



**CONSUMER EXPERIENCE OF
DIABETES SERVICES**

QUALITATIVE RESEARCH

JULY 2007

Inner East Primary Care Partnership



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1. INTRODUCTION

The Inner Eastern Primary Care Partnership (IEPCP) is contributing to the Eastern Metropolitan Region (EMR) Diabetes System Improvement Program.

Accordingly, the IEPCP has decided to audit the experience of consumers with Type 2 diabetes. This data will be used for planning, improvement and accountability purposes.

IEPCP commissioned three focus group discussions and six in depth individual interviews in May/June 2007, with the possibility of collecting quantitative data at a later stage.

The results from these discussion groups and interviews are summarised in the following pages.

2. OBJECTIVES

IEPCP sought in depth information about:

- The pathways through Type 2 diabetes services
- The experience of living with diabetes
- Consumers expectations
- EMR performance in providing diabetes services
- Services accessed
- Service gaps, and
- Improvements recommended

3. APPROACH

During May and June 2007, focus group discussions were held with:

- Three focus groups of community health and hospital consumers
- Clients of general practice, community-based programs, community health, hospital outpatients and recent hospital inpatients across the Eastern Metropolitan Region.

Four home interviews were conducted and two consumers were interviewed at Whitehorse City Council offices. Approximately 120 consumers were contacted by the IEPCP Integrated Chronic Disease Program Manager to recruit the 21 participants. The main reasons given by consumers for declining participation were illness, hospital visits, carer responsibilities and time constraints.

The IEPCP ICDM Program Manager sat in on several interviews and focus groups. In an effort to encourage open and frank discussion, it was explained to all participants that John Wooles (discussion facilitator) and Hannah Halloran (ICDM Program Manager) were not staff members of any of EMR services.

The consumers were chosen at random from diabetes service caseload lists. Processes for engaging consumers varied across different agencies/programs. They were telephoned and invited to the discussion group by the IEPCP ICDM Program Manager.

4. SUMMARY OF CONSUMER RECOMMENDATIONS

Interviewees made many improvement recommendations. They can be grouped under four headings:

4.1 CLEARER, CONSISTENT INFORMATION

- Increased preventative publicity, more pamphlets, advertising etc
- Increased diabetes education for GPs
- Timely referral by GPs to diabetes educators
- Increased clarity and consistency of information across service providers

“Diabetes is not in the public domain. More publicity is required.”

4.2 PROACTIVE, INDIVIDUALISED FOLLOW UP SERVICES

Interviewees regularly commented on lack of follow up by services and lack of opportunity for 1:1 consultation with educators and dieticians. In addition, appointments were too far apart, or ceased after four-six weeks.

“You can’t expect blokes who are in denial to proactively attend clinics...we need a prod.”

4.3 MAKE IT EASIER TO BUY CORRECT FOOD

Food and diet control were seen as key. Suitable food should be clearly labelled and located in supermarkets and made more affordable.

“Medications and diabetic food make a big hole in my pension.”

4.4 PROVIDE ‘ONE STOP SHOPS’ FOR DIABETES

Interviewees commented that they often learnt about aspects of diabetes, for example, caring for their gums, eyes and feet, by accident.

Diabetes services are often buried within other services in hospitals – for example, within the Heart Unit.

“I’d rather know what is available at a one-stop diabetes shop. Why not have a diabetes clinic, like a cancer clinic, with a diabetes educator available? So you don’t just feel lucky if you find a service.”

4.5 CONCLUSION

IEPCP now has a major opportunity to:

- Respond to these consumer recommendations
- Upgrade diabetes services, and
- Systematically improve diabetes services in Melbourne’s east

In the medium term, the qualitative issues in this report could be tested in a more comprehensive quantitative study.

5. THE PATHWAYS THROUGH DIABETES SERVICES

A majority of interviewees rated the smoothness of their transition from one diabetes service to another, as 'adequate' or 'needs improvement'.

It was clear that many older interviewees, who had been diagnosed several years ago, had been left to their own devices.

"I didn't know what diabetes assistance was available - it was all luck."

"I did all my diabetes research myself. I didn't have any help."

"I was diagnosed 14 years ago, but it was up to me to insist to get a referral to the Box Hill Hospital endocrinologist."

