



# 2019 Annual Report

**Supporting children and young people with diabetes in Wales**

[www.cypdiabetesnetwork.nhs.uk/wales](http://www.cypdiabetesnetwork.nhs.uk/wales)

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# Hello, and welcome to our Network's Annual Report for 2019

This report is being written while NHS Wales faces the huge challenge of a global pandemic. In this unsettling situation it is really worthwhile to look back and reflect on the progress made in calmer times.

The NPDA results for Wales again show national improvement. The average HbA1c for young people cared for by teams in Wales has dropped again, with a drop of over 6 mmol/mol since the Network began in 2015. This represents a real improvement in potential health benefits for the young people we care for and teams should feel justly proud about this achievement.

## More than just data

However, life with diabetes is much more than just HbA1c scores – a point that was made by 15 year old Emily, who spoke at our Network Meeting in May 2019. Emily described how she felt about her diabetes in a passionate and moving way. I am so grateful to all the people who have diabetes, or who have family members with diabetes, who have spoken at our events. They inspire us to keep trying to deliver the best care possible.

We have all also been inspired by the story of Hypo Dino (see page 3). This great story book was written by Katie, who has Type 1 diabetes, and illustrated by her friend, Ava. Tim Dinosaurus – the Hypo Dino – faces lots of challenges in his job as a spy, and managing his diabetes is one of them!

Hypo Dino is a great story that has struck a chord with people with diabetes. It is the first resource published by our Network actually written by a child with diabetes and we are really grateful to Katie and Ava for sharing their creation with us.

There is much for us to be proud of as a Network, as you will find out in the pages of this report!

With best wishes,

**Dauida Hawkes**

Dr Dauida Hawkes  
Chair, Children and Young People's Wales Diabetes Network

Follow the Network on Twitter @CYPDN\_Wales  
Email the network on [cyp.diabetesnetwork@wales.nhs.uk](mailto:cyp.diabetesnetwork@wales.nhs.uk)

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# Living with diabetes

In November 2019, the Children and Young People's Wales Diabetes Network published 'Hypo Dino' - the adventures of Tim Dinosaurus, a heroic dinosaur spy foiling the plans of an evil villain. As well as his superhero style missions, Tim has an additional challenge to overcome, because he also has to manage his Type 1 diabetes.

Hypo Dino is the creation of Katie Courtney and Ava Morgan, both age 9. Katie was diagnosed with Type 1 diabetes in June 2017. Shortly after her diagnosis the girls were inspired to start writing and illustrating a book about Hypo Dino and his adventures after a local author visited their school.

Katie brought the picture book to one of her clinic appointments, and her team asked if she would be willing to share it with other children in Wales.

"Tim is not just a dinosaur, he is a dinosaur spy," explains Katie. "And he also has Type 1 diabetes. Sometimes on a mission he has a hypo which stops him from battling his enemy, the evil Doctor Nocter."

Carol Fraser is a Paediatric Diabetes Specialist Nurse in the Paediatric Team at Morriston Hospital, and has known Katie and her family since Katie was diagnosed. "When Katie showed us her book, we thought it was great," she says. "It's funny, and we think a lot of children will relate to hypos sometimes getting in the way of important stuff, like battling evil geniuses and saving the world."

"As it's written by the girls, we're hopeful that other young children faced with a diagnosis of Type 1 will identify with Hypo Dino. It also sends out the positive message that while



Type 1 diabetes is a challenge, and can sometimes get in the way, it shouldn't stop you from having fun and following your dreams."

Further adventures of Tim Dinosaurus may follow as Katie and Ava have already started working on sequels to the original. "We are working on a story of when Tim goes on holiday," says Ava. "And also another book about Tim having to be brave when he goes to get his blood tests done. I enjoy drawing the dinosaur when Katie writes the stories."



**Hypo Dino is available for all children with Type 1 diabetes in Wales through their clinics. Copies can also be requested from the Children and Young People's Wales Diabetes Network**

# 2019 in the Wales Network



SEREN Active, a new education module, was launched to help children and young people understand how to manage their diabetes on a day-to-day basis. (In this photo: Claire from the Swansea Bay team and Will from Ysbyty Glan Clwyd)

Parents from Hywel Dda University Health Board who use 'closed loop' systems talked about their experiences with members of teams from across Wales, to increase knowledge and understanding among healthcare professionals. (In this photo: Simon and Krystle from the Hywel Dda team with the parent speakers after the meeting)



Several children with Type 1 diabetes, and their families, climbed Pen Y Fan together in April, supported by the Network, 1BloodyDrop, Diabetes UK Cymru and MyLife Diabetes





SEREN Connect, a new course about life with diabetes, was launched at the NHS Wales Diabetes Professional Conference in September. SEREN Connect has been written by Sara Crowley, the NHS Wales Transitional Care Co-ordinator, and is being rolled out by paediatric and adult diabetes teams across Wales

NHS Wales teams were very successful at the 2019 Quality in Care Diabetes Awards. The new referral pathway for primary care developed in Cardiff & Vale University Health Board (and rolled out nationally by the Network) and the Wrexham Maelor Transition Team both won awards. The Cardiff & Vale Paediatric Diabetes Team were highly commended for a futsal project, and the NHS Wales standard for young people moving to adult services was also highly commended



Our Network established new working groups in 2019. The Schools Group aims to improve care for young people with diabetes in educational settings. The Guidelines Group is working to standardise policies and procedures across Wales. The Psychology Working Group brings together all the psychologists working in paediatric diabetes teams in Wales to share expertise and improve care through working together.

