

Cross-Party Group on Diabetes

Note of meeting held on Wednesday 19 June 2019

Scottish Parliament, Edinburgh

Present: Rupert Pigot, Angela Mitchell, Linda McGlynn, Fraser Gibb, Kirsty McKinnon, David Stewart, Emma Harper, Brian Kennon, Suzie Gallagher, Julie Watson, Sir Michael Hirst, Craig Cameron, Linda Milne, Alison Ballantyne, Shelia Reith, Esther Rue, Caitlyn Rue, Hilary Whitty, Andrew McGuigan, Lucille Whitehead, Sheila Minty, Kerry Douglas, Mary Moody, Toni Liddell, Rachel Williamson, Elspeth Campbell, Liz McKay, Jeff Foot, Izzy Thomson, Bob McQueen, Scott McKinnon, Donald Rentoul, Conn O'Neill, David Stewart MSP

Apologies: Agnes Milne, Bruce Knight, Vicky Alexander, John McKnight, David Coates, May Millward, Keith Walker, Billie Wealleans, Marilyn Bolland, Belinda Hacking, Kenneth Robertson, Isobel Miller, Ian Sloan

1. Welcome and introductions from Rupert Pigot, Diabetes Scotland, who announced the purpose of the meeting: to discuss ways to increase the uptake of Continuous Glucose Monitors (CGM) in Scotland. He introduced the two presenters – Dr Fraser Gibb and Kirsty McKinnon.
2. Presentation by Fraser Gibb, Scottish Diabetes Group Type 1 Chair. He said health outcomes for people with Type 1 diabetes were tied to minute-to-minute management – unlike most other health conditions. He said people with Type 1 needed to be empowered to make these vital decisions well in their day-to-day lives.

He said that only 25 per cent of people in Scotland were achieving their glucose targets, and that although this figure is improving, it does not compare well internationally -- Sweden and the Netherlands perform much better, for example. He explained that CGM is a sensor that gives minute-to-minute information on glucose levels. It also gives you an idea of the direction your levels are heading. CGM gives complete access to information rather than just a snapshot of glucose levels four or five times per day. He said that very few people have access to CGM, and that the target for people to gain access to CGM is not very ambitious. By contrast he said that flash glucose monitoring has no alarm, so there is nothing to wake you up if your glucose is rock bottom.

He said there was a massive disparity in provision of CGM across health boards. In addition, he said that the data shows that if you are more affluent, you are more likely to manage your diabetes better. And there is a greater uptake of technology within this group.

He explained that there were many reasons for this. But a central issue is that self-managing diabetes requires extensive numeracy skills. He said that things can be improved for people with technology, but that at present this might actually be making it worse.

He said that diabetes care was being revolutionised for a small group of people. Expensive technology, combined with a mobile phone app, means that highly motivated individuals can achieve near normal glucose levels.

He said that even better technology was just around the corner -- within a year fully closed loop systems may well be available in Europe. These systems will be more expensive but more accurate. It will be a technical cure for diabetes. Not a complete cure, but a complete step change. He explained it was very different from CGM and flash monitoring. He said that it would be a huge outlay, but it would effectively remove the burden of diabetes.

He said Scotland could be dragged kicking and screaming into the revolution or could become an exemplar. He highlighted the opportunity.

3. Kirsty McKinnon, mother of a Type 1 child.

She said her son was diagnosed with diabetes when he was seven, and that he had no idea about his glucose levels – he couldn't tell the difference if they were very high or very low. She said that he was now twelve. Before he had CGM he had never been to sleepover. He had never been out with friends to the park. He had to give up basketball. He had to have his bedroom door open always. Kirsty said that the change in her son's life now he has CGM is huge. His blood sugar is much more stable – the CGM does its job perfectly.

She said the change in the rest of the family's lives has also been huge, and that they can now sleep knowing that alarms will wake them if their son's glucose levels are not stable.

She said that was the biggest change -- before CGM they had to do two or three hourly checks on her son's glucose levels, sometimes every hour. She said it was like life with a newborn – extreme tiredness makes it hard to function. She added that it was very stressful having to do such vital math even when exhausted.

Kirsty said that since getting CGM her son has become a confident young man. He can go to after school sports and has taken up basketball again. When he attends high school he will be able to go without the constant interventions he needed before he had CGM.

She said that CGM has also meant that she can return to work part-time as she is no longer tired all the time. And they receive far fewer calls from school. She said that where a child has Type 1, the mental health of all family members must be considered. She said that CGM had changed all their lives for the better.

