

# Cross Party Group on Diabetes

## 6-8pm, Tuesday 21 March 2023

### Present

#### MSPs

Emma Harper MSP  
David Torrance MSP  
Jackie Dunbar MSP

#### Guests

Dr Brian Kennon, Clinical Lead for Diabetes  
Dr Fraser Gibb

#### Non-MSP Group Members

Alison Templeton  
Alyssa Faulkner  
Andy Burton, Diabetes Scotland  
Angela Mitchell, Diabetes Scotland  
Daniel O'Malley, Diabetes Scotland  
Grant Reilly, DHI  
Ian Aitken  
Ian Sloan, diabetes patient group NHS Fife  
Lesley Murdoch, Lochlan's Legacy  
Lochlan Murdoch, Lochlan's Legacy  
Mary Moody, Tech Collective and IPAG  
May Millward, West Lothian Group  
Niamh McClure  
Shelley Murray  
Shona Shankland  
Sioned Ellis, Diabetes Scotland

#### Non-MSP Group Members who attended virtually

Mhairi Macdonald, Diabetes Scotland  
Allan Goldie  
Amber Khan  
Dave Curry  
Jinty Moffat  
Sheila Trachsler  
Graeme Arthur  
Stuart Mclaughlin  
Lorna Breeze  
Alison Ballantyne  
Jean Langford  
Sue Hampson

Lesley Ross  
Norma Fraser  
Christine Ritchie  
Paul Niven  
Emma Jane Doble  
Esther Rue  
Margo Watson  
Isobel Macleod

## Apologies

Paul O’Kane MSP – Co-convener  
Alex Cole-Hamilton MSP  
Jackie Baillie MSP  
Miles Briggs MSP

## Agenda item 1

Emma Harper MSP welcomed attendees to the first in-person diabetes CPG since lockdown and noted the hashtags #diabetesCPG #lochlanlegacy #type1doesntstopme #diabetestechcantwait to use on social media.

## Agenda item 2

### Discussion topic: fair and equal access to diabetes technology

Dr Fraser Gibb presented on inequalities in access to tech and outcomes.

- Deprivation-related disparities in tech use and meeting HbA1c targets
- Importance of good management to reduce risk of death by ~1/3
- Unique link between outcomes and numeracy skills in diabetes
- Consistent demand for tech across SIMD groups and genders

Dr Brian Kennon presented on the Scottish Health Technologies Group (SHTG) assessments, funding for diabetes technology, and the ANIA pathway.

- SHTG did the first assessment on libre and one of the first on hybrid closed loop
- Central funding has been provided to health boards for pumps and CGM over the last decade, plus £20m capital funding in the last 2 years
- It would cost £300m/year to put 70% of people with type 1 diabetes in Scotland on hybrid closed loop tech
- 3 of 6 initial proposals to the Centre for Sustainable Delivery, which focuses on adopting and scaling up innovative solutions to healthcare, concern diabetes
  - Proposal to develop a national onboarding programme to help boards improve access to hybrid closed loop tech which has already purchased (NB. this is not a £300m/year commitment) has been supported

Daniel O’Malley introduced the *Diabetes Tech Can’t Wait* campaign.

- Postcode lookup tool to launch on Thursday
- Scottish Health Technologies Group recommendation on hybrid closed loop technology preceded £14.6m funding from Scottish Government
- Importance of both numerical data and lived experience stories
- **Asked attendees to use postcode lookup tool and take actions**
  - **Contact your MSP to ask them to write to your Health Board about plans to continue funding hybrid closed loop**
  - **Share your story**

Lochlan and Lesley Murdoch presented on Lochlan's Legacy.

- Charity event on type 1 and mental health
- Sent 5 vanloads of supplies to Ukraine
- Basic Awareness and Understanding of Type 1 Diabetes in Football course
  - Now CPD accredited; supported by SFA
  - Niamh McClure created videos for coaching education programme
  - Delivering to football clubs in west of Scotland; hoping to expand
- T1D Trailblazers won Digi Inventors Challenge run by Digital Health and Care Innovation Centre (DHI); created an app to give coaches, parents and young people information on type 1; Scottish Tech Army and DHI to support further
- Interactive workshop and quiz for coaches; for clubs with a member with type 1 diabetes, Lochlan's Legacy initiate a meeting to complete player profile
- 'T1D & Me: Giving Youth a Voice' steering group working on a questionnaire to be piloted in East Ayrshire Council
  - To be issued to all aged 12-18 with type 1 and in full-time education
  - Collect young people's views to assist with future events and projects, including a roadshow to be attended by tech company representatives
  - Want to have a T1D and Me bus and attend matches and other events

## Open forum questions

Alyssa Faulkner: UNCRC contains an article on children's right to adequate healthcare; can we use momentum behind UNCRC incorporation to push for diabetes tech?

