APPG: From Lab to Life - Minutes

17:00-17:05 –**Derek Thomas MP, Chair of the APPG**, Opening remarks

We're celebrating 100 years since the discovery of insulin – and this has saved enormous numbers of lives.

We've found lots of different ways to support people to manage their condition, but we've not yet found a cure and people are still relied upon to manage themselves. The pandemic has been a nightmare for people with LTCs without access to support that they've been used to. MPs have been trying to think about how to return to normal with all the pressures on the system. The NHS is so successful and in demand and we need to find a way for people to get the care they need.

17:05-17:15 – **Anna Morris, Assistant Director of Research Strategy and Partnerships, Diabetes UK**

We've come a long way with diabetes but still a long way to go.

It all started in 1921 where insulin was discovered by Banting and Best. Until insulin was available, type 1 diabetes was seen as a death sentence – sometimes months but often weeks or days. It was a huge breakthrough.

In 1922, insulin was given to the first person – Leonard Thompson. There have been many breakthroughs, and I'll take you through some of those.

1934 – Diabetes UK was set up and founded

1977 – A huge medical trial was set up, which lasted 20 years, seeing if people with type 2 diabetes would experience fewer complications if their blood sugars was in a target range.

1977 – Diabetes UK bought the first artificial pancreas to the UK to support people to stabilise their blood sugars. We now know that there are artificial pancreases in development that can fit in your pocket.

1983 – The first insulin pen was developed by Dr Shiela Reith in Glasgow. It revolutionised the way that insulin was delivered. Before it was with a syringe and was painful and difficult to deliver. The first prototype was developed and a trial, funded by DUK, was developed and was put on the market in 1983.

1986 – Diabetes UK funded a trial of retinal screening to identify early damage to eyes due to diabetes. In 2010, a DUK study found that retinopathy is now no longer the leading cause of sight loss among working age people.

2017 – DiRECT: Diabetes UK funded a study, its largest ever, which showed that for some people with type 2 diabetes it is possible to put their diabetes in remission through a low-calorie diet. Of those who received the intervention, nearly a half of people put their diabetes in remission after a year – leading to an NHS England pilot. This gives millions the hope of a future free of type 2 diabetes.

What's next? Insulin was a life-changing breakthrough, but now we need new and improved approaches for people – and we're hoping for a cure. Thanks to research funded by us, JDRF and others. We know in type 1 diabetes, insulin-producing beta cells are attacked by the immune system. Transplants and donors are available for few people, but it has its challenges. So scientists are trying to make an unlimited supply of beta cells using stem cells. This month there has been news from Harvard and a company who are running a clinical trial – the data from the first participant showed very positive results, with reduced insulin requirements and improved blood glucose levels. This gives us hope for the future.

We also can think about how to find a way to manage the immune attack in order to develop a cure. Immunotherapies are being developed which show that the immune attack is delayed and lengthened – and in 2022 we hope the first immunotherapy will be licenced.

Technology also improves how we manage diabetes and our hope for the future is that a fully automated artificial pancreas can be available for anyone who could benefit from it. Recent NICE guidelines that provide more technology is hugely welcome, but they're not mandatory. I'd like to highlight the Diabetes is Serious campaign which calls on the government to provide ring-fenced funding for diabetes tech.

17:15-17:30 – **Rachel Connor, Director of Research Partnerships, JDRF**

Whether we develop type 1 diabetes or not, we have the right number of beta cells that we need to live effectively. At some point in some people's lifetime, an immune reaction can start to attack the beta cells that produce insulin. Over time, the number of cells decline. But, as you can see, at diagnosis, over 50% of beta cells are lost before we think that a person might have diabetes. We believe that this is actually at the point where there are roughly a third of cells left. These cells continue to decline once insulin is externally given, but it never really hits zero. We believe people who live with type 1 diabetes for decades still have some beta cells.

There are lots of different stages to diabetes – but the point of diagnosis of type 1 diabetes is actually stage 3 of developing type 1 diabetes. There are stages where you have diabetes but just don't know it yet, so finding that time can promote better treatment.

Challenges – finding people who will benefit it hard, and we need to collect good evidence. We also don't know whether this treatment will be a one-off course or something much longer.

We also know that managing type 1 diabetes with insulin is overwhelming. It can also be very overwhelming being diagnosed and that there might be another therapy that you need to rapidly deliver. We also need to think about the cost/benefit timescales. Immunotherapy is expensive, but can have a lifetime of impact – but measuring this impact is very difficult to do.

There's a relatively small pool of people with type 1, so is there the market for it? We also know that type 1 diabetes can come on at any point of life, and so we might need a range of therapy option. 50% of people diagnosed with type 1 diabetes are children, and conducting clinical trials on children is something we need to do very carefully – but the impact means we can make a huge impact.

Overcoming challenges:

Genetic testing and monitoring is possible, and this could be a key way to pick up people who'd benefit from immunotherapy.

Insulin is not a cure, and we need to do something else to make living with type 1 diabetes easier.

Connect Immune Research is a coalition of organisations that focus on overcoming market challenges for autoimmune conditions and immunotherapy. It's possible the biological processes among these conditions are similar, even if they focus on different tissues – so by working together we can develop new therapies more quickly, generate more interest in developing therapies from commercial players and lower costs.

We conducted some research at JDRF which looks at the barriers to accessing tech for type 1 diabetes. This research showed that your level of education and access to information, your socio-economic situation and your attitudes to tech can be substantial barriers.

We recommend that healthcare professionals should have the knowledge of tech on their fingertips, and that people should be meeting with specialist healthcare professionals. We also think CCGs should do more to reach people with type 1 diabetes from lower socio-economic groups.