There were mixed reports from interviewees who had been diagnosed more recently:

"My doctor alerted me to diabetes services."

"The transitions between services were good and easy."

"Transition from the GPs nurse wasn't that smooth. I needed more information on who to contact, and where support was located."

"My hospital didn't follow up or assist me with my diabetes."

Four typical examples of pathways taken by interviewees are included in Appendix 1. The common themes in these pathways are:

- That the GP has diagnosed diabetes, but
- Over time, there has been a cessation in the relationship between consumers and dieticians or diabetic educators
- Pathways were dependent on the initial point of contact, and were often limited to one sector

Additional relevant comments:

"Our first point of contact was with a GP. We were then sent to a diabetes educator to get a gluco meter and a referral to a dietician and a podiatrist."

"My GP recommended and referred me to a diabetes educator within a month. I attended classes with 10-12 others. It was two hours once a week for eight weeks but it stopped there. I have also seen an eye specialist and a podiatrist."

"I initiated my first diabetes test, the doctor didn't."

"I've been a bit lazy. I went to a GP for an ulcer. He gave me a blood test. After a blood test, my GP suggested I talk to his nurse."

"My GP suggested a diabetes test. I was sent to the diabetes educator at Maroondah and at William Angliss. This was back in May 2003. I attended eight one hour sessions. My wife also attended and learned about cooking etc. Unfortunately, I now have heart, diabetes and kidney problems."

"Community Health support is excellent. If I had to see a private podiatrist, instead of seeing one at the community health centre, the cost would be prohibitive. Likewise with proper shoes - that would be expensive otherwise."

6. THE EXPERIENCE OF LIVING WITH DIABETES

Interviewees placed significant value on diet control and the support they receive at home.

Social/family support:

"My partner supports me best with diet control."

"The people at home are my best supports."

"Everybody was helpful. I was quite happy. I knew about it, my mum's family had it."

"I go for a walk with Good Life at Box Hill Council."

"My wife is my best supporter."

"My GP diagnosed my diabetes. I find the eight tablets a day not working. I commenced insulin 10 years ago. My grandson watches over my diet and my daughter is a Diabetes Educator. I have been to many specialists, but I find my GP is best. My endocrinologist gives me little advice and tells me to come back each six weeks and charges me \$60 each time."

"I received help through Maroondah Hospital."

"My chemist visited and explained the diabetes kit."

Other:

"My lifestyle is about diet control. I have read a lot. I now need more detailed assistance."

"The diabetes nurse educator and Diabetes Australia are very good."

"I don't see my kids or neighbours much. I visit the Community Health Centre and Maroondah Hospital."

"I am aware of diabetes, but I am lazy. I was more active when I was employed."

"I need to make sure my eyes are ok. This is a key symptom."

"I exercise a lot. I only take one tablet a day."

"I hate not being able to eat sweets. Otherwise it's ok."

"Initially I didn't want to believe it. I'm not too bad."

"I forget to take my bloods. It doesn't worry me."

"Thankfully I haven't got a sweet tooth. My downfall is bread. I eat a loaf a day."

"I don't care. I eat chocolate and cakes."

"Chemists now do all the diabetes stuff, although not in Lilydale."

"It is important to have things checked quickly when you are newly diagnosed with diabetes. You panic a bit when you are first diagnosed."

7. CONSUMER EXPECTATIONS

Consumers expect good advice and education, 'straight answers', promotion material to prevent diabetes, access to support groups as well as timely appointments with diabetes clinicians.

"I need and want straight answers to straight questions."

"I expect timely appointments, for example, it is now six weeks to get an appointment with a podiatrist."

"I could have avoided diabetes had I been better advised about prevention techniques."

"It is important to have things checked quickly when you are newly diagnosed with diabetes. You panic a bit when you are first diagnosed."

"I expect education. There is little education out there. GPs are limited in what they know. Not all GPs will refer you. My GP didn't refer me to a dietician. I now eat six times a day. Sometimes my sugars are too low for example, and I collapse. I like it to be six."

"I expect good advice. I expect to be put in touch with a diabetic support group."

"I expect more advertising for assistance with diabetes and to learn from others in support groups."

