

Social, Psychological, and Health Needs of Type II Diabetes: A Focus Group Study of the Western Health Board



**Department of Public Health
October 1998**

**Social, Psychological, and Health Needs of Type II Diabetes:
A Focus Group Study of the Western Health Board**

**Report
by**

**The Department of Public Health
Western Health Board**

**Authors: Ms Siobhan O'Neill
Dr David S. Evans**

October 1998

EXECUTIVE SUMMARY

Diabetes mellitus is a major cause of ill health globally with a prevalence rate of 2-5%. Of particular concern is the range of preventable complications arising from type II diabetes (the commonest form) particularly for those over 60. This study aimed to achieve an understanding of the experience and needs of adults with type II diabetes in the Western Health Board area, how these needs are met and how they might be met in the future. A qualitative, focus group methodology was employed.

Three focus groups were held with individuals aged 55-65 years from Galway, Mayo and Roscommon. Results showed that diagnosis of diabetes appears to be late and in many cases only discovered by chance. After the initial shock, individuals do come to terms with diabetes, however the majority did worry about certain aspects of their diabetes. Diabetes has led to a major impact on many of the group's social life, in particular the drinking of alcohol. A significant number of participants were not able to effectively manage their diabetes; diet, weight control, and exercise posed particular difficulties. Use of health services was mainly limited to the General Practitioner; the majority of people were happy with the services received. A number of improvements to services were suggested, and there appeared to be a need for more social and psychological support, education and information.

The results highlight aspects of diabetic care and services requiring more systematic investigation and identify areas where needs may not be met. Specific recommendations include research into:

- Current levels of service, gaps in service and factors affecting utilisation of services
- Alternative methods of detecting diabetes in the general population
- The effectiveness of referral systems
- Training needs of health professionals involved in diabetic care

It is recommended that people with diabetes are involved in ongoing education; information leaflets, books and videos about diabetes should be easily available. People with diabetes should also be made aware of their entitlements under the Long-Term Illness and medical card schemes. There is a clear need for psychological support services and for professionals involved in diabetes care to have adequate training in communication skills.

CONTENTS

EXECUTIVE SUMMARY	2
1. INTRODUCTION	5
1.1 Research Background	5
1.2 Rationale	6
1.3 Aims and Objectives	8
2. METHODOLOGY	9
2.1 Research Methodology	9
2.2 Focus Groups	9
2.2.1 Recruitment of Participants	9
2.2.2 The Discussions	10
3. RESEARCH RESULTS	12
3.1 Introduction	12
3.2 How Diagnosed with Diabetes	12
3.3 Social and Psychological Impact of Diabetes	12
3.4 Physiological Impact of Diabetes	14
3.4.1 Fatigue/tiredness	14
3.4.2 Hunger	15
3.4.3 Diet and Weight and Exercise	15
3.4.4 Development of Complications	16
3.5 Use and Perception of Services	16
3.6 Provision of Information and Education	17
3.7 Summary	19
4. DISCUSSION	20
4.1 Introduction	20
4.2 Psychological and Social Aspects of Diabetes	20
4.2.1 Worries and Fears	20
4.2.2 Beliefs About the Seriousness of Diabetes	20
4.2.3 Psychological Symptoms	20
4.2.4 Social Support	21
4.2.5 Management	21
4.2.6 Dietary Adherence	21
4.2.7 GP-Patient Communication	21
4.3 Physiological and Medical Aspects of Diabetes	22
4.3.1 Diagnosis	22
4.3.2 Treatment and Care	22

4.3.3	Side Effects	22
4.4	Information and Education	22
5.	CONCLUSIONS AND RECOMMENDATIONS	24
APPENDIX		27

1. INTRODUCTION

1.1 Research Background

Diabetes mellitus is a major and growing cause of ill health in Western Europe currently affecting approximately 2-5% of the population. Over 100 million people world-wide suffer from the disorder with projections indicating that there will be over 230 million people with diabetes by the year 2010 (Macarty and Zimmet, 1994, cited in Zimmet, 1997). Diabetes is amongst the five leading causes of death by disease in most countries (Finch and Zimmet, 1988, cited in Zimmet, 1997). It is estimated that for every person diagnosed with diabetes there is another who remains undiagnosed and that an individual has had diabetes for four to seven years prior to diagnosis (Harris *et al.*, 1992, cited in Zimmet, 1997). Consequently a high proportion of people with diabetes present with complications at diagnosis.

Diabetes mellitus is a disorder of the metabolic systems responsible for the utilisation and storage of glucose, the main energy source derived from food. The disorder is characterised by deficiencies in the production or utilisation of insulin, which leads to high blood glucose levels or hyperglycaemia (Cox & Gonder Frederick, 1992). Diabetes is a chronic condition and complications resulting from diabetes can lead to a diminished quality of life and premature mortality. There are two main types of diabetes, type I or insulin dependent (IDDM) and type II or non-insulin dependent (NIDDM).

Type I diabetes or IDDM, affects mainly young people, with an abrupt, often life-threatening onset of symptoms and requires long term treatment with insulin injections. The main symptoms of this type of diabetes include high blood glucose levels, excessive thirst, frequent urination, weight reduction and tiredness (American Diabetes Association, cited in Cox and Gonder-Frederick, 1992). This type of diabetes is caused by a combination of genetic and autoimmune processes, which together destroy the pancreatic cells that produce insulin. Compensatory fat metabolism leads to high levels of fatty acids in the blood which can lead to ketoacidosis (where the kidney malfunctions causing wastes to accumulate and poison the body) (Cox & Gonder-Frederick, 1992; Sarafino, 1994).

Type II, NIDDM is more common, 80-85% of all Europeans with diabetes are in this group (Karvonen *et al.* 1993, cited in Zimmet, 1997). It affects mainly middle aged (40+) and elderly people and has a more gradual onset. NIDDM is caused by a combination of pancreatic cell dysfunction and insulin resistance and is characterised by a gradual onset with minimal or no symptoms of metabolic disturbance; in many cases the condition remains undiagnosed until the onset of complications. The pancreas produces some insulin and hence treatment may not require insulin injections. This type of diabetes is usually managed through diet, exercise and sometimes, oral hypoglycaemics. This category also includes diabetes treated by diet alone. Type II diabetes tends to be hereditary and is also associated with lifestyle factors such as obesity, lack of physical activity and stress (Zimmet, 1997).

