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South Glamorgan Community Health Council

# **Patient Experience Report of Cardiac Services In Cardiff & the Vale of Glamorgan**

April 2022



# **Accessible formats**

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download it from our website or ask for a copy by contacting our office.

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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, videoconferencing and social media to hear from people directly about their views and experiences of NHS services as well as through community groups.

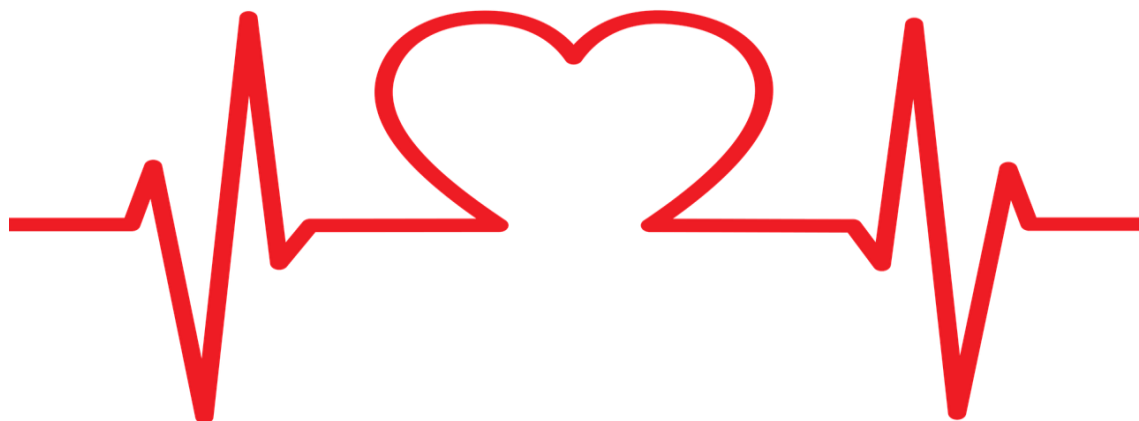
There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.

# Introduction & Background

The South Glamorgan Community Health Council strives to hear from patients and the public across all demographics, communities, and groups within Cardiff and the Vale of Glamorgan.

As well as requesting general feedback from the public on matters concerning their healthcare, the CHC also run specific, targeted campaigns for information and feedback from patients with specific health conditions or disabilities, or on specific services within the NHS, in order to ensure we hear from all groups of society in regards to their healthcare provision.

In this instance, the CHC wanted to hear directly from patients who suffer from Cardiac conditions, about their experiences when accessing NHS Cardiac Services in Cardiff and the Vale of Glamorgan.



In March 2020, the Covid-19 pandemic caused unimaginable disruption to all aspects of everyday life, including access to Healthcare services.



Government restrictions imposed in response to the pandemic, around social distancing, PPE and infection control, as well as increased workforce pressures caused by sickness and self-isolation requirements, resulted in a reduction in capacity of services across the NHS. This in turn has led to increased waiting list numbers and extended delays to diagnostics and treatment for patients within the NHS system.

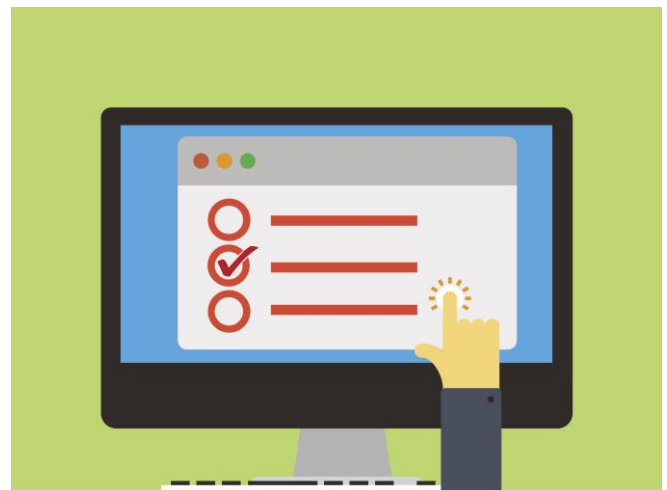
The CHC recognises the importance of gaining insight into what life is like for those who have experienced delays, and who are on a waiting list for their initial appointment, diagnostics or treatment. With the intention of making recommendations to Cardiff & Vale University Health Board on how to improve the experience from a patient point of view, if appropriate to do so.



# What we did

Due to the Covid-19 Pandemic restrictions, the South Glamorgan CHC has been unable to carry out physical scrutiny visits to NHS Services across Cardiff and the Vale of Glamorgan as we would under normal circumstances. As a result, we have been required to adapt the way we connect with patients and the public across Cardiff & the Vale of Glamorgan, in order to gather their views and experiences of accessing NHS Services.

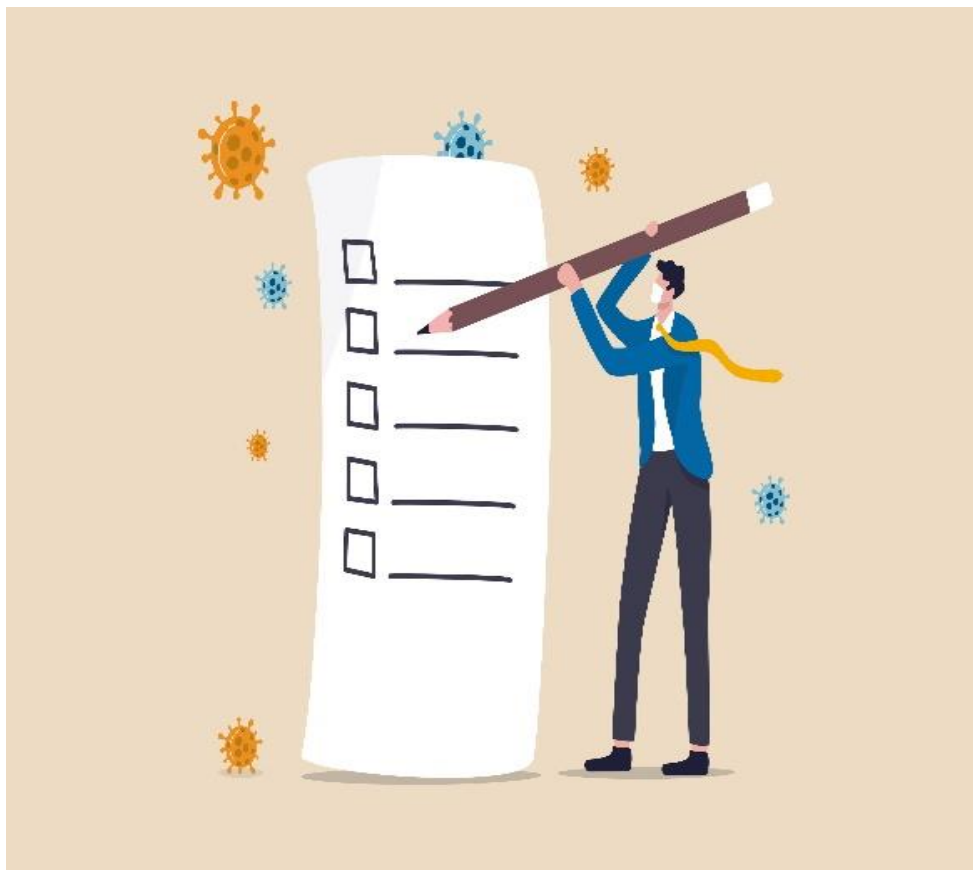
The South Glamorgan CHC devised and published an online survey to gain feedback from patients around their experiences when accessing Cardiac Services in Cardiff and the Vale of Glamorgan.



