

Hywel Dda Community Health Council



# Has your child been to hospital?

What you told us about your experiences

July 2022



# **Accessible formats**

This report is also available in Welsh.

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# About the Community Health Councils (CHCs)

CHCs are the independent watchdog of the National Health Service (NHS) within Wales. CHCs encourage and support people to have a voice in the design and delivery of NHS services.

CHCs work with the NHS, inspection and regulatory bodies. CHCs provide an important link between those who plan and deliver NHS services, those who inspect and regulate it and those who use it.

CHCs hear from the public in many different ways. Before the coronavirus pandemic, CHCs regularly visited NHS services to hear from people while they were receiving care and treatment. CHCs also heard from people at local community events, and through community representatives and groups.

Since the coronavirus pandemic, CHCs have focused on engaging with people in different ways.

This includes surveys, apps, video conferencing and social media to hear from people directly about their views and experiences of NHS services as well as through community groups.

There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.



**Carries out regular visits to health services to hear from people using the service (and the people providing care) to influence the changes that can make a big difference**



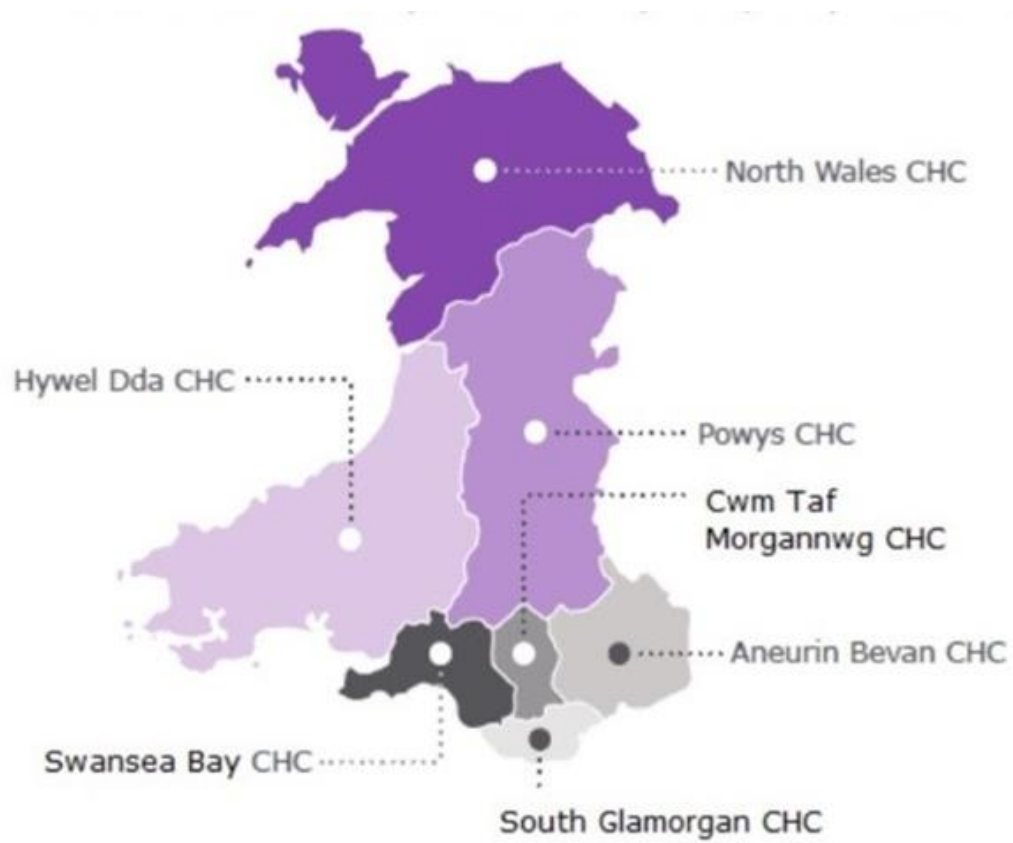
**Reaches out to people within local communities to provide information, and gather views and experiences of NHS services. CHCs use this information to check how services are performing and to ensure the NHS takes action to make things better where needed**



**Gets involved with health service managers when they are thinking about making changes to the way services are delivered so that people and communities have their say from the start**



**Provides a complaints advocacy service that is free, independent and confidential to help people to raise their concerns about NHS care and treatment.**



# Introduction & Background

The CHC has been involved in children's services regularly in recent years. We have asked people about their experiences since the Health Board made changes in 2014. More changes have happened since then and more are planned. We know that challenges faced by the Health Board are difficult and complex. There are staffing challenges to overcome, patient safety issues to consider and a range of local concerns in the public around a service that feels increasingly distant for many. The Health Board is looking at the future of children's services once again and we will ensure that the patient voice is part of the planning process.