4. Rupert Pigot thanked the presenters and opened up the discussion, asking: What is needed to drive uptake of CGM? How can disparities across Scotland be tackled? And how to approach the significant amount of investment needed?

Fraser Gibb said there was a hugely emotive argument for pediatric provision of CGM. He said these arguments also applied to adults with Type 1. He encouraged patient groups to push for greater provision of CGM, and for

politicians to be receptive. He said that the technology was on the cusp of a sea change and that with new developments the ceiling of uptake would be in the 90 per cent range – far higher than CGM or flash monitoring. He said that this has the potential to cut across the health inequalities that currently exist. He encouraged people to campaign.

Brian Kennon, Chair of the Scottish Diabetes Group, said that no one could be unmoved by stories like that of Kirsty and her family. He said that action was needed at government level and health board level. He said that if a person fit the criteria for CGM, the health board should fund it – provision should be driven by clinical indication. He recognized that this is easier said than done. He said that the iLet technology had the potential to turn diabetes management around. He cautioned that this technology had only been used in short-term trials, and that safety infrastructure needed to be built in. He said that the third sector voice was vital. He said that a strategy was needed to inform decision-makers about this technology and its potential impact.

Kirsty McKinnon spoke about the process of getting CGM. She said she wrote to her MSP and to anybody she could think of that might be able to help. But she was told time and again that the funding was not there. She said she felt that the turning point was when medical professionals witnessed the impact diabetes was having on her son's mental health – he was upset when talking about how he couldn't ever have his bedroom door shut. He started to resent being diabetic and this affected his receptiveness to treatment. She said that the mental health side of things was huge for diabetic children.

Linda Milne, mother of two children with Type 1, said that we can't afford not to have CGM. She read out statistics on NHS costs for the interventions and care needed as the result of poorly managed diabetes, including for -- heart attacks, heart bypass operations, strokes, and amputations. She said that with greater provision of CGM many of these costs could be avoided.

Sir Michael Hirst said he belonged to a generation who wished this sort of technology had been available 30 years ago. He said that no health board or government would introduce new technology without thorough analysis of the cost benefit. He asked whether this had been done. He said that calculations around hospitalisations avoided would be comparatively straight forward, but that the impact of new technology -- as described by Kirsty McKinnon -- was incalculable.

Fraser Gibb said that the technology was advancing very quickly and that there would soon be a huge body of literature to support cost effectiveness. He added that at present people were also self-funding -- those that can afford the technology are investing in it. But that this is increasing health inequality at present.

Jeff Foot, Type 1, said he had CGM and he was awaiting the technology to get a loop. He said that there was a lot of confusion around technology, and asked what patient groups should be lobbying for exactly – CGM? Or iLet? Or what should be the aim?

Brian Kennon said that people need to lobby for what is already available, to ensure that there is a footprint in technology. Lobbying for existing technology, and building the evidence for impact, will help build the case for new technology when this becomes available.

David Stewart MSP, said that there were a number of factors behind the growing problem of health inequality. He said that bringing in targets for CGM had helped, and that central control was needed to ensure this happened. He emphasized that we have a national health service, but that in reality this service was very different for those living in Inverness than for those living in Edinburgh, for example. He said he saw technology as playing a vital role. He said that more needed to be spent on reducing health inequalities.

Conn O'Neill, from Roche, asked whether service models and contracts would be better way to invest in future technology.

Scott McKinnon father of a Type 1 child said that there was a lack of information about carbohydrate values on restaurant menus, which made decision-making hard in this setting.

David Stewart said that the food industry was working on this, to include carbohydrate counts on menus.

Jeff Foot said patient groups were lobbying for new technology and asked what was the best route to push for this?

Brian Kennon said that working together – across research, procurement, third sector and all other stakeholders – was the best route. He asked who should own health data?

Conn O'Neill said that since GDPR no company wanted to hold onto data. He said that new technology should be designed to work with the systems that already exist.

Brian Kennon said that not accessing data real time hampers the ability to drive technology forward.

Donald Rentoul, from Dexcom, said that sharing data was optional when using Dexcom technology. He also said that working with big data was anonymous and powerful. And companies are looking at this as a way to drive technology forward.

Conn O'Neill encouraged the NHS to use its power to leverage change on this issue. He said that when making a purchase decision the NHS had power to stipulate what it wanted.

Mary Moody, Type 1, said the increase in competition and choice for CGM was a good thing and empowered people living with diabetes.

5. Closing remarks:
Rupert Pigot thanked all for attending and announced that the next Cross-Party Group on Diabetes would meet on 17 September 2019.