The survey was listed on our website, and publicised through our Facebook and Twitter social media channels. Details of the survey were also included within our regular stakeholder briefings. The survey was available for completion in both English and Welsh.

The survey was available online for completion from 31<sup>st</sup> August 2021 to 29<sup>th</sup> November 2021 and 11<sup>th</sup> January 2022 to 31<sup>st</sup> March 2022 and asked respondents to provide information around the following:

- ❖ Referral pathway.
- ❖ Length of wait from referral to appointment, for diagnostics and for surgery.
- ❖ Patient satisfaction and experience during initial appointment, diagnostics and surgery.
- ❖ Effects of delays on mental health, well-being and quality of life.
- ❖ Communication and monitoring.
- ❖ Suggestions for service improvement.





# Who we are hearing from

The CHC survey was open to patients who had any experience of interacting with Cardiac Services in Cardiff and the Vale of Glamorgan, as well as those who were awaiting their initial appointment following referral from another Healthcare professional or Service.

The CHC received a total of 50 completed English online surveys, although not all respondents answered all questions.

<b>50</b> (100%) of respondents chose to complete the English language version of our survey.	<b>10</b> (20%) of respondents were still awaiting their first appointment with Cardiac Services	<b>18</b> (36%) of respondents were referred to the Cardiac Service following a visit to Hospital.
<b>30</b> (60%) of respondents were referred to the Cardiac Service by their GP.	<b>9</b> (18%) of respondents were still awaiting their first diagnostic appointment.	<b>4</b> (8%) of respondents were still awaiting their surgery.



# What we heard

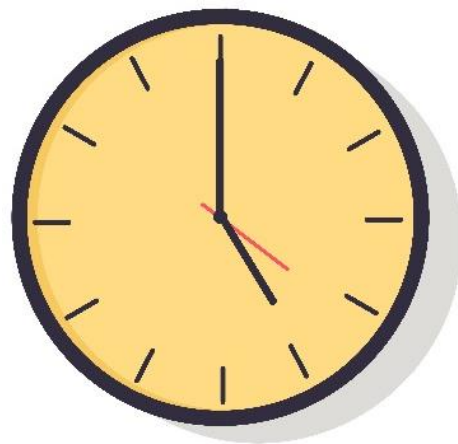
## At a glance....

<p><b>21</b> (42%) of people were seen by the Cardiac Services within 0-2 months of their initial referral</p>	<p><b>31</b> (79%) of people rated their appointment experience positively</p>	<p><b>20</b> (50%) of people received their diagnostic appointment 0-2 months after their initial appointment.</p>
<p><b>26</b> (90%) of people rated their diagnostic experience positively</p>	<p><b>19</b> (61%) of people received their surgery within 0-2 months of their diagnostic appointment.</p>	<p><b>22</b> (96%) of people rated their surgery experience positively</p>
<p><b>13</b> (35%) of people have experienced delays in initial appointments with Cardiac Services due to the pandemic.</p>	<p><b>12</b> (55%) of people have experienced delays in diagnostics due to the pandemic.</p>	<p><b>3</b> (19%) of people have experienced delays in surgery due to the pandemic.</p>
<p><b>0</b> people reported being given enough information on the reason for the delay or clear information on how their delayed appointment would be re-booked.</p>	<p><b>17</b> (35%) of people reported being regularly monitored by the Cardiac Team.</p>	<p><b>33</b> (72%) of patients would rate their overall experience of Cardiac Services positively.</p>

