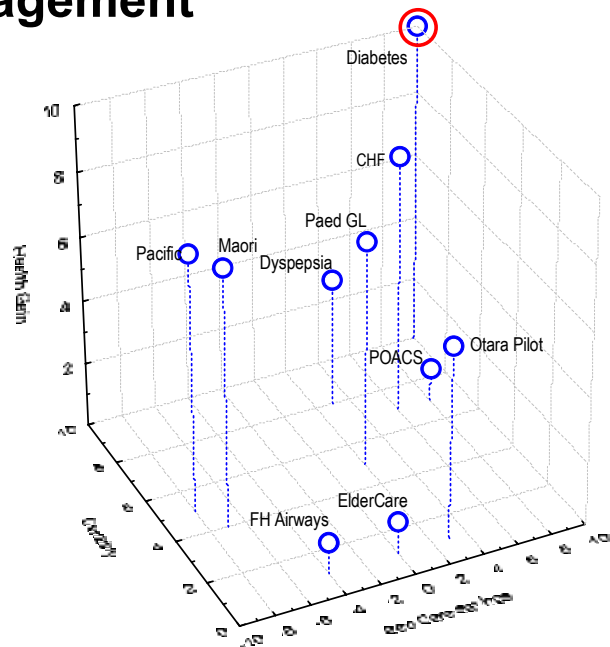


## Counties Manukau District Health Board

### Integrated Care Evaluation 2000-2001

#### Diabetes disease management

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Auckland UniServices  
December 2001



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## Executive Summary

The diabetes disease management project aimed to establish an integrated diabetes disease management programme, using best care guidelines, patient held care plans, free three monthly reviews, and comprehensive data collection, all supported by a diabetes care coordinator.

The project was notable as a test site for the use of an “Integrated Care server” to provide a data warehouse facility with the ability to provide clinicians with feedback on clinical management, and with the potential to facilitate information sharing between clinical care providers.

A previous diabetes integrated care pilot has revealed significant role conflict between doctors and diabetes nurses. This was not observed in this project, with providers enjoying mutually supportive relationships. Levels of patient satisfaction were high across all ethnic groups.

Some early data was available from the IC server, downloaded on 17/10/2001. It contained all the enrolment data for patients from the Mangere Family Doctors (122) and Health Pacifica (66) sites, and follow-up data for 67 patients – 55 from MFD and 12 from HP.

The data showed that a significant drop in the percentage of people with elevated HbA1c was achieved, yet there was no change in lipids or BP, and average cholesterol remained (surprisingly) low. It was estimated that 20% of recalled patients were non-compliant with medication. More data are required to determine if the observed drops in HbA1c are sustainable.

One of the evaluators (BG) visited Mangere Family Doctors on 29 November to discuss how the project had developed since the initial round of qualitative research.

In the intervening period the project had implemented “alerts”, the provision of treatment guidelines, supplied to providers by email. This had been very favourably received by providers, and identified as a potential major contributor to improved patient care. A practical example of how this facility could enhance patient care was described, in which the IC server had identified that a patient was eligible for a statin but not yet receiving one.

Another example was the observation on aggregate data that patient BP measurements actually appeared to be increasing. This led to a practice discussion, with specialist support, of the importance of BP control and strategies for achieving it in diabetic patients (probably more important than glucose control in preventing renal disease).

Diabetes integrated care requires a culture of information sharing and teamwork. This is not universally accepted in the private business environment of general practice. One of the challenges of implementing disease management is to provide a level of assurance to general practice that the viability of their businesses will not be threatened by participating in programmes.

The success or otherwise of many integrated care pilot projects also seems to depend on the drive and commitment of key individuals (“champions”). A model successful in one setting might not work in another, or indeed be a generic solution. Considerable further resources may be required to successfully implement the same intervention across the wide variety of practices in the CM DHB area.

On the data available to date, however, it is clear that the diabetes disease management project shows great promise. The results that have been obtained to date illustrate real and significant reductions in HBA1c levels. If these are sustained CM DHB could expect, according to international evidence, an average 30% reduction in total health care costs for these patients.

## **Introduction**

The diabetes disease management project aimed to establish an integrated diabetes disease management programme, using best care guidelines, patient held care plans, three-monthly reviews, and comprehensive data collection, all supported by a diabetes care coordinator. The consultations (4 per year) were provided free of charge, building on the Ministry of Health “get checked” initiative.

The project was also notable as a test site for the use of a “Integrated Care server” to provide a data warehouse facility with the ability to provide clinicians with feedback on clinical management, and with the potential to facilitate information sharing between clinical care providers.

Over the evaluation period the intervention was implemented in Mangere Family Doctors and, in June 2001, by Dr Siro Fuatai at Health Pacifica. The intervention at Health Pacifica did not involve the use of explicit patient held care plans.

## **Description of evaluation**

The evaluation of the diabetes disease management project had four components:

- A review of an evaluation of a similar service run by Mangere Health Resources Trust as one of the national integrated care pilots. This is available in full in the report of post-implementation reviews. This review was used to assist in the design of this evaluation.
- An analysis of data provided by the project, from practice-based systems and from the IC server.
- A programme of qualitative research conducted with providers and clients, with separate focus groups conducted for Maori and Pacific clients (in Samoan and Tongan).
- An analysis of secondary care data for enrolled clients

This project also provided an opportunity to investigate provider experience with the IT systems associated with the project – these issues are examined in this report as they arise, but they are also explored in the separate Integrated Care IT evaluation.

## **MHRT diabetes integrated care project review**

We reviewed the evaluation of the earlier Mangere Health Resources Trust diabetes integrated care pilot. The report provides good insights into provider relationships, including the participating providers' perceptions and attitudes towards the Diabetes Care Coordinator (DCC). The main finding was the significant level of mistrust between the roles of the GP and DCC. It appears that GP's fear losing control of the care of their patients with diabetes, although the precise nature of these fears was not explored fully.

This atmosphere reduced communication between the DCC and GPs to the detriment of providing a coordinating service. GP's perceived the DCC role as transient, which was reasonable enough given that the project was for a limited time. They were also unconvinced that the DCC had the capability to provide care in some circumstances, and thus questioned the overall value of the role.

The DCCs felt that their role was made difficult by GP attitudes and at times, felt completely unsupported by GPs. However, practice nurses reported that they had been successful in building a relationship with the DCC, and that this had had a positive impact on patient care.

The report further identified a need to increase Maori involvement and consultation with the project. The team was criticised for the lack of Maori input into the provider's service and for the lack of consultation with Maori consumers of the service.

An understanding of the consumer's experience of the service is not covered by the report. However, 47 people who experienced the service completed a survey questionnaire. The survey findings are very positive in that consumers valued the DCC role and perceived that their knowledge of diabetes had improved. There is a need to further understand the basis of the patient/DCC relationship and the impact of the DCC role on GP/patient relationships.

The report did not explore the extent to which specific interpersonal factors were responsible for the lack of support for the DCC role.

As a result of this review the CM DHB integrated care evaluation team suggested that an action research approach would be a useful evaluation methodology. Such an approach is often useful in creating shared visions and encouraging teamwork through finding joint solutions to the problems that inevitably arise in a pilot project. This was discussed with the project team but it was decided not to proceed with this approach.

## **Analysis of data to date**

The data that the following analyses are based upon was downloaded from the “Integrated Care server” on 17/10/2001. It contained all the enrolment data for patients from the Mangere Family Doctors (122) and Health Pacifica (66) sites, and follow-up data for 67 patients – 55 from MFD and 12 from HP.

### ***Limitations of data analysis***

There are a number of important limitations of the data analysis presented here.

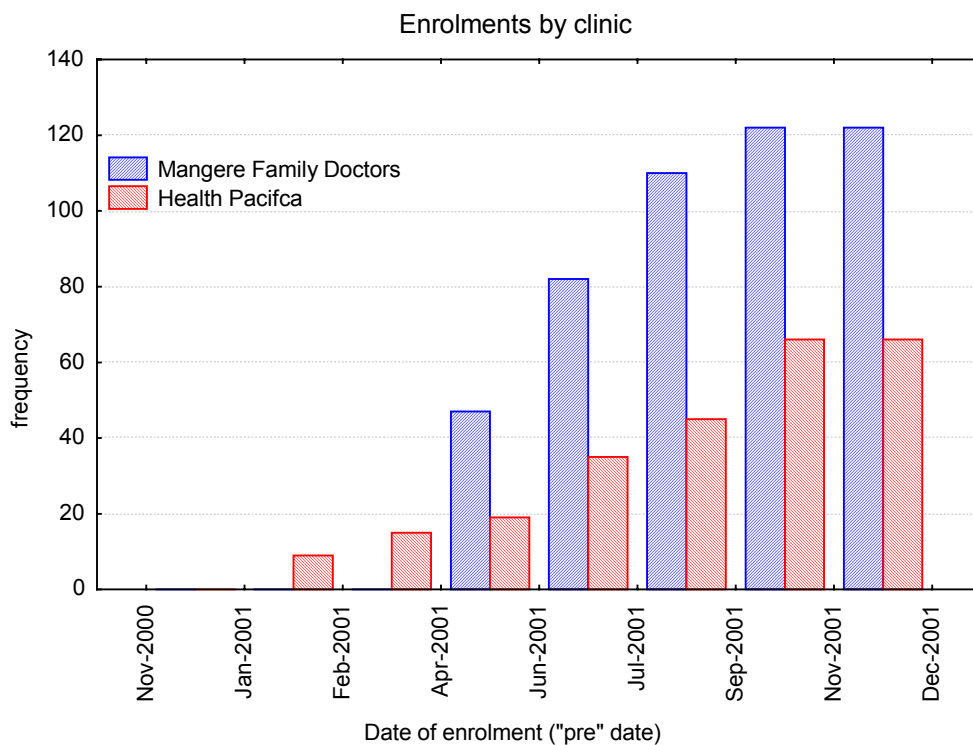
- The analysis is limited by the small numbers of patients enrolled at the time of evaluation. We have not split the analysis by provider, although that will be interesting once more data is available.
- The evaluation is limited by the short period of time that the intervention had been running for.
- A related issue is that the follow-up data that is available is a three-month follow-up (however see later for a closer look at this issue). Much longer term trends need to be analysed to determine the sustainability of any observed changes.

