

Service Users' Experiences of Type 2 Diabetes Mellitus Services within Hull

Professor Thozhukat Sathyapalan

Chair in Academic Diabetes, Endocrinology and Metabolism, Hull York Medical School
Honorary Consultant Endocrinologist, Hull and East Yorkshire Hospitals NHS Trust

Professor Liz Walker

Professor of Health and Social Work Research, Faculty of Health Sciences, University of Hull

Janine Keating

Advanced Research Dietitian, Centre for Cardiovascular and Metabolic Research, Hull York Medical School

Lisa Baldwin

Unit Manager, Academic Diabetes, Endocrinology and Metabolism, Hull and East Yorkshire Hospitals NHS Trust

Hull NHS Clinical Commissioning Group

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1. LIST OF ABBREVIATIONS AND DEFINITIONS

BGM	Blood glucose monitoring
CCG	Care Commissioning Group
DM	Diabetes Mellitus
DNA	Do Not Attend
ERY	East Riding of Yorkshire
FGDs	Focus Group Discussions
GP	General Practitioner
HRI	Hull Royal Infirmary
NDA	National Diabetes Audit
NICE	National Institute for Health and Care Excellence
NHS	National Health Service
T2DM	Type 2 Diabetes Mellitus
UK	United Kingdom

2. BACKGROUND

Diabetes Mellitus (DM) is a global epidemic (1). In the UK, 3.2 million people were diagnosed with DM in 2013, a number which is expected to rise to 5 million by 2025 (2). Approximately 90% of people diagnosed with DM have type 2 (2). The risk of developing DM is multifactorial and includes genetic, lifestyle and environmental factors (2). Obesity, physical inactivity, an unbalanced diet, smoking and poor blood pressure control are inextricably linked to the risk of T2DM and risk of serious complications for those already diagnosed. All of these factors are associated with a higher level of social and economic deprivation (2).

Hull NHS Clinical Commissioning Group is responsible for organising services for an adult population of 232,475 people, of whom an estimated 14,749 (6.3%) have been diagnosed with DM, and a further 2,200 with undiagnosed DM (3). Although the health profile of Hull 2015 shows the percentage of people registered with a G.P. with diagnosed DM (recorded DM) to be the same value as the rest of England, the values of risk factors associated with developing T2DM and its complications are, in fact, significantly higher (4). These risk factors are obesity and smoking, with the deprivation value (51.8) being more than double the rest of England (20.4). In addition, the percentage of physical activity is lower in Hull than the rest of England (4). This data suggests that the value of recorded DM for population of Hull will surpass the rest of England in the future.

DM related complications incur significant costs to both the patient and the NHS through ill health, disability and increased hospital admissions. To reduce the risk of diabetic complications such as blindness, kidney failure, foot ulcers and amputations, heart attacks, heart failure, stroke, and premature death, NICE (5) recommend that every person diagnosed with DM should receive the following nine health checks at least once per year; HbA1c, blood pressure, cholesterol, eye screening, foot examination, kidney function, urinary albumin, body mass index and smoking review. In addition to this, NICE clinical guidelines (5) make recommendations for treatment targets for glucose control, blood pressure and serum cholesterol. As per the NDA, 2012-2013, 74% of people with T2DM in Hull received all care processes (excluding eye screening), whilst only 38.5% achieved the treatment targets (6).

As part of effective patient self-care, NICE clinical guidelines recommend that all people with DM are offered structured patient education programmes (5). As indicated by the NDA, 2012-2013, 29.5% of newly diagnosed people with T2DM were offered a structured

education course in Hull in their first year of diagnosis, of which 1.8% were recorded to have attended. This is below the average of 3.6% for England and Wales (6).

Given the results of the NDA 2012-2013, the 2015 health profile of Hull and the fact that T2DM accounts for the majority of people diagnosed with DM, it is vital that the opinions of Hull service users with T2DM are understood, recorded, and incorporated in the continued development and delivery of appropriate services. This reflects the aim of the Hull CCG 2020 programme which states, “people will be supported by services that fit their needs and lifestyle, designed in partnership with them”, an aim which will support a “healthier city”. This study foregrounded the needs and experiences of service users with T2DM through capturing their perspectives.

3. OBJECTIVES

3.1. Primary Objective

To describe service users' experiences of T2DM Services within Hull

3.2. Secondary Objectives

To identify which T2DM services are used or not used within Hull

To identify any reason(s) for utilising or not utilising T2DM services within Hull

To determine how accessible T2DM services are within Hull

To determine how valued T2DM services are within Hull

To determine how satisfied service users are with T2DM services within Hull

To identify any suggestion(s) for T2DM service development within Hull

To develop a methodological tool for patient experiences of T2DM services in England and further identify areas for service development

4. METHODS

The study used sequential mixed research methods in a two staged approach. Stage one involved in-depth face-to-face interviews and Focus Group Discussions with the findings being used to develop a questionnaire for stage two.

4.1. In-depth Interviews: Care Homes

Using a purposive sample across Hull and the ERY, 10 key informant interviews were undertaken with local authority and privately owned care homes that support residents with T2DM. We have combined the data collected from all 10 care homes as there were no differences in data between geographic locations and some post codes were located in both areas. Staff were recruited via direct contact with the care homes and those interviewed included managers, team leaders and senior care workers. Each interview was facilitated by the same member of the research team at a time and place convenient for the participant, and lasted approximately one hour. All interviews were recorded on an audio-recording device.

4.2. In-depth Interviews: DNAs

Using a purposive sample, 5 interviews were conducted with T2DM service users who reside within Hull and who have been recorded as not attending appointments, defined for this study, as someone who missed 2 or more consecutive appointments for their T2DM care without explanation. G.P. surgeries, retinal screening and the Diabetes Centre databases were used for identification and recruitment purposes, to help ensure that the perspectives of service users from both primary and secondary care settings were included in the study. Each interview was facilitated by the same member of the research team at a time and place convenient for the participant, and lasted approximately one hour. All interviews were recorded on an audio-recording device.

4.3. Focus Group Discussions

Participants were adult service users diagnosed with T2DM who reside within Hull. The participants were grouped into the following age categories; 18 - 39 years, 40 - 64 years and 65 years plus. These age groups were selected as data indicates that how service users need, utilise and experience services differently across age groups, especially those aged under 40 years (7). Of the age categories, six FGDs were conducted; 2 x 18-39 years, 2 x 40-64 years and 2 x 65 years plus. A total of 30 service users participated in the FGDs.

G.P. surgeries, retinal screening and the Diabetes Centre databases were used for identification and recruitment purposes, to help ensure that the perspectives of service users from both primary and secondary care settings were included in the study.

FGDs were conducted at the Michael White Centre for Diabetes and Endocrinology, which was easily accessible by public transport. Each FGD was held at a time convenient for most individuals to attend, and lasted between 1-1.5 hours. The FGDs groups were co-facilitated by the same two members of the research team and two audio-recording devices were used to record each discussion.

4.4. Questionnaire

The content of the questionnaire was informed by a preliminary analysis and overview of the qualitative data from the in-depth face-to-face interviews and the FGDs. The questionnaire was then peer reviewed by the Hull and District Diabetes Support Group prior to distribution. The questionnaire covered a range of topics including, for example; demographic details (age, gender, level of education, post code), convenience of appointment times for accessing various health care professionals (GPs, General Practice Nurses, Diabetes Specialist Nurses, Diabetes Consultants, Podiatrists, Dietitians, Psychologists), out of hour appointments, accident and emergency department access, telephone consultation with Practice Nurses and Diabetes Specialist Nurses, access to structured education, weight loss programmes, healthy living programmes, exercise programmes, access to retinal screening and foot care, access to long-term condition support, access to participating in research studies, use of social media and the importance of telehealth and telecare. The questionnaire was available in paper format only and so all questionnaires were accompanied by a prepaid envelope for their return.

3056 questionnaires were distributed to adult service users diagnosed with T2DM who reside within Hull and who did not take part in either an interview or the FGDs. GP surgeries, retinal screening and the Diabetes Centre databases were used for identification and recruitment purposes, to help ensure that the perspectives of service users from both primary and secondary care settings were included in the study.

4.5. End of Study

The study ended on 29th March 2017: four weeks after the last questionnaire had been sent.

4.6. Analysis

Where possible a mixed methods analysis was applied to enable a greater insight than may be gained through the use of a single method. This included the integration of both

components of the study, thus exploring convergence and divergence and confirming or corroborating findings.

4.6.1. Qualitative Analysis

A thematic analysis (8) was used for the qualitative data collected from the in-depth interviews and FGDs. During the fieldwork regular discussions were held with the research team to discuss emergent findings from the fieldwork material.

All interview material was transcribed verbatim. Careful reading of interview transcripts enabled comparisons by age and geographic location.

All FGD transcripts were read by members of the research team. Using a coding frame, all transcripts were coded and thematised. Through this thematic analysis the team explored emergent patterns, categories and themes.

Qualitative data analysis was supported by the use of NVivo.

4.6.2. Quantitative Analysis

The results of the questionnaires were entered into Microsoft Excel and transferred to IBM SPSS statistics for analysis. This data was then subject to descriptive analysis.

5. RESULTS

5.1. In-depth Interviews: Care Homes

Seven themes emerged from analysis as summarised below:

5.1.1. Number of Residents with T2DM

Knowledge of individuals' T2DM status was patchy. Two participants did not know how many of their residents had T2DM, and one participant only included those receiving insulin in the figures provided. Levels of awareness were not linked to workers' level of seniority; managers were no more likely to know this than senior care workers, for example.

T2DM was generally not considered commonplace by participants. One participant stated that they had only ever encountered one person with T2DM and most stated that the low numbers, where provided, were the norm.

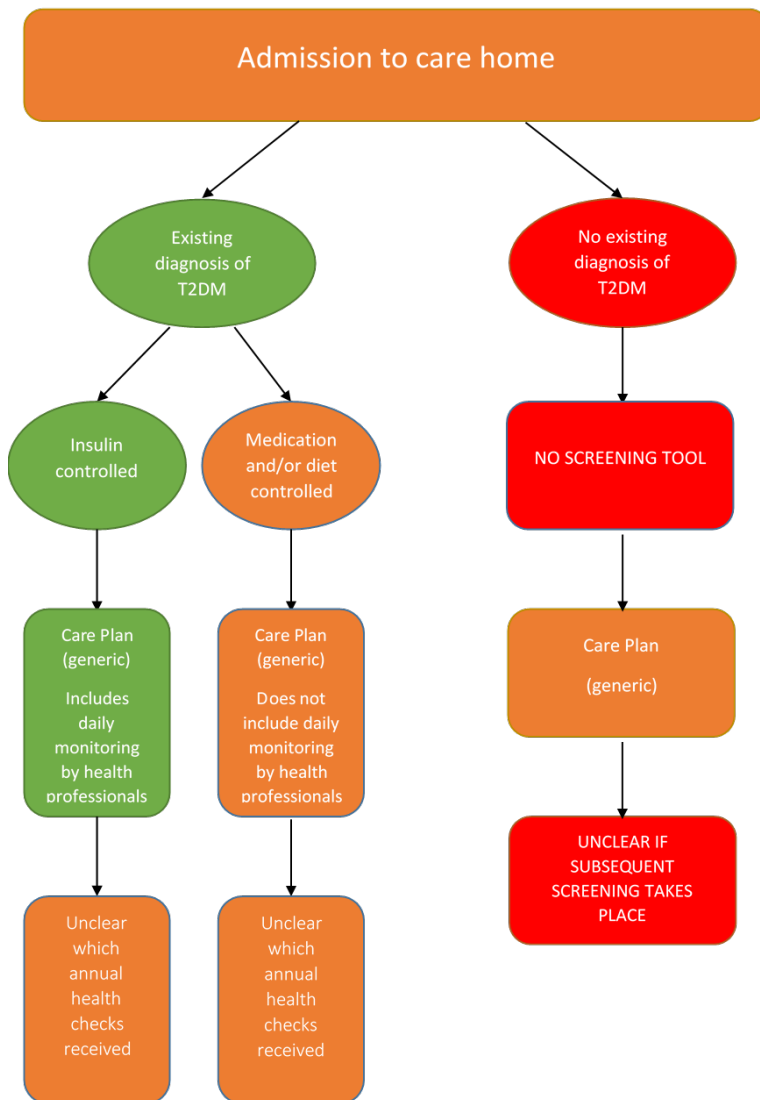
5.1.2. Defining T2DM

The way in which T2DM was defined and/or understood by care home staff was based specifically on the treatment received by service users. This was of central importance to care home staff because, in every case, they clearly distinguished between the two groups.

Service users were divided into 'those receiving insulin' and 'those who were not'. Service users who received insulin were *always* defined as having T2DM, by the care home staff, whereas there was a difference among the staff around whether or not they defined service users who received medication and/or controlled their T2DM through diet as having T2DM.

If residents received insulin, participants stated that service users received daily monitoring and support from district nurses. If residents took medication and/or managed T2DM through diet, the picture was unclear, there was a lack of clarity about whose role it was to support such service users; what support they should receive; and how often they should receive it.

Flow chart 1 below shows the link between services and treatment:



5.1.3. Screening and Monitoring

No participants reported using a screening tool for T2DM on admission to a care home. It was also unclear whether there were any future time points where screening might take place for those without a diagnosis. Instead, participants reported relying on existing information on admission. If there was a diagnosis, this information was incorporated into an individual's care plan. Only one participant, who worked in a care home with residential and nursing provision, reported using a monitoring tool:

What we do is use the fifteen point plan off the Diabetes UK website and sort of use that as a guide, well for the full maintenance really of, of diabetes...CQC pointed us in the direction of that, and yeah, it's been useful, it's useful for doing the care plans.

Those residents on insulin were monitored daily by district nurses, although participants generally did not go into detail as to what this monitoring entailed. There was a lack of clarity about who should monitor people with a diagnosis of T2DM who were on medication and/or diet controlled, and when and how.

