Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Cefnogi pobl sydd â chyflyrau cronig

This response was submitted to the Health and Social Care Committee consultation on supporting people with chronic conditions.

CC73: Ymateb gan: Response from:

All Wales Diabetes Patient Reference Group (AWDPRG)

Grŵp Cyfeirio Cleifion Diabetes Cymru Gyfan
LLAIS DIABETES YNG NGHYMRU

All Wales Diabetes Patient Reference Group
THE VOICE OF DIABETES IN WALES

Response by the All Wales Diabetes Patient Reference Group(AWDPRG)

Senedd Health Committee call for evidence on supporting people with chronic conditions

Version 1.0 | May 2023

The All Wales Diabetes Patient Reference Group has a key role in supporting the All Wales Diabetes Implementation Group to gain the views of people living with diabetes across Wales.

This will help inform and shape future services.

Ensuring a collaborative approach to Diabetes Care across Wales, and to sustain an environment that supports equitable diabetes care.

Contents

1. Abbreviations

1. Throughout this document the following abbreviations have been used:

- **AWDPRG** - All Wales Diabetes Patient Reference Group
- **AWDiG** - All Wales Diabetes Implementation Group
- **DSN** - Diabetes Specialist Nurse

2. Remit of the AWDPRG

2. The remit of the AWDPRG is to:

- help to support the development of future health and social care services in Wales to promote diabetes self management;
- support the development of a patient centred approach to develop services that meet individual needs and ensure the co-production of care;
- raise awareness of essential Annual Health checks, screening services, Voluntary and community services to those living with diabetes in their Health boards;
- escalate Diabetes service issues to the All Wales Diabetes implementation Group;
- provide assurance to their local groups that Diabetes service issues are escalated to the AWDiG and update on the issues raised;
- cascade the information from the AWDiG to local patient groups and communities;
- help to develop the clinical pathways and provide feedback to ensure they reflect the patient experience;
- provide patient knowledge and experience to the subgroups; and
- provide feedback at the health boards diabetes delivery and planning groups.

3. The voice of People with Diabetes in Wales is now regularly heard by the Welsh Government, Health care professionals, clinicians, NHS and Social Care policy makers and health board decision makers across Wales through the work of the AWDPRG.

3. Makeup of the AWDPRG

Members of the AWDPRG are volunteers with a variety of forms of diabetes including representatives who are carers for people with diabetes and parents of children with diabetes. These volunteers represent each of the health board areas of Wales and meetings are only quorate when all Health Board areas are represented.

4. The AWDPRG seeks to find volunteers by self nomination and informal interview prior to joining the group and agreeing to our Code of Conduct. Whilst the Health Board area that individuals receive their treatment and support within is relevant to ensuring the group hears and represents the views across the whole of Wales, individuals are encouraged to develop a network within the diverse community of people with diabetes across Wales.

5. Our group membership engages both face to face and through various online communities for people with diabetes within existing settings and through creation of bespoke events by the group.

6. Group members are also seek to embed themselves within the structures for improving diabetes pathways within their individual health board area. In Cardiff and the Vale UHB Area, for example, representatives from the AWDPRG are on the local Diabetes Steering Committee and are in the co-production group that developed and maintains the patient led portal for access to services - https://KeepingMeWell.com

7. Meetings of the group also invite representatives of third sector partners including Diabetes UK Cymru[1], JRDF[2] and the Mentor Ring[3] to both update on their work within the field across Wales and offer their expertise to further the aims of the group including supporting our outreach to the patient community and using our networks to publicise their support activities for patients.

[1] https://www.diabetes.org.uk/in_your_area/wales

[2] https://jdrf.org.uk/

[3] https://mentorring.org.uk/

8. The AWDPRG also runs a dedicated Young Person's Reference Group to ensure the voices of young people with diabetes are also clearly represented.

Whilst the AWDPRG is grateful for the previous financial support, encouragement, and organisational support of the All Wales Diabetes Implementation Group (AWDiG) and wider NHS Wales Health Collaborative, the AWDPRG asserts that it is established as an independent body whose purpose is to ensure that the patient voice from across Wales is heard on matters relating to Diabetes care in Wales.

4. Background

To give it its full name "Diabetes Mellitus", commonly referred to as "Diabetes" is a disease in which the body's ability to produce or respond to the hormone insulin is impaired, resulting in abnormal metabolism of carbohydrates and elevated levels of glucose in the blood.

9. Whilst the most common forms of the disease within the population[4] are:

- **Type I** - Type 1 diabetes is where your blood glucose (sugar) level is too high because your body can't make insulin.
- **Type II** - When you have Type 2 diabetes the insulin your pancreas makes can't work properly, or your pancreas can't make enough insulin. This means your blood glucose (sugar) levels keep rising.

