Insights into Weight Management Services for people living with type 2 diabetes

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Background

Effective weight management services can play a key role in helping people living with type 2 diabetes manage their condition, and in some circumstances support people to go into remission. However, provision of these services varies considerably across the country.

This insight project picked up on previous findings by Diabetes UK to hear directly from people living with type 2 diabetes about their experiences with weight management services. Prior to this work, Diabetes UK has commissioned and conducted a number of insight projects examining different aspects of weight management services for people with type 2 diabetes. These insights have highlighted the patchy availability and lack of oversight to weight management services and found that stigmatising attitudes from healthcare professionals can present a barrier to accessing services for people with type 2 diabetes. Focus groups with people living with type 2 diabetes were carried out by Diabetes UK to hear about experiences, barriers, and enablers for accessing weight management support. These were supplemented by commissioned interviews with people with type 2 diabetes from South Asian backgrounds by Magenta Research.

Research aims

The aims of this project were to examine the experiences of people living with type 2 diabetes in accessing weight management information and services. Factors which served to either support or hinder weight management efforts were of particular interest, whether they be related to attitudes, perceptions or previous experiences. The research questions were:

- What were people's experiences of weight management whilst living with type 2 diabetes?
- What acts as a barrier to weight management / weight management services for people living with type 2 diabetes?
- What drives engagement with weight management / weight management services for people living with type 2 diabetes?

Following the first set of focus groups, interviews conducted by Magenta with people with type 2 diabetes from South Asian backgrounds followed the same research questions as well as:

- What are the specific barriers relevant to these communities that would need to be addressed to improve engagement with/access to weight management services.

Methodology

The first set of focus groups included four sessions with people living with type 2 diabetes, guided by a discussion guide in a semi-structured format. Each focus group lasted approximately 60-90 minutes, containing between 4-7 participants.

Participants

- 23 people with type 2 diabetes took part across 4 focus groups in August 2022
- Each focus group had between 4-7 participants
- 6 respondents were aged under 60; 11 aged between 60-69; and 6 aged 70+
- 17 participants were female
- 7 had been diagnosed within the previous 6 years
- All participants were of white ethnicity

In August 2023 a further 14 online semi-structured interviews each lasting up to 60 minutes took place with people from South Asian backgrounds.

Participants

- 7 x females, 7 x males
- Aged between 33 and 63
- 5 x Indian heritage; 6 x Pakistani heritage; 3 x Bangladeshi heritage
- Mix of marital status and social grades

Findings

Experiences of independent weight management

Relationship between type 2 diabetes and weight

For many of the participants, weight management efforts have been a continual and lifelong process, often beginning before they had been diagnosed with diabetes and continuing through to the present day.

The balancing act between food intake and controlling one's diabetes was problematic for some participants.

> *"But things like the medication and the side effects […] you're constantly always thinking about like, can I eat this or what should I eat or what should I have for breakfast, what should I have for lunch, so it does take up a lot of brain space."*

Life commitments

Work and family commitments were often reported to take priority over weight management efforts, despite intentions and motivation.

Cost is also a factor, in that healthy foods are more expensive. For some people, they have to balance eating healthy fruit, or meats like chicken with their ability to afford them. This often means cutting down on healthy food to balance their budget.

Social pressures:

A common reported challenge by participants to maintaining a healthy weight are the pressures faced when eating out with family and friends. The change in food options, the availability of nutritional information and peer pressure to conform with others were all cited as potential difficulties.

> *"I've just been on holiday with one of my daughters and I found it quite difficult to find things to eat, and I'm afraid I just, erm, just ate everything in sight [laugh], and I'm usually much more careful with what I eat."*

Amongst South Asian participants there was a recognition by many that a large part of their traditional diet was not healthy for them. This was compounded by cultural expectations instilled from childhood to finish the food on their plate and social and religious occasions which centred around eating.