# Measuring quality of care for children and young people with diabetes in Wales

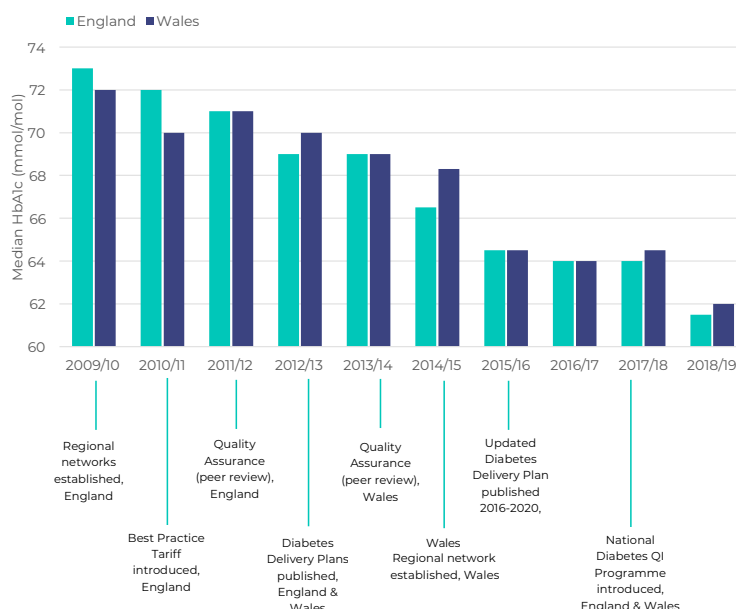
## How are we doing in Wales?

The National Paediatric Diabetes Audit (NPDA) measures the quality of care we deliver, and the outcomes for children and young people. In this report we have selected some important categories that show how well teams are delivering care and supporting young people.

### A national view

We use HbA1c as the main indicator of successful management of diabetes by children and young people in Wales. This year the median average HbA1c has reduced to 62 mmol/mol in Wales. The chart (right) shows how this means HbA1c has dropped by 10 mmol/mol in the past 10 years.

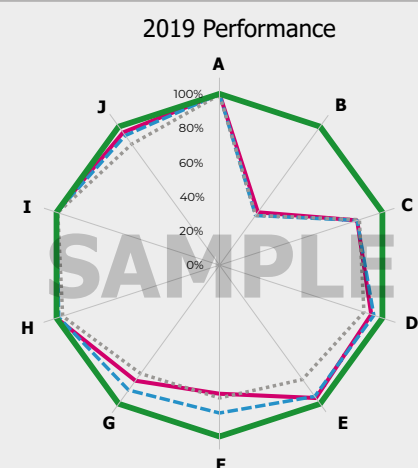
We have published the median HbA1c rates for each unit on the health board pages. The NPDA recommends using the unit median HbA1c to review year on year progress, because the median score is less affected by extreme results.



The NPDA also published two "spotlight audits" in 2019. The Technology Audit showed that, overall, insulin pump use in Wales is less than the average for England and Wales. However, there is variability in the Network, with some units exceeding the national average. The Workforce Audit revealed that the total number of staff in diabetes teams in Wales is slightly greater, on average, than in England, but again there is variability between teams in terms of staff numbers.

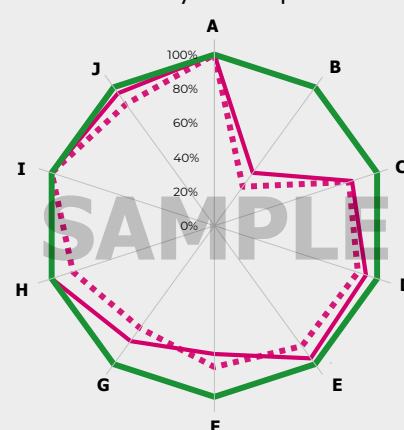
## Understanding the radar plot diagrams

Every unit is measured on their performance on key areas. Using 'radar plot' diagrams we can see whether young people are receiving the care that they need and the outcomes of that care. On each diagram there are four lines. There are two radar plots for each unit in the network.



The green line is the target – 100%. The grey line is the average for England and Wales. The blue line is the average in the Wales Network. The red line is how the individual unit has scored in the NPDA.

## Year-on-year Comparison

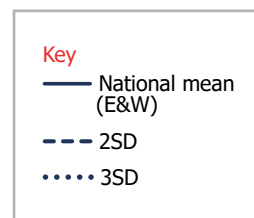


The green line is the target – 100%. The solid red line is how the individual unit has scored in the NPDA in 2018-19. The dashed red line is the individual unit's data from the NPDA in 2017-18.

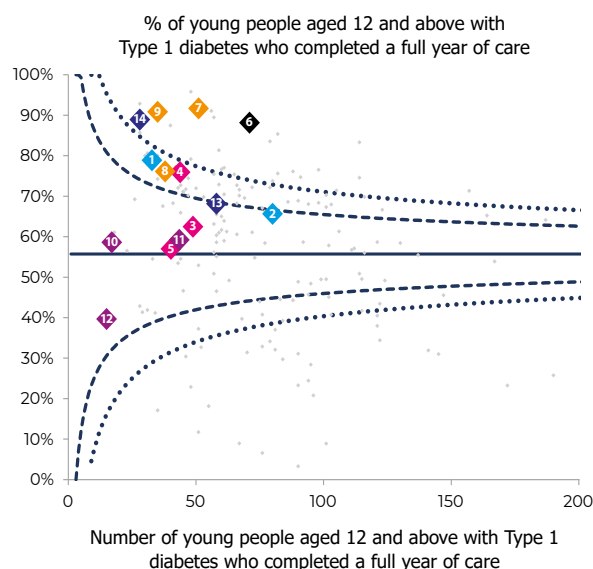
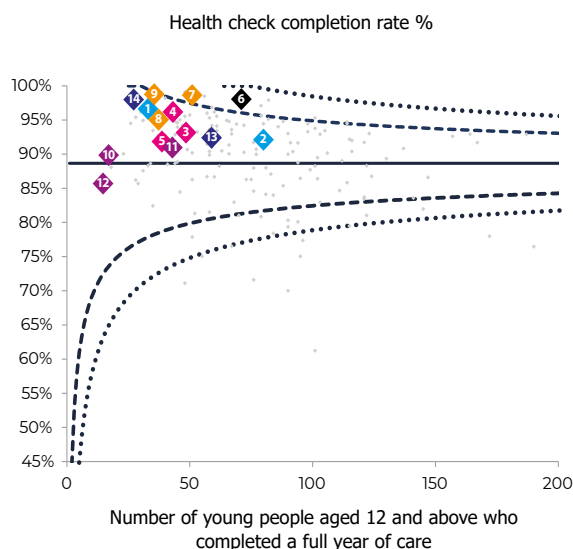
## Information from the National Paediatric Diabetes Audit (NPDA)

These graphs show how the units in Wales performed compared to the national average in 2018-19, the most recent published data, and also variation between units. We have numbered the units to make it easier to see how units are performing.