### ***Patient enrolment and follow-up***

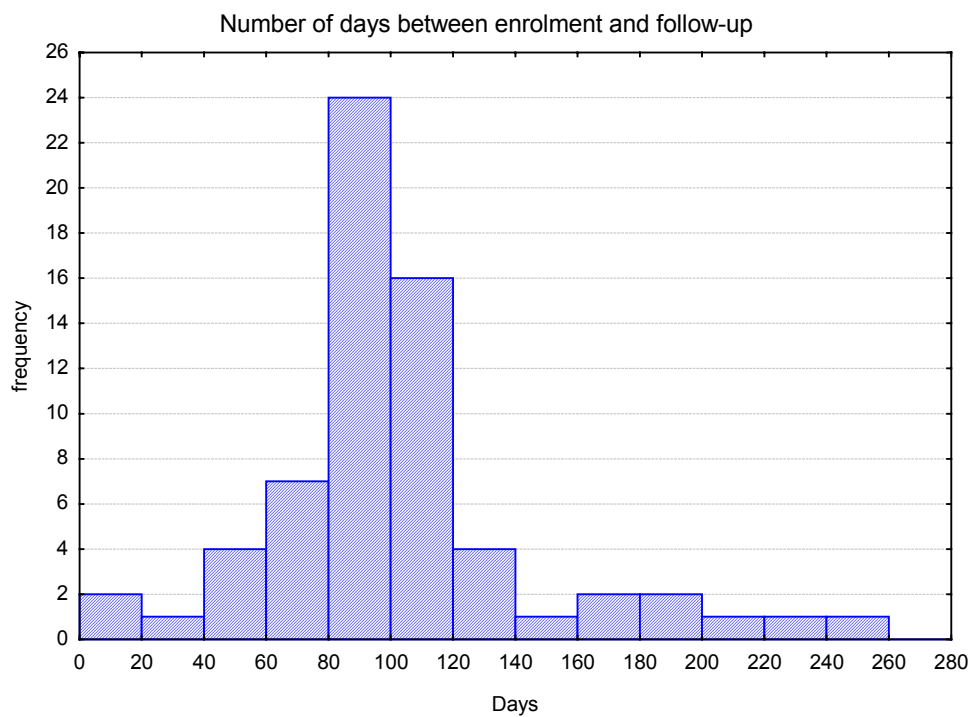
As stated above, there were 188 patients enrolled in total, 122 from MFD and 66 from HP. Follow-up data was available from 67 patients. This data was collected at a wide range of time periods after the enrolment visit. This will be the normal experience in real life general practice, as opposed to a trial environment. We wanted to see how many patients had attended a scheduled followed up visit. There is a field in the IC server database that is called “Recalled”, however whenever it is “true” there is always a “post” visit. This would imply 100% response to recall, which is possible but unlikely. The field probably meant “had attended a recall”. We looked instead at the date of the first visit, and looked to see if a patient should have had a three month follow-up visit, allowing 2 weeks grace. Typically follow-up will be within three months to renew prescriptions – which only provide three months medication.

The first graph shows cumulative enrolment for each project:





The following graph shows the difference between the date of enrolment and first follow-up visit, in days (expected 3 months = 90 days)



The table below shows the number of enrolled patients that attended a follow-up visit, according to data in the IC server, within 14 weeks (i.e. allowing 2 weeks “grace”).

Description	number
Total number enrolled patients	188
Total number of follow-up visits	67
Number of patients enrolled before 3 July 2001	90
Number of these patients that have a follow-up visit	36
Number that have a follow-up visit within 14 weeks of first visit	32
% with timely “3/12” follow-up	36%

Upon discussing this data with providers it was explained that much of the first visit data from HP had been entered retrospectively, but that in many cases follow-up visits that would have occurred within three months were not entered. Sometimes this was because the IC server did not accept attempted uploads of data, and sometimes it was because data in notes had not been retrospectively entered into screening templates.

### ***Clinical data***

The evaluation plan asked that “pre” and “post” recordings would be reported for a number of clinical measures. These are presented below, based on data supplied from the IC server. The follow-up data (“pre”), as indicated earlier, was collected between 0 (!) and 240 days after the enrolment (“post”).

Indicator	Enrolment	Follow-up
Smoking “YES”	21% (n=188)	6% (data missing for 121/188 cases). One person changed from “YES” to “PAST”, no other “quitters”
Total Cholesterol	5.6 (3.2-9.6, n=188) 5.6 (3.2-8.2, n=67)	5.5 (3.2-8.8, n=67)
HDL Cholesterol	1.2 (0.6-4.1, n=183) 1.3 (0.7-4.1, n=67)	1.2 (0.7-4.1, n=67)
* Statin (NB value of “30” ignored)	9% (n=188) 13% (n=67, i.e. had f/u)	15% (n=67)
* ACE inhibitor	49% (n=188) 55% (n=67, i.e. had f/u)	52% (n=67)
BP average systolic/diastolic	135/80 (n=188) 134/79 (n=67)	137/80 (n=67)

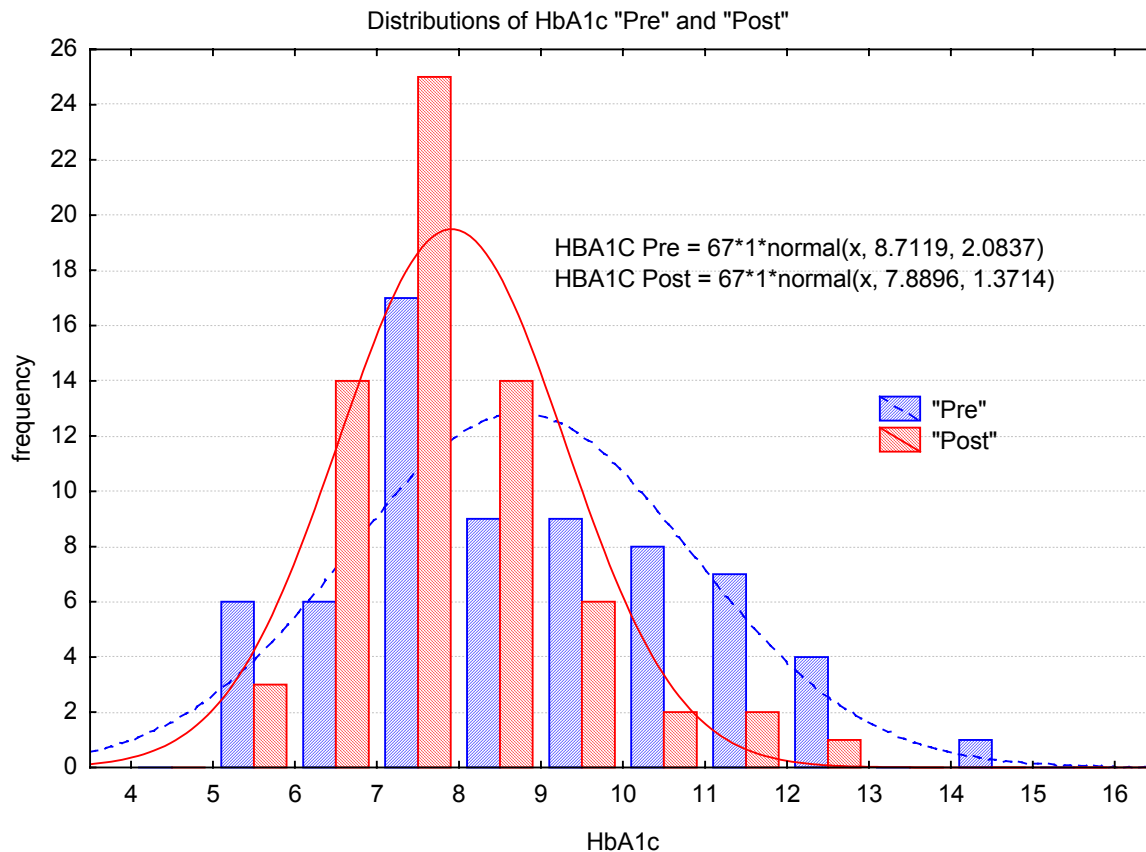
\* For these measures, and many others (e.g. feet checked, nephropathy) the data downloaded from the IC server did not distinguish between missing and negative responses (data reported only for cases with follow-up visit). This should be rectified immediately as it is easy to misinterpret – e.g. CM DHB progress reports misreport statin use as declining.

## HbA1c

The following table illustrates the changes in proportions of patients with HbA1c above 9 at “pre” and “post” measurement.

Measure	“pre”	“post”
% patients with HbA1c > 9	47% (n=188) 43% (n=67)	16% (n=67)
Average HbA1c	8.9 (5.2-17.3, n=188) 8.7 (5.4-14.9, n=67)	7.8 (5.7-12.5, n=67)

The HbA1c data is illustrated below as a comparison of distributions “pre” and “post” for those 67 patients that were in both rounds:



The mean has dropped 0.9 %, as we knew from the descriptive statistics in the above table, but there is also a change in the shape of the two distributions, as the high end outliers have come towards the mean. The non-normality of the differences in HbA1c scores (a Shapiro-Wilk with  $p < .001$ ) was noted, precluding the use of dependent t-tests. A non-parametric test (Wilcoxin matched pairs test) showed the differences in HbA1c to be highly significant ( $p < .00001$ )

## ***Discussion***

At this early stage of the project we would not have expected to see any major changes in aggregate clinical outcomes. There are no changes in BP or lipids. We might have expected a change in statin and ACE-inhibitor prescribing (process measure). A total cholesterol of 6 or greater may make a person with diabetes eligible for a subsidised statin, to protect renal function.

