Cross Party Group on Diabetes
6-8pm, Wednesday 8 May 2024

Present

MSPs

Emma Harper
MSP Paul O'Kane
Jenni Minto Minister for Public Health and Womens Health

Guests

Dr Brian Kennon, Clinical Lead for Diabetes

Non-MSP Group Members

Emma Nieminen, Alison Grant, Jacqui McKenzie, Bushra Riaz, Carolyn Oxenham, Dr Susan Eley Morris, Elizabeth Murphy, Fiona Macintyre, Isabel Macleod, Jennifer Boyle, Jinty Moffett, Joel Milner, Kirsten Hogg, Kirsty C, Kirsty Jarvis, Lesley Murdoch, Lesley Ross, Mary Moody, May Millward, Graeme McArthur, Michelle Brogan, Norma Fraser, Paul Niven, Ron McDowall, Ruth Chapman, Sarah Morrison, Susan Fletcher, Sheila M, Sheila Traschler, Thelma Good

Apologies

Alex Cole-Hamilton
MSP Jackie Baillie MSP
Miles Briggs MSP

Agenda Item 1:

- Paul O'Kane welcomed everyone to the CPG. Emma Harper will be joining later as she is in another debate on asthma now.
- No apologies.
    - Lesley Murdoch requested apologies to be recorded from Lochlan Murdoch BCyA.

Agenda Item 2:

- Daniel introduced today's CPG topic: care processes that people living with diabetes should receive. People living with diabetes submitted questions to be asked of the Minister and other speakers; these were sent to the Minister in advance.

Agenda Item 5: Processes of Care - A Scottish Perspective

- Brian introduced the 9 processes of care and Scottish data from 2022, showing a variable uptake in these. As a health system, we're not too bad at carrying these out. Covid had a sharp negative impact on care process completion, but we are now starting to see some recovery. Acknowledge that we were doing better in the halcyon days of 2016/2017, when QOF was incentivising some of the care processes. Data from 2024 shows improvement but we're still not where we were pre- pandemic.
- Highlight that this data shows warts and all, and that Scotland has the best data on diabetes in the world. When you get such complete data capture, by default you get a drop off. When you present this to HCPs they will say of course we screen feet, but once you dig in deeper you realise it may be done but isn't being recorded in SCI-Diabetes. For foot screening for example, we're very exacting. We expect risk stratification that's meaningful for your care, not just checking a pulse, which might be adequate in other countries.
- Hats off to paediatric colleagues, as they're doing great at care processes for children.
- It's not about browbeating people to get these done, it's about how we can do things differently and make sure people are getting desirable outcomes. Disconnect between number of people having care processes done vs people who are achieving optimal outcomes. Should maximise outputs from doing to maximise outcomes.
- Retinal screening in Scotland is the best in the world, but many people still have diabetic eye disease so this is what we should focus on.
- Only 20% of outcomes are determined by healthcare system. Need to think about how the healthcare system can work with the other 80% to truly make an impact on outcomes, not just processes of care. A whole system approach. Easy to say, much harder to achieve.

- Looking at data from GGC, there are vast differences in levels of deprivation based on HSCP. We can't expect to do the same thing to people and get the same outcomes. Quarter by quarter, outcomes are very similar. Change is difficult at individual and organisational level, can't keep doing the same thing over and over again.
- Start to look at doing things differently, e.g. home HbA1c testing, maybe lipids next. In In Glasgow will start taking a bus to target areas with high DNA rates with paediatric patients.
- Healthcare systems are not trusted environments for a lot of people, how can we start to utilise community assets and work in partnership?
- This isn't about diabetes; this is about the individual. Let's think about multimorbidity and extend it to social determinants of health. Look towards offering a much more holistic package to suit individuals.
- Scotland is well placed to drive positive change with collaboration from various parts of the sector.
- Brian clarified that eye and foot screening recall time is now every 2 years rather than annually if you are determined to be at low risk.

<u>Questions:</u>

- Alison Templeton noted that optometrist can also do eye screening. Brian responded that not all optometrists/opticians can do retinal screening, so make sure to check.

Audrey Nichol, MSP, joined the meeting.

- Alyssa Faulkner: noted she had only had her feet checked twice in her 11 years of living with diabetes. Are there currently any proposals or solutions towards increasing care process completion?

Jenni Minto and Emma Harper joined the meeting. Jenni Minto apologised for having to reschedule the CPG previously.

Item 3: Jenni Minto

- Jenni Minto outlined Diabetes Improvement Plan 2021-2026, overseen by the SDG. She thanked Dr

Kennon for being at the helm for the last 6 years. Also thanked Brian and Daniel for their presentations. We must ensure we have robust mechanisms in place so that we have adequate surveillance for care PLWD receive.