5.1.4. Training

Five participants reported receiving T2DM training, although this was often many years ago. Three participants were not clear about whether they had received specific T2DM training, and two had not received any training at all. Providers varied, and no participants were aware of a rolling programme of training. One participant was aware of the 'fifteen point plan' by Diabetes UK (possibly referring to the 15 Healthcare Essentials (Diabetes UK, 2016)), but no other participants were aware of any national diabetes guidelines.

5.1.5. Accessing services in Hull and ERY

Treatment determined access to services. Residents on insulin were monitored by district nurses, others were not.

Only one participant reported that the care home had 'a fully stocked hypoglycaemic kit', although it was unclear who was able to use this (care home staff, district nurses or both). There was also a lack of clarity from other participants:

They normally give us, tell them to have Lucozade, don't they, to start with...but nine times out of ten the nurses are here because they'll check the BMs, so they see it.

We do have Glucogel, but it's only the District Nurse that can administer that you see, we can't. At one point the staff could, but then it was taken away and they said, no...I've no idea why that changed...

The variety and lack of clarity around how care home staff would respond to hypoglycaemia appears to be linked to 1) apparent low numbers of residents with T2DM; 2) little or no T2DM

training; and 3) a lack of clarity regarding who is responsible for monitoring residents with T2DM.

Nutrition was viewed as the primary responsibility of care home staff, although they occasionally made reference to support from district nurses. Care home staff reported that nutrition was a part of all care plans and that every resident would have a care plan. However, some participants referred to the challenge of balancing the control of T2DM through diet and individual choice:

This particular gentleman has lost one of his toes through diabetes, he's very blasé about it...Yesterday there was treacle sponge, I said, I'm sorry, you can't have that, it's too much sugar. Oh it doesn't matter he said. I said but your blood sugars were such and such this morning. He said oh it doesn't matter, it's been over thirty before today and nothing has every happened, and I think, ooh.

With regards to multiagency working, participants reported finding it difficult to contact health professionals to get up-to-date information about residents. Four participants stated that there were problems with multi-agency information sharing, and six participants were happy with multi-agency information sharing arrangements. Only one participant reported always receiving health appointment outcomes, whether results were negative or positive. All other participants reported having to chase up all results, often waiting several weeks, or only being contacted if 'something was wrong'. Maintaining good relationships with district nurses was important for effective multiagency working. Although information sharing with GPs was seen as fairly unproblematic, sometimes difficulties arose when prescribing took place by phone, for example,

We seem to have to go through the receptionist rather than, you know, the GP responding, I mean, and we know they're busy, but after the surgery they could ring back and say what's the problem? And it's the receptionist that rings back and says, I've spoken to the GP he's going to give you some eye drops for this or whatever... without actually speaking to the staff, so it goes through that second person...and sometimes the information that they relay back to the GP is not the correct information.

Commenting on external health professional support, one participant pointed to the different levels of care experienced by people living in residential care as distinct from those receiving nursing care:

I think the support's wonderful when there's a problem...if everything's tottering along nicely we don't get any input, so I suppose if we seek it, it's there, we know it's there, but otherwise it's just the once a year checks...I would like more of an input with it...I mean for the residentials, the nursing isn't so bad because the nurses have more input but with the residentials, it's a lot of pressure on the senior care assistants who don't have the nursing knowledge.

Care home staff clearly play a key role in delivering T2DM services, yet state they often need more support to do so.

With regards to satisfaction with T2DM services, among the staff interviewed, there were differing views on how satisfied they were with T2DM services. It is important, however, not to make a direct link between care home staff satisfaction and the quality and scope of services residents with T2DM receive.

5.1.6. Use of technology

Access to the internet varied among participants and there was mixed views on the use of technology to support training, with practical issues being raised.

Six participants explicitly referred to using the internet to access information about T2DM. However, how and when they could access information online was unclear, with two participants stating they used their phones:

We don't have [access to internet] here, we only have it in [specific room] which we don't have access to but we've all got phones so obviously we all Google

If I'm not sure about [something] I'll always look, get my phone and look on the internet, Google and things and see what's wrong. I often, even for different things, if we get a new medication

Any implementation of online resources or training would therefore need to take this into account. This finding appears to be linked to a lack of formal, regular training where participants report being reliant on Google to answer their queries.

Participants had mixed views on other uses of technology. Some participants reported a reliance on 'pen and paper' but recognised this may change in future. One participant suggested a new diagnostic tool might be useful, for example:

I think diagnostic tools, a specific thing for diabetes and for other conditions, so yeah, so a diagnostic tool...is this related to diabetes, where do we go?

Any additional use of technology, for training or service provision will need to take account of the practical constraints outlined above.

5.1.7. Care Home Staff Suggestions for T2DM Service Development

Care home staff reported that they would benefit from receiving the outcome of medical appointments, whether negative or positive, directly to the care home.

They suggested that health professionals should be encouraged to take mental as well as physical health into account when arranging appointments outside the care home. For example, a minority of participants reported finding it difficult or impossible for GPs to visit service users in care homes, and although they were pragmatic in terms of limited resources, many participants stated home visits would be ideal for service users with co-existing conditions, such as learning disabilities or dementia:

And I know sometimes home visits are difficult because [surgery] think, well, he can walk...So they see that he can get to the surgery so why do you need him to come here?

She's elderly, she's got learning disabilities, she can get quite anxious and upset if she's waiting for long periods.

It was also reported that some health professionals had difficulty communicating with people with learning disabilities, with information being shared directly to care home staff at health appointment, rather than the service user, which some participants who found frustrating:

If you take them to a GP, the GP goes, oh well, what's the problem today? And looks at the staff, well I haven't got a problem, but this lady has got one!

With regards to training, the majority of participants reported that they would like more and regular training on T2DM, including basic, general information about T2DM and nutritional information. It is important to note that three participants referred to knowing a piece of information because of their personal experience, rather than formal training.

Participants emphasised the importance of making any interventions, tools or training inclusive for people with learning disabilities and dementia.

5.1.8. Summary of Findings

- Care home staff are unclear how many residents have T2DM
- The way in which care home staff define T2DM affects the diabetes care they receive
- If an individual receives medication and /or is diet controlled, it is unclear who monitors their condition, how often and when
- If an individual is not diagnosed with T2DM on admission to a care home, they do not receive any screening for the condition
- Care home staff have little or no T2DM training
- Divisions between health and social care impact on the ability of service users residing in care homes to access T2DM services
- Care home staff stating that they are satisfied with T2DM services is not an indication that service users receive satisfactory T2DM services

5.2. In-depth Interviews: DNAs

Following data analysis three core themes were identified: being diagnosed with T2DM, its consequences and impact; managing the complexities of T2DM and accessing services; barriers/facilitators to access and recommendations. All names used in this section are pseudonyms.

5.2.1. Being Diagnosed with T2DM: Its Consequences and Impact

Physical Symptoms

T2DM significantly impacted on the everyday lives of participants. Participants experienced a number of challenging physical symptoms, largely as a result of complications associated

with T2DM, including, neuropathy, tooth loss, amputation of toes, problems with vision and most participants had a number of other long term health conditions, further complicating the impact of T2DM. These included obesity, osteoarthritis, and high blood pressure. Tooth loss, in particular, was a significant issue for two participants; both spoke of their embarrassment and shame and covered their faces many times during the interview.

Loss of independence, livelihood and social isolation was a common experience. The impact of limited mobility affected participants' ability to leave their homes, even to undertake everyday tasks such as walking the dog, which facilitates social contact and increases mobility. No longer being able to drive curtailed independence and general travel. In addition, work, social and family interaction was very limited for most people. One participant spoke of being 'trapped inside the house' and the feeling of helplessness associated with being unable to effectively care for themselves.

Mental Distress

All participants reported experiencing mental distress, particularly depression and anxiety. One participant, for example, referred to his life as a 'non-entity', repeatedly stating that T2DM had shaken his confidence.

Simon stated:

It hit me for six really, it's knocked a lot of confidence out of me, it's, erm, yeah, it's a bad thing, you know because I can't walk them because, you know, they're original, my, my dogs really, you know, you know, I think the dogs feel it as well, people think it's daft but I think, you know, the older dogs are getting as depressed as I am but, [laughs] but that's another story I think. He's of same mood as me, he doesn't move far really but, so, but yeah, diabetes has really knocked me for six, the effects of it, especially over the last two years.

Michael commented similarly:

But I just, like I say I'm just stuck, I don't know where to go from here, I just feel like the road's stopped and there's a big brick wall in front of me and I've explored as far as I'm aware every avenue, and I can't seem to, to find out which is the best one for me, so yeah, diabetes has had a big impact in my life, yeah, well it has for the last ten years.

He continued:

I have had enough of diabetes, I'm sick of it, it's, it's like a big ball and chain round you really because even if I go on holiday I've got to make sure I've got all this medication with me, I want to be healthy, I'm forty seven, I'm not old.

Participants also described their *fear of future* complications and deterioration, such as losing limbs, dying young and ongoing symptoms resulting in significant anxiety:

if you took my legs off, that'd be it, I'd just go, I'd just go, well, if they say well, we'll take your legs off or anything like that then, and that'd be me, that'd be me finished because I, I've already lost one mate (Mick).

Michael said:

It does worry me, you know, worries me for my family at times as well, you know, we, what, how bad I'm going to get but nobody there seems to have an answer, you know and like I say it's a big worry, especially with a family and I don't want to die young, I want to see my kids grow up.

One participant, in particular, described her ritual which she undertakes nightly due to a fear of hypoglycaemia and going to sleep at night.

Janet said:

yeah, it is scary, but you kind of, you don't put it away, you kind of say, if I make sure before I go to bed at night I have a sugary, I always have Ribena and I always have that by my bed, so before I go to sleep at night.

Impact on the Family

T2DM was spoken of as highly intrusive, overwhelming and a condition which prevents people from living a normal life. The impact was felt in relation to their families as well as themselves. Participants' spoke of being unable to participate in everyday family activities, like playing with their children and creating additional responsibilities for their partners and children, particularly when they were unable to take care of themselves:

I can't go out and play football with my lads, I've still got a lad at home who's, you know, fifteen (Simon).

Simon continued:

I'm tired when I leave work a lot more and, but it's, some nights, even though I'm on sleeping tablets and what have you but some nights I'm, they don't work that's when they don't work then, you know, you've got a sleeping tablet hasn't worked, you know, you're zombified for a day or. So it does, it does impact on your family life, you know, because, erm, you know, you can't do...

Participants also spoke of the impact of their depression and mood swings on their families. And were keen to 'protect their children' from what they described as 'bad eating'.

Taking Type 2 Diabetes Mellitus Seriously

With hindsight (and the experience of complications) participants reflected that they did not ascribe sufficient seriousness to their initial diagnosis with T2DM.

Simon said:

It was like, maybe when I first got it, most people are [diabetic] and that but now the pain is horrendous in my feet, and they keep saying about my mouth....

Sally stated:

[its] taken a long time to take the disease seriously.

Simon continued:

I wish it, I wish there was more information that I could, I still find, you know, the acceptance of what you've got and what the side effects are, you know, still sometimes hard to sink in, you know, I've always been a pretty active person but not really happening.

Janet similarly commented:

It took me a long time to accept it and to like really take my meds properly and take it seriously really,

While some participants indicated that it has taken some time for them to absorb the seriousness of their condition, one participant also suggested that this was a wider public perception.

Janet continued:

Everyone thinks, oh diabetes, it's only diabetes or it's only diabetes two, not even diabetes one, but do you know what, read the leaflets.

The impact of living with a *stigmatised condition* was also very apparent, with participants describing either having:

Type 1 or the fat one (Simon).

Participants described being told what to do by others who did not have T2DM. For example, Simon commented:

[People say] Get off your poor me attitude and take a walk, do the exercise because then you might not need the big medication, you might get away with control by diet, and that will be so much better for you and of course they just look at me, ha, well I, I'd love to be out there, I'd love to take the dog for a walk.

5.2.2. Managing the Complexities of T2DM

T2DM was experienced as a complicated and demanding condition to manage, including daily tasks (medication, blood glucose monitoring), annual screening/checks, food and weight management and coordinating appointments, including those for other medical conditions.

Participants spoke of the need to be 'self-managers', of relying on themselves to take care of their disease and 'working out what to do for yourself' and their 'tacit knowledge' of the

condition was seen as a way of managing. However, Simon also queried who he might call in the event of there being any difficulties:

So I don't take Gliclazide so I'm not as bad as I used to be, they were making me iller, shooting my bloods down and up and so I haven't bothered to be fair for, for quite a while, I've got all the equipment, you know, but I haven't really bothered, you know, maybe that is, but there again at the end of the day my blood's low or high it's, my body will tell me that, you know, and if it's, you know, what, there's not a lot I can do about it because they don't, who am I going to ring up and tell that my bloods are low and my bloods are high or, it's usually low, below four is it?

Janet said:

I should do it [BGM] three times a day. Ah ah, I do it once a day unless, and I've, because I've been with this now for over a year, I can, I can know when I'm, my blood sugars are high, I get very sweaty, I get very hot, erm, I feel very dry in my throat, erm, so I know if my, I, I have my ways of knowing,

Some participants felt they were in control of their T2DM. For example, Simon said:

I'm managing it the, you know, the best I can, you know, I have a feeling if I didn't manage it the way I do it'll probably be a lot worse than I am, so, but yeah, I think so, yeah.

However, Michael commented:

The diabetes or the weight it's me controlling this. No, no, it manages me, definitely.

Being in or out of control of T2DM was linked to a number of things, notably, the management of medication, weight gain and appointments; three central issues in the self-management of T2DM for this group of participants.

Medication

Taking regular medication was intrusive for some participants; it was an ongoing reminder of their condition and something that requires continual management. These participants talked about how challenging they found it.

