# How do newly diagnosed patients with type 2 diabetes in the Waikato get their diabetes education?

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## ABSTRACT

**INTRODUCTION:** Education is accepted as the mainstay of management for people with diabetes. However, there are few population-based studies describing what education has been delivered from the patient's perspective.

**AIM:** To ascertain the sources of education for patients with newly diagnosed type 2 diabetes; what education was received and what were the patients' views of group education. Delivery of education to Maori was compared with non-Maori.

**METHODS:** A cross-sectional survey of patients identified from the Waikato Regional Diabetes Service database. Patients identified in one calendar year, having a diagnosis of type 2 diabetes and being aged between 20 and 89 years were included in the survey. Patients were sent a four-page questionnaire. Non-responders were followed up by telephone.

**RESULTS:** 333/667 patients (50%) responded. The principal source of education for Waikato patients was general practice, from the general practitioner and/or the practice nurse. Ninety-three percent of patients reported that they had received some education about diabetes at the time of diagnosis. There was no difference between Maori and non-Maori in the reported levels of diabetes education received, but the patient perceived knowledge score was significantly lower for Maori in all aspects studied.

**DISCUSSION:** The overall impression was that patients were receiving appropriate information about diabetes, but there does appear to be room for improvement in some areas, particularly the importance of blood pressure and lipid control. We believe that further research on the educational needs of Maori and ethnic minorities is needed.

**KEYWORDS:** Diabetes; family practice; education; New Zealand

## Introduction

Type 2 diabetes is a lifelong condition that is associated with increased risk of cardiovascular disease,[1] renal disease,[2] peripheral vascular disease and blindness.[3] It is a disease that requires self-management by the patient and so it is understood that when they are diagnosed they need access to relevant information about their disease. Some diabetes education programmes have been shown to improve self-care,[4] glycaemic control[5,6] and general health status and well-being in patients.[7,8,9] Education programmes have also been used to target the reduction of risk factors such as weight, blood pressure and serum lipids,[10] but with less success. Patients who are from a lower socioeconomic background may be less receptive to education and less likely to implement behavioural changes[11] yet often these groups are also most at risk of developing complications of diabetes.[12] Reaching disadvantaged groups such as Maori and ethnic minorities needs to be an important consideration in all education programmes to allow the education to be delivered as effectively as possible.[13]

The Waikato District Health Board serves a population of 360 000 people, of whom 21% identify as being Maori. It has a well developed regional diabetes service which provides advice for patients

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with diabetes—particularly those with type 1 diabetes or those with complications of their diabetes such as renal disease or established cardiovascular disease. The service also offers a retinal screening service and so almost all newly diagnosed patients with type 2 diabetes within the Waikato are known to the service.[14] The Waikato Regional Diabetes Service mentors and supports general practices in the management of diabetes through the provision of a practice nurse education programme, regular updates for general practitioners and the provision of 17 diabetes nurse specialists of whom 10 are based in the community. There are also community health services provided by the District Health Board (DHB), including seven community dieticians who provide a comprehensive range of dietetic services. Some of these dieticians are available to see patients with type 2 diabetes in the community if required.

Initial management of newly diagnosed patients with type 2 diabetes, including their education, is expected to be managed in primary care. Within the Waikato DHB, primary care is provided by a number of different agencies—there are four Primary Health Organisations (PHOs), two main general practice management groups and 11 Maori providers.

The Waikato Local Diabetes Team (a multidisciplinary group set up by the DHB to advise on diabetes services) were concerned that patients may not be receiving sufficient diabetes education after diagnosis. They had received a proposal to purchase a community-based diabetes education programme, based on group education sessions, that would be available to all newly diagnosed patients. Before any decision on purchasing such a programme was reached, it was proposed that a survey should be carried out to ascertain how patients were currently receiving their education, what education they were receiving and what their views were of group education. We also wanted to compare the experiences and views of Maori with non-Maori to ensure any changes to the delivery of diabetes education would reflect the needs of Maori patients.

