DIABETES
All Party Parliamentary Group

Meeting

Type 1 Diabetes Research
Thursday, 28th March 2019
Committee Room 6, Houses of Parliament
1:45 – 3:30pm

About 8% of adults and 90% of children with diabetes have Type 1. More than 3,000 children are diagnosed with diabetes every year. It has nothing to do with diet or lifestyle, and everyone with Type 1 diabetes will need to cope with taking on the work of a pancreas themselves, measuring their blood glucose and administering the needed insulin every day. It can be exhausting.

But despite the significant risks of the condition, 57% of people with Type 1 diabetes still don't get their eight basic health checks every year, leading to fewer than one in five people with Type 1 meeting their recommended treatment targets. Not surprisingly, compared to people without diabetes, people with Type 1 diabetes are around four times more likely to have a heart attack or a stroke.

What hopes can research bring for people with or at risk of Type 1 diabetes? How can innovation and technology improve the way Type 1 diabetes is managed and prevent devastating and costly complications?

While there isn't a cure for Type 1 diabetes right now, scientists are developing and testing treatments to potentially stop people at risk from ever developing the condition and even slow the attack in those recently diagnosed. **Could one day these treatments be available?**

For the half a million people already with Type 1 diabetes in the UK, hope can come from access to a closed-loop delivery system, an 'artificial pancreas' that can remove most of the struggle of managing diabetes. But with uptake of technology being historically slow and patchy, **how can we ensure life-changing technology gets to the hands of those that need it the most?**

The meeting was chaired by **The Rt Hon Keith Vaz MP**, Chair of the APPG for Diabetes.

Anna Morris, Assistant Director of Research Strategy and Partnerships at Diabetes UK

Right now, over 300,000 people are living with Type 1 diabetes in the UK – enough to fill Wembley stadium several times over.

Over 300,000 people take insulin every day to stay alive, and will do so for the rest of their lives. Because the cells in their pancreas responsible for producing insulin have been destroyed by their very own immune system.

And insulin has been the treatment for controlling blood glucose levels in people with Type 1 diabetes for nearly a century. But the ways in which people monitor their blood glucose levels and take their insulin have changed dramatically over the past decades, thanks to research giving rise to new technologies like flash monitoring and insulin pumps. Research is also helping people to live longer, healthier lives, as we learn more about how to reduce their risk of complications.

But despite these significant advances, less than one in five people with Type 1 diabetes is currently able to keep their blood glucose levels below the line that we know would reduce their risk of complications. And today, in 2019, almost half of people with Type 1 diabetes have some form of retinopathy.

Clearly, our work is not done. And scientists are looking for other options beyond our century-old treatment, insulin. We understand more than ever about what causes Type 1 diabetes, and we now know that the immune attack underpinning Type 1 diabetes develops many years before someone is diagnosed.

Today we will hear about how Professor John Todd and a global research team are taking advantage of this fact, screening babies to find those at high risk of Type 1 diabetes and test potential ways to intervene early enough to prevent a diagnosis.

Scientists are also searching for ways to stop the immune attack in people who already have Type 1 diabetes, rather than those at risk. In 2014, Diabetes UK joined forces with JDRF to fund the Type 1 immunotherapy consortium: a network of scientists and clinical research sites across the UK working together to drive this critical research forward.

And while our ambitions are to prevent and cure Type 1 diabetes in the future, we recognise the importance of research to help people with Type 1 diabetes live well with their condition now.

And the technology field continues to move forward with the development of an artificial pancreas. With this in mind, Dr Sufyan Hussain will tell us about how the technology field is bringing us closer to the artificial pancreas. These devices will link a glucose sensors to a pump to automatically administer the right amount of insulin at the right time, brings hopes to many. However, as we will learn from him there are big gaps in implementation and therefore issues in delivering even more basic technologies to those who can benefit. There is an urgent need to focus on improving these if we are to improve outcomes for those with type 1 diabetes and benefit from new technologies like the artificial pancreas.

