



Diabetes Research &
Wellness Foundation



AUTISM & DIABETES PROJECT

PHASE 1

CONSULTATION REPORT

Kate Webb – Autek CIC

Steve Bond - Autek CIC



CONTENTS

Executive Summary.....Page 1-2

Introduction.....Page 3-5

- Diabetes Research & Wellness Foundation (DWRF)
- Autek
- Solent Diabetes Association (SDA)
- Rotary Direct Membership
- Current research into this topic

Consultation.....Page 6 - 14

- Diabetes Interviews
 - Type 1
 - Type 2
 - Gestational
- Workshops
 - Room One
 - Serendipity
 - LD
- Increased risk and gaps in research

Analysis of the findings.....Page 15 – 21

- Unique challenges faced by autistic individuals with diabetes
- Aspects of autistic life that make diabetes more challenging
- Technology

Next Steps for the Project.....Page 22

- Planned developments and resources
- Future Videos
- Research

Conclusion.....Page 23

Perspectives/QuotesPage 24 – 31



EXECUTIVE SUMMARY

Our consultation into the challenges faced by autistic people managing diabetes (type 1, type 2 and gestational) has revealed that this is a topic that hasn't previously attracted a lot of attention. That's not to say that health care professionals (HCPs) don't adapt their approaches when supporting an autistic person, more that there is no formal approach to doing so.

We learned that there are many facets of being autistic (or neurodivergent in a wider sense) that interact with diabetes management. These include the more obvious ones around eating habits, food sensitivities, needle phobias, and social interaction, making support groups and some appointments inaccessible.

We also discovered some lesser-known traits such as interoception, where body signals around hunger / thirst or blood glucose levels are not understood, Rejection Sensitive Dysphoria (RSD) which leads to huge levels of guilt, and Pathological Demand Avoidance (PSD) which requires mediative approaches from HCPs otherwise information isn't considered.

We learned that in order to understand the interaction of autism and diabetes, we need to consider both characteristics of autism itself, and aspects that derive from the life experiences of autistic people living in a non-autistic world.

This paper provides a rich narrative and pulls together insights from 30 autistic people who are managing diabetes in different types, including pre-diabetes. These people cover a wide diversity including gender, gender diversity, age and ethnicity and cover a wide spread of co-occurring conditions which shape the experience of managing diabetes.



In terms of next steps, we want to achieve three objectives.

1. Continuing to raise energy levels around this topic for NHS, Public Health, and VCSE. We don't want this to go away.
2. Create communication resources to help autistic people managing diabetes of all types. It is our belief that a suite of videos is the best way to do this, and to create communications that are autistic friendly and provide very clear information from which autistic people, supported by HCPs, can manage their diabetes.
3. Set up a research project that takes forward the analysis presented in this paper and develops new approaches to managing diabetes for autistic people. During the consultation, we learnt that everybody's diabetes is different, and all autistic people are different. This leads us to believe that a person-centred approach is necessary and that the research can help to create a framework whereby these differences can be understood and a plan made for the person. It is our belief that such research can only happen through a research partnership between people with lived experience and those supporting them.

We are incredibly grateful to each and every one of the participants and the HCPs and voluntary sector organisations who make this consultation possible.

And to Diabetes Research and Wellness Foundation (DRWF) for funding this consultation, and to our other partner organisations Solent Diabetes Association and Rotary International.



INTRODUCTION

Our Collaboration.

We have established an expanding partnership of individuals and organisations dedicated to improving outcomes for autistic people managing diabetes. This report marks the conclusion of a comprehensive consultation involving professionals and autistic individuals, exploring their experiences. The initiative was funded by the Diabetes Research and Wellness Foundation (DRWF) and delivered by Autek CIC, with invaluable support from an increasing network of experts across healthcare, public, and voluntary sectors.

Diabetes Research and Wellness Foundation (DRWF)

DRWF is a registered charity in the United Kingdom, dedicated to providing comprehensive information and support for people living with all types of diabetes. The organisation's mission centres on promoting good self-management practices and enhancing the overall quality of life for those diagnosed with diabetes - "Staying well until a cure is found".

Autek CIC

Autek CIC is a social enterprise founded on lived experience, supporting disabled and neurodivergent individuals in leading lives that reflect their personal choices and preferences. Autek achieves this through the creation of informative and engaging videos, leveraging firsthand understanding of the challenges that autistic people encounter.

Solent Diabetes Association

The Solent Diabetes Association (SDA) is a charity that helps people and families living with diabetes in Portsmouth and Southeast Hampshire. Its goals are to promote research into preventing and treating diabetes, raise public awareness, and provide education and resources to the local community.