*Table 1. Demographic characteristics of respondents, N=333*

| | |
|---|---|
| **Ethnicity** | |
| **Maori** | 57 (17%) |
| **Non-Maori** | 276 (83%) |
| **NZ European** | 251 (75%) |
| **Pacific** | 10 (3%) |
| **Indian** | 8 (2.4%) |
| **Asian** | 4 (1.2%) |
| **Other** | 3 (0.9%) |
| **Gender** | |
| **Female** | 153 (45%) |
| **Male** | 180 (54%) |

## Methods

The study was a cross-sectional survey carried out in December 2008, of patients categorised as having type 2 diabetes and diagnosed in a 12-month period. Patients were identified from the Waikato Regional Diabetes Service register. The register is held on a Microsoft Office Access database and holds information on patients' age, gender, ethnicity, type of diabetes and year of diagnosis. We selected patients with a year of diagnosis of 2007, aged between 20 and 89 years of age and categorised as having type 2 diabetes.

A questionnaire was developed asking a series of questions including basic demographic data, a series of questions regarding the education received, who provided it and self-perceived knowledge. Demographic data was collected to help validate the data from the Waikato Regional Diabetes Service register. Input into the design of the questionnaire was obtained from a specialist diabetes nurse, a dietician, a Maori researcher, a general practitioner and consumer representatives. The questionnaire was then piloted by a diabetes nurse educator on a small sample of diabetes patients who would not be involved in the main study. This led to some minor modifications. The final questionnaire focussed on important aspects of diabetes care such as diet, blood glucose, blood pressure, cholesterol, foot care, eye care, exercise and smoking. The patients who responded to the survey were assigned to a group known as 'respondents'. Patients who had not responded after a period of six weeks were followed up by telephone and were assigned to a group known as 'late-responders'. Maori patients were followed up by two Maori researchers.

Ethnicity was categorised into New Zealand European, Maori, Pacific (i.e. having an ethnic origin from the Pacific Islands—principally the Cook Islands, Samoa, Tonga etc.), Asian (meaning from South East Asia, i.e. China, Japan, Korea etc.) or Indian (i.e. from India, Sri Lanka or Pakistan) or other. For the purpose of analysis we compared Maori with non-Maori. Ethical approval was granted by the Ministry of Health's Northern Y Ethics Committee (Reference NTY/08/84/EXP).

## Analysis

All data were entered into a Microsoft Office Excel spreadsheet. Analysis was undertaken using SPSS statistical package. Kruskal–Wallis test was used to test the difference in knowledge scores between Maori and non-Maori. Chi-square test was used to test the differences between Maori and non-Maori in method of diabetes diagnosis, diabetes education and support.

## Results

We identified 675 patients aged between 20 and 89 years, diagnosed in 2007 and categorised as having type 2 diabetes. Two hundred and sixty-three patients responded to the initial mail-out, eight of whom were excluded (six were deceased). We attempted to contact all the remaining patients by telephone. This resulted in a further 78 'late responders' who completed questionnaires after this follow-up. The remainder declined to participate or were not contactable by phone. We therefore estimated a 333/667 (50%) response rate. The mean age of respondents was 63 years compared with 59 for non-respondents. New Zealand Europeans were most likely to respond (58%) whilst there was a lower response rate for Maori (39%) and Asian/Indian (36%).

In those that responded there was a 91% agreement between the self-identified ethnicity reported on the questionnaire compared with the ethnicity recorded on the Waikato Regional Diabetes Service register and there was a 95% agreement with the year of diagnosis ±1 year. Fifteen percent of patients said they were current smokers, 12% of non-Maori and 27% of Maori. The responses to the questions were analysed comparing Maori and non-Maori (Table 2)

A small number of patients reported that they had not received any education about diabetes at the time of diagnosis. Information on other key topics was also reported as having not been provided by a minority of patients (Table 2). There was no significant difference between Maori and non-Maori in the reported levels of diabetes education, with the exception of education on smoking cessation (which is not surprising given that Maori smoking rates are higher). However, the patient perceived knowledge score was significantly lower for Maori in all aspects studied.

With regards to exercise, 37% of patients said they were doing more exercise than when they were diagnosed, 9% were doing less and 54% had not changed the amount of exercise they did. Several people noted that one of the reasons they were now doing less exercise was due to decreased mobility associated with old age, or due to comorbidities. Some people also noted that they have always been very active and therefore the amount of exercise they do has remained the same.

