Welcome to the first Annual Report for the Children and Young People’s Wales Diabetes Network.

We have had a busy first year since we formally launched in September 2015. In this report you will read about our achievements as a Network so far, our future aims and aspirations, and the performance of the 14 teams who serve the children and young people of Wales and their families.

We have drawn information from a number of sources to create this report. In addition to the Brecon Group Register of children with Type 1 Diabetes in Wales – which is being recognised as one of the best resources for research into Type 1 diabetes available in the world – we have also looked at the National Paediatric Diabetes Audit (NPDA), the Peer Review quality assurance process, and the Patient Reported Experience Measures (PREM) audit.

We have waited to publish this report so we could include the results of NPDA that was carried out in 2015-16, our first year of operation as a Network. These results were published at the end of February 2017 and we are glad to include them here as a snapshot of how our teams are doing around Wales.

These important measures all point to common challenges for teams across Wales. Staff time is an important one, especially dedicated time for diabetes from dietetic and psychology members of the teams. Access to technology, such as insulin pumps, is another area highlighted in all the audits. But generally the picture we are seeing is one of high quality care being delivered despite the many challenges our teams face, and overall improvement in key clinical outcomes such as average levels of blood glucose (HbA1c).

We are committed as a network to challenging ourselves to provide the best possible person-centred care for the children and young people we serve. Diabetes is a life-changing condition for children and their families and the resilience, adaptability and courage of these young people as they live with this condition inspires us all to work hard to ensure the impact of diabetes on their lives is reduced as much as possible.

Chris Bidder
Dr Chris Bidder, Clinical Lead, CYPWDN

Follow us on Twitter @CYPDN_Wales
Structured education rolled out across Wales
The SEREN course explains diabetes and its successful management in an accessible and engaging way. Developed entirely in Wales by members of the Brecon Group, the project made rapid progress following the formation of the Network and Welsh Government investment. In March 2016, team members from every paediatric unit in Wales were trained to deliver the course to newly-diagnosed children aged 11 and over. Versions for children under the age of 11, and a parents book, are now in development and are due for delivery in early 2017.

Having one programme in place across Wales means the CYPWDN can guarantee all children who are diagnosed in Wales receive all the information they need to help them adapt to life with diabetes. SEREN has been presented to the national Children and Young People’s Diabetes Network, which includes all the regional networks in England. There is much interest from the English networks in using SEREN as well. This is a great example of the work in Wales having a far-reaching impact outside Wales too.

Promoting the rights of children with diabetes
The CYPWDN has collaborated with Diabetes UK Cymru and over 15 other leading health and children’s organisations in discussions about ensuring children and young people with medical conditions in Wales have the same statutory protection in school as children in England. Schools in England have to ensure children with diabetes receive support for their medical needs and have access to the same opportunities and activities as other children. Because of a difference in the law, children in Wales do not have this protection. While many schools provide admirable care for children with diabetes, we have heard cases of schools refusing to help children administer insulin or other treatments, and being excluded from certain activities.

The CYPWDN co-authored “An Excellent Chance” with staff from Diabetes UK Cymru. This evidence document gathered the experiences of healthcare professionals in Wales and also from families, as it made the case for a change in the law in Wales. It has been presented to the Welsh Government as they consider their legislative agenda. The issue of statutory protection to end discrimination has also been raised through the CYPWDN in Welsh Government consultations.

Sharing learning and best practice
We have held our first network meetings, attended by staff from every health board. Key issues affecting teams across Wales have been discussed. The meetings also provide an opportunity to discuss and agree national guidelines and standards.
How we know how well we are doing

There are three main measures we use to monitor how well we care for children and young people with diabetes and their families. These three measures are:

**The National Paediatric Diabetes Audit (NPDA),** which includes data from all paediatric units in England and Wales. This records whether people get the recommended levels of care they should, and also how well children and young people are supported to manage their blood glucose levels (HbA1c).

