphasised the importance of having information about LMCs and other maternity services, where the information is detailed, up-to date and accurate, particularly in relation to the location of LMCs and services. Many women were unaware that early antenatal care is important for a successful pregnancy outcome. This highlights the central role of education in improving access and uptake of antenatal and maternity care in the CMDHB (Corbett and Okesene-Gafa 2012).

In regards to the quality of antenatal care, women who were unhappy with their care identified issues with LMCs being too judgmental, not providing enough information and not taking the women’s concerns seriously. The women who were most satisfied had continuity of care throughout their pregnancy (Corbett and Okesene-Gafa 2012).

**Barriers to effective diabetes care**

In a study of personal barriers to diabetic care, Simmons et al (1998) identified 30 barriers to diabetes care as perceived by multi-ethnic groups in New Zealand. Barriers included psychological, educational, physical and psycho-social barriers. In spite of an increased awareness of self efficacy, locus of control, decision making and belief systems as key drivers in health behaviours, very few tools and resources are available to clinicians to help them change patient interactions (Simmons et al 1998).

Baxter (2002) claims that diabetes services and interventions that target ethnic minorities must be accessible, culturally competent, community based and ensure the empowerment of the communities they are operating in. Baxter (2002) includes the following recommendations for improved diabetes care for Māori.

- Training of health practitioners in understanding and addressing the needs of Māori with diabetes and understanding the context of Māori lives.
- Development of quality resources on diabetes for Māori (including nutrition resources).
- Training and employment of more Māori health practitioners to work in the area of diabetes.
- Raising awareness within Māori communities about diabetes and outcomes that can be expected.
- Involvement of supports and whānau.
- Ensuring Māori ownership of community development initiatives and partnerships with Māori for these initiatives.

In a study investigating the influence of internet-based interventions on diabetes outcomes for Māori, Reti et al (2011) found a significant difference between having access to the internet and being able to use it to participate in online education or interventions. Māori in Northland were less likely to be able to use the internet (despite having access) than non-Māori. The study raises questions around the effectiveness of internet-based health interventions for Māori with diabetes and poor computer skills.

Diabetes interventions which target the general population will not necessarily reach disadvantaged groups (Glazier et al 2006). Interventions designed to reduce health inequalities need to take into account the specific barriers faced by each group and reflect the needs of that group. In addition, the involvement of local groups and communities is important (Glazier et al 2006).

In a study conducted in South Texas, Larme and Pugh (2001) investigated practitioner beliefs regarding barriers to effective diabetes care. Barriers included factors which occur in private practice settings, such as: time and financial pressures; general public/patient factors including low public awareness of diabetes, food insecurity and poor nutritional habits; low income and education levels; and health care system factors including an emphasis on treatment rather than prevention. Providers in this study reported that patients with lower education and/or literacy levels had ‘difficulty understanding clinicians’ explanations regarding diabetes management, and that inaccurate beliefs (such as insulin causing rather than preventing complications or that herbs and home remedies are adequate to control diabetes) sometimes interfere with care’ (Larme and Pugh 2001, p. 1730).

The providers also reported that a lack of culturally appropriate low-literacy teaching resources is a barrier to effective diabetes education. Interestingly, diabetes nurses in the same study emphasised the need for tools over education programmes for their patients, as they felt that patients could manage their own care if they had the proper tools. The nurses also said education efforts were best directed towards health practitioners, as this way more patients would ultimately be reached.

**Beliefs and attitudes**

A study on attitudes towards GDM among a multi-ethnic cohort in Australia, by Carolan et al (2010) found that women from non-Caucasian ethnicities may be at risk of poorer self-management of GDM due to, among other reasons, a lower appreciation of the seriousness of GDM.

In discussing effective communication with pregnant adolescents, Stang (2000) claims individuals with low literacy cite family and friends as their primary source of health and nutrition related information, which can be problematic as this information may have little scientific validity. This reliance on family and friends can be a barrier to behaviour change or, in some cases, may even be detrimental to the health of a mother or baby. This reliance on friends and family highlights the importance of
educational programmes and initiatives for GDM focusing on the entire family, instead of the pregnant woman alone.

**Patient-provider communication**

Patient-provider communication is a key component of quality health care and one which has been receiving increasing attention as research continues to link good patient-provider communication with positive health outcomes (Kogan et al 1994; Endres et al 2004; Peek et al 2011).

The importance of good communication is highlighted by Rothman et al (2004), who claim that the success of their diabetes disease management programme in the United States was in part due to the deliberate use of communication strategies on the part of the health practitioners, including:

- decreasing the complexity of information given to patients
- using concrete examples
- limiting the number of topics covered in one session
- avoiding medical jargon where possible
- focusing on selected critical behaviours
- using the teach-back method to ensure comprehension.

McLaughlin (2009) also highlights the increased use of standards of care such as confirming patient understanding by the teach-back method. Weiss (2007) describes teach-back as a comprehension technique where the patients have to explain or demonstrate what they have been told by a health practitioner. The teach-back technique is recommended in place of asking the patient whether they understand what they have been told and most importantly puts the responsibility for ensuring patient comprehension on the clinician. Research shows a correlation between using the teach-back method and improvements in patient understanding and health outcomes, including better diabetes control (Weiss 2007).

In their study on preferences and behaviours towards shared decision making among patients with diabetes, Peek et al (2011, p. 422) state that shared decision making, described as ‘a process wherein patients actively contribute to the information-sharing and decision-making process with providers’, is associated with improved diabetes control, greater self-efficacy and participation in self management of diabetes, among other positive health outcomes. The study also found communication disparities among African American and white patients, with African American patients more likely to defer treatment decisions to their health provider despite these patients being just as likely as white patients to want to participate in the process of decision making. The study also reports that African Americans with diabetes may be more likely to initiate discussions with their providers and ask more questions about their diabetes care, which suggests that racial disparities in shared decision making are not driven by a lack of patient engagement. The study also showed that lower levels of education are associated with a greater likelihood of a patient taking a passive role in shared decision-making (Peek et al 2011).
The importance of patient-provider communication is again highlighted in a study by Kogan et al. (1994) which examined the relationship between advice about healthy behaviour and antenatal care procedures as two separate components of the content of antenatal care. Advice about healthy behaviours was found to be a critical factor in healthy birth outcomes, and the study recommended this become a core aspect of antenatal services for all women, particularly women with high-risk pregnancies. These studies (Kogan et al. 1994; Peek et al. 2011; Weiss 2007) show how critical provider-patient interaction is to good health outcomes.