Rotary Direct Membership

Rotary Direct Membership allows people to join Rotary without needing to be part of a particular club. This means members can get involved with Rotary projects straight away and contribute directly to different initiatives.

Current Research into this topic.

There is a lack of information around the topic of autism and diabetes. What little there is seems to show very different results.

On the topic of prevalence, research projects disagree¹². Some show significantly higher prevalence of diabetes for autistic people, whereas others found no significant difference.

This is surprising because, at least theoretically, it is a simple piece of information to gather. GP records have flags for neurodivergence and for diabetes, and so they can be accessed to look at rates for neurodivergent people and rates for neurotypical people.

This, of course, misses out on people who either aren't diagnosed autistic / living with diabetes, people who choose not to tell their GP about their neurodivergence, people who don't engage with their diabetes diagnosis, or people who don't attend a GP practice (which is something we hear about a lot in the autistic community). But it's a start.

In terms of advice and guidance for health care professionals working with autistic patients in either pre-diabetes or who are managing diabetes, there is virtually no

¹ <https://www.sciencedirect.com/science/article/pii/S0149763422000811>

² <https://pmc.ncbi.nlm.nih.gov/articles/PMC7931154/>



information. ³BreakthroughT1D have published a paper highlighting common issues that autistic people may face living with type 1 diabetes including dealing with uncertainty and change, hyperfocus on detail rather than seeing the bigger picture, sensory issues including the use of technology, challenges with interoception and recognising what is going on in the body, autistic shutdowns and burnout, sensory issues around taste and texture and problems with hospital environments triggering sensory issues. They offer no guidance as to how to help such people living with diabetes.

The issues noted by BreakthroughT1D are recognised by the authors of this report and, in some way, provide the motivation for our project. We know that being autistic has many aspects which overlap / impact diabetes management and we want to develop ways to communicate better with autistic people how to manage diabetes, and how health care professionals can adapt what they do to better support autistic people.

As part of our consultation into autism and diabetes, we aimed to speak with a range of health care professionals and discover whether there are different approaches taken with autistic people, or whether our review of literature is correct in that this isn't an area which has attracted focus previously.

³ <https://breakthrough1d.org.uk/knowledge-support/managing-type-1-diabetes/type-1-diabetes-and-neurodiversity/autistic-adults-and-type-1-diabetes/>



CONSULTATION

To truly enrich our insight into the day-to-day experiences of autistic people living with diabetes, we set out on a dynamic and inclusive consultation journey. Our approach blends insightful face-to-face conversations and accessible online meetings, ensuring that a wide range of voices are heard and valued, no matter where participants are based. By combining these methods, we create a welcoming space in which individuals can share their stories, challenges, and triumphs, helping us build a deep, authentic picture of what it means to manage diabetes as an autistic person.

Face-to-Face Consultation

Consultations took place in Portsmouth. We worked with local groups like Portsmouth City Council's Room One service, and Autek's community connections. To make sure we heard from autistic people with learning disabilities, we also worked with the Red Sauce Theatre Company and Portsmouth's Integrated Learning Disability service.

Consultation Activities

Our consultation actively engaged participants through a variety of dynamic formats, including one-to-one discussions, small group workshops, and storytelling sessions, complemented by creative methods designed to foster meaningful involvement. By offering a welcoming and flexible environment, these activities encouraged autistic people to share their experiences openly and in their own words, ensuring that each person felt valued and heard. The aim was to spark honest and insightful conversations, drawing out rich perspectives and enabling everyone to contribute to a deeper understanding of the lived experience of managing diabetes while being autistic or neurodivergent.



Participant Diversity

We connected with 30 individuals, each bringing their own unique perspective. Our participant group was wonderfully diverse, embracing a vibrant spectrum of neurodivergence alongside autism—including people with ADHD, Dyspraxia, Dyslexia, and learning disabilities. By welcoming such a broad range of voices, we're determined to make sure our project truly reflects and addresses the many challenges and experiences within this dynamic community. Our participants came with different intersectionality including age, gender, gender diversity, ethnicity and multiple co-morbidities which greatly affected their management of diabetes.

Reporting and Dissemination

We're committed to sharing the results of our consultation in a clear and engaging way. By capturing the voices and lived experiences gathered throughout this process, we aim to shine a spotlight on the unique hurdles faced by autistic people living with diabetes and their families. These insights will not only deepen our collective understanding but will also shape the next steps of our project—helping us to develop better support and resources that genuinely reflect the needs and aspirations of autistic people living with diabetes.



INTERVIEWS

This section invites readers into the lived realities of people living with diabetes in - type 1, type 2, and gestational - each diagnosed at varying moments in their lives. Through the personal stories shared, we provide insight into the unique journeys towards diagnosis and the day-to-day challenges of managing diabetes for autistic people.

