

Education and information issues among people with diabetes

JUNE 2002

Catherine Chittleborough
Julianne Cheek
Janet Grant
Patrick Phillips
Anne Taylor

DEPARTMENT OF
HUMAN SERVICES



Diabetes Clearing House

Centre for Population Studies in Epidemiology
South Australian Department of Human Services

This work is copyright. It may be reproduced and the Centre for Population Studies in Epidemiology (CPSE) welcomes requests for permission to reproduce in the whole or in part for work, study or training purposes subject to the inclusion of an acknowledgment of the source and not commercial use or sale. CPSE will only accept responsibility for data analysis conducted by CPSE staff or under CPSE supervision.

Published June 2002 by the South Australian
Department of Human Services
Centre for Population Studies in Epidemiology
PO Box 287, Rundle Mall, Adelaide, 5000
South Australia, Australia

The National Library of Australia Cataloguing-in-Publication:

Education and information issues among people with diabetes.

ISBN 0 7308 9185 2.

1. Diabetics - Education - South Australia. 2. Diabetics - Services for - South Australia. 3. Patient education. I. Chittleborough, Catherine. II. South Australia. Dept. of Human Services.

616.4620071

Further copies of this publication may be purchased from CPSE or may be downloaded from the CPSE web site:
<http://www.health.sa.gov.au/pehs/cpse.html>

Table of Contents

EXECUTIVE SUMMARY.....	7
CHAPTER 1: INTRODUCTION.....	11
1.1 BACKGROUND.....	12
1.2 AIMS	14
1.3 ETHICS.....	14
CHAPTER 2: METHODOLOGY.....	15
2.1 NORTH WEST ADELAIDE HEALTH STUDY.....	16
2.1.1 Sample selection.....	16
2.2 QUALITATIVE METHODOLOGY	17
2.2.1 Focus group recruitment.....	17
2.2.2 Focus group participants	17
2.2.3 Focus group methodology	18
2.2.4 Qualitative data analysis.....	21
2.3 QUANTITATIVE METHODOLOGY.....	22
2.3.1 Questions.....	22
2.3.2 Data collection.....	22
2.3.3 Interviews undertaken	23
2.3.4 Data analysis	24
2.3.5 Participants.....	24
CHAPTER 3: RESULTS	25
3.1 RECURRENT THEMES OF FOCUS GROUPS.....	26
3.1.1 Where people with diabetes obtain diabetes-related information.....	26
3.1.2 Satisfaction with diabetes-related information obtained	27
3.1.3 Perceived gaps in diabetes-related information and education, and proposed solutions.....	27
3.1.4 In an ideal world, information that people with diabetes would like to receive and the format in which they would prefer this information.....	28
3.2 SUMMATIVE THEMES OF FOCUS GROUPS	29
3.2.1 Knowing how to access educational resources.....	29
3.2.2 The need for follow-up to ensure optimal information provision for evolving educational needs	29
3.2.3 Variability of information provision between general practitioners.....	30
3.2.4 “Diabetes is something you don’t always think about” but everyone needs to!.....	31
3.2.5 Using opportunistic networks for dissemination of educational information.....	33
3.2.6 Other specific education and information needs	34
3.3 QUANTITATIVE RESULTS	35
3.3.1 Satisfaction with diabetes-related information	35
3.3.2 Understanding of diabetes-related information	37
3.3.3 Improvements and changes to diabetes-related information	38
3.3.4 Access to diabetes-related information.....	39
3.3.5 Awareness of diabetes issues among the general community	42

CHAPTER 4: DISCUSSION.....	45
APPENDIX A:	51
APPENDIX B:	53
APPENDIX C:	55
APPENDIX D:	57
APPENDIX E:	59
APPENDIX F:	61
REFERENCES.....	73

Acknowledgements

This project was made possible by a Diabetes Australia Research Trust Program Grant. It formed part of the North West Adelaide Health Study, a collaborative project of the South Australian Department of Human Services, the University of South Australia, The University of Adelaide, and the North Western Adelaide Health Service (The Queen Elizabeth Hospital and Lyell McEwin Health Service campuses).

The authors would like to thank the other members of the study research team: Professor Richard Ruffin, A/Prof David Wilson and Ms Eleonora Dal Grande, Ms Jacqueline Hickling and the clinic staff for their contribution to this project, and Ms Karen Wake for her assistance with administration of the focus groups.

EXECUTIVE SUMMARY

This report details the qualitative and quantitative results of an investigation into the diabetes-related education and information issues among people with diabetes in the north west region of Adelaide. The 133 participants for the purposes of this study, of whom focus group participants (n=29) were a sub-set, comprised an almost equal number of men and women, with just over half aged between 50 and 69 years, and another third aged 70 years and over.

Source and amount of diabetes-related information received

- Three-quarters of participants reported speaking to a general practitioner about their diabetes in the last twelve months, and approximately 20% reported speaking to a nurse educator in a hospital-based diabetes centre or a specialist.
- Only 10% of people with diabetes had spoken with an optometrist or ophthalmologist in the past year, 9% with a dietitian, and 8% with a podiatrist. Another 10% had not spoken to any health professional about their diabetes in this time.
- Almost one-quarter of participants identified Diabetes Australia (24%) or its newsletter “Conquest” (24%) as a source of diabetes-related information, followed by the use of pamphlets, brochures and booklets, the Internet, and other people with diabetes.
- Focus group participants reported a high degree of satisfaction with diabetes classes held by general practitioners and with information obtained from diabetes associations and centres. Some participants expressed a need for more individual sessions with diabetes educators.
- Most study participants (75%) reported receiving a sufficient amount of diabetes-related information. However, approximately 1 in 5 study participants reported that they were not getting enough information about diabetes.

Satisfaction with type of information about diabetes

- Most participants reported being satisfied or very satisfied with the information and education they currently received.
- Some focus group participants reported dissatisfaction with the amount of attention that general practitioners are giving to their diabetes, with doctors sometimes being perceived as poor at monitoring blood glucose levels.
- The dissatisfaction expressed by some focus group participants did not relate to the quality of the information received, but with knowing where to get information and what to ask for.

Perceived gaps

- Focus group participants highlighted the need for people with diabetes to be reminded about ongoing consultation, and for this to be seen as an opportunity for them to be asked about their information needs.
- Participants reported a need for more information on diet and the long-term effects of diabetes on eyes, kidneys, feet and the cardiovascular system.

In an ideal world

- Focus group participants expressed an interest in speaking to educators and other people who have diabetes.
- Participants reported requiring more information about food preparation, food choices when shopping and dining out, and where to buy suitable foods, suggesting a labelling system to make shopping easier.
- Some focus group participants identified the need for more information to be made available in doctors' rooms and chemists, such as posters that outline symptoms of diabetes.
- They also requested information regarding the possible effects of other medications and conditions on their diabetes, and an interest in gaining a greater understanding of diabetes, why it occurs and the meaning of blood glucose levels.
- Focus group participants also suggested that general practitioners be more proactive about screening high-risk groups for undiagnosed diabetes, and that screening tests be more readily available in public areas, such as shopping centre malls, chemist shops, etc.
- Some focus group participants expressed an interest in a 24-hour telephone information service. However, only 42% of study participants considered that it would be somewhat or very useful.

Accessing information resources

- Some focus group participants reiterated initial difficulties with knowing which questions to ask to find the relevant information.
- The majority of study participants (94%) reported knowing where to go or who to ask to find out diabetes-related information.
- Only 14% of study participants reported ever using the Internet to access diabetes-related information.

Information and education beyond the initial diagnosis

- Many focus group participants felt that beyond the initial diagnosis of diabetes, information and education was more limited and ad hoc. This was supported by the results of the questionnaire, which found that 52% of people with diabetes who had been diagnosed for over twelve months felt that their information needs had changed since first diagnosis.

Variability among General Practitioners

- Diabetes clinics and classes run by general practitioners were generally considered an excellent source of information among focus group participants. Some focus group participants, however, expressed dissatisfaction with the provision of education and information from their general practitioners, yet were reluctant to change practitioners.
- This suggests a need for people with diabetes to be educated on how to communicate with their general practitioner about their education and information requirements.

Opportunistic networks

- Almost half (46%) of participants had attended a diabetes support group or session since being diagnosed with diabetes and, of these, 67% reported finding them very helpful. These opinions corresponded with comments made by focus group participants (some of whom were unaware that these type of groups existed), who felt that education and information from other people with diabetes was beneficial.

Diabetes is something that everyone needs to think about

- Overall, 47% of participants considered that people in the general community were not aware of things that could increase their chance of getting diabetes. There was general support for a community awareness campaign, particularly aimed at young people, to inform about issues such as high risk groups, symptoms of diabetes, preventive measures, where to get tested for diabetes and long term effects of the condition.
- It was also considered by some focus group participants that families and carers of people with diabetes also required more diabetes-related information.

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND

This study explored the issues about the diabetes-related education and information needs of people with diabetes who participated in the North West Adelaide Health Study. The North West Adelaide Health Study is an established biomedical cohort study of chronic conditions including diabetes, asthma, and chronic obstructive pulmonary disease among a representative population aged 18 years and over in the north west region of Adelaide. The north west region has a greater than average health burden and this, combined with a lower than average socioeconomic status, makes it a target for strategies to improve population health.

Diabetes is recognised as a health priority area at both a National and State level, due to its high overall burden of disease in terms of morbidity, disability and mortality, the potential for health gain through prevention and lessening of the impact of the disease, the existence of cost-effective interventions, and the disproportionate impact on certain sub-groups in the population^{1,2}. Data from more than ten years of population studies in South Australia has shown diabetes to be a disease that affects more than 4% of the adult population, and one which has a substantial impact on the physical and mental functioning, premature mortality and health service use³. Australia-wide, it is estimated that there are over 900,000 people with diabetes, many of whom do not know they have it⁴. A South Australian study has also identified a substantial under-diagnosed population; that is, people who have been told they have something other than diabetes, such as high blood sugar⁵.

In 1999, the National Diabetes Strategy 2000-2004 was released, with the aim of energising the National Diabetes Health Priority Area⁶. The National Diabetes Strategy stated that diabetes prevention and care should address the needs of individual consumers and communities and encourage their participation in decision making about the nature of the health services they require⁶. This is consistent with the increasing recognition of the importance of exploring the perspectives and views of consumers in order to better inform strategies for dealing with diabetes.

Studies such as the UK Prospective Diabetes Study have shown, through its advanced knowledge about the treatment and management of diabetes and related complications, that the management of risk factors is worthwhile⁷. The South Australian Diabetes Study identified, however, that risk factors for complications, particularly behavioural and self-care factors, are not yet well managed in people with diabetes⁸.

Hepworth and Mensforth⁹ qualitatively explored how people with diabetes managed their condition and identified that many gaps existed in the understanding of diabetes among people with the condition. In the case of diabetes complications, for example, few people were aware that cardiovascular disease was associated with diabetes, or that diabetes could cause problems with the renal system. Many were also unaware of the distinction between normal, everyday activities and the aerobic exercise required to lower insulin resistance and improve blood glucose levels. Most people in this study were members of Diabetes Australia, and were also appreciative of the role played by diabetes nurse educators. Information was obtained about the types of education that people with diabetes had received, such as literature or management courses, but satisfaction with this education and recommendations for changes were not explored.

