

IT'S STILL MISSING:

**DIABETES UK NORTHERN IRELAND'S
RESPONSE TO THE DRAFT MENTAL
HEALTH STRATEGY 2021-2031**

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Introduction

Diabetes UK Northern Ireland welcome the publication of the draft Mental Health Strategy 2021-2031 for Northern Ireland.

We acknowledge it has been drafted in the context of mental ill-health and suicide severely impacting our communities, which is an acute complication of Northern Ireland's particular circumstances and, in the Health Minister's words, "*limiting the life chances of our young people and constraining our potential across society*". We disagree with nor seek to challenge anything that is currently within the draft Strategy.

However, we are concerned that there is little acknowledgment within the ten-year draft Strategy of the mental, emotional, and psychological impacts of long-term, life-long and often life-limiting conditions such as diabetes. The mental health needs of people living with long-term conditions like diabetes is still missing in health and social care policy.

Our response to the consultation will focus on what diabetes is, the numbers of people living with diabetes in Northern Ireland and the impact of diabetes on people's mental health. This will be followed by recommendations on what needs to happen in Northern Ireland which we believe can support the *Providing the Right Support at the Right Time* theme in the draft Strategy. **We strongly urge the Department of Health to act upon our recommendations to ensure the mental health needs of people living with diabetes are acknowledged and met.**

To inform our response and support our recommendations, in March 2021 we held a workshop with people living with various types of diabetes and a report on that workshop will be contained in this response.

We also welcome the appointment of Northern Ireland's first-ever Mental Health Champion and we are grateful for the time and support Professor Siobhan O'Neill and her team has given to us as we developed our response and engaged with her around our recommendations.

Diabetes in Northern Ireland: the basics

In Northern Ireland, as of 2021, there are just under 105,000 people with a diagnosis of diabetes. When a person has diabetes, they will have one of several serious and life-long conditions affecting a person's blood glucose and insulin levels

Approximately 90% of people with diabetes have type 2 diabetes. When a person has type 2 diabetes, the insulin they make cannot work effectively or they cannot produce enough

of it. This means their blood glucose levels keep rising. Approximately 70-80% of cases of type 2 diabetes can be prevented or delayed. The risk factors for developing type 2 diabetes include age, ethnicity, family history and being overweight. For these reasons type 2 diabetes is most commonly found in older adults.

For the approximate 9,500 people in Northern Ireland with type 1 diabetes, they cannot make insulin at all. Type 1 diabetes cannot be prevented or delayed, and what causes type 1 diabetes to develop is not known. While type 1 diabetes is often diagnosed later in life, it is the most common form of diabetes in children.

In 2018/19, just over 2,200 women in Northern Ireland had gestational diabetes, which develops during pregnancy. When a woman has gestational diabetes, it is due to the hormones she is producing making it hard for her body to use insulin properly. Gestational diabetes usually goes away after giving birth however it is possible for a woman to develop type 2 diabetes following a diagnosis of gestational diabetes, and less commonly some women develop type 1 diabetes.

There are other, rarer forms of diabetes and the numbers in Northern Ireland for these conditions are low.

The impact of diabetes on mental health

What all types of diabetes have in common is that they are complex and demanding conditions with potentially debilitating consequences. People with long-term conditions such as diabetes are twice as likely to experience mental health problems as the general population¹. Effective management of diabetes is often dependent on how people with diabetes care for themselves and are cared for. This requires constant personal motivation and changes in behaviour and routine. Diabetes is much more than just physical and living with the condition is tough. Keeping on top of it can be a struggle for many people – it is often described as relentless; there is never a break in the condition. It is not surprising, therefore, that the impact of diabetes on emotional and psychological wellbeing can be profound, and people with diabetes often experience specific challenges such as diabetes distress and burnout², when it becomes extremely difficult to cope with the condition's day-to-day demands.

¹ [Long-term condition and mental health Chris Naylor February 2012 \(kingsfund.org.uk\)](#)

² [What is diabetes distress and burnout? | Wellbeing | Diabetes UK](#)

People living with different types of diabetes often tell us the overwhelming nature of the condition can also affect the emotional and psychological wellbeing of those close to them, such as parents, carers, and family members.