**Communicating with young pregnant women**

As half of Māori women having children are aged 24 or under, consideration needs to be given to factors affecting communication with younger people. In communicating effectively with pregnant adolescents who have limited literacy or comprehension skills, Stang (2000) states that, among other factors literacy and numerical skills as well as comprehension are key to enabling an adolescent to understand complex information and situations. In addition to recommendations for developing effective printed materials, Stang (2000) highlights the importance of listening, group discussion and hands-on activities in the nutrition education of pregnant adolescents. Group activity is the most highly rated method of nutrition education among individuals with low literacy, including adolescents, with cooking classes and demonstrations shown to be one of the most preferred methods for receiving food and nutritional information (Stang 2000).

**Diabetes self-management**

Self management is an important component of good diabetes care (McLaughlin 2009). Knowledge of GDM or T2DM and its effects are key factors in an individual’s ability to effectively manage diabetes, but it is not the only factor (Simmons et al. 1998; McLaughlin 2009). In the case of GDM, behavioural aspects such as lifestyle changes are key to successful pregnancy outcomes (Moses et al. 2009).

Incorporating and maintaining lifestyle changes into everyday life is a big challenge, especially post-partum, and requires, as well as knowledge of GDM or T2DM and its effects, additional knowledge about how lifestyle changes positively impact on the condition. Decision making, problem solving and self-efficacy are required for effective self management and behaviour or lifestyle changes (Prochaska 2008; McLaughlin 2009; Mulvaney 2009).

Prochaska (2008) depicts behaviour change as a process (as opposed to an event) involving a number of stages. The stages of behaviour change are: precontemplation; contemplation; preparation; action; maintenance and termination. The middle stages of preparation and action are the most changeable with a high chance of people with diabetes mellitus both progressing or regressing, depending on the support they receive. Effective decision making, including careful consideration of the pros and cons of each action, is a key factor in a person’s ability to progress through the stages. Viewing behaviour change as a process has important implications for how GDM interventions are developed and implemented as each stage of the process will require a differing approach, different support and
different resources. The timeframe for experiencing the stages of behaviour change is significantly condensed for GDM (in comparison to diabetes mellitus) as GDM lasts approximately 12 weeks.

Problem solving is a key skill in the effective self management of diabetes mellitus. Mulvaney (2009, p. 99) claims that ‘low self adherence typically indicates an interaction between barriers to self-management and inadequate application of coping and problem solving skills’. Like behaviour change, problem solving also involves a number of stages. These are problem awareness, barrier identification, solution generation, implementation planning, implementation, outcome evaluation and revision. Although these stages seem straight-forward, problems often arise in the application of the process, due to the nature of the barriers patients face at each stage, including a lack of motivation and insufficient support (Mulvaney 2009).

Providing patients with information on their performance levels, and giving feedback on their behaviours, clinical indicators and general problem-solving progress are typical components of self management interventions (Mulvaney 2009).

Problem-based learning (Mulvaney 2009) begins the learning process with a relevant self management problem, such as a patient having insufficient time or motivation to exercise. The solutions that are created for the initial problem are then generalised to other self-management problems. Motivation is critical for effective diabetes self management and Mulvaney (2009) also emphasises the need for patient-centred motivation in problem-based learning programs. Once again, the timeframe for this is significantly reduced in GDM as the condition lasts approximately 12 weeks.

Mulvaney (2009, p. 103) highlights ‘the quality of the patient-provider collaboration’ as a potential barrier to problem-solving with difficulties in this collaboration potentially arising from the different ways in which patients and providers approach the task of self-management. Patients may view self-management tasks as a guide and attempt to adapt provider recommendations to suit their own lifestyle, while providers may in turn focus on ‘the need for patients to change their lifestyle to accommodate diabetes self-management’ (Mulvaney 2009, p. 103). Although both these approaches will likely result in change, the quality of the patient-provider relationship may be affected as the patient and provider have different ideas as to what constitutes both a problem and adherence (Mulvaney 2009).

The importance of the learning being controlled by the patient is highlighted in an article by Bennett et al (2008). The authors state that ‘while learner-derived priorities may not fully overlap with the priorities of medical providers, they [the provider] have the advantage of inherently garnering commitment from the mother’ (Bennet et al 2008, p. 14).

**Approaches to education**

Patient education is seen as a crucial component of high quality diabetes care, including GDM care (Kogan et al 1994; Stang 2000; Renkert and Nutbeam 2001; Endres et al 2004; Rothman et al 2004; McLaughlin 2009; Mulvaney 2009; Carolan et al 2010; Naik et al 2011). Diabetes self-management education needs to be relevant to patients’ personal lives and self-management support interventions need
to ‘encourage patients to use personalised approaches to diabetes risk assessment, goal-setting and problem solving’ (Naik et al 2011, p. 1).

In a study that compared the effectiveness of two methods of diabetes education, Naik et al. (2011) found that in contrast to traditional approaches, where experts teach the necessary information and make recommendations for patients to follow, the empowerment approach promotes critical thinking and autonomous behaviour. This approach places the core diabetes content to be learnt, in the context of personal barriers and daily roles, thereby strengthening the personal significance of the content, rather than relying on rote memorisation and recall.

McLaughlin (2009) outlines factors for the individual, the health care provider and the wider health system to lift health literacy levels and improve GDM outcomes. For the individual patient, personal empowerment is critical so that each woman can take control of her GDM status and self-manage her condition effectively. For the health care provider, it is useful to take a universal precautions approach to each health encounter, taking specific actions that minimise risk for all patients, as described by the Agency for Healthcare Research and Quality (2010). Using basic language and communication strategies, such as the teach-back method to ensure patient comprehension, are also recommended. For the health system, improving awareness among key stakeholders of the impact of health literacy in pregnancy outcomes, and a dedication to effective communication, culturally competent use of resources, culturally appropriate resources and improved health care access for all women with GDM are all important (McLaughlin 2009). Although this research is focused on the United States, these recommendations can be applied to the New Zealand context.

**Key messages of relevance to New Zealand**

There are a number of key messages from the research into GDM interventions which could be used in New Zealand.

- **Active, participatory approaches** that encourage patients to take control and self-manage their condition are more successful than traditional approaches to diabetes management. Because of the inherent difficulty in changing behaviours, the wider family needs to be involved in any education effort or initiative (Glazier et al. 2006; Naik et al. 2011). Because family and friends are the primary source of information for pregnant women experiencing low health literacy, any educational effort or initiative for GDM needs to focus on the entire family, not just the pregnant woman (Stang 2000).