Provision of education and information forms a major part of chronic disease management strategies. People with chronic disease who receive education are presumed to be in a better position to take responsibility for their own health, participate in their own health care and management, and thus maximize their health outcomes¹⁰. Knowledge and information, however, is not necessarily translated into action or better health behaviours^{11,12,13}. For example, adherence with health schedules in particular is determined in part by the person's individual perception of the disease and its management^{14,15}. Traditional compliance approaches have concentrated on the relationship between physician and patient, provision of information and improving knowledge^{10,16,17}. This disease- or doctor-centred approach, however, is limited in that it fails to address the wider context in which adherence is determined. An understanding is required of the individual's perspective of their disease, how they manage it, and how they think management, including education and provision of information, could be improved.

In line with the National Diabetes Strategy, for people with diabetes to effectively manage their diabetes and prevent diabetes-related complications, they need to understand the condition, its effect on health, and the practicalities of management¹⁸. For this to occur, we need to know about the educational resource requirements of people with diabetes, and in what form they would prefer these resources.

The use of both qualitative and quantitative methods in this study enabled comprehensive exploration of the views of people with diabetes about diabetes-related information and education. The study used focus groups, consisting of a sample of people with diabetes from the North West Adelaide Health Study, to explore the

views and perceptions about the content, usefulness, and access to current diabetes-related information and education among people with diabetes, as well as their perceived barriers to effective use of this information. Some issues arising from the qualitative investigation were also quantified through a survey of all North West Adelaide Health Study participants who had been told by a doctor that they had diabetes.

1.2 AIMS

The aims of this study were:

- To qualitatively determine the diabetes-related education and information needs and issues among people with diabetes;
- To quantify these needs and issues using a population questionnaire developed from the qualitative component of the study;
- To thereby identify the education and information needs of people with diabetes.

1.3 ETHICS

All necessary ethics approvals were obtained both from the University of South Australia and the North Western Adelaide Health Service Ethics Committees. Particular consideration was given to the principles of informed consent, self-determination including the ability to withdraw from the study at any time without prejudice, confidentiality of information and anonymity, protection from harm and secure storage of data. All focus group participants provided written consent.

CHAPTER 2: METHODOLOGY

2.1 NORTH WEST ADELAIDE HEALTH STUDY

2.1.1 Sample selection

Participants in the focus groups were recruited from the North West Adelaide Health Study. All households in the north western area of Adelaide with a telephone connected and the telephone number listed in the Electronic White Pages (EWP) were eligible for selection in the North West Adelaide Health Study. Participants in the North West Adelaide Health Study understood the longitudinal nature of the study and were aware that they may be contacted in the future for further interviews or biomedical assessments.

Of the 2510 participants in the North West Adelaide Health Study who attended their clinic appointment as part of that study, 5.5% (n=137) reported that they had been told by a doctor that they had diabetes (diagnosed diabetes). An additional 1.3% (n=31) had not been told by a doctor that they had diabetes, but had a fasting plasma glucose level greater than or equal to 7.0mmol/L (previously undiagnosed diabetes). All participants who attended the clinic were sent a letter of their biomedical results. Participants with a fasting plasma glucose level greater than or equal to 7.0mmol/L had this highlighted on their results letter and were recommended to attend their doctor to have their diabetes status checked.

The original study design included a proposal to qualitatively explore the education and information issues of both people with diagnosed and previously undiagnosed diabetes (from the North West Adelaide Health Study clinic) in four focus groups: two groups with diagnosed diabetes, and two groups with previously undiagnosed diabetes. An unanticipated problem arose, however, during recruitment for the focus groups. It was assumed that all participants with elevated blood glucose at their clinic appointment would subsequently be diagnosed with diabetes by their doctor. It was found, however, that participants classified as having newly diagnosed diabetes in the clinic were not, in fact, all diagnosed by their doctor as having diabetes at the time recruitment for the focus groups took place. This was either because they had not attended their doctor for follow-up of their clinic results or, if they had been to their doctor, a diagnosis of diabetes was not confirmed. Under the ethical obligations of the study, the study team was careful to ensure that diagnosis remained the responsibility of participants' general practitioners. In addition, since the aims of the study were to determine the education and information issues related to diabetes, it was not appropriate to include those people who had elevated blood glucose at their clinic appointment but who did not have a diagnosis of diabetes confirmed by a doctor.

In light of this, the study design was modified to conduct four focus groups of people who reported being told by a doctor that they had diabetes, that is, people with diagnosed diabetes. Participants classified as having previously undiagnosed diabetes from the clinic were therefore excluded from the study. Thus an important, albeit unintended, finding from the present study is the need for an improved mechanism in the North West Adelaide Health Study to determine whether the doctor has diagnosed diabetes following biomedical assessment. It also highlights the importance of researcher sensitivity when dealing with any group of participants, but particularly those whom may be confronted with the notification that they may have a chronic condition.

2.2 QUALITATIVE METHODOLOGY

2.2.1 Focus group recruitment

A random sample of participants in the North West Adelaide Health Study who reported being told by a doctor that they had diabetes were followed up with a telephone interview (Appendix A). The purpose of this interview was to invite them to take part in a focus group to explore the issues surrounding their diabetes-related information and education requirements. An appointment was made for individuals who expressed interest in participating in the study to attend a focus group. These respondents were sent a letter (Appendix B) confirming their focus group appointment time and location, and an information sheet about the study (Appendix C).

2.2.2 Focus group participants

The four focus groups were held at the two major hospitals that comprise the North Western Adelaide Health Service – The Queen Elizabeth Hospital (n=3) and The Lyell McEwin Health Service (n=1).

Focus group participants were required to:

- have a known diagnosis of diabetes;
- have previously participated in the North West Adelaide Health Study;
- be 18 years of age or over; and
- be able to speak and read English.

A total of 29 participants attended the focus groups. The four groups numbered 8, 7, 9 and 5 participants respectively. Demographic information about the participants is listed in Table 2.1. The mean age of participants was 67.5 years (SD 9.85 years, range 52 to 83 years).

Table 2.1: Focus group participants, by demographic variables

	n	%
Sex		
Male	20	69.0
Female	9	31.0
Area of residence		
Western Adelaide	24	82.8
Northern Adelaide	5	17.2
Total	29	100.0

2.2.3 Focus group methodology

A focus group “typically consists of six to twelve individuals who are asked to discuss topics suggested by a facilitator”¹⁹. Focus groups use a structured interview and group process to determine feelings and/or opinions of small groups of participants about an identified area or topic of interest. It is this collective activity on an area of focus that gives *focus* groups their name. The potential of focus groups to “obtain the views of clients, care-givers and service providers about health and health care”²⁰, has been gaining momentum in contemporary health research.

Focus groups are more than group interviews. The group interaction is instrumental in producing the data^{20,21,22,23}. As Gillis and Jackson point out, “some issues that would be raised in individual interviews may never be expressed in a group setting; on the other hand, as group members talk about issues, they may come up with suggestions and solutions that may not emerge from separate interviews”¹⁹.

Advantages of focus groups as a qualitative data collection technique include the relative ease of undertaking them (assuming an experienced and skillful facilitator), efficiency in terms of costs, the relatively rapid ability to obtain results and the fact that people tend to express views that they may not in other settings. The structure of a focus group enables the facilitator to clarify issues as they arise and explore any unanticipated but potentially fruitful discussions. Responses from focus groups have high face validity due to the clarity of the context and detail of the discussion. In this

study the investigator who facilitated the focus groups had extensive experience in the successful use of qualitative methods and facilitation of focus groups.

One disadvantage of focus groups, common to all qualitative research approaches, is the limited extent to which it is possible to generalize findings. In this study, however, triangulation²⁴ was used through the development of a questionnaire based on the findings of the focus groups, which enabled generalisability of results. A second disadvantage is that there is potential for more articulate or strong willed individuals to dominate group discussions: however the use of an experienced facilitator in our study addressed this issue. There was a strong emphasis on involving all participants by establishing clear understandings in the group about the topics for discussion and the need for all members to be able to contribute to the discussion.

2.2.3.1 Initial probes for focus groups

The initial probes forming the questioning route for the focus groups were determined by the focus of the study; namely satisfaction with current diabetes-related educational resources and their mode of delivery, ways in which they could be improved, and identification of where the gaps are in terms of these educational resources.

The probes were developed around three areas: the type of and level of satisfaction with educational resources, the methods used to access these resources, and ways in which these would apply “in the ideal world”. It must be emphasized that the probes were used as starting points with the focus group being conducted in an open-ended manner where participants were free to discuss any issues that were pertinent to them. The probes used are listed in Table 2.2.

Table 2.2: Initial probes for focus groups

	Probes
Area One: Educational Resources	<ol style="list-style-type: none"> 1. What are the educational resources about diabetes that you currently receive/utilize? 2. Where did you obtain information about the educational resources available? 3. How satisfied are you with these educational resources about diabetes? 4. What do you perceive are the gaps in educational resources about diabetes? 5. How do you think educational resources about diabetes could be improved?
Area Two: Accessing the Resources	<ol style="list-style-type: none"> 1. How do you gain access to the educational resources about diabetes? 2. How satisfied are you with your current access to educational resources about diabetes? 3. What do you perceive are the gaps in access to educational resources about diabetes? 4. How do you think access to educational resources about diabetes could be improved?
Area Three: In The Ideal World	<ol style="list-style-type: none"> 1. If you had to identify three major pieces of information you want about diabetes what would they be? Why? 2. When would you seek this information and how would you use it? 3. How, in an ideal world would you want to obtain this information? Where? What format? (E.g. pictures; text; length; size; detail)
Other issues	Participants were also asked if there were any other issues they would like to raise in relation to their diabetes educational needs.

2.2.3.2 Conduct of the focus groups

At each focus group the facilitator was assisted by two observers/recorders. In some groups, a few participants were accompanied by their partners who “sat in” on the focus group. During the introduction to the session, the aims and focus of the focus group were re-iterated, the way the focus group would be conducted was outlined, and all ethical issues regarding consent and participation were reinforced, including the fact that the session was being tape-recorded. Each participant read and signed the study consent form (Appendix D) before the commencement of the focus group. Each participant was given a \$20 honorarium to cover out of pocket expenses such as travel and car parking.

2.2.4 Qualitative data analysis

All focus groups were audio-taped and the tapes were then transcribed for analysis. The analysis involved four major stages^{25,26,27}:

- the entire tape was studied to give a sense of the whole;
- themes and categories were identified;
- recurrent patterns were identified;
- summative themes and research findings were developed.

To assist in ensuring validity, at least two members of the research team independently reviewed each transcript. Reviews were exchanged, any disagreements or differences identified were discussed and attempts were made to reach a consensus. Themes and issues across interviews were then generated and progressively grouped into categories of similar themes. This is in keeping with Norman et al²⁸ who point out that the “formulation of categories is done inductively by sorting the incidents into clusters that seem to group together”. The inductive analysis of the transcripts produced major categories of themes/issues pertaining to the educational requirements of people with diabetes.

With respect to operationalising the four stages of analysis outlined, the following analytic procedure was undertaken. Each focus group transcript was analysed around the three broad areas that formed the initial framework for the discussion. The results of this initial analysis for each focus group can be found in Appendix E. At this stage, content relevant to each probe area was identified and listed, excerpts of data illustrating points were noted and summative statements were identified. These statements were made by either the facilitator summarizing the interpretation of the discussions and clarifying the participants’ interpretation, or by group members encapsulating the thrust of the discussion up to a certain point.

2.3 QUANTITATIVE METHODOLOGY

2.3.1 Questions

The questions for this part of the study were based on the issues about diabetes-related education and information that emerged from the focus groups. The questionnaire was embedded within other questions as part of the North West Adelaide Health Study and is presented in Appendix F. This questions that specifically relate to the focus groups are F17 to F38, F42, and F43.