In diabetes, mental and physical health have a two-way relationship: while the demands of living with the condition can affect how people feel; struggling emotionally can make it even more difficult to keep on top of self-management. In turn, when diabetes cannot be well managed, there is an increased risk of dangerous complications such as diabetic ketoacidosis (or 'DKA') which is a life-threatening medical emergency that results from a severe lack of insulin in the body. Other common and dangerous complications include diabetic retinopathy, which is caused by high blood sugar levels damaging the retina which, left untreated, can cause blindness; and diabetic foot disease, which untreated can cause extreme pain, ulcers, and amputations leading to further physical disability and increased mortality.

Diabetes and food are also closely linked and there are particular instances of disordered eating behaviour and eating disorders among people with diabetes. One example is diabulimia, which is a serious eating disorder that only affects people with type 1 diabetes. When a person has diabulimia, they reduce or stop taking insulin to lose weight. As a person with type 1 diabetes needs insulin to live, it is extremely dangerous.

Diabetes UK believe the relationship between routine diabetes care and mental health is essential. Diabetes services that incorporate emotional and psychological support can help people improve both their physical and mental health, reduce pressure on services, and save money – but people with diabetes have told us that the provision of such services is extremely patchy in Northern Ireland.

Too Often Missing (2019): the findings

In 2019, Diabetes UK published a report, *Too Often Missing*, on making emotional and psychological support routine in diabetes care. The report resulted from a survey of 2,000 people living with diabetes and more than 300 parents and carers from around the UK. In addition, Diabetes UK also surveyed 1,150 GPs and healthcare professionals.

The *Too Often Missing* report found, broadly, there was a UK-wide deficit in the recognition of emotional and psychological support needs of people with diabetes, and specialist support to meet those needs. The report also found:

- Seven out of 10 people living with diabetes felt overwhelmed by the demands of the condition

- Of these, three-quarters said their self-management was affected by the emotional struggle
- Three quarters of people with diabetes who felt they needed specialist support could not access it

The report identified what people living with diabetes wanted to see:

- Emotional wellbeing being a routine part of care
- A person-centred approach to diabetes reviews and consultations
- Greater signposting to peer support

The report also said, for healthcare professionals, what was needed was:

- Training and upskilling for diabetes staff to better identify the emotional and psychological needs of people with diabetes
- Greater awareness of what mental health services were available for people with diabetes to enable them to be signposted and referred
- Greater education and awareness in of diabetes for mental health professionals

While excellent progress has been made in Northern Ireland through the Diabetes Network, much more remains to be done, collectively by policy and decision-makers – and it can still be said that two years on, emotional and psychological support is, broadly, still missing from routine diabetes care and support.

Informing our response: a workshop held with people living with diabetes

In March 2021, to inform our response to this consultation, we held an online workshop with approximately 15 people living with diabetes. We are grateful for the time and the willingness of those who attended to discuss this consultation and share their lived experience.

Firstly, attendees were asked 6 online yes/no poll questions to get quantitative feedback on the level of emotional and psychological support attendees receive.

1. Do you ever feel overwhelmed by the demands of diabetes?

A majority – 70% – of attendees felt they feel overwhelmed by the demands of the condition.

2. Do you feel comfortable and supported to talk about your emotional wellbeing with a healthcare professional if you need to?

60% said they felt supported to talk about their diabetes-related emotions with a healthcare professional. While this is a welcome majority, it is clear much more

needs to be done to enable non-clinical conversations about emotional wellbeing in healthcare settings.

3. Does your GP or healthcare professional ask how you are in each appointment, and look out for those close to you?

60% said they were never asked how they were in each appointment. Much more needs to be done to encourage healthcare professionals to offer a simple “how are you?” in routine appointments.

4. When you ask for information, are you shown where to find resources that are right for you?

60% said they were not shown where to find resources that were right for them. It is clear more needs to be done to on healthcare professionals’ awareness of resources – particularly from the third sector – that could assist with the mental health needs of people with diabetes.