Both types of diabetes are associated with long term complications, many of which are a consequence of high levels of blood glucose causing arteriosclerosis. This can occur in both the large blood vessels

(causing heart disease, stroke and gangrene in a limb) or in the small blood capillaries in the eyes, kidneys and brain (Sarafino, 1994). Diabetes is the commonest cause of adult blindness in developed countries. People with diabetes are 17 times more prone to kidney disease and diabetes is the leading known cause of end stage renal disease in the US (Klein & Moss, 1992, cited in Zimmet, 1997). Arteriosclerosis is the most common macrovascular complication of diabetes; it accounts for at least two thirds of deaths of people with diabetes (Panzram, 1987, cited in Zimmet, 1997). Another common complication of diabetes, neuropathy, is caused by the high blood glucose levels resulting in a chemical reaction which depletes the myelin surrounding the nerve fibres. This results in the person losing sensation in the affected area or having abnormal sensations in other parts of the body. Other symptoms can include, dizziness, urinary incontinence and sexual impotence in males (Sarafino, 1994).

It is generally accepted that the degenerative changes associated with diabetes mellitus are to a large extent preventable through blood-glucose control (Shillitoe, 1991: The DCCT Research Group, 1993: The UK Prospective Diabetes Study Group, 1998). The treatment goals of people with both types of diabetes thus focus on normalising blood glucose levels and preventing long-term complications. The regimen usually involves monitoring blood or urine glucose levels, medication, diet and exercise. They require the patient to make comprehensive lifestyle changes and psychosocial adjustments. Studies have found that “many, if not most, patients with IDDM are non-compliant with one or more aspects of their treatment regimen much of the time” (Drash & Becker, 1990). Compliance is not uniform amongst diabetes patients; whilst some people do not adhere to any aspects of their self-management programme others are more selective. The components of the regimen that are most intrusive into the person’s lifestyle are those most likely to be omitted. Dietary adherence has repeatedly been shown to be the greatest single problem for adults with diabetes (Sarafino, 1994; Shillitoe, 1991).

Most people with diabetes are also aware that strict self-management and metabolic control do not necessarily prevent long-term complications or short term difficulties (Shillitoe, 1991). According to Drash and Becker (1990), “an unsatisfactory outcome, both physically and psychologically, can easily lead the patient to decide that certain aspects of the therapeutic programme are not worth the effort”. The patient will also be aware that on the occasions when dietary rules were broken or when an injection of insulin was missed, nothing untoward happened. The fact that the benefits of adherence to dietary, exercise and medication recommendations are not immediate and cannot be guaranteed thus results in poor compliance. Compliant behaviour is often punished when the patient’s blood sugar levels dip low resulting in hypoglycaemia accompanied by unpleasant side effects Gonder-Frederick *et al.*, 1985). Stress can also precipitate non-compliance and affect glycaemic control. The relationship between stress and control may be indirect; leading to increased alcohol intake or binge eating, or direct, through the release of stress hormones (e.g. epinephrine which elevates blood glucose (Cox & Gonder Frederick, 1991). People who are diagnosed with diabetes in adulthood may have particular difficulties in ‘changing the habits of a lifetime’ and adjusting to meet the demands of the self-management regime; they are therefore at increased risk of developing complications (Bates, 1986).

1.2 Rationale

Given the evidence of strong relationships between clinical outcomes and psychosocial factors it is appropriate that the experience of people with diabetes is examined within a psychosocial context and that the psychosocial as well as the medical needs of these patients are addressed (Shillitoe, 1991). It is also important that the psychological effects of health care programmes and treatment regimens are evaluated and that patients are given an opportunity to express their opinions on how services could be modified to improve their quality of life (Dunn, 1993).

The National Health Strategy (Department of Health, 1994) recommends that priority be given to support the growing population of elderly and the promotion of healthy ageing. Given the prevalence of type II diabetes in older adults and the potential for the prevention of complications it is appropriate that the needs of this group be explored. Research into the effects of diabetes and treatment on quality of life is also in line with the national strategy as it encompasses a holistic approach to health care, taking account of the “psychological, social and environmental factors influencing patients’ health status”.

Type II diabetes has been chosen due to its greater prevalence. It has been decided that older adults be studied because it is in older adults that type II diabetes is most likely to be diagnosed (Western Health Board, 1998). This age group are at high risk of non-compliance with self-management recommendations and resistant to lifestyle change. There is also great potential for the prevention of complications in patients aged 55-65 years (the highest rates of complications and diabetes related mortality is within those over the age of 65) and so this age group is an appropriate target of future interventions.

According to the Long Term Illness/ General Medical Services database (Western Health Board, 1998), there are approximately 5,000 people receiving treatment for diabetes in the area covered by the Western Health Board; giving an overall prevalence of 1.4%. As it is estimated that over 50% of people with type II diabetes remain undiagnosed the actual figure is likely to be much higher (Harris *et al.*, 1992, cited in Zimmet, 1997). To date no research has been carried out into the experience of people with diabetes in the Western Health Board area. The results from this study will provide us with a valuable insight into some of the main social and psychological effects of type II diabetes for adults living in the West of Ireland. They will assist the Western Health Board in the planning of interventions, treatment and care services for adults with type II diabetes in order to maximise their quality of life and delay or prevent the onset of complications. The findings will also be used in the planning and design of quantitative needs assessments and future research into the effects of treatment and care programmes on quality of life or health status.

1.3 Aims and Objectives

The aim of the project is to achieve an understanding of the experience and needs of adults with type II diabetes in the Western Health Board area, how these needs are met and how they might be met in the future.

The specific objectives of the research are:

1. To establish the medical, social and psychological consequences of having diabetes for this group.
2. To identify the needs of this group with regard to services.
3. To examine the ways in which these needs are currently met.
4. To assess levels of satisfaction with the ways in which these needs are currently met.
5. To generate ideas and suggestions for new service or modifications to existing services.

2. METHODOLOGY

2.1 Research Methodology

A qualitative methodology was considered appropriate for this study due to the nature of the information required and the existing shortage of such information. As little is known locally about the needs and experiences of people with diabetes there is nothing upon which to base a quantitative study; key areas may therefore be missed. Qualitative studies yield highly valid information about subjective experiences; a quantitative study would lose this depth and meaning and may miss important points. The information yielded by this study would not only be of value to policy makers and service planners but would also highlight important areas which require quantitative measurement.

2.2 Focus Groups

The focus group is a method of group interview in which the group interaction is used to generate data. The method can be used to examine “not only what people think, but how and why they think that way” (Kitzinger, 1995). Focus groups can provide us with richer information about the knowledge, attitudes and experiences of the participants. They are particularly useful in highlighting cultural norms, shared values and common knowledge and can facilitate the discussion of sensitive subjects. The use of focus groups can also help empower the research participants; they become an active part of the research process as they get an opportunity to voice their opinions. Focus groups are particularly relevant for research with the ultimate aim of improving services as they facilitate the expression of criticisms (which people may be reluctant to mention in individual interviews) and the exploration of the advantages and disadvantages of different solutions. They can also encourage participation from people who are reluctant to be interviewed or who feel they have little to say (Kitzinger, 1995).