'I'*m Bangladeshi so that means that, if somebody's inviting us over from a similar background and you don't eat rice, that's offensive. Or you don't like their food for example*'
(Female, 30-34, Bangladeshi)

Some people with South Asian backgrounds also spoke about the lack of cultural appropriate dietary advice for type 2 diabetes.

'The dietician just said to me lentils are good for you. Yeah, that's fine. Lentils are very good for me. But how do you make the lentils? Cause I can make lentils my way. But that's adding it to a curry with butter in it.'

The psychology of dietary choices

The psychology of overeating or unhealthy food choices was seen as central both to why people experienced difficulties in managing their weight and why many weight management services failed to connect with them.

> *"I suppose my big problem is that I'm a terrible comfort eater."*

> *"It's also a rough time and that made me eat rubbish and that's my downfall."*

There was a strong belief that individual issues with food choice were not driven by lack of personal knowledge, but by one's psychological relationship with food.

> *"A lot of it's about the relationship with food let's face it, it's not about food in itself you know, it's about how you relate to food and what makes you eat, picking up what [participant] said a stressful job and eating at all sorts of times, so his relationship with food is going to be different from other people."*

Emotional difficulties and depression:

Emotional difficulties, ranging from anxiety to clinical depression, were often linked to issues with weight and diabetes management. Upset around weight and physicality was often a very long term issue, having started long before they had diabetes. Shock, embarrassment and fear often featured around the time of diabetes diagnosis too.

> *"I started off being quite positive and making changes, but during the pandemic I've really struggled and I'm now the heaviest I've ever been, I'm also really struggling with my*

depression and I live on my own so the willpower and emphasis to actually do stuff, it's much easier to actually grab the stuff I know I like even though I know its not good for me."

Experience of weight management services

Information on weight management for type 2 diabetes

Healthcare professionals are not consistently providing information

Many participants were confused about what the 'ideal' diet looks like. Many felt that their GPs don't have the time to provide weight management advice. Being prescribed diabetes drugs at diagnosis with no conversation about diet/weight management was a common experience.

> *"So I had asked, what about any diet help or whatever, what should I be eating and it was just very brief, just like cut out fizzy drinks don't eat cakes, there was no actual information really, and then they had said that I would get an appointment with a diabetic nurse in the next 4 weeks or something, which never happened."*

Others spoke about the frustration they felt when their healthcare professionals didn't appreciate the side effects that their type 2 diabetes medication was having on their weight. The idea that healthcare professionals were unable or unwilling to understand how diabetes management and weight management could be in conflict was a common complaint.

> *"And it got to the stage where it annoyed me so much that at one point I just challenged my doctor. I showed him the leaflets from several of my medications and they had side effects: weight gain."*.

People with type 2 diabetes are unsure where to find the best source of information

For many, websites such as Diabetes UK provided valuable sources of information, but people were also frequently overwhelmed by the range of information online and confused by conflicting advice (such as whether to follow low calorie or low carbohydrate diets).

> *"I've been able to do a load of research online about it and I have to say, low carb, even on Diabetes UK and the NHS, it's very confusing. You read one report and it says this, you read another report it says that."*

For those looking for motivation to lose weight, social media was often cited as a useful resource. Following social media accounts of people who are dieting and using their progress as inspiration is a good motivator for weight loss for some.

Impact of stigma

Stigma from society

Participants were keenly aware of the societal stigma directed at people with type 2 diabetes, commenting on the perception that it is a self-inflicted condition and a burden on the NHS.

"I'm very aware of different stories in the press about how us diabetics have just brought it on ourselves because we are lazy fat slobs or something like that, I feel really really like a really bad person, and I don't like feeling like a really bad person."

This stigma added to the emotional difficulties arising from weight and diabetes management and could encourage comfort eating for some, strengthening an emotional attachment to food which in turn creates further feelings of blame and guilt which impact on weight and diabetes management efforts.

Stigma experienced in healthcare settings

Stigmatised exchanges with healthcare professionals were common. Some respondents considered this to be confirmation that others believe they are responsible for their condition.