I'm sick to death of taking these diabetic tablets. I go, I keep them in like a sandwich box, with the lid on them and I open it up and I think here we go again, I'm sick of it, I've had enough I don't want to do it no more but I know I've got to take them otherwise I'm going to be poorly, I just can't win (Michael)

There are times when I really just want to flush everything down the toilet, I hate taking meds, I hate having to rely on that, so, you know, and when my mental state's not good that's generally like (Sally)

I find that really really depressing and it's not an exaggeration, I hate it, I hate taking them, so. (Michael)

Integrating medication into daily working life was difficult. Michael, who had two jobs, both involving shift work described how hard it was to fit medication into his routine:

I do forget to take my tablet in a morning, sometimes I'm, you know, when you're rushing around and you're late.

He describes going to collect his daughter to take her to school after a night shift:

[I went from] Goole back to Hull to pick her up and she wasn't even ready. So I took her to school then I realised I'd forgot my tablets, so then I had to go back home, take my tablets and, it's just, can be a nightmare at times, can be a nightmare, I mean I've got three kids at home, living with me at home, I don't know if you're a parent but...

The amount of medication which some participants needed to take was also identified as challenging. For those participants with comorbidities this situation was compounded, for example, participants reported taking medication for depression, high blood pressure etc:

I'm on the medication for it, so it's, erm, that's why I'm on so many tablets, all these mad tablets, blood pressure and, but everything's settled if you know what I mean (Simon)

I was on one tablet a day, now I'm on twenty one tablets a day but it's. Seven in a morning, two or three during the day, five on a night, so that's like, it comes to about twenty tablets or something but yeah, I'm usually pretty organised with them, erm, I

rarely miss them, well I do miss them but, you know, forget to take them now and again (Simon)

Quantity and, in some instances, fear and discomfort with medication, as well as depression, meant that medication was sometimes forgotten, taken erratically or not taken at all:

I took some yesterday, took Gliclazide and that was it, supposed to take them two or three times a day but I forget to take them on a night, do you know what I mean? (Mick).

I do try to manage my diabetes with my medication as, as best as I can but there is days I do forget, I'm not going to lie to you, sometimes I do forget, can't always remember (Michael).

Sometimes I forget my insulin or I forget the needles and then, erm, I'll starve myself, I won't eat because I know that I'll, you know, rubbish kind of eating and not having an injection, so, I kind of, I don't know, I suppose I suffer that way, I get a lot of abscesses, usually in my groin, I got one, I've got one on my inner thigh (Sally).

And, and when, when I feel depressed I neglect myself, I don't eat, I don't sleep, I don't take my meds, you know, so, erm, yeah (Sally).

I should take insulin but I don't like taking it, it frightens me, I mean they give me it here but I only used it once and it, it frightens me to use it (Mick).

Mick spoke of the difficulty he had accessing the tablets he needed to take:

I can't open the, you know, the foil, I've got to open them with my teeth, then I don't bother, some days I don't bother taking them or anything like that, but if they were already made, blister pack, and all like that, yeah, I mean I, I'd do them, if there was there to take each day I'd do them but you've got to open the packets, it takes me all the time to open them, well the wife helps me now and again like, but it takes a lot of time so.

Weight

A central feature of controlling T2DM is managing weight/weight gain. The obesogenic environment of Hull was hard to ignore, with take-away food easily and cheaply accessible. The impact of immobility and disability restricted movement and maintaining enthusiasm for exercise and gym programmes was both difficult and expensive. Diet pills and weight loss programmes were costly and for the most part unhelpful, certainly in the long term. Participants spoke mostly of their shame and distress at being overweight and obese. Being obese was highly stressful and participants simply felt 'stuck' and 'trapped' in their bodies.

Janet said:

I went from being twelve, thirteen stone to I'm now about seventeen stone, and that impacts on your diabetes, that also impacts on your psychological, I feel really fat, I feel horrible.

Talking about recent photographs she had taken she said:

My daughter took pictures and I hate the pictures, absolutely hate the pictures. A, it shows me I'm in a wheelchair and B, I look fat, and it's a, a circle and unless they let you do things like take these tablets where you can do your exercise, or find some way of doing exercise with mobility problems, then you're always going to have this, diabetes will just keep going around and around, you can't not have diabetes, once you've got the diabetes two, it's like a vicious little circle, especially for people with mobility problems.

Another said similarly:

I think a lot of my depression is down to my weight and then it's down to my diabetes but if didn't, if I wasn't so fat I wouldn't have diabetes would I? (Michael).

Advice from health professionals regarding weight met with mixed responses. One participant commented that he had never been told to lose weight, where as another expressed frustration at receiving repeated advice which they were unable to act on.

The diabetes or the weight it's me controlling this, but I get sick of people, especially healthcare professionals saying you need to lose weight, I know this, tell me how I

can do it, guide me, help me, don't just say you need to lose weight, here's some leaflets, here's a book, help me through it because it's alright sending someone away with all good intentions, so many weeks, so many months down the line, someone's going to, I, I think it's like an alcoholic, I think food is an addiction, sometimes you can have a food addiction, like, like a drug addict, they need weaning off it, yeah, we need food to survive but I probably don't need as much food as I'm taking in but when your body's saying you're hungry or I'm bored or I'm worrying, which I constantly do what do I do? I turn to food, that's my drug and I can't get off it, does that sound stupid? (Michael).

Appointments

Managing T2DM successfully requires managing multiple appointments, including; blood tests, screening (eyes and feet), and regular check-ups. If patients are living with other conditions (including complications from T2DM), they require additional management. Keeping track of and attending appointments requires mobility, independence and organisation.

I get confused and then I might think oh well I've got an appointment next week but, I know I've got an appointment but then when it's come to it, I, I'm confused about where I should be or who I'm seeing or what, why, why I'm seeing someone, I'm a lot better these days because I've got a diary and I try to write everything down because obviously when you've got a busy life, you, you forget stuff, don't you? Well I certainly do as I get older (Sally).

They send me letters and I open them and, then I just put them on the mantelpiece and I get another letter and put, another letter, sometimes I'll open them, look at the date and when was the last one.

Difficulties with memory were mentioned repeatedly by participants as was the challenge of travel and transport particularly if mobility and dependency on public transport were issues:

I get all sorts of appointments and unless they're local i.e. here, I find travelling to them is absolutely a nightmare (Janet).

You try and get on a bus home from Holderness Road and you aren't, you aren't doing it very easily because everybody coming out of town's got on that bus before

you so wheelchairs, pushchairs, they're all on before you, so you've got, you're standing there waiting and waiting and waiting (Janet).

No, I have missed appointments over the years but kind of, I don't know, I know it's my own fault, it all, for whatever reason I've missed it, but you kind of end up feeling like you're being pushed from pillar to post and then when you end up seeing that many people, you know, it can be confusing about who I'm seeing what for, you know, who for what (Sally).

Managing T2DM for these participants was burdensome and challenging in many ways. Intermittent support (health system and family), difficult life circumstances and limited alternatives resulted in feelings of being trapped/stuck in a cycle of ill-health, shame and despondency, with few options to change their situation.

5.2.3. Accessing Services: Barriers, Facilitators and Recommendations

Participants identified a number of barriers to accessing services. These included accessibility, particularly of specialist services and transport, for example, to the Brocklehurst Building. Participants indicated that services and support were uneven and irregular, and did not know always who to contact or which services were available. There were mixed views on e-health support and the use of the internet. While some participants were able to access their GP surgery and manage their T2DM, with the T2DM/practice nurses, others found it more difficult to get an appointment.

Michael said:

You ring your GPs, can I have an appointment? No, well ring up at eight o'clock in morning, then you can't ring up at eight o'clock in morning because every Tom, Dick and Harry's ringing the surgery. You know, GPs don't ask what's going on in your life, they, you know, they're there to, I'm not blaming GPs, if anybody's to blame for this, it's me, er, GPs don't have enough hours in a day, you've got a ten minute appointment if you're lucky but then.

Participants did not always find podiatry and dietetic services responsive to their needs or successful in helping them to manage their weight, commenting thus:

There's just not that support for us fatties (Michael).

I did see a dietitian here but I just thought it's a waste of time, she's saying you've got to manage your portions, yeah, I know I've got to manage my portions and then, but when you're not eating regular how can you manage your portions? You can't, if you're on the run (Michael).

Michael continued:

but it doesn't work with a dietitian, I mean I just don't know where to go from here, I'm stuck, I'm stuck.

I've seen podiatry once, in all these years I've only seen them once (Michael).

Janet commented positively on the support provided by occupational therapy:

I try and walk around the house without using the wheelchair although my OT has been absolutely brilliant because she has already, we've already discussed this, there's going to come a time in the future where I won't most probably be able to do as much as I can do now, so we've already done the brick work. As you can see the house is now, I can turn the wheelchair in the house, I can get out into the back garden, this has all been done so that when I actually get to the point I need it, I'm not then having to go through the system to try and get it done.

Conflicting information about appropriate food choices was also a source of frustration:

I need to know what you want me to eat, you tell me what I should have in a day, not what I am having in a day, I know, it sounds really selfish but I can't get my head round it, you know, people put all these books in front of you, or say you need to eat this, you need to eat, eat rice and peas and stuff, but you can't have too much rice, you can only have it so many times a week, have a jacket potato with some beans, but you can only have that, oh yeah, supposed to eat healthy, have a tuna sandwich but don't go mad on the bread because it's full of carbs, you can't, everything you're supposed to eat is bad for you and now they, I don't know if you listen to Radio Four but I listen to it a lot, there was some guy on there the other day say oh no do, all these people have got it all wrong, you need to eat fat, eh? Yeah, we've done a study on it and you need to eat fat, you're not eating enough fat that's why you're

getting fat, so what do you want me to do, stuff my face with sausages and bacon all day? (Michael).

5.2.4. Service Development and Delivery

Participants made a number of suggestions for service development and delivery. These included:

Psychological Support

Participants said:

.... I wish at times, you know, when you're having a bad time that there was just somebody you could ring up (Simon).

It just knows that there's someone at the end of the line, or I'm seeing someone once a week what can help me and give me the guidance I need (Michael)

[It would be like] someone watching you, someone sort of like guiding you in the right way (Michael)

A One Stop Shop

This would assist with the coordination of appointments and enable continuity of care. As Sally said:

I would see everybody who I'm supposed to see without, you know, there's going to be a lot less risk of me forgetting . . . it can be quite daunting going to new places and constantly meeting new people and, and then, erm, you, you kind of have to explain yourself all over again and, you know, it's, it, it gets really boring, I suppose and makes me feel disinterested, which I know is not good. . .

Healthy Weight Management

Up to date, consistent information on food choices and mobility practices relevant to individual life, cultural and economic circumstances.

Care coordination

Consistent support with the management of multiple health conditions, appointments, medication and accessibility.

5.3. Focus Group Discussions

Four core themes have been identified in our analysis of the FGD data: The impact of T2DM on daily life; management and maintenance of T2DM; the impact of being involved in clinical research and suggestions for service development and improvement. Each of these themes will be reported upon and where differences have been identified across the age groups, these will be identified.

5.3.1. Living with a 'Diabetic Identity': The Impact of T2DM on Daily Life

T2DM significantly impacted on the daily lives of participants with some saying they now had a 'diabetic identity'. Participants reported being very shocked and surprised at their diagnosis. Initial responses to diagnosis was reportedly mixed: some people spoke of being in denial or not understanding the seriousness of the diagnosis at first, while others suggested the initial urgency of their response dissipated over time. Participants also indicated that being diagnosed with T2DM had resulted in complete life-style change, including diet and exercise.

Erm, I would, a sense of denial in the first instance because, then shock, because, erm, er, it took a long time to, erm, I believed it, but I didn't, erm.

Came as a complete shock, wouldn't necessarily say denial at first but because type two diabetes, apart from thirst and weeing in the night and things like that, it's, you don't always get symptoms, I've never had an operation, I've never broken a bone and, yes, my BMI is over, is probably around thirty one, thirty two but other than that not a smoker, hardly drink anything, erm, had quite a decent appetite, I used to say my favourite meal was buffet.

Physical Symptoms

Some participants highlighted the intrusive and sometime disruptive nature of symptoms, such as mood swings, thirst, fatigue, neuropathy and excessive sweating. Mobility

difficulties, increased urination which, for example, impeded participation in social events and other practical activities such as driving long distances, tiredness and sleeping throughout the day were also highlighted as intrusive and sometimes disruptive. These physical symptoms also contributed to feelings of loneliness and social isolation.

Mental Well-being

Poor mental well-being was a significant issue for many people. Boredom and isolation, particularly among participants who were not working, (in all categories, but particularly those aged above 65 years) was hard to manage and participants felt a loss of independence as a result of no longer being able to drive because of their T2DM. Depression, anxiety and fear were common responses, particularly when participants were fearful of becoming hypoglycaemic. One participant, for example, carried a back pack at all times for emergencies.

I've got a little bit paranoid as well, I carry that bag with me, I've been carrying it for years, it's worn out now. I've been carrying it for years, I have that machine, I have a bottle of Lucozade, I have sweets because I'm scared that I have an hypo and just be there, and that's it, you know, the end of me type of thing, that's how much it's really affected me sort of like in a mental [way].

Fear of the future, particularly complications related to T2DM, for example, amputation and possible loss of a driver's license were identified as very worrying and participants described experiencing low self-esteem and self-consciousness, particularly where this was linked to weight gain and social isolation. Career and work disruption was also reported. There was sadness at being unable to undertake some daily activities, such as playing with their young children and grandchildren, and some participants spoke of not wanting to share their anxieties or distress in order to protect their partners and other family members. These comments reflect FGD participant concerns:

I do feel quite scared for the future. I'm on a three year driving licence.

He won't go out anywhere, he's lost all sense of communication and he, he won't, he's no friends left, he, because he doesn't talk to anybody, if you take him out he's just, he just goes to sleep.

. . . but the reason why I don't go out because it's a bit embarrassing that you're always off going to the loo, er.

Sleeping a lot, well I can sleep fifteen, sixteen hours a day, that's because I'm not occupied.

I've taken a sabbatical from teaching, it's a stressful job anyway, erm, my thing is stress, I eat when I'm stressed, I try to, I've probably got an addiction with food when I'm stressed, erm, but I do notice my blood sugar readings go way off the chart when I'm stressed, erm, so I'm taking a year out, going back in a year's time, hopefully a bit trimmer, [laughs] erm, and a bit more focussed.