2.2.1 Recruitment of Participants

Thirty people (ten from each county of the Western Health Board) between the ages of 55 and 65 years who had been diagnosed with type II diabetes were recruited for the purposes of this study. Participants were randomly selected from the Long-Term Illness/ General Medical Services database (a database containing details of individuals with diabetes in the Western Health Board area under the Medical Card or Long-Term Illness schemes).

Potential participants were initially contacted by letter (copy in appendix) and by telephone. Recruitment continued in stages until ten people from each county had agreed to attend. All those who had said they would attend were sent letters reminding them of the time and date of the sessions and the importance of them attending a few days before the discussion.

Table 2.1: Summary of the people who attended the focus groups

	Invited Participants		Uninvited Participants		Partners, Drivers, etc...		Total
	Male	Female	Male	Female	Male	Female	
Galway	2	3	0	0	0	0	5
Mayo	4	4	1	0	1	0	10
Roscommon	2	3	0	0	1	1	7
Total	8	10	1	0	1	1	21

As the above table shows, the focus groups comprised of five to eight invited participants and others. Two people brought along partners or other relatives to drive them to and from the sessions and one person brought along a relative who had diabetes. There were five participants in the Galway and Roscommon groups and nine in the Mayo group giving a total of nineteen participants.

The focus groups were held in the following locations:

Galway: The Corrib Great Southern Hotel, Monday 31st August

Mayo: The Welcome Inn, Castlebar, Monday 7th September

Roscommon: The Abbey Hotel, Wednesday 9th September

All groups were held from 7.30 to 9.00 pm and refreshments were provided.

2.2.2 The Discussions

A 'topic guide' (a framework for the discussions and ideas for questions to generate conversation and discussion) was developed which consisted of open-ended questions and detailed 'probe' questions. It was intended that only the general questions were to be used as far as possible, so that the participants could raise issues that were priorities for them. The detailed probe questions were for use if conversation dried up or to guide the discussion if important issues had not been mentioned.

The sessions began with an introduction from the moderator who welcomed everyone and asked for consent to audio record the discussion. A flip chart was used to explain the three sections of the discussion; participants were encouraged to speak freely to each other and the importance of confidentiality was highlighted. The group members were firstly invited to introduce themselves and describe how they found out about their diabetes.

Each discussion comprised three main sections. The aim of section one was to establish the needs of people with diabetes living in the West of Ireland. The general, open-ended question for this section was: *What is it like to have diabetes?* The more specific questions dealt with how diabetes affects everyday life. Section two addressed how needs are currently met and explored all aspects of services for people with diabetes. The open-ended questions for this section were; *Which services do you use regularly?* and *How satisfied are you with your current treatment?* Again more detailed questions were asked about individual services. For section three of the discussion, the groups were asked to provide ideas for new services or improvements to existing services. The sessions ended with a resume of the main points and issues raised; the participants were invited to comment on the accuracy of this.

3. RESEARCH RESULTS

3.1 Introduction

The following results represent a summary and interpretation of the three focus groups of people with type II diabetes aged 55-65 years for the Western Health Board area. The focus groups aimed to provide an understanding of their needs, how their needs are met, and how they might be met in the future. A total of 21 individuals (19 of whom had diabetes) participated in the focus groups (5 from Galway, 10 from Mayo, and 7 from Roscommon).

3.2 How Diagnosed with Diabetes

Individuals were first diagnosed as having diabetes through either receiving tests or treatment for other conditions, or from presenting symptoms to the doctor that may have been directly related to diabetes. For example:

“I had a pain in my back, so I went to the doctor and she said ‘I have to take a sample’ and she nearly died, it was lacking something in my sugar. So it was straight away to the Regional Hospital where the tests were done”

“I was drinking a-lot of water, I drank a drum, two drums of water I think in two days”

The onset of type II diabetes is gradual, with minimal or no symptoms. Early diagnosis is very important, as complications may be prevented through management and treatment (The DCCT Research Group, 1993; The UK Prospective Diabetes Study Group, 1998). It does not appear that these individuals were diagnosed early, as it was only by chance or when key symptoms were present that diagnosis was made. Nobody reported being diagnosed as part of a regular check up with their doctor. If such an approach had been used, many of the complications experienced by a significant proportion of participants may have been prevented. The method of diagnosis also indicates that there may be a significant number of individuals within the Western Health Board area that have not yet been diagnosed as having diabetes.

3.3 Social and Psychological Impact of Diabetes

The five people who spoke about their reactions to diagnosis all reported experiencing feelings of shock and worry:

“I got the shock of my life”

“when I was diagnosed I did get a shock”

For most, coming to terms with having diabetes involved acknowledging that it was a lifetime disease and something that they had to live with. Typical comments included:

“I know it is a lifetime disease. It’s a thing that when you get up in the morning you think to yourself ‘I will start again today’”

“I just had to get it into my head that I was going to live with it, be diabetic for the rest of my life and try to forget about it”

It also involved acknowledging that it is possible to live a relatively normal life, providing that they followed their self-management regime to keep their diabetes under control and stopped worrying. Many stressed that things could be worse and that other conditions were more serious than diabetes. For example:

“I had a brain tumour twenty years ago... I was on my death bed then... I can live with the diabetes... You can save a life once you are on your tablets whereas with cancer, god help us, that’s a worse thing”

“you never go through your life without getting something. That’s for sure, you know what I mean like, if it wouldn’t be that it would be something else like. Backaches or something”

Whilst coming to terms with diabetes is important, it can be seen that in doing so, many participants did not view diabetes as a life threatening disease (e.g. less serious than cancer). However diabetes and its complications are life threatening. Individuals do need to understand and come to terms with this issue to facilitate effective management. Researchers have found that people who believed that their diabetes was serious were more likely to comply with their self-management regime and achieve glycaemic control (Brownlee-Duffleck *et al.*, 1987).

Although most participants indicated that they had come to terms with their diabetes, the majority were worried about certain aspects of their diabetes. The main worries elicited were not being able to cope, passing the disease onto relatives, and developing complications:

“I think everyone has a-lot of fears, a lot of fears in there. A fear of not being able to cope I’m not able to cope, I’m just not able to do it any more”

“I have a daughter and she likes a-lot of sweets, and my grandchildren... because that’s what you’d be afraid of. Is it hereditary, could you answer me that?”