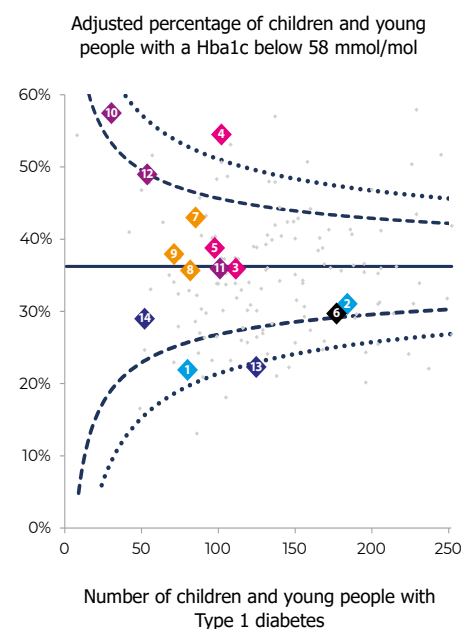
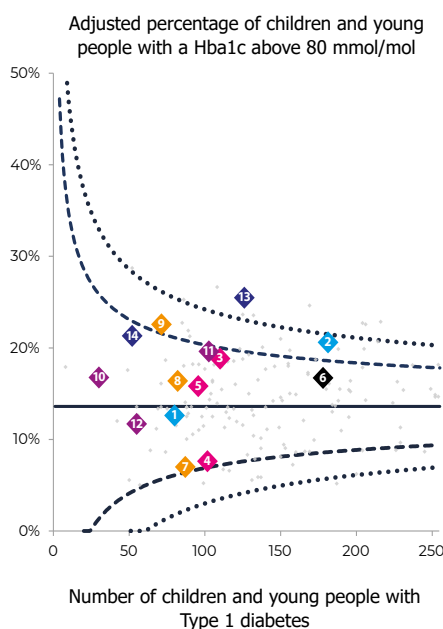
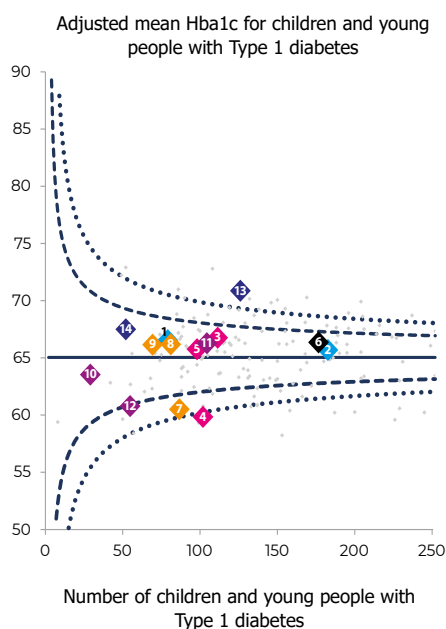
If a unit is in the 'funnel' in the middle of the graph, then that unit is providing care that matches other units. The dotted lines indicate units whose results are within "two standard deviations" or "three standard deviations" of the average. Being placed outside the funnel indicates a unit has either done much better than average, or is not recorded as providing care to the same level as other units. The NPDA classes units over 2 SDs from the average as an 'alert', and over 3 SDs as an 'alarm'.



### Delivery of care processes



### HbA1c outcomes



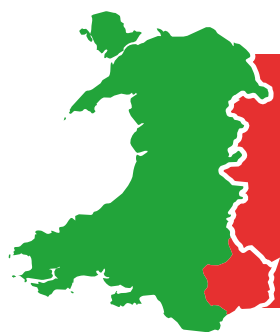
### NPDA scores for Paediatric Diabetes Units in Wales

#### KEY:

- 1) Nevill Hall Hospital
- 2) Royal Gwent Hospital
- 3) Glan Clwyd Hospital
- 4) Wrexham Maelor Hospital

- 5) Ysbyty Gwynedd
- 6) University Hospital of Wales
- 7) Prince Charles Hospital
- 8) Princess of Wales Hospital
- 9) Royal Glamorgan Hospital

- 10) Bronglais Hospital
- 11) Glangwili Hospital
- 12) Withybush Hospital
- 13) Morriston Hospital
- 14) Neath Port Talbot Hospital



# Aneurin Bevan University Health Board

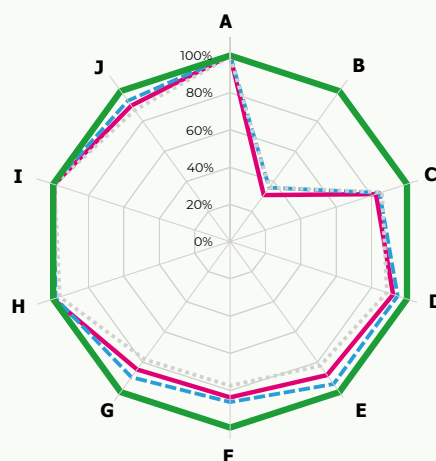
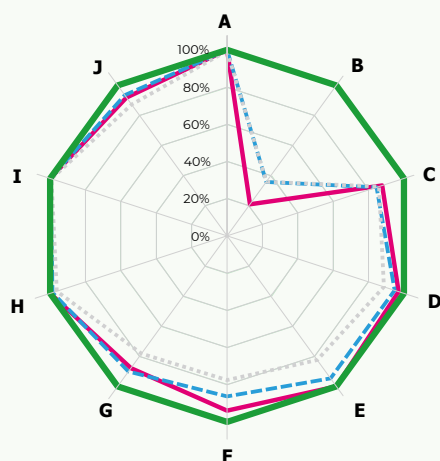
## Nevill Hall

(87 patients)  
Pump patients 18.8%  
(2018: 17.2%)