Impact of T2DM on the family

Some participants had caring responsibilities, for children, parents and partners (who were themselves unwell and/or disabled), which their T2DM made more challenging. T2DM and/or early death of other family members, for some participants, profoundly influenced their reactions to T2DM.

Participants, particular those in the 18-39 age category, whose parent/s also have T2DM, expressed a determination to live differently and make alternative food choices. They saw themselves as trying to reconfigure their family history. Some indicated that their parents made, and continue to make, poor food choices and commented that they did not want to inherit these.

my parents are both type two diabetics and in their mid-sixties, erm, and they have not made good choices, changes, they've not made changes to their diet, they're still eating high level crappy carbs, big massive meals.... I'm shocked on reflecting that they have not made better choices before now because I didn't really understand what diabetes was before..... who knows maybe I wouldn't be sitting here right now..... I've got to stop the circle being repeated.

You didn't even think about it – because you just ate like everybody else.

Family food choices and food practices (ways of eating) were thus being questioned. This was the case particularly where participants had young children and felt a responsibility to eat healthily. In response to these anxieties, participants were configuring new ways of

eating, shopping and preparing food. One person spoke of being aware of these choices when shopping, doing what he called a *Diabetic shop*.

Participants in the 18-39 age cohort spoke explicitly of a responsibility for their (and their children's) future. One participant said:

in terms of what the children need in their diet, erm, I'm fully aware that I am, I could give them the opportunity to reduce their chances of being in the same boat as what I'm in, with the extra knowledge and the education that I've, that I've got, erm, to stop the circle being repeated, so.

[We] need to think forward to the next generation. . . [I] still have 30 years!

They (and some participants in the 40-64 age category) also spoke of the particular stresses and responsibilities of middle age, of looking after two generations whilst maintaining their own homes and working lives. This resulted in particular stresses, negatively affecting their T2DM, including 'stress-related eating'.

Occupation

Maintaining work was challenging for some participants and others identified their occupations as contributing to their condition, or certainly to weight gain. Sedentary occupations, including office work e.g. call centres, those who travelled a great deal, and those who undertook shift work (which resulted in missing meals, eating irregularly, and in a hurry) including taxi drivers, were most affected.

I used to drive taxis for a long time and weight crept on, eating junk food and, and stuff like that, snacking, sat down for long periods, no exercise.

I used to be a bus driver and a taxi driver and getting up early in a morning, my, my dad used to be a bus driver and the family got a habit of breakfast, a cup of tea, a few biscuits and out, so I, you know, I'd snack a lot with the biscuits, well used to, I've cut them right down now and the, I've changed my diet where I, on my phone I check everything,

I've lost my control on my diet , because I have to travel a lot to XXX, because of my job and everything and I have to stay in hotels and everything and the food

you take there and I am, and the time, the amount of time, you're tired and everything, so it's, my lifestyle has not been changed but I am in illusion [denial] because my HB1 is still in control, I can get a bit elevated but today's a bit of shock at twelve.

5.3.2. Management and Maintenance of T2DM

'We are coming more and more our own doctors':

What is involved in the self-management of T2DM?

FGD participants spoke of their reliance on tacit knowledge and their intuitive understanding of their own bodies. Self-awareness/knowledge was combined with body monitoring and weight watching. Many participants described the monitoring they undertake, including the use of apps, to maintain control of their condition. One participant commented:

every single day I do my blood sugar first thing in the morning, I do my blood pressure first thing in the morning, I then always have my breakfast and I know in my own feeling whether I'm, whether I'm okay or not.

I use this app a lot, ever such a lot, everyday, I do my bloods 3, 4 times a day and, you know, it's usually about 5, a bad day could be 7, you know and, so yeah, I tend to make me responsible.

It is up to us to manage our diet, isn't it?

Self-management required hard work and commitment, self/body knowledge, knowledge of T2DM, and a clear understanding of how to navigate the health care system which some participants felt confident and supported to do, whilst others reported feeling bewildered, confused and wanting information. For example, a point of discussion in all FGDs was feedback from blood tests. Some participants never received feedback and did not know what the results meant, if they did. This is a conversation between participants:

Because I go, I go twice a year and they do, er, they, they take blood it's HBA1C which, erm, shows how you control your diabetes, you know, better.

But if you say to them what's the numbers? They've got to tell you.

Do you know what the numbers mean?

Yeah.

Oh right.

Because they give, you can get a chart, get on the internet.

Others said:

If you don't go back and say then nothing happens, they assume you're alright and that's the, you have to be strong about and go to the doctor and say no.

It's up to you. It's up to you yes, and you know this, it's your body.

[But] A lot of people find it difficult.

Well they do, it's confidence in the GP as well isn't it?

And if you don't like what you're hearing from them, ask to see another GP.

One participant describes receiving a blood glucose monitoring (BGM) machine from her GP practice:

I was given a blood monitoring machine. But the nurse was too busy to show me how to use it, so they told me to go to the chemist, that the pharmacy would teach me but the pharmacist had to Google it to get it on YouTube to see how to do it, so the.. Then she, a young girl just told me to go away and I still don't know the numbers. So I don't use it. Because I don't know what number my blood is supposed to be.

Participants described needing a strong system and network of support to manage T2DM. This support and access to structured education programmes was important from the point of diagnosis, however, for some participants this was not forthcoming. One participant said:

They called me in, says you're diabetic, that was it, finish, other than that, say the courses the, I've had none of those, none whatsoever. I had to find out myself for the, what you could have and what you couldn't have. So they've turned around, no sugar,

no salt, no biscuits, erm, nothing with fat in it, that's how I controlled it myself, but I've had no advice as to how to control it, which is why I picked up...

No-one's told me, so all I know is I've got it and I don't really know what it is, apart from high sugars.

I don't know nothing about diabetes other than taking my medication.

Some participants put support in place themselves, for example, accessing information online, sometimes in the absence of professional advice and families also played a central role in providing support. Participants commented:

See all the information I've got I got myself though, I haven't been told by the NHS. I was left to struggle, to learn alone

[I've] just been me finding out for myself to be fair..... the only thing I've been told to do is, you prick your finger, if your blood level's between 7 and 9 it's alright, if it goes over 9, that's you, know, you need to sort something out and stop eating like that....

I went to the doctors I had the blood test, they said, of yeah, you've got T2DM, gave me the pills, gave me a booklet and that was it, that was it. Every month I get my pills, once a year I go for a review, I get my eyes done once a year, have my feet checked once a year and that's the extent of what I know about diabetes

One participant stated:

All I got was pills and pie chart.

Whilst this comment, perhaps, speaks to this person's sense of clinical abandonment, it also highlights the central role that medication inevitably plays in the control of T2DM.

Medication

Coordinating and organising medication was clearly central to effective T2DM management. For some participants this was complicated by taking medication for other conditions, including high blood pressure and arthritis. Pharmacists were identified as playing a crucial role in the management and organisation of medication. The volume of medication, side

effects and its integration into daily life posed challenges for some participants and injecting insulin remained painful for others.

Because I just don't want to hulk this bloody great bag about if I'm honest, I just don't want to cart it about, you know. Yeah, well it, it's just awkward isn't it? You know, I'm not into man bags and all that sort of stuff, it's not, not my thing, you know what I mean.

I still hurt myself injecting, there must be some sort of secret technique and I haven't got it, because I hurt myself when I inject, I genuinely do. I cringe when I'm about to do it.

Being in control of medication was also seen as important in taking charge of T2DM.

It makes you feel better don't you? You feel as though you're helping yourself.

There was, for many people, a clear sense that self-management was the most effective and, for some, the only approach to successful management of their condition. This, though, ironically, requires a purposeful and organised three layered approach in which clinical systems, health professionals and patients work effectively in partnership to achieve desired outcomes. However, balancing this complex interplay of factors was often challenging. Effective support also proved to be unpredictable and somewhat random, being predicated on the awareness, knowledge, skills and willingness of individual practices and practitioners, rather than a whole system approach to consistent care. As such, participants identified a range of barriers to effective self-management.

Barriers to Management

Conflicting advice, inconsistent information, guidance and care were mentioned regularly. Some participants identified Primary Care as a particular area of difficulty. Patients stated they often had to wait a long time to get an appointment with their GP, that it was very hard to access the same GP and services available were inconsistent. For example, some GP practices conducted 6 monthly check-ups, whereas others were done on an annual basis, some provided support with BGM machines, others did not and foot checks were undertaken in some clinics and not in others. The time available for participants during a check-up was limited and some were unsure about which information, particularly about food choices, to trust. Participants also commented that access to dieticians, physiotherapists and podiatrists

was limited. Navigating receptionists in some GP practices was challenging and one participant moved practice after his medication was reviewed, and he had not been informed of the outcome of his review. Restrictions on resources and cuts to services were also highlighted.

my GP would be saying don't eat biscuits all the time but you can have one once in a while and then someone else I'd see, like the nurse for my blood tests, oh do you have bananas? Yeah. Don't have more than one. It's like well surely two bananas a day is better than a packet of biscuits and there's a lot of conflicting information about that but, erm, really it was, the information there about what foods you should do or what you should recommend eating and what to avoid a lot of or having a bit of, erm, I've had to find out for myself, I've really had to go online and find out mainly about refined sugars, glucose, fructose and how the body breaks it down

In a focus group conversation participants said:

I've got a good GP but you don't get long with him, five minutes if you're lucky and he's about to retire actually, but, I have to remind him for, you know, am I due for any blood tests and things like that? Doesn't, doesn't come natural.

Yeah, yeah, I, I find, I find that problem as well.

They're not approaching you.

You've got to ask, yeah.

I get a letter through the post.

No, I don't get anything like that, no.

T2DM associated complications generated a positive response for one participant:

I was always really tired, I'm, I think since diagnosis it's, it's better, I've had some really good treatment, erm, although it did get a lot better once I had more problems, it'd have been nice at the start for a little bit more guidance on which direction to go in because it was kind of you're diabetic, here, [laughs] here's your sheet, off you go, and it's only when I started getting the problems that people seemed to really nail it

down to me, look, this is what you need to do, this is how you need to change your life, erm, so I think if I'd had better guidance at the start I might not be as bad as I am now,

For some participants, the absence of readily available and accessible advice was very frustrating:

It's like God; all I want is a bit of advice.

General information given to participants about T2DM was often seen as negative, threatening, restrictive and often about what 'can't be eaten or done'. Participants commented that there are 'too many don'ts', with some saying it was not uncommon to be teased by friends and family members. Public perceptions were sometimes experienced as judgmental and stigmatised. One person commented:

But new people who meet you and they, and you discover that first of all [you have diabetes], they have that same kind of recoiling action

[People say] everybody in Hull is obese and things like that. [And] so obesity is going to push up the diabetes I should imagine.

Certainly, living and working in an obesogenic environment such as Hull was also identified as an obstacle to positive management of T2DM. The ready availability of fast foods and the perception that Hull is a 'fat/ obese' city contributed to negative self-perception.

Facilitators of control

While many participants identified a number of barriers to services, and thus support, which might enable them to manage their own condition effectively, this was not the case all the time, or uniformly across all services used and some participants had a very enabling and facilitative experience. Some spoke of working in close partnership with their GPs and DM/practice nurses, sharing results and making joint decisions. Positive experiences with weight loss programmes, and good use of online systems for repeat prescriptions and appointments all enabled effective control and management of T2DM.

. . . but I see the same Practice Nurse every, twice a year and she knows that I want the results so when I see her I make an appointment for a week later and I take my

notebook and she gives, tells me what the results are, I write them down so I've got a, I've got a, every six months a pile of records so I can see how things are progressing.

As far as I'm concerned it seems to work more like a team where I'm, I'm seeing the, the Practice Nurse, erm, every six months, erm, they run the blood test and then once a year they check your feet.

Mainly it's my GP, erm, I have my eye test once a year, I get a letter through from them and I get the, the drops in the eyes and I get all the, erm, the tests for that, erm, I get a six months appointment with the nurse where they take my bloods, check my feet, do my height, my weight, erm, and usually I get the, I don't really get much feedback off it unless there's a problem, apart from recently when they were saying your bloods are getting a bit high, we need to see an improvement or some, actually look at alternative meds, erm, I basically worked as best as I can and they came back and said it's a lot better, so, you know, basically keep doing what you're doing, but, erm, I generally don't get feedback every time unless there's a problem.

Well I can only talk about my group practice and they're absolutely fan, its XXXX Group Practice... you've a phone number, if you're not very well the doctor will ring you back and they're absolutely, absolutely fantastic, absolutely fantastic. In fact even, even, one of the diabetic nurses there, had a prob, went to Scarborough a couple of years ago and I had a, had these shoes on and my toe kept pushing to the front because Scarborough's quite hilly, up and down, I had a bruising on my toe and it was, had to have antibiotics and she even came round and dropped the prescription off to me, you know, that's how good they are, they're absolutely fantastic surgery.

he was a really good GP because he would be saying you've done really well, keep up doing what you're doing, erm, if there was other times when it wasn't he'd be saying look this is going the wrong way, if we keep going down this road you're going to have, you know, irreversible effects, we're going to have to up your medication, you might end up having insulin, you've got to sort this out, we worked out ways of keeping it down and mainly I think because of his help is why, erm, I haven't had any medication changes,

it's generally a very positive thing, I'm not treat like a kid, they don't look at me and go ooh, anything like that, and they don't, they just basically say you know why you're

here, you know, what you're doing and, erm, we know that you're managing it okay and just keep doing what you're doing or if the results are coming back, when I go back again and they say look this isn't on,

Positive engagement with health systems and practitioners was also found in participant's involvement in clinical research which provided an additional layer of potential support.

5.3.3. Being Involved in Clinical Research

Participants stated that they found involvement in clinical research highly beneficial. Contributing to clinical knowledge about T2DM was rewarding and the care that they received, including direct access to practitioners, regular monitoring and support, were incentives to participate.

The best thing for me personally is since I started on these studies.