What makes these accounts especially compelling is the spotlight on how factors like autism shape each individual's experience, highlighting just how diverse and complex life with diabetes can be. By weaving together these different perspectives, this section not only enriches our understanding but also calls attention to the critical importance of recognising neurodiversity and other intersecting factors in providing meaningful support and care to those affected by diabetes.

We learnt from professionals supporting our process that everybody's diabetes diagnosis is different, and from autistic people, that each autistic person has different strengths and challenges. This makes the intersection of the two, compounded by the other conditions that the individual is managing at the same time, difficult to map out. The stories we heard form, perhaps, the best way of really understanding this intersection.

Type 1 – Young Person

At just 10 years old, a young person's life was turned upside down when they developed type 1 diabetes, experiencing symptoms like constant thirst, frequent urination, and weight loss, which led to a hospital stay and a challenging diagnosis. There was no one medical event which triggered the diabetes and so it wasn't clear how long the symptoms had been developing. With medical support and family training, they gradually learned to manage their condition, including injecting insulin and checking blood glucose levels.



Support from a dedicated care team and early mental health intervention made a big difference. By 13, advanced devices like a continuous glucose monitor and insulin pump brought more freedom and reassurance, though securing them required persistence.

Managing food and their social life remains tricky, and misunderstandings about diabetes and autism-related selective mutism sometimes makes things harder.

Despite the obstacles, technology and support have helped the family grow more independent and resilient, inspiring them to raise awareness and advocate for better understanding of type 1 diabetes.

Type 2- Older Age

This interview explores the experiences of an autistic / ADHD adult in their sixties managing type 2 diabetes. After years of being pre-diabetic, a diagnosis came during the COVID-19 lockdown due to reduced activity and changing eating habits.

Treatment began with metformin and later included dapagliflozin, but not insulin. Healthcare support focused mainly on routine checks, offering little tailored advice, prompting the individual to seek peer support.

Autism added challenges, especially with needle sensitivity, which led to this person not being able to finger-prick. ADHD's executive function challenges also affected diabetes management including remembering to take tablets and planning eating habits. Temporary access to a continuous glucose monitor (CGMs) provided valuable insights for a person with poor interoception (this person doesn't feel hunger, for example). However, CGMs are costly and not NHS-funded for non-insulin-dependent or non-obese patients, so the individual now pays out of pocket. The experience highlights a need for more personalised, neurodivergent-aware healthcare.



This person has suffered for a long time with Autistic Burnout which has negative implications on eating and hence managing diabetes. High sugar food provides a temporary boost which enables them to cope during phases where burnout is worse.

Type 2- Middle Age

This candid interview provides an inspiring look at the challenges and triumphs of living with type 2 diabetes. It explores the daily realities of managing the condition, including tracking weight, blood markers, and the positive impact of an NHS nutritional programme on weight loss and blood glucose control.

The interviewee openly discusses how trauma and mental health struggles have made maintaining a healthy lifestyle difficult, sometimes leading to isolation and physical symptoms. Regular medical monitoring and support from healthcare professionals and loved ones are shown as crucial.

A connection was made by this participant between addiction and diabetes. Autistic people are prone to addiction – it arises from monotropic behaviour. The process by which the body responds to ingesting high GI foods can, itself, be addictive.

Ultimately, this story emphasises that managing type 2 diabetes effectively requires caring for both mental and physical health.

Type 2- Size Matters

Meet a remarkable individual navigating life with autism and ADHD, all while managing the complexities of type 2 Diabetes.

Their journey is further complicated by being overweight and having an autoimmune condition, both of which require ongoing injectable treatments. But what truly sets them apart is their unwavering self-advocacy. They stand firm in their identity as a 'fat person' and passionately defend their rights as a disabled individual, boldly resisting pressure to change their body.



Their encounters in hospital have been anything but easy. The anxiety and feelings of stigma they endure are heightened by the negative attitudes and assumptions of some medical professionals towards patients who are overweight. Yet, they are clear about what they need: to be treated with dignity, to receive clear explanations about their care, and above all, to be met with empathy – not blame, which is far too often placed on fat people with diabetes.

This story sheds light on a wider issue: autistic individuals are especially susceptible to eating disorders, and many autistic people who are overweight avoid seeking medical care altogether due to the fear of stigma and blame.

It's a powerful reminder that everyone deserves to be seen, heard, and respected – no matter their size or diagnosis.

Gestational

Explore the journey of an extraordinary neurodivergent woman during her third pregnancy, which took an unexpected turn when she was diagnosed with gestational diabetes.