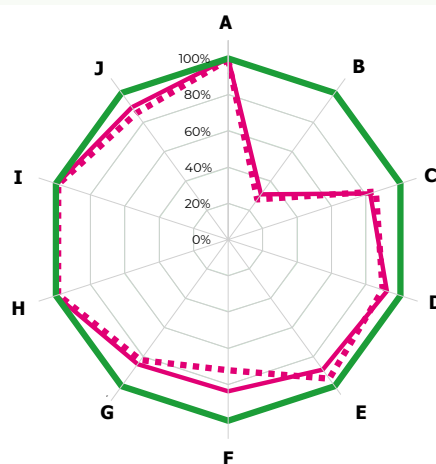
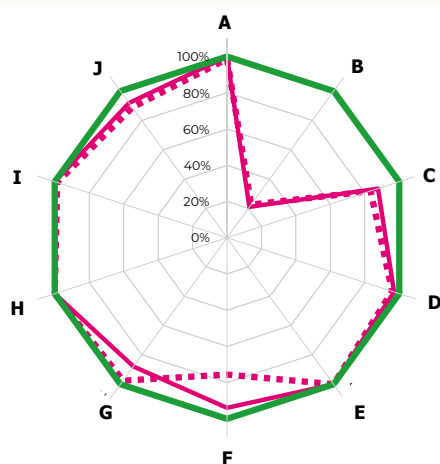
## Royal Gwent

(206 patients)  
Pump patients 26.6%  
(2018: 24.2%)

2019 Performance



Year-on-year Comparison



Median HbA1c	% receiving all 7 essential checks	
66.0	2019	78.8
67.8	2018	73.2
68.0	2017	68.1
69.5	2016	63.4
71.0	2015	n/a
5 year change: ▼ 5 mmol/mol		
4 year change: ▲ 15.4 percentage points		

Median HbA1c	% receiving all 7 essential checks	
62.0	2019	66.3
63.0	2018	55.7
63.0	2017	66.7
64.5	2016	50.1
68.0	2015	n/a
5 year change: ▼ 4 mmol/mol		
4 year change: ▲ 16.2 percentage points		

■ Unit performance 2019 ■ Unit performance 2018 ■ Wales ■ England and Wales ■ Goal target

A - HbA1c health check (%); B - Adjusted % HbA1c <58 mmol/mol; C Unadjusted HbA1c <80 mmol/mol D - Health check completion rate\* (aged 12+); E - Foot exam health check (aged 12+) (%); F - Eye screen health check (aged 12+) (%); G - Albuminuria health check (aged 12+) (%); H - BP health check (aged 12+) (%); I - BMI health check (%); J - Thyroid health check (%)





# Betsi Cadwaladr University Health Board

## Glan Clwyd

(118 patients)  
Pump patients 9.6%  
(2018: 7.4%)



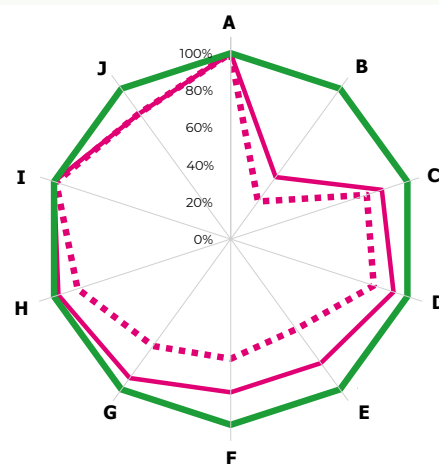
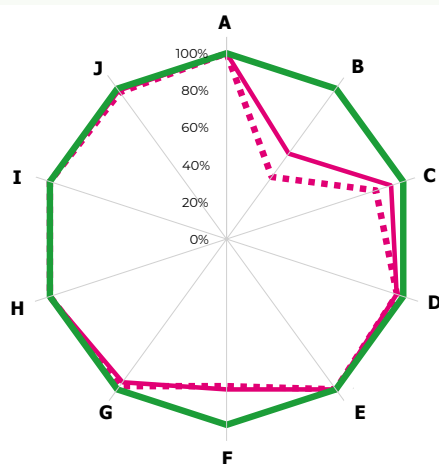
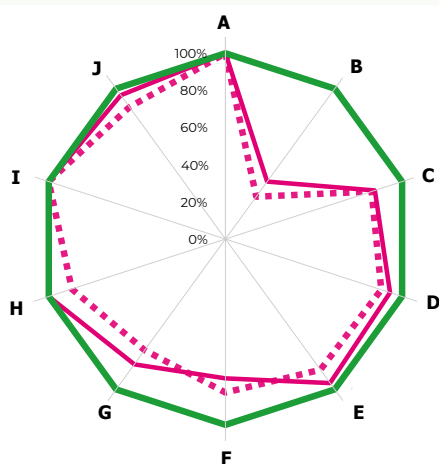
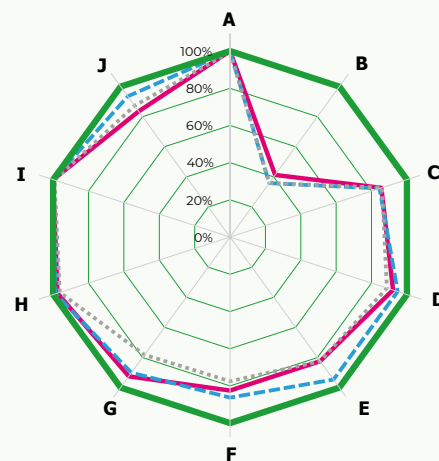
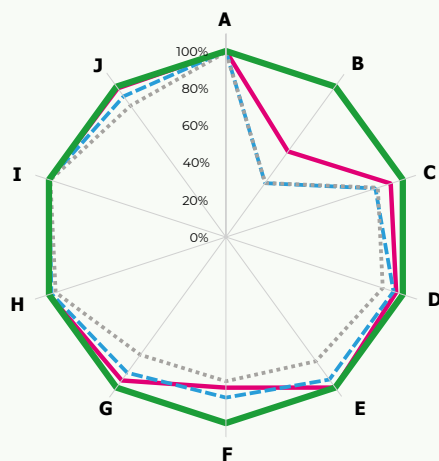
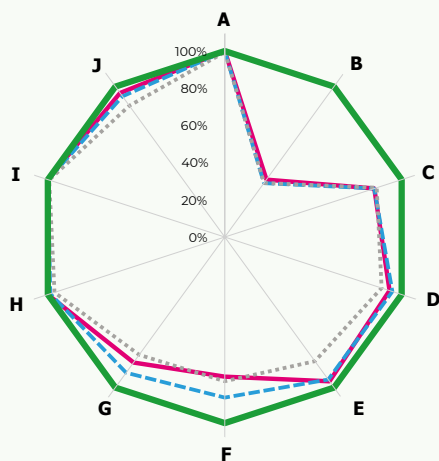
## Wrexham