The average cholesterol of 5.6 gives a clue that this group of patients is possibly already well controlled. What is surprising is that many of these patients had an HbA1c that was greater than 9. This would be an uncommon presentation. In subsequent discussion with providers it was suggested that, at least for some of these patients, this might have been an artifact of retrospective data entry of HbA1c but not of cholesterol results. Thus the recorded “pre” cholesterol result would reflect effects of the intervention, but the “pre” HbA1c would not.

Forty three percent had an HbA1c above 9 on initial visit and this had dropped to 16% at the first review visit. The drop in the average HbA1c of 0.9% correlates with a nearly 30% reduction in health care costs.

This is a very impressive drop over just three months. The sustainability of this drop needs to be monitored, as it may be the initial effect of exposure to new processes that has caused the improvement, particularly if increased compliance with medication is responsible. The overall impression of these results is that more time is required to enroll more patients and to accumulate individual patient data over a longer period of time.

## **Provider and consumer qualitative research**

### ***Background Review***

The report of the Mangere Health Resources Trust National demonstration diabetes pilot, the precursor to the current project, provides good insights into provider relationships that developed during the course of the project. The findings suggest that there were some problems between the roles of the GP and Diabetes Care Coordinator (DCC). It appeared that GP's feared losing control of diabetes patients (the reasons for this are not well elaborated) and viewed the developments as a further "proliferation" of diabetes care. Overall GP's negatively perceived the DCC capacity to manage diabetes and questioned the overall value of the role. Practice nurses reported that they had been successful in building a relationship with the DCC. From a nursing position, this was seen as successful cooperation.

Qualitative understandings of the consumer's experience of the service are not covered by the report. Reviewing the initial evaluation highlighted the need to further understand the basis of the patient/DCC relationship and the impact of the DCC role on GP/patient relationships. These were areas of particular focus in the design of this evaluation.

At the time of this qualitative evaluation, the project team calculated that approximately 80 people had been enrolled with the project. The reasons for referring to the diabetes specialist nurse were cited as:

- HbA1c above 9 in a existing patient
- Newly diagnosed patient

Only patients from the Mangere Family Doctor arm of the intervention participated in this qualitative research, as the Health Pacifica component was not fully functional at time of evaluation.

### ***Qualitative evaluation design***

The qualitative evaluation took a general inductive approach utilising coding frames adapted from grounded theory methodology.

Professionals involved in delivering the integrated care service were invited to take part in 1.5 hour focus groups or an in-depth interview, depending upon their preference. One week prior to the discussion taking place, each participant was emailed a request to bring a case scenario to the group. They were asked to consider the context of the case, results of the enrolment, areas that had worked well and those requiring further improvement. The discussion covered areas identified in the attached provider discussion guide.

On the advice of the practice team, interviews were selected as the method for the consumer research to maximize the privacy and confidentiality of participants. Individuals who had experienced the diabetes project through their attendance of the Mangere health centre were invited to take part in an in-depth interview. A researcher, matched in ethnic background, conducted the 1 hr interview at a time and place suitable to the participant.

## Sample

The research aimed to represent the following professional groups:

- General practitioners
- Practice nurses
- Diabetes specialist nurse (primary and secondary care)
- Maori, Pacific Island and 'Other' consumers of the service.

Consumer participants, selected as representative by age and sex from the complete list of patients enrolled in the project (provided to the evaluators by the Mangere Family doctors) were approached personally by an experienced recruiter and invited to take part. Consumers were offered a \$30 payment to cover any travel/child care expenses incurred by their participation.

The table below describes participants.

Organisation	Participants
Mangere Family Doctors	General practitioners Practice nurses
Diabetes specialists	Primary care nurse Secondary care diabetes specialist nurse
Consumers	<ul style="list-style-type: none"> <li>• 6 non Maori/PI consumers: <ul style="list-style-type: none"> <li>➤ 3 newly diagnosed,</li> <li>➤ 3 experiencing poor control of the condition</li> </ul> </li> <li>• 6 Maori consumers</li> <li>• 6 Pacific Island consumers</li> </ul>

## **Data collection**

Two provider in-depth interview and a focus group, lasting 2 hours, were completed at the provider location in July 2001. Eighteen consumers took part in interviews, lasting 1 hour in their homes, throughout July and August 2001.

## **Data analysis**

Data was coded using a system of substantiate labels for emerging themes. These were developed into categories of information using an axial coding frame to describe the properties of the theme, context, constraining or facilitating factors, resulting action/interactions and consequences or outcomes. The findings are presented to convey understandings sought by the discussion guide.

Provider findings were sent to professional participants for validation purposes. At that stage, comments/additions, further clarifications were invited. Any information tendered through the validation process is signaled as such.

## **Issues with the data collection**

The evaluation did not focus on specific behaviour changes for either consumers or professionals involved in the service. At the time that the work was completed, the service was in an evolutionary state of establishment. It is recommended that a later stage, qualitative/quantitative attribution research techniques should be employed to create more understanding about behaviour changes that result from the integrated care approach.

## **Main findings**

The main findings are split into two sections, namely providers and consumers. Each section is presented to describe involvement with the project, identify strengths, threats and limitations of the approach, explore integration and present recommendations.

### **Provider involvement**

Implementation of the diabetes-integrated care, at the Mangere health centre, involves a multi-disciplinary primary and secondary care team. General practitioners noted that they are responsible for the initial data capture for diabetes patients who are enrolled ‘opportunistically’ when they present to the surgery. The practice nurses are involved with the education, monitoring and nursing cares for the patients. Primary and secondary care diabetes nurses receives referrals from the GP’s to review patients who are either demonstrating poor control of their condition [HBA1C above 9] or have been newly diagnosed.

*“My patients have benefited greatly from the project. They have the support of a team, nurse specialists who know a lot more about diabetes care than I do.”*

“Rookie” GP

*“I have been involved in diabetes for a long time with reasonable systems. This project has been an exercise in action research and it is working well, from the feedback we have had from the patients, they feel supported ...its evolved as it has rolled out.”*

Experienced GP

The two comments above highlight the most commonly cited value “support” of the approach from two important positions, that of a newly qualified team member and an established GP.

### **Provider position: Diabetes integrated care strengths, threats and limits**

The project was positioned as visionary, an opportunity to build a prototype transferable to other chronic disease areas. It was thought to be necessary for optimal efficiency in the use diabetic resources. Participants advocated that time were being saved, for both professionals and patients, through timely and appropriate access to a team. Appropriate referrals to diabetes specialist nurse/Dr. ’s were deemed to result in savings for GP and PN time whilst offering patients more time with an appropriate professional.



*“Patients need the time, we often do not have. It is time saving for all – they get access to the people they need to spend time with.”*

The diabetes nurse was seen as strength and critical to the integrated care approach, namely as a/an:

- Educator for patients and professionals.
- Catalysts for information flow/actions important for good diabetes management.
- Support/advisor when specialist knowledge is required.
- Creating a focus for diabetes care.
- Guide (Where to go for what, when and how to get there).

Timely and easy access to secondary care diabetes specialists, nurses and doctors was perceived as a success of the approach. GP's argued about the level of specialisation involved in diabetes care. They agreed that all GP's/PN's need baseline diabetes knowledge for GP but that there are a percentage of diabetic patients, who at some stage during their management, will require access to more specialist care.

*“Is the aim to make all GP's and PN's specialists. It is like anything, they will select their own specialty.”*

*“We all need a baseline knowledge ...Look at the numbers of people you see a day with diabetes. There is a top 5% who need to access specialists.”*

Team sharing, skill transfer and education intra and inter professionals and between patients and professionals had been afforded and was advocated as a success within the approach.

*“It is educating our practice staff and patients- nurses, GP's – It is a great opportunity. Through virtual clinics, accesses to specialists, families are involved.*

*“Problems have moved from in here [pointing to the GP consulting room] to solutions out there [meaning the wider community].”*

Free care was viewed as the initial incentive for patients to access the service. This was acknowledged as the important first step in removing barriers to diabetes care. Practitioners reported that consumers, having taken the first step into the project, reported values beyond the ‘something for free’ and had indicated that they were motivated towards the approach.

*“The free gets them in and that is what we need...They are seeing the value, they tell us about it.”*

Providers, below, positioned four states, as potential threats/barriers to diabetes integrated care. These are discussed in the ‘Integration’ and ‘Recommendation’ sections.

- Complex information technology (further detail in GP interconnectivity report)
- Lack of time and effort towards change management.
- Requirement for a team 'sharing' culture.
- Lack of understanding between primary and secondary care.

## Integration

Integration was perceived as a process involving human and information technology systems. The former was positioned as the focus 'driver' and the latter as a tool of integration.

*"The real difference will be made by people. It is about the patients and those involved in the care. That's human not IT, IT is the support tool, nothing more."*

Case scenarios presented to explain the integration, illustrated successful use of human resources. The diabetes care 'human' systems had evolved to fully support the integration. This had necessitated the development of primary and secondary care relationships. It was explained that these relationships had experienced some difficulties where primary care professionals perceived 'takeover' behaviour by secondary care. Primary care participants explained that they are the experts of primary care.

