







Cardiff and Vale University Health Board Wales Cancer Patient

Experience Survey 2021/22

Health Board Report



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1. Executive Summary

The results presented in this report are from the third Wales Cancer Patient Experience Survey (WCPES) which was conducted by IQVIA in 2021/2022, on behalf of Macmillan Cancer Support and the Wales Cancer Network.

The WCPES is designed to measure and understand patient experiences of cancer care and treatment in Wales to help drive improvement both nationally and locally. The findings of the national report, supported by a data dashboard, as well as accompanying Local Health Board and Trust reports, will help us to celebrate what is working well, but also inform further improvements in cancer care by highlighting areas of importance, raised by people living with cancer across Wales. Please note when you read the report you will see that some of the percentages don't total to 100%, this is because of the rounding process used to analyse the data. Please see section in Chapter 7 titled 'Other Reporting Conventions' for more detail.

The COVID-19 pandemic brought unprecedented changes to the delivery of clinical services as a means of reducing the spread of the virus which impacted on the experience of care. As this iteration of the WCPES includes the experiences of those who received treatment from 1st January to 31st December 2020, the additional impact on services and delivery during the COVID-19 pandemic is included. Fewer patients came into hospitals and GP Practices for face-to-face appointments, many consultations were undertaken virtually, and those who attended face-to-face appointments for investigations and treatments, were often asked to do so alone. Whilst this was done in order to comply with national guidance around infection prevention and control, this will have affected experiences.

The impact of the pandemic varied across Health Boards and Velindre at different times depending on the numbers of COVID cases, services, and workforce capacity. As primary care (e.g. access to GP and pharmacy), community services (e.g. health and social care), secondary care (e.g. hospitals and specialist services), and the third sector (e.g. charity support) were all disrupted, significant adaptations to how these services were accessed and delivered were made. This in turn may have affected the sharing of practical, supportive, and holistic information across the cancer pathway, from information being given in person, to needing to rely on postal/ remote/digital approaches.

It is important to recognise the background context of the pandemic when interpreting the report as a means of fully appreciating the circumstances in which patients were reporting their experiences. This report has been produced to accurately reflect what people who experienced cancer care during this time have shared with us. Whilst it does not judge provision of care in any way or indeed rationalise or interpret these responses, reflecting on some of the comments people have shared around the impact of COVID-19, makes for sobering reading in a way that must support continuous learning and improvement. The quantitative and qualitative feedback are considered as being of equal importance and is designed to be read as two parts of one report.

We are hugely grateful to the thousands of people living with cancer who took part in the survey for providing such detailed feedback on their experiences of diagnosis, treatment, and care and we commit to improving experiences in the future.

Headline results

The survey results for Cardiff and Vale University Health Board are positive. **92%** of respondents rated their overall care as 7 or more out of 10 (a slight drop from **95%** when the survey was last carried out in 2016), with only **2%** rating their overall care as between 0 and 3 out of 10 (**1%** in 2016). **91%** said they were always treated with dignity and respect while they were in hospital (**89%** in 2016).

Other positive scores in the survey include:

- 93% of respondents said they were always given enough privacy when they were being examined or treated
- 94% of respondents said they were given all the information they needed about their operation
- 92% of respondents said they were given all the information they needed about their test
- 95% of respondents said hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital

However, in other areas, responses were less positive. These include:

- 49% were offered the opportunity to discuss their needs and concerns
- 39% of respondents said their healthcare team completely discussed with them or gave them information about the impact cancer could have on their day-to-day activities (for example, their work life or education)
- 37% of respondents said their family or someone else close to them definitely had enough opportunity to talk to a healthcare professional
- 28% of respondents said that, after leaving hospital, they were definitely given enough care and help from their GP and the GP practice
- 27% of respondents said they had been offered a written care plan
- 29% of respondents said that, since their diagnosis, someone had discussed with them whether they would like to take part in cancer research (e.g. clinical trials)

Key Workers, Clinical Nurse Specialists and other health professionals

We know from previous iterations of this survey that having access to a Key Worker and a Clinical Nurse Specialist (CNS), is associated with better patient experience across the entire care pathway. In Wales, everyone with a cancer diagnosis should have a named Key Worker and the opportunity to have a supported conversation about meeting their needs.¹

93% of respondents said they were given the name and contact details of their Key Worker. 65% of these respondents said that it was easy to contact them. 84% said that, when they had questions to ask, they got answers they could understand all or most of the time. 78% said their Key Worker provided them with all the information they needed to make informed decisions about their treatment.

In this survey, **92%** of respondents said their care included access to a CNS, (**84%** reported that their CNS was also their Key Worker, **8%** said their CNS was not their Key Worker). **67%** of the respondents who had access said it was easy to contact them. **86%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **78%** said their CNS provided them with all the information they needed to make informed decisions about their treatment.

74% of respondents said that their care included access to another health professional, such as a physiotherapist, dietitian, speech and language therapist, occupational therapist or lymphoedema specialist. **63%** of respondents who had contacted their other health professional said that it was easy to do so. **77%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **77%** said their other healthcare professional provided them with all the information they needed to make informed decisions about their treatment.

Time to first seeing a GP or other doctor

59% of respondents reported that it was less than 3 months from the first time they thought something might be wrong with them until they first saw a GP or other doctor. This is an increase on the 2016 score of **56%**.

Welsh language

'The Welsh Government's strategic framework for the Welsh Language in health and social care aims to support Welsh speakers to receive services in their first language.' ² and is in the context of the Welsh language strategy 'Cymraeg 2050' ³ which sets out Welsh Government's vision for reaching a million speakers by 2050.

Within the survey, people living with cancer were asked if they were able to speak in Welsh to staff if they needed to. 90 respondents who answered this question (10%) indicated that they needed to speak to staff in Welsh; of these, 23% agreed 'Yes, completely' that they were able to do so.

¹ Key workers for cancer patients (WHC/2014/001) (Welsh Government 2014)

² More Than Just Words Five Year Plan 2022-2027 (Welsh Government 2022)

³ Cymraeg 2050: A million Welsh speakers (gov.wales) (Welsh Government 2017)

Comparisons with 2016

31 questions in the survey are broadly comparable with 2016 (see section 5). Of these 23 scores have worsened and 8 have improved.

The 3 largest improvements related to CNSs and Key Workers:

- 66.6% of respondents in 2021/22 reported it was easy for them to contact their CNS 56.3% in 2016 (+10.3%)
- 91.6% of respondents in 2021/22 reported their care included access to a CNS –
 86.6% in 2016 (+5.0%)
- 92.8% of respondents in 2021/22 reported they were given the name and contact details of their Key Worker 89.1% in 2016 (+3.7%)

The 3 largest declines related to care after leaving hospital/support at home:

- 28.3% of respondents in 2021/22 reported that after leaving hospital, they were definitely given enough care and help from their GP and the GP practice 54.3% in 2016 (-26.0%)
- 47.7% of respondents in 2021/22 reported that they were definitely offered practical advice and support in dealing with the side effects of their treatment at home –
 62.4% in 2016 (-14.7%)
- 55.8% of respondents in 2021/22 reported that after leaving hospital, they were definitely given enough care and help from health or social services 67.3% in 2016 (-11.5%)

2. Introduction

The Wales Cancer Patient Experience Survey 2021/22 is the third iteration of the survey, first undertaken in 2013. This survey has been designed to measure and understand patient experience of cancer care and treatment in Wales to help drive improvement both locally and nationally. The findings of the survey will help celebrate what is working well and inform ongoing improvements in cancer care, by highlighting areas of importance, raised by people living with cancer across Wales, and their associated findings.

We express our gratitude to the thousands of people living with cancer who took part in the survey for providing such detailed feedback on their experiences of cancer diagnosis, treatment, and care. We also extend our thanks to those who supported the development of the survey, attended the engagement sessions, and those who gave up their time to help test the survey.

Cancer care in Wales is underpinned by high-quality person-centred care; this can mean having a good conversation about their concerns, understanding if they need signposting to financial advice or counselling and making sure there's a named point of contact throughout their care.

Person-centred care has been a long-established component of cancer care in Wales, initially set out in public policy under the Cancer Delivery Plan (2011-2016)⁴, Cancer Delivery Plan (2016-2020)⁵ and most recently in 2021 through the Cancer Quality Statement⁶. Our approach to person-centred care is evidence-based and embedded in the National Optimal Pathways. As part of the Single Cancer Pathway, the National Optimal Pathways provide the standards for health boards and trusts to develop consistent and embedded approaches to delivering person-centred care across Wales⁷. The National Optimal Pathways set out the need for a Key Worker and Holistic Needs Assessment to take place as a standard part of a person's cancer care and to ensure their wider needs are met.