(109 patients)  
Pump patients 31.7%  
(2018: 26.9%)



## Gwynedd

(102 patients)  
Pump patients 19.8%  
(2018: 16.8%)



Median HbA1c	% receiving all 7 essential checks	
61.5	2019	62.5
65.5	2018	56.5
63.0	2017	38.9
67.0	2016	39.3
73.0	2015	n/a
5 year change: ▼ 11.5 mmol/mol		
4 year change: ▲ 23.2 percentage points		

Median HbA1c	% receiving all 7 essential checks	
55.8	2019	76.2
60.0	2018	77.1
59.0	2017	89.1
65.0	2016	85.0
66.1	2015	n/a
5 year change: ▼ 10.3 mmol/mol		
4 year change: ▼ 8.8 percentage points		

Median HbA1c	% receiving all 7 essential checks	
61.0	2019	57.5
66.8	2018	26.7
64.3	2017	10.6
65.0	2016	0.0
65.5	2015	n/a
5 year change: ▼ 4.5 mmol/mol		
4 year change: ▲ 57.5 percentage points		

■ Unit performance 2019 ■ Unit performance 2018 ■ Wales ■ England and Wales ■ Goal target

A - HbA1c health check (%); B - Adjusted % HbA1c <58 mmol/mol; C Unadjusted HbA1c <80 mmol/mol D - Health check completion rate\* (aged 12+); E - Foot exam health check (aged 12+) (%); F - Eye screen health check (aged 12+) (%); G - Albuminuria health check (aged 12+) (%); H - BP health check (aged 12+) (%); I - BMI health check (%); J - Thyroid health check (%)



# Cardiff & Vale University Health Board

All the NPDA measures for every unit in Wales can be accessed through **NPDA Results Online** you can compare units to each other across a whole range of metrics; including population statistics like ethnicity; whether children and young people receive psychological screening; delivery of carb counting education; numbers of children with other autoimmune conditions; emergency hospital admissions, and much more.

Visit [www.rcpch.ac.uk/resources/npda-results-online-find-your-results-national-paediatric-diabetes-audit](http://www.rcpch.ac.uk/resources/npda-results-online-find-your-results-national-paediatric-diabetes-audit) to access all the different figures

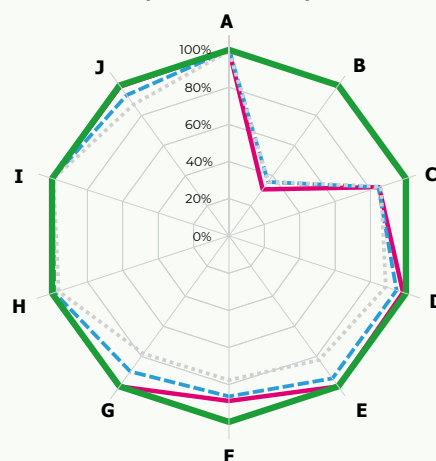
## University Hospital of Wales

(206 patients)

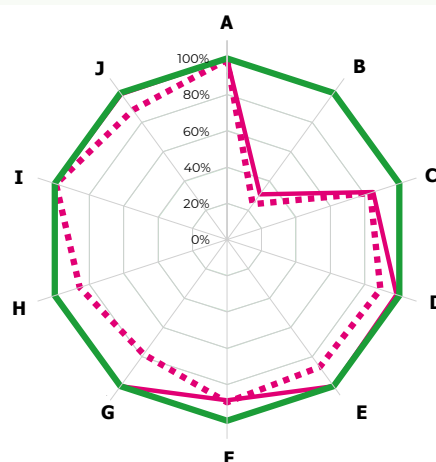
Pump patients 33.3%  
(2018: 33.5%)



2019 Performance



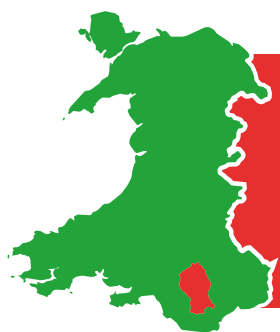
Year-on-Year Comparison



Median HbA1c	% receiving all 7 essential checks	
63.0	2019	88.7
65.8	2018	69.9
66.0	2017	73.0
64.0	2016	75.0
72.0	2015	n/a
5 year change:		4 year change:
▼ 9 mmol/mol		▲ 13.7 percentage points

■ Unit performance 2019 ■ Unit performance 2018 ■ Wales ■ England and Wales ■ Goal target

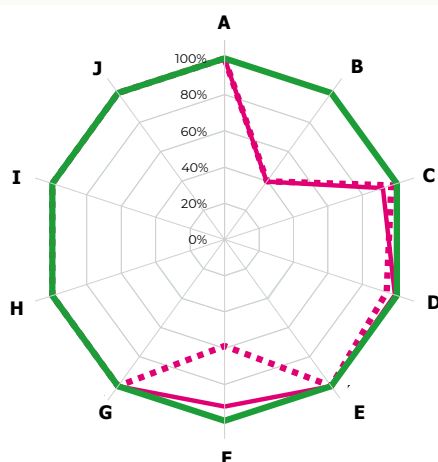
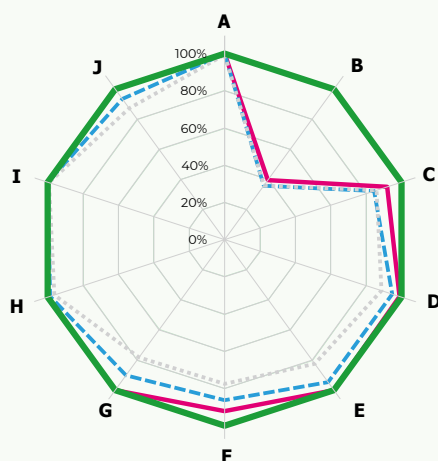
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# Cwm Taf University Health Board