*"Who does what and how it will work in our practice is our business."*

*"I still have a strong sense that they [referring to secondary care] are saying that this is what we will get those people in primary care to do – It is out work environment not theirs."*

Information technology was described as "developing" and cited as a source of frustration for many of the participants. Some GP's rejected the IT system testing and advocated that the system should be 'tried and tested' before being implemented to support a live project. They positioned the current [July 2001] IT system as a hindrance to effective management. Others, more closely involved with developing the systems, were appreciative of the opportunity to pilot the disease management templates.

*"I want the least obstacles between me and an action plan for the patient and an end point that is beneficial to them. The IT is a nightmare – the time that you spend with the glitches – that's time you should be spending with your patients."*

The glitches were explained as a series of issues that had arisen throughout the IT implementation. An example being, the practice patient management system, Med Tech 32, has only 32 fields available in templates, the disease management template required 64 fields. Further developments revealed that whilst there are 32 fields in MedTech, there appears to be a difficulty recording the data from the final field.

*“There have been glitches, as you would expect with a developing system. From today, the prompts will be there.”*

The quote above refers to IT system prompts (or “alerts”), these were explained as ‘evidence based practice’ prompts. It must be remembered that, at the time of interview, professionals had not experienced using the system under these conditions. It was anticipated that the prompts would add value and increase motivation towards the IT system.

From a diabetes position, IT templates (at July 2001 stage) were reported to be cumbersome due to an illogical questioning flow. It was stipulated that the templates had evolved into three due to practice, project and Ministry of Health diabetes data requirements. All participants agreed that the templates should be reviewed.

*“There are areas of overlay where you ask the question in one field and enter the results in another. It needs reviewing but that is happening”*

## **Consumer findings**

### **Diabetes integrated care consumers backgrounds**

Participants described established relationships with the surgery and commonly, a specific GP. They had been invited to enroll onto the project as either a newly diagnosed diabetic (3) or having recently experienced problems controlling blood sugars (3). Participants, established diabetic individuals and newly diagnosed persons, described processes of adjustment to accommodate diabetes into their lives. Exploration of individual experiences highlighted significant lifestyle issues underlying their interpretation and management of diabetes. Newly diagnosed individuals conceptualized diabetes as an assault on lifestyle choices and described a process of negotiation as they adapted to the condition. These individuals felt confronted between social lifestyle identity and the diabetes diagnosis.

*"It was a complete shock, one which is not easy to get to grips with. It changes your whole life, what you can and can't do...at first you can't get to grips with it or I couldn't"*

*"I was angry at first, really angry but that passes and you begin to change things slowly. It meant changes for the whole family my son resents it. I tried different foods, being analytical, I wanted to see the results so try it, test it..."*

### **Expectations of the diabetes integrated care approach**

The project was understood as a 'free service' for diabetic patients, offering education and visits with a diabetic nurse specialist under the supervision of the GP. None of the participants positioned the project as the collation of information. They anticipated that GP's and nurses would closely monitor their blood glucose control. Participants expected support from nursing and GP professionals to manage the condition, timely and consistent advice and guidance as problems/issues arise.

*"It is free that is a bonus but we expect their support. I have to live, manage it but they have to support me to do that...as I said things do change with it"*

### **Consumer position: Strengths of the diabetes integrated care approach**

Participant's individual accounts of their diabetes demonstrated that the condition is viewed as a constant unpredictable presence that can require ongoing changes for accommodation into lifestyle. The project was seen as understanding this reality. Participants stressed that the ongoing daily demands and chronic unpredictable nature

of diabetes reinforces their need to have a reliable, accessible, approachable, supportive professional who can help through difficult situations.

*“Things are always going to change. You never know when you will have to look again and they are there, you know that they will help you. You can talk about how you are, not just on the outside but on the inside...and that does change”*

As a result of the diabetes integrated care approach, participants, recruited to the project as newly diagnosed with diabetes (i.e. in the last 5 months) or exhibiting poor control with HbA1c's over 9, thought that they had established a more comfortable position between diabetes and their lifestyle. They valued the time spent with the GP and diabetes nurse specialist in helping them to gain more control and acceptance of the condition.

*“I have accepted it and it is down to them. They have helped me work through it. I know that it is hard but I know what I am doing now”*

The acceptance and management of diabetes appeared to be dependent on the acquisition of knowledge, adapting behaviour and taking time to understand the implications of having the condition. Participants valued that the free visits and time devoted by the nursing component of the project facilitated learning at a pace dictated by the individual.

*“She can give you the time and you can learn at your own pace. You never feel stupid asking questions. I know that I have usually asked that before but she does not mind.”*

The “free” access to services, provided by the project, was referred to as a “bonus” but not positioned as an incentive to enroll in the project. Participants appreciated that diabetes care is expensive and acknowledged the free care as helpful to their ongoing use of services. The incentive to enroll in the project was reported to be a combination of the offers of closer monitoring, information, guidance and/or support.

*“It is good that it is free but I enrolled for the information to tell me what to do. You need to know as much as you can and two eyes are better really. You get their support, her and him [GP and nurse]”*

Consumers estimated that GP's time was a more “precious” resource than nurses time. Participants felt that they were saving the doctors time by accessing the diabetes nurse and trusted information delivered by nursing professionals. The diabetes nurse specialists were recognised, by participants and GP's, as having excellent knowledge about the condition.

*“The doctor is busy, he can't be spending an hour with you to talk about diabetes. But, you need that time and X can spend it. She gives you time and that helps him too.”*

Diabetes nurses were positioned by consumers as more socially approachable than GP's for lengthy discussions and/or access to answers to individual lifestyle type

questions. Participants perceived that they could waste the GP's time asking about non-medical issues, they feared been seen by the GP as 'slow to learn' and/or as a possible time waster.

*"I can ask her anything, anything at all. You just call...imagine doing that with a doctor, no, you would not waste their time. She never thinks your silly."*

Participants valued the integration between GP and nursing services and the integration of their care through diabetes nurse coordination. They were aware that information was shared and anticipated that this had been of benefit to their management.

*"She talks to him [referring to the GP], I know. That is good, cause I know that she will tell me when he needs to see me and the other way round"*

*"You know that there is this visits and that visit. But now, being on this, she tells you, its due and why you should go and arranges that it happens"*

Participants volunteered their project logbooks to illustrate events that had led to or resulted from their enrolment in the project. In discussing the records, they illustrated good understandings of blood sugars, necessity to keep within the ideal range, connection of the condition with other disorders [real or potential] and important factors related to diabetes management [exercise, non sugar products, lean meat, etc.].

*"I really turned a corner when I understood what it was and what I should be doing. At first I didn't, couldn't have done it without x [Refers to Diabetes nurse]."*

*"She knows more than him because that is her thing, diabetes. You can understand her too..she is natural and approachable. She even gave me a mobile number, I try not to ring it but if the odd thing comes up, I know I can call."*

Education provision by the GP and diabetes nurse was perceived to compliment each other. Participants illustrated that the GP assess' and monitors the medical condition. The diabetes nurse was seen as taking time to ascertain lifestyle and comfort the proposed diabetes management. They explained that both professionals were accepting of individual preferences and that changes had been negotiated.

*"She asked me what I ate, I was impressed with that as a start off. My favorites, what I like to do...we looked at that things that had to change together."*

*"We have been talking about exercise. I am not very good at that and she knows I do not like it. But we have agreed and I am starting next*

*week. When I get off the bus, I will be walking to the next street and round”*

[His wife laughed and said this would have to be “seen to be believed!”]

### **Consumer position: Threats and limitation of the diabetes integrated care approach**

Some older patients, who had long term established relationships with diabetes and a GP, perceived being handed over to the diabetes nurse for checking purposes. They felt that this was because they had become too time consuming for the GP and that the diabetes was ‘out of control’ due to physical deterioration aligned with older age. On the basis of this perception, some older people harbored resentment towards the approach.

*“I was happy with him really. You know I trust them both but I do prefer him. I have such a lot going on with me, I know that he is busy so he’s got her checking on me.”*

Newly diagnosed participants advocated that the project should encourage access to patient support groups. They requested more information about contacting other people managing the condition. Some thought that the project would be complimented by inviting such groups to be a part of it.

*“I wanted to talk to other people really...you know others who have it. They could help you get in touch with groups and things”*

In one reported case, a GP failed to alert a participant to a positive diabetes test result. One month later, whilst visiting a different GP, they were told of the actual result. The participant advised that the communication of the actual result was not well managed and advocated that the diabetes nurse specialist should be accessible when initial diagnosis are given.

*“They should have told us. I was disappointed in them. She could be there and offer help straight away.”*

### **Diabetes integrated care consumer satisfaction**

Overall, consumers reported high levels of satisfaction with the diabetes project. The support, advice, access and education that they had received as a result of the project informed satisfaction. The approachable and personal service given by the diabetes nurse was a significant factor in expressions of high levels satisfaction.

*“It is an excellent service...what more can I say. They are doing it really well. I have been a diabetic for years and this is the best thing that has happened.”*

*“What has happened?”[Researcher]*

*“You know, the education, the support...she is natural,  
approachable...she is human and that counts.”*



# **Maori consumer qualitative research**

## ***Executive summary***

### **Methodology**

Six qualitative interviews were performed with Māori between the age of 45 and 75 years of age in South Auckland, one week in July 2001. Information was gathered about consumers' perceptions of treatment received from a Diabetes Care Coordinator (DCC). The questions asked were about the strengths and limitations of the service, their diabetic background, expectations of the service, treatment processes experienced, cultural considerations, outcome of the service, how satisfied they were and the components of satisfaction, service integration and the change in their healthcare since utilizing the DCC.

Data collection and analysis employed the use of tape recordings, note taking and coding the information into themes. Problems associated with this research are also discussed.

### **Findings**

Findings were coded into several sections as mentioned above in the methodology.