We want to make sure the NICE guidance makes its way to every member of our community, irrespective of where you live or your situation.

17:30-17:40 – **Grant Price, living with type 1 diabetes**

I've had type 1 diabetes for 37 years. I'm currently on pump therapy and use a sensor. The key thing for me is when I was told I had diabetes, I didn't know how much it would impact on my lifestyle. My condition is under good control and I have no other health conditions – I am able to regularly exercise.

I was diagnosed in 1984 having come back from travelling. I had all the classic signs of type 1 diabetes, but I looked healthy as I was very tanned. Eventually, when I returned to the UK, my mum could tell I wasn't well, and a doctor immediately diagnosed me. I went to hospital overnight and in my stay there I gained 7 kilos overnight due to how dehydrated I was.

It's had an impact on my life – I don't drink as my symptoms of having a hypo are very similar to being drunk. When my sugars run high I get very hot and dehydrated, which is an issue when I'm playing sports and can be dangerous.

The difference that both pump therapy and sensor technology have had on my ability to work and live a fuller life is significant. They have enabled me to be more active with less stress and worry about how my sugar levels are fluctuating and the damage they may be doing to my body and the consequences for my long-term health. Without access to these 2 great technologies my lifestyle would be very different, as would be the outlook for my mental and long-term physical health – not to mention the reduction in the burden I might otherwise place on the NHS going forward.

17:45-17:50 – **Professor Partha Kar, National Specialty Advisor for Diabetes with NHS England**

Diabetes is a chronic disease, and it is not just managing one thing, it is managing a multitude of things. 0.02 to 0.01% of patients time is with a healthcare professional, which is based on a generous estimate.

There are 3 planks of any long-term conditions management: self-management, peer support and access to trained professionals. There is a shortage of access to trained professionals across the globe, so you must rely on the other two planks to an extent.

We made a promise to get flash glucose monitor prescribing to 20% and have exceeded this expectation and it is now at 50%. A lot of kudos given to colleagues, CCGs and people with diabetes, driving this forward.

We are now in the middle of real world evaluations, so far several hundred patients have been recruited across the country to take part in the artificial pancreas trials on the NHS. The data will be collected and submitted to NICE in March, and we then expect them to make a decision on the artificial pancreas.

Excitingly, last week the NICE draft guidelines landed, we are now able to say flash and CGMs should be offered to everyone with type 1 diabetes. We are now in the consultation period, but it should hopefully go through smoothly. Once CGMs are opened up for people with type 1 diabetes, alongside our current data streams, it should open the door for artificial pancreas.

Future areas:

Pump uptake is an issue, there is lots of variation and information, how does a patient with type 1 know what they are eligible for and what pumps are available. We need to encourage more peer support to increase uptake and information. A lot of patient groups ask about interoperability, and this is an area we are working on in the NHS.

17:50-18:25 – **Q&A**

How does the NHS manage contracts with MedTech companies, to ensure they are in the interest of the patient?

Partha Kar: Competition is a good thing, and one of the issues at the moment is that there is little competition, for example Abbott are the only manufacturers of Flash glucose monitors – if someone else made it, he would bring them through to.

We are trying to improve competition with the NICE guidelines. Allowing us to look at alternatives if they are not offering what is in the best interest of patients.

How can I get the education out to people like me, who are patients that want to make a difference?

Partha Kar: There is now a free online education portal for people with diabetes and its usage is being tracked as the NHS wants to see who is accessing these education programs, because areas where there is low technology uptake, people say they are not trained – so we are providing free education modules for this.

We are finishing off work on peer support groups and will invite everyone to contribute to it as we want every area, every diabetes centre, to have access to peer support groups where they are.

Is it possible to explain the NICE consultation, I signed up as a stakeholder so I can comment, I want to spread the word so need to get this right. Can you give more indication on how we can take part?

Partha Kar: Log in, register yourself and please give your views, we want that. A response does not have to be negative; we welcome any input positive, negative and constructive comments.

So NICE guidelines how long do you estimate before we can receive RTCGM on the NHS?

Partha Kar: The consultation closes on the 22nd of December, after this they look at everything they have and should publish in March 2022 and after they publish, depending what happens over the next few months with the virus, I suspect June, July or August.

What is the impact on people with type 1 who are restricting or omitting their insulin to lose weight?

Partha Kay: There is a piece of work we have started on diabulimia. The idea is that there will be a centre in each region of the country dedicated to people with eating disorders. We are waiting for these trials to be done, we are waiting for these trials to be concluded to see the results.

Are the criteria for pumps going to be reviewed?

Partha Kar: NICE are looking at the closed loop system now. The bar set to receive a pump is now set by NICE at 8.5% and people are concerned this is high – when of course people should want to keep it lower. This is the question we are going to ask NICE, should this bar come down with the current work on closed loop systems (artificial pancreas).

Can we not be offered legacy pumps?

Partha Kar: Keep an eye on the procurement work that we are doing next year which is about trying to open the doors. Some of the issues are with company licensing.

Can you see any future reform to training courses such as DAFNE? Making them more virtual and more accessible and not needing a whole day off work may be key to opening them up.

Anna Morris: A current piece of work at Diabetes UK centres around groups which think about gaps and opportunities in research, and one has recognised this question. We have invited experts in the area to speak to our group about further research that may need to be undertaken to improve the opportunities for people with diabetes.

Partha Kar: Nobody says anywhere that you need to do education, or you can't get technology. NICE says you should offer education to people but it is not a requirement. I have never told a patient that if you don't do education, you are not getting the technology.