8. EMR PERFORMANCE IN PROVIDING DIABETES SERVICES

A majority of interviewees rated services as 'needing some improvement'.

Specifically, interviewees consider that GPs should be better informed about diabetes, especially about the important role of the diabetes educator.

Feedback re GPs:

"Overall I rate performance as needing improvement. I have to make the running. For example, I have heard about a new insulin. Will I end up on it?"

"I found my doctor a bit hazy and a bit scary about diabetes."

"GP's don't have the time. They can be 'off hand' and you have to wait for long periods to see them."

"I am educating my GP regarding high blood sugar and adjusting my insulin."

"I have only been to a GP. He was not that helpful."

Feedback re Specialists:

"I rate performance as requiring a lot of improvement. You need to look after yourself but my endocrinologist doesn't give me enough advice or time. I find my GP doesn't know much about diabetes. He needs more education."

Diabetes Australia

"Diabetes Australia in Collins Street is good and only a phone call away. Their website is very good too."

Diabetes Educators

"You need to see a diabetes educator. I received no advice from a specialist."

"I should have been told about the value of a diabetes educator."

"The diabetes educator was good."

Dieticians

"You have to be careful. I went to see a dietician for many years and I concluded I was receiving no startling assistance."

Other:

"I would rate diabetes services as good."

"I went to the aqua centre for the exercises for over 50's. I learned this by accident."

"Council courses have been helpful. I started them a bit by accident."

"I went to the nurse diabetes educator. There was a six week initial course and no follow up."

9. DIABETES SERVICES ACCESSED

100% of interviewees had visited their GP at some stage in relation to diabetes. 60% had accessed Community Health services, 80% had visited allied health staff 60% had accessed diabetes educators, 30% had visited hospital, and 30% had seen a specialist.

Two interviewees commented that they had only seen their GP:

"I visited my GP three or four years ago and had a blood test for cholesterol. He picked up I had high blood sugar. My GP didn't refer me to anyone else. He just prescribed tablets."

"I have only been to a GP. He was not helpful."

10. DIABETES SERVICE GAPS

Interviewees saw a need, in particular, for increased assistance with physiotherapy and diabetes education.

"I would value more physical therapy. I need encouragement to have a commitment."

"I should be doing more exercise. More physio assistance would be good, for example rowing and walking machines."

"I should have done more study and overcome obesity, and been more active as a child."

"I could help and advise other diabetics. Some diabetics shock me with what they eat. For example, too much white bread and fruit juice. Also, hospitals don't provide alternative meals. For example, they have white bread and fruit juice. Catering in hospitals is privatised to reduce costs and they provide cheap cuts."

"I should exercise more but I can't get out. I would value a visiting physio therapist."

"I would value a visit from a physical therapist."

"I would recommend diabetes education 1:1. As it was, I went to two sessions and stopped."

"A regular exercise program wouldn't help me. I am lazy but I also have no good footwear."

"Dieticians disappear after three months. They all disappear after three months and leave a phone number, but I am too busy to ring."

"I am educating my GP regarding high blood sugar and adjusting my insulin."

"I attended one four hour diabetes education session. It was too much in one session. I would prefer more sessions over a longer period for example, one over hour over six times would be better with time for questions. You could also get more input for example, from a physical therapist."

"I would like to meet others with diabetics. I only found out about support groups four years after I was diagnosed. I found out through my diabetes educator. I went to the diabetes educator at the hospital, but it was booked out."

"When do I need to consult an eye specialist? I strongly encourage people to see an eye specialist. Community Health centres should have a list of eye specialists."

"My diabetes educator is my case manager. It is difficult to see a diabetes educator in Whitehorse. But it is easy to see one in Monash. I'd like to see one regularly."

"I would like to see a diabetes educator 1:1."

"Better advertising about diabetes is required."

"Telling the GP about diabetes is like water off a duck's back. A GP locum reduced my diabetes tablets and it worked."

"I found information about diabetes myself."

"There is no diabetes educator available in Lilydale. I saw one in Ringwood."

"Support and testing is critical. Testing by GP's is a key responsibility. Testing should be free."

"GP's are a key. Every GP should order full blood examinations for consumers."

"All diabetics should do gentle exercise."