## Prince Charles

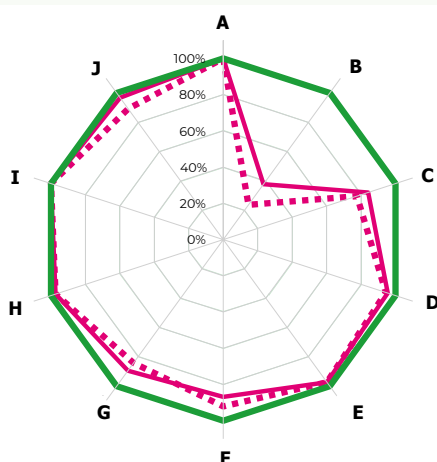
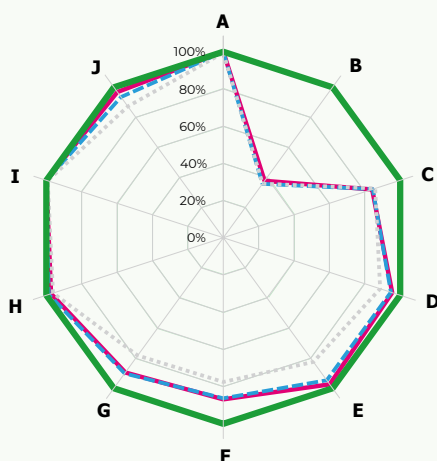
(92 patients)  
Pump patients 72.7%  
(2018: 75.5%)



Median HbA1c	% receiving all 7 essential checks
61.3	2019 92.2
61.0	2018 58.7
58.5	2017 86.4
60.0	2016 58.5
61.0	2015 n/a
5 year change: ▲ 0.3 mmol/mol	4 year change: ▲ 33.7 percentage points

## Princess of Wales

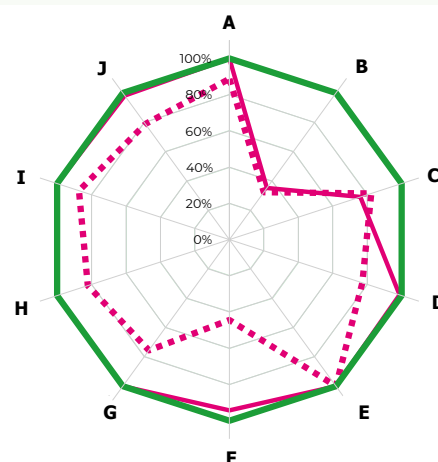
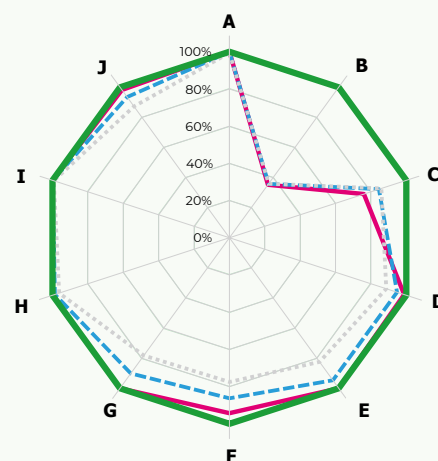
(85 patients)  
Pump patients 26.8%  
(2018: 29.5%)



Median HbA1c	% receiving all 7 essential checks
64.3	2019 76.3
71.5	2018 71.7%
66.0	2017 51.4%
65.0	2016 n/a
71.5	2015 n/a
5 year change: ▼ 7.2 mmol/mol	3 year change: ▲ 24.9 percentage points

## Royal Glamorgan

(76 patients)  
Pump patients 50.0%  
(2018: 55.2%)

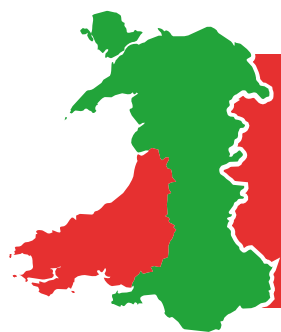


Median HbA1c	% receiving all 7 essential checks
63.0	2019 91.4
65.0	2018 22.2
61.0	2017 97.8
62.0	2016 95.6
66.0	2015 n/a
5 year change: ▼ 3.0 mmol/mol	4 year change: ▼ 4.2 percentage points

■ Unit performance 2019 ■ Unit performance 2018 ■ Wales ■ England and Wales ■ Goal target

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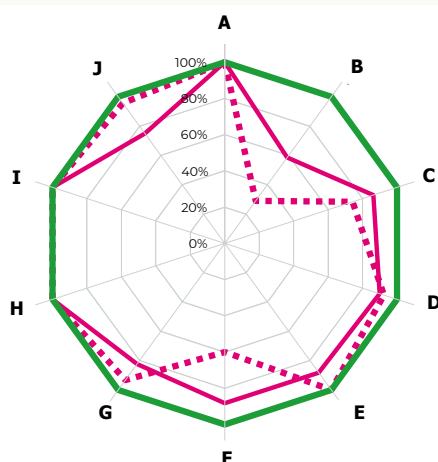
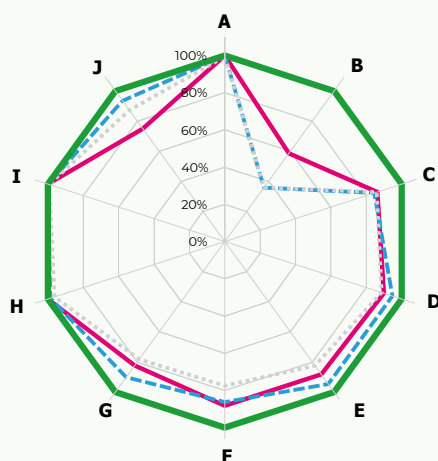
# Hywel Dda University Health Board

## Bronglais

(31 patients)



Pump patients 48.3%  
(2018: 37.5%)