I have only scratched the surface of what research has and will achieve for people with or at risk of Type 1 diabetes, and I hope I have convinced you that research holds a great deal of promise for our future. But we know that greater investment is the key to getting there.

For every £1 currently spent on diabetes care in the UK, only half a penny is spent on research. A greater investment would allow us to realise the impact we so desperately want much more quickly, improving the care and support people with Type 1 diabetes receive now, and leading us to ways to prevent and cure Type 1 diabetes in the future.

We at Diabetes UK hope that by working together, as scientists, research funders, policy makers and advocates, we can reach a world where diabetes can do no harm.

Dr Sufyan Hussain, Consultant Diabetes Physician at Guy’s and St Thomas Hospital

Thank you very much for the privilege of inviting me to speak here.

Type 1 diabetes became a reality in my life when I was diagnosed at the age of 10. Life was very different and challenging growing up in a 3rd world country in the early 90’s with type 1 diabetes as I experienced. After 9 years on multiple daily injections, I was fortunate to have received help from a charity at Cambridge where I was studying to help self-fund an insulin pump in 1999.

It was life changing.

Armed with these experiences, I want to make diabetes technology accessible to everyone who needs it.

Higher incidence of complications in type 1 diabetes – investment to prevent expensive and life changing complications needed

But firstly, I want to discuss our national outcomes and highlight why we need to invest in better care for type 1 diabetes. Compared to type 2 diabetes, type 1 diabetes has different causes, different natural history, its more intensive requiring multiple daily doses of insulin and blood sugar checks right from the start. It's a condition that can affect any age, however it often starts at a younger age than type 2 diabetes. This means a higher lifetime burden of an intensive form of diabetes. Hence, you would expect more complications. As you see on page 1 of your handout, that's unfortunately exactly the case; whilst it only 8% of diabetes, it accounts for a higher degree higher degree of life changing cardiovascular, kidney and eye complications. And the same can be said for its impact on mental health. And just to remind ourselves most of our diabetes budget (60% across all forms) is spent on treating expensive complications, treatments costing 10's of 1000s of pounds, rather than managing the condition well.

National outcomes for Type 1 diabetes – Outcomes poorer for Type 1 diabetes versus Type 2 diabetes: urgent need to improve type 1 diabetes care nationally

So you would have thought that if this is the case, we should be trying to manage type 1 diabetes even better than type 2 diabetes to prevent the complications and high cost associated. Is this the case? On page 2 of your handout you will see that in fact outcomes for type 1 diabetes in adults are poorer than type 2 diabetes. 70% of people – 7 out of 10 - with type 1 diabetes fail to achieve the very conservative target of an HbA1c of 7.5% - HbA1c being a marker of glucose levels over a 3 month period. We are not discussing newer standards but just conservative HbA1c of 7.5%. Not great unfortunately and there is more. As you can see in page 2 of handout younger people and those with type 1 diabetes achieve less of the three key treatment targets for diabetes which are blood pressure, cholesterol and glucose control. This is the group we want to focus on. Surely it's a sign that we are investing in the wrong ways of delivering care. There's more data that I don't have time to discuss, including the huge variation in type 1 services throughout the country. But I hope that with what I have told you we can agree that we need stronger investment in preventing complications rather than treating expensive complications in Type 1 diabetes.

Can technologies help improve type 1 diabetes care and outcomes? So can technologies help us deliver better type 1 diabetes care? Absolutely YES. We have no shortage of RCT, real world data and experiences from leading centres such as where I work with some of the best national outcomes for type 1 diabetes - technology does improve lives for type 1 diabetes. What are these diabetes technologies? So what are these diabetes technologies? There is a whole range of them. However the ones I would like to focus on are pumps, glucose sensors and the artificial pancreases. Pumps are small programmable devices such as this (showing my pump) - which are worn by the user and deliver insulin under the skin in an accurate and flexible manner. Like this example (showing my sensor), which I am self-funding, glucose sensors or real time continuous glucose monitoring are devices that provide continuous information of glucose including trends or direction of change that help immensely in planning life and managing diabetes. This is different from flash because you get continuous real time glucose readings as well as alarms and alerts when sugars are high or low. Very helpful in making diabetes safer and most who use this describe it as having a blindfold lifted - You can see where things are going and plan life safely. Over the recent years we have seen great progress in the capabilities of pumps and sensors - simplicity of use, and better connectivity between pumps, glucose sensors and even smartphones and watches. As a result of this we are in the era of the artificial pancreas. Pumps and sensors connected to and controlled by an algorithm that may reside on a smartphone; like this one (show example on phone). It delivers insulin in an automated fashion; - knows my sugar and adjust insulin as needed to spend more time in this green range and less time high or low; with manual input for meals or activity.