- Daniel O'Malley: support Alyssa's idea; campaign needs to first identify barriers to accessing tech, then engage with health system and more broadly; **appreciate talking to Alyssa after this to discuss how we can work together**
- Brian Kennon: important to use levers that currently exist, e.g. GIRFEC (getting it right for every child); tech isn't quite there yet to allow people to plug in and use without having numeracy skills, which is why structured education is required for access to tech, but within the next year or two, further development will cut right through this, so tech could be available at diagnosis as a norm
- Emma Harper: use levers e.g. debates in chamber, questions to health secretary and minister; strike when the iron is hot following leadership contest results; organise around World Diabetes Day on 14 November, e.g. presentation on bionic pancreases

Sheila Trachsler: need to raise inequalities between SIMD (social index of multiple deprivation) groups and ethnicities; there is a lack of data on tech use among BAME (black, Asian and minority ethnic) people

- Fraser Gibb: we don't have the data, although ethnicity is a field in SCI database; only a very small number of people with type 1 diabetes are BAME; need to act on what we know which is socioeconomic inequalities
- Brian Kennon: recognise inequalities by ethnicity, deprivation and gender; the need for structured education disadvantages people with differing numeracy skills, languages; SHTG assessment highlighted that clinical teams need to positively discriminate; again, tech is nearly in a place to allow some of current models (need for structured education) to be circumvented
- **Emma Harper: can raise questions on data at health committee**

Ian Sloan: how can we (diabetes patient group for NHS Fife) help share Lochlan's resources?

- **Grant Reilly: happy to discuss with Ian afterwards**
- Brian Kennon: good networks across clinical community in Scotland; **can use type 1 network, send Lochlan's resources to all paediatric departments in Scotland; would be good to discuss ways to join up on priorities around transitional care, schools, working with DHI to get DigiBeat into services**
- Lesley Murdoch: meeting with Mel from DigiBeat on Thursday

Emma Dougal: hybrid closed loop now means I am the one in control of my type 1 diabetes; how can we enable cultural change in the NHS to facilitate this shift in management?

- Fraser Gibb: tech can't be considered a specialty area in diabetes; Diabetes Network UK run courses; clinicians' role is to empower people to make their own decisions; care will ideally be as light touch as possible, through self-management and tech
- Brian Kennon: "culture will eat change for breakfast, lunch and dinner", hence the role of a national onboarding programme in upskilling clinicians; collaboration with industry partners who can support clinicians to understand tech

Mary Moody: health board formulary committees don't have knowledge of tech, causing delays and inconsistency, so is there scope for a national approach for formularies for diabetes tech?

- Brian Kennon: formularies are never friends of people with long-term conditions; if you push for formulary approach, you will end up with one preferred supplier and one back-up supplier; priority is cost-effectiveness
- Fraser Gibb: currently 4 months into negotiations with formularies in Lothian to make Dexcom 1 available; vendors choose whether to go down the prescribing tariff route or conventional route; Libre, Abbott and Dexcom 1 have gone down that route but doesn't imagine pump providers would do so; pumps and realtime CGM are prescribed through secondary care; there was a push for a national formulary committee a few years ago but nothing came from this
- Brian Kennon: MSP question about access to Dexcom 1 across health board areas
- Lesley Murdoch: in one of the first T1D meetings, all young people asked about tech and were keen to know more; in appointments, consultants primarily talk to parents; need to use youth voices to push for access
- Daniel O'Malley: looking forward to raising issue more in political sphere

Sheila Trachsler: what can be done to ensure there aren't so many discrepancies in access?

- Brian Kennon: highlighted the ANIA pathway

Angela Mitchell: heartening that we're all on the same page; we want to hear from everybody about experience of access or lack of access to tech, whether positive or negative.

[Note: the final few questions were taken together before answers were given]

Paul Niven: I'm coming up for insulin pump renewal and have been offered 3 pumps that are loopable but my HbA1c is too good for CGM; how do we ensure hybrid closed loop is available for those who will benefit the most, not only those who are struggling or have a higher HbA1c?

Sue Hampson: tech is wonderful but the psychological effect of being on tech (specifically omniper) wasn't addressed in Fife.

Margo Watson: How much responsibility does your clinic have to keep you up to date with tech?

- Fraser Gibb: Scottish Health Technologies Group criteria for hybrid closed loop includes not meeting glucose targets (HbA1c of  $\geq 53$ mmol/mol), frequency of hypos, extreme fear of hypos, diabetes distress; we can't compel health boards on how to spend their money, but the argument might be that if you meet SHTG criteria it's unacceptable for you to wait >6 months, 12 months, or it might be about trying to create pathways
- Brian Kennon: regarding psychological factors, it was important to include quality of life and diabetes distress in the Scottish Health Technologies Group cost effectiveness assessment; recommend that Paul Niven drive the point of diabetes distress when making the case for tech. Regarding clinic responsibility, lots of diabetes teams aren't as up to date on tech as they should be or might be worried about raising expectations; this needs to be challenged health care professionals shouldn't be gatekeepers but facilitators. Don't underestimate the power of positive messaging around quality of life; it's this messaging which is most impactful, not messaging around lack of access (which is unfortunately true for all conditions).

## Agenda item 3: Action items

Emma Harper:

- Ask chamber/ministerial questions on ethnic minority data
- Potential debate about diabetes technology in November
- Questions around the choice of technology available to people
- Raise awareness of digibeat and Lochlan's Legacy
- Make sure everyone is connected and can share on social media

Daniel O'Malley:

- Email going out to all Diabetes Scotland supporters and the Tech Collective with postcode lookup launch on Thursday
- Parliamentary motion to be circulated on Friday
- Details to follow on World Diabetes Day parliamentary event on 14 November

## Agenda item 4: Any other competent business

None. Daniel O'Malley confirmed we do not need to approve the minutes from the last meeting as it was an AGM so will approve at the next AGM.

## Agenda item 5: Date of next meeting

The next CPG meeting will be 13 June 2023, hybrid. Topic TBC.

To book a place or for more details please contact Daniel John O'Malley, Campaigns & Public Affairs Officer, Diabetes Scotland: [daniel.omalley@diabetes.org.uk](mailto:daniel.omalley@diabetes.org.uk).