5. When you need help from a mental health profession who understands diabetes, do you get it quickly?

An overwhelming majority, 80%, said they did not get mental health support quickly when needed. This is of particular concern given the impact of a relentless condition such as diabetes on a person’s mental health, and the knock-on effects this can have on how someone with diabetes can manage their condition.

6. If you ever need more emotional and psychological support related to your diabetes, do you know who to talk to?

70% said they did not know who they can talk to. Again, this is concerning. It is important a person living with diabetes, including those who care for them, knows where to find greater mental health support.

Attendees were then invited to participate in a focus group-type discussion. Four questions were posed to participants which allowed for ten-minute discussion on each question.

A summary of what was learnt from the workshop is below. A full, comprehensive summary of the discussion can be read as an appendix to this response.

What did we learn from the workshop?

On what living well with diabetes looked and felt like to people:

Support and understanding from friends, family, and colleagues

Attendees thought that support and understanding from family, friends, and work colleagues contributed to them living well with their diabetes. A lack of this support, as well as irregular work patterns or inflexibility from employers, can contribute to making it very difficult for people living with diabetes to manage their condition.

Support and understanding from clinicians

Attendees said living well is often made difficult when some GPs or healthcare professionals do not acknowledge the emotional impacts of diabetes, from the point of diagnosis onwards. This can often act as a barrier to receiving further emotional or psychological support. In the words of one attendee: *“There’s no instruction manual when I was diagnosed...I felt stupid”*. Attendees said it was crucial that healthcare professionals understood that the day-to-day demands of living with diabetes were massive.

A feeling of control

“Not feeling like my diabetes was interfering in living my life and being able to do whatever I wanted to do is living well”, one attendee said. Living well is also understanding their own condition – expecting their blood glucose highs and lows and why that might have happened: *“It’s the not knowing that creates the worry”* that impacts on a person’s wellbeing.

Access to diabetes technology

Access to diabetes technology such as flash and continuous glucose monitors and insulin pumps, for those people with type 1 diabetes who choose to use them, was mentioned as often helping to give that feeling of control and improvements in quality of life they enabled people with diabetes to live well.

However, there are unintended consequences of technology – attendees said it can sometimes lead to information overload. It was said that *“constantly checking phones”* to check on their own or their diabetic children’s rates can lead to anxiety, stress, and burnout.

On how diabetes services met their emotional and psychological needs:

Patchy provision of care and support across Northern Ireland

It was clear that there are current variances in care from Trust to Trust in terms of how people with diabetes' emotional and psychological needs were met. Some attendees found it hard to accept that one person could receive a level of support in one Trust they could not in their own Trust. Mental health support in diabetes care needs to be provided in a standardised way across Northern Ireland, so people with diabetes know they can receive the right emotional and psychological support no matter where they live.

Few are asked 'How are you?' in routine appointments

Most attendees had never been asked in appointments how they were emotionally coping with their diabetes. In the words of another attendee, in their experience *"they only ever focus on bloods and feet"* and there was little emotional awareness.

One attendee said their subsequent mental health crisis could have been prevented had the simple question of 'How are you?' had been asked. Attendees felt that if some healthcare professionals provided the space and took more time to ask about how a person was coping emotionally, more preventative measures such as onward referral could be put in place.

Access to information

Attendees felt there was little information available, in a standardised way across each HSC Trust, on the mental health support services available to them. Greater signposting, and knowing what information is available, would help enable their emotional and psychological support needs to be met.

The impact of life changes

Another attendee said their emotional and psychological support needs are often highest when they are undergoing life changes such as menopause and moving to a new house. They felt diabetes services, in linking with mental health services, needed to take more cognisance of this, given the impact it could potentially have on managing their diabetes

On the impact of diabetes on mental health:

"It never leaves you"

Diabetes was unanimously described as exhausting – attendees said they often felt consumed by their condition because, in the words of one attendee, *"It never leaves you –*

it has to affect your mental health". Some had experienced extreme low mood due to the relentless nature of living with diabetes.

The impact of diabetes on parent-carers is considerable. Despite not having diabetes themselves, they too 'live' with the condition. Some parent-carers often constantly check their children's blood glucose levels and the worry and anxiety associated with ensuring their children live well can lead to their own stress and burnout.