10. The symptoms of diabetes mellitus, particularly of type 1 diabetes, include going to the toilet a lot, feeling very thirsty, being unexpectedly thinner and feeling tired. Often referred to as the 4 T's of Diabetes.

11. Diabetes is considered a "chronic condition" as in any form it cannot be "cured" it can only be "managed" to minimise the possibility of both short term and long term complications.

[4] https://www.diabetes.org.uk/diabetes-the-basics/types-of-diabetes/diabetes-mellitus

12. More than 209,000 people in Wales are now living with diabetes. This is 8% of the population aged 17 and over - the highest prevalence in the UK - and numbers are rising every year.[5]

13. Management of the condition can be by a combination of diet, exercise, tablets and/or injectables including, most commonly in Type 1 diabetics, the regular injection of insulin to replace the routine function of the pancreas.

14. Management of Type 1 diabetes by means of carb counting and insulin injection, either manually or via a pump devices, has been shown to result in people with Diabetes needing to make an additional 180 decisions per day.

15. There are other, less common types of diabetes mellitus, which Diabetes UK have information about on their website[6]:

- **Gestational diabetes** – this is diabetes that can develop during pregnancy, which normally goes away after you have given birth.
- **Maturity onset diabetes of the young (MODY)** – This is a rare form of diabetes which runs strongly in families.
- **Neonatal diabetes** – This is a form of diabetes that a baby can be diagnosed with below the age of six months.
- **Wolfram Syndrome** - Wolfram Syndrome is a rare genetic disorder which is also known as DIDMOAD syndrome.
- **Alström Syndrome** - Alström Syndrome is a rare genetically inherited syndrome which has a number of common features.
- **Latent autoimmune diabetes in adults (LADA)** – This type of diabetes seems to straddle type 1 and type 2 diabetes, so some people call it type 1.5 diabetes or type 1 ½ diabetes.

[5] https://phw.nhs.wales/topics/diabetes/

[6] https://www.diabetes.org.uk/diabetes-the-basics/types-of-diabetes/diabetes-mellitus

- **Type 3c diabetes** - Type 3c diabetes is a type of diabetes that develops when another disease causes damage to the pancreas.
- **Steroid-induced diabetes** - Steroids can cause high blood sugar levels, so some people who take steroids can go on to develop diabetes.
- **Cystic fibrosis diabetes** – This is a type of diabetes that affects people with cystic fibrosis, and is caused by the build-up of sticky mucus in the pancreas.

16. Our group also regularly considers the implications of co-morbidity or multi-morbidity where an individual patient manages two or more chronic conditions. This can include attempting to resolve conflict between expert clinicians within one field of expertise who do not always understand the diabetes management of the patient as well as the individual does themselves.

17. It is also important to us that we consider the impact of diabetes on carers and the support available to the range of carers which includes formal arrangements for those who require, family who act in a caring role on a regular basis or only during times of difficulty and parents (and others with caring responsibilities for children) of children and young people with diabetes who cannot yet or are learning to manage the condition for themselves.

5. Areas for consideration

The following areas of consideration were proposed by the Health Committee in their call for evidence[7] and we attempt to address each in turn below:

NHS and social care services

The readiness of local NHS and social care services to treat people with chronic conditions within the community.

[7] https://business.senedd.wales/mgConsultationDisplay.aspx?ID=513

Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.

Support available to enable effective self-management where appropriate, including mental health support.

18. Diabetes self-management is demanding and complex. Activities such as monitoring blood glucose, injecting insulin, taking oral medications, regular physical activity and healthy eating all require a comprehensive understanding of diabetes, as well as health coping and skills in problem-solving and risk reduction. Diabetes is more than a physical health condition, it has behavioural, psychological and social impacts and demands high levels of self-efficacy, resilience, perceived control and empowerment.

19. It is estimated that a person with Diabetes make an additional 180 decisions per day[8] than someone without the condition. That amounts to about once every 5 minutes that you are awake.

20. Care for people with diabetes is a collaboration between the individual, their primary care team (GP and Practice nurses) and specialists within their local Diabetes Centre (DSNs, Consultants etc) and their family / support network.

21. During the early stages post-diagnosis ongoing intensive support from specialists such as a Diabetic Specialist Nurse (DSN) is essential and levels of DSN availability are only just returning to normal after resources were re-directed to other streams during the height of the pandemic.

22. Time for routine clinics within diabetes centres is still reduced and where individuals do not actively seek support they can go for extended periods without their management regime being checked and adjusted by a suitable professional. Care is sometimes provided via a series of messages passed backwards and forward via the medical secretary, which though helpful is not ideal.

[8] Research by Stanford University in 2014 - https://scopeblog.stanford.edu/2014/05/08/new-research-keeps-diabetics-safer-during-sleep/

23. Access to training courses such as basic Carb Counting or the more advanced DAFNE[9] (Dose Adjustment for Normal Eating) and the MyDesmond app[10] at the right time for each person are key to being able to maintain self management of the condition.