**Peer Review,** which reviews what each unit does by looking at their policies, procedures and the way units are structured. This looks especially at whether there are any risks or issues that should be concerning in the ways care is provided.

**Patient Reported Experience Measures (PREM)** are also collected over several months and give children and young people, their parents and carers the opportunity to say what they think is good about the service and where they think it could be improved. Quotes from the PREM have been included on the pages for each health board.

All units in Wales were peer reviewed in June 2016.

Information from the National Paediatric Diabetes Audit (NPDA)
These graphs show how the units in Wales performed compared to the national average in 2015-16, the most recent published data. We have numbered the units to make it easier to find out how units are performing. Scoring in the ‘funnel’ in the middle of the graph means a unit is providing care that matches other units. Scoring outside the funnel indicates a unit has either done much better than average, or does not seem to be providing care to the same level as other units.
NPDA scores for Paediatric Diabetes Units in Wales

KEY (Hospitals listed alphabetically by health board): 1) Morriston Hospital  2) Neath Port Talbot Hospital  3) Princess of Wales Hospital  4) Nevill Hall Hospital  5) Royal Gwent Hospital  6) Glan Clwyd Hospital  7) Wrexham Maelor Hospital  8) Ysbyty Gwynedd  9) University Hospital of Wales  10) Prince Charles Hospital  11) Royal Glamorgan Hospital  12) Bronglais Hospital  13) Glangwili Hospital  14) Withybush Hospital

Common issues in the Peer Review
Across Wales we have seen similar issues raised in the peer review process for almost all our units. The main concerns are over the number of qualified staff and the availability of expert advice at night and weekends. There are also concerns about access to dietitians and psychologists. Issues for individual units are mentioned on the Health Board pages.

The PREM Score
All our patients who took part in the PREM were asked how likely it would be that they would recommend the clinic to friends or family using a 0-10 scale. We have included the average score for every unit on their pages.

Network plans, priorities and projects

The Network has identified priority areas that will make a real difference to the lives of children and young people with diabetes and their families.

The Network has supported the introduction of the SEREN structured education programme in all parts of Wales. Children diagnosed with Type 1 diabetes in Wales now receive the same complete education package wherever they live in Wales.

Members of the Network have worked alongside Diabetes UK Cymru to persuade Welsh Government to introduce a statutory duty to ensure the healthcare needs of children are met in schools. While there are many schools offering superb care, there are still children who are excluded from school activities or are unable to safely treat their diabetes in school. In England children have a legal protection if they have healthcare needs and the Network would like to see a similar legal protection for children in Wales.

Improving care in schools

Moving on from paediatric services to regular diabetes services is often referred to as Transition. This process varies across different health boards and many young people find it difficult. The Network is contributing towards an all-Wales standard for Transition services.

Improving Transition services across Wales

Parents play an essential part

Three parents have agreed to become part of the network as Parent Representatives. The SEREN programme in particular has benefitted from input from parents sharing their experience and knowledge to help shape the course.

Nicky and Emma, two of our parent reps

We are working closely with the new NHS Wales Transitional Care Co-ordinator to improve care for the young adults who move on from our services.
Our Network has laid out plans for a national ‘out of hours’ service meaning parents and young people can access specialist advice 24 hours a day. This service should be provided under NICE guidelines. The Network’s proposal is currently being considered by Welsh Government.

It is very important for children to be tested immediately if they display symptoms of Type 1 diabetes. The Network is exploring ways to increase awareness of the symptoms of Type 1 diabetes and make sure GPs and community healthcare staff perform blood glucose tests on children and young people who have the symptoms.

As a Network we are also supporting the drive towards consistent approaches to providing insulin pumps, continuous glucose monitoring and other technology in all clinics in Wales.

For the latest developments visit www.cypdiabetesnetwork.nhs.uk/wales
Abertawe Bro Morgannwg University Health Board

Clinics in:
- Morriston Hospital (Swansea)
- Neath Port Talbot Hospital
- Princess of Wales Hospital (Bridgend)

Achievements 2015-16

New staff – the team has increased with the addition of a Diabetes dietitian, a clinical psychologist, two nurses, and an administrator. Link nurses have been established to support the specialist nurses and prepare for future staffing changes. The clinical psychology service is completely new for paediatric services in the health board.