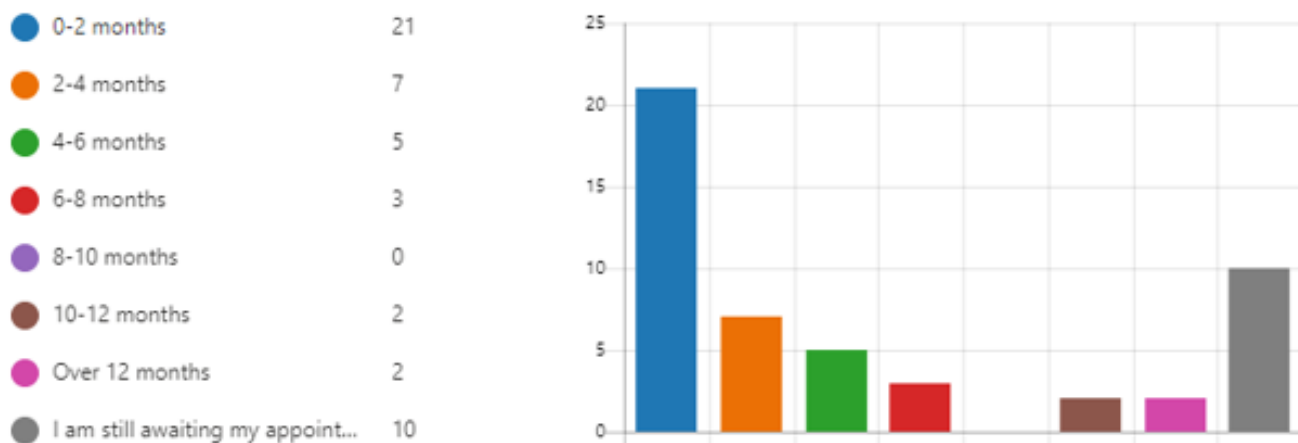
## Waiting Times

### Appointments

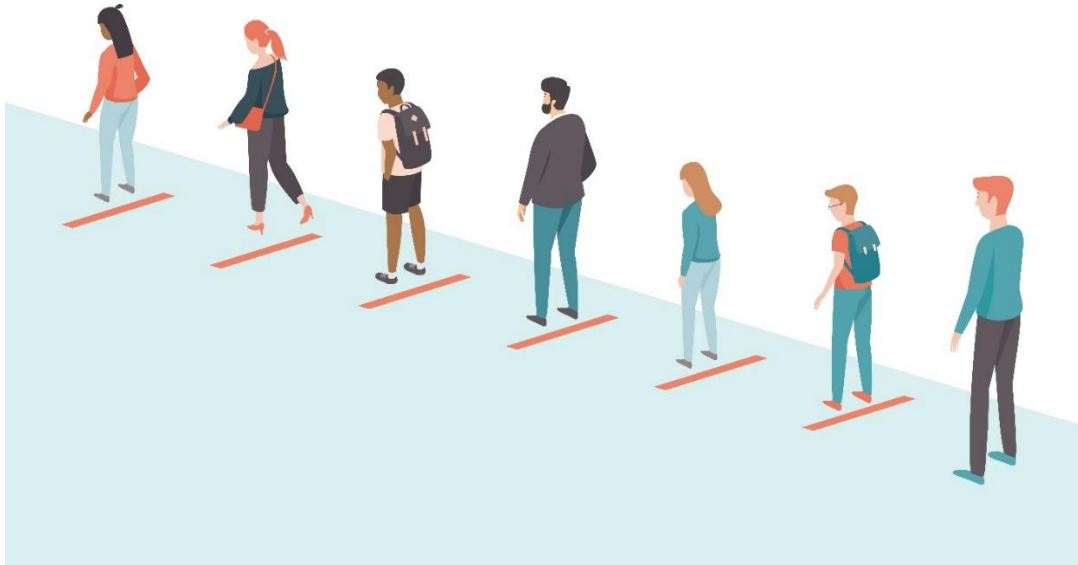
Our survey shows that of those patients who had received an appointment with Cardiac Services, **33** (82.5%) received their first appointment within 6 months of their initial referral.



It was disappointing to note that **2** (0.5%) patients waited between 10 to 12 months for their first appointment with Cardiac Services, and a further **2** (0.5%) patients waited over 12 months.



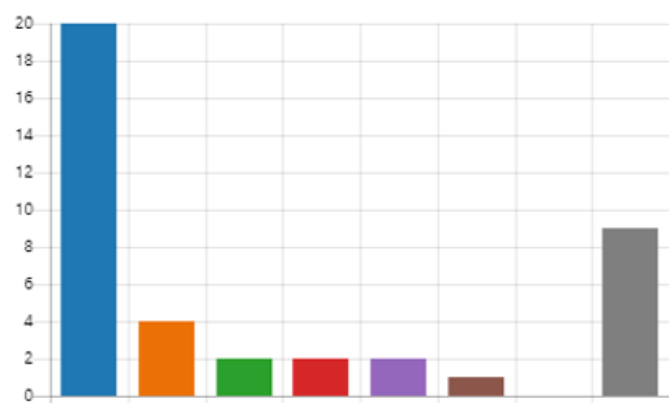
Of the 10 survey respondents who indicated they were still awaiting their first appointment with Cardiac Services, the length of time they have waited so far ranges from a few weeks to 6 months. One respondent commented they had been waiting *'too long'* with another commenting they *'can't remember'*.



## Diagnostics

When questioned, for those patients who were referred for diagnostics following their initial appointment, **26** (84%) respondents reported receiving their diagnostic appointment within 6 months of their referral.

Again it was disappointing to note that **5** (16%) respondents waited between 6 - 12 months for their diagnostic appointment following their referral.



Of the 9 respondents who reported they were will awaiting their first diagnostic appointment, one respondent stated:-

***'The scan I required is not available at Welsh hospitals. I had to travel to England. Appalling! Cardiac Perfusion Stress Test MRI'***

Others reported waiting for between 3 months and 7 months so far for their first diagnostic appointment.

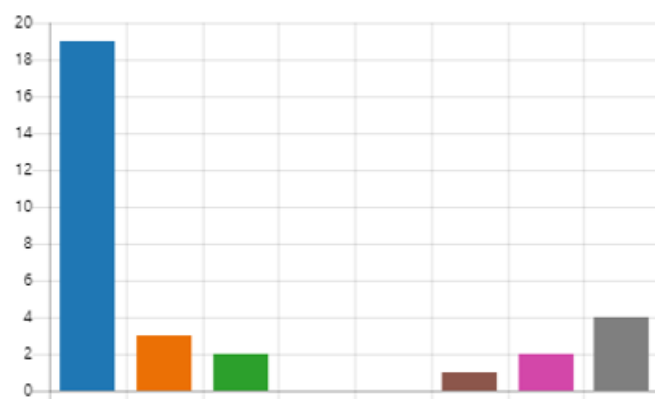
## Surgery

Following their diagnostic appointment, **19** (70%) patients who were referred for surgery, received their surgery within 2 months of their referral.



A further **5** (19%) patients received their surgery between 2 – 4 months, following their referral.

● 0-2 months	19
● 2-4 months	3
● 4-6 months	2
● 6-8 months	0
● 8-10 months	0
● 10-12 months	1
● over 12 months	2
● I am still awaiting my surgery ...	4

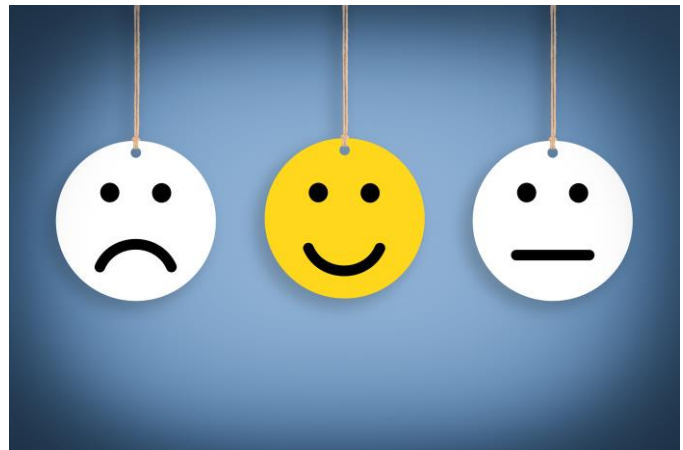


Of the four respondents who reported they were still awaiting their surgery, one respondent reported they had waited '*Over a year*' so far for their surgery appointment.