“And you know when you went to the clinic and they would show you the television video and what can happen to you and everything else; you start to wonder, god are you going to get blind and are your feet going to get bad and everything like that. God if that’s going to happen to me, I wouldn’t be able to accept it if it did”

Some individuals claimed that their diabetes had made them feel depressed (particularly those experiencing complications), while others stated that they experienced panic, anxiety, and irritability:

“in the diabetes itself, I find it has me more depressed... I’m more lonesome, more depressed. It has taken a-lot away from me... I know since I have heard that I was a diabetic it really got to me”

“I find also at times I’d become irritated... a bit jumpy in myself”

One person stated that his family had great difficulty in accepting his diabetes:

“I found that members of my family were embarrassed that I have diabetes. It was such an awful thing, you know what I mean. That is the truth, at the beginning they were, and they said that no other member of our family had it or anything like that, they make you feel kind of annihilated at nothing. If you went to their house, ‘what can I give you to eat?’ and all like that and I thought for a while that I was going to be put out in the field with the cattle, you know what I mean. But ah like you would just have to get on with it and everything and take care of things like that. I would never let it get to me, tis their ignorance or something like that. I get on with it”

For many, having diabetes has caused a major impact on their social life, in particular the drinking of alcohol. For some, reducing/abstaining from alcohol consumption caused anxiety, especially in social situations where others were putting them under pressure to drink alcohol. Many avoided social situations involving alcohol (e.g. going to the pub, going to a wedding) rather than experience the pressure and anxiety. For example:

“Oh you get really depressed... You do, you get sick then at this stage, like you just want to go home and get out of the way altogether, you just don’t want to be in company at all. Then they will say ‘what is wrong with you, are you in bad form?’ and you would prefer to be left alone, nobody to take any notice of you. It is like somebody that has any other handicap. Do you know, if you were just left alone, but ah, the fussing making it worse, do you know?... You can’t go out you know if there is someone home now or on holidays you cannot go out with them to have a drink with them or anything like that... You cannot take the champagne, you cannot take the white wine you cannot take... There’s lots of things you have to, just do without, and it kind of spoils it for you, do you know. Then as I say when friends come at that and you go out ‘well what are you drinking?’, I will have a Ballygowan’, ‘God will you drink a right drink, isn’t it just as dear to buy a Ballygowan as it is to buy a pint or something like that you know”

“But it is very hard on people pushing at you ‘have a proper drink’ and all like that... It is very hard to get out of a situation like that and you have to kind of get out of it, out of the room altogether”

“It’s an awful thing when you can’t walk into a pub and have a lash, I’d say you could have one but I wouldn’t have one... I wouldn’t go in at all if you couldn’t have a lash”

It is clear that having diabetes can have a profound social and psychological impact. To effectively manage type II diabetes, comprehensive lifestyle changes and psychosocial adjustments are required. These results indicate that some people may require social and psychological support to come to terms with and to effectively manage their condition.

3.4 Physiological Impact of Diabetes

Throughout the discussions a number of key physiological consequences of having diabetes were highlighted. These to a greater or lesser extent affected most participants. These were:

- Fatigue/tiredness
- Hunger
- Difficulties relating to diet, weight, and exercise
- Development of complications

3.4.1 Fatigue/tiredness

Many people stated that since having diabetes that they feel tired and fatigued and that they require more rest than they used to. For some, the problem was so extreme that

they had to give up their work:

“I am tired when I get up in the morning, I am tired after my breakfast. I drive the messages, that is my big job running about doing a bit of driving for the house and all that... I packed up work altogether. I was a farmer and a lorry driver.”

“I know that myself, I get tireder and I am just not able to get to do it now. When I do something I sit down for a while and rest for a little while and start off again at what I was going to do.”

Tiredness and fatigue are recognised symptoms of diabetes (American Diabetes Association, cited in Cox and Gonder-Frederick, 1992) and as such need to be addressed with individual patients.

3.4.2 Hunger

Some participants claimed that they often felt very hungry:

“these hunger pains comes over you and you don’t know where you are going to be”

This led to weakness, discomfort and for some people interrupted their sleep.

3.4.3 Diet and Weight and Exercise

Dietary control physical exercise and the maintenance of a healthy weight are key components to the effective management of diabetes and the prevention of complications.

Most participants found that dietary changes were difficult to adjust to. The key difficulty for most was avoiding sweet foods. There was much discussion about this issue, particularly about the sweet foods that were missed:

“Oh terrible and awful, it came awful hard to get used to it I can tell you because... you were told that you wouldn’t have to have sugar”

“And I thought to myself ‘oh what am I going to do, that is everything I like’... I thought when I came out... I’ll starve if I can only have this. It was hard to do it”

It appeared that because participants had to avoid sweet food, the desire for them had become greater. This had led to some group members breaking their dietary regime:

“I have a Kit Kat bar now and again, I’m being honest, I don’t tell lies. If I feel like having a sweet bar I take it”

There was much discussion about specialist diabetes foods as a substitute for sweet foods. Some had been told by the dietician that such foods ‘were not good for you’. Others complained that there was no comparison between such foods and ‘real’ sweet foods and that substitute foods were too expensive:

“it is ridiculous, you know what I mean, the price on bars of chocolate is ridiculous so I tend not to buy it any more. People making money out of somebody else’s misery”

The problem of adjusting to dietary changes may have contributed to the fact that a substantial number of participants had difficulties controlling their weight. This was despite the fact that participants did understand that weight control was very important:

“I know it’s my weight that’s against me a bit, I get the willpower to keep it down and then it goes back up again”

“Well the doctor said to me that the weight is the area, that you know you have got to keep down the weight”

Poor weight control may also have been linked to the fact that the importance of physical exercise in the diabetes management regime was not discussed by any of the groups. Exercise was discussed by

some individuals who used it as a means of alleviating the symptoms of stress and anxiety, however others claimed that they were unable to exercise due to the effects of their diabetes (e.g. foot and leg problems, tiredness).

It is evident that diet, weight control, and physical exercise are key areas of difficulty which may contribute to poor management of diabetes and subsequent complications.

3.4.4 Development of Complications

Diabetes is associated with the development of a number of long term complications, many of which were reported by participants in the discussion groups. The main difficulties experienced were poor eyesight, and a range of feet and leg complications. For example:

“I noticed since that my sight isn’t as good as it used to be, I wear glasses and I could see a fly a mile away... But am, for reading I would have to get my glasses and your sight, some mornings when you get up it would be a bit blurred so you would feel it that way”

“The feet was my problem and still is my problem...it’s just like you would be walking on glass and then it is just gone like that... it was like electric shocks... down there in the soles of my feet”

“I have terrible corns... going for a walk sometimes it is like a knife going up through the sole of your feet with the corns ”

A variety of other illnesses and conditions (which may not have been directly attributable to diabetes) were also experienced these included; high blood pressure, gastritis, stomach ulcers, stress, incontinence, asthma, fluid retention, cramps and bad teeth.

To a large extent, the complications attributable to diabetes can be avoided through high blood glucose control (DCCT Research Group, 1993: The UK Prospective Diabetes Study, 1998). The development of such complications along with the difficulties experienced controlling diet, weight, and exercise suggests that a significant number of participants were not able to effectively manage their diabetes.