Strengths of the diabetes service:

- Consistent regular monitoring
- Blood sugar stabilization
- Overall improvements in health
- Accessible financially and physically
- Clear concise and accurate information on nutrition, medication, testing, treatment and management
- One stop shop - centralisation of care

Limitations of the service

- Improve the procedures around appointment keeping
- Inclusion of rongoa Māori
- Improve the GP knowledge about diabetes management

Consumer expectations of the service

- Very few expectations of the services due to it being new
- More expectations of themselves and being able to care for their diabetes

## Treatment process

### General Practitioner

- Problems arose from clinic revolving door policy with doctors and continuity of care
- Lengthy time between visits with the doctor built anxiety about self treatment
- Outside referral were not appreciated due to large amount of travel
- GP gave inaccurate information about nutritional intake
- Diabetes once diagnosed seems to be the doctors primary concern on visits

### DCC

- Offered a more holistic approach to care and management
- Extremely accessible financially and physically
- Sound advice and information was given to consumers
- Regular monitoring and assistance in management built confidence
- Visiting people at home
- Offering a resource pack to consumer for personal use

### Self-treatment

- Food intake was more likely to be little and to their preference
- Food didn't necessarily mean what was recommended
- The importance of foot care was emphasized by Māori
- Rongoa Māori was an important aspect of care

## Cultural considerations

### Whānau obligations

- Adapting whānau behaviour to incorporates a diabetic and vica versa can often be difficult
- Attending hui and marae events where inappropriate food is served can be inhibiting

## Outcomes

- Have been improved management and health care
- Confidence has increased with the GP because of the referral

## Satisfaction

- Around integration and good communication between services
- Accessibility financially and physically

## Integration

- Good choice by the GP for referral to the DCC
- Devolution of more of the treatment from GP to DCC

### Changes in Health Care

- Reliant on health providers to offer a reasonable standard of living
- Use of high user and community services card
- Diabetes focus by the GP
- Increased health provider visits meant increased transport costs

### Discussion

Overall it appears the initiative has improved the health and wellbeing of Māori diabetics by stabilizing blood sugar levels and reducing the number of diabetic comas experienced. By offering a comprehensive and easily accessible service to Māori means they would utilize the health provider earlier and more often. The participants mentioned a small number of limitations of the DCC service. These are easily remedied and mostly around operations procedure. There were very little expectations from the consumers mainly due to its recent arrival to the clinic. Treatment issues from the GP centered on clinic policy, GP knowledge base, and referrals. For DCC treatment was seen more holistically and positive. Cultural considerations were about kai and being able to be active in te ao Māori. The positive outcome was that all participants improved their health and wellbeing through the intervention of the DCC. Satisfaction levels were high and were about accessibility, integration and centralisation.

## ***Methodology***

### **Sample design**

This research was aimed primarily at Māori however one of the participants identified as Cook Island Māori. Five Māori and one Pacific person were interviewed between the ages of 45 and 75 years. There were two females and four males in our sample. Recruitment was performed on our behalf one week prior to interview. The recruiter confirmed the interviews the night before with the participants. Five of the participants lived in Mangere and the last lived in Papatoetoe.

### **Details of data collection and analysis**

One Māori interviewer performed all the interviews with a tape recorder at the residence of the participants. The interviews were performed in a manner determined by the participant. The interviewer respected the kawa (protocols) set by the participants. The tape recordings were employed to capture an accurate account for the forthcoming analysis. All interviews were completed over a two day period in the last week of July.

Initially detailed note taking was executed from the data collected on the tape recordings. These were then coded into associated themes relevant to the reporting framework. Additional information that was supplied by the data supplemented the initial findings. At all times during analysis kaupapa Māori principles were implemented.

### **Possible problems/issues with the data collection**

The only possible problem that may have arisen during data collection and analysis was the interview carried out with the Cook Island Māori person. At this time we approached the interview in a culturally appropriate way to the best of our ability. This was achieved via greeting and whakawhānaungatanga.

## ***Findings***

### **Diabetes services strengths from a consumer position**

The fortnightly and monthly checks by the DCC have improved care management.

"The nurse has been really good".

The monitoring activities implemented by the Diabetes Care Coordinator has resulted in the stabilization of erratic blood-sugar fluctuations, reduction of Diabetes induced comas and overall improvements of health and well-being.

The features of the Diabetes Care Coordinator (DCC) service that appealed to the consumer and made a difference to their care regime were:

- Free (no charge) consultations.
- Free transport and home visits made it easier to access support.
- Comprehensive nutritional advice.
- Clear advice about diabetes medicines and testing equipment.
- Provision of information about all physical aspects of care.
- The supply of resource booklets that aid blood-sugar monitoring.
- Centralisation of diabetes support services (One-stop-shop).

### **Diabetes service limitations from a consumer's position**

There was very little perceived failure from the consumers perspective. One failure of the Diabetes Care Coordinator to keep an appointment was viewed very negatively. There was reluctance by the consumer to initiate another appointment, but instead wait for the GP initiated 3 monthly appointments.

The need to incorporate te ao Māori into the DCC treatment service. This will allow consumers to access a wider more holistic approach to care and management. It is the belief of the evaluator that more needs to be done from the service as the people interviewed seemed to be rather limited by their Diabetes. Participants were bed ridden, not capable of physically moving about easily and often unable to participate in cultural activities. Non-insulin dependent Diabetes should not be do disruptive to a patients lifestyle. Although patients had seen a marked improvement in their health there were still physical disabilities (black toes and legs) inhibiting their full recovery.

Improved care and knowledge from the Doctor about Diabetes had the effect of losing some faith in the GP this may have had a negative impact on the doctors' ability to look after the patient.

### **Recommendations:**

- Strengthening follow-up procedures around appointment keeping.
- Include rongoa Māori and alternative treatment regimes as part of care.
- GP are trained as much as the DCC on the effects of Diabetes.

### **Background/context**

To increase Māori input into the service provision for the Diabetes Care Coordinator role. This is carried out by the involvement and consultation with Māori consumers in order to better understand cultural requirements and perceived knowledge. This is envisaged to increase the knowledge and understanding of the relationships between DCC and patient and the impact of the DCC role on GP/patient relationships.

### **Consumer Expectations**

All of the consumers had an understanding of Diabetes from their experience of Diabetes affecting members of their family. It was felt that Diabetes may be attributed

to a family history or genetic predisposal to the disease. Stress was also considered to be a contributing factor.

The consumers welcomed treatment by the Doctors and their assigned status of Diabetes expert. The introduction of the Diabetes Care Coordinator was viewed very positively and of benefit to the consumers management of Diabetes. Hospitalization was considered to be the last straw. Participants concluded Diabetes to be a "horrible disease and its up to you" (to improve). Generally the consumer attitude towards diabetes is that "it is up to myself to manage diabetes". There is however a great fear of becoming an insulin dependent diabetic from all the participants.

The cost of GP consultations and the affordability of prescriptions was a telling factor for the care of Diabetes and because of the isolating and lonely nature of treatment there was a willingness to put up with the discomfort and hardship by not knowing any better.

*"I went three months without medicine because I couldn't afford it... every body said I don't look well... at that time I went to 74kg from 85kg".*

## **Treatment Process**

There were many themes emerging from GP's management of diabetes especially the frustration with revolving Doctor schedules at medical centers, resulting in the consumer consistently needing to re-explain condition and often receiving different care advice depending on which doctor was available. The advice that Doctors provided was only very basic information and the messages were too simplistic. Often leading to misguided diabetes management by the participants. The Doctors advice to

*"eat fruit and veges and cut down on the fatty meat"*

was found to be too simplistic and failed to adequately inform the consumer about the different foods and management of those foods.

*"The Doctor made it very, very clear to me that a lot depends on what I eat... but did not explain as the nurse did that apples and bananas are really high in sugar"*

*"The Doctor told me a little bit and I picked up information here and there...reading, the library".*

There appeared to one participant that there was a lack of customized care (no specialized services). He was a taxi driver, which meant that eating regular well balanced nutritional meals was often difficult. Rosterring changes and sitting in a vehicle meant that fast food facilities were easier to access food when required. Preparation of appropriate nutritional items ahead of time would mean that when it came time to consume these products they would less than appetizing. He made a request that the diabetes management be centered on the individual rather as a generalized Diabetic population.

Many participants felt the doctors' ability to adequately monitor their Diabetes was limited by only seeing them quarterly. They would be worried that their levels were not the best but would wait until their visit was due often a month away. This led to anxiety and unnecessary worry in turn altering their blood sugar levels. When they did see the doctor often the checks were mainly in order to obtain further medical prescriptions. Prescriptions even with the high user cards would add financial concern among the participants.

Previous care from the GP would lead to many other people involved in the follow up and referral of their diabetes care. This led to inconsistency and information often being repeated. Participants particularly disliked having to repeat themselves to many different sources that they would not see again. One comment made was that the information that they had received from the doctor conflicted with what the DCC had told them latter this was rather disconcerting to the participant. This information was about the use of sucryl (sugar alternative) in fruit preservatives. This lady said that her Doctor had said that sucryl was an appropriate sugar alternative and she would be able to use it. When the DCC found out about the sucryl

*"She told me that I could not eat all my preserves and now I have a cupboard full of fruit I can't eat".*

It was stated that there was also an element of frustration when visiting the Doctor about other health issues and the Doctor would always refer to diabetes and not treat the health problem in isolation. This appeared to be compounded by the medical clinics revolving Doctors schedules that effect Doctor/patient continuity of relationship.

In the case of a Diabetes amputee, home-help support was not offered initially, but was instead introduced when other complicating health problems arose. The absence of an offer to the entitlements of home help suggests a lack of follow-up and perception of care requirements. The failure to offer home help emphasizes the responsibility on to the consumer to manage their own affairs.