We can see from Figure 1 that the principal source of education for Waikato patients diagnosed with type 2 diabetes is their general practice. Some topics are more likely to be covered by the practice nurse (general education, diet, blood glucose monitoring) whilst other topics the

## WHAT GAP THIS FILLS

**What we already know:** There is evidence from many studies that education is effective for patients with type 2 diabetes. Waikato has the largest number of diabetes specialist nurses per population, but general practice is expected to be the principal source of education for newly diagnosed type 2 patients.

**What this study adds:** This study shows that a range of sources are used. We found most patients access education through primary care. There was no difference in the amount of diabetes education received when comparing Maori and non-Maori, but perceived levels of knowledge about diabetes were lower for Maori. The study highlights that different ways of providing education may be needed for Maori and Asian patients.

*Table 2. Diabetes diagnosis, diabetes education, support and self-perceived knowledge*

| | All patients | Maori | Non-Maori |
|---|---|---|---|
| **By whom were you diagnosed?** | | | |
| By your general practitioner | 300 (90%) | 51 (89%) | 249 (90%) |
| By your local hospital | 20 (6%) | 4 (7%) | 16 (6%) |
| By someone else | 13 (4%) | 2 (4%) | 11 (4%) |
| **Method of diagnosis*** | | | |
| Have symptoms and go to your doctor expecting you might have diabetes? | 42 (13%) | 13 (23%) | 29 (11%) |
| Go to your doctor/hospital with an illness but not think of diabetes as a diagnosis? | 69 (21%) | 17 (30%) | 52 (19%) |
| Have a routine blood test which showed diabetes? | 207 (63%) | 24 (43%) | 183 (67%) |
| Some other route to diagnosis | 12 (4%) | 2 (4%) | 10 (4%) |
| **Support group** | | | |
| Belong to Diabetes NZ (7 people belonged to other organisation as well) | 49 (15%) | 9 (15%) | 40 (15%) |
| Belonged to another group, but not DNZ | 6 (2%) | 3 (5%) | 3 (1%) |
| None | 268 (83%) | | |
| **Knowledge score out of 10 (mean ± SD)** | | | |
| Knowledge of diabetes in general* (n=312) | 6.9 ± 2.1 | 6.3 ± 2.5 | 7.1 ± 1.9 |
| Knowledge of diet and diabetes* (n=318) | 7.0 ± 2.1 | 6.4 ± 2.5 | 7.2 ± 2.0 |
| Knowledge of blood pressure* (n=321) | 6.4 ± 2.5 | 5.6 ± 2.7 | 6.5 ± 2.5 |
| Knowledge of cholesterol* (n=320) | 6.4 ± 2.6 | 5.7 ± 2.8 | 6.6 ± 2.6 |
| Knowledge of foot care* (n=321) | 6.6 ± 2.8 | 5.6 ± 3.0 | 6.8 ± 2.8 |
| Knowledge of eye checks* (n=316) | 6.8 ± 2.5 | 5.9 ± 2.7 | 7.0 ± 2.8 |
| **No information received about:** | | | |
| Diabetes management at the time of diagnosis | 24 (7%) | 3 (5%) | 21 (8%) |
| Diet/healthy eating | 16 (5%) | 4 (7%) | 12 (4%) |
| Exercise | 48 (15%) | 11 (20%) | 37 (14%) |
| Monitoring blood glucose | 49 (15%) | 8 (14%) | 41 (15%) |
| Importance of blood pressure check | 88 (27%) | 10 (18%) | 78 (29%) |
| Reducing blood cholesterol | 63 (19%) | 11 (19%) | 52 (19%) |
| Importance of foot check *(comment—asked as a knowledge question)* | 21 (7%) | 7 (15%) | 14 (5%) |
| Importance of regular eye check | 34 (10%) | 9 (16%) | 25 (9%) |
| Smoking cessation* | 48 (15%) | 11 (20%) | 37 (14%) |

*Significant difference between Maori and non-Maori, $p<0.05$

Note: Non-parametric Kruskal–Wallis test was used to test for difference in knowledge scores. Chi-square test was used for proportions.

general practitioner is more likely to cover (blood pressure, reducing cholesterol and exercise).