"[…] I did say well, I mean are we supposed to be sort of discussing goals and things like that and she said 'Oh you're a grown up lady, I'm sure you can figure those out yourself', and I, I thought 'what?!'"

The sense that healthcare professionals were unable to understand the difficulties or root causes of weight management difficulties led some participants to have very fractured relationships with care providers.

Conversations with healthcare professionals often framed their condition within personal responsibility and control narratives that proved unhelpful to the sustainability of their weight management efforts.

"I think that like some of the other people here, I would have liked… some information and some sympathy and perhaps, counteracting the feelings that I have that, you know, being diabetic that I'm single-handedly breaking the NHS."

In a few cases, participants suggested these attitudes led them to either fear or actively avoid discussing these issues with their healthcare professionals.

Access to services

Availability:

Many commented on the considerable frustration felt due to their lack of medical appointments, not just concerning weight management, but more broadly for their diabetes. This was seen as an impediment to receiving support and put some participants off trying to engage with NHS services.

> *"Yes, I must say I'm feeling a little abandoned now because my diabetes nurse only wants to see me once a year."*
>
> *"And this year I've had to contact them to ask for an annual, sort of, check up as it were to see how I'm going. So its kind of patchy I guess now I describe it, not a great deal of guidance on how to seek and get the relevant help."*

This fuelled suspicions for a few participants that healthcare professionals, particularly GPs, were not motivated to support them with weight management.

> *"[…] the GPs don't care less, they're not going to get paid for it, they just think nothing to do with me, I'm not getting paid for that, so just send them to the prescribers and the nurses and let them deal with it. End of. So it's sad, but it's reality."*

Time and cost:

The practicalities of attending weight management services formed a smaller theme within the focus groups but were discussed as potential barriers for some. One element was the necessity to attend sessions at a set time, which could be difficult to maintain alongside other responsibilities.

> *"I've tried to sign up to some of them but it's a set time and a set day and if you've got something else on that day its – but I would like to drop in and see."*

With private weight management services, the costs of access were also mentioned as a potential barrier to long-term use.

> *"The cost of it as well […] Which is a problem, would be a problem for me."*

> *"I went on slimming world which the GP paid for 3 sessions so I lost and put it back on."*

Patient agency:

Given the complexity of identifying and accessing weight management support, it is perhaps not surprising that those with the time, resources, and knowledge to navigate the system often found more success in accessing support that was right for them.

> *"So it wasn't sort of necessarily offered to me but it was, like, because I had asked about it multiple times they sort of gave in."*

These feelings encapsulated the belief that appropriate weight management support had to be fought for, rather than offered. Whilst individuals could report on good experiences of wider care, or of instances of support with weight management, the process was seen as one which individuals had to continually drive. Health services were often seen as ineffective in helping people to manage their weight in the longer term, and at worst, as a direct hinderance to these aims. Whether as a result of poor accessibility, perceived and/or experienced stigma or a lack of consideration for individual needs, those who had achieved a level of weight management they were satisfied with usually attributed it to personal agency achieved in spite of, rather than in partnership with, formal weight management services.

Variation in support

Regional variance:

Another barrier to accessibility of services highlighted was regional variance. This referred to variation in both availability and perceived quality of the advice and services which could be provided.

> *"it was only about 5, 7 years later, I've moved quite a bit, so one of, it depends because each surgery is so different in how they deal with you, erm, and I've been very lucky and had two very good surgeries but in the meantime I've had one that was mediocre."*

The perceived variation in quality of support between different areas was strong enough that some participants actively moved or changed surgeries to try and obtain the help they felt would be best for them.

> *"I did an awful lot of reading round the subject and I thought this isn't going to work, so I changed my GP. That was why I changed the GP, because I felt completely unsupported, and uh, but my new surgery are much better."*

Positive healthcare professional relationships:

Participants explained how much the positive experiences with their healthcare professionals were valued.

