Minutes of the Cross Party Group on Diabetes 12pm, 8th July 2021

Attendees:

Jayne Bryant MS Dr Lee Gonzalez

Josh James Cath Washbrook

Dai Williams Joel James MS

Dr Altaf Hussain MS Peredur Owen Griffiths MS

Samuel Kurtz MS Brody Anderson

Corinna Bretland Wendy Gane MBE

Jon Matthias Helen Boggis (for Vikki Howells MS)

Ryland Doyle (for Mike Hedges MS)

David Thomas

Mark Isherwood MS Chris Cottrell

Dr Julia Platts Heledd Roberts (for Rhun ap Iowerth MS)

- Opened the meeting and thanked everyone for coming. Gave a brief overview of the state of diabetes in Wales. Wales has the highest rates of diabetes in the UK. In 2020 there were an additional 10,695 diagnoses meaning there are now 209,015 around 8% of the population over 17 and cases are. Estimates suggest there are a further 65,501 people with type 2 diabetes who have not yet been diagnosed, as well as a further 580,000 people who are at high risk of developing type 2. As a result, diabetes is one of the fastest health crises that we face in Wales. It costs the NHS in Wales around £500m a year, around 10% of its budget, 80% of which is spent on avoidable complications.
- JJ Moved to the first agenda item, establishing the CPG. Noted great engagement in the 5th Senedd hoped this would continue. Opened the floor to those who wanted to join the CPG:

Senedd members

- Jayne Bryant MS
- Dr Altaf Hussain MS
- Samuel Kurtz MS
- Peredur Owen Griffiths MS
- Joel James MS
- Mark Isherwood MS
- Vikki Howells MS

Noted other MSs had emailed in intention to join the CPG, and thanked members of office staff who were here representing those who were unable to make the meeting but were keen to join the CPG.

Expert members

- Wendy Gane MBE
- Jon Matthias
- Dr Julia Platts
- Chris Cottrell
- Joshua James
- Dr Rose Stewart
- Sujatha Thaladi
- David Thomas
- JJ Proposed terms of reference for the group.

Terms of reference were agreed by those present at the meeting.

Opened nominations for Chair of the CPG. Jayne Bryant MS was nominated by Samuel Kurtz MS and seconded by Dr Altaf Hussain MS.

There were no other nominations, Jayne Bryant MS was elected to Chair the CPG.

JB Thanked all, including returning and new members, stated that we were really looking forward to working cross-party to support people with diabetes in Wales.

If you cannot make a meeting in the future, please do send a staff member.

Moved to the election of secretariat of the Cross-Party Group.

Nominated Josh James on behalf of Diabetes UK Cymru to the role of the secretariat and seconded by Altaf Hussain MS.

There were no other nominations Josh James was elected as Secretariat of the CPG.

- JJ Introduced Dr Rose Stewart to talk about mental health and making the case for Diabetes Psychology.
- RS Since last spoke at the CPG there is now a department of diabetes psychology at BCUHB and taken on the Chair of the UK diabetes psychology network.

The reason we have diabetes psychology is because diabetes is such a challenging condition to live with. Managing diabetes is like beating your own heart. It creates huge psychological burden. A lot of this was identified by Diabetes UK Cymru's "Too often missing" report in 2019. 75% of people with diabetes feel like they cannot access the right support. This is because diabetes psychology is rare. Anxiety and depression are 50% more prevalent in people with diabetes, suicidal intent is 3x higher, and young people with the condition are 3x more likely to develop eating disorders.

A great deal of research has been done to show that worsening psychological health equates to worsening diabetes management, this becomes circular with each leading to the other.

Currently outside of the unique service in Betsi Cadwaladr there is 1 whole time equivalent in Hywel Dda and no other adult diabetes psychology across the country. We cannot send people to adult general mental health services because the conditions and issues are specific to diabetes, and not covered in generic training. These include; diabetes distress, diabetes burnout, type 1 eating disorders, fear of

hypos, needlephobia, repeat DKA, psychological insulin resistance and coping with complications. Sending people to generic services leads to unsatisfactory results.

Diabetes psychology is prudent healthcare in action, it reduces morbidities, longer life, lower stress, and takes pressure of the NHS. 80% of the NHS budget is spent on diabetes complications which are preventable. Where someone with T2 diabetes has poor mental health their NHS costs go up by 50%, this is money that could have been saved.

Adult diabetes psychology can also support young adults who often see their diabetes management go "off the rails" somewhat. Supporting young adults to manage their condition through teenage years equals better life in the future.

Adult diabetes psychology reduces rates of DKA admissions. Each DKA admission costs on average £2045. DKA is strongly associated with psychological distress and is most common amongst young adults. In Betsi Cadwaladr, the pilot scheme showed that we could reduce DKA rate amongst young adults by 40% with diabetes psychology.

We worked out that we could produce net savings to the NHS of between £714,696 and £1,151,660 by the end of year 5 with a adult diabetes psychology service with 3 whole time equivalent clinical psychologists.