- **More focus** needs to be placed on preconception counselling and early pregnancy care. There is growing understanding of the need for increased awareness of GDM as a serious condition and for increased awareness of the importance of early detection and prevention by individuals and health care providers as well as better long term follow up of women who have experienced GDM. Effective patient-provider communication is a key factor in achieving this (Larme and Pugh 2001; McLaughlin 2009).
• The health literacy demands faced by pregnant woman are complex and those faced by women with GDM are significantly higher and compressed into a short 12-week timeframe. There is a need for more culturally relevant GDM resources for women with low health literacy (Bennett et al 2008).

• A number of studies have highlighted the central role of the provider in ensuring good patient-provider communication (Endres et al 2004; Peek et al 2011; McLaughlin 2009; Weiss 2007). Provider training in the principles of patient-centred communication including the ability to effectively use communication tools and strategies such as the teach-back method to ensure patient comprehension need to be included in any strategy to improve GDM outcomes in New Zealand.
References: Literature review - health literacy and gestational diabetes mellitus


Appendix 3: Health literacy demands for Gestational Diabetes Mellitus

Profile 1: GDM Screening - GCT

Knowledge

- Understand what GDM is.
- Understand the purpose of screening for GDM.
- Understand that their LMC can give them information and advice about GDM.
- Understand the concept of informed consent. Screening for GDM is an individual choice and they need to agree to the screening.
- Understand the risk factors associated with GDM (e.g. belonging to a particular ethnic group, family history of T2DM, being obese, rapid and excessive weight gain during pregnancy, being older).
- Identify if they have any risk factors for GDM.
- Understand that GDM can occur in women with no risk factors.
- Understand the complications for both baby and mother associated with undiagnosed and untreated GDM (e.g. pre-eclampsia, caesarean section, perineal trauma, congenital heart disease in babies, macrosomia, stillbirth, shoulder dystocia, hypoglycaemia, respiratory distress syndrome and jaundice).
- Understand the process of initial screening for GDM (it is a blood test, called a Glucose Challenge Test or GCT) that takes place in a lab: they need to drink a sugary solution and then wait at least 1 hour before they have a blood test; and they shouldn’t eat or drink anything too sweet before taking the GCT as this may affect the results).
- Understand that they will be given a form by their LMC that they give to the lab receptionist when they arrive for their screening test.
- Understand the purpose of the GCT is to test how quickly the body absorbs sugar or glucose into the blood and if the body absorbs sugar too slowly then it is a sign that they could have GDM.
- Understand that their test results will be sent to their LMC.
- Understand that a high or positive result does not mean they have GDM, but they will require a second diagnostic test.
- New vocabulary e.g. GCT, GDM, glucose, hypoglycaemia, pre-eclampsia.

Skills

- Read printed or online information about GDM and the GCT.
- Use vocabulary skills and strategies to learn new vocabulary.
- Ask questions of LMC about GDM (risk factors, outcomes, complications, screening process, treatment) and discuss concerns with them.
- Speak to family and friends about GDM and the screening process.
- Listen to answers and make decision about screening.
- Read form for lab test.
- Speak to lab receptionist and/or technician to answer their questions and ask questions.
- Use numeracy skills to manage their time for the lab test (up to 1.5 hours).
- Use numeracy skills to understand the parameters of the test (glucose concentration needs to
be less that 7.8mmol/L. If it is higher than this, will need to have another test).
- Discuss results with their LMC (speaking and listening skills).
- If result is positive, use critical thinking skills to synthesise all information and decide on whether
to have next test.

Profile 2: GDM Testing - OGTT

This profile builds on, and is additional to, the profile required for GDM screening - GCT.

Knowledge
- Understand that the second test is called the Oral Glucose Tolerance Test (OGTT) that will
  confirm whether they have GDM.
- Understand why they are having a OGTT.
- Understand that having the OGTT is also an individual choice and that they need to agree to
  have the test.
- Understand that the OGTT takes between 2 and 3 hours to complete and that most of this time
  will be spent waiting in a lab.
- Understand that the OGTT involves drinking a sugary solution and then waiting for 2 hours.
- Understand how the OGTT is different from and similar to the GCT.
- Understand that a blood test will be taken both before they drink the sugary solution and 2
  hours after they drink the solution.
- Understand that they must not eat or drink anything for at least 8 hours before the OGTT.
- Understand that they cannot eat, drink or smoke during the 2-3 hours that it takes to do the
  OGTT.
- Understand that if they vomit up the sugary drink they will need to repeat the OGTT again.
- Understand what the parameters of the OGTT are and what the results mean (a glucose
  concentration of more than 9.0 mmol/L is diagnosed as GDM).
- Additional vocabulary e.g. oral glucose tolerance test.

Skills
- Read printed or online material about the OGTT.
- Use vocabulary skills and strategies to learn new vocabulary.
- Ask questions of LMC about GDM (OGTT, treatment) and discuss any concerns.
- Speak to family and friends about GDM and the OGTT.
- Listen to answers and make decision about having the OGTT.
- Discuss with the LMC who is going to make the appointment for the OGTT. If necessary make the
  appointment.
- Use numeracy skills to manage their time for OGTT (up to 3 hours).
- Discuss results with their LMC (speaking and listening skills).
- In the event of a diagnosis of GDM, discuss the next steps with the LMC (treatment through
  lifestyle changes such as diet, exercise and potentially medication as well).

Profile 3: GDM treatment

This profile builds on, and is additional to, the knowledge required for screening and diagnosis of
GDM - GCT and OGTT.
Knowledge

- Understand that they have GDM.
- Understand that their care will be shared between their LMC and the diabetes clinic team (where available).
- Understand that they will need to change their lifestyle to meet the requirements of their GDM treatment (diet, exercise and possibly medication).
- Understand the need for regular blood sugar monitoring and how to do this.
- Understand the role of diet and exercise in the treatment of GDM.
- Understand the purpose of the diabetes clinic (where available) and the services it provides.
- Understand that they will need to attend the diabetes clinic (where available) every 3-4 weeks for the remainder of their pregnancy, the reason for that and the activities that they will need to undertake during those visits.
- Understand that they will meet with a dietician at the diabetes clinic (where available) who will give them advice about their diet during their pregnancy.
- Understand that if their blood sugar levels exceed a certain level, they will need to take medication to treat GDM.
- Where relevant, know the name of the medication, how to pronounce it and understand how it works.
- Where relevant, understand how to take their medication (e.g. if insulin they will need to self-inject), what side-effects it could have on them and what side effects to report to health practitioners.
- Understand the implications of a diagnosis of GDM for this baby, themselves and any future pregnancies.