## **Diabetes Care Coordinator**

The features of the Diabetes Care Coordinator (DCC) service that appeal to the consumer and make a difference to their care regime were that the consultations were free of charge; transport to the clinics was provided or the DCC made home visits; clear concise advice about nutrition, medication and testing; information was provided about all aspects of diabetes care and management through a resource kit; and centralisation of diabetes support services (One-stop-shop).

In each consumer's case the absence of medical charges for the services of the Diabetes Care Coordinator (DCC) contributed to their willingness to take-up the GP's offer of referral. This response contrasts to situations where financial barriers have influenced diabetes care, for example one consumer stated

*"I went three months without medicine because I couldn't afford it... every body said I don't look well... at that time I went to 74kg from 85kg".*

The intervention of the DCC has enabled the consumer to learn more specific advice about the sugar content in different fruit and vegetables. The increased understanding of foodstuffs has stabilized "erratic blood-sugar levels".

## **Self Treatment**

### **Food**

Generally the consumers' attitude towards diabetes is that

*"it is up to myself to manage diabetes by watching the food that I eat".*

The consumer management of diabetes by regulating food intake depended on learning from their own experiences of what worked well for them, for example

*"I only eat one meal a day to keep control of diabetes"*

### **Foot care**

One consumer stated " He (the Doctor) referred me (to the DCC) when my toes got infected". This was due to self-treating feet because they needed care.

Treating feet with Primrose oil was stated to be preferable to talcum powder

*"I've found talcum powder builds-up and holds the moisture, whereas Primrose oil works a lot better"*

### **Rongoa Māori**

One consumer explained "Past treatment of diabetes with Rongoa Māori was preferable to the prescribed medicines and helped with high blood pressure" and

*"I was feeling a lot better when I was going to see that Tohunga..."*

## **Cultural considerations**

### **Whānau obligations**

Balancing food and cooking differences with other family members upsets routine. The GP 's must take into consideration the whole whānau while treating the Diabetic to ensure that the treatment incorporates the setting in which they live. A sister and her whānau have taken one of the participants and this has meant he must fit into their eating the households eating patterns and timing. For the whānau that has meant they must change eating habits to include more boiling and less frying.

When one whānau member is diagnosed with Diabetes this puts incredible strain on the rest to the whānau. This is seen particularly financial as Diabetes sufferers move onto Invalids benefits when they have originally been employed.



Marae / Hui food is sometimes unsuitable for Diabetics. This can cause non-attendance at cultural and social events, which is an important part of cultural activity. Due to the age group that we interviewed their cultural input is highly regarded in te ao Māori. This is a time when Māori of this age are drawn upon by the younger generations to teach.

The participants are of an age that they often have to balance their own care with the health needs of their spouses and extended whānau that are integral to their lives. One participant spoke of her partner triple bypass that complicated her Diabetes management because he was the only driver and primary provider to the household. Diabetes is often perceived as a lesser illness to some of the other afflictions e.g. the high incidence of disease on Māori; this has the effect of in proportional strain on those with diabetes who expect to care for their loved ones.

## **Outcomes**

The fortnightly and monthly checks by the DCC have improved care management.

*"The nurse has been really good".*

Participants commented that they appreciated the level of monitoring that the DCC was able to perform. This monitoring enabled the Diabetes Care Coordinator to ensure erratic blood-sugar fluctuations were stabilized, better operational behaviour (hygiene) about testing blood sugars, improved information about warning signs of high and low blood sugars, reduction of Diabetes induced comas, reduction in medication administration, more detailed nutritional advice and overall improvements of health and wellbeing. Consistent and ongoing care has allowed rapport to be built between patient and DCC, which in turn developed confidence and respect with the care being received. The overall outcome is the improved information sharing about diabetes as a whole.

The biggest impact that seems to have happened is around the perception of the GP in the eyes of the patient. The patient recognizes the initiative as an extension of GP care and therefore the doctor receives the credos. As the creation of the DCC position within the practice can cause the patients to conclude that the Doctor knows what he is doing thus promoting confidence in their ability to care for them.

## **Satisfaction**

Generally the participants were satisfied with a scheme that enabled their care to be handled by only two people (Doctor and DCC) this meant they didn't need to tell their medical history over and over to different people each time they went to be checked on. On the one instance when a participant needed to see a doctor and his regular GP was away he found explaining himself was 'annoying' and he felt 'hoohaa' with that doctor.

The way the DCC and doctor had integrated the diabetes care into a single clinic was vastly improved from having to travel into town (Valley rd, Mt Eden), Howick surgery and / or the super clinic. Participants felt the service was more like a 'one stop

shop' for Diabetes treatment. This had the effect of lowering stress level by having only to go to one place rather than several. Integrated care also meant that only two people had to know intimate details about lifestyle and because they were in close proximity could communicate as required about patient management. One of the main areas of satisfaction was that some of the care received from the health service for Diabetes was that they were given free of charge. The DCC nurse offered her services for free and the information given around testing hygiene and timing, appropriate blood sugars and nutritional requirements. The doctor had given only some of the basic information, as his time was limited during consultancy. Participants highly valued the accessibility to the DCC as they could either be picked up or visited. This was especially important during the winter months as they were less likely to seek assistance if they had to leave their house requiring extra effort.

## **Integration**

The referral of patients by their General Practitioner to the services of the Diabetes Care Coordinator (DCC) positively impacted consumer healthcare. The participants to this study reported the main outcomes of the Diabetes Care Coordinator involvement were an increased understanding of diabetes and its long-term health effects, an extra awareness of comprehensive dietary information, an improved monitoring and care regime, an increased understanding of prescription medicines and blood-testing procedures and finally an improved management of their diabetes practices.

The consumer perception towards the General Practitioner was also improved by the referral to the DCC. This can be interpreted as the consumer giving recognition to the referral as part of the GP's prescribed treatment of Diabetes. This may in part be due to the consumers' unfamiliarity with the service role and title description of Diabetes Care Coordinator, and because the DCC is referred to as "the nurse out back" and "the diabetes lady", the consumer regards the DCC as merely a nurse that works for the GP.

## **Suggested Improvements**

Devolving GP's responsibility for Diabetes medical prescriptions to the DCC, therefore avoiding the corresponding consultation charges and weaving rongoa Māori treatments into the integrated healthcare approach.

## **Changes in Healthcare**

An additional area that impacted on the participants during their care was the change in the way they relied on health services for an acceptable standard of living. Some of these issues included the extra expenses due to the increasing number of visits to their GP, the need for a high health care user card and the increase in prescription costs. Now that they were seen as high users of health care they also received a community services card, which for some this meant that they were no longer normal and were starting to become a 'burden on society'. This may add stress to an already stressful situation, however most of the participants saw the community services card as a blessing that assisted them financially for their health care.

When visiting their GP for other ailments the GP seemed to be primarily concerned with the Diabetes treatment and less worried about other ailments. Participants felt that going to the GP was difficult enough without the doctor not listening to the complaint they were there for.

Participants were inconvenienced by escalating transport costs, due to more frequent visits to the DCC (fortnightly) and the GP (monthly). For those who were still able to go to the clinic the rising petrol prices and increased mileage was starting to take a toll.

## ***Discussion***

The findings from this qualitative research are discussed from the point of view of project strengths and limitations, consumer expectations, treatment processes, cultural considerations, outcomes of the service, satisfaction levels and components, the integration of the services and the changes in the consumers health care since being involved with the DCC.

### **Projects strengths**

Overall it appears the initiative has improved the health and wellbeing of Māori diabetics by stabilizing blood sugar levels and reducing the number of diabetic comas experienced. The DCC service offers many elements that are appealing to Māori consumers particularly the ease in accessibility both financially and physically. The advice and information about nutrition, medication, testing and managements is clear and concise. Centralisation of care between the DCC and GP was extremely important to consumers. This meant that they only went to a single place to get all the diabetes care they required.

By offering a comprehensive and easily accessible service to Māori means they would utilize the health provider earlier and more often. This has the effect of reaching people before the disease has got too far and necessitates hospitalisation thus decreasing the burden on secondary services.

### **Project limitations**

The participants mentioned a small number of limitations of the service. These are easily remedied and mostly around operations procedure. Ensuring that the DCC maintains and keeps to appointments, the doctors are kept up to speed about improved diabetes management and that rongoa Māori be integrated into some of the treatments.

### **Consumer expectations**

There were very little expectations from the consumers. Reflected by the fact few went to the doctor to get assistance when they needed to. Māori generally felt that if they didn't look after themselves then no one else would. If they weren't eating the

right food then it was their fault they were sick, consequently they would need to get better by themselves.

Little anticipation was experienced about the service mainly due to its recent arrival to the clinic. The doctor had provided their care before and any referral (although met with some hesitation) would be followed and given an initial chance.

## **Treatment process**

There were three levels of treatment received by the consumer. Firstly their GP, then the DCC and their own treatment. There were a few issues that arose with the GP after receiving the care from the DCC. Māori trusted the GP and would do what he requested but when they went to the DCC some of the trust diminished. Problems were experienced around the clinics revolving door policy leading to the frustration of having to explain again and again their issues to different doctors. GP were less likely to give the more detailed information that consumers received from the DCC. Only basic information about nutrition, medication, management, treatment and care were offered by the GP initially. This meant that the consumers were misguided and made mistakes in their management leading to hospitalisation.

Quarterly monitoring schedules by the GP were not enough. Consumers felt limited leading to a lack in confidence in the diabetes, self-management.

The doctor made a considerable number of referrals to specialists for secondary effects associated with diabetes, which in turn discouraged Māori due to the amount of traveling to places distant to homes in South Auckland. Having to get about to other clinics was difficult and economically draining.