Such systems have been in use in an academic setting for some time. But we really owe it to a group of people with type 1 diabetes known as the DIY or do it yourself diabetes community in leading the way in using it in every day normal settings by providing hacks, codes and algorithms to make this work. They have showed us health care professional what we have been wanting and how to do it. With commercial, medically approved systems on the horizon, the DIY community has given us a clear vision type 1 diabetes care needs to be like in the future – automated systems that deliver better glucose control, less complications, less hypos, less burden for the person with diabetes and even less need for health care professional - patient interaction once you are up and running….the dream!

UK Uptake of technology – low compared to Europe, huge variation and socioeconomic disparity

So we have all this exciting tech, but where are we with this in the UK? On page 3 of your handout you will see the uptake of insulin pumps in comparison to other European countries. Doesn't look great unfortunately. And even within England and Wales there is a high degree of variation on uptake of pumps as shown in 3. Something I experienced whilst training in London. One centre might be have a thriving pump service but few miles away the story is completely different with no clear mechanism for CCG funding. And what's more concerning is the socioeconomic disparity as highlighted in lower part of page 3. You are less likely to be on a pump if you come from a socially deprived background – numeracy skills, level of education, language, ethnicity unfortunately all play a part in the ability to access pumps. The story for glucose sensor is even more concerning with a greater level of variation and even less uptake nationally.

Reasons

So why is this? Multiple reasons contributing to this wide gap in implementation.

- Firstly technology requires money.
- Our policies governing criteria for funding as set by NICE (The National Institute for Health and Care Excellence) are very binary and restrictive.
- Even with this restrictive criteria there are variations in culture of commissioning especially in regions where there isn't a clear understanding of why an expensive technology may need to be funded for type 1 diabetes when type 2 diabetes can be managed without this expense.
- On top of this, we have a very complex reimbursement process that means heavy administrative work for health care professional making it harder to access funding and more hoops for people with diabetes to jump through.
- There are other big challenges such as availability of diabetes nurses and dieticians who are trained in technology and have time in their jobs to do this. 1 in 4 to 5 pump services are having to hold of pump starts as waiting lists are over a year.

Need for improvements in access to technology - What is being done?

There has been recent progress from NHSE on some aspects of commissioning flash and sensors in pregnancy; however how its impact on local commissioning and implementation waits to be seen.

Separately to the NHS we have seen the formation of a multi-disciplinary professional diabetes technology network to help educate, train and champion diabetes technology.

What can be done and how can parliament help?

However a lot more needs to be done.

It is really down to funding and investment– to provide resources to widen the criteria for pumps and glucose sensors and more resource for health care professional training

So with this in mind what can parliament do?

1. Help address poor outcomes for type 1 and investment gap in preventing complications in this group especially with technology.
   I would encourage members of parliament to ask commissioners from their own constituencies regarding type 1 and type 2 diabetes outcomes, spend on complications and spend on technology to see the imbalances. I obviously have my own firm beliefs in what needs to happen. But I am sure by going through this process you will understand the steps needed too. Type 1 diabetes care is fundamentally different from type 2 diabetes.