Skills

- Read printed or online information about GDM.
- Ask questions of LMC and staff at diabetes clinic about treatment of GDM and discuss any concerns.
- Speak to family and friends about treatment for GDM (medication, diet and exercise).
- Use numeracy skills to manage diabetes clinic appointments.
- Use numeracy and reading skills to manage blood monitoring (e.g. timing and reading meters).
- Use critical thinking skills to manage hyperglycaemia and hypoglycaemia.
- Calculate doses of medication.
- Participate in group or 1:1 education sessions at diabetes clinic using reading, writing, speaking and listening skills to check and clarify information (e.g. asking questions, paraphrasing, summarising).
- Read information about medication including instructions about how to administer.
- Listen to oral instructions about taking medication.
- Ask questions about food and exercise e.g. eating takeaways or eating out, or not sure what exercise is suitable.
- Read information on food and drink packaging.
- Calculate nutritional content of serving sizes.
- Use critical thinking to synthesise all information and take action as required.
- Use vocabulary skills and strategies to learn new vocabulary e.g. Metformin.
Profile 4: Post-partum testing and prevention of T2DM

This profile builds on, and is additional to, the knowledge required for screening, diagnosis and treatment of GDM.

Knowledge

- Understand the difference between GDM and Type 2 Diabetes Mellitus (T2DM).
- Understand the purpose of a post partum test that is to confirm GDM or diagnose T2DM.
- Understand that this test is another OGTT.
- Understand that they can choose whether to have the OGTT done or not and reasons for having the test.
- Understand that, depending on the results, they will either have a diagnosis of GDM or T2DM and that there are implications for both diagnoses.
- If they are diagnosed as having had GDM then they need to understand the importance of annual checks for T2DM with their GP and early screening for GDM in subsequent pregnancies.
- Understand the relationship between GDM and future T2DM for both themselves and the baby.
- Understand the lifelong role of healthy eating and exercise in the prevention of future T2DM.
- If they are diagnosed with T2DM they will need to understand what actions they need to take to manage their T2DM and how these actions differ from and are similar to the actions required for managing GDM.

Skills

- Discuss post-partum testing with LMC. Ask questions of LMC and discuss any concerns before the baby is born.
- Speak to family and friends about the post partum OGTT.
- If they are not being followed up by the diabetes clinic, ring their GP or practice nurse to collect the lab form and make an appointment at the lab.
- Read the form for the lab test.
- Discuss test results and diagnosis with diabetes clinic nurse and/or GP or practice nurse.
- Depending on the results, read information about T2DM.
- Discuss diagnosis with diabetes clinic nurse and/or GP or practice nurse and write action plan for managing T2DM.
## Appendix 4: Stocktake of Gestational Diabetes Mellitus Resources

These are free, downloadable resources for patients

<table>
<thead>
<tr>
<th>Resource title and other information</th>
<th>Link</th>
</tr>
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<tbody>
<tr>
<td>Diabetes New Zealand, NZ</td>
<td></td>
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<tr>
<td>• What is Diabetes?</td>
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<tr>
<td>• Are you at risk of Type 2 Diabetes?</td>
<td></td>
</tr>
<tr>
<td>• What are the symptoms of Diabetes?</td>
<td></td>
</tr>
<tr>
<td>• I don’t want to get Type 2 Diabetes. How can I reduce the risks? (posters)</td>
<td><a href="http://www.diabetes.org.nz/__data/assets/pdf_file/0017/4229/at_risk_posters_2.pdf">www.diabetes.org.nz/__data/assets/pdf_file/0017/4229/at_risk_posters_2.pdf</a></td>
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<tr>
<td>Diabetes New Zealand, NZ</td>
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<tr>
<td>Diabetes New Zealand, NZ</td>
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<tr>
<td>Can I have a healthy baby? Diabetes and pregnancy (information booklet)</td>
<td><a href="http://www.diabetesaustralia.com.au/PageFiles/10290/A5%20Booklet%20Can%20i%20have%20a%20healthy%20baby.pdf">www.diabetesaustralia.com.au/PageFiles/10290/A5%20Booklet%20Can%20i%20have%20a%20healthy%20baby.pdf</a></td>
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<tr>
<td>Diabetes Australia, AUS</td>
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<tr>
<td>Diabetes Australia, AUS</td>
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<tr>
<td>National Diabetes Services Scheme (NDSS), AUS</td>
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<td>National Diabetes Services Scheme (NDSS), AUS</td>
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<tr>
<td>Title</td>
<td>Author/Institution</td>
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<tr>
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<tr>
<td>When I was pregnant I found out I had diabetes (poster)</td>
<td>National Institute of Health (NIH), US</td>
</tr>
<tr>
<td>Early origins of diabetes (policy briefing for health practitioners)</td>
<td>International Diabetes Federation, US</td>
</tr>
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### Hard copy resources for patients in Counties Manukau District Health Board

<table>
<thead>
<tr>
<th>Resource title and other information</th>
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<tbody>
<tr>
<td><strong>How to take Metformin tablets</strong> (A4 handout)</td>
</tr>
<tr>
<td>Counties Manukau District Health Board, Diabetes in Pregnancy Team, June 2010</td>
</tr>
<tr>
<td><strong>My Diabetes record book</strong> (book)</td>
</tr>
<tr>
<td>Novo Nordisk</td>
</tr>
<tr>
<td><strong>Diabetes during pregnancy</strong> (A5 pamphlet)</td>
</tr>
<tr>
<td>Counties Manukau District Health Board, Women’s Health Division, January 2010</td>
</tr>
<tr>
<td><strong>Pregnancy and Diabetes</strong> (A5 Booklet)</td>
</tr>
<tr>
<td>Counties Manukau District Health Board, Women’s Health Division, February 2007</td>
</tr>
<tr>
<td><strong>Healthy eating for women with diabetes during pregnancy</strong> (A5 Booklet)</td>
</tr>
<tr>
<td>Counties Manukau District Health Board, Nutrition and Dietetics Department, August 2011</td>
</tr>
<tr>
<td><strong>Breakfast Ideas, Snack Ideas, Lunch or Dinner Ideas</strong> (A5 pamphlet)</td>
</tr>
<tr>
<td>Counties Manukau District Health Board</td>
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</table>
Diabetes in Pregnancy. When you need insulin (A5 booklet)  
Counties Manukau District Health Board, February 2011