2.3.2 Data collection

The quantitative component of this study formed part of a follow-up interview of the North West Adelaide Health Study. In addition to the diabetes-related education and information issues, this interview investigated issues relating to diabetes complications, asthma, cardiovascular disease, and demographic and contact detail information for long-term tracking of participants. The entire questionnaire is listed in Appendix F. All participants (n=2510) who had previously undertaken the clinical component of the North West Adelaide Health Study were eligible for inclusion in this follow-up interview. Participants were sent a letter (Appendix E) informing them about this next stage of the North West Adelaide Health Study and that they would soon receive a telephone call.

When initial contact was made with the household, the interviewer initially identified themselves, the purpose of the survey and who they wished to speak with. Where required, appointments were made to call back at a more convenient time for the participant.

A Computer Assisted Telephone Interview (CATI) system was used to conduct the interviews. CATI provides a way of efficiently and reliably automating survey data by allowing immediate entry of data from the interviewer's questionnaire screen to the computer database. The advantage of this system is that it correctly sequences questions as specific answers are given. In addition, it enforces a range of checks on each response with most questions having a set of pre-determined response categories. CATI allows open-ended responses to be transcribed exactly by the interviewer.

Data collection was undertaken between 9.30am and 8.00pm. Professional interviewers conducted the telephone interviews and were supervised by study personnel. At least

six call-backs were made to the telephone number to interview the selected person. Different times of the day or evening were scheduled for each call-back. If a person could not be interviewed immediately, they were re-scheduled for interview at a time suitable to them. Where a refusal was encountered, the participant was not called back again. Replacement interviews for persons who could not be contacted or interviewed were not permitted.

2.3.3 Interviews undertaken

The overall sample response rate was 92.5%. From the 2510 participants to be contacted there was a loss of 157 participants due to non-connected phone lines (74), non-residential numbers (1), fax/modem connections (13), and incorrect phone numbers (69), therefore leaving an initial eligible sample of 2353. There was no contact after six attempts made to 97 participants, 7 refused to participate, and 32 were unavailable to participate. In addition, respondents were not interviewed because they only spoke a foreign language (2), were incapacitated (15), or were deceased (23). One interview was terminated. A total of 2176 interviews were conducted. The response rate was calculated as shown in Table 2.3. This report concentrates only on the participants who had been told by a doctor that they had diabetes (n=133).

Table 2.3 Response Rate

	n	%
Initial eligible sample	2353	100.0
Non contact-after 6 attempts	97	4.1
Refusal	7	0.3
Respondent unavailable	32	1.4
Foreign language	2	0.1
Incapacitated	15	0.6
Deceased	23	1.0
Interview terminated	1	0.0
Completed interviews	2176	92.5

2.3.4 Data analysis

Raw data from the CATI system were imported into SPSS for Windows format. Data were then analysed using SPSS Version 10. Data were weighted to Australian Bureau of Statistics Census data by age, sex, area of residence and probability of selection in the household to accurately reflect the North West Adelaide adult population.

2.3.5 Participants

When the data were weighted, the total sample was n=2124. The analysis for this report was conducted on the 133 participants interviewed (6.2%, 95% CI: 5.3 – 7.4) who had been told by a doctor that they had diabetes. Table 2.4 shows the age and sex profile of the participants.

Table 2.4: Age and sex profile of people with diabetes

	n	%
Sex		
Male	69	52.1
Female	63	47.9
Age group (years)		
18-39	11	8.1
40-49	11	8.3
50-59	30	22.8
60-69	38	28.5
70+	43	32.3
Total	133	100.0

CHAPTER 3: RESULTS

This chapter details the results of the qualitative and quantitative components of the study. Recurrent and summative themes that emerged from the focus groups (n=29) are identified. Results of the quantitative measurement of these themes (n=133) are then outlined.

3.1 RECURRENT THEMES OF FOCUS GROUPS

As noted in Section 2.2.4, refinement of themes and categories resulted in identification of recurrent patterns. The issues about diabetes-related education and information requirements identified by each focus group were aggregated and listed below. Several of the recurrent patterns were also quantitatively measured in the questionnaire, as detailed in Section 3.3.

3.1.1 Where people with diabetes obtain diabetes-related information

- General Practitioner (GP) in consultations;
- Classes held by a GP;
- Major hospitals (for example Royal Adelaide, The Queen Elizabeth, and Ashford Hospitals);
- Booklets and pamphlets from a doctor's surgery and hospital wards/outpatients;
- Diabetes associations and centres including:
 - Diabetes Australia, South Australia – located on Sir Donald Bradman Drive, Hilton, also has a telephone help-line service;
 - 'Conquest', the Diabetes Australia newsletter;
 - Diabetes Outreach Services and the Diabetes Centre at The Queen Elizabeth Hospital;
- Workplace;
- Opportunistic sources such as relative or friend's place of employment;
- Diabetes specialist;
- From participation in research about diabetes (Ashford Hospital);
- Media - television, radio, magazines;
- Books; and
- Dietician.

3.1.2 Satisfaction with diabetes-related information obtained

- Mixed satisfaction with information from GPs, with predominant dissatisfaction related to the amount of attention GPs give to patients' diabetes.
- High satisfaction with diabetes classes held by GPs.
- High satisfaction with information from Diabetes House (Diabetes Australia – South Australia) and diabetes associations in various formats including one-on-one verbal information, classes, monthly publications, and written pamphlets and booklets.
- Very often dissatisfaction was not with the quality of information received, but difficulty in accessing information, that is, knowing where to get information and knowing what to ask for.

3.1.3 Perceived gaps in diabetes-related information and education, and proposed solutions

- Lack of follow-up once diagnosed with diabetes. Phone calls or letters are needed to remind people to attend for follow-up consultations and to explain why this is important. Follow-up should also include assessment of information needs.
- GPs perceived as sometimes poor at monitoring patients' diabetes and remembering to do regular blood tests.
- Need more information on the full effects of diabetes, for example its effect on feet and eyes. There is also a perceived need for follow-up of these conditions in addition to diabetes, including follow-up information on these conditions.
- Would like more preventative information on associated conditions (feet, eyes etc) so that these may be avoided or identified quickly.
- Feel that there is not enough general awareness of diabetes. Strong consensus on the need for more widespread awareness campaigns about diabetes. Aspects of such awareness raising could include:
 - Targeting young people in schools for education;
 - A media campaign to inform the general population if they are at high risk or if they are experiencing symptoms of diabetes and have not been diagnosed;
 - Education for family members and carers of diabetics;
 - Education on both type 1 and type 2 diabetes;
 - Making GPs more aware about being proactive in testing more people for diabetes to reduce the number of people with undiagnosed diabetes;
 - Posters in doctors' surgeries outlining symptoms of diabetes;

- Diabetes testing caravans, similar to cholesterol testing;
- Emphasising the long term, “dramatic” effects of diabetes, such as blindness and amputation, in an effective media campaign.
- People with diabetes learn much from other people with diabetes and would like to attend support groups or have the opportunity to meet and talk.
- More information should be made available in doctors’ rooms and chemists.
- More one-on-one information should be available from diabetes educators.

3.1.4 In an ideal world, information that people with diabetes would like to receive and the format in which they would prefer this information

- To learn from educators who also have diabetes, and to meet with other people with the same condition.
- To know much more about food; not just what to eat but how to prepare food, making choices when dining out, how to make every day food choices, where to buy suitable foods, and dietary substitution. A labelling system ‘suitable for diabetics’ was suggested since shopping decisions can be difficult.
- To access more holistic information on diabetes, for example, about related effects on eyes, kidneys, and circulation, so that complications may be avoided. There is a need for more preventative (what to get checked and when) rather than just treatment information.
- To learn about the effect of diabetes on other conditions and medications.
- For their GPs to be more proactive concerning their diabetes, including more discussion of preventative measures and control.
- For more people to know about the high-risk groups to decide whether a test for diabetes would be advisable.
- To gain a greater understanding of their condition, why diabetes occurs and what their glucose readings mean so that they are better able to take a proactive role in their health by deciding when they need to see a doctor.
- For greater public awareness that begins at an early school age.
- For a general media campaign for increased diabetes awareness through television, radio, popular magazines (*Woman’s Day* etc).
- For information to be in simple language.
- (Some) to have access to a telephone information service especially when lack of physical proximity to services prevents access.

3.2 SUMMATIVE THEMES OF FOCUS GROUPS

The six summative themes that emerged from the specific, recurrent, content-based patterns identified in the focus group transcripts are detailed below. In addition, specific education and information needs articulated across groups have been identified. Several of the summative themes were also quantitatively measured in the questionnaire, as detailed in Section 3.3.

3.2.1 Knowing how to access educational resources

A very pervasive theme concerned difficulties with *how to get* information when it is required. Once participants had accessed information, they were generally satisfied with the information they received. There was a high satisfaction with information from specialized Diabetes Centres and in particular the magazine *Conquest*, a publication of ‘Diabetes Australia’. Some participants, however, had not accessed any information, as they did not know how to go about this. Among those who had obtained information, many reported initial difficulties finding that information. As one put it: “*You have to be a detective to find some stuff*” (1:5:271-272)^a. Therefore participants strongly identified the need for people with diabetes to be provided with the types of diabetes-related information that was available and from where it could be obtained: “*I think there is plenty of information available for diabetics for those who know how to get the information*” (2:4:231-232) and “*there is information about so long as you ask for it*” (2:6:360).

3.2.2 The need for follow-up to ensure optimal information provision for evolving educational needs

Another clear theme to emerge from the analysis was that although many participants were given information about diabetes when initially diagnosed, many felt that both the information provided, and actual access to information, beyond this initial stage was limited and very ad hoc. They spoke of the need for more ongoing and systematic provision of information, and a process to be put in place for follow-up of people with diabetes to ensure that their educational and information needs were being met.

As one participant talking about information and education provision put it:

^a (1:5:271-272) *The numbers in brackets are reference numbers for the transcripts of the tape recorded focus groups. The first number (1:5:271-272) refers to the transcript number, the second (1:5:271-272) to the page number, and the last (1:5:271-271) refers to the line numbers at which the quoted text appears in the transcript.*

“It can be overwhelming at first and you go home and think ‘I can’t cope’ especially if you don’t have a support system to help you. So if you did have the follow-up I think that would be very helpful for most people.” (4:4:215-217)

In addition, participants identified that they needed some initial knowledge or experience in order to know what other information they needed. They agreed with the summary statement *“You have to know enough to know what to ask for” (2:6:362)*. This is suggestive of a need for an incremental level of information provision - the exact nature of which will be determined by the individual concerned: *“a really important thing about the information is being available when you need it” (4:8:429-430)*. This highlights the continuing individual nature of information needs.

Further, often as participant’s health status changed, so did their information needs:

“So as you get sick with other things because of your condition you need to find out a little bit more” (2:4:182-183).

3.2.3 Variability of information provision between general practitioners

Participants had all obtained information and/or education about their diabetes from their GPs. This is not surprising given the centrality of the GP role in the ongoing management and monitoring of chronic conditions such as diabetes. A very apparent theme emerging, however, was the great variability in both the amount and quality of educational material that was provided by GPs. Responses covered the whole spectrum from;

“I am not satisfied with my GP. I don’t have a very high opinion of him” (2:3:164);

and

“My sister was told [by GP] she had diabetes and was told to change her diet nothing else, so she went to the shop and got ham and white bread, now how is that going to help?” (1:2:96-97);

to

“He [the GP] runs a diabetic clinic every three months with a nurse coming and he doesn’t expect me to go every time but I have gone a couple of times” (4:2:73-74);

and

“I get mine [information] from the GP. A class comes fortnightly and it has information for me” (2:1:38-39).