Technology – The team has started using new software to improve audit submission rates and save time on collecting data.

Education – SEREN, the all-Wales structured education programme is being used throughout the health board. The team has also run a diabetes education update for healthcare professionals across the health board.

Engaging with children and young people – the team ran a weekend children’s summer camp at Llangranog, and also a successful weekend autumn camp for teenagers in Llangorse.

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Median Average HbA1c</th>
<th>% receiving 7 Care processes</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>2014-15</td>
<td>2015-16</td>
</tr>
<tr>
<td>Morriston</td>
<td>69.4</td>
<td>66.0</td>
</tr>
<tr>
<td>Neath Port Talbot</td>
<td>70.0</td>
<td>66.0</td>
</tr>
<tr>
<td>Princess of Wales</td>
<td>71.5</td>
<td>65.0</td>
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Children and Young People’s Wales Diabetes Network (& Brecon Group)
We have always received the best care and treatment from the consultant, registrar and specialist nurses. They always listen to my concerns, which as a parent is extremely important."

– Parent, Morriston Hospital

The team are very supporting and can also give me advice whenever I need it. Whether I am at home or at clinic ... my team have helped me with every query that I have had."

– Child, Neath Port Talbot Hospital

### Risks and Concerns

#### 2014
- **Immediate Risk**
  - Dietitian time

#### 2016
- **Immediate Risk**
  - Nursing time due to sickness / maternity leave

- **Serious Concern**
  - Consultant time
  - Nursing time
  - No psychologist
  - Cover arrangements
  - Insufficient clinics

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We have always received the best care and treatment from the consultant, registrar and specialist nurses. They always listen to my concerns, which as a parent is extremely important."

– Parent, Morriston Hospital

The team are very supporting and can also give me advice whenever I need it. Whether I am at home or at clinic ... my team have helped me with every query that I have had."

– Child, Neath Port Talbot Hospital
Aneurin Bevan University Health Board

Clinics in:  
- Nevill Hall Hospital (Abergavenny)  
- Royal Gwent Hospital (Newport)

Engaging with children and young people – the Gwent children’s diabetes team continue to run fun, age appropriate and educational activities outside the clinic setting. During the past 12 months we have run a family evening, a Christmas party for the under fives, an activity day for the 8-13s at Hilston Park and a teenage activity day at the Celtic manor. We have also run a dedicated education and activity day for all the year six children in preparation for their transition to secondary school. These activities were all well supported with good feedback.

Achievements 2015-16

New staff – our team has seen some changes with new consultants, a new nurse, a new dietitian and psychology support introduced for the first time. The team is working on a business case for a full time psychologist to work in the team. The team has also benefited from the appointment of a new administrator.

Technology – the team has introduced ‘point of care’ HbA1c testing in all the paediatric and adolescent diabetes clinics since November 2015. This has been really well received by the children and their families as it is a much easier process.

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<tr>
<td></td>
<td>2014-15</td>
<td>2015-16</td>
</tr>
<tr>
<td>Nevill Hall</td>
<td>71.0</td>
<td>69.5</td>
</tr>
<tr>
<td>Royal Gwent</td>
<td>68.0</td>
<td>64.5</td>
</tr>
</tbody>
</table>
Risks and Concerns

2014
Immediate Risk
None identified

Serious Concern
- No ‘point of care’ HbA1c testing in clinics
- No psychologist
- Insufficient clinic capacity

2016
Immediate Risk
None identified

Serious Concern
- Unclear provision of psychology services
- Insufficient clinic capacity
- Out of hours support and advice for hospital in-patients

Peer Review

Our nurses have always offered us fantastic support and have also gone above and beyond our expectations of them.”
– Parent, Royal Gwent Hospital

Excellent in all areas. Amazing, friendly and always available and more than happy to help when needed.”
– Parent, Royal Gwent Hospital

Achievements 2015-16

Improved clinic experience – all 3 hospitals in the health board now use software to download information from meters and pumps, and provide ‘point of care’ HbA1c testing in clinics, to enable staff to offer individualised care to families.