11. IMPROVEMENTS RECOMMENDED

Consumer recommendations can be categorised under four headings:

- Provide clearer, consistent diabetes information
- Provide better individualised follow up services
- Make it easier to buy correct food, and
- Provide 'one stop shops' for diabetes

11.1 CLEARER DIABETES INFORMATION

"There should be more diabetes prevention information available from GPs, for example pamphlets."

"More diabetes education for GPs."

"Advertise diabetes courses."

"From my GP, I needed a clearer description of my diabetes status, punctual, reliable, clear information and next steps. Not 'finding out afterwards' and complacency."

"When you are first diagnosed there should be quick referral to a diabetes educator."

"When I was first diagnosed, I didn't understand it."

"There should be more screening and awareness for diabetes for example, in shopping centres. Diabetes is widespread. My only symptom was a dry mouth."

"Diabetes is not in the public domain. You don't know where to go. More publicity is required, prevention would better. Many people don't know how it happens."

"There should be more information which is more regular on how to prevent diabetes and how to cope once you've got it."

"Use big print brochures and make it easy to get through the system."

11.2 PROACTIVE INDIVIDUALISED FOLLOW-UP SERVICES

“There should be more follow up with consumers to prevent complications. I did a six week course, six years ago with the Box Hill diabetes nurse educator. There has been no follow up.”

“If you are in hospital, ask for a diabetes educator. Otherwise you won’t see one. I was six weeks in Maroondah Hospital. They knew I was diabetic, but they didn’t send anyone to see me, for example – a diabetes educator – and you are stressed in hospital.”

“I missed the first visit to Monash and I felt I had let them down, so I didn’t go back. Had they phoned, I would have gone back. As it was, I couldn’t have been bothered. A courtesy call to me would have helped. The problem is if you miss an appointment, it is four weeks before you can get the next visit. It should be next week. They need to be more proactive, even if I don’t miss visits.”

“There should be follow up from the Carrington Road Clinic.”

“My appointments were too far apart.”

“I would value one person to manage my diabetes care – a case manager.”

“Diabetes Australia should follow me up, as should the diabetes educator.”

“Dieticians normally work with small groups, not 1:1. Their six week course should be strongly encouraged, if not compulsory.”

11.3 MAKE IT EASIER TO BUY THE CORRECT FOOD

"I am getting used to it. It is pretty hard because diabetic foods are expensive. You have to pay for medication and foods. It makes a pretty big hole in your pension."

"It takes too much time in the supermarket. For example, 10 minutes per aisle. Have a diabetes aisle or a special needs aisle."

"The dietician recommends fruit, but I found it really expensive. I am on the pension and have other bills to pay."

"Food is the key. The labelling of food could be improved. What does diet / lite mean?"

"Look after yourself. I check my blood sugar twice a day then review what I have eaten."

"All diabetics are liars (about their blood sugar) for example they eat chocolate and drink alcohol and say their reading is five or six."

11.4 PROVIDE 'ONE STOP SHOPS' FOR DIABETES

"I'd rather know what is available at a one-stop diabetes shop. Why not have a diabetes clinic like a cancer clinic with a diabetes educator available? So you don't just feel lucky if you find a service."

"There should be a one-stop-shop for diabetes. I didn't know I needed to look after my gums, eyes and feet. It was by accident."

"Diabetes services are buried within everything else in hospitals for example – the Heart Unit."

"My diabetes diary should be larger. I like to take it with me to medical appointments. It is too small and has insufficient room in it."

"Improve the layout of the diabetes diary. The current one is for the Type I diabetes. There should be wider columns and a bigger diary for elderly people."

"My GP suggested blood tests. I then went to the Monash Heart Unit. My GP sent me to a dietician two years ago. I couldn't afford to keep going at \$60 twice per week. I would go to my dietician if it was free. I value diet advice."

"The diabetes educator is the key person."

"I would welcome more regular exercise and physio. I attend one exercise session per week."

"Provide more diabetes educators. There are none in Yarra Ranges."

"A first visit with a diabetes educator should be 1:1, not 1:26. At present, 1:1 is not offered."

"We need a Type 2 clinic."

"Diabetes needs to be on politician's radar."

"A physio co-ordinator to link me with exercise programs would help."