24. Whilst the NHS across Wales has continued with some of the advancements in remote delivery that came out of necessity during the pandemic, those who would prefer face to face learning are still facing a backlog/waiting list to be able to attend learning necessary to ensure safe and effective management of their condition.

25. One example of emerging support is that Cardiff UHB are working, through their Co-Production Forum, on the formalisation of Peer Support volunteers/workers. This is where a person with diabetes can, in the name of the Health Board and recommended by a DSN, offer to assist either accessing required support or encouraging the active use of proscribed management regimes in a practical way. This is still in early stages but is a model the AWDPRG is keen to see developed in a formal way as existing informal Peer Support is seen by many people with Diabetes as essential to fully understanding their condition beyond what the official line from clinicians can teach us. Some online peer content is available but it is difficult to be confident in the information - online peer support with support from Diabetes health care teams would also support people with Diabetes to manage their condition better.

26. Clear clinical pathways for people with Diabetes are also vital to ensure that, should complications occur, there is a clear escalation route established to obtain the required support. As shown in the AWDPRG Annual Report for 2022-23[11], we have been working with relevant clinical experts to review and update the clinical pathways and also provide supporting materials to explain these pathways to patients as well as ensure that the clinical language is correct.

27. Whilst the AWDPRG has been consulting with clinical professionals on individual pathways, we are concerned that the Welsh Government has yet to provide an updated Diabetes Delivery Plan for Wales and we continue to be working from the Delivery Plan 2016 to 2020[12]. The situation in Wales has changed as has external guidance including NICE guidance with respect

[9] https://dafne.nhs.uk/

[10] https://www.mydesmond.wales/

[11] **All Wales Diabetes Patient Reference Group - Annual Report 2022-2023**

[12] https://www.gov.wales/sites/default/files/publications/2018-12/diabetes-delivery-plan-2016-to-2020.pdf

to the treatment of Diabetes, and these changes are not yet reflected in the strategic delivery plan from the Welsh Government.

28. The National Diabetes Audit should give figures on how many of the 8 essential care processes (defined by NICE Clinical Guidelines and Quality Standards) are being undertaken for people with diabetes each year. It shows how easy this data is to obtain that, in drafting this response, we struggled to find the most recent dataset to be able to quote how low those figures have dropped during and since the pandemic.

29. Further research showed that Wales does not participate in the quarterly updates from GP Practices that NHS England receives/publishes and so the latest data for Wales is currently for 2020-21 with 2021-22 summary data not due to be released until August 2023.[13]

30. Whilst anecdotally services have started to recover and patients should be seeing more of the 8 essential care processes being covered, we do not have access to the data at present to interrogate how far this recovery of service has progressed and, with these stated timescales for the National Diabetes Audit publication, will not until it is too late for the data to be of use with the more than 16 months time lag on the current datasets between action by clinicians and the publication of the reported data.

31. The AWDPRG has made it a priority of engaging with people with Diabetes from minority ethnic communities. Within these communities there is a disproportionately higher level of type 2 diabetes and a lower level of engagement with type 2 diabetes services.

32. There is documented poor engagement with Health services by people from Minority ethnic communities and this can have an impact on their health outcomes.

33. As part of the AWDPRG's awareness work we have put on successful diabetes educational events in areas of higher proportion minority ethnic communities such as Butetown in Cardiff. We have also engaged charities such as The Mentor Ring who are embedded within these communities to ensure that messages about good diabetes management are shared within the community.

34. We have plans to hold similar days for Yemen and Somali communities and to work with the growing refugee populations across Wales but this work can only be done if funding from

[13] https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit

NHS Wales is sufficient and timely to facilitate the work both in expert staffing and in covering venue and publicity costs. The reorganisation of the NHS Collaborative into the NHS Executive has seen all coordinated funding for cross-Wales health projects dry up this year and makes planning for any growth of "All Wales" work impossible.

Multiple conditions

The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.

The interaction between mental health conditions and long-term physical health conditions.

35. As an auto-immune disease, it is not unusual for people with Diabetes to have more than one health condition to manage. Often finding that the interactions between treatment regimes and clinical teams are something that the individual has to manage as the understanding of how a treatment will affect Blood Glucose management is lacking in non-diabetes specialists and DSN resource is scarce.

36. The AWDPRG also supports the call from experts such as Dr Rose Stewart and others (including the Senedd's CPG on Diabetes[14]) through the Diabetes UK campaign for dedicated and specialist psychological support to be made routinely available to people with Diabetes as part of their healthcare team.