3.5 Use and Perception of Services

Participants were asked which health services they used and their opinions of these services. The following services were discussed:

- GP
- Dietician
- Leg and foot specialist
- Diabetic clinic
- Diabetic nurse
- Eye specialist

Although a wide range of services were elicited, the GP was the service used by the majority of participants on a regular basis. Some individuals visited their GP more often than others and there was a great deal of variation in the reported regularity of check ups from people who were treated by their GP. For those who had used other services there also appeared to be a lack of regular contact and recalls to attend (e.g. diabetic clinic, diabetes nurse). Some people did not appear to be aware that other services were available. Many people reported that the services immediately after diagnosis were good but that contact with the specialists had decreased ever since.

The majority of people were happy with the services they received. This was particularly the case for the GPs who received praise for their expertise and interpersonal skills, particularly their role in alleviating worry:

“I am very pleased with the service I am getting like. I think that I am well looked after... I do have to go up to the County Hospital every six months like for a check-up... I couldn’t look for anything more... I couldn’t expect to get anything more”

*“I go to my doctor in Ballina Dr *** and if I am very good, he’ll answer any question I want, any problem like and I find him caring like and I am pleased with him... and I know that he is there when I want him”*

There were some individuals however who were unhappy with services. For example, some pointed out that they were unable to talk to GPs as they seemed too busy. A number of people had to pay for medical treatment and services and many were confused about their entitlements under the Long-Term Illness and medical card schemes. Others commented that the overall level of service was poor for people with diabetes:

“When you go into the doctor, he is busy, he will give you the prescription and ‘how are you feeling?’ and you say, you might be busy too and you say ‘I’m okay’, and you go out and you mightn’t be okay at all”

“There isn’t much of a service really for diabetes when you look back, sure there’s nothing... Sure there isn’t really you know”

In terms of improvements to services, the following suggestions were made:

1. More frequent check-ups (e.g. clinic, eye tests)
2. Co-ordinated clinic service where eye, dietetic, and foot care specialists could be accessed.
3. Automatic recall and regular -ups.
4. Provision of free blood testing machines.
5. Provision of free medication to all people with diabetes.

Due to the evident social and psychological needs of the groups, the question of whether individuals would like the opportunity to see a psychologist or counsellor was raised. Responses were varied on this issue, with some claiming they did not require the service and others saying that it would be useful. Some individuals stated that a little support would help people with diabetes. Two of the three groups mentioned that they valued the opportunity that the discussion groups had given them to talk to other people with diabetes. Knowing what other people go through helped them overcome worry and understand their condition better:

“I was very glad when I got the invitation to be able to come and speak about it... It gives you a chance to know what other people are going through... the same as what you are going through yourself”

“It was nice to talk about it, about any sickness you know really. If everybody spoke in groups like this on and off, about their sicknesses people wouldn’t be half as worried you know”

These findings do highlight the fact that there is a need for those with diabetes to have more social and psychological support, which for most could be achieved via informal support networks or health professionals trained in communication and counselling, whilst for a minority, specialist psychological services may be required.

3.6 Provision of Information and Education

The topic of information and education was raised at all three focus groups, although only the Galway group talked at length about it. Most people stated that they knew little about diabetes at diagnosis, and still did not know enough about their condition, its side effects and complications. The following responses were typical:

“I didn’t realise what diabetes was. And even to this day I don’t...But the diabetes itself, I do not understand what it is. I don’t, I really don’t. What it’s really supposed to be; is it supposed

to be in the pancreas, where is it or what is it?"

"I think that when you got it first it should have been explained thoroughly to you, you know, don't mind about your diet, but the side effects, what could happen, what couldn't happen... well, it is just that we would like to know what's the side effects... such as gangrene, your feet or your legs or whatever, what causes it, you know what... things like that"

"we don't know the side effects, they never explained anything you know"

Only three individuals specifically talked about reading literature on diabetes which they found useful in terms of the advice and information given. One individual stated that the Western Health Board should provide more literature, particularly for GP's to hand out to patients. In addition, some participants stated that the public should be better educated about diabetes so that they could recognise the symptoms in themselves and so get diagnosed early.

Whilst information does appear to be available from the Health Board and other sources, it seems that not enough is reaching those with diabetes. This is particularly the case for verbal information from health professionals such as GPs.

3.7 Summary

The research results highlighted a number of issues which will be discussed in more depth in the following section. In summary, the key issues emerging were:

1. Diagnosis of diabetes appears to be late and in many cases only discovered by chance.
2. After initial shock, individuals do come to terms with diabetes, although the majority did worry about certain aspects of their diabetes. Some do not appear to view their condition as life threatening.
3. Diabetes has led to a major impact on many of the group's social life, in particular the drinking of alcohol.
4. A significant number of participants were not able to effectively manage their diabetes.
5. The issues of diet, weight control, and exercise are key areas that may contribute to poor management of diabetes and subsequent complications.
6. The majority of people were happy with the services they received. The main service used was the GP.
7. A number of improvements to services were suggested, and there appeared to be a need for more social and psychological support.
8. Not enough information and education is reaching those with diabetes.

4. DISCUSSION

4.1 Introduction

The research results have illustrated the needs of adults with type II diabetes, how those needs are currently met and how they might be met in the future. The key issues that emerged are now discussed outlining implications for health care planning.

4.2 Psychological and Social Aspects of Diabetes

4.2.1 Worries and Fears

Most of the participants were extremely worried about their diabetes, many reported feelings of shock and worry at the diagnosis and others were concerned about not being able to cope or the possibility of passing it on to relatives. Such concerns are commonly reported by people with diabetes (Shillitoe, 1991) and can be addressed in a number of ways. Support at crucial stages (e.g. diagnosis or the onset of complications) could come from informal networks (friends and family), however some people may require the support of a professional who has an insight into the condition as well as counselling skills. Those who expressed concern about passing diabetes on to their families may also benefit from education and, in some cases genetic counselling (Shillitoe, 1991).

Worries about not being able to cope can be addressed directly by teaching coping skills to help people with diabetes deal with difficult situations (such as pressure to drink too much alcohol at social events or pressure to break the diet). People who feel that they might not be able to cope may benefit from the knowledge that there exists somebody who could help them through a crisis (Shillitoe, 1991).

4.2.2 Beliefs About the Seriousness of Diabetes

The possibility of developing complications also caused considerable worry, however the only complications mentioned were those relating to eyes and feet. The possibility of premature death or heart and circulatory problems were not discussed. Many of the participants held the belief that diabetes was less serious than other conditions for example, cancer. This may indicate that they do not take their condition seriously enough or are not fully aware of the life threatening complications of diabetes. The people who worried about their diabetes only at the time of diagnosis may also have become complacent about their condition. It is likely that these people would be at high risk of non-compliance and poor management (Brownlee-Duffleck *et al.*, 1987). A recent study (OConnor *et al.*, 1997) found that people who took their diabetes seriously or who understood the threat that diabetes represented were more likely to respond well to a care intervention. Complacency and the perception that diabetes is not serious and life threatening could be addressed through education and in discussions with health professionals (Shillitoe, 1991).