In the past we have made a number of visits to women and children's settings since the service changes. These have happened in 2015, 2016, 2017 and 2018.

These visits have helped us understand the experiences of families and children, which we reported to the health board and others, e.g., the Royal College of Paediatrics and Child Health (RCPCH).

Women and children's services remain a priority for us as people continue to worry about them. We know that parents, carers and children have needed to use services during the pandemic with hospitals under enormous pressure. It has also led to further temporary changes in Withybush hospital. The Paediatric Ambulatory Care Unit (PACU) has been a valued setting in Withybush hospital even though it closed at night. More recently it was re-purposed at the start of the pandemic to help deal with flows of patients as the hospital had to adapt to strict infection control rules.

This meant that more children have had to travel to Carmarthen for paediatric care. The future of children's services remains a topic under discussion by the Health Board.

As a result we decided to run a survey to understand people's experiences. We wanted to know what it was like accessing care during this very difficult period, knowing this needs to influence the care provided now and planning for the future.

## **What we did**

In the past we have focused on visiting clinical areas and speaking with families face-to-face. However, during the pandemic we felt the risks of spreading Covid in hospitals were too great to do this. Therefore, we used a survey approach publicised via social media and our stakeholder contacts. We ran the survey during the early months of 2022 and had a healthy response rate of 109 completed surveys. The questions were designed to be simple, we asked people to tell us some basic information around why they accessed the NHS, what was good about their experience, what wasn't good and for any other views around the NHS care received.

## **Who did we hear from?**

We mainly heard from parents or carers of children. With Glangwili hospital providing most paediatric care we weren't surprised to see that the majority of survey responses (72) centred on people's experiences there.



We received 31 survey responses from Withybush, seemingly centring on experiences in A&E. 3 responses focused on Prince Philip Hospital.

## What we heard

Generally, people were very positive about the way NHS staff cared for them. This is an important point to make given that NHS staff have been under enormous pressure for a long period of time.

**"The staff were friendly, helpful and very good with my son. Made him feel at ease".**

**"The lady in charge was absolutely fabulous and so lovely to my son reassuring him he would be ok**

**It was good that we got to visit our local hospital and be seen so quick even though they are under-staffed".**

**"The nurse who triaged my daughter was lovely and said I had done the right thing in bringing her in and was very patient and friendly with my daughter and myself".**

**"Audiologist was ready on time, we weren't rushed, she was very good with my son and spoke Welsh which is his preferred language".**

It is encouraging to hear that so many people felt that staff were friendly and helpful. All parents and carers will know how difficult it can be to take a poorly child into a busy hospital setting, particularly during a global pandemic. Although other concerns arose during this project, the CHC feels that a warm and caring approach is crucial in the face of so many other problems. Clearly this was experienced by most people who completed our survey.

In a small minority of responses, we did hear that some felt staff were rude or less caring.

**"Doctors could be more aware that they are dealing with a child that's never experienced an injury or hospital visit before."**

**"I was absolutely disgusted by the way I was treated and spoken to by the nurse. He had no empathy and was incredibly rude and patronising. I understand completely that the staff have been through incredibly difficult times and that they may have been under-valued. I can fully understand why people become so upset and frustrated if they are met with this kind of attitude on arriving at hospital".**

Whilst these kinds of concerns were thankfully less common, they are important to acknowledge. Many people recognised that staff were under enormous pressures.

**"The poor staff that are working look exhausted. They are rushed off their feet. Trying so hard to give their all and do the job they love".**

However, patients should expect care that is compassionate and empathetic every time they go to a hospital.

In our survey, about a third of responses raised the issue of long periods of waiting in hospital settings (or in some cases outside hospitals in a car). We know that waiting a long time to be seen or to be told about the next step on the patient journey is difficult as an adult but is much harder as a poorly child and can be very difficult for the person who is looking after them.

The CHC understands that during the period when we ran our survey, the NHS experienced major staffing problems and couldn't run its hospitals in the way it normally would. This restricted the amount of people who could be seen and meant that many people found themselves waiting for very long periods. Thankfully, not everyone who responded to our survey encountered long waits, but it was still a major theme.

**"A&E was carnage, waited 10 hours for doctor".**

**"Took over an hour to get there. 9/10 hour wait time. Chaos but emergency surgery needed".**

**"Just the length of time we had to wait but I expected it as I know the services are stretched".**

**"Making a child wait 3 hours in an ambulance just to go to the children's PACU is absolutely ridiculous. Extremely stressful for my son who is also autistic and completely terrified of hospitals and ambulances."**

The CHC fully appreciates that the particular circumstances that created long waits for people were very difficult to avoid. However, we still think this still gives an opportunity to learn about patient experience as people wait for urgent care.