This iteration of the survey includes the experiences of those who received treatment during the COVID-19 pandemic (1st Jan 2020 - 31st Dec 2020) and will therefore reflect experiences of the changes to services and delivery during this time. The survey was commissioned and managed by Macmillan Cancer Support and the Wales Cancer Network. The survey provider IQVIA are responsible for the designing, dissemination, implementation, analysis, and interpretation.

⁴ https://www.iccp-portal.org/system/files/plans/120613cancerplanen.pdf

⁵ http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/161114cancerplanen.pdf

⁶ https://gov.wales/quality-statement-cancer-html

⁷ https://gov.wales/national-optimal-pathways-cancer-whc2022021

3. Methodology

3.1 Sample Process

All 7 Health Boards and a tertiary cancer centre (Velindre Cancer Centre, part of Velindre University NHS Trust) participated in the survey. The sample for the survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged after an inpatient episode or day case attendance for cancer-related treatment between 1 January and 31 December 2020.

The fieldwork for the survey was undertaken between 23 October 2021 and 13 February 2022.

3.2 Questionnaire distribution

As in 2016, the survey used a mixed-mode methodology. Questionnaires were sent by post in English and Welsh, but also included an option to complete online, also in English or Welsh. 21 days after the initial mail out, a reminder letter was sent to those who had not responded. A further, final, reminder was sent after another 21 days to non-responders, this included another copy of the questionnaire. A Freephone helpline was available to respondents to ask questions about the survey, to enable them to complete their questionnaires over the phone, and to provide access to a translation and interpreting facility for those whose first language was not English or Welsh.

3.3 Assignment of respondents to a Health Board / Velindre

In 2016, individual Health Board scores were produced by assigning people to their Health Board of residence, regardless of where they were treated. Feedback confirmed that this was the preferred approach for interpreting the results again in 2021/22. The exception to this is Velindre Cancer Centre because it is a tertiary cancer centre treating people from multiple Health Boards.

The reporting for Velindre Cancer Centre is based on patients discharged most recently from the cancer centre – as in the 2013 and 2016 surveys. Therefore, Velindre Cancer Centre is treated separately in this report and is not compared to the 7 Health Boards in Wales. For this reason, as well as the fact that it is a specialist cancer centre within a Trust, Velindre Cancer Centre is treated separately in this report.

Approval of this approach for the 2021/22 was agreed by the steering group that oversaw the programme.

There have been a number of changes to the Health Boards since the 2016 survey. For the 2021/22 survey assignment was into:

- Aneurin Bevan University Health Board
- Betsi Cadwaladr University Health Board
- Cardiff and Vale University Health Board
- Cwm Taf Morgannwg University Health Board
 - As of 1st April 2019, Cwm Taf Morgannwg University Health Board took over responsibility for healthcare services in the Bridgend County Borough Council area from Abertawe Bro Morgannwg University Health Board
- Hywel Dda University Health Board
- Powys Teaching Health Board
- Swansea Bay University Health Board
 - Swansea Bay University Health Board (formerly Abertawe Bro Morgannwg University Health Board) was created on April 1, 2019, after responsibility for providing healthcare services in the Bridgend County Borough Council area passed from Abertawe Bro Morgannwg University Health Board to Cwm Taf Morgannwg University Health Board

Powys teaching Health Board Is responsible for planning, commissioning and providing local health services to address local needs of the 133,000 people living in Powys. The very rural nature of Powys means that the majority of local services are provided locally, through GPs and other primary care services, community hospitals and community services. With such a sparsely populated area there is no District General Hospital within Powys therefore Powys teaching Health Board pay for Powys residents to receive specialist hospital services in hospitals outside of the county in both England and Wales.

The patients completing the CPES from Powys teaching Health Board, would have had most of their cancer care outside of their Health Board of residence. E.g. diagnostics and surgery, radiotherapy, chemotherapy.

When interpreting Powys teaching Health Board's results, the reported experience will reflect the whole patient pathway which may span multiple Health Boards/Trust.

This report therefore gives an insight into the cancer experience of respondents who live within Cardiff and Vale University Health Board's administrative area.

3.4 Standardisation of Health Board Data (adjusted data)

This report uses a combination of standardised (adjusted) and unadjusted data. The purpose of standardisation is to make comparisons in data fairer. Standardisation is the process of supressing any differences that may be present due to local variation in terms of patient demographic profile. By adjusting for factors not within the Health Board's control that can have an impact on the perceived performance of a Health Board, such as a respondent's demographic background, economic status, or medical condition, standardisation gives a truer picture of any differences in quality across providers.

It was agreed that data would be adjusted by age, ethnicity, IMD quintile (deprivation), sex and tumour group when Health Board performance is compared – as in the 2016 survey.

Unadjusted data has not been changed in any way – it is an exact reflection of the answers respondents provided after anonymisation.

When Health Boards are not being compared, unadjusted data (data that has not been standardised) will be used.

3.5 Board average score and All Wales score

Adjusted data is used in this report where Health Boards are being compared. In all other cases the data is unadjusted. Where Health Boards are compared, both here and in individual Health Board reports, they are compared against the 'Health Board average score'. This is an average (mean) of all the Health Boards' individual scores. Calculating the average avoids larger Health Boards being overrepresented in setting the standard against which they and other Health Boards are assessed.

When unadjusted data is presented, the total score will be the **All Wales Score**. This is the total positive score of all respondents in the sample. Unlike the Health Board average score, this score does not account for the difference in numbers from each Health Board, and each respondent in the sample is represented equally.

The All Wales scores and the Health Board average scores shown in the charts will differ due to this process.

4. Response rates

The sample size for Cardiff and Vale University Health Board was 1,706 cancer patients.

Of these **91** were removed as they were ineligible. Ineligible patients were those who had died between the sample being finalised and receiving any of the survey letters (**63**), had moved address (**14**) or had informed the helpline they were ineligible for another reason (**14**).

The eligible sample size was therefore calculated as **1,615** patients. A total of **935** questionnaires were returned completed, giving an overall response rate of **57.9**%.

Completed questionnaires were received by post from **757** respondents (**81.0**% of responses); and **167** (**17.9**%) chose to complete their questionnaires on-line. **11** respondents called IQVIA's Freephone helpline to give their responses over the telephone.

As in previous years, because of the very large sample, high response rate, and high completion levels for each question, the data is highly robust from a statistical point of view.

More information on statistical tests undertaken can be found in the Technical Document at https://wcpes.co.uk/library

Response rates

Post



81.0%

Online



17.9%

Telephone



112 /0

Translation



0%

The tables below show the percentage and response by tumour group, sex, age, ethnicity, and sexuality.

Tumour Group	Number of respondents	Percentage of total respondents
Breast	195	20.9%
Other cancers ⁸	166	17.8%
Haematological	114	12.2%
Prostate	107	11.4%
Colorectal / lower gastrointestinal	102	10.9%
Urological (excluding prostate)	83	8.9%
Gynaecological	50	5.3%
Lung	41	4.4%
Head and neck	29	3.1%
Upper gastrointestinal	19	2.0%
Skin	18	1.9%
Sarcoma	6	<1%
Brain / central nervous system (CNS)	5	<1%

Sex of respondents	Number of respondents	Percentage of total respondents
Female	496	53.0%
Male	439	47.0%

 $^{^{\}rm 8}$ The list of codes that make up the Other cancers category are detailed in Appendix 2.

Age of respondents	Number of respondents	Percentage of total respondents
16-24	6	<1%
25-34	9	1.0%
35-44	34	3.6%
45-54	89	9.5%
55-64	200	21.4%
65-74	319	34.1%
75-84	231	24.7%
85+	47	5.0%

It is important to acknowledge the small number of responses received from Asian, Asian British, Black, Black British, Caribbean, Mixed or multiple ethnic, and other ethnic groups.

Equality and diversity statistics in Wales report that 94% of the general population in Wales describe themselves as White⁹, and this mirrors the proportion of responses to the survey.

While it appears the ethnicity of people responding to the survey is broadly representative of the general population of Wales, it means there is less data available on the experiences of Asian, Asian British, Black, Black British, Caribbean, Mixed or multiple ethnic, and other ethnic groups.