The GPs who ran classes or clinics for people with diabetes were thought of as an excellent source of information, and the classes were well received as a whole across all groups. There was some suggestion that younger, as opposed to older, doctors are more aware of the need to provide education and information about diabetes.

Of interest was the number of participants who expressed dissatisfaction about education provision from their GP about their diabetes, but who were unwilling or seemingly not desirous of changing GPs. Only one participant in all of the groups recommended changing GPs if information was not being provided and even this had a proviso – *“if he doesn’t you should change your doctor, but then you need to make sure he has your medical records”* (1:1:35-36).

3.2.4 “Diabetes is something you don’t always think about” (4:5:256) but everyone needs to!

A strong theme, with several inflections, was that the whole community needs information about diabetes – not just those who already have it. There was a very apparent emphasis among the groups on the need for education about the prevention of diabetes and not just the treatment and management of it, which appeared to participants to be the emphasis at present in most educational materials. Participants were adamant that everyone needs to know about diabetes – what it is, what it does to you, how it should be monitored and why, and what to do to minimize the chance of getting it:

“They should put pamphlets in every letterbox, warn people that way” (1:3:135).

Also:

“The most important thing is to get people to have a test for diabetes because there are lots walking around who don’t know they have it and sometimes they are in a very serious condition when they find out” (4:6:335-335).

Participants advocated a wide education campaign designed to raise general awareness of the condition both in terms of recognizing possible symptoms and what the condition can lead to. One group suggested this could be similar to the recent “Could it be asthma?” campaign. One participant captured the flavour of the discussion well when they stated:

“Like with cigarette packets saying what cigarettes do to you, use TV to make people more aware. Everybody watches TV; diabetes is just like smoking with its problems. Diabetes is probably far worse but there is more education of what smoking does to you than diabetes” (4:7:343-346).

In addition, participants felt awareness raising and education in the wider community context also needed to focus on understanding the needs of people with diabetes, such as in restaurants and at social events. As one person put it:

“It is hard when you go somewhere and everyone is sitting there with a beer or wine and you ask for a glass of water” (4:6:285-286).

Focus group participants also highlighted the need to educate the wider community about diabetic emergencies including medic alert bracelets. One participant noted:

“I have been kicked out of hotels because the bouncers thought I was drunk. There should be an educator to go around to all government departments and all hotels because how do you know that someone walking down the street isn’t a diabetic?” (4:4:223-225).

All four groups suggested that education about diabetes needed to start at an early age and recommended school curricula formally incorporate education about diabetes. This was both to encourage children to take long-term preventative measures such as watching what they eat, through to being aware of what to do if someone at school with juvenile diabetes collapses. The Internet was suggested as a strategic way in which younger people might be likely to access such educational resources.

Paralleling such calls for education in schools were suggestions that educational materials need to specifically target family members or significant others of people diagnosed with diabetes. Again the reasons were two-fold, firstly to recognize the need to be aware of what diabetes is and to be tested for it themselves:

“to make sure your children know about diabetes and work on the next generation, that they are aware of it and are aware they should be tested” (1:9:460-461);

and secondly, to know how to handle diabetes or diabetic emergencies:

“I think too as much as you need the education I think [it’s important] your partner gets it too. My wife was mortified to start with but once educated started to come around and after the first session she felt better” (4:5:273-275).

3.2.5 Using opportunistic networks for dissemination of educational information

This theme was implicit within much of the discussion. When asked where educational information about diabetes was obtained from, many participants spoke of the opportunistic use of friends, relatives or work-mates. The media, both printed and electronic, was also cited as a diabetes information source. These sources did not replace the use of GPs and other health-related practitioners or organizations as information providers – rather they were used in addition to these. Most focus group participants also reported undertaking self-education of some form, with varying degrees of success.

Participants highlighted that another excellent way to access educational resources and information was through interaction with other people with diabetes. There was a lot of interest in group information exchange as most participants felt that other people with diabetes were an excellent source of information:

“If a group of people were interested enough to meet once every six weeks or so and interact with each other and find out what is working and what isn’t, what new information is out there. I think a group of people together would work really well” (3:5:299-302).

For many participants, the focus group they were attending was their first real chance to interact with others with diabetes. It was noticeable that in all four groups many participants remained behind at the conclusion of the group to talk informally and ask each other questions. This suggests that less structured support networks and groups may be a means of accessing educational materials that is not yet fully tapped.

Further, participants felt that those who actually had the condition were better placed to offer education to those with diabetes:

“I think sometimes people that actually have the condition themselves might be able to educate a lot better and people could communicate with them on a different level” (3:7:403-405).

Participants believed that others with diabetes could be more empathetic and realistic, based on their own experience. As one participant remarked, commenting on the education received about diet *“dietitians are usually very thin, eat small meals and are not used to eating like us!” (3:7:417-418)*

3.2.6 Other specific education and information needs

Some specific education and information needs were identified by participants in addition to those already discussed in other parts of the findings reported here.

These needs included (listed here in no particular order):

- A better understanding of the cause of diabetes;
- A better understanding of fluctuations in blood glucose levels – what do the readings mean rather than simply being told what is a healthy range for the readings;
- Clearer information on all aspects of food preparation and consumption such as: shopping and food choice including navigating the supermarket and managing the budget; cooking; choices when dining out; alcohol consumption; specific product information;
- Information on the effect of the interaction between diabetes and other medical/health conditions – particularly those typical in older people;
- Education about the long-term effects of diabetes and what to expect especially with regard to preventing/minimizing these effects, for example on eyes and feet.

3.3 QUANTITATIVE RESULTS

Several of the recurrent and summative themes identified in the focus groups were quantitatively measured in a questionnaire administered to all study participants with diabetes (n=133). These quantitative results are listed below.

3.3.1 Satisfaction with diabetes-related information

The focus groups revealed mixed satisfaction with the amount of information received, and this issue was quantified in the questionnaire. Table 3.1 shows the amount of diabetes-related information and education that people with diabetes received.

Table 3.1: Amount of diabetes-related information received

Amount	n	%
Too much information	3	2.1
About the right amount	99	74.9
Not enough information	26	19.9
Don't know	4	3.1
Total	133	100.0

People with diabetes were asked how satisfied they were with the information and education they received about diet and the possible long-term effects of diabetes, both currently and when they were first diagnosed with diabetes (Table 3.2). People who were diagnosed within the last twelve months (n=16, 12.1%) were only asked about the information they receive now, not when they were first diagnosed.

Table 3.2: Satisfaction with information and education about diet and long-term effects of diabetes, currently and when first diagnosed.

	When first diagnosed		Currently	
	n	%	n	%
Diet				
Very satisfied	42	36.0	38	29.0
Satisfied	48	41.1	61	45.7
Mixed feelings	14	12.1	6	4.5
Dissatisfied	6	5.3	5	4.1
Very dissatisfied	1	1.1	1	1.0
Did not receive any information	3	2.5	20	14.9
Don't know	2	1.9	1	0.9
Long-term effects				
Very satisfied	46	39.6	38	28.6
Satisfied	43	36.8	68	51.4
Mixed feelings	10	8.3	5	3.8
Dissatisfied	7	6.0	6	4.6
Very dissatisfied	1	0.3	-	-
Did not receive any information	8	7.1	15	11.2
Don't know	2	1.9	1	0.4
Total	117	100.0	133	100.0

Those people (n=10) who were dissatisfied or very dissatisfied with the information and education they received currently about diet or the long-term effects of diabetes were asked the reasons why they were dissatisfied. These reasons are listed in Table 3.3.

Table 3.3: Reasons for dissatisfaction with information received about diet and long-term effects of diabetes

Reason*	n	%
Not enough information	4	42.9
Couldn't understand it	2	18.2
Not detailed enough	1	9.0
Other	7	70.0

* Multiple responses possible

3.3.2 Understanding of diabetes-related information

Focus group participants reported a need for a better understanding of diabetes, particularly in relation to their diet, the long-term effects of diabetes, and fluctuations in blood glucose levels. These issues were quantified in the questionnaire.

People with diabetes (n=133) were asked if they understood what foods they should be eating to best manage their diabetes. They were also asked if they understood about the possible long-term effects of diabetes on other parts of the body, such as eyes, feet, heart, nerves, kidneys. These responses are listed in Table 3.4.

Table 3.4: Understanding of diet and long-term effects of diabetes

	n	%
Understand foods should be eating		
Yes	123	93.0
No / Don't know	9	7.0
Understand about long-term effects		
Yes	125	94.6
No	7	5.4
Total	133	100.0

People with diabetes were asked if they ever measured their blood glucose levels (Table 3.5). Of those people who did measure their blood glucose levels, 89.5% reported that they understood why their glucose levels sometimes went up and down (Table 3.5).

Table 3.5: Understanding of blood glucose levels

	n	%
Do you ever measure your blood glucose level?		
Yes	120	90.2
No	13	9.5
Don't know	1	0.4
Total	133	100.0
Do you understand why your glucose levels might sometimes go up and down?		
Yes	107	89.5
No	10	8.7
Unsure/Don't know	2	1.5
Total	120	100.0

3.3.3 Improvements and changes to diabetes-related information

The perceived gaps in diabetes-related education and information were a recurrent theme of the focus groups. In addition, focus group participants noted that their education and information needs changed as their health status changed. These issues were therefore quantified in the questionnaire.

People with diabetes (n=133) were asked about the diabetes-related issues that they would like more education or information on. Their responses are listed in Table 3.6.

Table 3.6: Diabetes-related issues on which people with diabetes would like more education or information

Issue*	n	%
Diet	16	12.3
Long-term effects of diabetes on eyes	14	10.7
Long-term effects of diabetes on kidneys	14	10.7
Long-term effects of diabetes on heart or cardiovascular system	14	10.5
Long-term effects of diabetes on feet	12	8.9
Shopping for correct food	7	5.4
Measuring glucose/why levels go up and down	3	2.2
Dining out	2	1.7
Medication	2	1.4
Exercise/Fitness	1	0.4
Other	12	8.9
Already get enough information	44	33.3
None	43	32.6

* Multiple responses possible

People with diabetes who were diagnosed longer than twelve months ago (n=117) were asked if they felt that the type of information about diabetes that they needed had changed since they were first diagnosed (Table 3.7).

Table 3.7: Change in type of diabetes information needed

Do you feel that the type of information about diabetes that you need now has changed since you were first diagnosed?	n	%
Yes	60	51.6
No	49	42.4
Unsure/Don't know	7	6.0
Total	117	100.0

Some focus group participants felt that they would benefit from access to a telephone information service. People with diabetes (n=133) were therefore asked how useful a 24-hour diabetes information telephone service would be to them (Table 3.8).

Table 3.8: Usefulness of a 24-hour diabetes information telephone service

How useful would a 24-hour diabetes information telephone service be to you?	n	%
Very useful	11	8.3
Somewhat useful	44	33.4
Not useful	70	53.1
Don't know	7	5.2
Total	133	100.0

3.3.4 Access to diabetes-related information

Focus group participants reported obtaining their diabetes-related information from a variety of sources. These sources were further investigated in the quantitative questionnaire. People with diabetes (n=133) were asked which health professionals they had talked to about their diabetes in the last 12 months. Their responses are listed in Table 3.9.