Some of the information provided by the GP was later seen to be inaccurate. Confirmation from other sources revealed the inaccuracy effect being initial confusion and then lack of confidence in the GP and what was told to them. There was some mention that once diagnosed with Diabetes the focus was predisposed to the disease rather than a more holistic approach to healthcare. The DCC offered a more holistic approach to care and management of diabetes from the diabetic's perspective. They were more likely to share information and offer advice on regular occasions that would assist in recurrent monitoring which allowed patients to stabilize blood sugars and become healthier generally.

The ability to visit patients at their homes meant less stress on the consumer getting to and fro from the clinic. The resources pack provided to each consumer were extremely helpful and were often put to good use when the person required more information about particular issues.

Overall the care received by the patients from the DCC was brilliant. This built confidence in their all round care and management. Participants commented this increased faith in the doctor and the possibility of living with such a debilitating disease but being able to cope with it a lot easier. This made things a lot less stressful generally.

Self-treatment for the purposes of this discussion pertains to food, foot care and rongoa Māori. Many Māori self regulate food intake (cultural considerations) and use the trail and error technique to see what works and what doesn't. Even when receiving good concise information about nutrition from both GP and DCC Māori are still more likely to eat what they like but in moderation. Improved foot care was experienced after the DCC gave advice about managements. Finally one participant mentioned rongoa Māori was incorporated into the care. The effect that this had was to lower his blood pressure and improve his wellbeing. Consideration of the incorporation of alternative treatments to parallel the DCC service could improve health among Māori more rapidly.

## **Cultural considerations**

There were three areas to be discussed from the findings concerning culture. They were whānau, marae obligations and kai (food). Māori in the age group interviewed play an important part in te ao Māori. Being older means they have earned great respect and there are a few expectations that they have of performing in the whānau and at the marae. These expectations are to be able to teach and show marae procedure to younger generations. When you are unable to perform to your previous full capacity this can lower self esteem and increases tension for the person involved.

Kai has always been a central part of any occasion big or small for Māori. Due to the limitations nutritionally with Diabetes about food intake it may appear offensive to your host if you do not participate in eating with them. Marae food and food at hui are often not suitable for Diabetics so compromises must be made between health and not offending your host.

## **Outcomes**

All participants improved their health and wellbeing through the intervention of the DCC. Lower blood sugar levels, less diabetic comas and fewer hospitalisations from their care and management procedures. Patients experienced increased hygiene levels during testing procedure, which meant less opportunity for infection. Improved knowledge about diabetes and therefore more awareness about warning signs about diabetes related events.

The biggest impact seems to be indirectly related to the service in that the GP has by default gained more trust from the consumer because they referred to a service that has improved their health immensely. This is even though initial treatment may have been inaccurate by the GP. Consequently Māori have an increased confidence in the care allowing them to access the services more readily and earlier.

## **Satisfaction**

Centralisation of care to the one clinic has been beneficial to all. There was no need to explain more than twice issues about diabetes, firstly to the GP then the DCC. The outcome being a more satisfied less aggravated person.

Offering the services free of charge was the biggest motivation for the DCC utilisation initially however as rapport built, the knowledge, advice and resource pack they received alongside the home visit and improved health status makes the DCC a highly valued service among Māori diabetics.

## **Integration**

Integration was viewed very positively, only having to go to the one clinic to receive all their diabetes care. Most Māori regarded the DCC as part of the clinic services offered and integration was actually one of the same service. One improvement Māori said could assist them was the devolution of prescription writing to the DCC so they would not need to see the doctor so much and the costs would be kept down. If the DCC was not able to prescribe then true integration would be the DCC could request prescription from the doctor without additional charge.

## **Changes in Healthcare**

Māori experienced that the way they received health care had altered during the process of diabetes care. Being able to access the doctor and prescriptions cheaper with the use a higher user and community services card had a positive financial impact and negative social impact. Māori diabetics did not wish to be a burden on society and the use of the DCC may have lessened this anxiety if only a little.

## Provider and consumer recommendations

- Diabetes was recognised as a constant presence in a person's life that is unpredictable, personal and may not always be accepted, i.e. good control today does not mean good control for life. Consumers advised that the condition impacts on lifestyle at many different stages during an individual's career. They advocated that this must be recognised by health services and provisions made, outside of usual GP or PN consultations, to negotiate through difficult periods.
- The role of the diabetes nurse was positioned as critical to the ongoing management of diabetes. It was seen to enhance relationships between the GP and patient and viewed positively by all parties. This contrasts markedly with the evaluation of the predecessor to this project (the Mangere Health Resources Trust Integrated Care Pilot). Providers and consumers advocated that the diabetes nurse/coordinators role be supported and further developed to support primary care professionals and consumers in delivering high quality diabetes care.
- Free access to the service was not positioned as the main incentive for enrolment. However, it was stipulated as an important factor in ongoing use of the service. Both providers and consumers felt that 'free time' for diabetes patients is an efficient use of health resources.
- Diabetes integrated care requires a culture of information sharing and teamwork. Providers cautioned that this situation does not exist in all general practice situations. It was thought that these environments would benefit from provision for professional management within funding arrangements.

*"Our practice may not representative...Without the team approach, integration would not happen..."*

- From the diabetes integrated care teams experience, implementation of integrated approaches necessitates "protected" time to manage change as the project is incorporated into individual practices. The time required was estimated to be between 4-6 months during which staff are trained, systems assessed, relationships developed and roles established. It was advocated that during the first 4-6 months implementation should be formatively evaluated using negotiated development measures, rather than process or outcome measures.

*"It does take time..it has to fit each practice, people have to buy into it, train to be a part of it...integration does not just happen"*

- Provider participants warned that the eventual IT system, to reach acceptance in primary care environments, must be quick to access, very user friendly, follow the logical flow of primary care patients through general practice and avoid unnecessary duplication of information whilst providing some EBP support.

*"If it is not right. I will not use it. The data collation is tedious, it does not flow..some questions seem obtuse..one field to another."*





## **Pacific consumer research**

### ***Executive summary***

Six diabetic clients of the Mangere Family Doctors diabetes disease management project were interviewed on a one to one basis. The participants were very supportive of the diabetic services provided for them within the South Auckland Area.

The participants spoke particularly highly of the home visits by the diabetic nurses and the advice by the health professionals for them to change their lifestyles particularly by eating more healthy food and doing regular exercises.

Participants felt that their knowledge of diabetes had improved through participation in the program.

As a result of their increased awareness about the causes of diabetes, participants expressed a willingness to relay their learning back to their own people.

Overall, participants had found the advice and treatment, provided by the project, easy to follow and useful for treating their diabetes.

Some individuals had experienced some language difficulties.

The service was positioned as treating clients professionally and respectful of cultural values.

*Note: The later commencement of the project at Health Pacifica (in August 2001) meant that clients from this service were not able to be included in the Pacific research. Health Pacifica asked us to note that they have staff that speak Samoan, Tongan, Nuiean and Cook Island.*

### ***Methodology***

The qualitative researcher who conducted the interviews is a member of the Samoan community in Auckland so the interviews could be conducted at times in the first language of the participants, if they were Samoan. Six interviews were conducted, with clients of the Mangere Family Doctors diabetes disease management project, using a general inductive methodology (GIM) based on the grounded theory ethnographic approach.

The qualitative researcher was particularly seeking information of the effectiveness of their care programme, their day-to-day experiences with the diabetics project, the benefits of the diabetes care project on their lives and its accessibility to them as patients. Patient's suggestions for improvements of the project are included.

## **Sample**

Six interviews lasting 1 hour were completed in the patients' home environment.

Recruitment was by telephone by an experienced recruitment officer. The recruitment person had told each of the participants the reason for the research. At the interview the interviewer iterated that participants answers would not affect the care that they were to receive.

## **Data Collection**

Interviews were completed consecutively on one day. A discussion guide was used to facilitate the interview. Information was collated into field notes that were analyzed later.

Field notes were coded into themes relating to areas of discussion. The notes under each question category were analysed under themes. Specific quotes were used to substantiate thematic content.

## **Issues with the Data Collection**

Many of the participants spoke English as their second language. Communication in all cases was satisfactory. The interviewer could talk in Samoan to the Samoan speakers but to the others spoke English.

## ***Findings***

### **Participants' Understanding of Diabetes**

The participants understanding of diabetics is that it is an illness where their bodies have too high a level of sugar and fat in the body. The key reason they have it they said was due to eating food with excess fat content. They also mention that they may have it because they have not been exercising or moving around and that it will not go away unless they exercise.

Interviewees appeared to know that "Island food" is not good for diabetes as much of their food is fatty and unhealthy.

#### ***"Lots of fat in Islander food"***

In general they said that they realized that diabetes is an illness that they can certainly control if they follow the treatment programme advised, are sensible with their diet and do try to do some exercises, but there is also no 'cure' for it. They were in agreement that they would have diabetes for life but for the two in their twenties and forties they know that if they sleep well and take medicine they can get a positive

outcome and feel that the diabetes is well looked after. They believed that diabetes was due to:

*“Not having the right/ balanced diet when getting old.”*

*“Not having exercise.”*

*“Lots of fat and sugar in food such as my taro and palusami”*

*“Being overweight.”*

Participants related a number of signs and symptoms that had signaled the conditions onset.

*“Sore arms and legs which I thought were cuts and later on were diagnosed as her being a diabetic.”*

*“Tiredness and sleepiness”.*

None of the consumers expected that treatment would improve their cases. They had expected their treatment would control the diabetes

## **Diabetes Care Coordinator**

The consumers commented positively on the information provided by the diabetic nurse, typically through a home visit, and the doctor during surgery visits.

Participants related that the DCC advice and treatment was easy to follow and thus, they had been able to comply with most of it. They advocated that being Pacific Islanders it was helpful to have someone in their family assist them in their cares. The home visiting service provided by the DCC had facilitated this.