4.2.3 Psychological Symptoms

Whilst most people had adjusted to their condition, a number of participants mentioned that their diabetes made them feel depressed; others claimed that they experienced symptoms of panic, anxiety and irritability. These symptoms may be attributable to low blood glucose levels (Gonder-Frederick *et al.*, 1985) or they may indicate a psychological disorder (affective and anxiety disorders are more

common among people with diabetes (Dunn, 1993; Peyrol and Rubin, 1997). People experiencing depression, panic, anxiety and irritability may benefit from a service whereby they could discuss their feelings and learn practical ways of dealing with stresses and anxiety (e.g. cognitive restructuring, relaxation skills and coping skills). Relaxation training has been associated with a reduction in blood glucose levels (Bradley, 1985; Fienglos, 1987; Lammers *et al.*, 1984) and maladaptive coping styles have been associated with poorer health status in diabetic populations (Kvam and Lyons, 1991).

4.2.4 Social Support

A few participants talked about the negative effect that diabetes has had on their social life and the lack of support from family members. The relationship between social and family support, adherence and glycaemic control has been demonstrated in a number of studies (Kvam and Lyons, 1991). The partner and family should therefore be educated about diabetes and ways in which they can support the individual and facilitate adherence with the management regime (Dunn, 1993, Shillitoe, 1991). The individual should also be taught skills to allow them to function in social situations where they are under pressure to break their regime and where they encounter prejudice because of their condition.

The value of meeting and talking with others with diabetes was discussed by many of the participants in this study indicating that support groups for people with diabetes would be beneficial. Dunn (1993) points out that group-based interventions can facilitate behaviour change through group interaction and are more cost effective than individual programmes.

4.2.5 Management

The difficulties that people with diabetes encounter in adhering to their management regime must receive attention as self-management is vital in the prevention of complications. Few people mentioned the subject of physical exercise yet this is a key component of effective self-management. Education about the value of regular exercise is clearly necessary. Individuals would also require advice regarding ways of incorporating exercise into their daily routine and into family life as it has been shown that people who do this are more likely to comply with their management regime (O'Connor *et al.*, 1997).

4.2.6 Dietary Adherence

The subject of diet and food was discussed at great length in all three groups; this aspect of the management regime caused the greatest difficulty. Given the enormous difficulties that the participants experienced regarding their diet, it is surprising that very few had contact with the dietician and nobody saw the dietician regularly. Participants viewed their diet in a very negative way and the discussion concentrated on what things they had to 'do without'. Some people continuously thought about food and developed cravings for foods which they were told that they could not have. Permanent dietary changes require a change in the way that the person thinks about eating, the diet must be viewed in a more positive way. The term 'diet' should be avoided; this word is often used to describe a short-term restriction of food intake and can have negative connotations of being strict, difficult and destined to fail. Men may also view dieting as something only women do. The focus should be on the benefits of a healthier way of eating for the individual and the family. Family members, especially those who do the shopping and cooking, should be educated about the eating plan and about the benefits of healthy eating generally (Arora & Arora, 1986; Cox and Gonder Frederick, 1992). People should be encouraged to slowly adjust the diet to fit in with their lifestyle and to introduce healthy alternatives to popular foods. This would lead to a change in the way that individuals think about food, cravings for sweet foods would be avoided and money would not be wasted on 'diabetic' foods (Arora & Arora, 1986). As the dietary changes tend to cause major difficulties it would be helpful for the person to have regular face-to-face contact with a professional to discuss problems, to provide encouragement and to monitor progress over time (Shillitoe, 1991).

4.2.7 GP-Patient Communication

Many people talked about how they expected their GP to provide information and reassurance to alleviate their worries. In some cases the GPs were good at meeting these needs, however others were not satisfied. Dunn (1993) reports that "the relationship between the diabetic patient and the other members of the health care team is at the core of diabetes care... poor compliance may be partially a result of problems in doctor-patient communication". It is therefore important that the GP understands the difficulties that the patient may experience and possesses the communication skills necessary to facilitate adherence. GPs should also be aware that patients expect information and reassurance from their GP so that these needs can be addressed.

4.3 Physiological and Medical Aspects of Diabetes

4.3.1 Diagnosis

A substantial number of people were first diagnosed as having diabetes from presenting symptoms to the doctor that may have been directly related to diabetes, or through either receiving tests or treatment for other conditions. Nobody reported being diagnosed as part of a routine health check up. This random method of diagnosis also indicates that there may be a significant number of individuals within the Western Health Board area that have not yet been diagnosed as having diabetes. Given the prevalence of diabetes and the importance of early diagnosis in the prevention of complications, alternative methods of detection should be explored. As some of the participants themselves suggested, public education about the signs, symptoms and the seriousness of diabetes may also be of value.

4.3.2 Treatment and Care

The GP service was used by the majority of participants on a regular basis and most people claimed that they were very happy with the services provided by the GP. There was substantial variation in the frequency of blood, eye, and feet checks reported by those who received treatment from their GP; only a minority of participants in this study had contact with a diabetes nurse and very few had visited the dietician or chiropodist. These checks are important in screening for complications and preventing morbidity and mortality through treatment and management (Zimmet, 1997). Protocols should therefore be developed regarding the frequency of reviews and check ups.

A few participants received treatment for their diabetes at a diabetes clinic, these people reported that they were very happy with the services there. Others commented that such a clinic would provide the ideal service. Some participants also expressed a desire for a call-recall system whereby they receive regular appointments for check ups. A number of services (e.g. diabetic nurse, chiropodist, dietician) were under used by the participants in this study and some people appeared not to be aware that these services existed. These findings point to a need for studies examining the level of services for people with diabetes and the reasons why the available services are not used.

The question of whether people with diabetes should pay for medical services and treatment also warrants consideration. Many of the participants in this study felt that they were being treated unfairly because they had to pay for medication, blood testing machines and other medical services. Others were confused about which services and medications they should be paying for and seemed unaware about their entitlements.

4.3.3 Side Effects

The physiological effects of diabetes commonly reported include weakness, tiredness and hunger. The participants who felt tired and weak claimed that this had a profound impact on their quality of life and performance at work. Hunger was described as causing weakness and interfering with sleep. It is therefore important that the causes and consequences of these aspects of diabetes receive attention and are addressed with individual patients.

There also appears to be a relationship between tiredness, obesity and exercise for many of the participants. Some people felt too tired to perform any type of physical activity and yet were aware that tiredness was related to their obesity. They did not however acknowledge the possibility that tiredness, obesity and lack of physical exercise were related to one another. Moreover, the important role of exercise in the management of diabetes (Sarafino, 1994) was not mentioned in any of the groups. Some people believed that they were physically unable to exercise due to their complications, however they seemed unaware that even very mild exercise would have a therapeutic effect both physically and psychologically (Zimmet, 1997).