Table 3.9: Health professionals that people have talked to about their diabetes in the last 12 months

Health professional*	n	%
General practitioner	99	74.7
Nurse educator (eg. at hospital-based diabetes centre)	28	21.2
Specialist	25	18.5
Optometrist / Ophthalmologist	13	10.0
Dietitian	12	8.9
Podiatrist	11	8.2
Diabetes Australia	5	3.6
Other nurse or doctor at hospital	3	2.5
Other	10	7.3
None	13	9.9

* Multiple responses possible

People who had talked to a health professional in the last 12 months (n=120) were asked how helpful they found talking to a health professional about their diabetes (Table 3.10).

Table 3.10: Helpfulness of talking to a health professional about diabetes

	n	%
Very helpful	72	60.1
Somewhat helpful	36	30.3
Not helpful	8	7.1
Don't know	3	2.6
Total	120	100.0

People with diabetes (n=133) were asked where, other than talking to a health professional, they obtained information about diabetes. Their responses are listed in Table 3.11.

Table 3.11: Other sources of information about diabetes

Source*	n	%
Diabetes Australia	32	24.1
“Conquest” Newsletter (from Diabetes Australia)	31	23.6
Pamphlets / brochures / booklets	21	16.2
Internet	13	10.1
Other people with diabetes	12	9.0
Books	10	7.8
Magazines	9	7.0
Doctors' surgeries / waiting rooms	9	6.7
Diabetes Centre (at a hospital)	8	6.3
Newspapers	8	5.8
Friends or family who are health professionals	4	2.8
Radio	3	2.5
Television	3	2.2
Pharmaceutical company	2	1.9
Other	9	6.5
No specific source / everywhere	1	1.0
Unsure / don't know	3	1.9
None - don't obtain any information	32	23.8

* Multiple responses possible

People with diabetes (n=133) were prompted further to determine if they had ever used the Internet to find information about diabetes. Their responses are listed in Table 3.12.

Table 3.12: Internet access

Have you ever used the Internet to find information about diabetes?	n	%
Yes	19	14.3
No	114	85.7
Total	133	100.0

People with diabetes were asked if they had ever attended a diabetes support group or group session where they had met and talked with other people who had diabetes (Table 3.13). Of those people who had attended such a session, 93.2% found them to be at least somewhat helpful. Of those people who had not attended such a session, 52.3% thought they would be at least somewhat helpful (Table 3.13).

Table 3.13: Diabetes support groups or group sessions

	n	%
Have you ever attended a diabetes support group or group session where you have met and talked with other people who also have diabetes?		
Yes	60	45.5
No	72	54.5
Total	133	100.0
How helpful did you find these sessions?		
Very helpful	41	67.3
Somewhat helpful	16	25.9
Not helpful	4	6.9
Total	60	100.0
How helpful do you think these sessions would be?		
Very helpful	13	17.9
Somewhat helpful	25	34.4
Not helpful	30	41.0
Unsure / don't know	5	6.7
Total	72	100.0

People with diabetes were asked if they knew where to go or who to ask if they needed to know something about their diabetes (Table 3.14).

Table 3.14: How to find information if needed

If you need to know something about diabetes, do you feel you know where to go or who to ask to find out that information?	n	%
Yes	125	94.2
No	8	5.8
Total	133	100.0

3.3.5 Awareness of diabetes issues among the general community

A major theme of the focus groups concerned the awareness of diabetes among the general community. Questions about the perceived awareness of diabetes in the community were included in the quantitative questionnaire.

People with diabetes were asked how aware they thought people in the general community were about things that could increase their chance of getting diabetes (Table 3.15).

Table 3.15: Awareness among community about things that could increase chance of getting diabetes

	n	%
Very aware	10	7.5
A little aware	50	38.0
Not at all aware	62	46.9
Unsure / don't know	10	7.6
Total	133	100.0

People with diabetes were asked what diabetes issues people in the general community need to be made aware of. Their responses are listed in Table 3.16.

Table 3.16: Diabetes issues of which the general community need to be made aware

Issue*	n	%
Symptoms of diabetes	21	16.1
How to prevent getting diabetes	19	14.2
Diet	18	13.6
Where to get tested for diabetes	18	13.4
Long-term effects (eg. On eyes, feet, heart, kidneys etc)	18	13.4
Different types of diabetes	7	4.9
Regular checkups	6	4.8
Education of children / young people	6	4.7
General awareness	6	4.3
Family history as a risk factor	5	3.8
Exercise / Fitness	5	3.6
Overweight / Obesity	4	3.4
What it means to have diabetes (for partners, carers, friends)	4	3.4
How to help a person who is having a diabetic emergency episode	3	2.3
Management / control of diabetes	3	2.3
It can happen to anyone, any time	3	2.1
Causes	2	1.2
Risk factors / lifestyle that lead to diabetes	1	1.0
Seriousness of diabetes	1	1.0
Alcohol	1	0.6
Sugar content in foods	1	0.5
Prevalence of diabetes	1	0.5
Other	12	9.4
People in general community are already very aware of diabetes issues	2	1.3
Unsure / don't know	25	18.6

* Multiple responses possible

CHAPTER 4: DISCUSSION

Almost 20% of people with diabetes reported that they were generally not getting enough information about their diabetes. Most questionnaire respondents were satisfied or very satisfied with the information and education they had received in relation to diet and long-term effects of diabetes. Education on nutrition has been shown elsewhere to be effective in improving metabolic control, which in turn reduces morbidity and mortality associated with diabetes²⁹. Approximately 15% of questionnaire respondents, however, were currently not receiving any information on diet, and 11% were currently not receiving any information about the long-term effects of diabetes. Despite this, the reported understanding of diet and long-term effects was high, with 93% reporting that they understood about what foods they should be eating, and 95% reporting that they understood about the long-term effects of diabetes. This study, however, did not measure the proportion of respondents who actually did follow an appropriate diet, or who, for example, quit smoking for their long-term health.

Almost two-thirds of questionnaire respondents reported that they already received enough information, or that they did not want more information about any diabetes-related issues. This finding, which also emerged in focus group discussions, suggests that emphasis in educational resource provision therefore perhaps needs to move beyond considerations of the development of more information or even the form that information should take. Instead, focus also needs to be on how to promote existing information and how to access and use it. A contradictory finding from the questionnaire, however, was that, when prompted, almost all respondents reported that they knew how to find diabetes-related information if they needed it. Measurement of blood glucose levels is a common management practice for people with diabetes and, although this was raised as an issue in the focus groups, only 9% of questionnaire respondents reported that they did not understand why their glucose levels sometimes fluctuated.

Three-quarters of people with diabetes had talked to a general practitioner about their diabetes in the past year. Only approximately 10% of people with diabetes had talked to a dietitian, podiatrist, or optometrist or ophthalmologist in the past year, even though these health professionals may be instrumental in preventing and delaying the development of diabetes complications. Ten percent of people with diabetes had not talked to any health professional about their diabetes in the past year. Part of the role of the health care professional is to provide the knowledge, skills and support to empower the person with diabetes to make behaviour changes and manage their condition effectively³⁰. A recent American study, however, found that health care providers were more confident in their ability to instruct patients on issues such as diet and exercise

than on their ability to help them make changes in these areas³¹. Governmental, financial and time constraints limit how health care professionals can perform their role³⁰. The Commonwealth initiatives of the Enhanced Primary Care Package and Practice Incentives Program, aimed at improving the coordination of care of people with chronic conditions, may help to improve the links between general practitioners and other health services in order to prevent or effectively manage diabetes-related complications.

A clear theme emerging from the focus groups was the need for systematic follow-up on the education and information being provided by health care professionals. This follow-up should be as integral to the ongoing management of diabetes as follow-up routine checks on blood glucose levels. There is an ongoing need for information related to individual circumstances and not all information is needed initially. The need for diabetes-related knowledge may change or evolve, for example due to increasing age and changes in health status. Indeed, half of the questionnaire respondents who had been diagnosed for over a year felt that the type of information about diabetes that they needed had changed since they were first diagnosed. Although the focus groups were generally made up of people in the older age groups, issues were quantified in the questionnaire among people with diabetes of all ages.

Diabetes Australia was a common source of information for people with diabetes. Only 14% of respondents used the Internet to access information about diabetes, indicating that efforts to disseminate information through this medium may not reach the target audience. A recent South Australian study found that Internet access decreased with age, although the prevalence of online health seekers was constant³². It was concluded that the Internet can deliver public health information to a critical mass of Australians, but that such resources should not be developed at the expense of the elderly and the poor who are less likely to access them. This is particularly true for diabetes information, which is relevant for the population in the older age groups. Information disseminated via the Internet may become more important in future, however, as diabetes becomes more prevalent in people of younger ages, and more consumers turn to the Internet as a source of information³³.

Less than half of the questionnaire respondents thought that a 24-hour diabetes information telephone service would be useful to them. The question about the 24-hour telephone support service was included in the quantitative questionnaire not only because it was raised in the focus groups, but because it was considered a worthwhile strategy to investigate as part of the Strategic Plan for Diabetes in South Australia².

Results from the quantitative questionnaire showed that diabetes support groups or group sessions were viewed as helpful among those who had attended such groups. Of those who had not attended a group session, at least half thought that such a session would be helpful. This finding provides support for maintenance and continuation of group sessions and networks by diabetes centres and other agencies. Group sessions have been shown to be effective settings for interventions focused on knowledge, lifestyle or skills³⁴. Talking to others with diabetes, and being able to ask questions in a safe environment, can be a valuable form of support and encouragement, and can be utilized as a mode of educational delivery, possibly by trained facilitators who themselves have the experience of having diabetes.

General practitioners were identified as a major source of referral to other sources of information. It is therefore important that they have systematic, up-to-date information about such additional sources. The fact that friends, relatives, co-workers and the media were also used as sources of diabetes information suggests they could be harnessed positively in the provision of educational materials. It is important that health care providers are aware of where people with diabetes are getting information and education about their condition so that they can ensure that this information and education is accurate and can advise on how best to use and evaluate this information. If such sources are dismissed as irrelevant or unimportant, then the opportunity to correct any inaccurate information is lost. Such knowledge also enables health care providers to build on the education people have gained, ensuring an ongoing, formative approach to educational provision.

Almost half (47%) of people with diabetes thought that the general community was not aware of things that increase the risk of developing diabetes. Awareness of diabetes and the factors that increase the risk of developing the condition among the general population is essential for effective prevention. Awareness is also important for early detection, particularly given the prevalence of undiagnosed diabetes. The North West Adelaide Health Study estimated that for approximately every four people with diagnosed diabetes, there is one person with undiagnosed diabetes³⁵. The AusDiab study estimated this ratio to be even higher, with one undiagnosed for each diagnosed case⁴.

The finding that the general community needs to be made more aware of diabetes has implications for the development of diabetes educational materials and health promotion programs. The best ways of raising community awareness of diabetes in terms of the need for testing, understanding what diabetes is, the lifestyle impact

diabetes has on those who have it, and knowing what to do if involved in a diabetes-related health emergency situation, need to be explored. Educational materials are not only required for people who have diabetes – ‘everyone needs them’ was a clear finding that emerged. Schools, as well as families and significant others of those with diabetes need to be involved in, and provided with, educational programs and materials about diabetes and have access to information including where to get more information.

The present study was limited in that it excluded people who did not speak English. Non-English speaking population groups, from various cultural backgrounds, would have different diabetes education and information needs. This study also only included people with diabetes living in the north west region of Adelaide. Differences in service provision and other demographic, geographic and socio-economic factors may result in variation of the education and information issues and needs among people with diabetes across regions of Adelaide and South Australia.

