Scottish Parliament Cross Party Group on Diabetes

Minute of meeting: Tuesday 6th December 2016

Committee Room 5

Present:

Emma Harper MSP
Brian Whittle MSP
Richard Lyle MSP
Mark Cook
Vicky Alexander
Jodie Pollard
Ian Sloan
Fiona Hamill
Bill Paton
Jennifer Gilchrist
Christina Rigby
Allan Goldie
John Bernard
Jeff Foot
Steve Birnie
David Eadie
Hilary Whitty
David Cline
Pauline Linn
Shelia Reith
David Reith
Dave Duff
Alyssa Faulkner
Lucille Whitehead
Trudy McClemont
Alex Forster
Nigel Morgan
Billie Wealleans
Gillian Gunn
Colin McFarlane
Tom McKay
Barabel McKay
Aileen Hillis
Mary Moody
Sheila Minty
Chris Kelly
Iain Smith
Susan Gallagher
Lesley Anne MacRae
Vicki Kitson

Johnny McKnight
Rupert Pigot
Gavin Thomson
Kirsteen Murray
Darren Jordan
Derek Beatty
Mirijam Emsworth
Isobel Millar
Leigh Mair
Susan Fletcher
Margaret Henderson
Mhairi Macdonald

Apologies

David Stewart MSP
Alia Gilani
Caroline Styles
Collette Foord
Michael Mahoney
Sir Michael Hirst
Scott Graham

1. Welcome

Emma Harper (EH) welcomed everyone to the meeting.

2. Minutes

The minutes of the previous meeting on 22nd September, were proposed by Steve Birnie (SB) and approved by the Brian Whittle (BW).

3. Presentations

Jodie Pollard (JP) talked of her experiences of Type 1 diabetes and the changes and benefits brought from using an insulin pump and continuous glucose monitoring (CGM)

Dr Vicky Alexander (VA), Consultant Paediatrician, NHS Tayside discussed advances in technology for people with Type 1 and Type 2 diabetes for children and adults. (presentation attached)

4. Discussion

EH stated that she had a pump and used flash monitoring and talked of the benefits but talked about the challenges in paying for it. She has discussed the issue with the Minster for Public Health, Alieen Campbell MSP on how to move the issue forward. The benefits are clear for the incidence of overnight hypos and it seems that the most benefit could be derived for children.

Shona McDonald (SMcD) agrees that the biggest effect in looking after children is in the incidence of overnight monitoring.

BW asked that if the technology goes ahead, what are going to be the provisions for staff training?

VA responded that the industry who provide the services will deliver the training.

Dave Duff (DD) pointed out that there are trials of artificial pancreases taking place and that there has been a successful trial for inpatients for Type2 diabetes and that we have to keep in mind the huge amount of training that needs to be provided.

VA had asked about the trial, it has not been designed to be used in that setting.

Steve Birnie (SB) interjected that it was to prove the concept to control blood glucose.

VA added that from a training perspective units will have policies that will come with the insulin pumps.

Johnny McKnight (JMcK) said that a lot of work has been carried out on inpatients wards in the Scotland programme. At the moment the technology that DD has described is potentially available but it could be taking away resource from people with Type 1, it could be cripplingly expensive. JMcK advocated that technology should be directed at people the Type 1 population. In NHS Lothians they have evaluated the Abbot FreeStyle Libre but mainly just the socio–economic class 1 rather than class 5.

Other technology that can sound on alarm when low could work. There is a feeling that Scotland is lagging behind, there has been good work on pumps and a massive investment in training of diabetes specialist teams.

The quality of life has been improved so why is it ethically acceptable to base funding on lowering HbA1c? JMcK states that he is not aware of any Health Board rationing provision on HbA1c alone. Audits are the same across Scotland, the people with the highest HbA1c have got the best results through technology but it doesn't bring it down the most. There is a question of access.

Iain Smith (IS) stated that he is a grandfather to an 11 year old with Type 1 diabetes. Cost is an issue. She is currently on flash monitoring. IS asked JP if she thought that her experience was extreme?

JP replied that whilst she has been through a lot, she knows over 60 people with Type 1 who have been through varying degrees of problems.

Susan Gallagher (SG) talked about the experience of her partner how has had diabetes for 40 years and moved onto a pump to combat nocturnal seizures. In the 5 years that he has been on a pump nobody has been able to download the data on how he is managing. He was denied CGM and his pumps broke on Christmas day 2015. They found that could not get a response from the clinic.

Jeff Foot (JF) wanted to pick up on a couple of angles raised earlier: He asked JP what education she received for the technology she uses?

JP replied that her Diabetes Specialist Nurse (DSN) met her for discussions every two weeks to go through the patterns and what to eat.