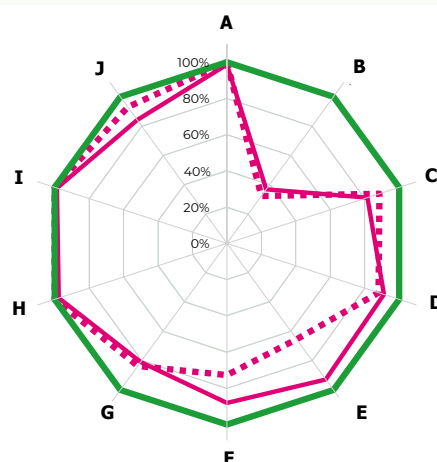
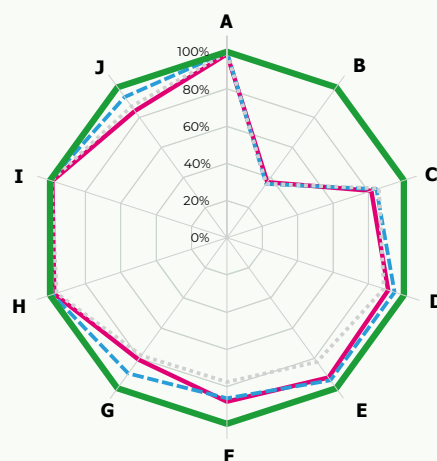
Median HbA1c	% receiving all 7 essential checks
55.0	2019 58.8
4.0	2018 53.3
66.1	2017 55.0
63.4	2016 30.0
66.0	2015 n/a
5 year change: ▼ 11 mmol/mol	4 year change: ▲ 28.8 percentage points

## Glangwili

(114 patients)



Pump patients 55.0%  
(2018: 50.0%)



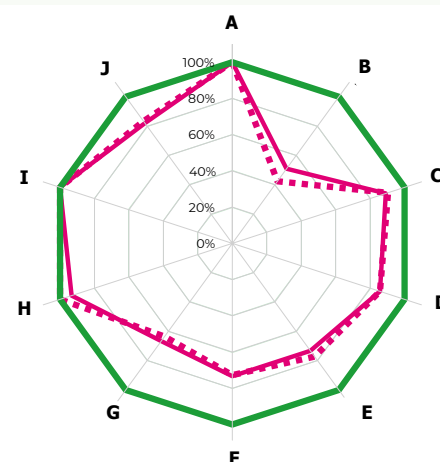
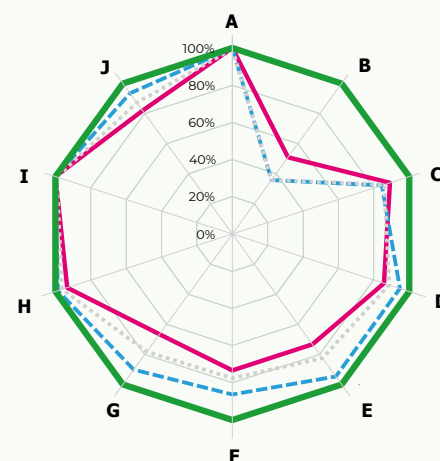
Median HbA1c	% receiving all 7 essential checks
64.0	2019 59.5
65.8	2018 34.5
62.0	2017 72.5
64.0	2016 37.2
65.0	2015 n/a
5 year change: ▼ 1 mmol/mol	4 year change: ▲ 22.3 percentage points

## Withybush

57 patients



Pump figures: 61.4%  
(2018: 46.2%)



Median HbA1c	% receiving all 7 essential checks
57.5	2019 40.0
62.0	2018 45.5
62.0	2017 39.1
67.3	2016 n/a
70.3	2015 n/a
5 year change: ▼ 12.8 mmol/mol	3 year change: ▲ 0.9 percentage points

■ Unit performance 2019 ■ Unit performance 2018 ■ Wales ■ England and Wales ■ Goal target

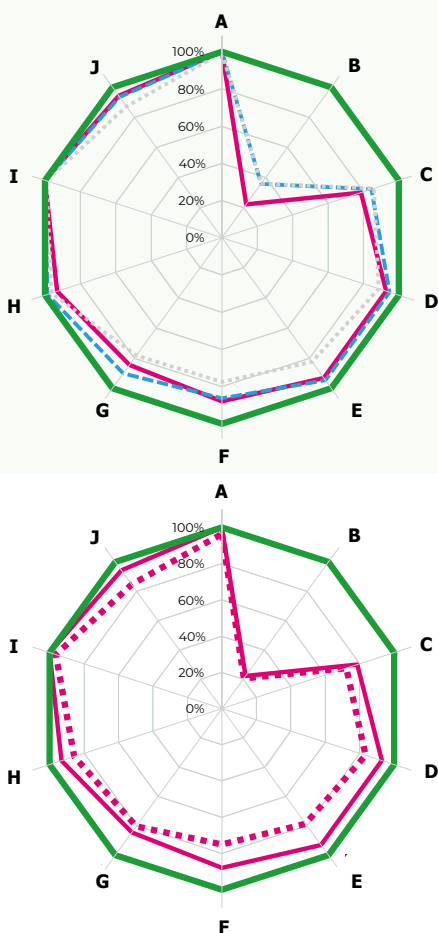
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# Swansea Bay University Health Board

## Morriston

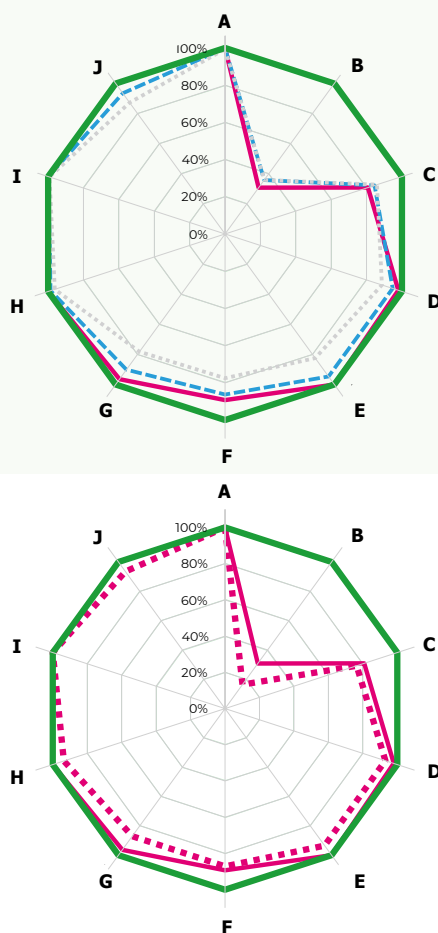
(132 patients)  
Pump patients 42.6%  
(2018: 44.1%)