A minority of patients also receive some education from a diabetes nurse specialist, a dietician, pharmacist and podiatrist (Table 3). An interesting point is that several people mentioned receiving detailed and helpful information from Accu-Chek (Roche), the manufacturer of their glucose monitors.

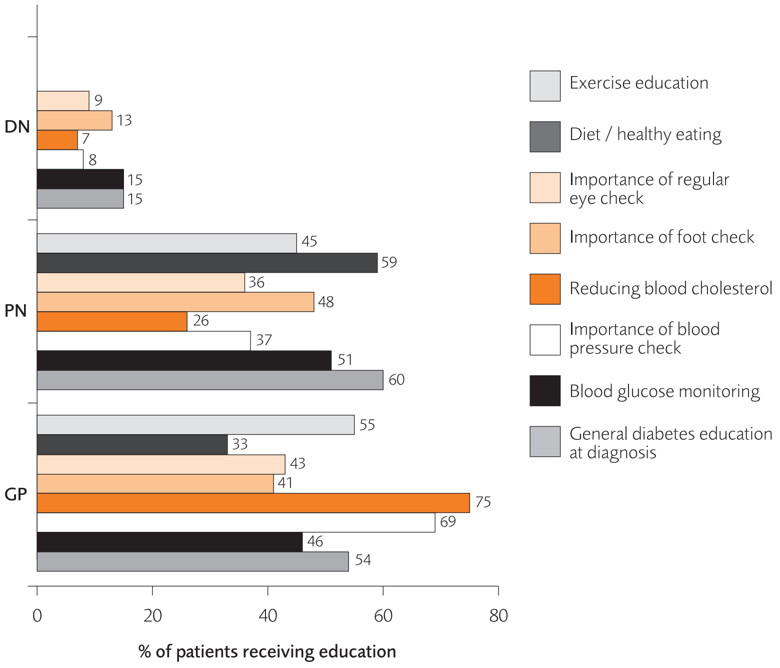
Other data from the survey are reported in Table 4 and include information about the use of the Internet for diabetes education and patients' preferences about the inclusion of family or the use of group sessions for education.

Only eight people said they got most of their information about diabetes from the Internet.

## Discussion

We identified 675 new cases of type 2 diabetes in the Waikato district in 2007. This is likely to be an underestimate of the incidence as we know from other studies in our region that some 10–15% of patients are not referred to the Regional Diabetes Service and are therefore not on the register.[14] We have shown that diabetes is most commonly diagnosed in asymptomatic patients who attend their general practitioner. This is especially true for non-Maori where 67% appear to have been identified through routine screening. On the other hand, only a minority of Maori (43%) surveyed, reported being identified through screening. Peel et al. have shown that those diagnosed through screening are likely to have a more emotional response to their diagnosis[15] which may influence the patient's ability to absorb information at the time of diagnosis.

*Figure 1. Three most common sources of diabetes education*



*(GP—general practitioner; PN—practice nurse; DN—diabetes nurse)*

As expected, diabetes education was mainly delivered in primary care by general practitioners, practice nurses and allied health professionals. Only a few patients said they had received diabetes education from diabetes nurse specialists or hospital consultants. Whilst 93% of patients reported receiving education at the time of diagnosis, it is a concern that 7% say they were not given information. As well as assessing whether patients had received education on key topics, we also tried to estimate the effectiveness of patient education. Whilst acknowledging that patient perceptions are subjective, we believed it was useful to get some feedback about their level of knowledge. This exercise showed that, generally, Maori considered their knowledge at a lower level than non-Maori. More objective measures of patient knowledge could have been used. This was considered but would have made the questionnaire extremely long and may have worsened