JF Pointed out that the training is very demanding in resource.

Alyssa Faulkner (AF) added that her nurse did not know how to use the pump and gave her the manual to learn.

Mhairi Macdonald (MM) pointed out that in the Highlands, it is Medtronic that helps and answers questions.

Vicki Kitson (VK) pointed out that there are different technology manufactures area as many as the different types of systems and this has created problems understanding the different services offered. She asked what is the best technology available and how is the data gathered and stored.

EH asked if we need to lobby Health Boards on this?

Margaret Henderson (MH) Declared an interest, that she works for Medtronic. She said that she would talk to SG following the meeting and pointed out that national procurement has narrowed down the types of pumps to three.

Brian Whittle (BW) asked about the cost of training and to consider the savings across the lifetime of the patient and this long term benefit.

JF countered that it is not the resource that is the cost but the people to fill this and they are hard to find.

Chris Kelly (CK) Stated that each Health Board has numerous programmes and that the resource issue is a distraction. Education takes place in groups, peer learning and peer support. CK welcomed JP's talk and highlighted that the sensor augmented pump is a fraction of the cost of some of the drugs that have been provided and in addition JP is functioning member of society and paying taxes. The long term benefits to Scotland are apparent.

AF mentioned that she has been funded for CGM and an insulin pump and because of this is independent and has been able to see the benefits.

Shelia Minty (SM) pointed out that within the technological debate there is the ethical implications about choice and giving people the choice.

Leslie Ann McRae (LAMcR) added that she is on a pump and has a child that is on a pump. The pump is a Medtronic model and the set of data it delivers to the user is not as in depth as the data delivered to the clinicians, which can be frustrating.

Susan Fletcher (SF) Declared that she worked for Medtronic and understood the perspective of LAMcR and added that it will be rolled out to users in 2017 to have the same data. It was originally framed this was to avoid overloading the user with data.

EH asked if there is data of people available on insulin pump therapy and CGM and what difference the technology is making?

JMcK replied that there is data on the amount of people with Type 1 and a breakdown of the HbA_1C. This can, depending on the criteria detail the users of insulin pump and the change in mean HbA_1C. For CGM, there must be a definition of the group, for instance it could work to asses hypo seizures.

Mirijam Emsworth (ME) stated that she was on insulin pump therapy and using flash monitoring. She challenged that if you use the stipulation of having a high HbA_1C to receive this technology to help them manage the condition, you are discriminating against people that are manging their condition well and avoiding high HbA_1C. She asked if there have been any calculations done to examine the cost of a pump and the cost of test strips?

MM claimed that it is £50 per fortnight and believes it is a substantial saving to the NHS.

Mary Moody (MMo) pointed out that there are so many different technologies and that there must be a level of standardisation to make it easier for NHS staff can understand how it works.

Kirsteen Murray (KM) added that the contract for the procurement of insulin pumps will be up for tender in 2017 and that ensuring a contract that properly reflects patient's needs will be vital.

VA addressed the cost savings by pointing out that there is still a need for fingertip testing so that the cost savings would not be that great.

VK added that to better understand the cost savings the savings over the long term should be a factor.

Dave Duff (DD) voiced the opinion that though the data was invaluable it was much harder to quantify the quality of life element.

LAMcR added from the psychological point of view there is the possibility of being overwhelmed.

Erin Naylor (EN) said that there are not enough psychological resources. To provide proper pump support emotional wellbeing is in integral part to make sure it works.

JF mentioned that he had seen CK deliver a session in Stirling and saw the benefits for the group and added thtat the social needs can be a useful avenue of support and that we should use it more.

JP replied that it is indeed very good but some clinics are reluctant to use it.

EH added that yes, clinics are very weary.

MM responded that the online aspect of support had both positives and negatives. Things need to be clear and you should check with your healthcare professional. Some Health Boards view this as a data protection issue which creates problems.

Steve Birnie (SB) said that there has been a level of improvement but that the problem is mainly an IT issue and will take a while to change. For instance using Skype calling could work.

JMcK mentioned how remote monitoring was in use at the Diabetter clinic in Rotterdam.

EH added that remote monitoring was already helping in other areas.

Ian Sloan (IS) asked VA why NICE was not taking an interest in this?

Gillian Gunn (GG, Scottish Government) replied that NICE and SIGN guidelines (for Scotland) are clinical guidelines and as such would not encompass this aspect.

DD concluded the discussion with the statement that Scotland must be ahead of the game in this respect and that technology was vital to helping people manage their diabetes.

EH thanked VA and JP and closed the meeting.

The next meeting will be on 21st February at 6pm, covering prevention.