Because you get more help here, er, help, help, guidance shall we say, here, through going and as the lady said you can ring XXX.

I've been to this clinic a couple of times, both on the research side and on the other side and the research side gives you far more information and everything than, than the other side really, you know, like me when I've been on trials and that, trying to get more information.

The FGD (as a research experience) highlighted the longer term value of peer support interventions as the conversation and sharing of information (particularly on food), advice and experience between participants which took place, provided reassurance and general support.. A conversation between participants demonstrates this:

Could I ask the others, when they say they go to sleep?

Yeah.

Have you noticed when you wake up your balance is out slightly?

You've to watch it once your sugar's up because that's the way you tell if you ... you go to sleep don't you?

And even if your blood pressure's alright, I think it, this is one of those things that happens because you're getting older.

Now I have water retention, I'm on water tablets and that affects my diabetes.

Swelling in the legs and things like that.

I was on water tablets for a bit but I aren't on them now.

if you can, go on Diabetes UK website, there's a list of, I think it's fifteen entitlements if you have diabetes, different things you're entitled to, podiatry and checks and all and, er, they're, you're actually entitled to it, you can go to GP and say I'm not getting this and I should be and they, and they ought to arrange it for you.

Well, I've got to know a lot more today than I have in the last 6 months really, so yeah.

5.3.4. Service Development and Delivery

FGD participants identified a number of areas for service development and delivery:

- The systematisation of service provision across GP practices
- Clear support and guidance at the point of diagnosis
- Involvement of family members at the point of diagnosis
- Check-ups with the diabetes / practice nurse to be held more frequently than once a year. This was seen as motivational and as a way of providing up to date information and advice particularly with respect to food and symptom management
- Automatic feedback on blood tests with clear explanations of results
- Systematic and consistent information about screening checks, medication and healthy food choices are required
- To be supported with self-learning and management – enabling self-care to support 'understanding yourself'. A particular focus on the 30-40 age group was highlighted as a cohort who tend to ignore their own health
- Updated lists of services available throughout the city - who to contact, when and how? Including information on managing hypoglycaemia

- Access to improved dietary and podiatry services
- Coordinated, joined-up care
- The provision of psychosocial services and support
- Group and social peer support
- Organised exercise for physical and social benefit
- Concessions at the gym
- Wider use of online support e.g. support groups - anonymity may suit some patients more than face-to-face interaction

5.3.5. Summary of Findings

- Effective self-management of T2DM requires collaborative systems of empowerment and support between service users, their families and relevant health services
- Inconsistency in service provision, particularly in primary care, was highlighted as an obstacle to effective management
- Participants identified the need for consistent and up to date, information on self-care, food choices and healthy weight management
- Participants identified the need for readily available support and informed advice as well as specialist services, including podiatry and dietetic services, to maintain healthy positive outcomes
- Participants identified the negative impact of T2DM on mental well-being
- Involvement in research trials enhanced knowledge of T2DM and enabled ready access to health care

5.4. Questionnaire

5.4.1. Response Rate

Figure 1 illustrates the number of questionnaires distributed through to analysis. The response rate for the questionnaire was 57%. Questionnaires that were defaced, where respondents did not reside in Hull or where a postcode was not reported, were excluded from analysis.

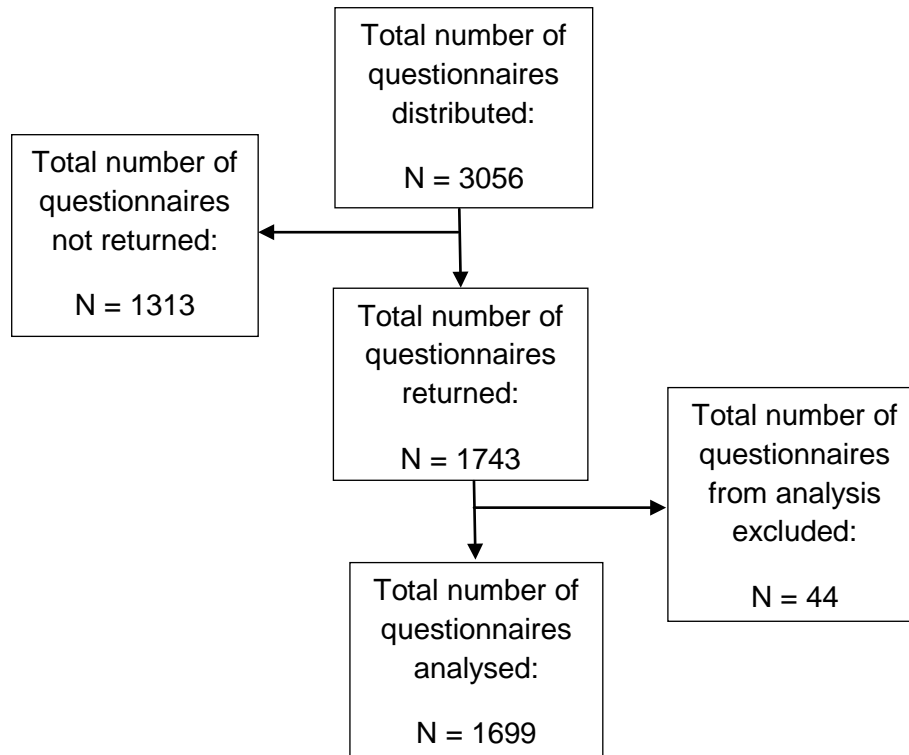


Figure 1 Flow chart documenting the number of questionnaires distributed through to analysis

5.4.2. Postcodes

As per the table 1, nine post codes were recorded by the respondents.

A Table to Show the Postcode of Respondents%	
Postcode	% of Respondents
HU2	2
HU3	14
HU4	14
HU5	19
HU6	12
HU7	12
HU8	12
HU9	13

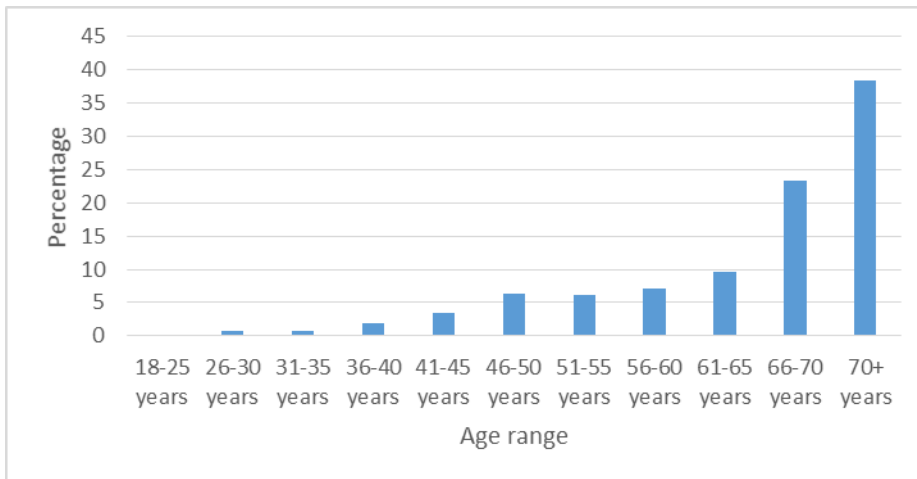
Table 1 Postcode of Respondents

5.4.3. Gender

Fifty-seven percent of respondents were male.

5.4.4. Age Range

Bar Chart 1 illustrates that the number of respondents increased as per the age range with the majority of respondents being from the 70+ age group, followed by those aged 61-65 years.



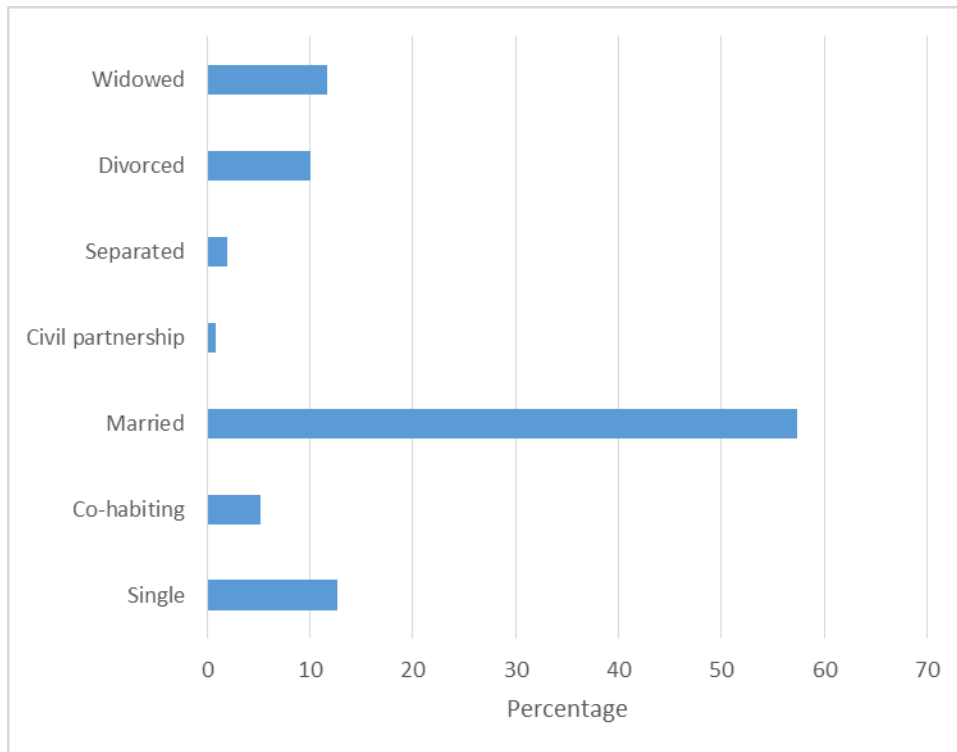
Bar Chart 1 Age Range of Respondents

5.4.5. Ethnicity

The overwhelming majority of respondents were 'White British' (95%). The remaining respondents categorised themselves as one of 10 other ethnic groups although none accounted for more than 1% of the sample.

5.4.6. Marital Status

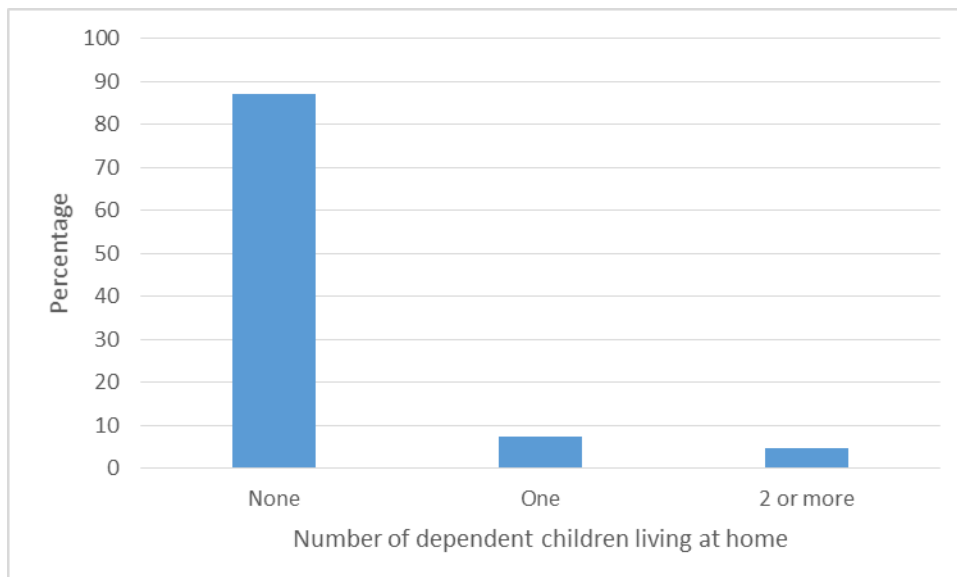
The majority of respondents were 'married' (57%). The remaining respondents categorised themselves as one of 6 other marital groups.



Bar Chart 2 *Marital Status of Respondents*

5.4.7. Number of Dependent Children Living at Home

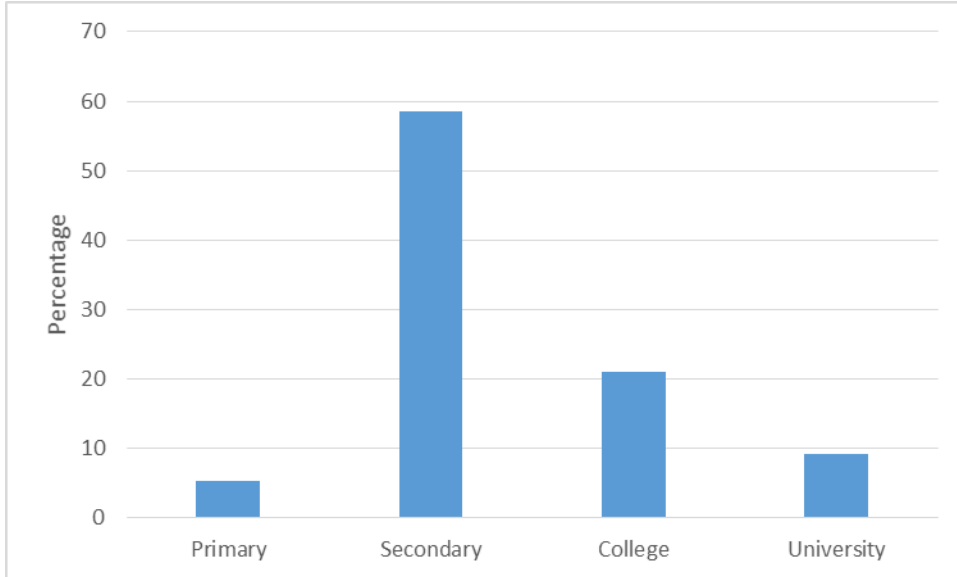
The majority of respondents had no dependent children living at home.