Self Management Diary (A5 booklet)  
Counties Manukau District Health Board

### Hard copy resources specifically for Māori patients and their family

Te Hauora o Hine Te Iwaiwa: Keeping Healthy in Pregnancy and gestational diabetes (foldout pamphlet)  
Nga Maia O Aotearoa Me Te Wai Pounamu

### Hard copy resources for health practitioners in Counties Manukau District Health Board

<table>
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</table>
| Diabetes guidelines. Diabetes in Pregnancy (A4 booklet)  
Counties Manukau District Health Board, Women’s Health Department  
Updated September 2011 |
| Treatment of Hypoglycaemia (laminated flowchart A4)  
Counties Manukau District Health Board |
| Management of Hypoglycaemia in the Postnatal Area (photocopied handout A4)  
Kidz First Neonatal Unit |
| Diabetes in Pregnancy Schedule of Care Guideline (A4 handout)  
Counties Manukau District Health Board |
<table>
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<th>Resource</th>
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<tr>
<td>Guideline: Entry Criteria and referral into the Diabetes in Pregnancy Service</td>
<td>(A4 handout) Counties Manukau District Health Board, Women's Health Department Updated April 2011</td>
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<tr>
<td>Consensus statement. Gestational Diabetes (A4 handout)</td>
<td>New Zealand College of Midwives</td>
</tr>
<tr>
<td>Roles and responsibilities in the hospital setting (A4 handout)</td>
<td>New Zealand College of Midwives</td>
</tr>
<tr>
<td>Transfer Guidelines (photocopied booklet)</td>
<td>New Zealand College of Midwives</td>
</tr>
<tr>
<td>Balancing insulin and delivery (A4 handout- information table)</td>
<td>Novo Nordisk</td>
</tr>
<tr>
<td>Referral guidelines for consultation with obstetric and related specialist medical services (A4 handout)</td>
<td>Primary Maternity Services Notice 2007</td>
</tr>
</tbody>
</table>
Appendix 5: Resource by Nga Maia and Health Literacy Review

Resource by Nga Maia

Keeping Healthy in Pregnancy

Risk factors for GD
- Polycystic ovary syndrome
- Being overweight
- A family history of diabetes
- Having unexplained preterm birth or stillbirth
- A previous large baby
- Being aged over 30
- Having high blood pressure
- Having a high blood sugar level

What does GD mean for me and my baby?
GD can cause health problems in both mother and baby. If you have GD, a specialist team will be available to help you manage your condition to keep you and your baby well.

What is gestational diabetes (GD)?
GD occurs when a woman's body can't cope with the sugar levels in her blood. A blood test is taken to check for GD during pregnancy.

Keeping Healthy in Pregnancy

Exercise: healthy kai and staying smokefree alcohol free and drug free will help keep you and your baby healthy during pregnancy.

Risk Factors: Exercise doing some physical activity each day to help maintain blood sugar levels and keep the body strong.

Te Haurua o Hine Te Iwiwa

For more information:
www.ngamaia.co.nz
www.diabetes.org.nz

Maintain healthy before and during your pregnancy also lowers your risk of getting gestational diabetes.

Exercise: doing some physical activity each day to help maintain blood sugar levels and keep the body strong.

Kai: eating lots of fresh fruit and vegetables whole grain foods high fat low sugar kai. Water is the best drink.
Cecile's Haputalega

Five Beautiful Babies: Learning

...
Te Maramataka
Pregnancy Calendar

He kākano koe i ruia mai i Rangi Ātea.
You are sacred beyond measure.

Manaakihia te whare tangata.

Kia hua te whenua, ka puāwai te hua
A nourished base, a healthy life.

Whānau support fosters healthy mokopuna, parents and whānau.

Orioki, waiata, karakia, te reo, he akoranga hohonu.

Keep active
Ahakoa he iti, he pounamu

4mm long. Lumps form that develop into organs and body.

6 weeks

2.5cm long. Arm and leg buds start to form. Eyes, nose, fingers and toes start to appear.

10 weeks

Tūohu ki runga
Tūohu ki raro
Strengthens lower back
8.7cm long. Pepi may start sucking thumb. Mum should start feeling movements in the next few weeks.

14 weeks

Hīkoi
Walking helps keep you fit. Check for toilet stops beforehand.

Pēpi is growing and learning

22 weeks

Noho ki mua
Helps put pepi into a comfortable position.

Prepare ipu whenua

30 weeks

Kanikani
Dance to the music. Keeps you fit and it's fun too!

Prepare birth plan

40cm long. Eyes open and can focus. Pepi's hands are fully formed. Lungs still developing.

Noho kūwhera
Strengthens legs and pelvic region for birth.

51 cm long (approx). Pepi is fully developed and ready to be born.

39 weeks

Mirimiri whāea and puku
(avoid feet, ankles and wrists)

Hopehope
Swing hips side to side. Strengthens hips and helps position pepi's head for birth.

Due date:

Kaukau
Weightless in water. Swimming strengthens in a low stress way.
### Health Literacy Review