Increased incidences of eating disorders

Eating food, so often taken for granted by people without diabetes, is sometimes not an enjoyable experience for some people with diabetes. For example, one attendee said having type 1 diabetes has changed the way they look at food: a person without diabetes looks at a plate of food and often thinks little of it, other than looking forward to eating it; a person with diabetes looks at the plate and immediately calculates the content of carbohydrates and sugars.

The close link between diabetes and food can lead to increased instances of eating disorders and disordered eating among people with diabetes. For example, diabulimia is a dangerous eating disorder that only affects people with type 1 diabetes – when someone reduces or stops taking their insulin to lose weight, and this has life-threatening consequences.

"It's the small things that can impact so much"

Consuming the smallest amount of alcohol can affect a person's blood glucose, which in turn, effects the quality of their sleep and therefore their overall wellbeing.

Even the effect of physical exercise on blood glucose levels also made some attendees think of partaking in exercise – so important to a person's wellbeing – was often not worth it.

Wearable technology for people with diabetes – one attendee put it as *"always being connected to something"* – despite the benefits for those who choose to use technology, has unintended consequences on things such as intimacy; being afraid to give a person with type 1 diabetes a hug in case their insulin pump is damaged, or disrupt the person's insulin supply by knocking their cannulas or tubing, or cause injury.

The pandemic

The impact of the coronavirus pandemic was cited as a negative factor on wellbeing. People with diabetes are classed as clinically vulnerable, meaning they have a heightened level of risk of serious illness from Covid-19. One attendee said the worry of contracting

the virus led to periods of anxiety and sleeplessness that they thought was perhaps not often experienced by someone at low risk of serious illness from the virus.

On what good mental health support services for people with diabetes looked like:

Attendees thought that **more training was needed for healthcare professionals to understand the emotional struggle of diabetes** and to enable healthcare professionals to identify when an emotional problem becomes a psychological problem. **Signposting itself was also identified as generally lacking in current service provision**, and this needed to improve.

Good care would also mean the **standardisation of care across Northern Ireland**, so people living with diabetes could access the same level of mental health support no matter where they lived.

Attendees also thought there needed to be **greater linkages between diabetes services and mental health services**, and to ensure both services mutually understood each other. Another attendee, who lived with an eating disorder, said there was no link between diabetes services and **eating disorder services**. This concerned other attendees, given the rates of diabulimia for people with type 1 diabetes and other eating disorders faced by people with type 2. Despite a commitment from the Department to remove siloed working, it was clear from attendees there were 'too many silos'. There was agreement in the group **that services should be joined up** and silos should be reduced so that people can access the care they need, when they need it.

Mental health support also needed to be embedded within routine diabetes care and reviews, and **healthcare professionals should be encouraged to talk about how a person with diabetes is coping emotionally**. For people with type 2 diabetes, many of whom do not have reviews like those with type 1 diabetes, **general practitioners should embed mental health support within their practice in the same way**.

Our recommendations: what needs to happen in Northern Ireland

We strongly urge the Department of Health to incorporate the following recommendations within the theme of Providing the Right Support at the Right Time in the Mental Health Strategy.

1. *The Department of Health must ensure that the mental health impact of diabetes is recognised in all aspects of diabetes care, through care and support planning and better patient-healthcare professional conversations*

Healthcare professionals – including consultants, GPs, and diabetes nurse specialists – must ensure they provide the opportunity for conversations about emotional wellbeing during routine appointments by asking their patients how they are coping with their condition, and what more can be done to help them.

With diabetes, only three hours per year are spent with a healthcare professional while the remainder of the year is spent alone. We believe it needs to be more than just ‘bloods and feet’ at check-ups and at clinic. More openness to ask a patient “How are you feeling?” normalises talking about mental health and highlights what might be impacting physical health outcomes. Often, this can prevent a mental health crisis.

Good progress has been made by the Diabetes Network to prioritise emotional and psychological support across its workstreams. As well as this, many diabetes healthcare professionals across Northern Ireland are already excellent at providing emotional support. However, HSC Trusts as well as the Department of Health also must ensure more healthcare professionals working with people affected by diabetes are supported and equipped to care for their patients’ emotional and psychological wellbeing.