Undeterred, she managed her health with strict diet and exercise, yet the diagnosis complicated her childbirth plans and increased risk factors.

The lack of understanding and support from healthcare staff for both her autism and medical condition led to mental health struggles, further worsened by limited family support and the demands of caring for her autistic daughter. Her hopes for a comforting home birth were dashed, highlighting both the shortcomings in maternity care for neurodiverse people and her remarkable resilience.



WORKSHOPS

Workshop 1 – Portsmouth City Council's Room One

At this workshop, we listened to the real-life stories of three autistic people living with prediabetes, type 1 and type 2 diabetes. Participants shared honest reflections on the support they've received from the NHS and other services, revealing both the triumphs and challenges of their journeys. Their voices shed light on what truly helps – and what could be improved – to make life with diabetes a little bit easier for everyone.

Managing Diabetes

Participants described this as a tough journey, especially for autistic individuals and those with ADHD. Imagine trying to keep on top of your diet and medication while also grappling with low confidence in the kitchen, confusion around nutrition, and the daily challenge of sticking to routines. Sensory sensitivities can make even the smell or texture of certain foods overwhelming, while sugary snacks often feel like an irresistible temptation.

Support matters

Autistic and neurodivergent people need advice that actually fits their lives, ideally from trusted sources like the NHS. Reliable information and a helping hand tailored to their unique needs can make all the difference. For some autistic people, the need for high quality information can be very important in terms of getting a deep understanding of the condition. However, if the NHS information is inaccessible then there is a risk of turning to less well-informed sources. High quality videos would help bring together reliable information in a format that is easily understood.

Medication

This is another hurdle. Memory lapses, attention difficulties, and struggles with executive function can mean missed doses or accidentally doubling up. But there's hope for autistic people: establishing set routines, using visual reminders, and leaning on organisational tools can help keep things on track.



Ultimately, everyone's experience is different. That's why a one-size-fits-all approach simply won't do. This group were keen on attending a support group for autistic people managing diabetes. Something that Room One is planning to set up. The ideas of talking as a peer group were seen to be valuable for learning and adapting behaviour, but the thought of a 'traditional' support group would put them off attending.

Workshop 2 – Autism Hampshire's Serendipity Group in Portsmouth

A lively and supportive community space, where autistic individuals came together to openly share their experiences and insights about living with both autism and diabetes. People exchanged practical tips, discussed everyday challenges, and celebrated their personal victories. By connecting with others who truly understand, members not only gain valuable knowledge about managing their health, but also foster a strong sense of belonging and mutual encouragement.

Facing the Challenge: Getting Good Health Information

It can be hard to find clear and trustworthy health advice, even from places like the NHS. People with diabetes often have to work things out for themselves, especially when it comes to managing their energy and blood glucose levels.

The group used pictures to explain how different foods act like fuel. Some foods give you energy quickly, while others release it slowly and help keep your blood glucose steady. This was felt to be a really clear way to understand and talk about the impact of food and exercise in managing diabetes.

Everyone is different, so it helps to keep a food diary and try to pick healthier snacks when you can. For this workshop, low carb pizza, biscuits and cake were on offer, and all participants loved these alternatives and how simple they were to make.

The group, supported by Janice Mason from the Diabetes UK support group "Carbs in the Kettle" also talked about ketones, which are acids your body makes when it



burns fat instead of sugar—usually when there isn't enough insulin. A small amount is okay, but too many ketones can lead to serious complications for people with diabetes.

The participants from the Serendipity group were also interested in attending a diabetes support group if it is managed in a way that is autism friendly, in the same way that this workshop was.

Workshop 3 – Red Sauce Theatre group people with Learning Disabilities.

The workshop involved 14 participants with mixed learning disabilities and autism, aged 22–60+, including two wheelchair users.

Four participants acted in a Books Beyond Words storytelling film about Type 2 Diabetes, supported by professionals and a diabetes nurse to ensure medical accuracy. The remaining participants, familiar with the process from auditions, watched the completed film.

Initially, only one participant had in-depth diabetes knowledge, but after the session—which included video viewing and a discussion led by the actors—all gained a better understanding of diabetes management.

The group valued the accessible approach, suggested more regular sessions at varied times, and recommended adding information about eye tests to future materials. They expressed interest in using this approach for other health topics and highlighted the importance of having a diabetes professional present.



Analysis of findings

We have grouped our findings into two different areas.

The first looks at challenges that arise from the condition Autism - the differences in the way that autistic brains are 'wired' that make a difference when trying to live with diabetes.

The second area explores challenges that arise from an autistic person living in a non-autistic world. This is akin to the social model of disability which argues that disabled people are mainly disadvantaged through the environment not the medical aspects of the disability.