4.4 Information and Education

Many participants felt that they did not know enough about diabetes in general and their own condition. It was also evident from the discussions that many knew little about how to manage their own condition and that many were misinformed. Knowledge, information and education are pre-requisites for self-management (Shillitoe, 1991). People with diabetes need to be informed about their condition

to prevent them from worrying unnecessarily and to allow them to effectively control their condition. They need to appreciate the seriousness of potential complications and the importance of self-management; they also need detailed information about their prescribed regime so that they can follow it closely (Glasgow, 1985). Effective diabetes education programmes should facilitate a change in the way that individuals think about their diabetes and the personal meaning of diabetes (Dunn, 1993; Shillitoe, 1991) and should include training in coping skills (adaptive coping strategies) and stress management (to mitigate against the negative effects of stress). Some people will also require assertiveness training and training in social skills to allow them to cope in difficult social situations. People with diabetes should be encouraged to read about diabetes to gain a better understanding of it. However education is about more than simply giving out leaflets and health professionals should be reminded that there are many adults with literacy problems for whom written information is useless.

Many of the participants believed that the public would also benefit from education about diabetes. Through public education people may recognise the symptoms of diabetes and seek tests thus improving the rates of early diagnosis. Public awareness may also help remove the stigma that surrounds diabetes and people with diabetes may be put under less pressure to break their regime in social situations.

5. CONCLUSIONS AND RECOMMENDATIONS

Focus groups with 19 adults with type II diabetes living in the Western Health Board area were held. The participants discussed their own subjective experiences, gave their opinions and raised issues which are priorities for them. The results have provided us with a highly valid insight into the needs and experiences of adults with type II diabetes in the West of Ireland. The results also highlight aspects of diabetes care and services which require further investigation to identify areas where needs may not be met. The following recommendations are made:

1. Current services should be examined with a view to increasing their utilisation by those with diabetes, identifying any gaps and investigating the potential of employing best practice systems of delivery (where not already in place).
2. Health professionals involved in the treatment and care of people with diabetes should also have an understanding of the difficulties that these people face and the psychological impact of the disorder. Current training needs including the potential necessity for updating and refresher courses should be explored.
3. Alternative methods of detecting diabetes in the general population should be investigated. Diabetes tests should be routinely performed at medical check ups.
4. The system of referral of patients with diabetes should be examined with a view to ensuring that they regularly visit all relevant specialists and are regularly screened for complications.
5. Education should be an important aspect of diabetes care. Individuals should be involved in an education programme dealing with both the physiological and the psychological aspects of the condition and self-management.
6. People with diabetes should have access to a professional with counselling skills who understands the physiological and psychological aspects of the condition. This person could answer questions, discuss aspects of the management regime causing difficulties and meet with other members of the family if necessary. This specialist could also facilitate support groups and be involved in teaching coping and relaxation skills and stress management.
7. The possibility of offering free blood testing equipment and other medical services to all people with diabetes should be explored. All people with diabetes should be made aware of their entitlements under the Long-Term Illness and medical card schemes.
8. Leaflets, books and videos about diabetes should be easily available (especially in Health Board premises) for people with diabetes and other members of the public.

REFERENCES

- Arora, B.M. & Arora, A. (1986). Dietary management in the elderly diabetic, *Practical Diabetes*, 3 (3)116-118.
- Bradley C. (1985). Psychological aspects of diabetes. In Alberti, K.G.M.M. & Krall, L.P. (eds) *The Diabetes Annual 1*, Amsterdam: Elsevier Science Publishers.
- Brownlee-Duffleck, M., Peterson, L., Simonds, J.F., Kilo, C., Goldstein, D. & Hoette, S. (1987). The role of health beliefs in regimen adherence and metabolic control of adolescents and adults with diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 55 (2) 139-144.
- Cox, D.J. & Gonder Frederick, L.A. (1991). Stress and diabetes mellitus in McCabe, P., Schneiderman, T., Field, T., & Skyler, J. (eds) *Stress and Coping*, Hillsdale N.J.: Erlbaum.
- Cox, D.J. & Gonder Frederick, L.A. (1992). Major developments in behavioural diabetes research. *Journal of Consulting and Clinical Psychology*, 60 (4) 628-638.
- Department of Health, (1994) *Shaping a healthier future: A strategy for effective healthcare in the 1990s*, Dublin: The Stationery Office.
- Drash, A.L. & Becker, D.J. (1990) Behavioural Issues in Patients with Diabetes Mellitus with Special Emphasis on the Child and Adolescent in Rifkin, H. & Porte, D. (eds) *Diabetes Mellitus: Theory and Practice*, London: Elsevier.
- Dunn, S.M. (1993) Psychosocial Aspects of Diabetes in Adults in Maes, S., Leventhal, H. & Johnston, M. (eds) *International Review of Health Psychology Volume 2*, Chichester: John Wiley and Sons Limited,
- Fienglos, M.N., Hastedt, P. & Surwit, S. (1987). Effects of relaxation therapy on patients with type I diabetes mellitus. *Diabetes Care*, 10 (1) 72-74.
- Glasgow, R.E. (1995). A practical model of diabetes management and education. *Diabetes Care*, 18 (1) 117-126.
- Gonder Frederick, L., Cox, D.J., Evans, W.S. (1985). Self measurement of blood glucose concentration: clinical significance of patient generated measurements. *Diabetes Care*, 8 (6) 627-619.
- Kitzinger, J. (1995). Introducing focus groups, *British Medical Journal*, 311 299-302.
- Kvam, S.H. & Lyons, J.S. (1991). Assessment of coping strategies, social support and general health status in individuals with diabetes mellitus. *Psychological Reports*, 68 623-632.

- Lammers, C.A., Nailboff, B.D. & Straatmeyer, A.J. (1984). The effects of progressive muscular relaxation on stress and diabetes control, *Behaviour Research and Therapy*, 22 (6) 641-650.
- OConnor, P.J., Crabtree, B.F. & Yanoshik, M.A. (1997). Differences Between Diabetic Patients Who Do and Do Not Respond to a Diabetes Care Intervention: A Qualitative Analysis. *Family Medicine* 29 (6) 424-428.
- Peyrot, M. & Rubin, R.R. (1987). Levels and Risk of Depression and Anxiety Symptomatology Among Diabetic Adults. *Diabetes Care*, 20 (4), 585-590.
- Sarafino, E.P. (1994) *Health Psychology: Biopsychosocial Interactions*, Chichester: John Wiley and Sons.
- Shillitoe, R. (1991) *Counselling in Health Care: Diabetes Mellitus*. In Fallowfield, L and Davis, H. (eds) *Counselling and Communication in Health Care*, Chichester: John Wiley and Sons.
- The DCCT Research Group (1993) The effect of intensive treatment of diabetes on the development and progression of long term complications in insulin dependent diabetes, *New England Journal of Medicine*, 90: 450-459.
- The UK Prospective Diabetes Study Group (1998) Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type II diabetes, *The Lancet*, 352 (9131) 837-853.
- Western Health Board (1998). Diabetes database, Department of Public Health (unpublished).
- Zimmet, P. (1997) The epidemiology of diabetes mellitus. In Detels, R., Holland, W.W., McEwen, J., & Omenn, G.S. (Eds) *Oxford Textbook of Public Health*. Oxford: Oxford Medical Publications.