2. *The Department of Health must ensure it works with the voluntary and community sector to provide, commission and signpost to services such as peer support and other information and support services for people affected by diabetes*

Policymakers, including HSC Trusts and the Department of Health, in support of the work of the Diabetes Network for Northern Ireland, must increase access and signposting to services offered by the third sector in Northern Ireland, such as social prescribing, already well-utilised by Northern Ireland’s community sector, and diabetes-specific support programmes.

Healthcare professionals should also be aware of the support services the third sector offer, for onward referral and signposting.

Examples of such services Diabetes UK offer include:

- Our *Befriender Service*, made possible through funding from the National Lottery Community Fund, offers regular friendly chats with volunteers who know what it is like to manage diabetes. The trained volunteers can offer information to sign post people living with diabetes to local services that can help support them if needed.
- The *Our Lives, Our Voices* programme, also made possible through funding from the National Lottery Community Fund, brings together young people aged 13 to 25 years living with type 1 diabetes to create opportunities to share their lived experiences and support each other. Through the programme they can also build their confidence to manage their condition, improve their mental health and wellbeing, and work with others to find solutions to issues that affect them daily.
- A network of online *Peer Support* throughout the coronavirus pandemic to continue to offer help to those with, affected by, or at risk of diabetes. The online Peer Support sessions run for five weeks with a different topic or speaker each week.

3. *The Department of Health must ensure that services providing diabetes care is supported by mental health professionals to ensure effective provision across Northern Ireland*

The Department of Health must ensure that diabetes services across Northern Ireland should include an integrated mental health professional – be that a counsellor, psychiatrist, or a psychologist – with knowledge of diabetes who can both give advice and provide care. This must be done in a standardised way so a person with diabetes can access the same level of care, no matter in which HSC Trust they reside, or where in Northern Ireland they live.

4. *The Department of Health should commission and implement an integrated care pathway for long-term conditions and mental health*

This will ensure greater personalisation of care and will provide for a multi-disciplinary approach across specialties with greater access to specialist mental healthcare and support when required. Governance and accountability through the Mental Health Strategy paired with increased mental health support for people with long-term conditions will allow for closer alignment of prevention and early intervention with physical healthcare to ensure people get the right support at the right time.

5. *The Department of Health must ensure all healthcare professionals providing general diabetes care have the skills and training to identify and support the mental health needs of people affected by diabetes*

With the correct training, the healthcare professional can discern if a person living with diabetes needs an emotional support or mental health intervention and to what level they need to be referred, for example online information, local support groups or referral to a mental health specialist with understanding of diabetes.

6. *The Department of Health must ensure that, similarly, mental health professionals should have knowledge of long-term conditions such as diabetes, and an understanding of the impact diabetes can have on mental health*

Community mental health teams, counsellors, eating disorder teams and other mental health professionals working with people living with diabetes should receive diabetes-related training. This will enable them to understand the mental health impact of diabetes and of associated mental health problems that can arise that are specific to diabetes, such as diabetes distress, diabetes burnout, disordered eating or diabetes-specific eating disorders such as diabulimia.

Conclusion

The day-to-day demands of managing diabetes can be a constant struggle affecting people's emotional wellbeing and mental health. In turn, people have told us that struggling emotionally can make it even more difficult to keep on top of self-management. When diabetes cannot be well managed, the risk of dangerous complications, such as DKA, blindness and limb amputations increase.

Diabetes services that include emotional, psychological, and mental health support can help people improve both their physical and mental health, reduce pressure on services, and for the health and social care system, save money.

Mental health and physical health go hand-in-hand, but services for people with diabetes has not always reflected this. We need to bridge the divide between physical and mental health services to ensure those with emotional and psychological difficulties related to their diabetes do not have their needs overlooked. It is critical that all diabetes care sees and supports the whole person and explores what matters most to them.

We strongly urge the Department of Health to incorporate the recommendations in this response within the theme of *Providing the Right Support at the Right Time* in the final Mental Health Strategy.