*Table 3. Sources of diabetes education, n (%)*

| | GP | PN | DN | DT | PH | PO | Eye | Other | HD |
|---|---|---|---|---|---|---|---|---|---|
| **General diabetes education at diagnosis** | 179 (54%) | 199 (60%) | 51 (15%) | 7 (2%) | – | – | – | – | 11 (3%) |
| **Blood glucose monitoring** | 117 (46%) | 130 (51%) | 37 (15%) | 8 (3%) | 9 (4%) | – | – | 22 (9%) | – |
| **Importance of blood pressure check** | 146 (69%) | 79 (37%) | 17 (8%) | 4 (2%) | 3 (1%) | – | – | 11 (5%) | – |
| **Reducing blood cholesterol** | 178 (75%) | 61 (26%) | 17 (7%) | 13 (5%) | 1 (0.4%) | – | – | 17 (7%) | – |
| **Importance of foot check*** | 101 (41%) | 117 (48%) | 32 (13%) | 3 (1%) | – | 23 (9%) | 1 (.4%) | 29 (12%) | – |
| **Importance of regular eye check** | 115 (43%) | 95 (36%) | 25 (9%) | – | – | – | 69 (26%) | 23 (9%) | – |
| **Diet/healthy eating** | 111 (33%) | 198 (59%) | – | 93 (28%) | – | – | – | – | – |
| **Exercise education** | 183 (55%) | 150 (45%) | – | – | – | – | – | – | – |

GP—general practitioner; PN—practice nurse; DN—diabetes nurse; DT—dietician; PH—pharmacist; PO—podiatrist; Eye—eye clinic/ophthalmology services; HD—hospital doctor

* comment—asked as a knowledge question

*Table 4. Diabetes education practice and preferences, N (%)*

| | All patients | Maori (n=57) | Non-Maori (276) |
|---|---|---|---|
| **Access to information** | | | |
| Having Internet access | 203 (61%) | 28 (49%) | 175 (63%) |
| ...at home | 172 (52%) | 22 (39%) | 150 (54%) |
| ...elsewhere | 31 (9%) | 6 (11%) | 25 (9%) |
| Have used Internet to look for diabetes information | 94 (28%) | 9 (15%) | 85 (31%) |
| **Diabetes education—practice and preferences** | | | |
| Have a family member included in diabetes education | 112 (34%) | 25 (43.9%) | 87 (31.5%) |
| Would like to have family included in diabetes education | 60 (31%) | 14 (41%) | 46 (29%) |
| Have attended group education session | 22 (7%) | 7 (12%) | 15 (5%) |
| Would not want a group session | 145 (57%) | 18 (44%) | 127 (59%) |
| Would prefer group sessions | 36 (14%) | 10 (24%) | 26 (12%) |

the response rate. An alternative would be to link patient responses to measures such as blood pressure, HbA1c or cholesterol levels. Reported understanding about blood pressure and lipids was poorer than knowledge in other areas. It may be that some patients did not receive information about blood pressure or lipids because they did not have evidence of hypertension or hypercholesterolaemia. However, management of blood pressure[16] and lipids[17] has been shown to be of major importance in reducing cardiovascular risk in patients with type 2 diabetes and increased emphasis on these topics by primary care staff may be needed. Fifteen percent of patients said they had not been advised about exercise and only a third of patients had increased their exercise since diagnosis. Regular exercise has many benefits for people with diabetes and increased emphasis on this by educators would seem to be something else to be targeted. It does seem that there is room to improve patients' knowledge of diabetes and its complications. In particular, although Maori report receiving education at similar rates to non-Maori, their self-reported measure of efficacy is lower, suggesting that the problem is not access to education but its effectiveness.

This study shows that the Internet is widely available to patients, but only 28% of patients (and 15% of Maori) have used the Internet to find information about diabetes. This suggests that many patients prefer to get their information from other sources. Some researchers have suggested older and less-educated diabetes patients are less likely to use the Internet.[18] Another study found more than 50 Internet sites providing patient-centred information for people with diabetes.[19] Whilst it is an easily available portal to information, perhaps we should consider giving patients advice about how to judge the relevance and reliability of information on the Internet. One excellent source of information is Diabetes New Zealand and it is disappointing that only 15% belong to this organisation and directly receive the educational material that is available to members. We are aware that Diabetes New Zealand pamphlets are often provided through general practice surgeries and so its influence is likely to be greater than has been described by patients in this survey. Another source of information we had not considered prior to this research was the role of companies such as Roche. They were identified by several people as a source of information regarding control of blood sugar levels and their involvement may be an option that could be explored further.