APPENDIX

THE TOPIC GUIDE

A flexible framework for the discussions and ideas for questions to generate conversation and discussion.

The sections consist of general, open-ended questions (in italics), open-ended questions for each section (in bold) and detailed probe questions (normal, indented). The detailed, probe questions will only be used if conversation dries up or to guide the discussion if certain issues have not been mentioned.

Introduction (structured)

Background Information

My name is Siobhan O'Neill and this is David Evans, we are researchers at the Western Health Board who are looking at services for diabetic patients in the area.

We aim to get an understanding of how your diabetes affects your daily lives and your opinions about the services that are available for you. This will assist policy making and decisions in relation to the services and intervention programmes for people with diabetes who live in the Western Health Board area and elsewhere.

Confidentiality

All the information given here today is confidential and will not be available to anyone other than the research team.

Consent for Taping and Ground Rules

We would like to get your consent to tape record today's discussion to ensure that we have a complete transcript of what people have said. If you would like access to the transcript at a later stage, please contact us. No statement will be attributed to an individual and only we will have access to the tape. There will be no way of tracing any comment to any individual and names will not be mentioned on any report arising from this research. To ensure that everybody gets a fair chance to share their views can we ask that only one person speak at a time and that no one will carry on side conversations with a neighbour.

As you can see from the flip chart there are three main things we want to learn about:

- 1. What it is like to have diabetes.*
- 2. What you think about the services you use.*
- 3. What improvements could be made.*

We want to hear all you have to say on the subject so feel free to talk to each other.

Introductions

We will start by introducing ourselves. If you could say a little bit about yourself, your name, where you are from and when you found out that you have diabetes.

Section 1: The needs of people with diabetes living in the West of Ireland.

Meeting objectives 1 & 2

Aims of discussions questions:

To explore and illustrate the nature of the medical, social and psychological consequences of having diabetes for this group and thus identify the needs of this group with regard to services

General Question: *What is it like to have diabetes?*

How does your diabetes affect your everyday life?

Have you had to make any changes to your life because of your condition? (Have they been easy or difficult?)

Are there any things that you would like to do, but can't do because of your condition?

Does your diabetes affect your family and other people?

Does your diabetes affect other members of your family?

Does your diabetes affect your relationship with your partner/ spouse?

Do you find that your diabetes limits your friendships and social relationships?

How do other people react when you tell them that you have diabetes?

Do you encounter any prejudice because of your condition?

Are you ever embarrassed by having to deal with your diabetes in public?

How often do you tell others about your diabetes?

Do you ever have to explain to others what it means to have diabetes?

Would you ever eat something you shouldn't rather than tell someone you have diabetes?

Has your diabetes affected your career or the way you do your job?

Has having diabetes affected your career prospects?

Have you encountered any prejudice or bullying in the workplace because of your diabetes?

Does having diabetes affect your performance at work?

How does your diabetes affect you emotionally?

Do you ever feel bad because you can't do the things you want to do?

Do you worry about the future?

What does your condition require in terms of treatment?

- How do you think your condition should be monitored?
- How often do you have low blood sugar?
- How often do you feel physically ill?
- Do you feel restricted by your diet?
- How satisfied are you with the time you spend exercising?
- Do you suffer from any other illnesses or disabilities as well as diabetes?

Section 2: How these needs are currently met

Meeting objectives 3 & 4

Aims of discussions/ questions:

- To determine levels of awareness of current services and access to those services
- To examine the ways in which the current services meet the different needs
- To explore attitudes towards the services
- To determine levels of satisfaction with existing services

The following services should be discussed: diabetes nurse, junior doctors, consultants, GP, psychologist/ counsellor, dietician, chiropodist and ophthalmologist.

For each service discuss

1. Generally, what they 'think' about the services.
2. Access issues and location.
3. Interpersonal and communication skills of the practitioners.
4. Satisfaction with the amount and quality of information (and education) received.
5. Overall satisfaction with service (how well their needs are met).

General Questions: *Which services do you use regularly?*
How satisfied are you with your current treatment?

Are there any services available for you that you don't use? (Why?)

- Which medical staff would you like to get to see more often?
- Do you find it easy to get appointments with the medical staff?

Are you happy with the way that the medical staff talk to you?

- Do the medical staff you see explain things properly to you?
- Are you happy with the length of time they spend talking to you?
- Are you happy with the length of time they spend listening to you?
- Do you find it easy to talk with the staff who are looking after you?

Do you feel that you know enough about your diabetes and it's treatment?

- Are you happy with the amount of information you have about how to look after yourself and prevent complications?
- Is it easy for you to get answers to all your questions about your diabetes?

How satisfied are you with the services that you currently receive?

- Do you think that the specialists you see have enough information about your diabetes and it's treatment?
- What are the strengths and weaknesses of the existing services?

Section 3: Ideas for changes.

Meeting objective 5

Aim of discussions/ questions: To identify suggestions for new services or modifications to existing services.

What changes would you like to see made to the existing services for people with diabetes who live in the area?

- Are any new services required?

How could access to the services be improved?
What changes would you like to see made to the information and education services for people with diabetes?
What would the ideal service(s) be like?
How could your quality of life be improved?
Do you require any further assistance to manage your condition?

Ending

Wind the session down a few minutes before the specified time.

Give a brief resume of the main points and issues raised.

Ask: *Do you think we've missed anything?*

Thank everybody for their time and inconvenience and explain that the results will be very useful.

Reiterate confidentiality and take details of participants who want a transcript or further information about the results of the study.

Probes for use During the Focus Groups

1. The silent probe
2. The 'Go on I'm listening' probe
3. The 'journalist's' probes e.g. When? Who? Where? What? How?
4. The immediate elaboration probe
e.g. 'Can you tell me a bit more about that?'
'What happened after that?'
'What did you think/ feel about that?'
'Why is that? Why do you think that is?'
5. The retrospective probe
e.g. 'Can I take you back to something you said earlier.....'
'You said....., could I ask you a bit more about that?'
'You said you felt embarrassed about, why did you feel embarrassed?'