Ethnicity of respondents	Number of respondents	Percentage of total respondents
Asian background	12	1.3%
Black / African / Caribbean background	4	<1%
Mixed / multiple ethnic background	10	1.1%
Other ethnic group	1	<1%
White background	848	90.7%
Not available	60	6.4%

Sexual orientation of respondents ¹⁰	Number of respondents	Percentage of total respondents
Heterosexual	840	89.8%
Bisexual	3	<1%
Gay or lesbian	13	1.4%
Other sexuality	0	-

⁹ https://gov.wales/equality-and-diversity-statistics-2017-

2019#:~:text=94.8%25%20of%20the%20population%20of,or%20'Other%20ethnic%20group

¹⁰ <1% of respondents said that they didn't know or were not sure, 2.9% of respondents said they preferred not to answer this question, and a further 5.3% of all respondents to the survey did not answer the question at all.

5. Comparisons with previous years

Following a comprehensive review with stakeholders, and testing the questions with people living with cancer, the questionnaire has been extensively revised since the 2016 survey.

- 16 new questions
- 19 questions removed
- 25 questions edited
- 2 pairs of questions combined

31 questions have been deemed as broadly comparable to previous iterations of the survey, however due to the significant overhaul to the questionnaire, time since the previous iterations, and changes to service during the COVID-19 pandemic, caution must be taken when making **any** comparisons.

Where questions are the same as previous iterations or have been edited but the meaning remains the same, the results for the related question in 2013 and 2016 are shown to add context to the 2021/22 results.

For each question with comparable data from previous iterations of the survey, there is a note indicating if it is:

- a) Directly comparable
- b) Comparable with changes see appendix 1

The 2016 version of the questionnaire and full record of changes is available at https://wcpes.co.uk/library

6. This report, and subsequent publications

This report sets out a summary of the results of the survey for Cardiff and Vale University Health Board.

Additional analysis is available in the national quantitative report, individual reports for each participating Health Board and Velindre Cancer Centre, and the national qualitative report.

This report is accompanied by an online reporting platform, which displays data tables and enables breakdowns by key variables. The online reporting platform can be found at https://wcpes.co.uk

The following guidance and survey materials have also been made available alongside the published results:

- Sampling guidance (detailed instructions provided to DHCW on who should be included in the sample)
- A copy of the 2021/22 questionnaire
- Technical documentation (detailed outline of processes undertaken for statistical analysis, record of comparability and record of scoring)

All of these documents are available at: https://wcpes.co.uk/library

7. Understanding the results

The 2021/22 questionnaire contained 89 individual questions. 8 questions related to patient demographics and 81 asked about the cancer journey.

Within the 81 questions, 23 were 'informational', or routing questions, for example Q07 (In the last 12 months have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?), and 58 questions related to patient experience in a way that can be evaluated.

This report contains charts for each of the 58 evaluative questions, plus 2 informational questions that were deemed to contain important data. For this reason, not every question in the survey has been charted.

Standardised and unadjusted raw data

Throughout the results section, a combination of standardised and unadjusted raw data has been used to provide a comprehensive view of the survey results.

Standardised data. Used in the Health Board Comparison Charts. This data provides an indication of how scores rank when making comparisons, by supressing any differences that may be present due to local variation in terms of patient demographic profile. Standardising the data in this way ensures that any comparisons drawn are reliable when determining variations in scores.

Standardising the data in this way ensures that any comparisons drawn are fair and reliable when determining variations in scores.

The process undertaken to standardise the data is based on age, ethnicity, IMD quintile (deprivation), sex and tumour group.

The percentage scores shown in the Health Board Comparison Charts will differ from those in the other charts because standardised data is being used.

Unadjusted raw data. Used in the Compositional and Longitudinal Charts. This data provides an unadjusted view of exactly how people living with cancer have responded to the survey. This view of the data is important to ensure full visibility of the survey results as a dataset in its own right.

Scoring

For each evaluative patient experience question in the survey, the individual (standardised) responses are converted into scores on a scale from 0% to 100%. To calculate these scores, each individual answer option to a scored question has been identified as either positive, negative, or neutral. The percentage score is calculated using the positive total as the numerator, and the total of positive and negative responses as the denominator. Neutral scores (e.g. "Don't know / can't remember") are excluded from the scoring calculation (i.e. not included in either the numerator or denominator). A score of 100% represents the best possible response and a score of 0% the worst possible response. The higher the score, the better the result.

Question 61 asks respondents to rate their overall care on a scale of 0 to 10. Scores have been given as the average on this scale.

Full details of the scoring methodology are in included in the technical document available at https://wcpes.co.uk/library

Health Board average score and All Wales score

Where Health Boards are compared, both here and in individual Health Board reports, they are compared against the 'Health Board average score'. This is an average (mean) of all the Health Boards' individual scores. Calculating the average avoids larger Health Boards being overrepresented in setting the standard against which they and other Health Boards are assessed.

When unadjusted data is presented, the total score will be the 'All Wales score'. This is the total positive score of all respondents in the sample. Unlike the Health Board average score, this score does not account for the difference in numbers from each Health Board, and each respondent in the sample is represented equally.

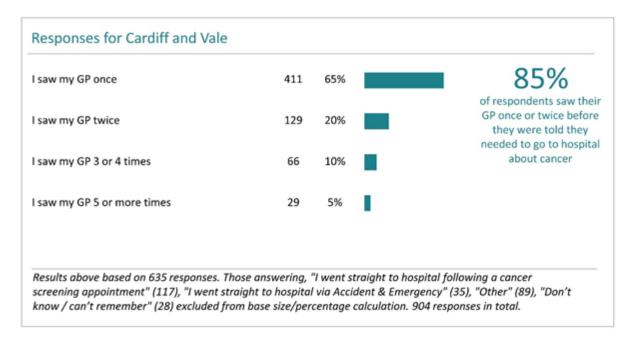
This process for presenting the data will result in the All Wales scores and the Health Board average scores showing as different in the reporting charts.

Evaluative patient experience questions

The 58 evaluative patient experience questions have been charted in 3 ways:

 Compositional Chart. The Compositional Chart uses unadjusted raw data. It shows the range of responses to the question. These charts exclude any non-specific responses such as don't know / can't remember.

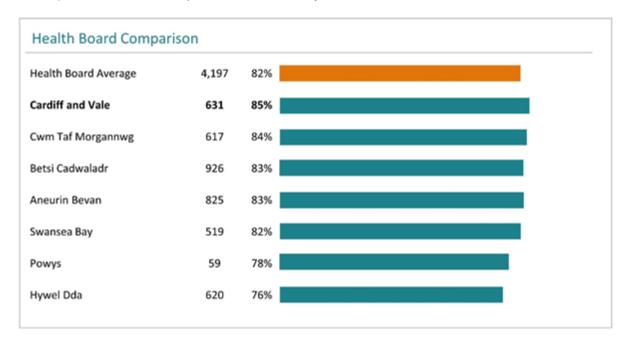
Example of a Compositional Chart - Question 4: "Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?"



2. Health Board Comparison Chart. The Health Board Comparison Chart uses the scored result for each question plotted against the equivalent scores for each Health Board and uses standardised data. The results are displayed in order of performance, from the highest to the lowest scoring Health Board.

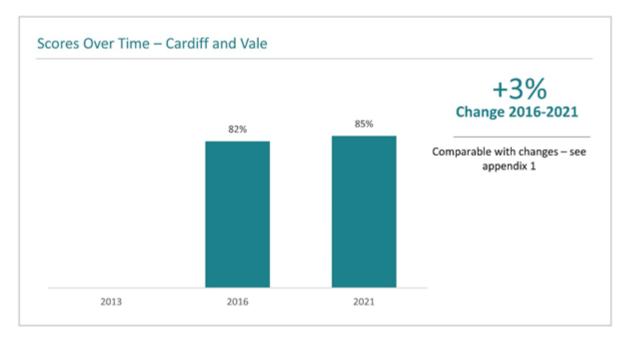
The percentage scores shown in the Health Board Comparison Charts will differ from those in the other charts because standardised data is being used.

Example of a Health Board Comparison Chart - Question 4: "Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?"



3. Longitudinal Chart. The Longitudinal Chart uses unadjusted raw data. Where a scored question is comparable to previous iterations of the survey, it has a longitudinal chart showing the 2013 and /or 2016 scores. Where there is no column for 2013, this is because there is no comparable data.