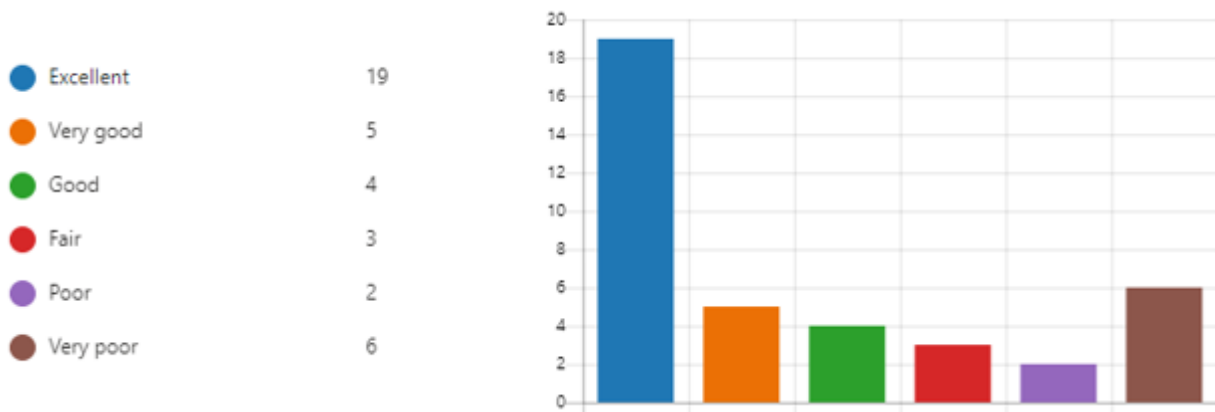
## Patient Experience

### Appointments

Our survey asked respondents to rate their experience during their initial appointment with Cardiac Services.



**28** (72%) respondents rated their experience positively, with **19** (49%) respondents rating their experience as '*excellent*'.



Positive comments provided by respondents highlight the excellent care they received, and the high praise they have for the staff involved in their care.

***I have dilated cardiomyopathy and have nothing but praise for the cardiac service at UHW and Llandough hospital. The service & care I've received has been nothing short of excellent! I was treated with the upmost respect and care & received excellent treatment. I get regular checks at UHW as I have an ICD fitted, and have no problems or delays with any appointments, treatments or waiting times.***

***'I had a cardiac arrest 4 years ago and obviously was treated very promptly and get checked every year.'***

***'Warm welcome, minimal waiting time - staff were all very flexible in my appointments'***

***'The treatment to replace my defective auortic valve was swift and I received excellent treatment from all hospitals that I attended particularly with the surgery at Llandough Hospital'***

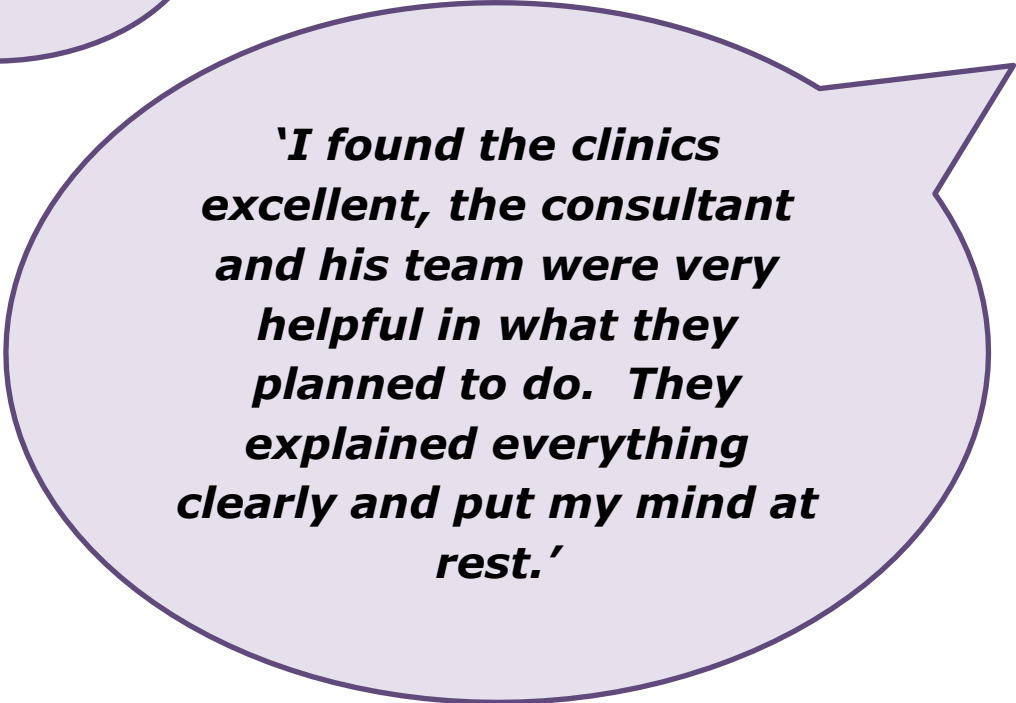
***'The amount of care I had up the UHW when I had my heart attack was amazing, every nurse was chatty and caring and every doctor talked me through everything that was happening, no complaints from me'***

***'Initial appointment with GP excellent followed by telephone conversation with consultant nurse'***





***'Excellent  
every  
time'***



***'I found the clinics  
excellent, the consultant  
and his team were very  
helpful in what they  
planned to do. They  
explained everything  
clearly and put my mind at  
rest.'***

It is with disappointment the CHC noted that **8** (21%) respondents rated their appointment experience as *'Poor'* or *'Very Poor'*

Comments provided by respondents around their negative appointment experiences include dissatisfaction with the length of wait for their appointment, difficulties with their appointment location, poor staff and a lack of follow-up contact or information:-



***'Unfriendly  
staff'***

***'I didn't get an appt I was in the waiting list but then I went to A&E as an emergency. My hospital treatment was excellent but the outpatient service is very poor'***

***'Appointment was a few minutes to be given EEG. No real information. Follow up results letter took a couple of months, worrying time.'***

***'We would love a clinic for adult congenital heart defects to be held in Llandough as we find UHW very difficult to get to and can't afford a taxi ,or at least all the tests I.e .t.t. echos to be done regularly there and carry on with telephone consults'***