<table>
<thead>
<tr>
<th>Name / Title</th>
<th>Te Hauora o Hine Te Iwaiwa: Keeping Healthy in Pregnancy and gestational diabetes</th>
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<tr>
<td>Produced by</td>
<td>Nga Maia</td>
</tr>
<tr>
<td>List any sponsorships</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>Published / Revision Date</td>
<td>Unknown</td>
</tr>
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</table>
| What is the purpose of this resource? | Explicit purpose: (only by the name of the resource)  
- To give information about keeping healthy during pregnancy.  
Implied purpose:  
- To give information about gestational diabetes (GD), including risk factors, ways to control GD and warning signs that a woman may have GD.  
- To encourage conversations about GD and keeping healthy during pregnancy, between midwives and pregnant women, and between pregnant women and their family.  
- To give practical advice about how a woman can keep active during her pregnancy.  
- To give information about the growth of a pepi (baby) during pregnancy. |
| Who is the target audience? | Explicit: (as per website) For hapu (pregnant) Māori women and their family.  
- Implied: (as per resource) For Māori women and their family. |
| Resource type | Pamphlet A5                                                                       |
| Access points | Information about the resource on Nga Maia’s website:  
- Unknown about other ways pregnant Māori women would access this resource. |
| Languages available in | English with some te reo Māori |
| Links to other information and/or services |  
- [www.ngamaia.co.nz](http://www.ngamaia.co.nz)  
<p>| Cost: | Free |</p>
<table>
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<tr>
<th>Resource content</th>
<th>Does the content match the purpose of the resource?</th>
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<tr>
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<td>Is the content relevant to the target audience?</td>
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<td>Are the most important messages/instructions at the</td>
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<td>Simple, familiar words are used that reflect the</td>
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<td>Technical or difficult concepts are explained using</td>
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<td>simple, familiar words and examples or analogies</td>
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<td>Key terms are used consistently throughout the</td>
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<td></td>
<td>resource</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Majority active or passive voice used</td>
<td>Active</td>
</tr>
<tr>
<td></td>
<td>There is one message per paragraph</td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>Inclusive language (we–you) is used</td>
<td>Sometimes</td>
</tr>
<tr>
<td></td>
<td>The resource reflects the diversity within the</td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>target audience</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The design features used help the reader find</td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>information easily e.g. consistent use of fonts,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>headings, tables, limited use of UPPER CASE, italics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>and underlining, effective use of white space</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Graphics and colour contrast remain effective when</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>photocopied or printed in black and white</td>
<td></td>
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<tr>
<td></td>
<td>Relevant, realistic images are used e.g. photographs</td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>(reflecting main audience, appropriate age ranges,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>both genders)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>There is consistency between use of visuals and its</td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>surrounding content</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Readability</th>
<th>SMOG</th>
<th>7.5</th>
<th>(age 13 or Year 9 in NZ)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Flesch Kincaid</td>
<td>7.5</td>
<td>(age 13 or Year 9 in NZ)</td>
</tr>
</tbody>
</table>

| Māori concepts and | Does the resource reflect Māori concepts and values, tikanga (customs) and wairua (spirituality)? |
|                   | Yes. It is clear that this resource has been written by Māori for Māori. |
| values (based on Te Whare Tapa Whā) | |

www.readabilityformulas.com/free-readability-formula-tests.php
### Summary: What works well

Comment on how this resource helps build health literacy (knowledge and understanding of gestational diabetes, and skills needed to negotiate their and their baby’s health).

- The imagery is very attractive, relevant and draws the reader into the resource and its content.
- Using Cecile and Leanne’s stories helps build reader awareness and connection to the information and their own pregnancy.
- The tone of both stories is natural and draws the reader into the messages. This helps build reader engagement and relevance to the content and their situation.
- The information shared via Cecile and Leanne’s stories includes clear messages, particularly around things a pregnant woman can do to manage her GD, and some warning signs that a pregnant woman may have GD.
- The Pregnancy Calendar is visual and a clever way to share information about pepi’s growth and ways a woman can keep active during her pregnancy. Images are clear, relevant and engaging. Messages are short and succinct.

### Summary: What could be improved

Comment on any improvements to:
- Purpose and relevance
- Usability / accessibility / navigation
- Overall building of health literacy

- State the purpose of the resource early in the resource. This will help readers to easily identify what the resource is about and how it relates to them.
- Provide more description of the screening process and who will assist you to arrange screening.
- The inclusion of risk factors implies screening is encouraged for women with risk factors, however universal screening is recommended for all women. Risk factors could be removed.
- This resource assumes the reader knows and understands:
  - what whole grain foods, low fat and low sugar kai are.
  - why it is important to maintain blood sugar levels and how this relates to keeping healthy.
  - health problems GD may cause for both mother and pepi.
- The information under ‘What is gestational diabetes (GD)?’ and ‘What does GD mean for me and my pepi?’ could be extended to provide clearer explanations in everyday language.
- Under the ‘Risk factors for GD’ sub-heading, encourage the woman to talk to her midwife or lead maternity carer if she has any of these risk factors or is worried about getting GD.
- Footnote at the bottom of page titled ‘Five beautiful babies: Leanne’s Story’ states ‘Cecile and Leanne’s full stories can be viewed on our website’ – On review of Nga Maia’s website there is no access to these stories other than a static picture of this resource.
- Help pregnant women and their family visualise the size of growing pepi. Include for weeks six and ten, actual size of pepi (e.g. 4mm, 2.5cm). Then for 14 weeks on, refer to common items that can help women visualise the size of their pepi.
- Could include an explicit link between a mother’s diet and how it provides essential nutrients to pepi. Whatever mother eats and drinks and breathes in, so does pepi.
- The resource would benefit from proofreading (e.g. consistency in spelling pepi – pēpi or pepi) and consistency in formatting.
Appendix 6: Resources - Booklet and Talking Points (suggested scripts for LMCs)

Six weeks after your baby is born you need to have another Glucose Tolerance Test to check if you still have diabetes. The diabetes service or your midwife can organise this check for you. Having gestational diabetes increases your chances of developing diabetes later in life so make sure your doctor organises a diabetes blood test for you every year.

This booklet was developed by Workforce as part of a research project, funded by the Ministry of Health, about testing for Diabetes in Pregnancy.
At 24-28 weeks your Lead Maternity Carer, also known as your LMC, or midwife, will ask if you want to be tested for gestational diabetes. It is your choice to be tested. The test is free.

Testing is offered to every pregnant woman because women may have no symptoms of gestational diabetes.

Gestational diabetes usually develops after 24 weeks of pregnancy. In some cases, your midwife may recommend testing earlier than 24 weeks if they see signs that you had diabetes before you became pregnant.

What is gestational diabetes?
Diabetes is when you have too much sugar in your blood. After you eat some food, your body turns the food into sugar in your blood. A hormone called insulin helps your muscles get sugar from your blood and use the sugar for energy. During pregnancy, your body produces other hormones to help your baby grow. Some of these hormones can stop insulin from working. This means the sugar in your blood builds up because the sugar is not getting to your muscles.

Why do I need to be tested?
It's a good idea to get tested because if you have gestational diabetes we need to treat it so you can avoid problems like complications during pregnancy, during birth, and ongoing health issues for you or your baby.

Treatment helps avoid many of these problems. And, gestational diabetes usually goes away after your baby is born.

What tests do I need?
There are two tests. The first test for gestational diabetes is a poly sac test. The poly sac test shows how fast your body uses the sugar in your blood. If your body uses sugar too slowly, it is a sign you might have gestational diabetes.

Your midwife will explain the testing process and answer any questions you have about gestational diabetes.

What happens when you are tested for gestational diabetes?

**Test 1: Poly sac test**
Your midwife will give you a form to take to the lab for a poly sac test. You do not need an appointment.

This test shows how fast your body uses the sugar in your blood. If your body uses sugar too slowly, it is a sign you might have gestational diabetes.