We were also concerned to hear about the environment people reported when their child was poorly or injured.

**"Nowhere to get food and drink all day. Nowhere for family/siblings to go."**

**"Sharing a waiting room with adults, since covid they seem to have lost the children's waiting room. On another occasion which I had to take him to Glangwili during early hours there were drunks and patients with drug problems in the same area"**

Some people also felt that hospital environments weren't always as clean as they should be.

**"There was no covid cleaning when patients were leaving the waiting room and the cleanliness wasn't great".**

Again it is accepted that the pandemic and related infection control rules meant that waiting areas were not ideal. However, with continued pressures in A&E settings looking like a long term reality, we feel the Health Board must look again at patient experiences, particularly for those with young children.

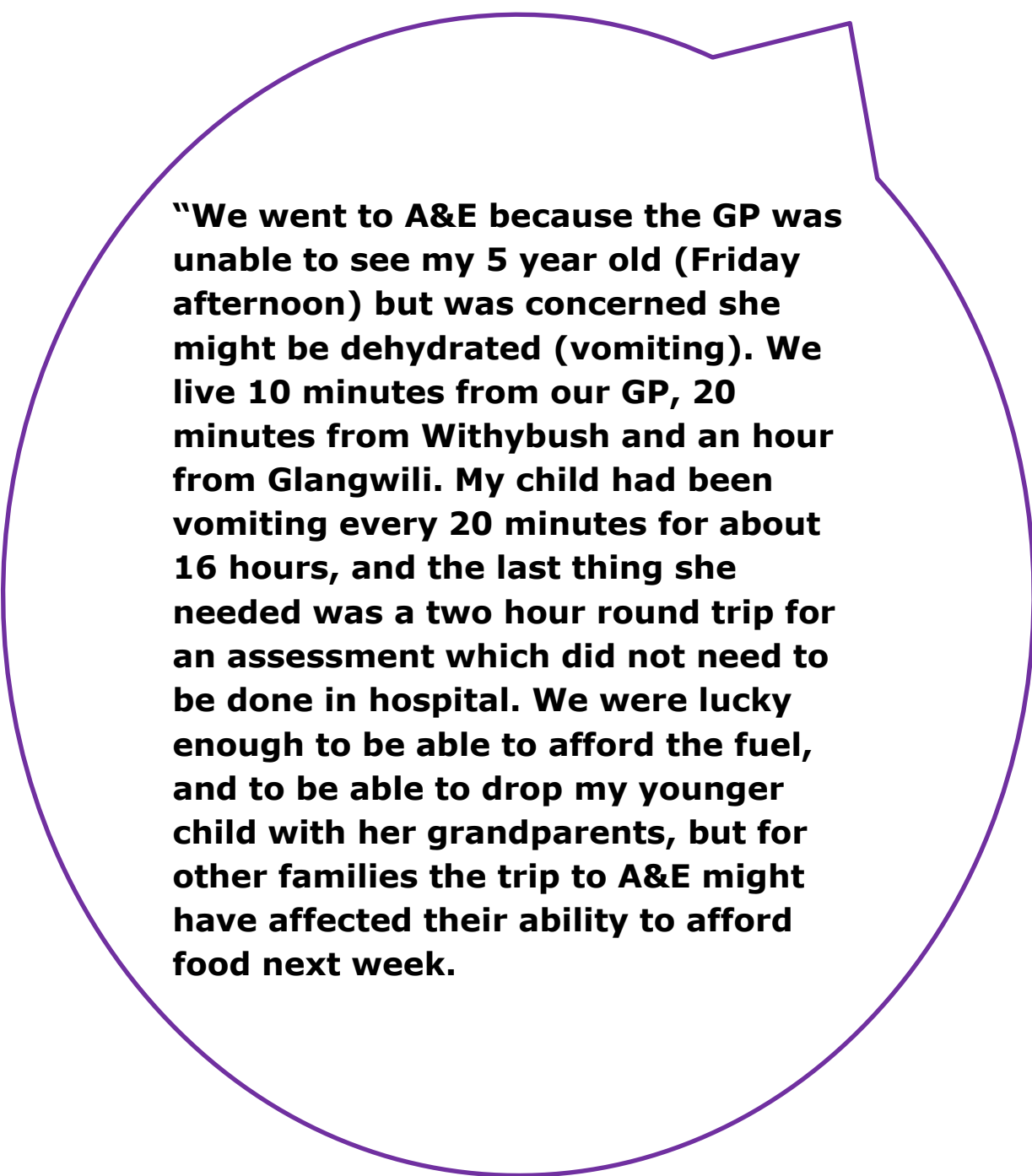
Journey times were another common feature amongst people's concerns. Typically, this was a point raised by Pembrokeshire residents who needed to drive to Carmarthen to access paediatric care although we appreciate that travel time can be a problem for a range of people in the Health Board area. Acknowledging this, it is important to highlight that longer journeys for parents and carers of poorly children can be really inconvenient and difficult.