There were a number of people who made comments such as 'I don't want my type 2 to turn into type 1' and 'how do I get rid of my diabetes'. These misconceptions indicate that, despite generally a comprehensive uptake of education, patients' understanding of diabetes and how the disease progresses is not always accurate. Part of the patient information provided should include an understanding of insulin, when insulin is recommended for people for type 2 diabetes and the role it plays in management of blood glucose.

Qualitative responses from patients on the questionnaire suggested more information was wanted about food and diet. One way of providing this education would be to offer group education sessions particularly as we have shown only a minority of patients access a dietician. Group education has been shown to be effective in reducing HbA1c, weight and blood pressure and increasing exercise rates.[20,21,22] In our survey there was a small group of 36 people who indicated that they would prefer group sessions, with an additional 58 people saying they would be happy to attend. However, the majority of respondents (57%) said they would not want to attend group sessions. Perhaps by offering group sessions as an option to newly diagnosed patients we can reach some of the people who are currently missing out; however group sessions would need to be implemented with several factors in mind, such as location, cost and timing. Many of the people surveyed still work and may be unable to attend day sessions. Some people also mentioned cost as a factor, saying they would only attend if it was free, with others saying they would be happy to pay a small fee. Almost everyone who expressed interest in group sessions said location was the most important factor, with people not willing to travel long distances. Anyone considering the introduction of group education sessions should take into account patient preferences.

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Including spouse/family/whanau was considered very important by some people, and even those who said they did not want their family included often said that they had shared their information. Giving people the option of bringing their spouse/family/whanau with them to medical appointments can help educate the entire family. We believe this is important in that it may not only help the person with diabetes obtain better control, but also influence other family members to make some lifestyle changes and reduce their own risk of developing diabetes.

Strengths of this study were that it recorded patients' experiences of the health care system and information was collected from a population-based sample of patients who were diagnosed within the same year. A weakness is that there was only a 50% response rate and for ethnic minority groups this was even lower. We tried to ensure a more representative sample of Maori by using the services of the Maori Health Unit to telephone Maori non-responders and, to a certain extent, this strategy was successful, although we only achieved a 39% response rate. The low response rate may be because Maori can be more mobile and so addresses and telephone numbers are less reliable when trying to contact patients. The initial response rate from the Asian, Indian and Pacific populations was also disappointing. When following up on the non-responders by telephone, one of the major obstacles encountered was the language barrier. This was mainly an issue with the patients who were Asian, although it was also encountered with some of the Indian and Pacific patients. Several of the Asian patients contacted spoke very little or no English and did not understand the purpose of the call. Of the people who did understand, all but one were reluctant to return the survey. Two of the people who declined cited language barriers as the reason for not wanting to return the survey. This language barrier could also result in a decreased understanding of the education provided about diabetes and could in turn lead to decreased control of their diabetes. A study of Asian/Indian health in New Zealand found that they have a higher prevalence of diabetes and are less likely to access health services. The study suggests that developing educational materials that are available in languages other than English may be required if this growing population of Asian/Indian patients with diabetes are to receive appropriate access to information about their diabetes.[23]

## Summary

In summary, whilst overall there seemed to be wide availability and coverage of diabetes education for newly diagnosed patients, a small number of patients are missing out. The information from this study has been reported to the general practice management group and to the Waikato Regional Diabetes Service. Suggestions include a routine question at the annual diabetes review to reveal those patients who had additional needs, and more emphasis on education about monitoring of blood pressure and lipids. There also seems to be a demand from patients for additional information about diet, exercise and lifestyle advice—this demand could be met by assessing the current information available at general practice surgeries in the form of booklets/pamphlets, identifying any gaps and ensuring additional materials are available. Encouraging people who have access to the Internet to access the Diabetes New Zealand website as a source of information might also be an option. Finally we believe that the disparities in perceived knowledge by Maori patients and the poor uptake of this survey by Asian and Indian patients would suggest that further research on the educational needs of Maori and ethnic minorities is needed.

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**COMPETING INTERESTS**
None declared.

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