Example of a Longitudinal Chart - Question 4: "Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?"

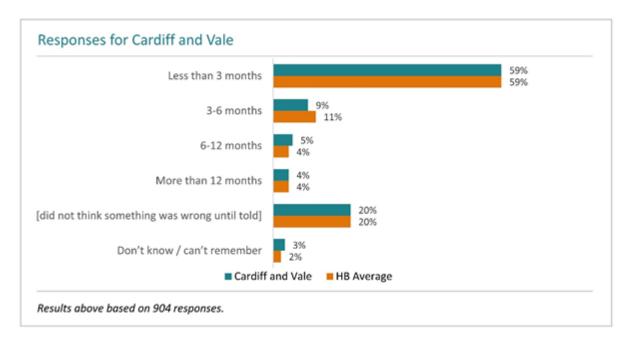


Informational (non-evaluative) questions

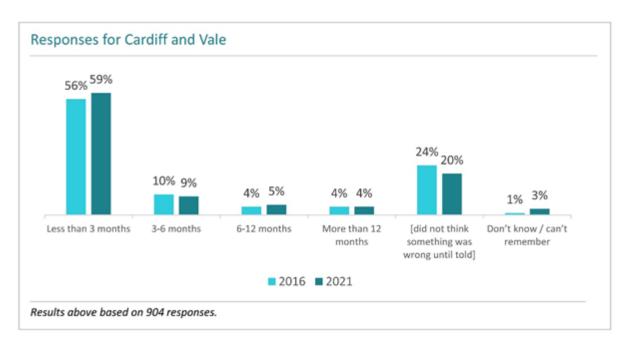
Despite not being assigned a score, 2 of the informational questions (Q02 and Q13) were deemed to contain important data.

The results for these informational non-evaluative questions are illustrated using Compositional Charts.

Example of a Compositional Chart for informational questions - Question 2: "How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?"



Example of a Longitudinal Chart for informational questions - Question 2: "How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?"



Other reporting conventions

Unanswered questions. The percentages are calculated after excluding those respondents that did not answer that particular question ('Missing').

Rounding. All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a question on a Compositional Chart may not total 100% because of this rounding. The rounding may also affect the appearance of the change over time shown in the Longitudinal Charts.

Not applicable and non-specific responses. Some questions have been recalculated to exclude responses where the question was not applicable to the respondent's circumstances, or they felt unable to give a definite answer. For example, on questions such as Q12 - "When you were told you had cancer, were you given written information about the type of cancer you had?" those saying "I did not need written information" or "Don't know / can't remember" are excluded from base size/percentage calculation. Where the total number of responses and base size are different, both figures are included under the charts.

Further information

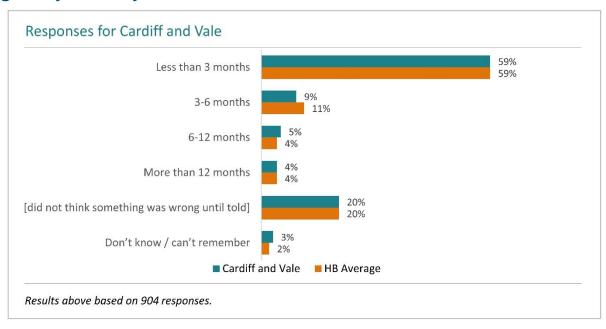
Full details on the standardisation and scoring is included in the Technical Document for this survey, which is published separately at https://wcpes.co.uk/library

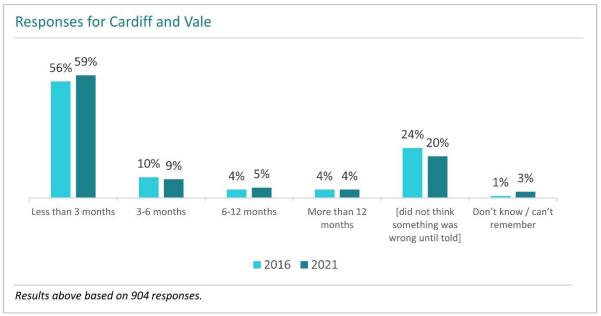
8. Survey results

This section contains charts for each of the 58 evaluative questions, plus 2 informational questions that were deemed to contain important data. For this reason, not every question in the survey has been charted.

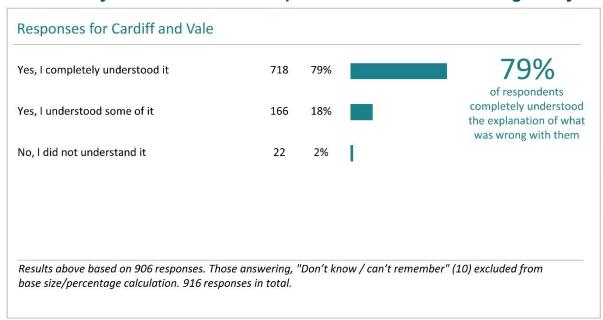
8.1 Before your diagnosis

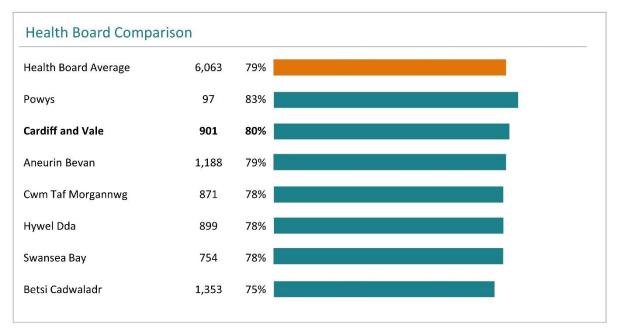
Question 2: "How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?"



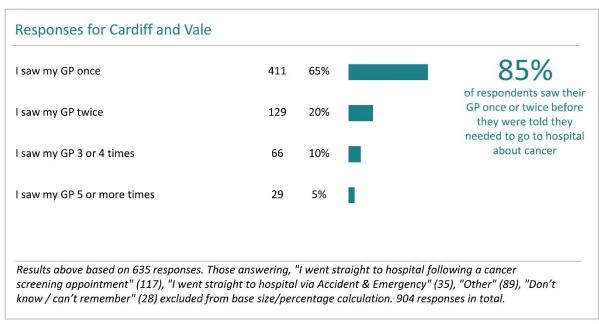


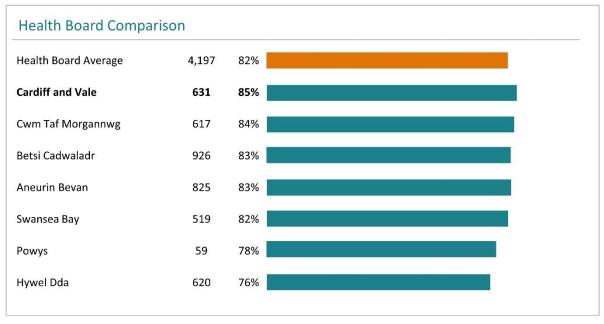
Question 3: "Did you understand the explanation of what was wrong with you?"

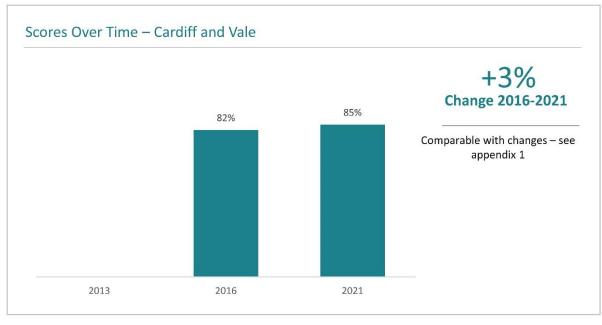




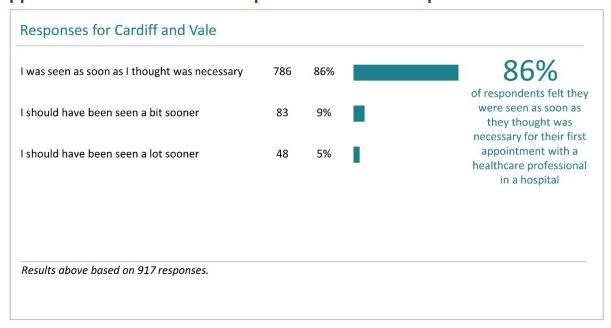
Question 4: "Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?"