***'Long wait to get the first appointment. The dr who saw me for years misdiagnosed me'***

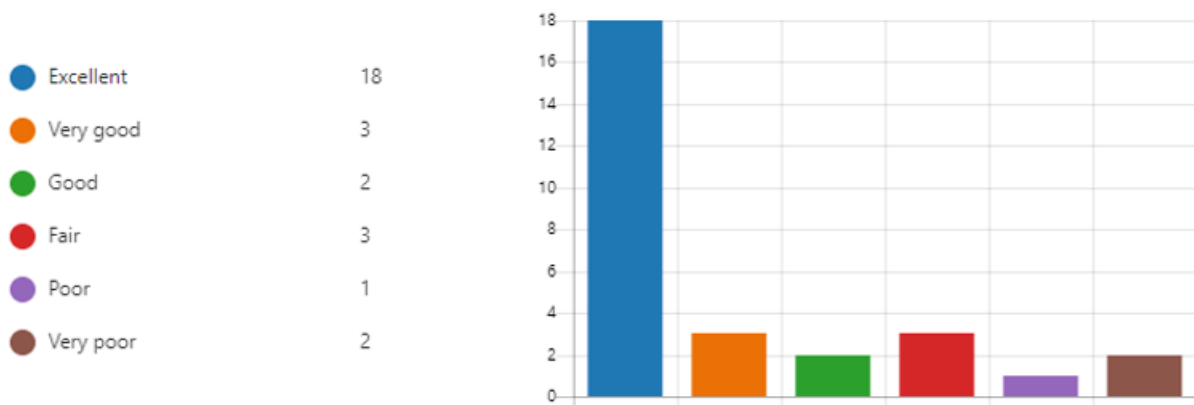
***'Get better doctor and better receptionist'***

***'I was hospitalised after going to A&E with af. Heart rate over 200. I am on lots of medication including amiodarone. Since then I've seen nobody. I have had 1 echo which shows my heart is enlarged. It is very frightening and the aftercare has been shocking. I've had telephone appts where the info is conflicting. I have another tel appointment today and if I don't get answers I will be going privately. I am lucky enough to be able to afford this. I was diagnosed 13 months ago and have seen nobody face to face''***

## Diagnostics

Our survey asked respondents to rate their overall experience during their diagnostic appointment.

**23** (79%) respondents rated their diagnostic experience as positive, with **18** (62%) respondents rating their diagnostic experience as 'Excellent'



Positive comments received from respondents regarding their rating of their diagnostic appointment experience praised good communication, staff and timely investigations.

**'Professional  
and  
comprehensive'**

***'The procedures are always carried out to a high standard and the staff are always happy to explain the procedure thoroughly so that you know what is happening & so as to re-assure you.'***

***'What caused my cardiac arrest got investigated very quickly'***

***'I was told follow up appointment would be 3months & it was 3 months waiting. Excellent!'***

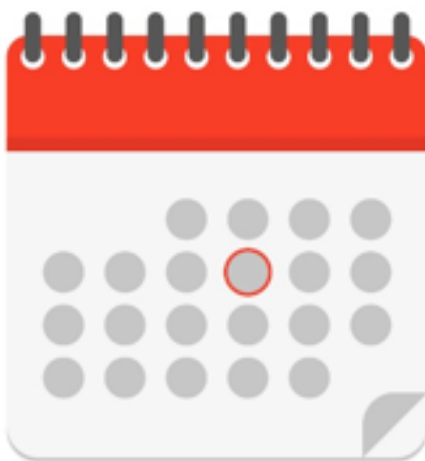


Disappointingly, **3** (10%) respondents reported their diagnostic experience as *'Poor'* or *'Very Poor'*

Negative comments received from respondents referenced long waits for results, and a lack of information provided during the diagnostic.

***'Took weeks to get the result'***

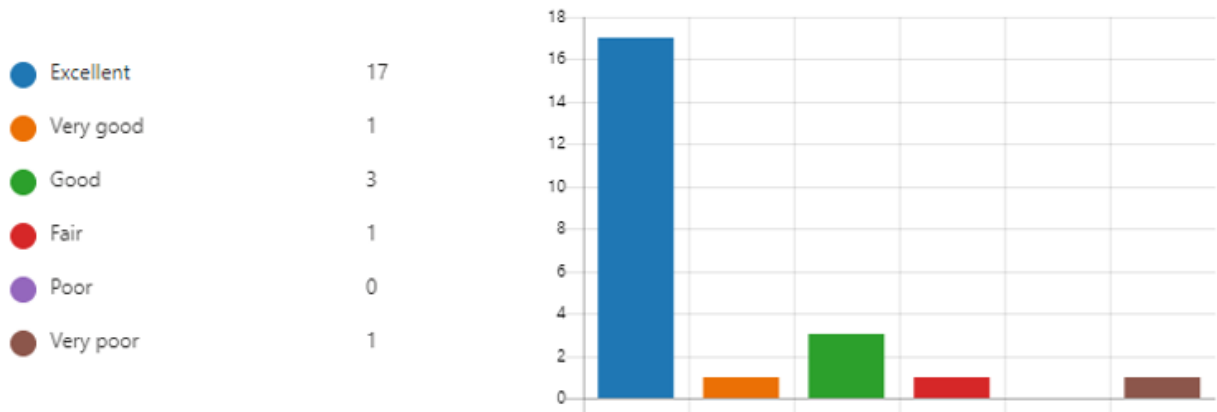
***'No information provided during heart scan. Follow up letter weeks later mentions slight left sided enlargement but no further follow up needed.'***



## Surgery

Our survey asked respondents to rate their surgery experience.

**21** (91%) patients rated their experience positively, with **17** (74%) respondents rating their experience as *'Excellent'*.



Respondents praised staff and the care they received:-

***'Can't fault the experience'***

***'Care was superb during my time in hospital'***

***'my surgeon was very reassuring and calming through the 2hour operation'***

***'the treatment and care I received at Llandough hospital was outstanding'***

***'I was treated with the upmost respect and care & made to feel safe & well looked after'***

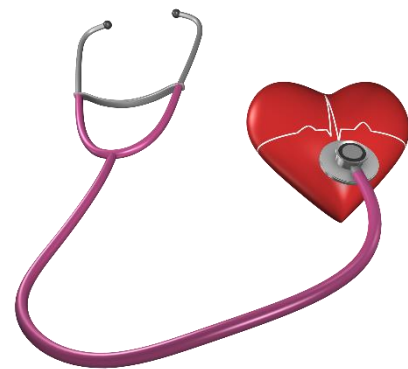
Only **1** (4%) respondent rated their surgery experience as *'Very poor'* but left no further comments on their experience.