> *"I have a GP now who's daughter and wife are both diabetics and he's very helpful as much as any doctor can be helpful in this current situation with covid and things."*

The feelings of trust, support and understanding stood in stark contrast to those with more negative experiences. Those with positive experience typically reported more frequent, longer term engagement, awareness of weight loss information specific to diabetes, and a partnership approach to managing the patient's health.

> *"I had a brilliant diabetes nurse, I can't praise her enough, especially as my uncle's just been diagnosed down in England and he doesn't have a diabetes nurse at all, he's not being well looked after."*

Poor healthcare professional relationships:

For others, healthcare professionals were often unable to understand their difficulties with weight management, and therefore were limited in the support they could provide.

> *"I think for me it's finding the balance, because some healthcare professionals will treat you as if you are an absolute fool, and I know fine well I'm not a fool, so when that happens it's a very negative experience and you really don't want to deal with them again."*

It was clear that some participants felt that their healthcare professionals' approaches were detrimental to their weight management efforts, rather than supportive.

> *"so I've seen dieticians from time to time, and sometimes its been a positive experience but usually what happens is you get so hung up on what you are eating or you're not eating that it ends up not working, and I've seen ones that were absolutely horrible to me."*

Suitability:

Various issues with the suitability of weight management services were highlighted. Some of these focused on the format in which support or information is delivered. People found it off-putting where there was a lack of choice in delivery format.

> *"people learn and feel comfortable in lots of different ways... Some people love to be in that group setting, some people don't, and it's, you know I was, my diabetic nurse mentioned the digital – do you want to join up to the digital thing and I thought oh my goodness do I want to do something else online with everything else I'm having to do."*

The perceived suitability of food choices for someone living with diabetes was also highlighted as a barrier to engaging with services, as well as broader concerns about a limited diet.

> *"I'm not going to go to Weight Watchers or Slimming World, that's eating a lot of fibre and brown bread and that, doesn't agree with me."*

Some participants also felt that the impact of their diabetes, or other health conditions, was not always considered. This prevented them from engaging in the activities they knew could help their condition, but they were not presented with any adequate alternatives.

> *"And to say that I should exercise more was just, it was a non-starter because I have severe asthma, I have, er, ostheoarthritis so there are times where just moving around is difficult, let alone exercising."*

Psychological Support

An additional factor which led participants to deem weight management services as unsuitable was the perception that they focused solely on the basics of food intake but did not address the underlying psychological or emotional aspects of eating behaviours.

> *"As I said before I know what to do eating wise, I know what meals I should be cooking, I've got lots of cookbooks, my mum was a professional cook so I know I can go to her for advice but for me its that emotional thing, which is why in the past before diagnosis I've tried Weight Watchers and stuff like that, but they don't address that emotional eating bit, and that's what I need help with."*

These participants saw weight management services as primarily set up to deliver nutritional information and advice. Whilst it was recognised that this was an important facet of services they also believed that this information was often too basic, and failed to get to the heart of the challenges they were facing.

Person centred support

For many, their experience of accessing weight management support hadn't been right for them because it had not been person centred, whether not focused on type 2 diabetes, or not supporting changes that could fit within their life or culture.

Choice of format

Some participants spoke about wanting to access a 'buddy system' where they could share advice and emotional support. Others prefer to access online support only as they feel intimidated when sharing experiences. While South Asian participants wanted culturally aware support, there was little demand for services which were exclusively for their community.

Some older participants highlighted their perception that weight management activities were geared towards younger people. Whether through the impact of comorbidities or where weight loss activities were pitched, some participants felt they would either not be able to take part in these or that they would not benefit from it.

> *"There was a group that started very local to me and it was for over 40s and that's no good for me being over 70 going to a group with over 40s because I wouldn't be able to maintain the speed or the intricacies of what theyre doing."*

Psychological support

The centrality of emotional eating as a barrier to sustained weight management efforts was not considered to be addressed by existing weight management services.,

> *"I've been on a low fat diet before for my IBS and I got lots of support for that, that's brilliant, but that doesn't help with the emotional connection that actually drives a lot of the problems, and that's why I then find it hard to talk to healthcare professionals."*

When considering in more detail why people face challenges sustaining weight loss when using weight management services, participants returned to the idea that these services address the symptom of overeating, without addressing in enough detail their underlying relationship with food.