Median HbA1c		% receiving all 7 essential checks
66.0	2019	69.0
70.3	2018	50.0
68.0	2017	42.9
66.0	2016	55.1
69.4	2015	n/a
5 year change:		4 year change:
▼3.4		▲13.9
mmol/mol		percentage points

## Neath Port Talbot

(64 patients)  
Pump patients 28.6%  
(2018: 30.4%)



Median HbA1c		% receiving all 7 essential checks
64.5	2019	89.3
65.0	2018	86.7
64.0	2017	85.7
66.0	2016	38.9
70.0	2015	n/a
5 year change:		4 year change:
▼5.5		▲50.4
mmol/mol		percentage points

■ Unit performance 2019 ■ Unit performance 2018 ■ Wales ■ England and Wales ■ Goal target

A - HbA1c health check (%); B - Adjusted % HbA1c <58 mmol/mol ; C Unadjusted HbA1c<80 mmol/mol D - Health check completion rate\* (aged 12+); E - Foot exam health check (aged 12+) (%); F - Eye screen health check (aged 12+) (%); G - Albuminuria health check (aged 12+) (%); H - BP health check (aged 12+) (%); I - BMI health check (%); J - Thyroid health check (%)

# Brecon Group Annual Report 2019

The Brecon Group of clinicians representing all paediatric diabetes services in Wales was established in 1995 with the aim of informing the then Welsh Office about the needs for clinical services for children and teenagers with diabetes. An early agreed priority was to establish the Brecon Cohort which is a diagnostic data-set of all people aged <15 years diagnosed in Wales, so that we could establish how many such people required clinical care and in which regions in Wales (Tables 1 & 2).

**Table 1. Under 15 year old incidence rates per 100,000 <15yr old population (ONS)**

Year	Cases	Population (10 <sup>5</sup> )	Incidence rates	Age
1999	131	5.57	23.5	U15
2009	143	5.18	27.6	U15
2019	167	5.29	31.6	U15

**Table 2. Under 15 year old newly diagnosed cases by Health Board where diagnosed in 2019**

Health Board	Jan	Feb	Mar	Apr	May	Jun	July	Aug	Sep	Oct	Nov	Dec	Total t1	Date nk	T2*	Mody
ABUHB	4	2	3	3	3	3	5	1	1	1	2	1	29	0	1	0
BCUHB	3	0	3	6	5	2	1	4	4	4	1	3	36	0	3	1
CAVUHB	3	2	1	1	4	3	2	1	1	1	3	1	23	0	2	1
CTMUHB	2	1	3	5	3	3	4	4	4	3	2	3	37	0	0	0
H DUHB	4	0	1	1	2	2	0	0	1	0	2	5	18	1	1	0
SBUHB	1	1	2	1	4	1	3	2	2	2	1	2	22	0	0	0

Our registrations of newly diagnosed cases have allowed us to capture data on the presence of diabetic ketoacidosis (DKA) at presentation of T1D. This allows us to monitor the effect of interventions designed to raise both public and primary care awareness of the symptoms suggestive of developing diabetes, in an effort to promote an earlier diagnosis. We have published data showing that our patients develop symptoms and present to primary care many months before diagnosis, suggesting that opportunities for an earlier diagnosis occur (Townson, 2019). Latest data show evidence that recent initiatives promoted by Welsh Government, Diabetes UK Cymru and critical case reviews of those presenting in DKA, have not significantly impacted rates of presentation in DKA at diagnosis (Table 3).

**Table 3. DKA rates over last 3 years**

Type 1	2017	2018	2019
DKA under 15	50	51	53
DKA 15 and 16	5	3	3
Total DKA	55	54	56
Total Type 1	165	166	177
% total type 1	33%	32.5%	32%

Numbers subject to 3 presentations 'not known' in 2019

The quality and power of what we can do with our database is dependent on the completeness of returns of new cases. Table 4 shows the numbers of notifications of new



cases by month. We thank those colleagues responsible for returning numbers of newly diagnosed cases and are pleased to note only a relatively small number of missing registrations. We would warmly encourage those centres with incomplete 2019 registrations to send to the Brecon Group office as soon as possible to help us maintain the high quality of our database.

**Table 4. Monthly notifications of newly diagnosed  
Type 1 diabetes under 15 years old**

Jan 17	Feb 6	Mar 13	Apr 17
May 21	Jun 14	Jul 15	Aug 12
Sep 13	Oct 11	Nov 11	Dec 15

Numbers subject to 1 missing date of diagnosis

In the last year we have also published data on the pregnancy outcomes of our cohort, many of whom are now in their young adult lives (Allen, 2019). These analyses have shown that, encouragingly, our young women with diabetes are less likely to become pregnant during their teens than those without diabetes. However, poor glycaemic control continues to be associated with an increased risk of a whole range of adverse outcomes. The babies of our teenage mothers are more likely to be admitted to hospital during their first year of life, suggesting that support for these vulnerable families is important.

An unpublished analysis of data on alcohol-related admissions from the Brecon Cohort was presented to a recent meeting of the Children & Young People's Wales Diabetes Network. This shows that those with diabetes experience a marked increased risk of hospital admission due to alcohol-related problems, compared to those without diabetes. Those with diabetes have maximum admission rates at a younger age (mid-teens) than the peak risk for admission in those without diabetes (18-22 year olds). These findings highlight the importance of improving the education and support provided by clinical services, to help young people with diabetes drink safely. The recent publication of SEREN guidance about alcohol for young people is therefore timely.

## References

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- Townson J, Cannings-John R, Francis N, Thayer D, Gregory JW. Presentation to primary care during the prodrome of type 1 diabetes in childhood: A case-control study using record data linkage. *Pediatr Diabetes* 2019;**20**(3):330-338. doi: 10.1111/pedi.12829

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\*Numbers of type 2 under 15 years subject to incomplete data regarding date of birth

- Not counted were 2 newly diagnosed and transferred in Type 1 diabetes (T1D) cases from outside Wales in 2019, or the 15 previously diagnosed type 1 cases that transferred in to Welsh units from elsewhere in 2019. Also not included were the 9 type 1 cases diagnosed at 15 and 16 years.



Our Network  
has agreed we  
want our services to  
display these values

## 2020 - looking forward to a milestone

2020 will mark the 5th anniversary of our  
Network and we hope to celebrate this and take  
stock of all we have achieved together.



## Contact us

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