- Recent inpatient audit has allowed us to understand more about inpatient care, particularly foot care in hospital, which Ms Minto has heard about through her constituents in Argyle & Bute.
- Resources such as My Diabetes My Way and Digibete should be used too.
- ANIA pathway investment; particularly interested in peer support roles developed based on feedback from PLWD on how education can be improved.
- Thanked Diabetes Scotland for their continued support with DIP and Healthier Futures Framework. Involvement panel to hear from people living with diabetes.
- Important to work holistically to support PLWD to live well. Here to listen and identify solutions together.

Item 4: Questions from the audience

Ms Minto is happy to provide written responses through secretariat to any questions.

What is the long-term plan for diabetes tech so Scotland isn't kept out of the loop?

- JM: Understand where this question is coming from and why it's being asked. Indicated there is an issue with funding; we're in the tightest financial situation Scotland has been in. Working closely with team of officials to ensure that we are providing the best evidence possible to encourage finances to come into the closed loop technology. Understand the difference tech makes to your lives and to the health service. ASK: Be really clear about the impact that having a closed loop system would make on your lives so that we can feed that into the financial process.

Unknown: ScotGov will announce funding to an NHS Board, which will then go to whatever the flavour of the day is, not necessarily diabetes tech. Can we change this system?

- JM: That would be a big change. They're closer to the needs of the area within their HB, so they make decisions on where this should be spent. Currently working through top-up funding option. Work that Diabetes Scotland does in raising awareness and meeting with myself is really important. If there are specific stories that would help these arguments, I would appreciate that.

JK: DTCW brought forward many stories on the difference tech makes. What people want to know is, what's coming next? Can see the plans and progress in England, so what's next for Scotland?

- JM: The work you're doing is so important, and I don't think anybody disagrees with the impact of tech. Making decisions on finances and where money should be spent is what's happening now.

Lesley Ross: When will people have access to tech to help prevent complications?

- JM: I feel really sorry that I can't come to every single person and tell them that we've found the money. I have worked to really ensure that people in g'vt finance truly understand. 50% of budget goes to NHS. Of that, only 10-15% goes towards preventative measures. Until we can get more money into the budget, it's these difficult judgements we have to make. That's why I've been pushing really hard and providing evidence to g'vt finance.
- BK: There is a strategy here that we're working on collectively, even if that information isn't getting to the entire community. We were the first system in the world to make a judgement on HCL, and those recommendations are a lot broader in terms of access than elsewhere. Got £20m of dedicated capital funding towards this. We've now got a national onboarding team, and down south they have massive workforce issues that are a barrier to implementing tech at scale. The fact that the national onboarding team can reach people from across the country with education and peer support all at once is incredible. There are some positives around this discussion that can sometimes get lost among the discussion. Nobody disputes how transformative this tech is, we all know it.

Alison Templeton: We're really angry with the waitlists right now, looking

at 10.7 years to wait for a pump for a newly diagnosed adult. Is it because it's technology and not a drug?

- JM: I remember meeting you a year ago and having the same conversation. We haven't got the level of funding right now to allow us to do it. Technology is incredibly important.

We've known about this for a long time, why wasn't it planned for?

Unknown: Tried to get access to a pump for a child at 9 years old who lost their mum last year but can't get access. The funding has to be made available and pathways have to be improved for people to get access faster.

Kirsty Jarvis: Funding Dexcom as part of HCL has been cut.

- JM: Believe you me, I'm trying to sort this. It's not easy. What we've heard tonight will absolutely be taken away and added to the documents that we are submitting. In my role, I look at everything from pre-birth to post-death and there are so many areas where you have to make difficult decisions. This is one area I'd like to move off my inventory. We're working our hardest to try to find the funding.

  Continue to use fantastic voice you have through Diabetes Scotland.

PO: Thanked the Minister, promised to send further questions that are asked after the Minister leaves.
Recognised that we got into some of the core issues there and heard people's anger, frustration, and concern.

Emma Harper: Potentially doing an AI enquiry as to whether investing up front on tech mitigates spending later on. HFSS consultation on just now, and semaglutide will end up costing lots of money too.
Fascinating from a health economics point of view, trying to get more information so we don't take away from acute care. Keen to hear from Brian in terms of what we're doing about economic analysis on prevention [of complications] vs acute care.

BK: Not just here in a g'vt role, firstly here as a clinician. Very difficult to disinvest in the front door of a hospital, acute care. A bit of hope… in 2018 we took Libre to the SHTG and were first country in the world to get a health economics assessment. Others questioned whether this is

the best use of £3m then. Now spend £24m/year.
Now have protected footprint for this within budgets. Soon Libre 2 will be interoperable with pumps and allow to loop. After NI, Scotland has the highest use of Libre 2 in the UK (and NI is only higher because they don't use other brands as much). Will get more people looping, even if it's not as fast as people in this room want. We should work as a wide diabetes community… in 7 years never seen as many MSP letters on anything around diabetes care, the campaign has been a fundamental part of how we have lobbied for this. Industry: design better studies that demonstrate the impact of these technologies. Take the people with HbA1cs of 100 and show the maximum impact to really drive access.