**"My drive took 45 minutes at 4am and was told if she started to turn blue then ring for an ambulance. To take all the stress and responsibilities alone with a sick child at 4am is not fair or safe".**

**We arrived at 3pm and were discharged at 4am. Then was expected to drive home another 1hour, 20mins. My partner was falling asleep at the wheel, I was just crying with the windows open keeping him awake and thinking how dangerous it was that we were even on the road after such a long stressful day".**

Parents and carers have been highlighting the inconvenience and stress of these journeys to the CHC since the 2014 service changes. It is important that short and longer-term plans for future services take this in account.

Some people also felt that they were travelling a long way, not because specialist care was needed but because basic assistance was not available locally.



**"We went to A&E because the GP was unable to see my 5 year old (Friday afternoon) but was concerned she might be dehydrated (vomiting). We live 10 minutes from our GP, 20 minutes from Withybush and an hour from Glangwili. My child had been vomiting every 20 minutes for about 16 hours, and the last thing she needed was a two hour round trip for an assessment which did not need to be done in hospital. We were lucky enough to be able to afford the fuel, and to be able to drop my younger child with her grandparents, but for other families the trip to A&E might have affected their ability to afford food next week.**

The CHC is not able to make clinical judgements on individual cases and it's difficult to confirm whether a hospital trip was necessary or not, but it's clearly important to ensure that that the Health Board's aim of delivering "care closer to home" is made a reality.

## Learning from what we heard

Hearing from families about their experience has been very helpful. There were some clear themes within the responses we received. Firstly, praise for staff was almost universal. It is important that we highlight this clearly and plainly.

Acknowledging the gratitude and respect of people who shared their experiences with us, and the positive feedback, it was also obvious that many people had a difficult and frustrating experience. We have worked closely with the Health Board throughout the pandemic period and understand the enormous challenges that this placed on the NHS system. Persistent staffing problems, high levels of demand and difficult rules around how space was used clearly impacted on people's experience, although without the efforts of frontline staff and managers it could have been much worse.

It is important that this period isn't seen in isolation as we feel that there are lessons to learn. When a child needs to go to hospital it becomes a clear test of how a busy system adapts to vulnerability, fragility and worry. The results of this survey show a mixed picture of both meeting and *not* meeting that challenge, even if parents or carers generally seemed happy with the clinical outcome.

# Recommendations

**01**

**For the Health Board to thank staff involved in children's urgent and emergency care for their caring and helpful approach to families during such a pressured period.**

**02**

**For the Health Board to ensure it is collecting patient experiences including those relating to staff attitudes to help its own organisational learning and continuously improve.**

**03**

**For the Health Board to look at the waiting areas in urgent and emergency care settings, with a focus on children and those who are most vulnerable. To include food/drink, information, child friendly areas etc.**

**04**

**For the Health Board to ensure that travel remains a key consideration in the planning and delivery of services in the short and longer-term.**



## Thanks

We thank everyone who took the time to share their views and experiences with us about their health and care services and to share their ideas.

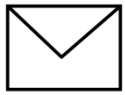
We hope the feedback people have taken time to share influences healthcare services to recognise and value what they do well – and take action where they need to as quickly as they can to make things better.

# Feedback

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.



## Contact details



Hywel Dda Community Health  
Council, Suite 5, 1st Floor,  
Ty Myrddin, Carmarthen, SA31 1LP



01646 697610



[hyweldda@waleschc.org.uk](mailto:hyweldda@waleschc.org.uk)



[www.hywelddachc.wales](http://www.hywelddachc.wales)



@HywelDdaCHC

# Response to our report from Hywel Dda University Health Board



## **HYWEL DDA UNIVERSITY HEALTH BOARD RESPONSE TO THE HYWEL DDA COMMUNITY HEALTH COUNCIL REPORT:-**

**“Has your child been to hospital?”**

### **RECOMMENDATION 1**

**For the Health Board to thank staff involved in children’s urgent and emergency care for their caring and helpful approach to families during such a pressured period.**

The General Manager for Women and Children along with the service and clinical management teams, have written to the staff within children services to thank them for all their hard work, commitment and dedication to the service. In terms of the All-Wales questionnaires, the team have full access to the responses from children, parents and carers. These are provided individually and as part of the team brief. These are also being extensively reviewed as a part of the wide-ranging review into Paediatric services which is due to report to the Board later this month.