Bar Chart 3 *Number of Dependent Children Living at Home with Respondents*

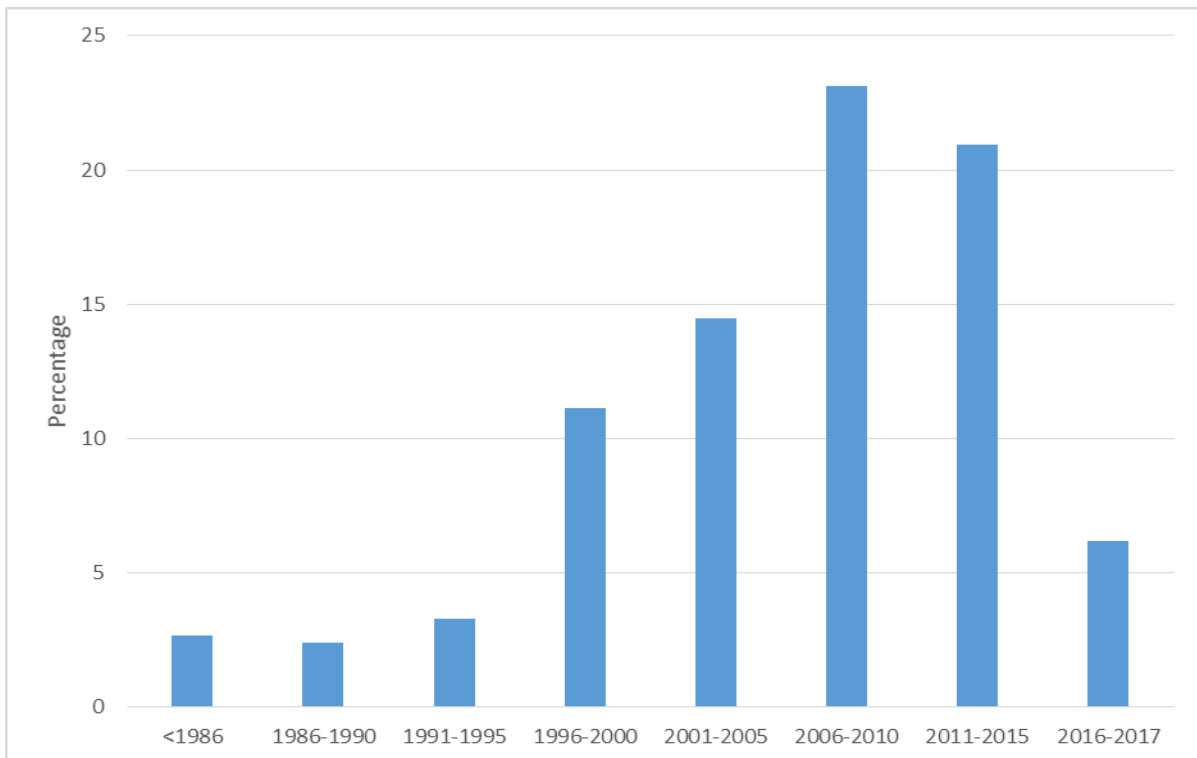
5.4.8. Level of Education

The highest education level most respondents reported was secondary school (59%).



Bar Chart 4 Level of Education

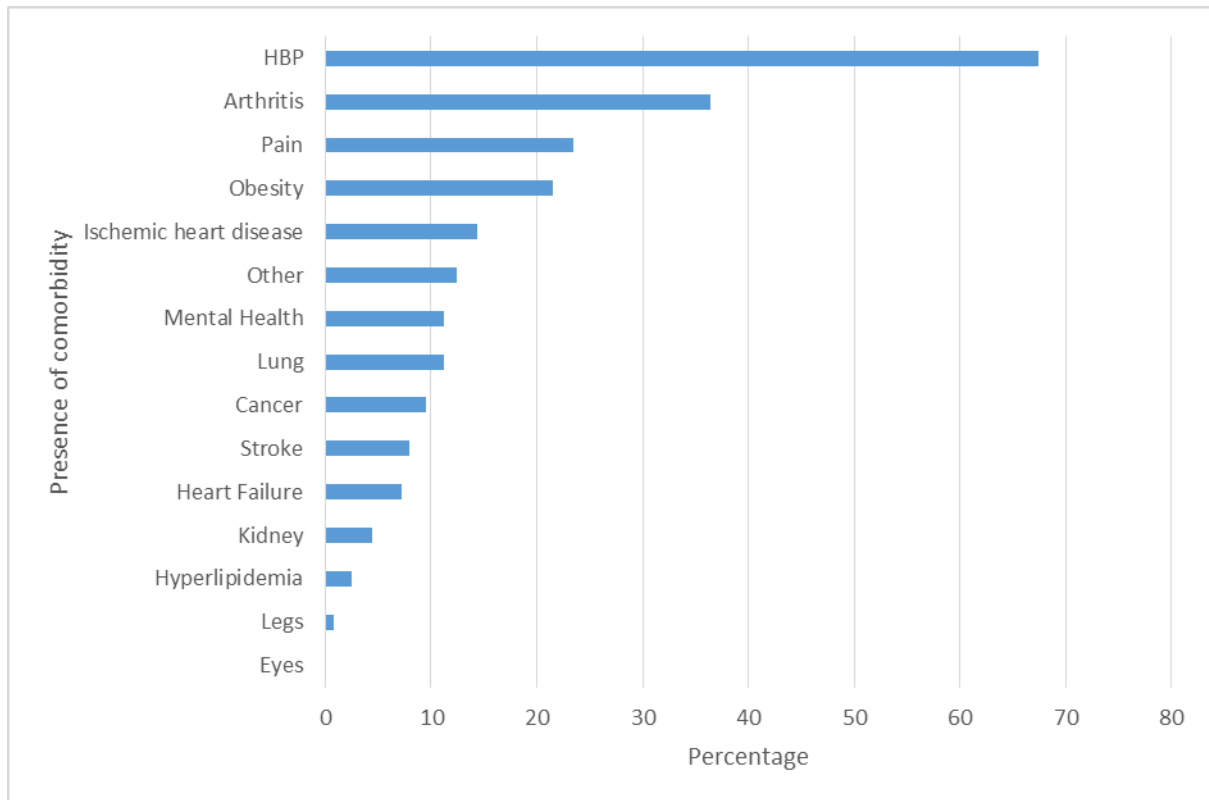
5.4.9. Year Diagnosed



Bar Chart 5 Year Respondent was diagnosed with T2DM

5.4.10. Co-Morbidities

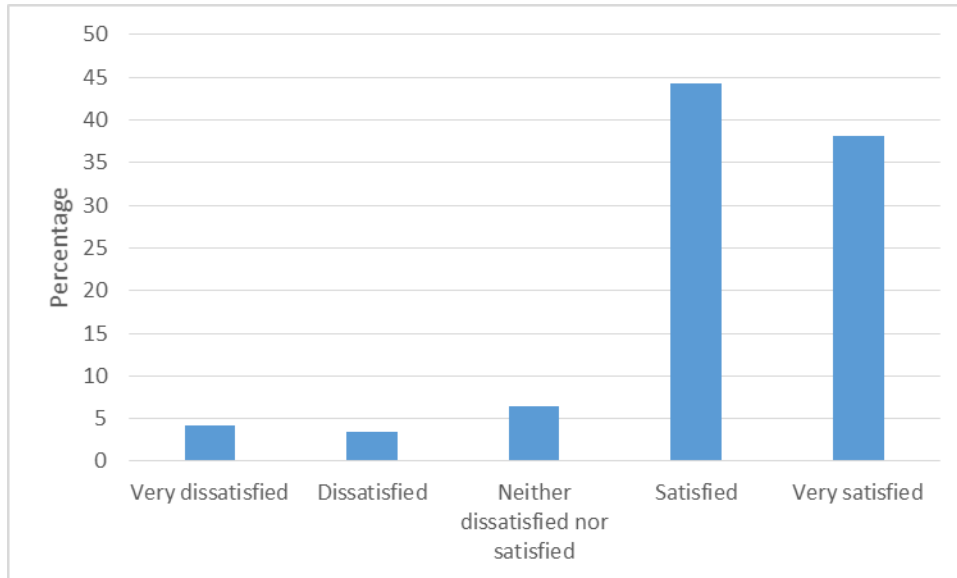
Respondents had various health co-morbidities with the main one being high blood pressure.



Bar Chart 6 Comorbidities

5.4.11. Level of Satisfaction with Health Checks

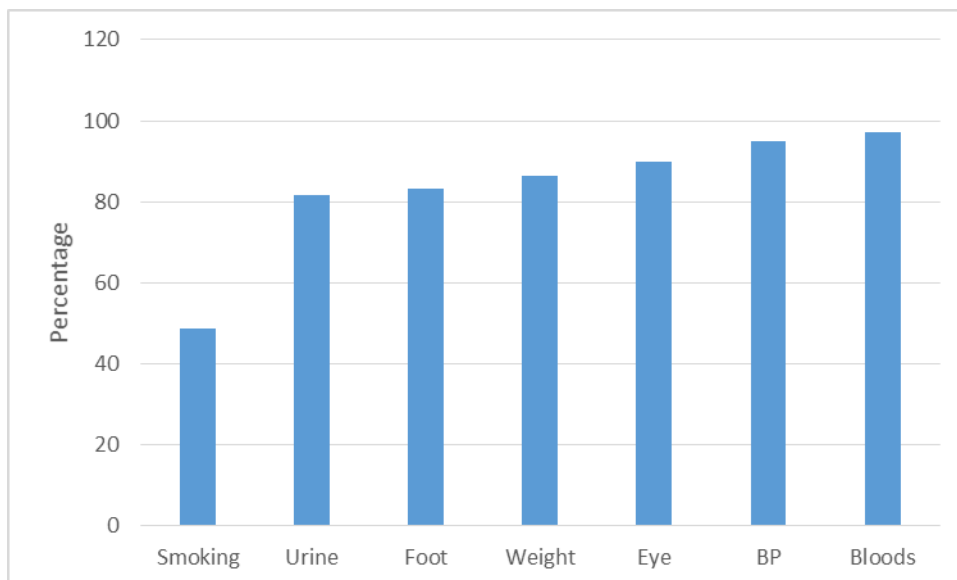
Bar chart 7 indicates that 82% of respondents were either 'satisfied or very satisfied' with the health check service they received.



Bar Chart 7 Level of satisfaction

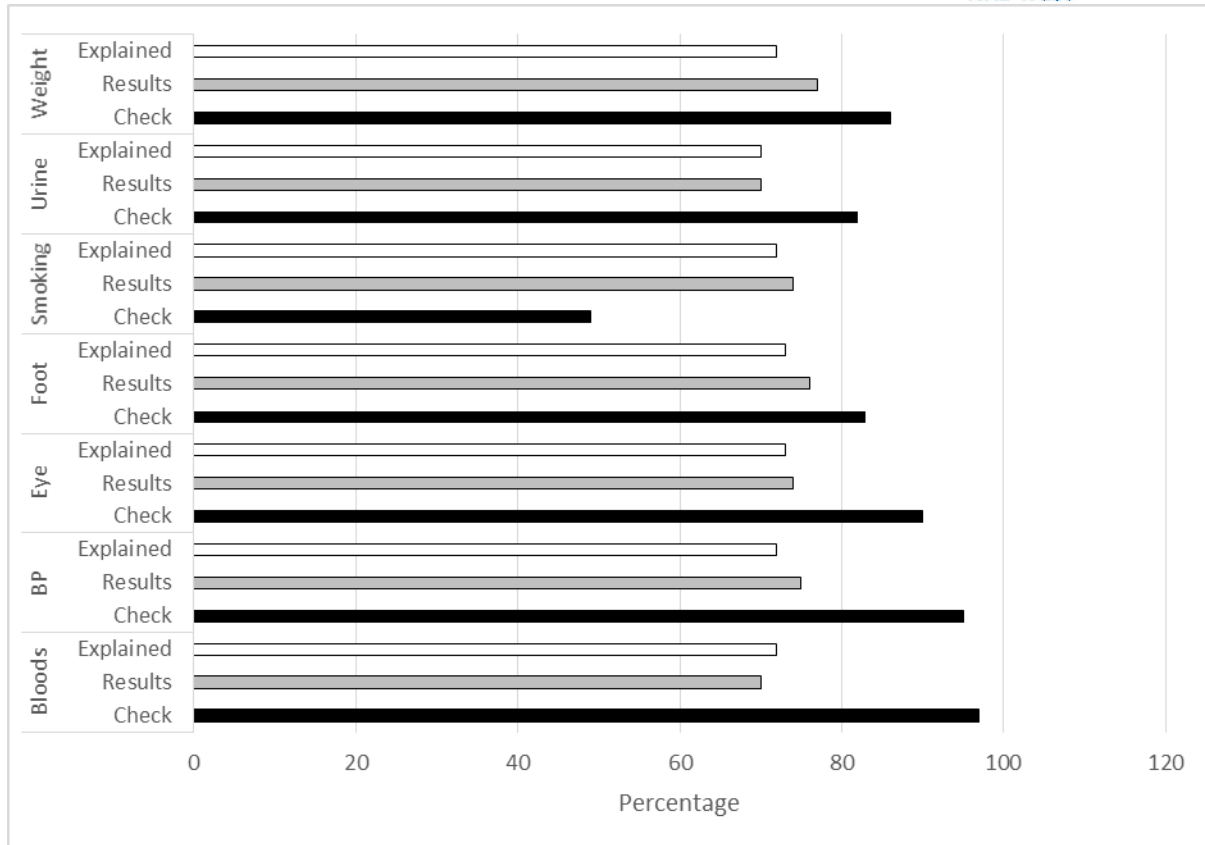
5.4.12. Type 2 Diabetes Mellitus Health Checks

Within the past year, over 80% of respondents had 6 health checks and 50% had their smoking status checked (bar chart 8).



Bar Chart 8 % of Health Care Checks Received by Respondents in the Past Year

Bar chart 9 presents a combined response which indicates that over 80% of respondents, had 6 health checks, knew the results and had received an explanation of their results.