Jinty Moffett: Lived with T1 for over 30 years, have lived in 2 HBs. Interested in BK's perspectives on social determinants and improving outcomes, because that's what it seems to all be about. Education right throughout the health service on how you work with PLWD is crucial (so people know what the checks are about). Clearly need to be creative with funding, I'm certain that the funding we have could go further.

Mary Moody: From IPAG Scotland. Several people have mentioned the work prevention… diabetes technology isn't about prevention, but immediate improvements to quality of life and health. Have been campaigning for 16 years but it feels like we're not getting anywhere.

- BK: Contest we're not getting anywhere. Over 70% of people are using Libre. A year ago, 1/5 had interoperable CGM. So many more do now. We're not getting there as quickly as we want to, but it's still a positive trajectory. Clarified prevention in terms of complications. Do appreciate how transformative these things are.

Steven Nixon: Son got funding last year, is there a risk that this funding is taken away?

- BK: Clearly there is a concern. Would be lying if I didn't say clinicians weren't worried about expansion of services (more so than removal of devices, except at end of pregnancy). Would be very disappointed with any HB that started to take devices off people. Need to be mindful there are criteria for going onto these systems and the responsibility of the individual to engage with the tech (using sensor >70% of the time) and having a mature discussion about it with the patient.

Daniel O'Malley: Have heard stories from people about waitlists and tech being taken away, continuing to find out what's going on and what the solution is. DTCW highlighted best practice but we know there's progress to be made. Rest assured there is a lot of work going on in this, but a bit of a drip feed in hearing back from HBs about their plans. Working with MSPs in Lothian to find a solution, work with Lothian HB to find an optimal outcome.

John Kinnear: Although these hasn't been a lot of public stuff, shouldn't underestimate the amount of work being done by Brian and colleagues at ScotGov behind the scenes on this! Brian may not post everything online.

Ruth Chapman: A lot of discussion already about money that was allocated, but still don't understand if there's general funding and then top-up money. Top-up was given for a specific use for diabetes tech as part of a strategic plan… when does it become unethical that that money isn't used for that use. Why is it acceptable that it gets used elsewhere, and how is that money accounted for?

- BK: For capital investment, it's a one-off payment. Challenge with tech is that it isn't one-off… you need £5m on a recurring basis. That money allocated for tech has been invested in those technologies, the problem is the challenge to meet recurring spend. We're aspirational, to get 100% of children and 70% of adults on HCL, but need >£120m per year every year. That's on part with Scottish Ambulance Service. That's unprecedented and highlights challenge. Ethics with healthcare spend is that things like cancer spend aren't recurring. Recurring funding presents a unique challenge.

Unknown (Ian?): Diabetes Fife Group are all T1, one of the side effects they've found is they're gaining considerable weight on HCL.

- BK: On HCL insulin requirements may fall. Part of the transformation is the freedom you gain, which is also dietary freedom, which may have an impact.

Jess: BIL is a renal consultant in Cambridge, where they had employed a youth worker to their clinic to ring up teenagers to get them to attend their appointments. Is this something that could be looked at to help young people attend appointments and improve outcomes?

- PO: Good point, can see people noting it down.

Alyssa Faulkner: Speaking to friend Emma Doble, who was saying that in medical research they often won't publish research without lived experience involvement. Is there someone with lived experience included in SDG, could this be an elected position?

- BK: SDG, John and JDRF sit on this. Have had lived experience reps on group before, but they felt it was better to sit on and influence subgroups, which drive a lot of the operational parts. Colleagues can surely talk about Communities in Action… so we can come to YOU to find out what's important. Having peer support as part of national onboarding team has been brilliant. Take it on board that's something we can encourage.
- JK: CiA intends to engage people from across all types of diabetes. As it develops, it will be a way to gather views to influence government and policy work, and feed into SDG.

PO: Action to follow up with the Minister about the questions that were lodged and the discussion that was had in this room. Important for politicians in the room to also be aware of this and push this. Important for First Minister to hear about this. We're hearing the passion, the anger, the concern to push things forward.

JK: Pretty sure this is Brian's last CPG (for real this time), so would like to formally thank Brian for his work over the last 7 years. We've had no better champion than Brian!

Agenda Item 6: AOB

- Next meeting is scheduled for 11 June but due to upcoming changeovers with National Lead and delay to this meeting, will push it back a little bit and keep people in the loop about the new date.

Meeting concluded at 19:33. PO encouraged people to keep in touch and let us know what more can do.

DO: To reiterate, will collate everything from the minutes and share with the Minister.