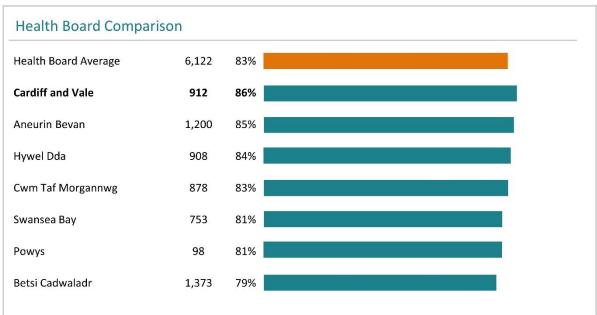




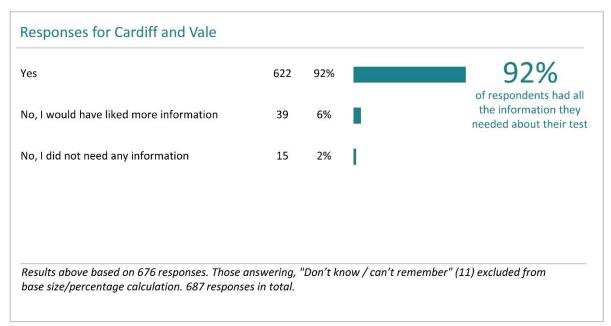


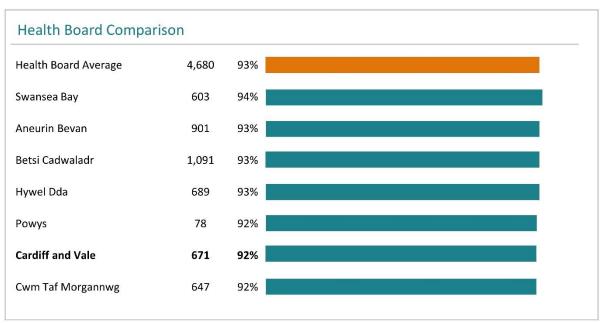
Question 6: " How do you feel about the length of time you had to wait before your first appointment with a healthcare professional in a hospital?"



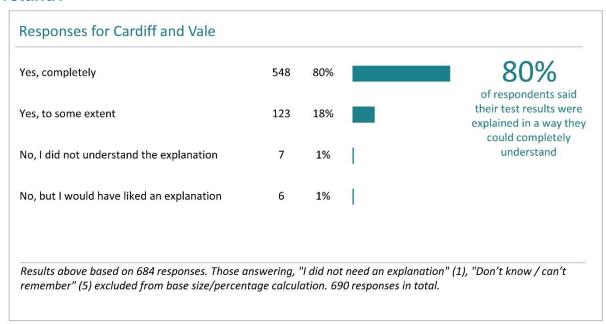


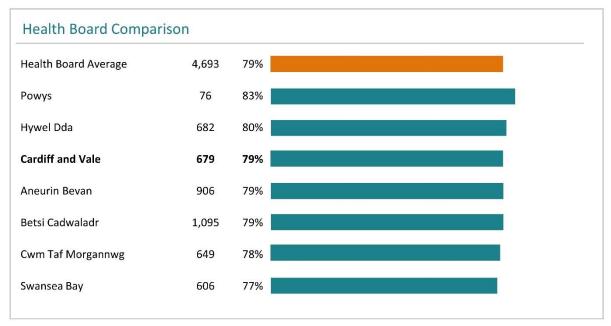
Question 8: "Beforehand, did you have all the information you needed about your test?"

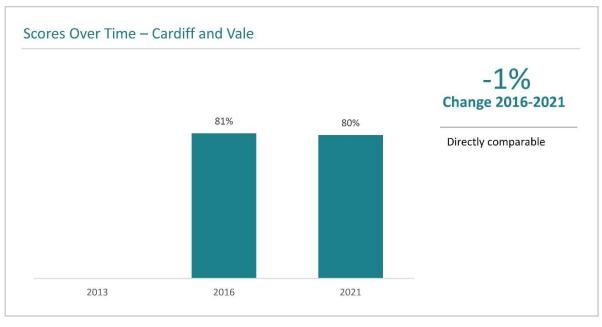




Question 9: "Were the results of the test(s) explained in a way you could understand?

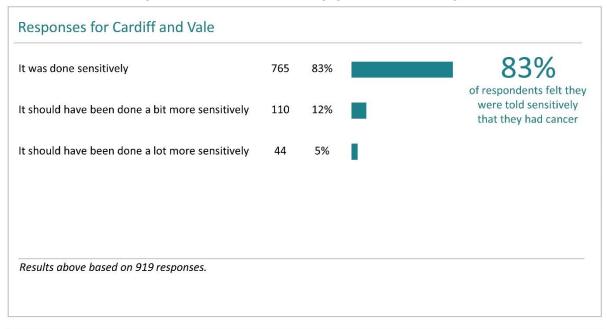


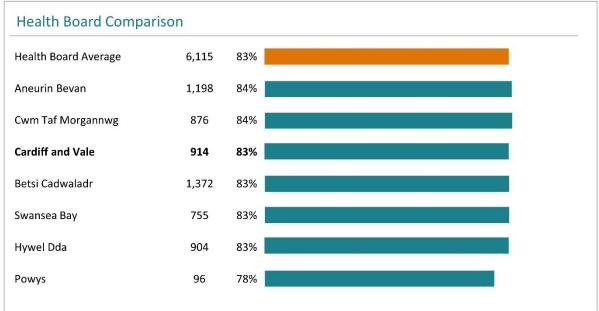


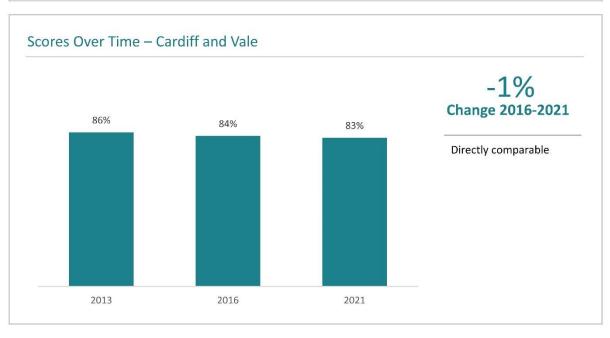


8.2 Finding out you had cancer

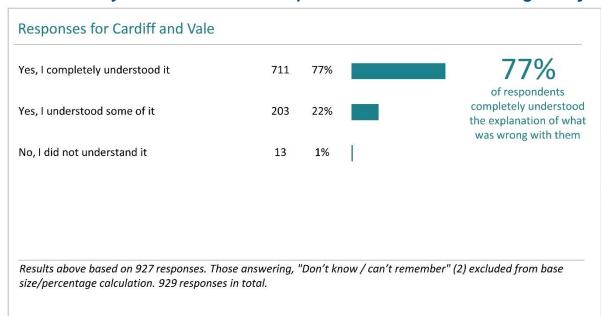
Question 10: "How do you feel about the way you were told you had cancer?"

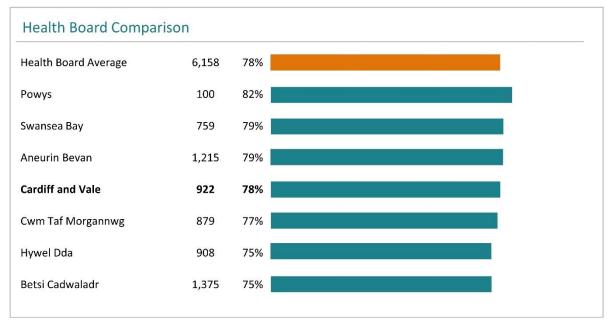


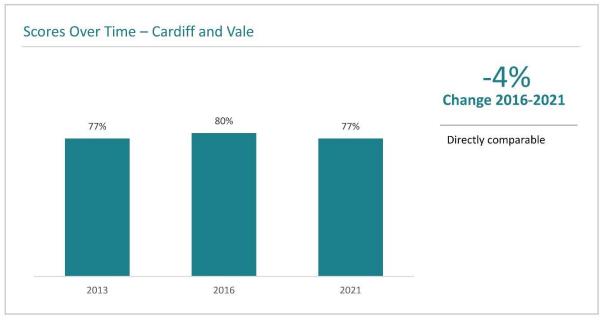




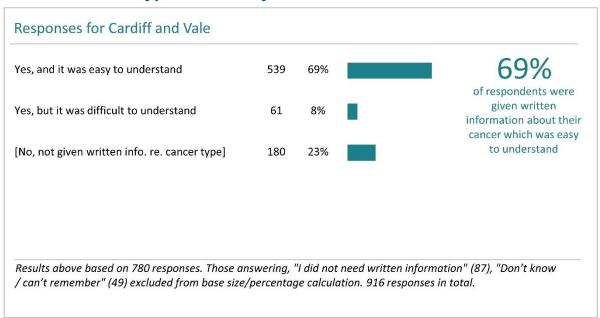
Question 11: "Did you understand the explanation of what was wrong with you?"