Bar Chart 9 Combined Response to Health Checks

5.4.13. Appointments

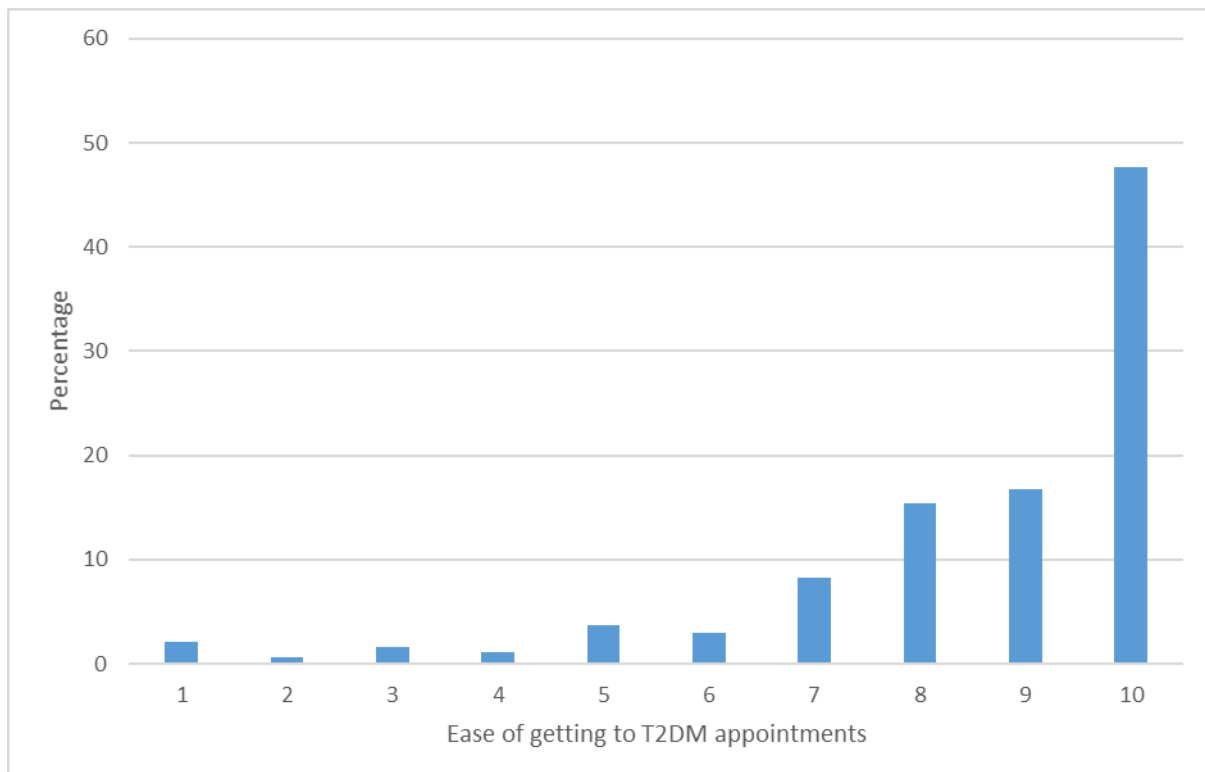
Respondents were asked about the number of T2DM-related appointments they attended in the last year. 69% of respondents attended 1 to 3 T2DM related appointment(s), with 19% attending between 4-6 appointments and 7% attending seven or more appointments (table 2).

**A Table to Show the number of
T2DM Related Appointments
Attended in the Past Year**

Number of appointments attended	Percentage
None	1
1-3	69
4-6	19
7-9	3
10 or more	4

Table 2 The Number of T2DM Related Appointments Attended by Respondents within the Past Year

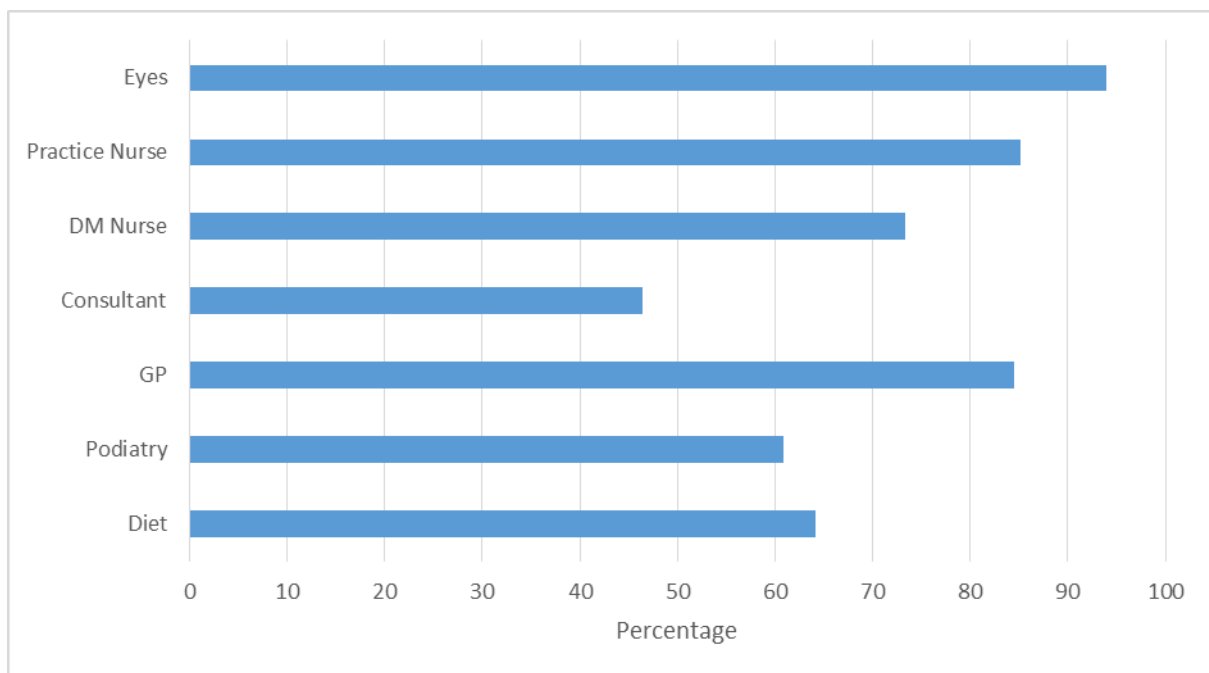
The figure below indicates that the majority of respondents found it easy to manage these appointments.



Bar Chart 10 Respondents Ease of Getting to their T2DM Appointment

5.4.14. Service Support

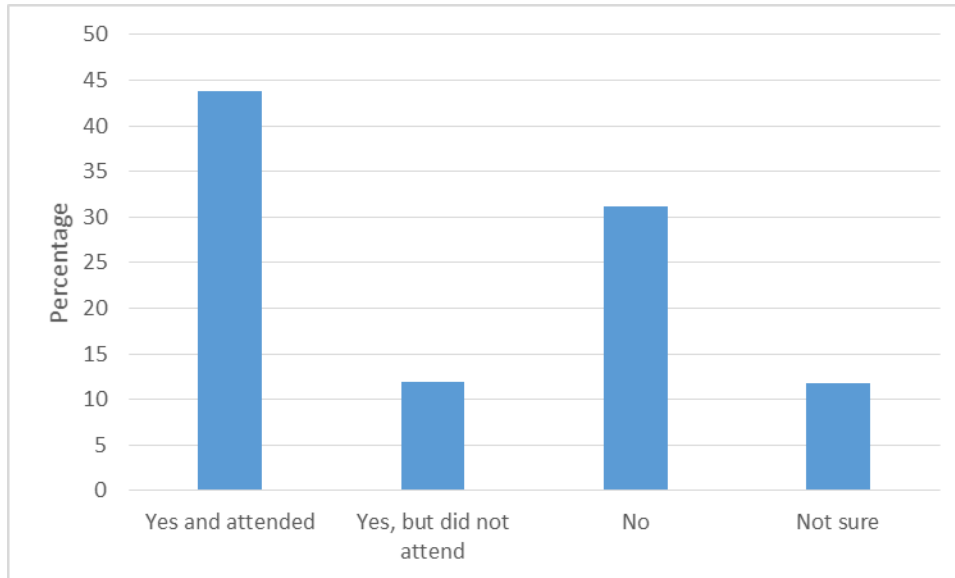
Respondents were asked if they felt they received enough support from services which they accessed or tried to access. Bar chart 11 indicates a mixed picture with 94% of respondents stating they received enough support from retinal screening services, 62% receiving enough support from podiatry services and 48% receiving enough consultant support. The latter figure is to be expected as many service users will not be required to access consultant support. It is important to note that almost 40% of respondents did not receive enough dietary or podiatry support.



Bar Chart 11 % of respondents who felt they received enough support from services

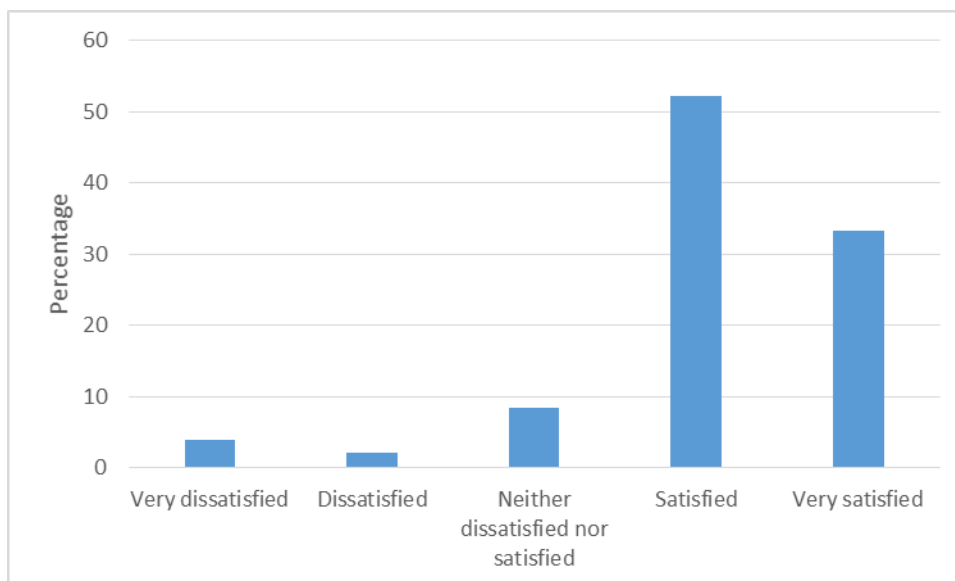
5.4.15. Education Programmes

Respondents were asked if, since their diagnosis of T2DM, they had been offered and attended a T2DM education programme. Bar chart 12 indicates that 44% were offered a course and attended it and 31% were not offered a programme.



Bar Chart 12 % of respondents who had been offered a T2DM Education Programme since diagnosis and of those who were offered what % attended.

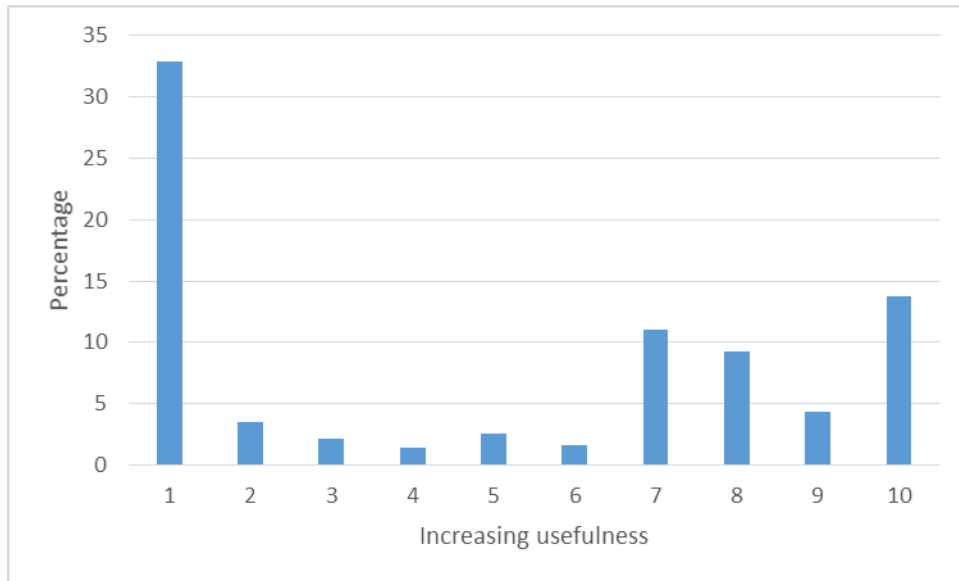
Of those that attended education programmes 85% of respondents were either 'satisfied or very satisfied' with the programmes, as indicated in figure seven:



Bar Chart 13 Respondents satisfaction with the T2DM education programme

5.4.16. Mental Health Services

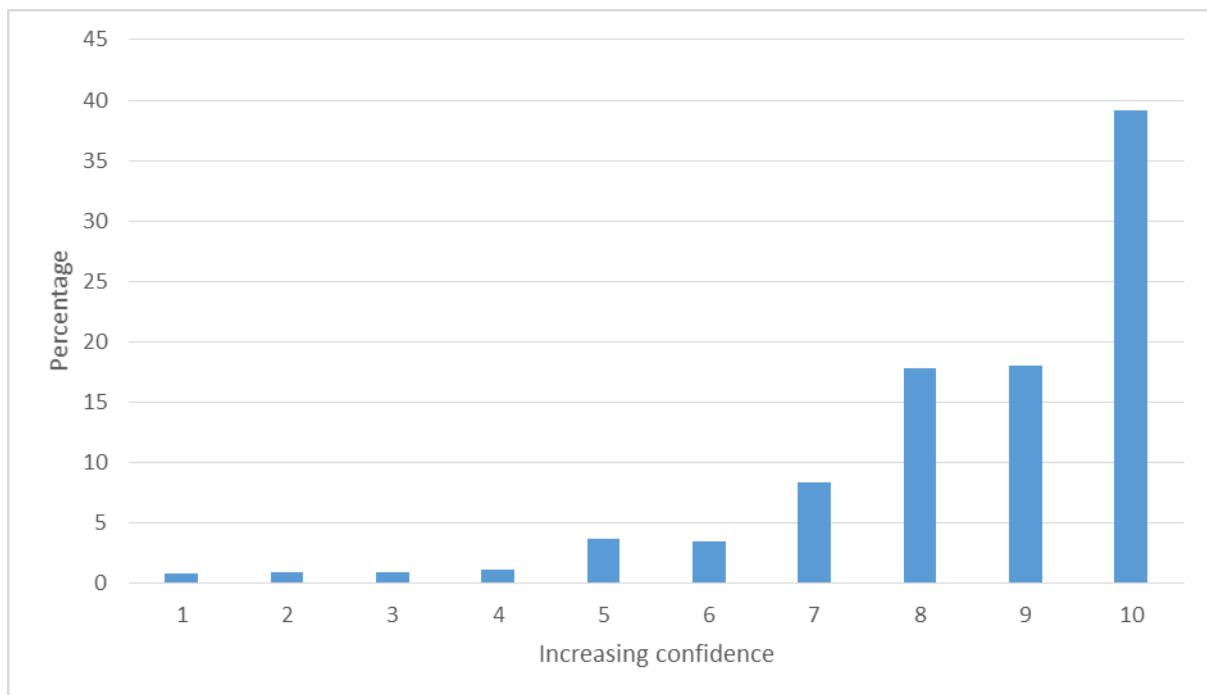
Respondents were asked if they would find it useful if mental health services were available to them. On a mean usefulness rating of between 1 – 10, respondents scored 4.8 with respondents' strongly in favour or strongly against the value that mental health services would present



Bar Chart 14 How useful mental health services would be to respondents if they were available

5.4.17. Confidence in Managing Type 2 Diabetes Mellitus

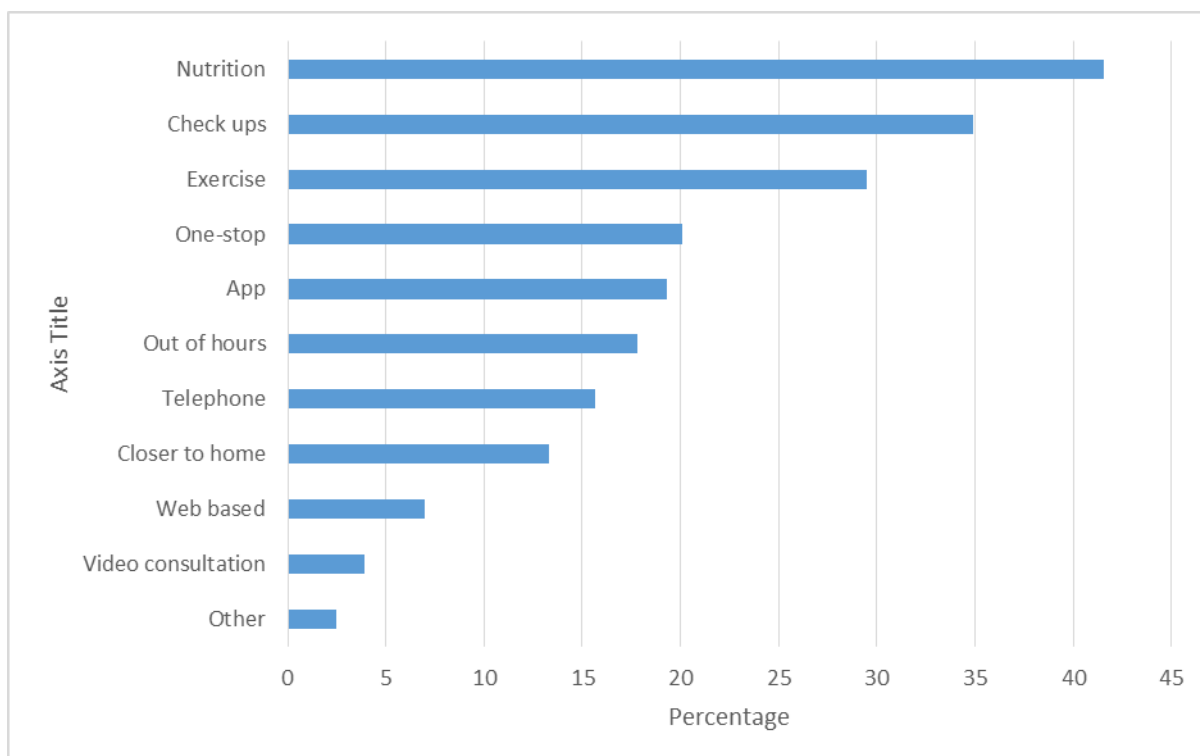
Respondents were asked if they felt confident in managing their T2DM. On a mean confidence rating of between 1 – 10, where 1 indicates less confidence and 10 indicates more confidence, respondents scored 8.5.



Bar Chart 15 How confident respondents felt in managing their T2DM

5.4.18. Service Improvement Suggestions

The 3 most popular suggestions for T2DM service improvement were more information on nutrition and exercise, and more frequent check-ups (bar chart 16).



Bar Chart 16 Suggestions for Service Improvement

6. DISCUSSION

With regards to care homes, the lack of information, training and awareness of T2DM is a striking feature of this data, particularly given the age and likely health status of the care home residents; so too is the absence of preparedness to respond quickly to hypoglycaemia, potentially resulting in serious consequences. The separation of health and social care is evident in this data where residents on insulin for T2DM receive different services from those on alternative treatments; this separation does not appear to enable informed and consistent T2DM monitoring and management for residents. The data indicate the need for: further training; provision of clear information on the management of T2DM in residential settings and further, more extensive research in this sector.

This small cohort of participants who DNA reflects the way in which people living with T2DM, particularly those with health complications and other life challenges can get stuck in a negative cycle (illness - not accessing services – additional complications) that further compromises their health and health care. It is evident that T2DM impacts on all aspects of their daily lives and the absence of mental well-being, and their struggles with mobility and weight management, are striking. Non-attendance at appointments is a multi-faceted and complex issue which highlights the complicated nature of T2DM management for both service users and health care practitioners and service providers.

As demonstrated by the FGDs, successful control of T2DM largely requires effective self-management. However, individual responsibility and daily management requires a network of support to both enable and alleviate the potential burden of self-management which can be high in the absence of coordinated health and social care. Families, communities and structured health services are all directly implicated in this process. The FGD data indicated that there are very successful partnerships and systems of support, however, many participants identified that their needs could be more effectively met in a range of areas.

The data from the questionnaire indicates that the majority of service users are satisfied with the T2DM services they receive. However, there are a small proportion of service users who are dissatisfied / very dissatisfied with the service provided for their health checks. Over 80% of respondents had 6 health checks and almost half had a check for their smoking status. Feedback on service support was general high, particularly for retinal screening, GP and practice nurse support; although almost 40% of respondents indicated that they did not receive sufficient dietary and podiatry services. There is an indication that mental health services would be welcome by some service users. Most respondents indicated that they felt confident in managing their T2DM. Information on nutrition; more regular check-ups and information on exercise were the most highly ranked in the list of possible improvements in T2DM services.

7. CONCLUSION

The data from the FGDs adds an important dimension to this study of service user access to, and experiences of, T2DM services. It provides detailed insight into the views and perspectives of services users who may not be satisfied with their T2DM services, who may experience challenges managing their T2DM and who want to provide a more detailed and experiential account of their interaction with health professionals. FGD data in general reflects greater frustration and less satisfaction and support with T2DM services and

structures to enable self-management. FGD data also covers a wider range of topics and the conversational methodology also facilitated the introduction of new and unexpected ones. There is though, a high level of congruency with the suggestions for improvement (with the exception of the Diabetes App) with the top three being the same as those made by FGD participants.

8. RECOMMENDATIONS

- To provide clear support and guidance at the point of being diagnosed with T2DM, this could involve the individual's family.
- To provide consistent and up to date information on self-care, screening checks needed, food choices, healthy weight management, medication and the services that are available to someone with T2DM.
- More opportunity for participating in clinical research studies in T2DM.
- To provide better access to specialist services, such as podiatry, dietetic and psychological services.
- To provide easily available support, informed advice and more frequent health checks if needed.
- To provide automatic feedback on blood tests and a clear explanation of test results.
- To increase use of technology, for example, making appointments online, use of emails rather than clinic letters, online support.
- To provide coordinated and joined up care; a one stop shop, especially for those who have more than one health condition.
- More focus on people with T2DM aged less than 40 years, as they tended to pay the least attention to their health.
- Improved training of care home staff with respect to T2DM management especially with respect to management of hypoglycaemia.
- Improved communication between care home staff and NHS staff (community, primary and secondary care) regarding care of individuals with T2DM.
- Development and implementation of care pathways for diagnosing patients with T2DM and screening of complications of T2DM in care homes.
- Create mechanisms to obtain regular service user feedback.

9. ACKNOWLEDGEMENTS

A big thank you to all participants, without you this study would not have been possible. We hope we have done you justice in capturing your views and getting them heard.

To the Hull and District Diabetes Support Group, thank you for peer reviewing the questionnaire. We really appreciate your ongoing support and enthusiasm for Diabetes research.

And lastly we extend our gratitude to our colleagues who peer reviewed this study and to those who have contributed to the data collection; your support has been invaluable.

10. REFERENCES

1. World Health Organisation. 10 Facts About Diabetes 2015 [19 July 2015]. Available from: <http://www.who.int/features/factfiles/diabetes/facts/en/>.
2. DiABETES UK. DIABETES: FACTS AND STATS 2014 [19 July 2015]. 3:[Available from: <https://www.diabetes.org.uk/Documents/About%20Us/Statistics/Diabetes-key-stats-guidelines-April2014.pdf>.
3. DiABETES UK. Hull Geo-type: Clinical Commissioning Group - England: Geowise Ltd; 2014 [19 July 2015]. Available from: <https://diabeteswatch.diabetes.org.uk/profiles/profile?profileId=1&geoTypeId>.
4. Public Health England. Kingston upon Hull Health Profile 2015: Crown Copyright; 2015 [updated 19 July 2015]. Available from: <http://webcache.googleusercontent.com/search?q=cache:08S17KgOy8EJ:www.apho.org.uk/resource/view.aspx%3FRID%3D171678+&cd=1&hl=en&ct=clnk&gl=uk>.
5. National Institute for Health and Care Excellence. Diabetes in adults quality standard: National Institute for Health and Care Excellence; 2011 [22 October 2015]. Available from: <https://www.nice.org.uk/guidance/qs6/resources/diabetes-in-adults-58299425989>.
6. National Diabetes Audit. National Diabetes Audit 2012–2013: The Health and Social Care Information Centre; 2014 [19 July 2015]. Available from: <http://www.hscic.gov.uk/catalogue/PUB14972/nda-audi-ccg-eng-hull-12-13-rep1.pdf>.
7. National Audit Office. The management of adult diabetes services in the NHS: The Stationary Office; 2012 [19 July 2015]. Available from: <http://www.nao.org.uk/wp-content/uploads/2012/05/121321.pdf>.
8. Ng J, Atkin SL, Rigby AS, Walton C, Kilpatrick ES. The effect of extensive flooding in Hull on the glycaemic control of patients with diabetes. *Diabet Med*. 2011;28(5):519-24.

11. APPENDICIES

11.1. Dissemination Day

A dissemination event for the joint CCG funded study ‘Service Users’ Perspectives on Accessing Type II Diabetes Mellitus Services in Hull and the East Riding of Yorkshire’ was held on 14 July 2017 at the University of Hull.

The project team of Professor Thozhukat Sathyapalan, Professor Liz Walker, Janine Keating and Lisa Baldwin delivered a joint dissemination day to the service user participants and to clinical colleagues from across both regions.



For those people who contributed their time and experiences to the project, the event offered an opportunity to explore some of the project’s key findings, which focused on the facilitators and barriers to effective management of T2DM.

The morning session (for service user participants) was particularly well attended and generated interesting debate about the ways in which service development in Hull and the East Riding of Yorkshire could be further improved.

11.2. Brochure

Distributed to service users on the dissemination day.

11.3. Service User Feedback

As part of the dissemination day, service users were asked for their feedback as per the tables below:

1.
Which suggestion would you prioritise?
Information on exercise Information on nutrition Diabetic apps
How would you like this implemented?
Through practice nurse or courses

2.
Which suggestion would you prioritise?
One stop clinics Information regarding Hull District Diabetes Support Group
How would you like this implemented?
Incomplete

3.
Which suggestion would you prioritise?
A set criteria for Diabetic right across the board
How would you like this implemented?
All health care have a set criteria so we all have the same treatment

4.
Which suggestion would you prioritise?
Diabetic app
How would you like this implemented?
Upon the basis of patient needs

5.
Which suggestion would you prioritise?
More than 1 check-up a year
How would you like this implemented?
At the doctors

6.
Which suggestion would you prioritise?
More diet info
How would you like this implemented?
At doctors plus more leaflets on dieting

7.
Which suggestion would you prioritise?
Education upon initial diagnosis
How would you like this implemented?
Referral to local clinics for advice on diet, lifestyle and what is diabetes – how it can affect you

8.
Which suggestion would you prioritise?
More mental health support
How would you like this implemented?
Counselling

9.
Which suggestion would you prioritise?
G.P. information

Work information
How would you like this implemented?
G.P. - times for Diabetics to allow time to discuss problems Work – information to educate the work environment with regarding to breaks (time off) , work round working hours

10.
Which suggestion would you prioritise?
More frequent check-ups
How would you like this implemented?
A bi-annual interview with a diabetic nurse carried out at a local centre A two yearly visit to G.P. for an assessment report

11.
Which suggestion would you prioritise?
To see the doctors and nurses mor regularly
How would you like this implemented?
Slip through the net my appointment was never sent

12.
Which suggestion would you prioritise?
More information for newly diagnosed patients One stop clinics
How would you like this implemented?
Start from G.P. diagnosis