37. It is also important when talking about the interaction of mental health conditions and Diabetes the prevalence of #T1DE (Type 1 Disordered Eating). With this condition, individuals adopt a disordered pattern of eating in an attempt to re-gain control over their lives around the symptoms of their Diabetes. The resulting insulin omission can lead to significant difficulties in managing diabetes effectively as a Type I diabetic requires some insulin simply to survive.

38. One of the challenges common amongst people with Diabetes is managing a significant administrative burden juggling tests, appointments, follow ups etc. Systemic change enabling co-scheduling of appointments and tests, along with online booking systems is essential to reduce this burden and associated stress, especially for people with Diabetes in full-time employment.

[14] https://business.senedd.wales/mgOutsideBodyDetails.aspx?ID=785

Impact of additional factors

The impact of the pandemic on quality of care across chronic conditions.

The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.

The extent to which services will have the capacity to meet future demand with an ageing population.

39. The biggest impact for people with Diabetes has been a lack of access to specialist resources we would usually expect. In the most extreme this was where DSNs were taken off specialist Diabetes work and called onto hospital wards to fill other nursing team vacancies.

40. For many people with Diabetes this has meant a reduction in routine interactions with their specialist team and increased difficulty in accessing support at times of crises. For some the inevitable consequence has been that they try less to access that crisis support as it has proven not to be available and so not see the full potential for how their condition could have been managed during this time. This might be through imperfect or unadjusted management dosing reigemes, lack of access to training such as a DAFNE Course or by a pathway to pump therapy that should have been a process of a few months turn into years.

41. Whilst the move to online services has been welcomed by those with the ability to utilise these facilities to increase their engagement with specialist services and minimise the down-time from the rest of their lives that their diabetes management causes. For those who do not have easy access to suitable technology it simply added another burden to managing their diabetes.

42. Feedback on some online provision of Diabetes related learning has also highlighted that trainers were not adequately technically provisioned or proficient to run courses in a digital way and that part of the day was "lost" due to not having the informal interactions with their peers that they would have had if the training had been held in the traditional manner.

43. The AWDPRG would be keen to see learning from the re-development of Retinopathy Services which was done with a user-centred Agile approach taken on by other key services within health boards across Wales. This not only includes specific services but also common processes such as appointment booking/re-arrangement where the current system is not fit for the 21st Century, does not reflect that a person with Diabetes may also have a working life and that managing their condition is one of a number of competing demands on their time.

Prevention and lifestyle

Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).

Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups.

44. Prevention of Type 2 diabetes and some other chronic conditions are known to be linked with lifestyle. A common thread that promotes good health and well being should be engrained in all government departments and their policies in a similar way that equality, diversity and protected characteristics are.

45. For those with Type 1 diabetes, the disease itself cannot be prevented. It is all about the early interventions for prevention of complications which can include loss of sight and lower limb amputations. Our concern here is the lack of basic routine monitoring (including measuring of the HbA1C) that has been seen during the pandemic and the lack of data on the 8 essential care processes being carried out recently for people with diabetes.

6. Summary

46. The AWDPRG is keen to continue a conversation with the Health Committee as you move into further stages of this inquiry.

47. We note the impact that the pandemic had on availability of services and the speed at which some services were able to be offered in new and innovative ways as a result of the change in circumstances.

48. Whilst some service levels are now returning to "normal" there remains a considerable backlog which has increased waiting times for key services and/or seen a decrease in frequency of "routine" appointments with specialist teams to ensure maximum efficiency of condition management for those with long term conditions such as Diabetes.

49. There is some movement forward which groups like the AWDPRG is keen to see done in a User Centred way, not only specific to our own condition but also improvements in technology for remote appointments or online booking that sees the person as a whole (with their co-morbitities) and which understands that the person has more to their life than "just" managing their condition.

50. We highlight to the committee our recent annual report[15] to give a flavour of what a Patient Reference Group can achieve when working in partnership with the NHS Collaborative.

51. Our value as a touch stone in giving a patient perspective is considered by many as a reality check. We are pleased to have been involved with diverse projects over the past year. We have played a key role in the re-organisation of Retinopathy services Diabetic Eye Screening Wales (DESW) post pandemic and the development of a number of diabetes clinical pathways.

52. We highlight our concern that the good work of our group is not currently able to continue as, in the process of the forming of the NHS Executive from the NHS Collaborative, no project funding has yet been made available for groups such as ours to apply for in 2023-24 and any staff seconded to work on a Wales-Wide approach to conditions such as diabetes have only, so far, been confirmed to be in post until September 2023.

53. Not only are we currently not able to build on our previous good work, all of our time is being spent on chasing funding for the basics of holding a meeting, either of the AWDPRG or with our key stakeholders - the people with diabetes across Wales - to ensure that services are being delivered to meet the needs of the People of Wales who need them.

[15] All Wales Diabetes Patient Reference Group - Annual Report 2022-2023