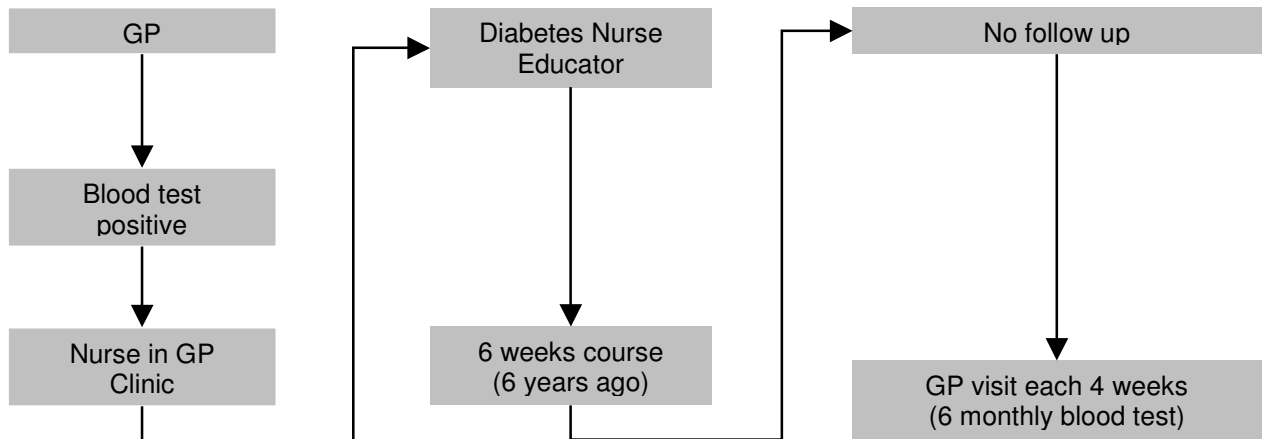
"You can't rely on blokes who are in denial to attend clinics. We need a prod that will work. Proactive follow up is needed."

"I should have been advised after six months to attend for more assistance, that is, more proactive follow up."