Unique Challenges that relate directly to Autism.

We had a lot of input from the interviews and workshops that supported the findings from BreakthroughT1D and provided a lot more rich content. We found that some aspects of autism supported good management of diabetes, whereas others confounded it.

The topic which affects diabetes management a lot can be summarised by the autistic trait of monotropism. This is characterised by a need for organisation, sticking to task, hyperfocus and the need for stability. Some issues relating to monotropism occur in the next section where the autistic person is living in what could be described as a polytropic world.

Monotropism can lead to autistic people becoming information rich about diabetes and its management which is a positive thing, unless the information sources are misunderstood or fake.



We heard from one autistic person who, whenever he is diagnosed with an illness or condition researchers it as deeply as possible and then translates his findings into his own experiences. This can lead to a level of expertise, but also to hyperfocus on one or more aspects whilst missing the bigger picture.

We heard from a person living with type 1 diabetes where monotropism was useful. This person has the same breakfast every morning which makes planning the insulin easy.

Executive functioning difficulties is a facet of ADHD and autism and can lead to challenges in planning and managing day to day activities. We heard how this can lead to missing taking medication and, more worryingly, double dosing. It also makes it much more difficult to plan a major change in one's life such as changing the way one eats or exercises. Attending medical appointments is more challenging for people with executive functioning difficulties as there are many separate processes that need to be executed.

Blending monotropism and executive functioning difficulties makes it doubly challenging when staff in the health care team change, as was related by several of our participants.

Another trait of autism lies in social interaction and communication. This includes literal thinking (another manifestation of monotropic thinking), and challenges understanding social cues particularly in group situations. This has implications to high quality conversations with health care practitioners who need to adapt the way they talk about diabetes, and inaccessibility of diabetes support groups. We were able to visit two social groups that were run in autism accessible ways which enabled us to both communicate in new and different ways, and to learn from them.



Autistic people often have sensory processing difficulties. This can vary from hypersensitivity to pain or certain noises which are experienced as pain, to difficulties with interoception – understanding signals that the body is sending out. This affects two main things with diabetes: 1) finger pricks, blood tests, injections, and applying diabetes technology and 2) picking up on signals from the body around hunger and high and low levels of blood glucose. A lack of good interoception and monotropism can also lead to addiction as discussed by two of the participants.

Sensory processing difficulties also affect the way autistic people eat. It affects taste and texture in food – some people not being able to tolerate the feeling of meat, fizzy drinks or the explosive experience of eating an apple. It also affects how food on the plate is eaten – for some autistic people they have to have each component of the meal separately, and we heard differences in terms of whether the preferred component was eaten first or last. We also were able to discuss and understand that it is preferable to eat the vegetables first, then the meat and then the potatoes.

Another facet of autism that emerged from the consultation that affects diabetes is autistic anxiety, which overlaps into the next section as many of the anxieties faced by autistic people exist because they interact with a non-autistic world. However, autistic people have a higher baseline level of anxiety compared with non-autistic people and so are more prone to the effects of anxiety. This also means that there is a smaller 'gap' before anxiety spikes leading to meltdown.

Anxiety affects diabetes management in two ways. Firstly, there is anxiety around change following the diabetes diagnosis. Rather than being a trigger this can lead to self-defeating behaviours followed by guilt. There is also anxiety looking for help from professionals or peers. Anxiety could also manifest around "am I doing it right?" or "is it ok to have one bag of crisps as a treat?" Anxiety is often fuelled by well-intentioned people "are you supposed to be eating that biscuit?" which can be taken literally as a criticism.



Two final autistic / neurodivergent aspects that we learnt about which are important for professionals working with autistic patients are Pathological Demand Avoidance (PDA) and Rejection Sensitive Dysphoria (RSD). These don't affect all autistic and neurodivergent people, and they are not conditions that are often talked about.

PDA manifests as an excessive reaction to seemingly small demands made on the autistic person. It most often occurs at times of heightened anxiety, and a conversation about a life changing condition like diabetes in a health care setting is an ideal setting for this. Demands can be simple things like asking a question "would you like to take a seat?"; asking two questions at the same time: "would you like to take a seat, or would you prefer to remain standing?"; or opening instructions "please tell me about your symptoms". And then there are bigger demands like "take these tablets two times a day with food"; or "exercise more". The key to working with demand avoidant people is to mediate them towards making better decisions.