As the ten-year Strategy is further developed, embedded, and implemented in Northern Ireland, we look forward to working with the Department of Health, HSC Trusts, the Diabetes Network, and the Mental Health Champion to further prioritise emotional, psychological, and mental support in diabetes care in Northern Ireland.

For more information on this response

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Appendix:

Comprehensive summary of the workshop held with people living with diabetes to inform this consultation response

The workshop was held on Tuesday 3 March 2021 at 7.30pm via the Zoom online virtual platform. It was attended by 15 people living with both type 1 and type 2 diabetes, who were invited to register to attend through Diabetes UK's volunteer support groups, parent/carer support groups and the Diabetes Network's service user forum.

Question 1 – What would living well with your diabetes look and feel like to you?

Attendees were asked to focus on the self and not necessarily the service.

One attendee thought living well meant having great support and understanding of diabetes from friends and family. Many agreed with this, and one added colleagues in work too. On workplace settings, another attendee said they once worked in social care and the nature of the job made it difficult to manage their diabetes due to irregular work patterns and inflexibility from their employer.

Another attendee, who lives with type 1 diabetes, said living well meant a feeling of control, which they said was helped made possible attending a DAFNE course. They felt that not feeling like their diabetes was interfering with their living their life and being able to do whatever they wanted to do was living well. Another attendee agreed with this, saying living well meant understanding their own condition – expecting their highs and lows and why that might have happened. It was the not knowing, they thought, that created worry which impacted most on wellbeing.

Technology such as flash/continuous glucose monitors and insulin pumps, it was thought, helped people with diabetes have that sense of control. However – and without doubting the quality-of-life improvements that technology can bring for those who choose to use it – there were pitfalls of technology leading to what was said of an unhealthy obsession with numbers. It was asked, was this information overload? This attendee cited examples of parent-carer friends constantly checking their phones to keep on top of their diabetic children's rates, leading to stress and burn-out, despite not necessarily having diabetes themselves.

One attendee remarked that there's no training or instruction manual on being diagnosed with diabetes. They did not know where to go for support and subsequently felt stupid with feelings of failure. Many attendees said that living well with diabetes is often made

difficult when some GPs and healthcare professionals do not always understand the emotional impacts of diabetes and ask them simple questions like how they are. Another attendee said that they had received zero psychological support from their diabetes team, despite flagging it as an issue.

Another attendee said that living well with type 1 diabetes is being in control enough to ensure it will not interfere in their life or hold them back in doing the things they want to do.

In closing, one attendee said they have worked really hard to get to a point where their type 2 diabetes does not take over their life - they live 'with' it.

Question 2 – Based on what you know about how diabetes services work, do you feel they meet your emotional and psychological needs?

Almost immediately it was clear from the perspective of some of those in attendance, there were variances in care from Trust to Trust, and perhaps variances between different types of diabetes.

One attendee said, in their Trust, diabetes services do not meet their emotional and psychological needs. They said, in their own experience, they saw no link between mental health and diabetes services when they were diagnosed with type 2 diabetes during psychiatric care. However, in response, another attendee who had type 1 diabetes since childhood, said they experienced good emotional and psychological support in their Trust and their GP surgery, despite experiencing mental ill-health and it impacting on their diabetes and their university studies.

When a discussion was prompted on asking, in routine appointments, how they were coping, very few had. Most attendees said they had never been asked about how they were coping emotionally. Another attendee felt their subsequent mental health crisis could have been prevented, had the simple question of asking how they were coping was asked. One attendee remarked that a healthcare professional only focused on their bloods and the feet and felt there was no psychological awareness. It was also said that parents were never asked how they were coping emotionally, in the struggle with managing their type 1 children's condition. One attendee questioned how acceptable the lack of emotional and psychological awareness was, given it is listed as one of Diabetes UK's '15 Healthcare Essentials' – should it be higher on that list, they asked? Attendees felt that if some healthcare professionals took more time to ask about how a person was coping emotionally more preventative measures could be put in place. They also felt, generally, there was little information on the mental health support services available to them and more information was required in a standardised way across each Trust. It was said that healthcare professionals needed to understand that the day-to-day demands of living with diabetes are massive.