Our survey also asked respondents to rate their overall experience with Cardiac Services in Cardiff and the Vale of Glamorgan

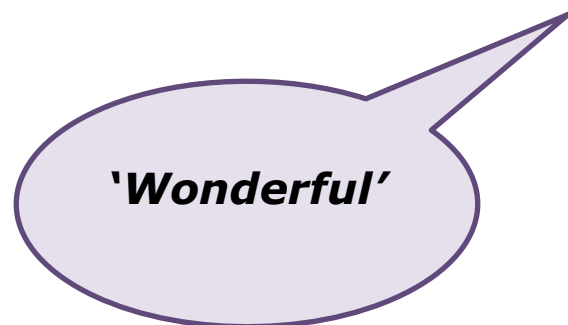
**33** (72%) respondents rated their overall experience positively, with **16** (35%) rating their experience as '*Excellent*'.



 Excellent	16
 Very good	7
 Good	10
 Poor	7
 Very poor	6



Respondents reported high praise for staff involved in their care as well as thorough, professional and timely treatment.



***'Very quick response when my daughter's heart murmur was detected. They sent someone up to the NICU within a few hours for her heart to be scanned'***

***'I like to think the cardiac team know what they are doing with patients'***

***'I'm very happy with the overall service, even though covid delayed my appointments'***

***'The whole experience from initial diagnosis, operation and subsequent recovery process was superb'***

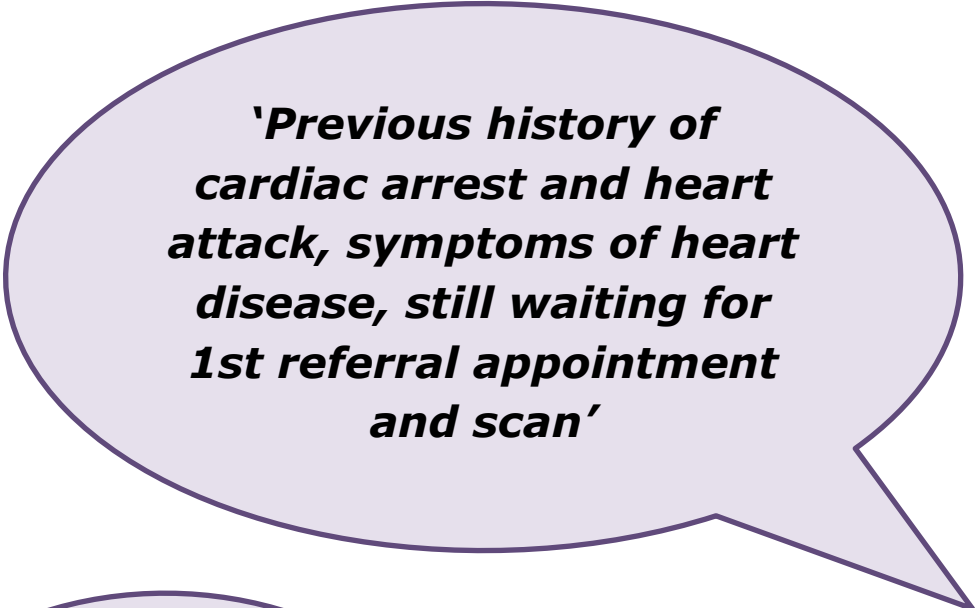
***'Dr (name removed) has cared for my son since 2 weeks of age, he is excellent, we are so pleased that he is also in the adult clinic'***

***'The cardiac team excellent but some of the night nurses weren't very nice and wouldn't help you'***

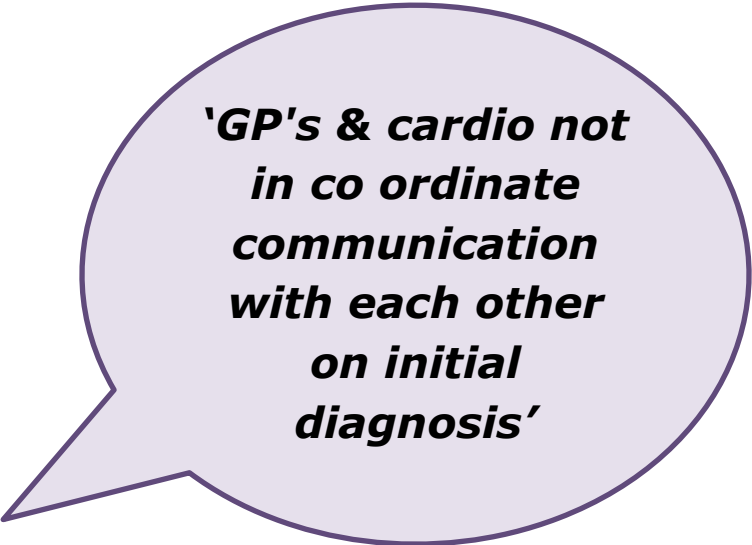


It was disappointing to note that **14** (30%) rated their experience as '*Poor*' or '*Very poor*'.


Negative comments provided by respondents in response to their overall rating of Cardiac Services in Cardiff and the Vale of Glamorgan cited lack of communication between Cardiac Services and patients, as well as lack of communication between different departments of the NHS. Other comments provided referenced waiting times for appointments, diagnostics and treatment, or lack of availability of services in Wales, forcing patients to travel to England.



***'Previous history of cardiac arrest and heart attack, symptoms of heart disease, still waiting for 1st referral appointment and scan'***



***'GP's & cardio not in co ordinate communication with each other on initial diagnosis'***



***'I was let out of hospital too soon'***

***'12 months from being referred to being seen when I was very worried about my symptoms feels unacceptable. It's likely I had covid that affected my heart in March 2020 - heart rate was dropping below 40 beats per min and I was told by the GP to phone 111 if I experienced unconsciousness/passed out?!?'***

***'Would be better if letter said why I'd been asked to come back, as it's quite distressing not knowing and not having set appointment'***

***'the outpatient service is poor so many unanswered questions I have no idea what is going on it is very concerning'***

**'No  
treatment  
yet'**

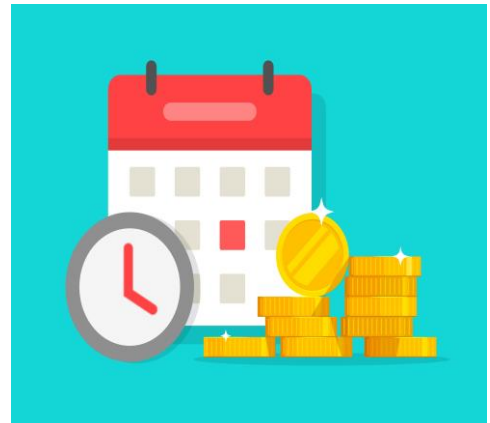
**'Don't seem  
to care'**

**'The scan I required is not  
available at Welsh hospitals.  
I had to travel to England .  
Appalling! Cardiac Perfusion  
Stress Test MRI.'**



## Delays

Due to the pressures faced as a result of the Covid-19 pandemic, delays to appointments, diagnostics and treatment are being suffered across the whole of the NHS.