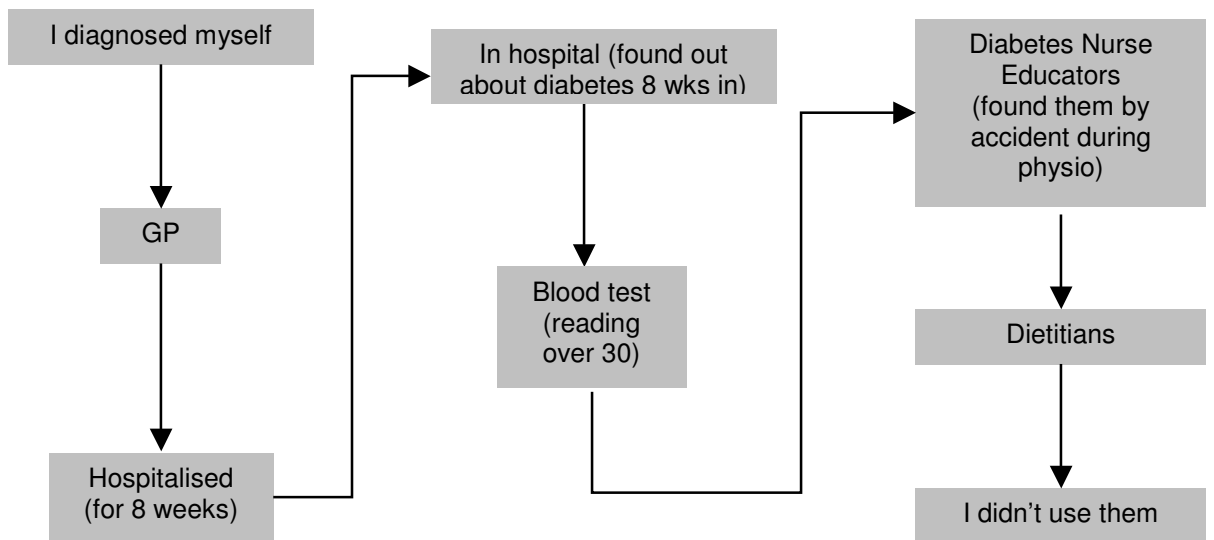
Appendix

- Examples of Pathways

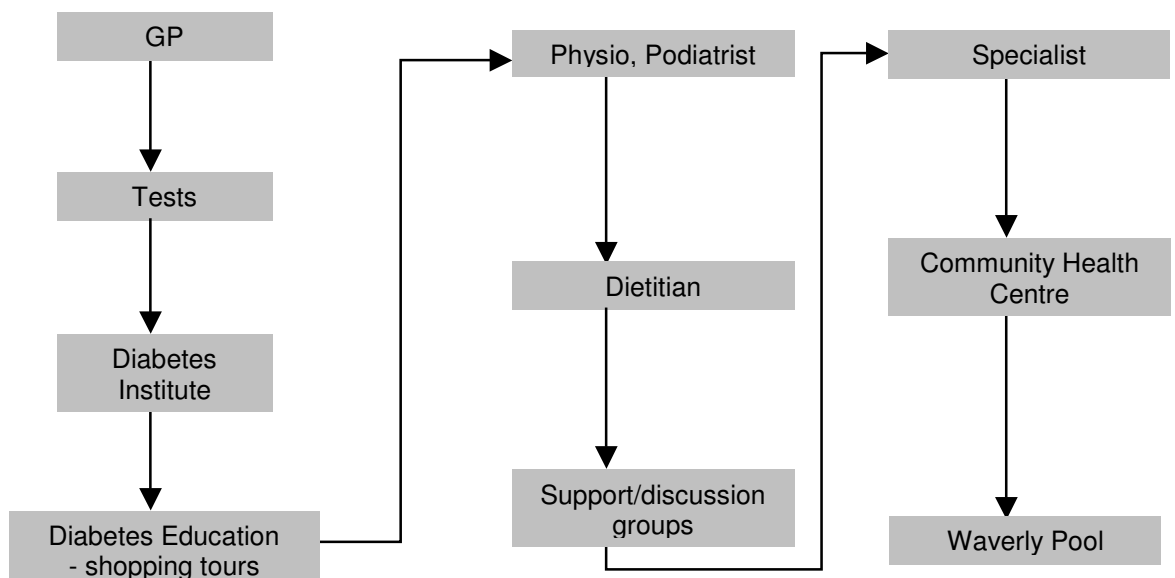
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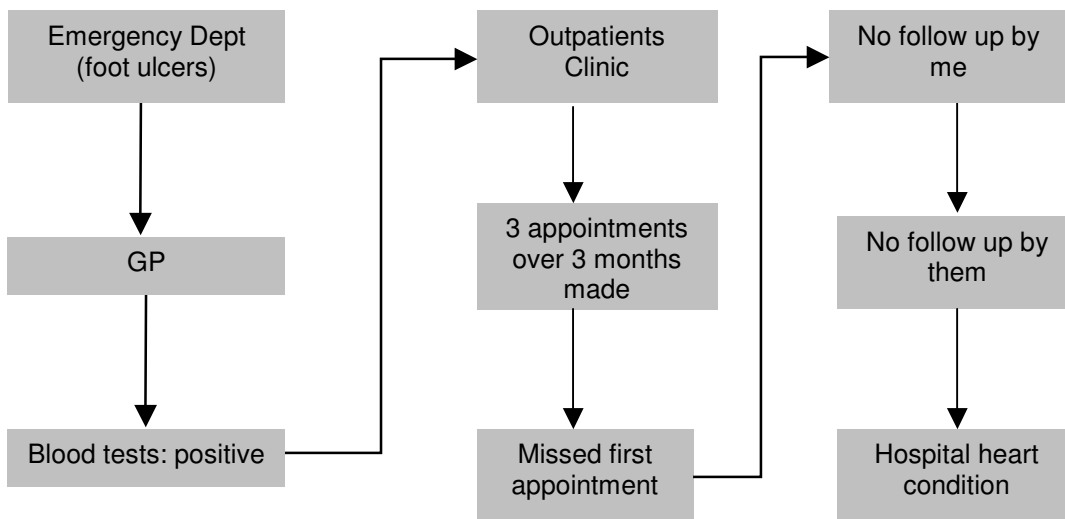
PATHWAY 2



PATHWAY 3



PATHWAY 4



PATHWAY 5