*“Parents remind me to take my tablets”*

Home visits were recognised as a very positive feature of the diabetes project. Participants expressed appreciation of the time taken to come to the home, facilitating observation of the individuals home care routine and providing support in discussing blood results and their meaning.

*“The diabetic nurse on home visits to check on my blood pressure and to check on my equipment.”*

*“The nurse checked on my conditions, and my food.”*

Participants felt that the project had raised their own, and the family's, awareness of the condition. As a result, they felt better able to control, monitor and treat the condition.

*“I try to explain to my family, a change of food behavior in diet is important and to eat more green vegetables and fruits. I now drink a lot of water instead of fizzy drinks”.*

*"It has helped me to teach myself that I can control my diabetes if I can control myself. I ignored to take my medication, I avoided eating healthy diet while I was young I spent a lot of money on junk food."*

The participants illustrated that being a part of the project had also given them opportunities to access services and information. They commented:

*"I am not alone with my diabetes. I am able to avoid and control it when I take full advantages of the services provided."*

*"I joined the support group in South Auckland- Health Pacifica, so that I can use my time to do something better."*

Participants were satisfied with the care provided by the diabetes project. In particular, they felt that it had increased their contact with both the doctor and the nurses.

*"I am happy with the treatment."*

*"Gives me very regular contact with the doctors."*

Participants had been referred to secondary care services and perceived that their access had been facilitated by the project.

All participants commented on the excellent support from the DCC. Education from the DCC was reported to be both morally supportive and constructed to suit the needs of the individual.

*"Education of the whole family is good."*

*"Information was very appropriate."*

*"Makes me think positive."*

*"She gave me a lot of new things. I changed my diet. I substituted a lot of my food. I tried to control my weight."*

They felt that the doctor and the DCC cares complement each other and appreciated the increased access to the advice of both individuals.

*"It all creates an awareness to seek medical advice at early stage"*

The offer of the 'free' service was appreciated and it was thought that it had created new contacts, increased communication between the patient and provider and streamlined access to other primary and secondary care services.

## **Cultural Considerations**

Participants perceived the services that they had received through being a part of the diabetes project were culturally appropriate. The professionalism of the nurse and doctor were admired. It was iterated that home visiting affords the opportunity of the patient to discuss their health on their own terms. The nurse's personal approach was

welcomed and seen to fit with their cultural values of respecting each other particularly respect of older people.

*“Service provided was acceptable and informative.”*

*“It is appropriate to give access and information within cultural beliefs related to food and exercise”*

Some participants noted no language problems, as below:

*“The language is very simple, used visual aids and demonstration to explore the actual programme.”*

Some individuals signaled that they had experienced some language difficulties trying to access information, verbal and written.

The participants viewed the different services involved in their diabetes care as working together. But, in particular, they explained that the care provided by the surgery team had appeared to be more integrated as information was being shared between the different professionals.

*“The GP and diabetic nurse worked together very well.”*

The impact of the advice and support provided appeared to have precipitated changes in diets, understanding of diabetes, medication concordance and attitudes towards exercises. :

*“I will insist to educate my family how to eat and how to exercise.”*

*“I will explain to grandchildren not to eat fatty food but eat vegetables and fruits.”*

*“Positive thinking about my diabetes is important”*

### ***Pacific Island consumer recommendations***

Generally consumer satisfaction with the diabetes disease management project was very high. The major factors contributing to satisfaction were the experience of extra time being spent with the doctor and nurse, and the experience of home visiting.

It was suggested that the program would benefit from providing more guidance towards other people, groups who have or have an interest in the condition.

The participants advocated that the project should be advertised within the community to increase the awareness of its existence.

## Secondary care data analysis

The chronic care projects were asked if they could supply the NHI numbers of the patients that had enrolled on to the project, and the enrolment date. We examined the secondary data on outpatient and inpatient patient contacts (including EC attendances) for the enrolled patients. We counted the attendance data for the one-year period prior to enrolment, and for the period between enrolment and the date secondary care data was extracted.

Thus we had 365 “pre” days of data for each patient (unless they were born in the prior year, in which case their data was appropriately censored), and a variable number of “post” days (22188 in this case).

There are some important limitations on the data:

- Patients may have visited other secondary care facilities
- Patients may have not been resident in CM DHB for the 1 year prior to enrolment.

When this method was applied to the Diabetes project we were able to construct the following table:

Diabetes secondary care analysis			Patient days in project	Inpatient events	Outpatient events	EC	Inpatient days
					\$60	\$80	\$220
		Before	68620	83	412	14	377
patients	188	After	22188	17	155	4	88
patients with NHI	188	annualised		53	479	12	272
		diff		30	-67	2	105
					\$ (4,041.76)	\$ 130.35	\$ 23,066.05
predicted saving	\$	19,154.63					
scaled to full project	\$	<b>62,150.68</b>					

These results appear to reflect increased engagement with outpatient clinics as one might expect for diabetic patients, for example with increased retinopathy screening, and reduced admissions to hospital (and reduced inpatient days).

## Follow-up data November 2001

One of the evaluators (BG) visited Mangere Family Doctors on 29 November to discuss how the project had developed since the initial round of qualitative research.

In the intervening period the project had implemented “alerts”, the provision of treatment guidelines, supplied to providers by email. This had been very favourably received by providers, and identified as a potential major contributor to improved patient care. A practical example of how this facility could enhance patient care was described, in which the IC server had identified that a patient was eligible for a statin but not yet receiving one. An application for a statin was subsequently forwarded for endorsement by a specialist.

Another example was the observation on aggregate data that patient BP measurements actually appeared to be increasing. This led to a practice discussion, with specialist support, of the importance of BP control and strategies for achieving it in diabetic patients (probably more important than glucose control in preventing renal disease).

The provision of reports of aggregate clinical data from the IC server to individual providers was imminent, and considered to be an important change management strategy.

There were still a few outstanding issues with the operation of the IC server, related to uploading data:

- Uploads appeared to be rejected if data for the same visit was resubmitted with more complete data, for example after blood test results were received. This would typically occur if two different providers saw a patient.
- The reasons for an upload being rejected were not notified, making it difficult for the provider to correct the erroneous form.
- The IC server imposed a strict window in which 3 monthly follow-up data could be submitted (of 2 weeks). Patient follow-up visits were sometimes outside this window.

These issues are related to the difficult issue of how to handle the mismatch between real life general practice and the desire to impose some structure on a possibly erratic stream of clinical information.

It was also suggested that a test for appropriateness of medication taking into account renal function should be incorporated into the list of “alerts” that the IC server could generate.

The PMS implementation of the data collection form was also still problematic, with the use of multiple forms still required in MedTech32; the Next Generation implementation at Health Pacifica was said to be considerably easier for providers to use. The difference between “missing” and “negative” values should be checked in

both systems, but especially in the Next Generation implementation. The features of the PMS system that most appealed to providers were the pre-population of fields from existing clinical data, and the automatic production of various referral forms, e.g. for glucometers or retinal screening.

## Conclusions and recommendations

The role of the diabetes nurse was perceived much more positively in this project than reported in an evaluation of the MHRT integrated care pilot. It was seen to enhance relationships between the GP and patient and viewed positively by all parties. Providers and consumers advocated that the diabetes nurse/coordinators role be supported and further developed to support primary care professionals and consumers in delivering high quality diabetes care. Acceptance of the diabetes nurse was high from both Maori and Pacific clients.

Diabetes integrated care requires a culture of information sharing and teamwork. This is not universally accepted in a private business environment. Indeed the success or otherwise of many integrated care pilot projects seems to depend on the drive and commitment of key individuals (“champions”). A model successful in one setting might not work in another, or indeed be a generic solution. More resources might be required to make the approach in this project work in other settings.

From the diabetes integrated care teams experience, implementation of integrated approaches necessitates “protected” time to manage change as the project is incorporated into individual practices. The time required was estimated to be between 4-6 months during which staff are trained, systems assessed, relationships developed and roles established.

The effect of the IT component of the project, the integrated care server and connectivity with practice PMSs, was difficult to assess. The components of active recall and follow-up, a diabetes register, protected patient time and a diabetes primary care nurse are known to be effective strategies for improving patient. There is no doubt that, longer term, the provision of an information sharing capacity, both primary / secondary and primary / primary will significantly enhance patient care. The provision of electronic clinical “alerts” was also welcomed in our follow-up visit. This has the potential to be a very significant force for provider behaviour change, as illustrated by the examples relating to detecting “unprescribed statins” and provoking improved management of elevated BP.

Provider participants warned that the eventual IT system, to reach acceptance in primary care environments, must be quick to access, very user friendly, follow the logical flow of primary care patients through general practice and avoid unnecessary duplication of information while providing some evidence-based-practice support.

The clinical outcomes present some interesting questions. A substantial drop in the percentage of people with elevated HbA1c was achieved, but it was surprising to the evaluation team that for a population in which a significant proportion had uncontrolled diabetes (i.e. with 43% having an HbA1c >9), average cholesterol both at the initial visit and at follow-up, was surprisingly low.



What were the key factors in the drop in HbA1c levels observed? For approximately 20% of the patients it was estimated by one provider that increased compliance with, or indeed resumption of, medication was the major factor. It is likely that non-compliant patients were the ones with highest HbA1cs, and thus much of the reduction in the percentage of people with HbA1c above 9 (from 43% to 16%) may be due to uncontrolled patients resuming medication. This of course is an excellent outcome. What remains to be seen is whether it can be sustained, given that these patients had become uncontrolled in the past. When data covers a longer time period the longer-term impact of the project will be able to be assessed more rigorously.

On the data available to date, however, it is clear that the diabetes disease management project shows great promise. The results that have been obtained to date illustrate real and significant reductions in HbA1c levels. The secondary care data to date is very encouraging. If these are sustained CM DHB could expect, according to international evidence, an average 30% reduction in total health care costs for these patients.