RSD manifests itself as an excessive reaction to criticism or, in the extreme, rejection. It's almost as though the person is actively looking for criticism or signs that they have done something wrong, at which point they beat themselves up. This is a condition that is often associated with ADHD. With diabetes, perhaps the most relevant aspect of supporting someone managing it is to remove the stigma as much as possible. "It is a medical condition rather than something you have done to yourself" and "it's ok to have a treat every now and again without feeling bad about yourself". When the annual blood test comes back with HbA1c high, "this can be the result of lots of different things, let's see if we can work out what to do to get the levels lower".

To be frank, health care professionals do not need to be PDA / RSD detectives, although it is useful to be alerted to the possibility of their being part of the



neurodivergence of the patient. Reducing demands and mediating solutions and reducing guilt / blame is something that works for everyone.

Aspects of Autistic Life That Make Living with Diabetes More Challenging

We were surprised to learn just how many of our participants had other co-occurring conditions and that these often took precedence over diabetes management. These included a vast range of organic conditions – far too many to list- as well as mental health. This, of course, isn't unique to autistic people, but we were surprised at the extent. A bit of research reveals that there is indeed higher prevalence of a lot of conditions for autistic people – interestingly, though, this research didn't find much of a connection with diabetes (autistic female with higher prevalence for pre-diabetes and autistic males with type 2 diabetes).⁴

Autism and mental health conditions were widely reported by the people we spoke to, and anecdotally, it is suggested that everybody who is recently diagnosed with neurodivergence should be treated for trauma. This relates to having to live in a world where the rules that everyone else lives by are not those that the autistic person lives by. It can be a very chaotic experience and requires tight controls (masking) to cope and often leads to burnout.

We learnt from our participants that mental health has a massive impact on diabetes management. What seems simple in normal circumstances becomes impossible during burnout, heightened anxiety or when working through trauma. Food becomes a crutch to help the person through this, and food decisions are usually not great with a focus on blood glucose levels. Our participants also reported high levels of guilt during these times as they knew that the decisions had impacts on diabetes.

Any health care professional supporting the autistic person living with diabetes needs to be aware of the conflicts with other health conditions, and a team-about-

⁴ <https://www.cam.ac.uk/research/news/autistic-adults-have-a-higher-rate-of-physical-health-conditions>



the-person approach works best. We heard about conditions where the use of steroids and other medications directly affects blood glucose levels, and the patient is not provided with any information as to how to manage this situation.

Stigma is a facet of autistic life, from early family experiences, reinforced in the school playground and continued into employment. Then, when diabetes hits, whether alongside being overweight or not, the stigma around “you caused this with your diet” compounds the effect of the existing stigma. It is very easy to not feel good about yourself. We were, however, incredibly impressed with the resilience and determination to succeed that we heard from our participants. Perhaps, though, this is part of the self-selecting process that brought them to our consultation.

Monotropism in a polytropic world is a cause of massive anxiety and challenges interacting with the health services. Something as simple as making and attending a doctor's appointment comes with many different steps, each of which can raise anxiety to unmanageable levels. Even if the appointment is made, the levels of anxiety can be so high that nothing meaningful comes out of it, and on occasion it can lead to misdiagnosis. We heard of one extreme case where the appointment directly led to trauma.



Technology

- Some participants had to pay for a Continuous Glucose Monitor (CGMs) themselves before getting NHS help, showing that diabetes technology can be expensive.
- These devices help with low blood glucose levels, but their high price and lack of NHS support for some people—especially those with Type 2 diabetes who do not use insulin or are not obese—mean many have to pay out of their own pockets.
- Not getting enough advice from healthcare staff on how to use these monitors can make things more stressful. It is important to have professionals who understand neurodivergence to help explain the results and reduce worry.
- Some people did not know about these technology options and needed to go to hospital for extra support, especially after being diagnosed with gestational diabetes, to check their blood glucose more often.



NEXT STEPS FOR THE PROJECT

Planned Developments and Resources:

- Support Group: A dedicated diabetes peer support group for autistic people will offer ongoing peer encouragement and practical help.
- Story Group: We would like to set up a new group which uses lived experiences of people living with type 2 diabetes to make information more relatable. This may be an extension to the Support Group, or something for the NHS to organise.

Future Videos

- Videos on using continuous glucose monitors (CGMs) for autistic people.
- Comparisons of type 1 and type 2 diabetes in autistic and neurodivergent contexts.
- Guides for autistic people living with type 1 and type 2 diabetes.
- Consideration of resources for gestational diabetes.

Research

There is a need for comprehensive research on supporting autistic people with all types of diabetes, from prevalence, through management and complications, and co-morbidities. The aim is to create resources to help health care professionals and autistic people working together to better understand and manage diabetes.

The goal includes forming a team including lived experience to ensure autistic voices guide the research programme.