However, there are issues in workforce. We need more clinical psychologists in Wales, as there is a huge training bottleneck. There is a 30% vacancy rate in psychology posts. We train 30 clinical psychologists a year in Wales, the lowest of any devolved nation. There are over 300 applications for ten spaces in training. England in increasing their DClinPsy training places by 60% over the next 3 years, Wales is not. We have no centralise commissioning process for psychology leads.

Investing in adult diabetes psychology will save huge amounts of money as well as make huge improvements to quality of life. The English system of IAPT is not effective in dealing with this.

- JB Thanked RS for the presentation and congratulated RS on the new service and role in BCUHB. Opened it up to questions.
- SK Are these clinical psychologists specialists in diabetes, or with a range of skills? In terms of specialising, can that make it harder to recruit?
- Yes and no. As clinical psychologists we are trained in all areas of mental health. We have an undergrad degree then two years' experience working in mental health, then take 3 years on a doctorate, in Wales there are two places which you can do this Cardiff and Bangor. On the doctorate you can start to specialise in different areas of clinical psychology. We tend to find we have people working in all types of different ways, but in physical health psychology, the key is having clinicians embedded into teams. The danger lies in delivering general psychology services meaning they have to take referrals from diabetes, to dermatology, to rare blood disorders, to cancer. This means clinicians are often not prepared to support individuals as they don't have a detailed understanding of their health condition which can be very risky.

The difficulty we have in recruitment is not specialising. Specialising in diabetes for example is actually quite an attractive opportunity. The problem is simply that there are no clinical psychologists out there. We really need to train more in Wales.

- WG I am very concerned at the lack of enthusiasm from health boards to fund these posts. Many HBs fund no adult psychology and in some HBs there is no child psychology either. Cwm Taf Morgannwg UHB for example despite being raised in peer reviews as serious, still has no child psychology. Psychology is the top priority within the patient reference group so on behalf of patients too, we ask Senedd Members to push for funding for this service.
- JB Thanked WG for her contribution. This will be an issue we will continue to think about as a group. Recommended to members that this is something we could take action on.
- DW Noted that he was retiring, and this would be his last CPG. We know this is prudent healthcare in action, why is Welsh Government not funding this hugely cost-saving service across Wales? It saves money and misery.
- JB Thanked DW for all his work and contributions through Diabetes UK Cymru
- JJ Also echoed well wishes to DW on his retirement.

There are two things Diabetes UK Cymru would really like Senedd Members to raise either in the Senedd or to the minister:

- An increase in training posts for clinical psychologists in wales
- Recognising the service that RS has set up in BCUHB as the standard that should be available across Wales.
- JB Based on the RS's presentation, would members be happy to write to the minister to ask her about psychology and to invite her to the next CPG where she can talk about her plans in this area and also hear from RS and other psychologists.

Lastly with a new Health Committee, they will be asking for suggestions for inquiries, perhaps this could be raised by members or DUK as an agenda item as workforce will be an issue they will want to look into. Are members happy with that plan of action?

The meeting agreed with the proposed action plan for the CPG.

- RD In the context of raising this with health boards that don't offer this service at the moment, can DUK draft a letter for members to send to their health boards on the issue? Also wished DW a happy retirement.
- JJ Yes of course. I will do this before the next meeting in conjunction with RS.
- JB Moved to the last agenda item on support for children with type 1 diabetes in schools.
- JJ In 2017 we Diabetes UK worked with Darren Millar MS and others including the Children's Network to draft an amendment to the ALN Bill. The purpose of which was to create a single, unified framework to support children in schools, based on the needs of the individual rather than the condition or reason for the support in school.

Recognising that people with diabetes face around 180 additional high-risk decisions a day, the attainment gap between those with diabetes and those without in educational settings, and the signs or symptoms of hypoglycaemia including tiredness, blurred vision, confusion and fatigue, meaning that incidences have the potential to have a big impact on learning ability, we felt that access to additional

learning needs support should be open to those with medical conditions, including type 1 diabetes.

We were thrilled to see support for this amendment from representatives across the Senedd, and for it to be supported in the Children, Young People and Education committee during scrutiny.

With the adoption of this amendment, we felt we had been successful in enabling the roughly 1,400 children and young people with type 1 diabetes in Wales who may need support in a learning environment to access ALN.

However, recently we heard that Designated Education Clinical Leads for each health board (a role created by the Act) were told that children with type 1 wouldn't be eligible for support under ALN. In a recent meeting with Welsh Government, myself and Dr Rob French from Cardiff University were told that the civil servants could not see "any instance where a child with type 1 would be eligible for support under ALN".

This was a real disappointment, and we have since heard anecdotally of learning environments that had planned support for children with type 1 on the assumption that they would be eligible for ALN, now facing funding shortages in their classrooms.

We feel this goes against the spirit of the legislation, which was to create a unified system of support for learners that is based on assessment of individual need.

So, having spoken to the Education Minister he has requested we write to him formally on this issue, and we would welcome your support on this issue.

JB Thanked JJ for raising this issue, agreed with other members that we would support a letter from the CPG on this. Asked for members to raise any other business (nothing was raised). Thanked all attendees for joining.

Meeting closed.