2. Influence stakeholders including NHSE for different commissioning approach and service delivery for type 1 diabetes
   Treatment and management of type 1 and type 2 is not the same. So shouldn't we be commissioning and designing services differently? We need your help to raise this matter as a parliamentary discussion
3. Improve access to technologies and reduce the implementation gap
   It's clear that we really need to take advantage of what technology can offer. I feel this can only happen if Parliament can help us to lobby for stronger national standards for type 1 care based on metrics that matter to people and include QoL, include hypoglycaemia frequency, time in range and updating our outdated and very restrictive NICE (The National Institute for Health and Care Excellence) criteria.

On that note I would really like to thank you for your time. I am sure you will agree that we need to invest more in preventing complications for type 1 diabetes and that diabetes technology is here to help us.

Sophie Lane, Patient voice

Good afternoon everyone - my name is Sophie, and I'm thrilled to be here today as a patient voice, to share some insight into living with Type 1 Diabetes, and the significance & potential that research and technological developments toward type 1 can have for people like myself.

I was diagnosed with Type 1 Diabetes when I was 12 years old. By this point, I was very slim, I drank a LOT of water, and had quite accurately been donned the nickname 'slack bladder' by my nearest and dearest. As is often the case, my family and I really had no idea of the relevance of these symptoms, and had brushed them off as nothing too serious. I got off lightly in many respects – I didn't feel unwell in myself, and was fortunately diagnosed before coming anywhere near a state of diabetic ketoacidosis – a complication which commonly occurs with type 1 diagnosis, and can be life threatening.

As I move into my 15th year of living with diabetes, I'm extremely positive about life with Type 1, and am a firm believer that diabetes shouldn't stop you from anything. I've achieved & enjoyed a heck of a lot over the past 15 years – I've travelled the world, I've worked and lived abroad in both America & Switzerland, and experienced so many fun things I would have never of expected of myself – learning to snowboard, running a half marathon, completing a couple of triathlons, and stupidly bungee jumping off a bridge in Whistler, to name a few. I studied at my dream University and had the time of my life, I secured & completed my dream graduate scheme, and am proud to have achieved a first-class Master's in Chemistry, a chartership in accountancy, and to now work in an industry I absolutely love.

So yes – it's safe to say that for me, Type 1 has never held me back – but that doesn't mean it's been easy. Type 1 Diabetes is hard – it's 24 hours a day, its unpredictable, its uncomfortable, unforgiving, frustrating, illogical, it sometimes exhausting and sometimes embarrassing. It's carb counting everything you eat, its adjusting insulin-to-carb ratios for what feels like the 100th time, it's trying to predict how on earth your hormones, emotions and activity levels will affect your blood sugars today – and trying to guess why it's completely different to yesterday. For me, it's up to 30 blood tests a day, 30 decisions to make, sometimes 30 mistakes and sometimes what feels like a constant battle of highs and lows, both physically and emotionally.

This is the reality of Type 1 – it's a lot. I think many people often see Type 1 as a few blood tests and a few injections a day - easy peasy – and I actually think that's a credit to all the people living with Type 1 who make it look that way on the surface, and just 'get on' with it. But below this, it's actually a really complicated condition, it can be really quite difficult to manage, and can also have a string of associated complications to consider.

Something that's made managing Type 1 Diabetes a lot easier for me – and truly speaking, has been life changing, is diabetes technology. I've worn a Freestyle Libre flash glucose monitor for over 3 years, and would now struggle to go without it. For those who aren't familiar, this is a small white disc that I wear on my arm {as you can see here}, which allows me to check my sugars in seconds simply by holding my phone to the sensor and scanning it. It also shows me a graph of blood glucose data over the past 24 hours – so if I want to know what my sugars were doing overnight, or in between scans, I can. Combined with some hard work, the Libre has helped me achieve the healthiest A1C I've had in 10 years, and given me confidence over my control of this condition for the first time in my life.

Another really encouraging and exciting area within T1 technology is the development of the artificial pancreas, or 'closed loop' insulin delivery system. Using a compatible insulin pump, a CGM and a few other pieces of kit, this system is able to predict future blood glucose levels, and automatically determine and dose the correct insulin requirements for a patient. With DIY platforms such as Tidepool Loop currently working to deliver an FDA-regulated solution, and recent studies publishing results to show an increase of over 10% for the amount of time spent in target glucose range under closed-loop therapy vs traditional pump therapy, this technology has some real promise.