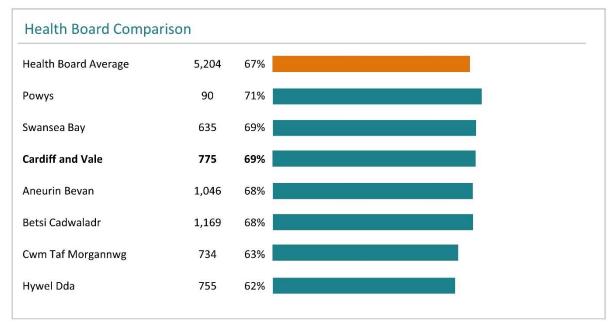


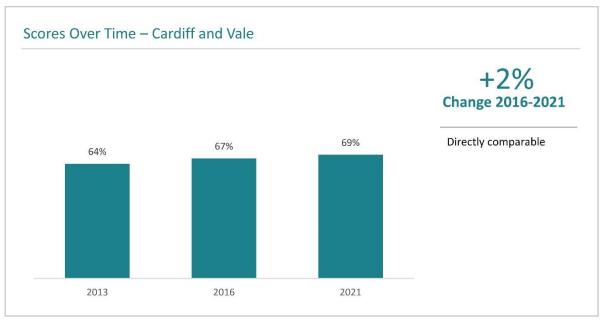




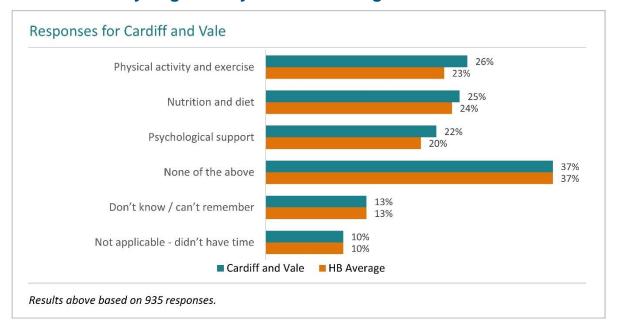
Question 12: "When you were told you had cancer, were you given written information about the type of cancer you had?"



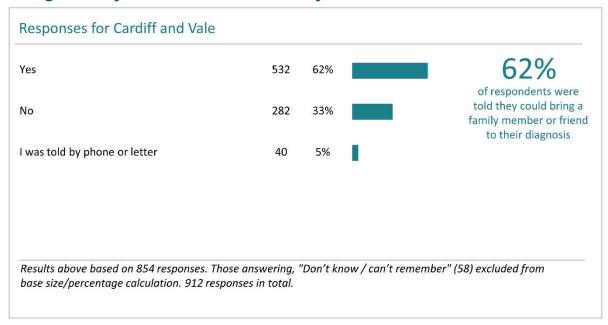


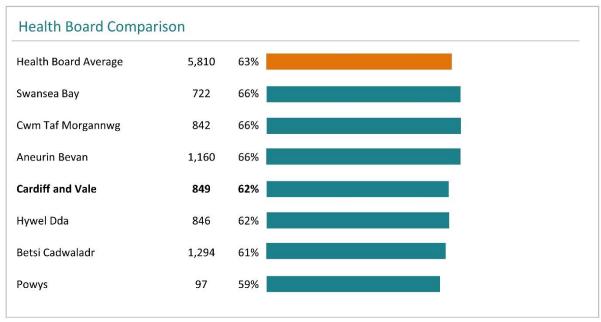


Question 13: "Were you given any of the following information before treatment?"



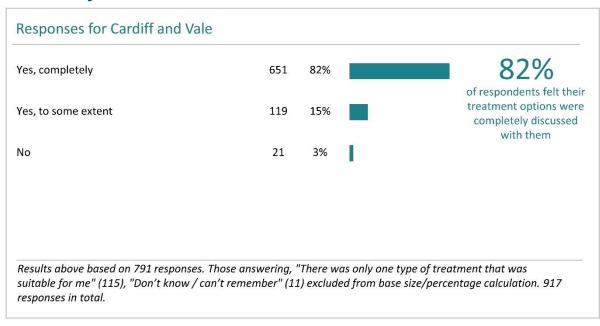
Question 14: "When you were first told that you had cancer, had you been told you could bring a family member or friend with you?"

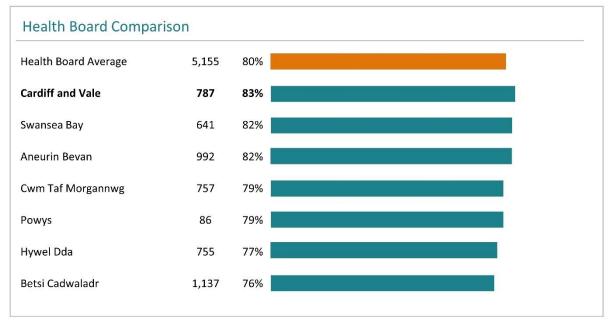




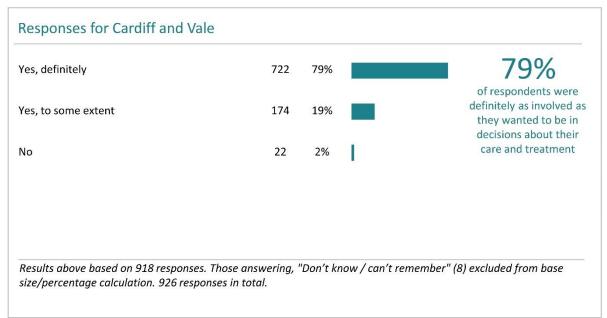
8.3 Deciding the best treatment and / or care for you

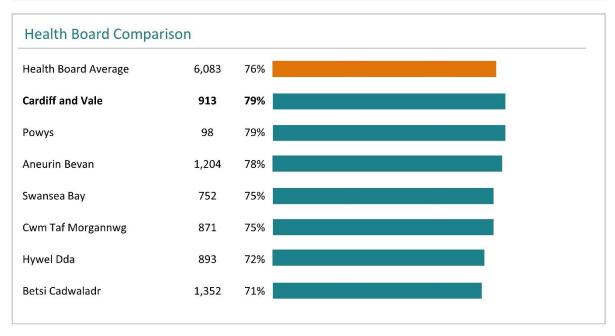
Question 15: "Before your cancer treatment started, were your treatment options discussed with you?"



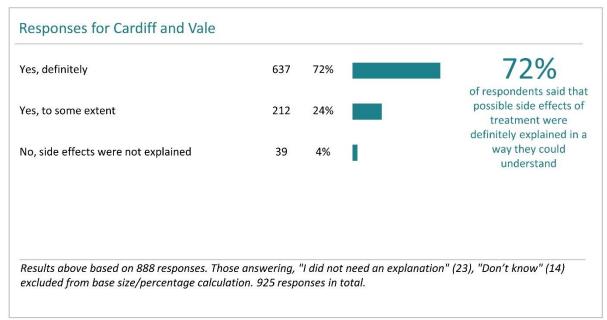


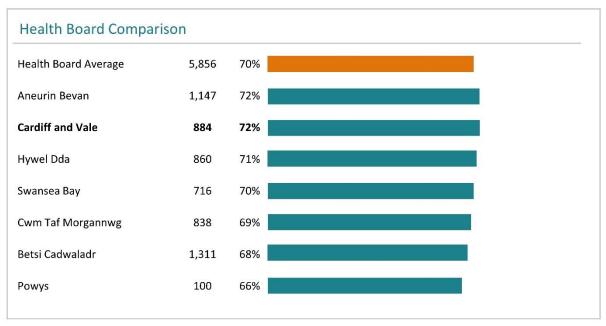
Question 16: "Were you involved as much as you wanted to be in decisions about your care and treatment?"