Overall, most questionnaire respondents reported satisfaction with the information and education they had received about diabetes. This is an interesting finding given that the focus groups tended to highlight dissatisfaction with information and education. Both the qualitative and quantitative results outline specific issues about which people with diabetes would like more information. Further research is required to determine if the perception of satisfaction with information is equal to actual knowledge about these issues when tested. There is potential for the North West Adelaide Health Study to investigate not only whether satisfaction with information and education is associated with a correct understanding of diabetes-related issues, but also whether this knowledge is translated into healthy behaviours. The findings also suggest a need for more ongoing education and support for general practitioners in terms of information about the diabetes-related educational resources that are available and how they can enable their patients to tap into such resources. Group sessions for education appear to be worthwhile investments, and providing resources for such sessions should be encouraged. People with diabetes also reported on the lack of awareness among the general community of diabetes-related issues, particularly prevention issues, which should continue to be the focus of health promotion policies and interventions.

APPENDIX A:

Recruitment interview for focus groups

**North West Adelaide Health Study
(DART grant)
Recruitment for focus groups**

CASE NUMBER: _____
 PHONE NUMBER: _____
 DATE OF INTERVIEW: ___ / ___ / 2001

1. Introduction

Good My name is from the North West Adelaide Health Study. A member of this household took part in the North West Adelaide Health Study last year at The Queen Elizabeth Hospital or the Lyell McEwin Health Service.

The person who took part in this study was
 Name _____ or
 [Age _____ Sex _____]

Is that you?
 Yes [] Go to 2. Recruitment
 No []

Can we speak to him/her now?
 Yes [] Go to 1. Introduction
 No [] Make appointment or
 note reason for refusal

2. Recruitment

In the North West Adelaide Health Study you told us that you had diabetes, or the results of your biomedical test in this study indicated that you might have diabetes. Is that correct?

Yes []
 No [] Go to Not eligible (3)
 Don't know [] Go to Not eligible (3)

Would you be interested in taking part in a focus group investigating your views on any diabetes-related educational resources and information that you have received since being told you had diabetes?

Yes [] Go to Information (4)
 No [] Thank you very much
 More information needed
 [] Go to 4. Information

3. Not eligible

We need to speak with people in the North West Adelaide Health Study who have diabetes, or who had a high blood glucose level according to their biomedical test. Obviously that does not include you.
 Thank you for your time.

4. Information

An information sheet outlining the study, and a consent form for you to sign will be sent out to you.

The focus group will only take about an hour and half. It will be held at The Queen Elizabeth Hospital. The location and map will be sent out with the information sheet.

You will receive \$20.00 to cover your travelling costs.

[Can read more details about the focus group from the information sheet.]

5. Venues, dates and times

[need 8 to 10 in each]

Date, time []
 Venue

Date, time []
 Venue

6. Postal Address

Name: _____

Address: _____

Thank you very much for being willing to be a part of this study.

APPENDIX B: Focus group letter

Dear «Title» «LastName»

Thank you for agreeing to take part in a focus group for part of the North West Adelaide Health Study. This part of the study is a qualitative investigation of educational issues among people with diabetes.

More information about the focus group is provided in the enclosed *Information Sheet for Focus Group Participants*.

If you have any questions or concerns, please feel free to contact Catherine Chittleborough, the coordinator for this part of the study, on **8226 0788**. If you wish to contact someone not involved in the study, please call Dr Linley Hartman, Chair of the University of South Australia Human Research Ethics Committee, on 8302 0327.

Your assistance in this important study is very valuable and greatly appreciated. We look forward to meeting with you at the focus group.

The North West Adelaide Health Study team.
14 Nov 2001

Your Focus Group meeting is at

«Hospital»
on «Datetime»
in the «Mtgroom»

APPENDIX C: Focus group information sheet

“Educational needs of people with newly diagnosed and established diabetes”

INFORMATION SHEET for FOCUS GROUP PARTICIPANTS

We are interested in what members of the community with diabetes think about the information and educational resources about diabetes that they have received or accessed. If they have not received or accessed any information about diabetes, we are still interested in what they need in terms of diabetes education and information. In order to gain access to community views we are conducting Focus Group interviews with participants of the North West Adelaide Health Study.

A Focus Group is a group discussion with 8-10 participants led by a facilitator. The aim of a Focus Group is to allow the participants to talk openly about the topic being studied. For this project, the Focus Group will include a group of people with diabetes from the community who are interested in talking to us about the diabetes-related information they have received since being diagnosed with diabetes, where they got it from, and what their views are on how information for people with diabetes can be improved. The discussion is audio-taped and then transcribed word for word.

The Focus Groups will be approximately 1.5 hours in length and will take place in a comfortable room at either The Queen Elizabeth Hospital or Lyell McEwin Health Service. The date and time for the Focus Group will be organised to suit all the participants. The information you share in the Focus Group will not be given to anyone except the researchers involved in the project. Your anonymity and confidentiality will be protected as no information identifying you will be kept with the audio-tape or transcript of the Focus Group discussion.

Your participation in the study is voluntary. If you agree to take part in this study you are free to change your mind and withdraw at any time. You can refuse to answer any questions and to request that any information provided by you may not be used in this research.

There will be a \$20.00 honorarium available for your participation.

We look forward to hearing your views on this important topic and thank you in anticipation of your help.

Questions?

If you would like more information about the study or have any concerns, you may wish to initially contact researchers, Ms Catherine Chittleborough (08) 8226 0788, or Professor Julianne Cheek (08) 8302 2675. If you would like to speak to someone not directly involved in the study, you may contact Dr Eimear Muir-Cochrane (Chair of the University of South Australia Human Research Ethics Committee) (08) 8302 2571, fax (08) 8302 2830.

APPENDIX D: Focus group consent form

CONSENT FORM - TO PARTICIPATE IN A FOCUS GROUP INTERVIEW

Project: “A qualitative investigation of educational issues among people with diabetes” – Part of the North West Adelaide Health Study

Researcher’s names: Professor Julianne Cheek

- I have read the Information Sheet, and the nature and the purpose of the research project have been explained to me. I understand and agree to take part in a Focus Group Interview.
- I understand that I may not directly benefit from taking part in the study.
- I understand that while information gained during the study may be published, I will not be identified and my identity will remain confidential.
- I understand that I can withdraw from the study at any stage and that this will not affect my status with the North West Adelaide Health Service or the University of South Australia now or in the future.
- I understand that I will be audio-taped during the interview and the tape transcribed.
- I understand that the tape will be stored in the Centre for Research into Nursing and Health Care and that only the researchers associated with this study will have access to the tape.
- I confirm that I am over 18 years of age.

Name of Participant:

Signed:

Dated:

I have explained the study to the subject and consider that he/she understands what is involved.

Researcher’s signature and date

**APPENDIX E:
Approach letter
for quantitative interview**

5 April 2002

Dear

Thank you for your continued participation in the North West Adelaide Health Study. By attending the clinic you have contributed valuable health information to the study.

We would now like to understand about changes that have occurred to your health since you visited the study clinic.

One of our interviewers will be contacting you in the next few weeks. The interview will be conducted over the telephone and will take around 15 minutes. All information collected will be confidential.

Your participation in the study is very important. The information will make a considerable difference to the future of health services and health outcomes for people living in this region.

If you have any queries about the study please contact Anne Taylor on 1800 635 352.

Yours sincerely,

A handwritten signature in black ink that reads "Richard Ruffin". The signature is written in a cursive style with a large, sweeping initial 'R'.

Dr Richard Ruffin
Professor of Medicine
The University of Adelaide
North Western Adelaide Health Service

APPENDIX F: **Quantitative questionnaire**

CASE: _ _ _ _

A. INTRODUCTION

A1 Good My name is from the North West Adelaide Health Study. May I speak withplease?

Either

1. Get person and repeat introduction
2. Make appointment to call back later

A2 You very kindly helped us by coming to the clinic for the study. Your comments now can help us understand any changes that have occurred in the time since your visit to the clinic. Would you have some time to answer a few questions?

1. Yes Go to A4
2. No – make appointment to call back later Thank you
3. No - Refusal Go to A3

Interviewer note: Can send introductory letter if requested by participant.

A3 Thank you for your involvement in the study so far. The study coordinator will call you to discuss your further involvement in the study.

Sequence guide: End.

A4 I can assure you that information you give will remain confidential. The answers from all people interviewed will be gathered together and presented in a report. No individual answers will be passed on.

Sequence guide: Go to B.

B. GENERAL HEALTH

The following questions are about your general health.

B1 Compared to the time when you had your clinic appointment for our study, how would you rate your health in general now?

(Single Response. Read Options)

1. **Much better now**
2. **Somewhat better now**
3. **About the same**
4. **Somewhat worse now**
5. **Much worse now**
6. **Unsure/Don't Know**

B2 Since your clinic appointment, have you been told by a doctor that you have any of the following conditions?

(Read Options. Multiple Response.

Interviewer Note: "Since your clinic appointment" includes seeing the doctor for follow-up of clinic results)

1. **Heart attack**
2. **Stroke**
3. **Angina**
4. **Heart disease**
5. **Diabetes**
6. **Asthma**
7. **Bronchitis**
8. **Emphysema**
9. **None of these**

B3 Since your clinic appointment, have you been admitted to hospital ...?

(Read Options. Multiple Response)

1. **With a heart attack**
2. **With angina**
3. **With heart failure**
4. **As a result of a stroke**
5. **For bronchitis**
6. **For emphysema**
7. **None of the above**

B4 How many times have you used these health services in South Australia in the last 12 months?

(Multiple response. Read Options.
Interviewer note: 0=none, 9999= unsure/don't know)

- | | |
|---|-----|
| 1. General practitioner | [] |
| 2. Community health centre | [] |
| 3. District nurses or other community nurses | [] |
| 4. Psychologist | [] |
| 5. Psychiatrist | [] |
| 6. Day surgery | [] |
| 7. Hospital – Accident & Emergency Department | [] |
| 8. Hospital – Clinic (outpatient/ specialist / allied health) | [] |
| 9. Eye specialist / ophthalmologist | [] |
| 10. Other specialist doctor (not in a hospital) | [] |
| 11. Physiotherapist | [] |
| 12. Chiropractor | [] |
| 13. Alternative therapist eg. naturopath, osteopath | [] |
| 14. Podiatrist | [] |
| 15. Dietician | [] |
| 16. Nurse educator | [] |
| 17. Other (specify) _____ | [] |
| 18. Unsure/Don't Know | [] |

C. GENERAL QUESTIONS

So that your information is kept up to date, these next few questions are about your personal and contact details.

C1 Could you please tell me if any of your contact details have changed since you attended the clinic?

1. Yes - Name (specify)

2. Yes – Street Address (specify)

3. Yes – Suburb (specify)

4. Yes – Postcode (specify)

5. Yes – Phone Number (specify)

6. Yes – Mobile Number (specify)

7. No []

C2 Our records show that your marital status is Is this still correct?

(Single Response)

1. Yes [] Go to C4
2. No []
3. Don't know []

C3 What is your marital status now?

(Single Response)

1. Married or living with a partner []
2. Separated / Divorced []
3. Widowed []
4. Never married []

C4 Our records show that your work status is Is this still correct?

(Single Response)

1. Yes [] Go to D.
2. No []
3. Don't know []

C5 What is your work status now?