As great as all this is, there's one problem – access. The Freestyle Libre currently costs me £1,300 a year to fund, and if I were to upgrade to a Dexcom continuous glucose monitor, this would move to nearly £2,000 a year. Despite the Libre technically being available on the NHS from November 2017, due to significant variances in funding criteria across UK Clinical Commissioning Groups, it was estimated a year on in November 18 that only 3% of the T1 population were able to access it. Thankfully, from April 2019 onwards, criteria for funding will become consistent across all CCG's, meaning that access to this technology will no longer be a 'postcode lottery'. However, with access still being criteria dependant, its predicted that this 3% will rise to only 20%. When discussing this with my consultant back in January, I was told 'not to hold my breathe'.

The worst problem I've faced around access and Type 1 is to insulin pump therapy. I've been on a waiting list for an insulin pump for nearly 2 years now, and with problems such as nocturnal hypos, the inability to exercise in the evenings due to severe hypoglycaemia, and future family planning considerations, I've now had numerous consultants state 'how motivated I am, and that I'd be an ideal candidate for pump therapy' – yet just last Friday, I was told once again that I have been refused.

Pushing for pump therapy can be hard work. It has involved me driving a change of hospital team, months of emails and phone calls with nurses, and perseverance with various suggested injection regimes that don't work for me and my lifestyle, and have led to exhausting, prolonged high blood sugars. I think the message I've found the hardest to swallow throughout this process was in an email from my healthcare team I received a few weeks back, stating that 'I don't meet the criteria for poor control' – in other words, you're control isn't great – but despite your efforts and willingness to work on this – it's not bad enough for us to offer you pump therapy. I find it devastating that if I were to turn up to clinic tomorrow morning and say I wanted to start planning for a family, no healthcare professional would recommend that I do so – my control is considered suboptimal - my Hba1c is too high, as would be the risk of complications to my baby – yet when I recognise this, and proactively start trying to gain access to pump therapy, to try tackle the problem sooner rather than later, I'm met with denial.

My hopes for the future with Type 1 is that access to technology becomes less of a battle, and available on an equal basis to those who will benefit from it. The research and development going into Type 1 at the moment is absolutely incredible, and gives me real hope for the living with this condition in the future – but frankly, what's the point in developing artificial pancreas' and closed-loop systems if those who need them can't access them? I would love to see the day where Type 1 care becomes preventative instead of reactive - where patients are given access to the best support & technological tools available from day one, so that we feel equipped and empowered to manage our condition the best we can, so that everyone can thrive with this condition, and ultimately reduce the risk of long term complications – which are not only costly to the healthcare provider – but also to our quality of life.

Dr John Todd, Professor of Precision Medicine at the University of Oxford

Dr Todd started by thanking audience members and the dedicated funders who have funded his research. He explained how his research works by screening newborns to find out those with a genetic risk of developing Type

1 diabetes, and then conducting a randomized trial to treat those babies in the hopes of preventing Type 1 diabetes.

Dr Todd explained that one way to avoid the immune attack that causes Type 1 diabetes is to train the immune system not to attack insulin producing cells – to make it blind or tolerant to insulin. “We are feeding children with oral insulin every day, for three years”, he says, “then we follow up at age 6, making it a seven-year trial. I have never seen such a complex trial become a reality so rapidly”. The study provides a path to primary prevention of beta-cell autoimmunity on a population based level. There is currently no other study in the world providing this.

Dr Todd explains how they had to screen over 300 thousand newborns, and how the families contacted have reacted overwhelmingly positively to the trial. “People really want to prevent it. I am determined to make an impact on Type 1 diabetes”. At the moment, the study is only active in four maternity hospitals in the Thames Valley, but Prof Todd expressed a strong desire to expand geographically.