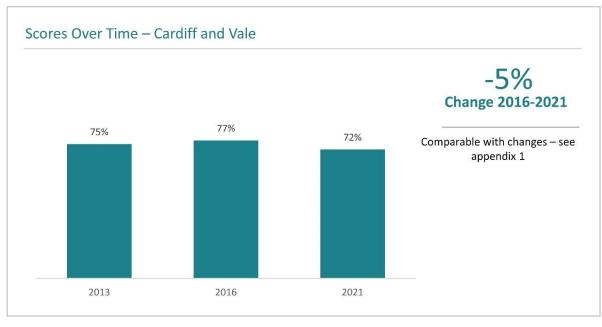




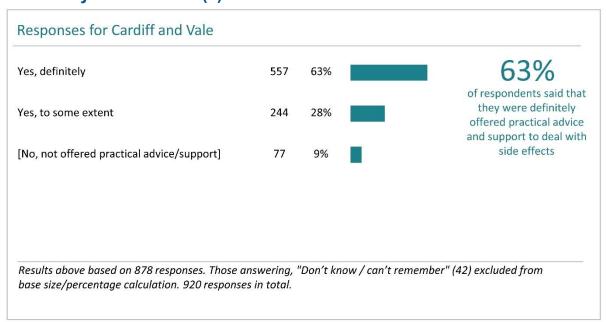
Question 17: "Were the possible side effects of treatment(s) explained in a way you could understand?"

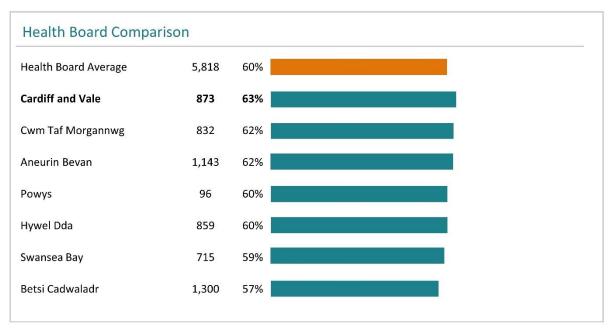




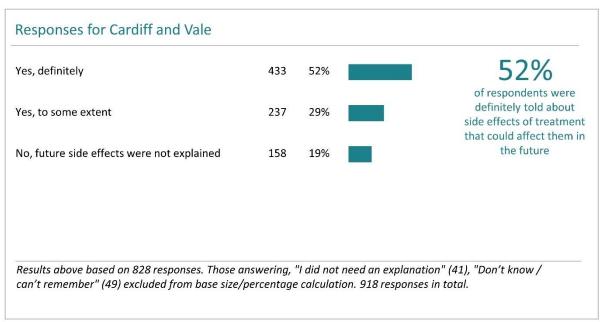


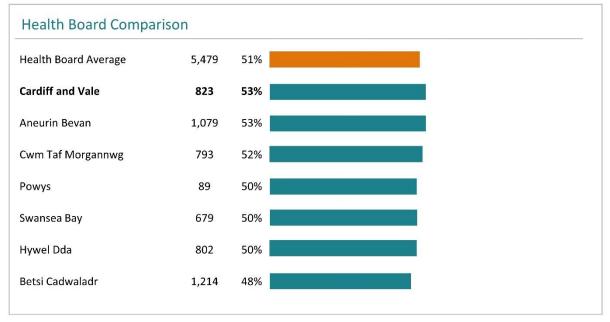
Question 18: "Were you offered practical advice and support in dealing with the side effects of your treatment(s)?"

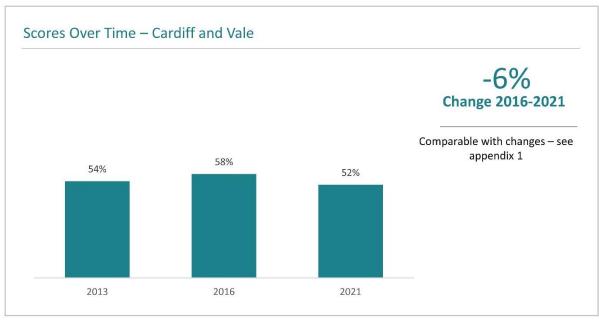




Question 19: "Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?"

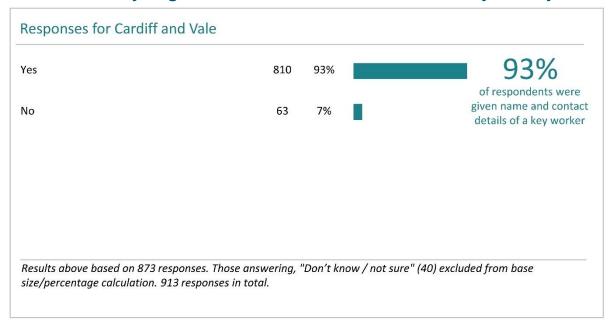


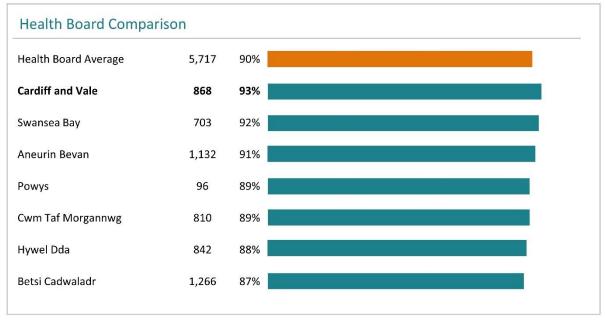


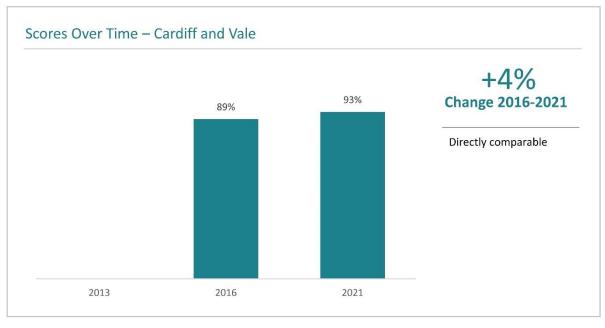


8.4 Healthcare professionals

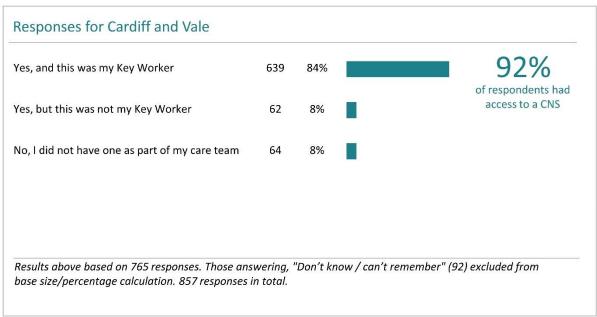
Question 20: "Were you given the name and contact details of your Key Worker?"

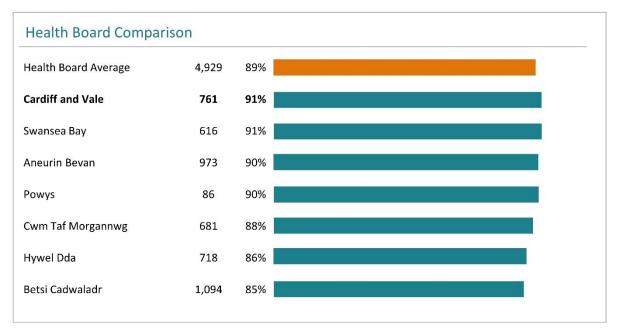


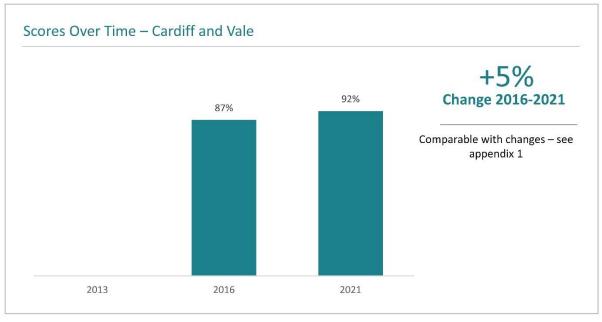




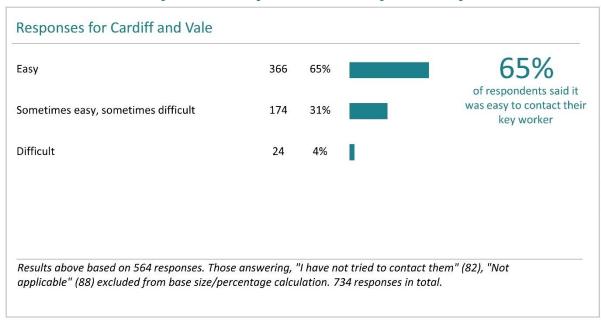
Question 21a: "Did your care include access to... A CNS?"