At the lab, give the receptionist your form. A lab technician will give you a sweet drink to finish in 10 minutes. Then you wait at the lab for an hour and stay relaxed. (While you are waiting, you can't smoke, eat or drink anything except a few sips of water)

After an hour the lab technician will take blood from you and the test is over.

Your test results are sent to your midwife who will call you if the result is high. This means your body might be taking too long to use the sugar in your blood, which is a sign of gestational diabetes.

If your first test is positive, you will need a second test, known as a Glucose Tolerance Test. Your midwife will talk to you about this test.

If you have gestational diabetes, your midwife will contact the nearest diabetes service that works with pregnant women.

The diabetes service and your midwife will care for you and your baby for the rest of your pregnancy. They will help you check the sugar levels in your blood and eat well during your pregnancy. They will help you decide if you need to use medication to keep your blood sugar at safe levels for you and your baby.
A guide for Lead Maternity Carers using: *Testing for Gestational Diabetes*

This is a guide to using the booklet about testing for gestational diabetes mellitus. The booklet is designed for a Lead Maternity Carer (LMC) to use with a woman who is at the stage of being offered screening for gestational diabetes.

We have also used ‘gestational diabetes’ rather than GDM or gestational diabetes mellitus. We think using the word gestational, with an explanation that this means ‘while pregnant’, helps reinforce that this type of diabetes is related to pregnancy. Acronyms are difficult to remember if you don’t know what they stand for, so using GDM can be confusing for a woman. However, as long as you explain and check understanding of terminology, you can choose to use the terms you think are most useful for women.

There are two parts to the booklet:

1. Explaining gestational diabetes and the risks to mother and baby. This will help a woman understand why she might agree to be tested and prioritise going for the test. It is also an opportunity to talk about any questions or concerns she has about gestational diabetes.

2. Explaining the testing activities a woman goes through. This helps a woman understand what to expect during an unfamiliar medical process. Explaining the process is also an opportunity to discuss any questions or concerns she has about the steps involved in testing.
Talking Points for the booklet: Testing for Gestational Diabetes

These Talking Points provide a possible script an LMC may use or adapt. The script includes good practice health literacy strategies, including Teach-back (which is asking someone to repeat back any advice you have provided). Some women may also want to talk to their family about screening before they decide what to do, so you could ask if they would like to invite their family to a discussion with you.

1. This booklet is about testing for gestational diabetes – this is a type of diabetes that you can get when you're pregnant because of all the hormonal changes your body is experiencing – it is usually temporary and goes away after a baby is born. The word gestation means 'while pregnant', so gestational diabetes means diabetes while pregnant.

2. Have you heard about gestational diabetes before? (Find out what the woman already knows – and then add and discuss any other relevant information.)

3. (If relevant) Do you remember being tested for gestational diabetes during your other pregnancies? (Discuss what a woman remembers about being tested. Then confirm what is same or different this time.)

4. As I said, some women get this type of diabetes when pregnant because some pregnancy hormones the body produces can stop the body from turning sugar in the blood into energy for the body. This is usually temporary and stops after the baby is born.

5. You are now 24 (or more) weeks, which is the time you can be tested for gestational diabetes. It is your choice to be tested. Testing does not harm you or your baby.

6. It's a good idea to get tested because gestational diabetes can lead to your baby having breathing problems, leading to a difficult birth, or being born with diabetes which can make them sick. Gestational diabetes can also make your pregnancy difficult if the diabetes isn't treated.

7. (If relevant) You have some of the factors which mean you are more at risk of having gestational diabetes. (Go through these factors.)

8. What else would you like to know about gestational diabetes?

9. Here is some information about the first screen for gestational diabetes. It's called a screen because it is a type of test which shows whether you have some signs of gestational diabetes – but it is not a definite diagnosis of gestational diabetes.

10. If the screen shows you have signs of gestational diabetes, you need to have a different test to make it clear whether you have it or not.

11. The screen is called the polycose test (or Glucose Challenge Test, depending on what it is called at the labs you work with). These five steps show you what will happen (discuss the five yellow steps in the booklet so a woman knows what to expect at the lab).

12. When I get your results from the lab I will call you and let you know if you need to have the second test.

13. What else would you like to know about the first screen?

14. Like all tests, this is optional, meaning you get to choose whether you want to be screened.
15. Do you agree to be screened for gestational diabetes?

16. (Yes) OK. Here is the form for you to take to the lab. *(Ask which lab a woman will use to make sure she knows where she can go.*) You don’t need an appointment. *(Provide a timeframe e.g. It would be good if you could be screened in the next week so we have the results before your next visit.)*

17. (No) OK. If you have any other questions about the screen just give me a call.

18. *(Use Teach-back.)* Just to check I have been clear, can you tell me what you have to do to get screened and I will listen to see if that I have given you all the right information. *(Review anything missed out such as where to get the test, staying at the lab, sweet drink, taking about an hour.)*

**In the event the woman has a positive polycose test**

Here are some Talking Points you could use for the conversation to prepare a woman for her second test *(adjust these points if a woman has had a GTT before – check what she remembers about the test).* We have not used the phrase ‘positive result’ in these Talking Points. The word ‘positive’ can be confusing, as a positive result may be perceived to be a good result, rather than positive for gestational diabetes. If you use the term ‘positive’, it will be helpful to explain what it means in this situation.

1. Your screen results show there are some signs you might have gestational diabetes. This is not definite – it is just a possibility at this stage.

2. You need to have a different test to make sure whether you have it or not. The second test is called a Glucose Tolerance Test, known as a GTT.

3. The GTT is like the first test but it takes longer. You have a sweet drink then wait 2 hours before you have a blood test. You have to rest and not eat or smoke anything during the test.

4. The thing that is really different with this test is that you can’t eat anything for 8 hours before the test. This means it’s a fasting test and the lab usually checks if you’ve been fasting – which means not eating for 8 hours. But drinking water is OK (no tea, coffee, fizzy drinks, etc). Women try to have this test early in the morning so it just means they skip breakfast and go straight to the lab.