We questioned respondents with regards to any delays they had suffered as a result of the pandemic.

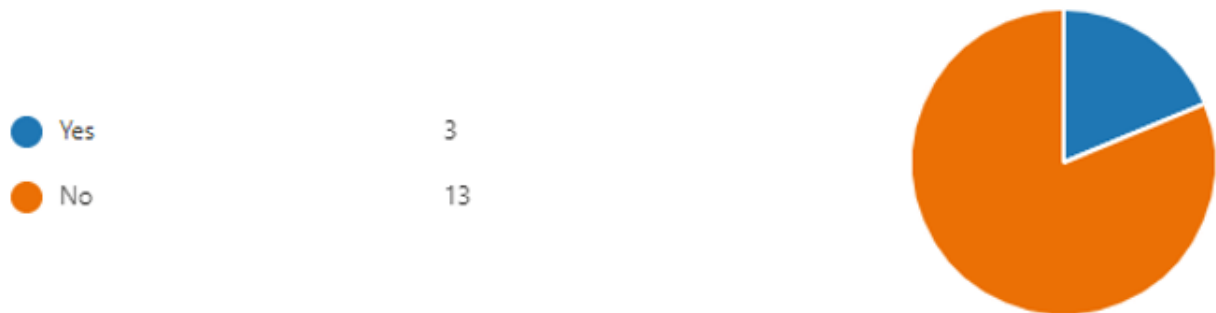
**13** (35%) respondents reported experiencing delays to their appointments due to Covid-19.



**12** (55%) respondents reported experiencing delays to diagnostics due to Covid-19.



**3** (19%) respondents reported delays to Surgery due to Covid-19.



Our survey gave respondents the opportunity to provide further information around the delays they had experienced:-

***'The first time I went footprint surgery it couldn't be done because of the complexity, I had to wait a further 8 months before it was carried out.'***

***'On list, covid blamed for backlog.!!?'***



***'I did have a check-up appointment cancelled during the pandemic but had a phone consultation and I also have a monitor at home as I have a pacemaker defibrillator fitted so if there's any problems the hospital staff no and ask to see me***

***'Covid blamed for waiting lists not acceptable if u have heart condition u could theoretically have stroke or heart attack!!***

***"We won't use public transport due to covid and find UHW impossible to get to especially at the moment a clinic for a.c.h.d in Llandough would be very very welcome."***

***'Waiting  
for echo'***

***"Still waiting for  
an 'urgent' scan  
despite having  
history of cardiac  
arrest."***

***"Still waiting  
for  
appointment."***

We specifically wanted to hear how those delays affected patients in terms of their mental health, well-being and quality of life. Unsurprisingly the responses referenced increased levels of stress and anxiety being suffered, impacting the quality of life of those patients.

***"Anxiety is through the  
roof. I am due a pace  
maker and I worry every  
day whether I am safe."***

***"Stressful"***



## Communication

The CHC wanted to hear from patients about the communication they received from the NHS around these delays.

We asked whether patients felt they had been given enough information about the reason for the delay in their appointments, diagnostics and treatment.

Only 3 respondents chose to answer this question but they all responded they had not been given enough information behind the reasons for the delay.



We then asked if respondents had been given clear information on how their delayed appointment would be re-booked?

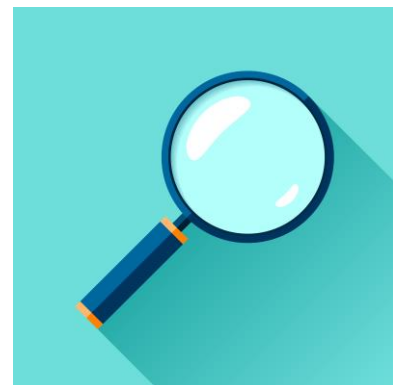
Again, only 3 persons answered this question, and all reported that they had not been given clear information on the re-booking process.



## Monitoring

Our survey asked respondents to provide information around any monitoring that was being provided by the Cardiac Team.

**17** (35%) respondents confirmed they were being monitored by the Cardiac Team



Positive comments received around this monitoring include high praise for staff and regular contact from Cardiac Services.

***"Dr (name removed) after the first follow up told me that there was no need for monitoring any more but said if any problems occurred to phone his clinic direct rather than go to my gp.."***

***"Can't praise the team enough!"***

***"I get yearly check-ups.."***

***"After successful operation I was discharged with appointments for various outpatient services."***

***"Had angio needed stents booked for the following week. Was just about to leave had a bleed straight to theatre then ccu excellent service."***

***"I had to be moved from Llandough to Heath. Now I'm being seen in a regular basis."***

The CHC was disappointed to note that the negative comments received in response to our request for additional information around monitoring by Cardiac Services, exceeded the number of positive comments received.

Patients reported a lack of communication, lack of care by staff, and a seeming lack of interest in the patient by staff.

Other patients had a lack of understanding of their care plans and felt they did not receive sufficient information around their condition, treatment or medication.

Others noted some monitoring was taking place, but not at an interval they felt was appropriate or cited concerns with a lack of follow up by Cardiac Services.

***"My daughter who was born 7 weeks prematurely, had a heart murmur detected when she was born. This was checked before discharge and I was advised a follow up appointment would be needed to check her heart. I am still awaiting an appointment date for this."***

***"Well if 3 telephone calls in 12 months is classed as regular."***

***"Was told by gp receptionist no result at practice ring hospital no answer."***

***"They checked my heart beat, said I was fine and sent me away. There's just no care there anymore. They want you in and out quick."***

***"I was in the university of wales hospital heath park. I went there in an ambulance to my arrival in A&E. The Nurses who first interviewed me was very rude to me because it's written on my files as attention sick which I don't know why?? And I was in deep pain I honest couldn't cope with the pains. I had a shock and a lost bladder so she couldn't believe me. I heard a bad experience in that department of A&E. I would like my name to be removed from that lies which I don't know. Please help me with what should I do to be treated fairly good, quick."***



***"Prof who called seemed uninterested."***

***"2 appointments, but no contact with a cardiologist and no follow up."***

***"I have outpatients telephone calls every 6 months but most of the time I haven't a clue what's going on. They change my medication and I'm not followed up."***

***"Had ambulatory monitor in December. Got sent link to questionnaire. Still awaiting appointment date."***



The final question of our survey, could also be viewed as one of the most important. The CHC asked respondents to provide information on what life is like for them, on the waiting list for Cardiac Services.