> *"you can find out suggestions of alternatives for bread, you know, things to avoid etcetera etcetera, and stuff that, that route, but again that's just things to eat, that isn't actually changing your lifestyle, a lifestyle is a coached thing that you need coaching in, I'm lucky, I didn't have a coach but I had the ability to sort of coach myself to follow something and accept that that's my lifestyle for the rest of my life, and then reward myself with something different that's not food."*

Sustainability:

Sustainability of weight management was a barrier in both the short and longer term. In the short term, many participants found the requirement to make significant dietary changes, such as low carbohydrate or restricted calorie diets, incredibly difficult to maintain.

> *"you know, I couldn't last more than about 3 hours with my plan from Weight Watchers."*

> *"while I do find the low carb thing works, as I said, its very hard to sustain."*

More broadly, a number of participants reported that although they could successfully lose weight whilst on a particular weight loss plan, they were unable to maintain that over time. This often formed a long term pattern of fluctuating weight and eating patterns that had to some extent become engrained in their behaviour.

> *"I think one of the things with weight loss that I've certainly learnt over the years is changing your diet radically for a couple of weeks makes absolutely no difference at all, you just have a rubbish couple of weeks, you might have a, you might suddenly think 'ooh my waistband feels a lot looser than it was, but unfortunately unless its just that slow incremental change of diet, you don't really get the long term affect."*

A few individuals expressed frustration that weight management interventions did not provide ongoing information. Therefore, when they faced setbacks or changes to their circumstances, it was not possible to gain appropriate support.

> *"Like I know that stuff because I been through it when I went to Weight Watchers and Slimming World. So I know what I'm supposed to be eating, but its not getting the weight off. Where's the back up? That's what gets me."*

Diabetes focused goals

A clear motivator for many participants was to improve control over their diabetes. Whether these efforts were considered successful or not by the individuals, it was usually a key driver of their efforts. Improved diabetes control was strongly correlated with the desire for an improved quality of life.

> *"[…] you're not doing this for weight management or anything else, my motivation is a longer life, I want a longer life than I would have had otherwise had I not changed completely my lifestyle, it would have been fantastic to have support that would have helped educate me in how to do that."*

It should also be noted that perceived success in weight management would often motivate further efforts in the future. Initial or early results would encourage further efforts as it demonstrated their value, even where these efforts had been particularly difficult. This was highlighted where weight management efforts could be clearly seen to have improved diabetes control.

> *"Cos that's whats, that's whats keeping me going, and I truly believe if I stick to it, there will come a point where it goes 'boomp' into the normal range. And, um, I'm so delighted I'm not getting those huge spikes anymore cos that's, knowing what I know now, its scary that I was doing that to myself."*

Family and community support

Social support structures were a strong source of support for some participants. Family and friends, whether they were living with diabetes or not, could provide helpful support and information to normalise dietary and lifestyle changes. In turn, these could help to make these changes more permanent.

> *"I think one of the most important things in helping is for the rest of the household joining in with the dietary – I was going to say restrictions but that's the wrong sort of slant on it. Yes, there are restrictions, but it doesn't mean to say you can't eat healthily, you can't enjoy what you're eating, and you can't have a wide variety of things to eat."*

Physical activity:

Physical activity was recognised as an important component of weight management, and where participants had the time and capacity to work this into their everyday routine, found that it beneficial.

> *"The only way I get consistent weight loss is a combination of diet and exercise. If I do the two I can keep it moving. I'm stuck at the minute so I need to try and get more exercise in but that's pretty much it."*

However, increased physical activity was not feasible for everyone, particularly for those struggling with diabetes complications or comorbidities.