5. Because this test takes longer, you’ll need an appointment at the lab. Do you want to make that appointment or would you like me to make it for you? *(Provide a woman with the phone number for her closest lab and opening hours for OGTTs, or arrange an appointment time and write this down for her.)*

6. What questions do you have about this test?

7. *(Use Teach-back.)* To check I have been clear, can you tell me what you need to do and I will listen to see if I have given you all the right information. *(Review anything missed out such as booking in, not eating for 8 hours before the test, staying at the lab for 2 hours, not eating or drinking anything except small amounts of water during the test.)*
### Video 1: First screening: Polycose Test

For an example of similar videos visit [http://www.youtube.com/watch?v=KFgr-elM9Hk](http://www.youtube.com/watch?v=KFgr-elM9Hk) and [http://www.youtube.com/watch?v=7BxSqehsEKA](http://www.youtube.com/watch?v=7BxSqehsEKA)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>To show women what to expect at the first lab test for Gestational Diabetes Mellitus.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target audience</td>
<td>Pregnant Māori women</td>
</tr>
</tbody>
</table>
| Key messages to include in video | - Some women get diabetes when they are pregnant because of changes in how your body deals with the sugars (or glucose) in the food you eat and drink.  
- Gestational Diabetes Mellitus testing is at 24-28 weeks.  
- It is your choice to be tested. The test is free.  
- If not treated, Gestational Diabetes Mellitus can cause problems for you and your baby so it is important to check if you have it.  
- Key events in the Gestational Diabetes Mellitus process as outlined in the ‘Information about Gestational Diabetes Mellitus’ document. This includes:  
  - Given a sweet drink to be consumed within 10 minutes  
  - Wait one hour  
  - Blood test is taken  
- Aiming for pregnant women to share her experiences honestly, with a focus on the test being a positive experience that she is glad she did. |
| Length | Up to 4 minutes |
| Scenes (4) | A young Māori pregnant woman (in her late teens or early 20s) is keeping a video diary of her pregnancy to show her pépi one day. She takes a friend/cousin with her to the lab. In this video clip she videos her Gestational Diabetes Mellitus testing journey.  
Scene 1:  
Camera on both in car. While driving to the lab, pregnant woman is talking with her cousin about Gestational Diabetes Mellitus and the polycose test.  
Scene 2:  
Her cousin videos her as she goes into the lab and talks to the receptionist, waits, is given the drink, waits again. Both looking at magazines and talking. |
Scene 3:
She has the blood test. Then leaves.

Scene 4:
Quick chat about how she feels about the test, baby and when she’ll hear about her results.

Draft script:

Scene 1: Driving to the lab
Cousin is driving the car with pregnant woman in passenger seat. Both having a conversation about where they are going and why.

Cousin Where are we going again?

Pregnant woman To the lab on Whittaker Street. I’ve got to get tested.

Cousin Tested for what?

Pregnant woman To see if I’ve got gestational diabetes while I’m pregnant.

Cousin Aye? What’s that?

Pregnant woman This type of diabetes you get when you’re pregnant, because your hormones are all different, it changes how your body gets energy from food.

My midwife said that now is a good time to get checked.

Cousin What does that mean?

Pregnant woman Well, I could have too much sugar in my blood apparently – and then pēpi could be getting too much sugar. Every pregnant woman needs to get tested. But my midwife said that because I’m Māori and there’s diabetes in the family, there is a higher chance I might get it while I’m pregnant – but it usually goes away once baby is born. It’s something that happens towards the end of pregnancy. This test will help them see if my sugar levels are high.

Cousin Oh, yeah, Uncle Pete has diabetes so I suppose it’s a good idea to check?

Pregnant woman Yeah. My midwife said that if I do have gestational diabetes it can hurt pēpi and cause problems for me. But if you know about it, you can treat it so we’re both OK. I don’t have to take this test but I want to make sure we are both ok and the test is free.

Cousin Sounds good. So what do you have to do?

Pregnant woman I’m not really sure about all of it but I have to drink a sweet drink and have a blood test. I’ll find out when we get there.

Cousin Cool.
### Arrives at lab.

<table>
<thead>
<tr>
<th>Pregnant woman</th>
<th>Can you video me on my phone? I’ve been keeping a video diary of my pregnancy and it will be cool to show pépi the things we did together before he was born.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cousin</td>
<td>Sure thing.</td>
</tr>
</tbody>
</table>

### Scene 2: At the lab

Camera on pregnant woman walking into lab.

She hands over her form to the receptionist.

<table>
<thead>
<tr>
<th>Receptionist</th>
<th>Checks the pregnant woman’s name and address.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Asks pregnant women to sit down and the lab technician will be with her in a minute.</td>
</tr>
</tbody>
</table>

| Pregnant woman | Sits down and looks around the lab. Quiet chat with cousin (looking into the camera).                                                   |
| Lab technician | Calls out pregnant woman’s name.                                                                                                        |
| Pregnant woman | Stands up and walks over to nurse.                                                                                                       |

*Normal conversation between lab technician and pregnant women for this test. Checks name and date of birth. Key points include: 10 minutes to drink; no eating or smoking while she waits for one hour; if she is sick or feels sick to let reception know; then I’ll come back and take some blood.*

*Pregnant women is handed glucose drink and given instructions.*

<table>
<thead>
<tr>
<th>Pregnant woman</th>
<th>Asks nurse a question e.g.:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Can I go to the toilet if I need to’ and ‘I know I’m not allowed to eat or drink - is that right?’</td>
</tr>
</tbody>
</table>

| Lab technician | Yeah, you can go to the toilet but if you’re sick tell the receptionist. And you are right - no eating, drinking, chewing gum or smoking - all you can have is a little bit of water. |

| Pregnant woman | Takes the drink. Initial reactions on drink are captured.                                                                               |
|                | Sits back down and talks briefly with her cousin about what the drink tasted like.                                                      |

### Scene 3: Blood test

Camera shot to clock then to pregnant woman. Cousin says 1 hour is up.

Lab technician returns to take blood test.

Quick conversation between the lab technician and pregnant woman about the test being finished, the results being sent to her midwife and that she can leave.

Pregnant woman asks lab technician how long it will take before her midwife gets her results.
**Shot showing pregnant woman and cousin leaving the lab.**

**Scene 4: Outside the lab**
Camera on pregnant woman standing outside the lab (or standing next to car or in the car).
Aiming for pregnant women to share her experiences honestly, with a focus on the test being a positive experience that she is glad she did.

<table>
<thead>
<tr>
<th>Cousin</th>
<th>Everything OK?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant woman</td>
<td>Well, the drink was a bit sweet but not that bad. Bit boring having to wait but whatever – worth it to keep pēpi healthy. If the test shows signs of high blood sugar, I will need to have another longer test so they can tell if it’s diabetes. Thanks for coming, can you come with me again if I need another test?</td>
</tr>
<tr>
<td>Cousin</td>
<td>Sure.</td>
</tr>
</tbody>
</table>