Unsurprisingly respondents provided examples of declining mental health, increased stress levels, living in fear of their condition, with some describing their lives as *'on hold'*.

Patients described having to be increasingly mindful of their daily activities so as not to exacerbate their conditions, whilst trying to go about their lives. The lack of knowledge around their condition or treatment causes much anxiety and worry.

***"Worrying."***

***"Managing but mindful not to over stretch."***

***"Just been diagnosed have reported symptoms several times. I'm very concerned that I may have a stroke/heart attack at any time. This is mentally wearing! Also physically wearing. Life on hold!!"***

***"Anxious for result"***

***"Absolutely terrible, not knowing is the worst part"***

***"I try and not worry too much. Life has to go on"***

***"Frightening"***

***"Very worrying."***

***"Having cardiac issues and no communicated results causes stress which exacerbates issues."***

***"It makes you anxious and constantly worried about your health."***

***"Anxious to know what is wrong with me....my breathing, pain and mobility getting worse"***

***"I have gone privately."***

## Suggestions for Improvement

Contained within all CHC surveys, is a question where we ask respondents to share with us any suggestions they may have, on how their experiences with Cardiac Services in Cardiff and the Vale of Glamorgan could be improved.



The following suggestions were provided:-

- ❖ Employ more staff
- ❖ Improve communication between staff and patients as well as between different departments of the NHS.
- ❖ Ensure face to face appointments are available if requested.
- ❖ Improve information provided to patients on medication, treatment plans, reasons for delays and how delayed appointments will be re-booked.
- ❖ Improve after care.
- ❖ Improve infrastructure to UHW
- ❖ Provide more feedback to patients following treatment.
- ❖ Ensure services offered in England are also available in Wales.
- ❖ Improve quality of meals provided in hospital.

***"I would like to see a doctor face to face."***

***"A simple confirmation would help."***

***"At a minimum, keep up with England in the provision of diagnostic services and treatments."***

***"Ring with results do really appreciate staff are busy"***

***"Communication was so poor. Follow up letters took so long for results. I would have appreciated seeing an actual doctor, but was seen by 'practitioners' ...In the last 2 years I haven't once had my blood pressure taken or bloods...."***

***"Cardiac floor in the hospital is very deficient and requires some investment. Not enough staff. Very poor infrastructures. Definitely waiting lists being an issue. Also having a congenital heart disease The dr considered that I didn't required regular check ups. I had to insist to be seen by them. They missed an enlarged aorta for years."***

***"Can give more feedback after treatment."***

***"I found the after care not very good."***

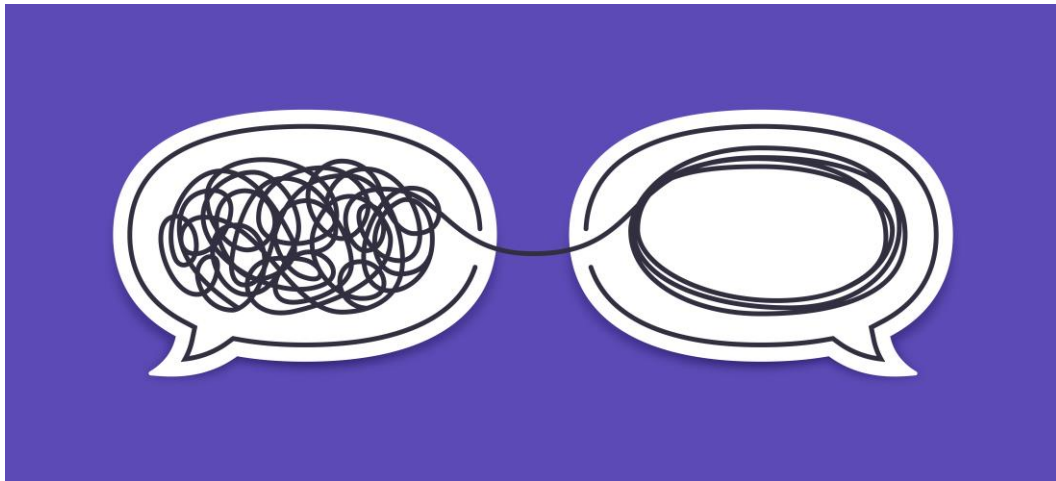
***"Early initial referrals from G.P. & early appts with cardio.."***

***"Food could be much better."***

***"More Doctors, Nurses and staff would make a huge difference as they are all run off there feet, doing many other jobs than their own. Most of the staff look exhausted.."***

***"Explain the medication. I was taking amiodarone which scared me as it's so toxic. Then they decide to stop everything. More follow ups on the medication and more explanation."***





## Learning from what we heard

From the results of our survey, we can see that the majority of patients who have interacted with Cardiac Services in Cardiff & the Vale of Glamorgan report a positive experience.

Waiting times for appointments, diagnostics and treatment have increased throughout the pandemic, but it is still encouraging to see that the majority of patients were seen by a Clinician for their initial appointment, diagnostic or surgery within 2 months of referral.

It was concerning to note that there are patients reporting waits of 12 months and over for their initial appointments with the Cardiac Team, diagnostic appointments or surgery. It was also of concern to hear that some patients are being required to travel to England for diagnostic appointments, as certain services are not available to patients here in Wales. This disadvantages some sections of society and may create a barrier to accessing those diagnostics for patients from a lower socio-economic background.

It was reassuring to hear that the majority of patients questioned rated their experience during their appointment, diagnostic or surgery as excellent.

Staff were afforded high praise through the survey responses, but it was also disappointing to hear in some instances that staff attitude or behaviour was not at a level patients would consider appropriate.

Patients have told us that life on the waiting list for Cardiac Services brings increased anxiety and fear. With patients having to be increasingly mindful or restrict normal day to day activities in an effort to avoid exacerbating their conditions or symptoms, with life being described as '*on hold*'.

It has been made clear through the results of this survey that communication and information is key. Poor communication and information around care plans, medication, appointments, treatments, delays and results only serve to increase the emotional distress and worry that many patients with Cardiac issues are suffering.

Patients are understanding of the pressures faced by the NHS and its staff due to the Covid-19 pandemic, but as life begins to return to 'normal' in terms of Covid regulations and restrictions, some patients now report it as being a convenient excuse used by the NHS for any issues encountered or delays faced, and many patients no longer find this acceptable.

# 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.

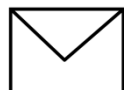
# Feedback

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.

This report is available in Welsh and English.



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If you write to us in Welsh, we will answer in Welsh. This will not lead to a delay in responding to your correspondence.

We welcome telephone calls in Welsh.

**South Glamorgan Community Health Council**