Access to technology – insulin pump use is increasing in all three centres in the health board and this will improve with the recruitment of more staff.

Education – staff members from the health board have played an integral role in the development of the SEREN programme, and the paediatric teams now deliver the SEREN programme to young people who have been diagnosed with diabetes. Additional education sessions and courses are offered to children and young people, including sessions on carbohydrate counting, moving to high school, and using insulin pumps safely.

Team funding approved – all three teams have had funding for additional nursing, psychology, dietetic support and clerical support. These roles will ensure greater support is available to children and young people, and their families.

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<tr>
<td></td>
<td>2014-15</td>
<td>2015-16</td>
</tr>
<tr>
<td>Wrexham</td>
<td>66.1</td>
<td>65.0</td>
</tr>
<tr>
<td>Glan Clwyd</td>
<td>73.0</td>
<td>67.0</td>
</tr>
<tr>
<td>Ysbyty Gwynedd</td>
<td>65.5</td>
<td>65.0</td>
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Children and Young People’s Wales Diabetes Network (& Brecon Group)
The team... make you feel heard and welcome and that you can speak and tell them your problems.”
– Child, Wrexham Maelor Hospital

The care from the doctor and diabetic nurse has been great and very helpful for us as a family.”
– Parent, Ysbyty Gwynedd

### Risks and Concerns

#### 2014

**Immediate Risk**
- Dietitian time

**Serious Concern**
- Consultant time
- PDSN time
- Psychologist time
- No POC HbA1c
- Cover arrangements
- Insufficient clinics
- Ward staff training
- Lack of a young adult service

#### 2016

**Immediate Risk**
- Dietitian time

**Serious Concern**
- PDSN time
- Psychology support

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Peer Review
Cardiff & Vale University Health Board

Clinics in: University Hospital of Wales (Cardiff)

Achievements 2015-16

New staff – the team now has a diabetes dietitian, a clinical psychologist, an extra nurse and an extra paediatric consultant. Funding has also been received for a schools diabetes educator. This has improved the educational packages and relationships with schools caring for children with diabetes.

Technology – clinics now have ‘point of care’ HbA1c testing meaning blood tests can be carried out in clinics. There is also a downloading facility for blood testing devices meaning clinical decisions can be based on more data.

Increased time – the clinic is now NICE and peer review compliant with 30 minute consultation times and 3 monthly appointments.

New clinic – the Llandough clinic started in April 2016 making it easier for families in the Vale of Glamorgan to attend clinic.

<table>
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<tbody>
<tr>
<td>UHW</td>
<td>72.0</td>
<td>64.0</td>
<td>75%</td>
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Children and Young People’s Wales Diabetes Network (& Brecon Group)
Diabetes has changed my life, but the clinic team have helped me get my life as normal as possible with constant support.”
– Child

“I feel safe in the knowledge that I can contact a member of the team at any time with any concerns I may have and messages are responded to promptly.”
– Parent

**PREM Score**
University Hospital of Wales
9.3

**Risks and Concerns**

<table>
<thead>
<tr>
<th>Year</th>
<th>Immediate Risk</th>
<th>Serious Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>None identified</td>
<td>Dietitian time, No psychologist, Study leave cover arrangements, No POC HbA1C</td>
</tr>
<tr>
<td>2016</td>
<td>None identified</td>
<td>Transition service</td>
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**Annual Report**
September 2015 – September 2016

*Peer Review*

The Cardiff paediatric diabetes team
Cwm Taf University Health Board

Clinics in:  
- Prince Charles Hospital (Merthyr Tydfil)  
- Royal Glamorgan Hospital (Llantrisant)

Achievements 2015-16

More clinics – increased number of diabetes clinics so that children and young people have the required number of clinical appointments, in line with national standards.