Dr Todd also explains how his trial works whilst debunking the myth that once a child is diagnosed with Type 1 diabetes, they have already lost all their insulin-producing cells. “That is not true”, he says. At the time of diagnosis, there are still a percentage of cells left, which are enough to minimise the gravity of complications.

When asked if Brexit has impacted his European-wide research, Dr Todd confirmed it was a challenge.

Discussion

Sandy Martin MP mentioned how one of the first things he got involved in Parliament was trying to champion a young person living with Type 1 diabetes, and the issues she was having at school and with accessing pump. “We need to be stronger on challenging the reframe idea that everything that what needs to be done is being done”, he said. **Sandy Martin MP** asked **Dr Hussain** if anyone would *not* benefit from accessing technology; **Dr Hussain** replied ‘no’.

George Howarth MP mentioned how he led three debates in Parliament on technology on the past years. “It is quite clear that technology has a massive role to play and we need to get to the bottom of the commissioning system.”

Sarah Gatward, who has Type 1 diabetes, raised the issue of how ‘need’ is defined and how it does not account for the mental health and emotional wellbeing benefits of technology. In response, **Sophie Lane** agreed and highlighted how she would have qualified for an insulin pump when she was younger, and not engaged with her diabetes, but does not qualify now that she is working hard to be healthier. “It is backwards and puts me in the position to consider making myself sicker, or lying to my healthcare professionals”. **Ana Morris** mentioned Diabetes UK, through a clinical group, identified the need to research the impact of technology on mental wellbeing and to capture mental wellbeing in trials, alongside biological measures. “That’s something we’re thinking about how to move forward”.

Members of the audience with Type 1 diabetes mentioned their own challenges with access to technology. **Keith** said he does not qualify to the Flash Glucose Monitoring criteria. “My fingers are getting sore, I am getting older. At some point, I will not be able to do it for long”. **Trudi Evans**, who is also attempting to qualify, spoke of the irony that one of the criteria for access is to ‘prick your finger more than eight times a day’, but she cannot get eight strips out of her doctor. “People do not appreciate how life changing technology is for diabetics”. **Paul Leadbeater** highlighted the relentlessness of Type 1 diabetes. “Technology should be for everyone, not for NICE criteria”. **Conrad Jarrett** mentioned his issue with losing the ability to recognise hypos, and how he has already lost his license but still has not been able to access a CGM. “The system is not geared up to support patients.”

In response, **Dr Hussain** mentioned what healthcare professionals tell CCG Commissioners is the greatest benefit of diabetes technology: making diabetes safer and easier. Unfortunately, he highlights that this is not reflected in the criteria. “It is really shifting our focus thinking about how we can empower the person with diabetes to do better”, he said, “I believe technology can sincerely improve mental wellbeing”.

Both **Dr Hussain**, **Conrad Jarrett** and **Sandy Martin MP** mentioned the need for a centralised mechanism to fund diabetes technology as a potential solution to this issue. But Dr Hussain highlights the importance of also considering the criteria for access. “Two out of ten people with Type 1 will be covered by the Flash Glucose Monitoring criteria. That means 80% will not be covered.”

Peter Davies and **Anthony Fisher** mentioned the importance of engaging the wider Type 1 diabetes community and informing and educating people on technology since young. **Julia Tyson** highlighted the need to look at other measures of diabetes than Hb1ac.

Members of JDRF inquired about a greater focus and investment on developing cross-condition research on auto-immune diseases. In response, **Anna Morris** thanked the colleagues and welcomed the initiative, highlighting the importance of charities coming together.

Dan Evans, from Abbott, clarified some concerns over the availability of Flash Glucose Monitoring. “We had supply issues in January and February, but we should be fine now”, he said, “Existing users can order it at our shop. New users cannot get it at the moment. We are investing significantly in manufacturing capacity and we hope this will change shortly.”

Keith Vaz MP closes the meeting. “Our next meeting will be on May 16 on ‘Children with Type 2 diabetes’. All points raised at this meeting will be consolidated in a report and sent to all MPs.”