CONCLUSION

Collaborative Efforts and Future Directions

The collaboration between the Diabetes Research and Wellness Foundation and Autek CIC highlights the vital need for tailored and inclusive support for autistic and neurodivergent individuals living with diabetes.

By placing the lived experiences of autistic people at the centre of the project, there is a concerted effort to develop accessible resources and prioritise co-production. This approach directly addresses both the practical and emotional challenges that this community faces in managing diabetes.

Insights gathered through interviews, workshops, and steering group discussions have revealed a wide range of needs and barriers. These findings underline the importance of providing flexible, person-centred care and ensuring ongoing peer support. Such measures are crucial to successfully meeting the diverse requirements of autistic individuals.

Looking ahead, it remains essential to pursue further research, advocacy, and sustainable funding. These steps will ensure that autistic voices continue to guide innovation and improvement in diabetes care.

By fostering greater understanding, empowering individuals to manage their health, and championing inclusion, this initiative lays the groundwork for lasting and meaningful improvements in the health and well-being of neurodivergent people living with diabetes.



Quotes from the Participants

Parent of person living with type 1 diabetes

"It was confusing and stressful, especially when my child was frustrated over food restrictions during treatment.

"Staff in hospital sometimes only talked to me instead of my child, which made things harder because of their selective mutism."

"We could call the diabetes care team any time, and they always helped us."

"We had to fight for access to the Dexcom, funding it ourselves before getting NHS support."

"Managing lunch at school was hard. Sometimes the wrong insulin was given because food wasn't carb-counted properly."

"We want to help people understand the difference between type 1 and type 2 diabetes."

Young person living with type 1

"I lost a lot of weight and my hair started falling out. It was really scary until things got better."

"I felt really anxious and nervous, and I always wanted my teddy bear with me in hospital.

"At first, I didn't want to do the injections or finger pricks myself, but gradually I did it with help."



"The Dexcom and pump give me more freedom – I don't have to think about my blood sugar all the time."

"The best thing about the pump and Dexcom is the freedom – I can focus more on what I enjoy, not just my diabetes."

"I didn't like being separated from other students at school events because of my diabetes."

"It's frustrating when people confuse type 1 and type 2 diabetes it's not my fault."

Person living with type 2 diabetes (Older Age)

"I was diagnosed with type 2 diabetes after years of being told I was pre-diabetic. It wasn't a surprise, given my family history, but it still felt daunting to move from 'watchful waiting' to actually having diabetes."

"During the COVID-19 lockdown, I couldn't keep up my usual routines. The change in diet and less exercise really pushed my blood sugar higher, and that's when medication became necessary."

"Managing medication started with metformin. The dosage kept increasing, and eventually, I needed a second medication to help clear sugar through my kidneys. So far, I've avoided insulin injections."

"Most of my appointments focused on physical checks and blood tests. I didn't get much advice about food or exercise that actually fit with my needs, so I had to look for support elsewhere."



"Because I'm autistic and sensitive to needles, I just couldn't do finger-prick blood sugar tests. That meant I was missing out on immediate feedback, and it was hard to learn how different foods affected me."

"Getting a continuous glucose monitor from a local charity was a game changer. Finally, I could see how my blood sugar changed in real time. It helped me understand my body so much better."

"Unfortunately, CGMs are expensive and not covered for someone like me by the NHS. I have to pay out of pocket, and no one at my clinic even mentioned it as an option."

"Sometimes, having all this data from the monitor makes me anxious or self-critical. It helps to have a healthcare provider who understands neurodiversity and can help me use the information in a positive way."

Person living with type 2 diabetes– Middle Age

"Being diagnosed with diabetes was a major life change for me. It was the wake-up call that made me try to lose weight and manage my blood sugar, but it was harder than I expected because of the emotional and psychological challenges."

"My weight has always gone up and down. At one point, I was about 24–25 stone, then managed to lose around 4.5 stone after doing the NHS shakes programme. My HbA1c dropped, which was a big relief."

"I tend to have an 'all or nothing' attitude with food. If I have a chocolate bar, I'll eat the whole thing, or I won't touch it at all. I think this might be linked to neurodiversity."



“Food has always been my way of coping, even if I didn’t realise it at the time. There’s some old trauma there that I never really dealt with, and that’s made it hard to keep a healthy lifestyle.”

“For six years, I hardly went out at all because my mental health was so bad. I was scared, and that led to putting on more weight and feeling even worse physically.”

“I tried EMDR therapy for my trauma, and it helped for a bit, but I still ended up gaining weight again. It just shows how complicated mental health and diabetes are together.”

“My doctors keep an eye on my cholesterol and HbA1c with blood tests. At first, I was only pre-diabetic, but it got worse and now I’m on medication and have had to change my treatment a few times.”