The last two years have been extraordinary and the whole team have worked extremely hard to consistently provide a high standard of care and meet the needs of children, young people and their families throughout our service areas.

This report from the Community Health Council will be discussed and shared with the Paediatrics teams via review at the Directorate’s Quality and Safety Meeting.

## **RECOMMENDATION 2**

**For the Health Board to ensure it is collecting patient experiences including those relating to staff attitudes to help its own organisational learning and continuously improve.**

Within the Emergency Department (ED), there has been significant work and investment with the ED staff from the Culture and Workforce Team. Whilst acknowledging the significant pressures and challenges that EU staff face they are working to the highest standards and Health Board values will always remain our focus and priority at all times and apologies would be sought in any instances that this was not achieved. To support and build on the resilience of the team, we have regular 'listening spaces' with the Culture team so that we can help nurture the staff professionally and personally to always work within the values set by the Health Board. We regularly collect patient experience and are aware that currently the patient experience is increasingly poor. As a result of this we have established a task and finish group to address these recurrent themes.

Within the children services we routinely monitor feedback from age-appropriate children and parent questionnaires and feedback forms. Questions relating to the nursing establishment and how care is delivered to the children is evidenced and there are free text opportunities to provide individualised narrative. Responses are regularly fed back to the teams so that the issues which are identified by themes and trends are addressed as soon as possible. There is also a weekly review of the feedback forms along with a monthly ward team review, supported by 'you said we did' boards.

We are in the process of piloting a feedback page on the website to respond to all families and children who have contributed to feedback in order for us to share the changes made.

As a part of the Health Board's investment in Warwick University's Behavioral Insights in Practice: For the Change Makers Programme, Paediatric Ambulatory Care Unit (PACU) in Glangwili General Hospital (GGH) has been chosen by one of the project teams to see how staff within the unit might be able to support and improve patient experience differently, taking ownership of feedback and patient experience locally. This project, named by the project team as "GEMS" (and sponsored by the Director of Finance, has been devised, amongst other things, to evaluate the parent's view of waiting times and waiting areas. Led by PACU staff, specific feedback is reviewed weekly in collaboration with the project team with the aim to act upon recommendations and bring about improvements. The project team will be presenting the findings to Board in December.

The service continues to work hard to engage with families and children on the ward as part of our engagement and feedback and 'you said we did'.

## **RECOMMENDATION 3**

**For the Health Board to look at the waiting areas in urgent and emergency care settings, with a focus on children and those who are most vulnerable. To include food/drink, information, child friendly areas etc.**

Within the Emergency Department (ED) a Task and Finish group has been established in response to the recurring themes from complaints and feedback. This will review each ED within the Health Board to determine what reasonable actions and/or changes can be implemented in order to improve the environment and experience for our service users. As part of this work we will include the needs of the child in order to try and improve the environment for them and their families.

Within children services we ensure that all children and young people are provided with nutrition and hydration whilst awaiting assessment and review. We appreciate that some children and their presenting complaint have to be kept nil by mouth, there have been no complaints received within our areas as a result. However, we are conscious of this concern raised in our Health board feedback from the emergency department which has been highlighted to the teams and also to our nutrition and hydration group.

During the COVID 19 response, it was acknowledged that Paediatric Ambulatory Care Unit (PACU) and Cilgerran ward had to close the parent's room due to COVID restrictions. However, all meals and drinks continued to be provided to the resident parent during their stay. Additionally, resident parents were unable to access the canteen due to the restrictions in the dining area but the catering team, ward hotel services and ward staff have worked hard to ensure all parents and children have received plenty of refreshments.

#### **RECOMMENDATION 4**

**For the Health Board to ensure that travel remains a key consideration in the planning and delivery of services in the short and longer-term.**

We would like to reassure you that there is ongoing work to address the concerns identified around travel, and this continues to be reviewed as a part of the current focus on Paediatric Services, as described above. Any children that require non-emergency transport home from hospital are all treated equally across the Health Board and we look at all cases individually if they need support. The Health Board has contractual agreements with local taxi companies in each county and especially for discharges where patients have been transported to GGH by ambulance; it is possible for the ward nurses to access a contract taxi (via the site management teams) to arrange for transportation home in the event that no other alternative can be arranged.

# **Hywel Dda Community Health Council**