(Single Response)

1. Full time employed []
2. Part time / casual employment []
3. Unemployed []
4. Home duties []
5. Retired []
6. Student []
7. Other (specify) []

D. RESULTS LETTER

These next questions are about your results from the clinic appointment you attended. On this letter you may have been advised to see your doctor if your results were marked with an asterisk or star.

D1 Do you remember receiving a letter about the results of your clinic appointment?

(Single Response)

1. Yes []
2. No [] Go to E.
3. Unsure/Don't Know []

Sequence guide: If Clinic Results Blood pressure \geq 140/90 Go to D2. Else Go to D3.

D2 Our records show that you may have had high blood pressure at your clinic appointment. Did you do anything about this?

(Multiple Response)

1. Yes - Saw doctor []
2. Yes - Other (specify) _____
3. Was already seeing doctor / having treatment before attending clinic / receiving results letter []
4. No []

D3 Sequence guide: If Clinic Results cholesterol $>$ 5.5mmol/L Go to D3. Else Go to D4.

D3 [Our records / They also] show that you may have had high cholesterol at your clinic appointment. Did you do anything about this?

(Multiple Response)

1. Yes - Saw doctor []
2. Yes - Changed diet []
3. Yes - Other (specify) _____
4. Was already seeing doctor / having treatment before attending clinic / receiving results letter []
5. No []

D4 Sequence guide: If Clinic Results BMI \geq 25 Go to D4. Else Go to E.

D4 [Our records / They also] show that you may have been overweight at your clinic appointment. Did you do anything about this?

(Multiple Response)

1. Yes - Saw doctor []
2. Yes - Changed diet []
3. Yes - Exercise more []
4. Yes - Other (specify) _____
5. Was already seeing doctor / having treatment / taking action before attending clinic / receiving results letter []
6. No []

E. ASTHMA

Sequence guide: If Self-reported Asthma = Yes (From Recruitment/Questionnaire A) Go to E1.

Sequence guide: If B2.6 = 1 (Asthma = Yes) Go to E6.

Sequence guide: If Clinic Results FEV1 Preventolin <80% Go to E3.

Else Go to F.

E1 Our records show that you told us you had asthma. Is that correct?

(Single Response)

1. Yes – have asthma [] Go to E6
2. No – do not have asthma []
3. Unsure/Don't Know []

E2 So to confirm that, have you ever been told by a doctor that you have asthma?

(Single Response)

1. Yes [] Go to E6
2. No [] Go to F.
3. Unsure/Don't Know [] Go to F.

E3 Our records show that at your clinic appointment your lung function was below the normal level. Did you do anything about this?

(Single Response)

1. Yes – saw doctor [] Go to E5
2. Yes – quit smoking []
3. Yes – cut down smoking []
4. Yes – Other (specify) []
5. No []

E4 Since your clinic appointment, has a doctor confirmed that you have asthma?

(Single Response)

1. Yes [] Go to E6
2. No [] Go to F.
3. Unsure/Don't Know [] Go to F.

E5 When you saw the doctor, did they confirm that you have asthma?

(Single Response)

1. Yes []
2. No [] Go to F.
3. Unsure/Don't Know [] Go to F.

E6 Do you still have asthma?

(Single Response)

1. Yes []
2. No [] Go to F.
3. Don't know [] Go to F.

E7 The next questions are about your asthma.

Have you been woken from sleep by asthma in the past month?

(Single Response)

4. Yes []
5. No []
6. Don't know []

E8 Have you been admitted to hospital because of asthma in the past year?

(Single Response)

1. Yes []
2. No []
3. Don't know []

E9 How many GPs have you seen for your asthma in the last 12 months? (Interviewer note: How many *different* GPs have you seen, not how many times have you been to any GP.)

(Single Response)

1. One []
2. More than one []
3. Have not seen a GP in last 12 months []

E10 How would you rate the severity of your asthma in the last month?

(Single Response)

1. Not a problem []
2. Mild []
3. Moderate []
4. Severe []
5. Don't know []

E11 Have you taken oral steroid medication for asthma in the past month (eg. cortisol, prednisolone)?

(Single Response)

1. Yes []
2. No []
3. Don't know []

E12 How often do you awaken during the night with asthma?

(Single Response)

1. Nightly []
2. Most nights []
3. About twice a week []
4. Weekly []
5. Monthly []
6. Less often than monthly []
7. Only at certain times of the year (i.e. seasonal) []
8. Never []

E17 Can you afford to buy your asthma medications when you need them?

(Single Response)

1. Yes – all of the time []
2. Yes – some of the time []
3. No []

E13 How often have you had an attack of asthma in the last twelve months?

(Single Response)

1. None []
2. Once or twice in last twelve months []
3. More than twice to once a month []
4. More than once a month to once a week []
5. More than once a week to once a day []
6. More than once a day []

E14 In the last twelve months have you had any days lost from work, school or home duties or usual activities from asthma?

(Single Response)

1. Yes []
2. No [] Go to E16

E15 How many days would you estimate?

(Single Response. Enter 999 if not stated)

1. Enter days _ _ _
2. Don't know []

E16 Do you have an asthma action plan (written instructions of what to do if your asthma is out of control)?

(Single Response)

1. Yes []
2. No []
3. Unsure/Don't Know []

F. DIABETES

Sequence guide: If Self-reported Diabetes = Yes (From Recruitment/Questionnaire A) Go to F1.

Sequence guide: If B2.1 = 1 (Diabetes = Yes) Go to F6.

Sequence guide: If Clinic Results Blood glucose ≥ 6.1 mmol/L Go to F3.

Else Go to F39.

F1 Our records show that you told us you had diabetes. Is that correct?

(Single Response)

1. Yes – have diabetes Go to F6
2. No – do not have diabetes
3. No – have high blood sugar
4. Unsure/Don't Know

F2 So to confirm that, have you ever been told by a doctor that you have diabetes?

(Single Response)

1. Yes Go to F6
2. No Go to F39
3. Unsure/Don't Know Go to F39

F3 Our records show that at your clinic appointment your blood glucose level was above the normal level. Did you do anything about this?

(Single Response)

1. Yes – saw doctor Go to F5
2. Yes – changed diet
3. Yes – Other (specify)
4. No

F4 Since your clinic appointment, has a doctor confirmed that you have diabetes?

(Single Response)

1. Yes Go to F6
2. No Go to F39
3. Unsure/Don't Know Go to F39

F5 When you saw the doctor, did they confirm that you have diabetes?

(Single Response)

1. Yes
2. No Go to F39
3. Unsure/Don't Know Go to F39

F6 How old were you when you first were told you had diabetes?

(Enter number of years. Enter 999 if unknown. Single Response)

1. Years _ _ _
2. Don't know

F7 Is that within the last 12 months?

(Single Response)

1. Yes
2. No

F8 During the past 12 months, did your diabetes interfere with your ability to work, study or manage your day-to-day activities?

(Single Response)

1. Yes
2. No Go to F10
3. Unsure/Don't Know Go to F10

F9 Did it interfere with these activities:?

(Read Options. Single Response)

1. A little
2. Moderately
3. Quite a lot
4. Extremely
5. Don't know

F10 Have you ever been told by a doctor that your vision has been affected because of your diabetes?

(Single Response)

1. Yes
2. No
3. Unsure/Don't Know

F11 Have you had your eyes examined by a doctor or an optometrist in the previous 12 months because of your diabetes?

(Single Response)

1. Yes
2. No
3. Unsure/Don't Know

F12 Have you ever had laser therapy on your eyes because of your diabetes?

(Single Response)

1. Yes
2. No

F13 Have you ever had cataract surgery?

(Single Response)

1. Yes []
2. No []

F14 Do you often suffer tingling, pins and needles, burning or pain, or loss of sensation in your feet, toes or lower limbs?

(Single Response)

1. Yes []
2. No []

F15 In the last 12 months have you had any days lost from work, school or home duties or usual activities due to diabetes?

(Single Response)

1. Yes []
2. No [] Go to F17

F16 How many days would you estimate?

(Single Response. Enter 999 if not stated)

1. Enter days ---
2. Don't know []

These next questions are about the diabetes-related information and education that you have received.

F17 Thinking about the amount of diabetes-related information and education that you receive, in general do you receive?

(Single Response. Read Options)

1. **Too much information** []
2. **About the right amount** []
3. **Not enough information** []
4. Don't know []

Sequence guide: If F7=1 (diagnosed in last 12 months) Go to F20.

F18 Thinking about when you were first diagnosed with diabetes, how satisfied were you with the education and information you received about your diet?

(Single Response. Read Options)

1. **Very satisfied** []
2. **Satisfied** []
3. **Mixed feelings** []
4. **Dissatisfied** []
5. **Very dissatisfied** []
6. Did not receive any education or information about diet []
7. Don't know []

F19 Thinking about when you were first diagnosed with diabetes, how satisfied were you with the education and information you received about the possible long-term effects of diabetes (eg. eye, foot, heart, kidney disease)?

(Single Response. Read Options)

1. **Very satisfied** []
2. **Satisfied** []
3. **Mixed feelings** []
4. **Dissatisfied** []
5. **Very dissatisfied** []
6. Did not receive any education or information about long-term effects []
7. Don't know []

F20 Now thinking about [more] recent times, how satisfied are you with the education and information you receive about diet?

(Single Response. Read Options)

1. **Very satisfied** []
2. **Satisfied** []
3. **Mixed feelings** []
4. **Dissatisfied** []
5. **Very dissatisfied** []
6. Do not receive any education or information about diet []
7. Don't know []

F21 Still thinking about more recent times, how satisfied are you with the education and information you receive about the long-term effects of diabetes (eg. eye, foot, heart, kidney disease)?

(Single Response. Read Options)

1. **Very satisfied** []
2. **Satisfied** []
3. **Mixed feelings** []
4. **Dissatisfied** []
5. **Very dissatisfied** []
6. Do not receive any education or information about long-term effects []

Sequence guide: If F20 or F21 = 4 or 5 (Dissatisfied or very dissatisfied) Go to F22. Else Go to F23.

F22 Why were you dissatisfied with the education and/or information that you have received recently?

(Multiple Response)

1. Not enough information []
2. Not detailed enough []
3. Couldn't understand it []
4. Too much information []
5. Other (specify) []
6. Unsure/Don't Know []

F23 Do you ever measure your blood glucose (blood sugar) level?

(Single Response)

1. Yes []
2. No [] Go to F25
3. Unsure/Don't Know []

F24 Do you understand why your glucose levels might sometimes go up and down?

(Single Response)

1. Yes []
2. No []
3. Unsure/Don't Know []

F25 Do you understand what foods you should be eating to best manage your diabetes?

(Single Response)

1. Yes []
2. No []
3. Unsure/Don't Know []

F26 Do you understand about the possible long term effects of diabetes on other parts of the body (eg. eyes, feet, heart, nerves, kidneys)?

(Single Response)

1. Yes []
2. No []
3. Unsure/Don't Know []

F27 What diabetes-related issues would you like more education or information about?

(Multiple Response)

1. Diet []
2. Shopping for correct food []
3. Dining out []
4. Long-term effects of diabetes on eyes []
5. Long-term effects of diabetes on kidneys []
6. Long-term effects of diabetes on feet []
7. Long-term effects of diabetes on the heart or cardiovascular system []
8. Exercise []
9. Measuring glucose []
10. Medication []
11. Impotence []
12. Coping / support []
13. Other (specify) []
14. Already get enough information []
15. None []

F28 Which health professionals have you talked to about your diabetes in the last 12 months?