Another attendee said emotional and psychological support needs are often highest when they are undergoing life changes such as menopause and moving to a new house. They felt diabetes services, in linking with mental health services, needed to take more cogniscance of this, given the impact it could potentially have on managing their diabetes

Question 3 – How does diabetes impact on your emotional and psychological health?

The impact of diabetes on a person's emotional and psychological health was unanimously described by attendees as exhausting. Attendees felt they were consumed by their condition. As one attendee put it, diabetes never leaves a person – it must affect one's mental health. In one case, an attendee felt in the past that they had experienced extreme low mood due to the relentless nature of living with diabetes – this was an experience shared by many in attendance.

It is the small things, so often taken for granted by people without diabetes, that impact so much. It was described by many attendees as an obsession with numbers. For example, one attendee said it changed the way they look at food: a person without diabetes looks at a plate of food and thinks little of it, other than looking forward to eating it; a person with diabetes looks at the plate and immediately calculates the content of carbohydrates and sugars. They felt eating food was not an enjoyable experience and this experience often leads to eating disorders and disordered eating among people with diabetes.

It was also said even consuming the smallest amount of alcohol affects their blood glucose, which in turn, effects the quality of their sleep and therefore their overall wellbeing. The effect of physical exercise on blood glucose levels also made attendees think of partaking in exercise – so important to a person's wellbeing – was often not worth it.

One attendee, whose partner also lives with diabetes, said there is little pressure within the home; they both share decisions around eating so many without diabetes take for granted. However, despite being a strong supporter of diabetes technology, the attendee felt that always being connected to insulin pumps means they can't be spontaneously intimate, because the risk of damage to the pump, injury or disrupting the flow of insulin is always there. They cited that for a person using diabetes technology, intimacy cannot be spontaneous and is often planned – an experience not often shared by people without type 1 diabetes.

One attendee expressed frustration knowing there are varying levels of emotional and psychological care for people with diabetes across Northern Ireland. They felt it was hard to accept one person with diabetes in a different Trust could access a level of care they could not.

Finally, the impact of the coronavirus pandemic was cited as a negative factor on wellbeing. People with diabetes are classed as clinically vulnerable, meaning they have a higher level of risk of serious illness from Covid-19. One attendee said the worry of contacting the virus led to periods of anxiety and sleeplessness that was perhaps not experienced by someone at low risk of serious illness from the virus.

Question 4 – What does good emotional and psychological support services for people with diabetes look like to you?

Attendees at this stage were asked to focus on the service itself.

It was unanimously agreed that healthcare professional training in mental health needed to improve; to understand the emotional struggle of diabetes and enable healthcare professionals to identify when an emotional problem becomes a psychological problem, and when, how and where to signpost. Signposting itself was something identified as generally lacking in current service provision.

It was also clear from attendees' experiences that emotional and psychological support provision for people with diabetes was patchy within and between HSC Trusts – a good service would ensure provision was regionalised and standardised across Northern Ireland.

Despite a commitment from the Department to remove siloed working, it was clear from attendees there were 'too many silos'. There was agreement in the group that services should be joined up and silos should be reduced so that people can access the care they need it when they need it.

Another attendee felt emotional and psychological support should be routine in type 1 diabetes care, and not referral based. They felt this was important as a person's psychology can often affect their glycaemic control. Encouraging talking about emotions within reviews was unanimously agreed by type 1s in attendance as a sign of a good service. It was said the simple act of asking how they are, and a listening ear mattered so much to people. When one attendee was first diagnosed with type 1, they said what they wanted was someone to talk to – and they did not get it.

The point was made by an attendee with type 2 diabetes that people with type 2 did not usually have reviews similar to those with type 1 – so it was particularly important for them to have emotional and psychological support embedded in general practice. Without this, there is a clear imbalance in the emotional and psychological support among the different types of diabetes.

Another attendee said therapeutics such as mindfulness had helped them and wondered if this could be incorporated into emotional and psychological support.

It was suggested regional drop-in centres, similar to that offered by Healthy Living Centres, could be established, where people call in, meet others for peer support but can also have access to professional support.