Increased staff time – an additional consultant paediatrician joined the team at Prince Charles Hospital, and the dietetic service has expanded with a dedicated paediatric dietitian for children’s diabetes services across the health board.

Improved use of technology – staff are now able to upload insulin pump and glucose meter data in clinic, to enable children and families to gain a greater understanding of their diabetes.

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<td>2014-15</td>
<td>2015-16</td>
</tr>
<tr>
<td>Prince Charles</td>
<td>61.0</td>
<td>60.0</td>
</tr>
<tr>
<td>Royal Glamorgan</td>
<td>66.0</td>
<td>62.0</td>
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</table>
**PREM Score**

Prince Charles Hospital
8.7

Royal Glamorgan Hospital
8.6

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**Good support, nice in clinic and all my questions are answered.”**
– Child, Royal Glamorgan Hospital

**They are always there should I need help with my daughter and I would happily recommend this clinic to others.”**
– Parent, Prince Charles Hospital

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**Risks and Concerns**

**2014**

Immediate Risk
None identified

Serious Concern
- Dietetic time
- PDSN time
- Psychologist time (inequity)

**2016**

Immediate Risk
- PDSN time
- Psychology time
- Dietetic time

Serious Concern
- Consultant time
- Transition

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Peer Review

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Members of the Cwm Taf paediatric diabetes teams
Hywel Dda University Health Board

Clinics in:  
- Bronglais Hospital (Aberystwyth)  
- Glangwili Hospital (Carmarthen)  
- Withybush Hospital (Haverfordwest)

Achievements 2015-16

New ways of working and an expanded team – While the health board is still recruiting to some posts, our team has increased with the addition of a new paediatric diabetes specialist nurse based in Bronglais Hospital. Children and young people are now also benefitting from the addition of a Psychologist with one day a week dedicated to diabetes. The team now has a consolidated one team approach across all 3 units, ensuring the same level of care is received by children and young people wherever they live in the health board. The team are actively hoping that funding will become available to implement the recommendations from the recent peer review process.

Developing the national education programme – Two members of the Hywel Dda diabetes team have taken instrumental roles in the development of the SEREN diabetes education programme. SEREN is now being used across Wales to help children and families following a diagnosis of diabetes.

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<td>Bronglais</td>
<td>66.0</td>
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<td>Glangwili</td>
<td>65.0</td>
<td>64.0</td>
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<tr>
<td>Withybush</td>
<td>70.3</td>
<td>67.3</td>
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Children and Young People’s Wales Diabetes Network (& Brecon Group)
PREM Score
Bronglais Hospital
8.9

PREM Score
Glangwili Hospital
9.2

PREM Score
Withybush Hospital
N/A

They’re friendly and kind and they listen to you.”
– Child, Glangwili Hospital

All members of the diabetes team are very approachable and helpful and make us feel at ease. My child and I always look forward to his next clinic visit.”
– Parent, Bronglais Hospital

Risks and Concerns

2014
Immediate Risk
- PDSN role unfilled
- Dietitian time

Serious Concern
- Consultant time
- PDSN time
- No Psychologist

2016
Immediate Risk
- Dietitian time
- PDSN time

Serious Concern
- Admin support
- Travel times for nursing staff
- Staff-patient ratio and need for more nursing staff
- Psychology time
Looking ahead for 2016 - 17

Our priorities for 2016-17 are:

- Develop new modules in our SEREN structured education programme and evaluate the way the programme is being used in Wales
- Continue advocating for the rights of children to have their medical needs supported in schools
- Develop an out of hours service to provide specialist advice for families
- Support the introduction of an all-Wales standard for Transition services
- Develop a quality improvement programme that will help all our units provide better care to patients
- Work with primary care colleagues to improve the diagnosis of diabetes in children and young people, and reduce the number of cases of diabetic ketacidosis

Contact us

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