(Multiple Response)

1. General practitioner []
2. Specialist []
3. Nurse educator (eg. at hospital-based diabetes centre) []
4. Other nurse or doctor at hospital []
5. Diabetes Australia []
6. Dietician []
7. Podiatrist []
8. Optometrist/Ophthalmologist []
9. Other (Specify) _____ []
10. Unsure/Don't Know []
11. None [] Go to F30

F29 How helpful do you find talking to a health professional about your diabetes?

(Single Response. Read Options)

1. **Very helpful** []
2. **Somewhat helpful** []
3. **Not helpful** []
4. **Unsure/Don't Know** []

F30 Other than talking to a health professional, where else do you obtain information about diabetes?

(Multiple Response)

1. Pamphlets/Brochures/Booklets []
2. Internet []
3. Television []
4. Magazines []
5. Newspapers []
6. Radio []
7. Books []
8. Diabetes Centre (at a hospital) []
9. Diabetes Australia []
10. "Conquest" Newsletter
(from Diabetes Australia) []
11. Other people with diabetes []
12. Doctors' surgeries /
waiting rooms []
13. Other (Specify) []
14. No specific source / everywhere []
15. Unsure/Don't Know []
16. None – don't obtain any
information []

Sequence Guide: If F30.2 = 1 (Use Internet) Go to F33.

F31 Do you have access to the Internet (either at home, work, library etc)?

(Single Response)

1. Yes []
2. No [] Go to F33
3. Unsure/Don't Know []

F32 Have you ever used the Internet to find information about diabetes?

(Single Response)

1. Yes []
2. No []

F33 Have you ever attended a diabetes support group or group session where you have met and talked with other people who also have diabetes?

(Single Response)

1. Yes []
2. No [] Go to F35

F34 How helpful did you find these group sessions with other people who have diabetes?

(Single Response. Read Options)

1. **Very helpful** []
2. **Somewhat helpful** []
3. **Not helpful** []
4. **Unsure/Don't Know** []

Sequence Guide: Go to F36.

F35 How helpful do you think attending such group sessions with other people who have diabetes would be?

(Single Response. Read Options)

1. **Very helpful** []
2. **Somewhat helpful** []
3. **Not helpful** []
4. **Unsure/Don't Know** []

F36 If you need to know something about diabetes, do you feel you know where to go or who to ask to find out that information?

(Single Response)

1. Yes []
2. No []

(Interviewer note: If necessary,
Diabetes Australia - South Australian Branch
159 Burbridge Road, Hilton, SA 5033
Phone 8234 1977)

These next few questions ask about how you think diabetes information and education could be improved.

F37 How useful would a 24-hour diabetes information telephone service be to you?

(Single Response. Read Options)

1. **Very useful** []
2. **Somewhat useful** []
3. **Not useful** []
4. **Don't Know** []

Sequence guide: If F7=1 (diagnosed in last 12 months) Go to F40.

F38 Do you feel that the type of information about diabetes that you need now has changed since you were first diagnosed?

(Single Response)

1. Yes []
2. No []
3. Unsure/Don't Know []

Sequence guide: Go to F40

F39 These next questions are about your health in the future.

Do you consider yourself at high risk of getting diabetes at some stage in your life?

(Single Response)

1. Yes []
2. No []
3. Don't Know []

F40 [These next questions are about your health in the future.]

Do you consider yourself at high risk of getting cardiovascular disease (eg. heart disease, heart attack, stroke) at some stage in your life?

(Single Response)

1. Yes []
2. No []
3. Already have cardiovascular disease / had cardiovascular surgical procedure eg. Bypass operation []
4. Don't Know []

F41 Have you ever been admitted to hospital ...?

(Read Options. Multiple Response)

1. **To have a limb amputated** []
2. **With a foot ulcer** []
3. **With kidney failure/disease** []
4. None of the above []

F42 These last questions ask about awareness of diabetes in the general community.

What diabetes issues do you think people in the general community need to be made aware of?

(Multiple Response)

1. Symptoms of diabetes []
2. Different types of diabetes []
3. Where to get tested for diabetes []
4. How to prevent getting diabetes []
5. Family history as a risk factor []
6. Long-term effects (eg. On eyes, feet, heart, kidneys etc) []
7. How to help a person who is having a diabetic emergency episode []
8. Education of children/young people []
9. What it means to have diabetes (for partners, carers, friends) []
10. People in general community are already very aware of diabetes issues []
11. Other (Specify) _____ []
12. Unsure/Don't Know []

F43 In general, how aware do you think people in the community are about things that could increase their chance of getting diabetes?

(Single Response. Read Options)

1. **Very aware** []
2. **A little aware** []
3. **Not at all aware** []
4. Don't Know []

G. CONCLUSION

G1 That concludes the interview. The study is progressing well. Are there any other comments that you would like to make about the study?

(Single Response)

1. Yes (specify) _____
2. No []

On behalf of the North West Adelaide Health Study Team, I would like to thank you very much for taking part in the study. Your participation in this study has made a very important contribution to the awareness of health issues in the North Western area of Adelaide. Thank you again for your time.

(Interviewer note: For further information, phone 1800 635 352, or Internet webpage at <http://www.nwadelaidehealthstudy.org>).

REFERENCES

- ¹ Commonwealth Department of Health and Aged Care and Australian Institute of Health and Welfare. *National Health Priority Areas Report: Diabetes Mellitus 1998 – Summary*. AIHW Cat. No. PHE 13. HEALTH and AIHW, Canberra, 1999.
- ² Department of Human Services in partnership with the Diabetes Health Priority Area Advisory Group. *The Strategic Plan for Diabetes in South Australia*. Adelaide, South Australia. 1999.
- ³ Parsons J, Wilson D, Scardigno A. *The Impact of Diabetes in South Australia*. On behalf of the South Australian Diabetes Health Priority Area Advisory Group. South Australian Department of Human Services, Adelaide, 2000.
- ⁴ Dunstan D, Zimmet P, Welborn T, Sicree R, Armstrong, Atkins R, Cameron A, Shaw J, Chadban S. *Diabetes and Associated Disorders in Australia – 2000: The Accelerating Epidemic. The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) Report*. International Diabetes Institute, Melbourne, 2001.
- ⁵ Parsons JE, Phillips PJ, Wilson DH, Scardigno A. ‘A touch of sugar’--a dangerous euphemism still alive and well. [Letter] *Australian & New Zealand Journal of Medicine* 2000; 30(6):739.
- ⁶ Commonwealth Department of Health and Aged Care. *National Diabetes Strategy 2000-2004*. Commonwealth of Australia. Canberra, 1999.
- ⁷ UK Prospective Diabetes Study. Cost effectiveness analysis of improved blood pressure control in hypertensive patients with type 2 diabetes: UKPDS 40. *British Medical Journal* 1998; 317: 720-726.
- ⁸ Phillips P, Wilson D, Beilby J, Taylor A, Rosenfeld E, Hill W, Parsons J. Diabetes complications and risk factors in an Australian population. How well are they managed? *International Journal of Epidemiology* 1998; 27: 853-859.
- ⁹ Hepworth J, Mensforth H. *Enhancing Diabetes Management*. Department of Public Health, The University of Adelaide, 1998.
- ¹⁰ Mazza SA. Does patient education in chronic disease have therapeutic value? *Journal of Chronic Disease* 1982; 35: 521-29.
- ¹¹ Goodall TA, Halford WK. Self-management of diabetes mellitus: A critical review. *Health Psychology* 1991; 10: 1-8.
- ¹² Wooldridge KL, Wallston KA, Graber AL, Brown AW, Davidson P. The relationship between health beliefs, adherence, and metabolic control of diabetes. *Diabetes Educator* 1992; 18: 495-500.
- ¹³ Blackwell B. Compliance. *Psychotherapy and Psychosomatics* 1992; 58: 161-169.
- ¹⁴ Bender B, Milgrom H et al. Nonadherence in asthmatic patients: is there a solution to the problem? *Ann Allergy Asth and Immun* 1997; 79: 177-186.
- ¹⁵ Leyshon J. When good compliance equals good asthma control. *Community Nurse* 1999; 5: 25-27.

- ¹⁶ Fawcett J. Compliance: Definitions and Key Issues. *Journal of Clinical Psychiatry* 1995; 56(suppl 1): 4-8.
- ¹⁷ Conrad P. Qualitative research on chronic illness: a commentary on method and conceptual development. *Social Science and Medicine* 1990; 30: 1257-1263.
- ¹⁸ Diabetes Australia and The Royal Australian College of General Practitioners. *Diabetes Management in General Practice*. National Capital Printing. Canberra, 1998.
- ¹⁹ Gillis A, Jackson W. *Research for Nurses: Methods and Interpretation*. F.A Davis Company: Philadelphia, 2002.
- ²⁰ Owen S. The practical, methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Journal of Advanced Nursing* 2001; 36(5): 652-658.
- ²¹ Morgan DL. (ed) *Focus groups as Qualitative Research*. Sage University Paper Series on Qualitative Research Methods, Vol 16. Sage, Beverley Hills, USA, 1988.
- ²² Kitzinger J. The methodology of focus groups: The importance of interaction between research participants. *Sociology of health and Illness* 1994; 16: 103-121.
- ²³ Kitzinger J. Introducing Focus Groups. *British Medical Journal* 1995; 311: 299-302.
- ²⁴ Pelto PJ, Pelto GH. Research Designs in Medical Anthropology. In *Handbook of Medical Anthropology*. Greenwood Press. Westport, USA, 1996.
- ²⁵ Ekman I, Segesten K. Disputed power of medical control: The hidden message in the ritual of oral shift reports. *Journal of Advanced Nursing* 1995; 22: 1006-1011.
- ²⁶ Cheek J. Nurses and the administration of medications. *Clinical Nursing Research* 1997; 6(3): 253-274.
- ²⁷ Cheek J, Ballantyne A. Moving them on and in: The process of Searching for and Selecting and Aged Care Facility. *Qualitative Health Research* 2001; 11(2): 221-237.
- ²⁸ Norman I, Redfern S, Tomalin D, Oliver S, Poland F, Curran M. Developing Flanagan's critical incident technique to elicit indicators of high and low quality care from patients and their nurses. *Journal of Advanced Nursing* 1992; 17: 590-600.
- ²⁹ Miller CK, Edwards L, Kissling G, Sanville L. Nutrition education improves metabolic outcomes among older adults with diabetes mellitus: results from a randomized controlled trial. *Preventive Medicine* 2002; 34: 252-9.
- ³⁰ Beebe C, O'Donnell M. Educating patients with type 2 diabetes. *Nursing Clinics of North America* 2001; 36: 375-86.
- ³¹ Chin MH, Cook S, Jin L, Drum ML, Harrison JF, Koppert J, Thiel F, Harrand AG, Schaefer CT, Takashima HT, Chiu SC. Barriers to providing diabetes care in community health centers. *Diabetes Care* 2001; 24: 268-74.
- ³² Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Prevalence of South Australia's online health seekers. *Aust N Z J Public Health* 2002; 26: 170-3.
- ³³ Wagner TH, Hu T, Hibbard JH. The demand for consumer health information. *Journal of Health Economics* 2001; 20: 1059-75.

References

³⁴ Norris SL, Engelgau MM, Venkat Narayan KM. Effectiveness of self-management training in Type 2 diabetes. *Diabetes Care* 2001; 24: 561-87.

³⁵ Taylor A, Dal Grande E, Chittleborough C, Ruffin D, Wilson D, Phillips P. *The North West Adelaide Health Study: Key findings, policy implications and research recommendations*. Centre for Population Studies in Epidemiology, South Australian Department of Human Services, Adelaide, 2001.