“Sometimes I notice my feet or hands feel cold and numb, and that’s a worry because I know it can be a sign of diabetes complications.”

“I’m trying to exercise more and eat better, but it’s still a struggle. My partner and my healthcare team have been a massive support, and I couldn’t do it without them.”

“Managing my diabetes isn’t just about medicine or diet – it’s about tackling the mental and emotional side as well. Both are just as important.”

Person living with type 2 diabetes – Size Matters

“Living with autism and ADHD while managing Type 2 Diabetes isn’t easy, but I am more than my diagnoses.”

“The injectable treatments and the realities of my autoimmune condition are part of my daily life, but I refuse to be defined by them.”



"I stand firm in who I am—a fat, disabled person—and I will always defend my right to exist without being pressured to change my body."

"Hospital visits can be daunting. The anxiety and stigma I feel are often worsened by the attitudes of some healthcare professionals towards people like me."

"What I need is simple: treat me with dignity, explain my care clearly, and show empathy—not blame—especially when it comes to my diabetes and my body size."

"It's no wonder so many fat people avoid seeking medical care—fear of blame and stigma is a reality for us."

"Autistic people are at higher risk of eating disorders, yet our needs often go unseen. We deserve to be heard and respected, whatever our size or diagnosis."

Person who was diagnosed with Gestational Diabetes

"I was shocked when I was diagnosed with gestational diabetes – I'd always been considered low-risk and my first two pregnancies were straightforward."

"It took a while for it to sink in, but after the initial disbelief, I was determined to manage it through diet and exercise."

"Not needing medication felt like a relief, and I was proud to keep my blood sugars stable for the rest of my pregnancy."

"Being far from family support and caring for my daughter, who is autistic and has epilepsy, definitely shaped my decision to plan a home birth."

"The maternity system feels more like a conveyor belt than somewhere I could get care that fits my family's needs."

"I wish there was more understanding and support for neurodivergent families going through medical experiences like mine."



Workshop 1

“I’ve had Type 1 diabetes for years, but I still don’t feel confident in the kitchen. Cooking healthy meals feels overwhelming, especially when I’m trying to avoid foods that could spike my blood sugar.”

“Sometimes I pick foods just because the packaging looks nice or says ‘healthy’, but I don’t always check how much sugar is in them. It’s easy to get caught out.”

“Sticking to a regular meal routine helps me manage my stress. I use the same simple recipes all the time—otherwise I find it too much.”

“I often forget to take my medication, and sometimes I worry I’ve taken it twice. It’s a daily struggle and I wish there was more support tailored to how my mind works.”

“I really struggle with certain food textures and smells, which makes cooking difficult. Even pricking my finger for glucose tests feels uncomfortable.”

“When I’m stressed, I can eat a whole packet of biscuits without thinking. I’m trying to find healthier alternatives, but it’s not easy.”

“Getting advice from the NHS helps me trust the information. I need guidance that suits my specific needs, not just general advice.”

“With ADHD, planning meals and remembering to follow recipes is tough. Visual reminders and checklists really help me keep on track.”



Workshop 2

"Sometimes, it's really hard to find clear answers about diabetes. Even with trusted sites like the NHS"

"Seeing glucose compared to fuel for a fire made things click for me. It's like coal is a quick boost, but wet wood burns slow and steady. I realise now it's better to eat foods that give me energy for longer, not just something that spikes and crashes."

"I didn't know that if my body can't get enough sugar, it starts burning fat and makes something called ketones. It's a bit scary because too many ketones sound dangerous, especially if you have diabetes and not enough insulin."

"I've found that eating more protein helps me feel fuller for longer and keeps my energy steady. It's also made controlling my blood sugar a bit easier."

"White flour is tricky for me. If I have too much, my blood sugar shoots up. I try switching to oat or almond flour, which doesn't make me spike as much."

"I love fruit, but I've learned to watch my portions. Whole fruit is better than juice, and if I stick to small amounts, it helps me keep my blood sugar in check."

"If I eat a doughnut, I know my blood sugar will spike quickly. It's not just about the sugar, but also the type of flour. I try to save things like that for special occasions and pick healthier snacks most of the time."



Workshop 3

“Watching the film helped me understand diabetes much better. Before, I didn’t know much at all.”

“Having someone here who knows about diabetes made me feel safe asking questions.”

“I liked that the storytelling made it easy for everyone to join in.”

“It would be good to have more workshops like this, and at different times so more people can come.”

“Can we have information about getting our eyes checked in the next film? That’s important too.”

“This way of learning could work for other health topics, not just diabetes.”