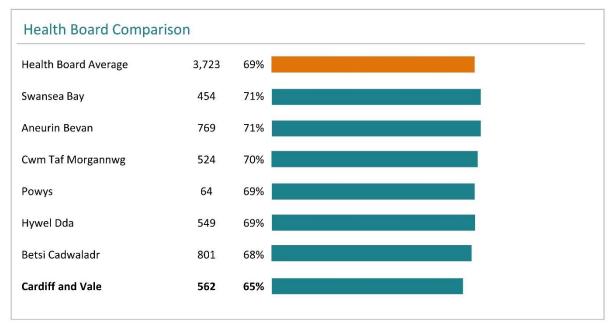


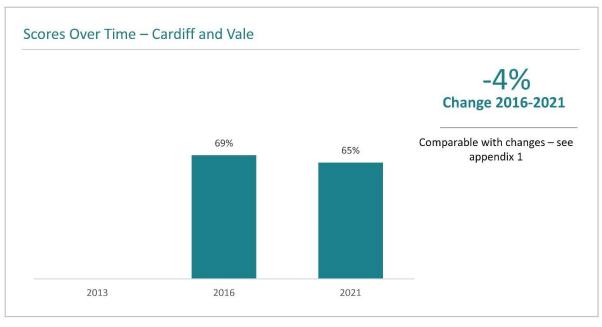




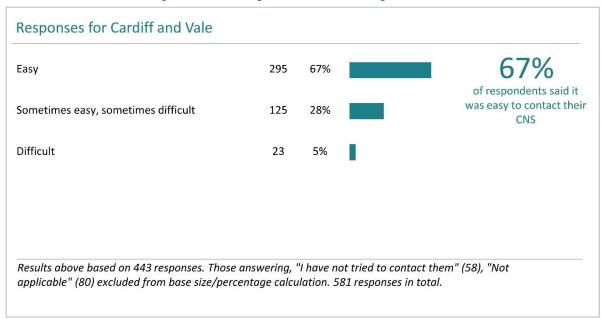
Question 22a: "How easy was it for you to contact your... Key Worker?"

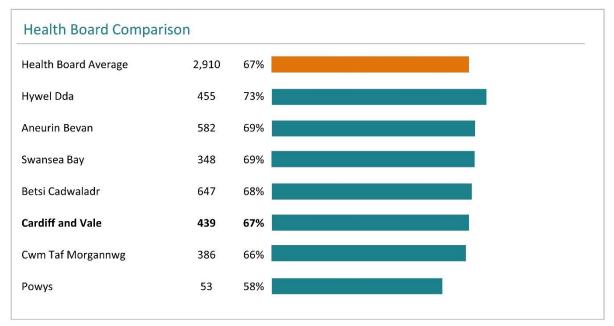


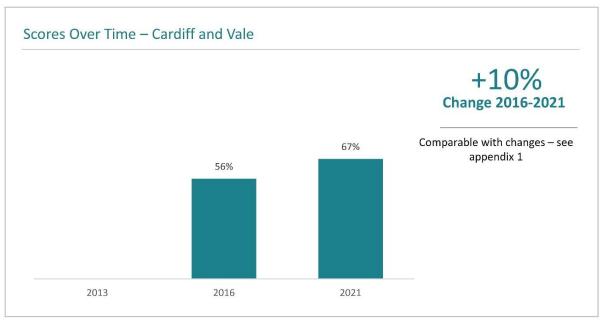




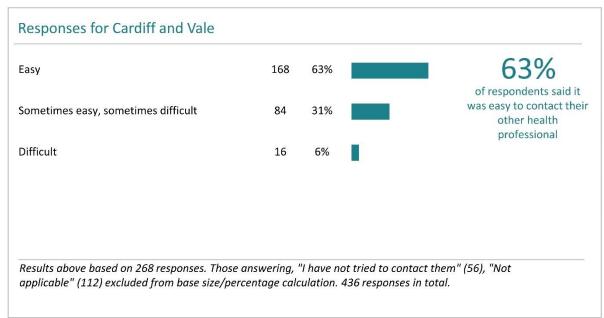
Question 22b: "How easy was it for you to contact your... CNS?"

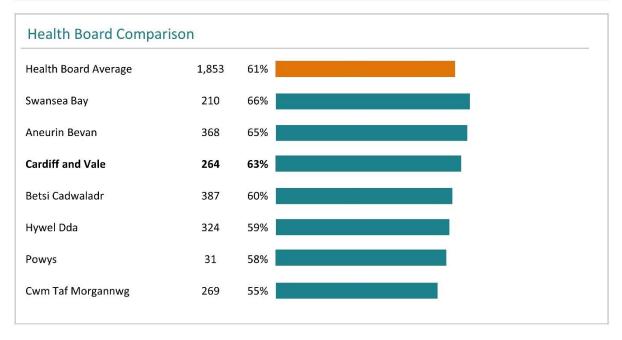




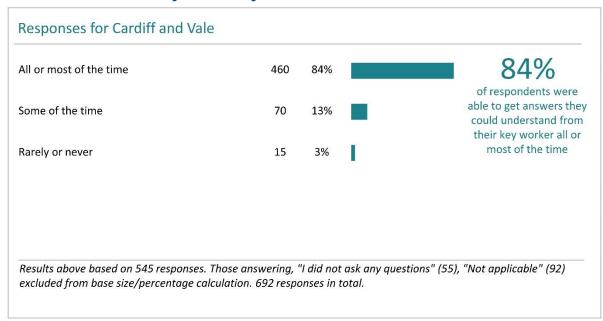


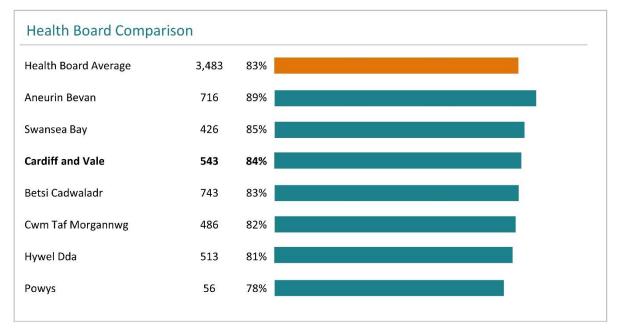
Question 22c: "How easy was it for you to contact your... Other health professional?"



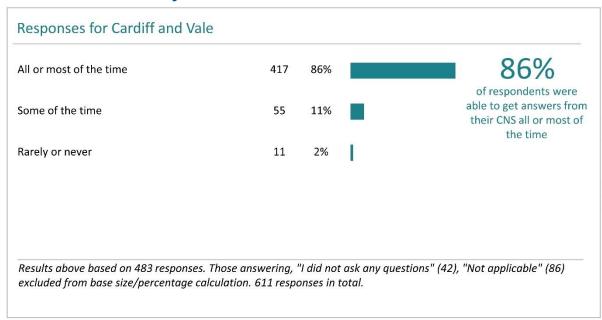


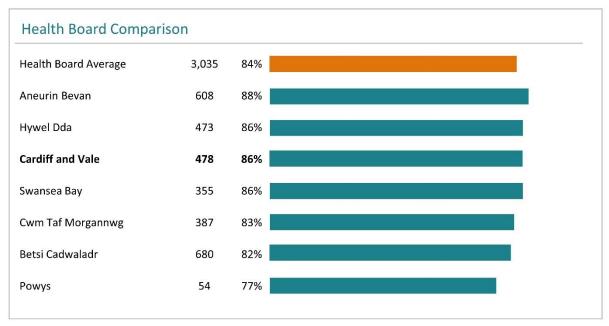
Question 23a: "When you had questions to ask, how often did you get answers you can understand from your... Key Worker?"

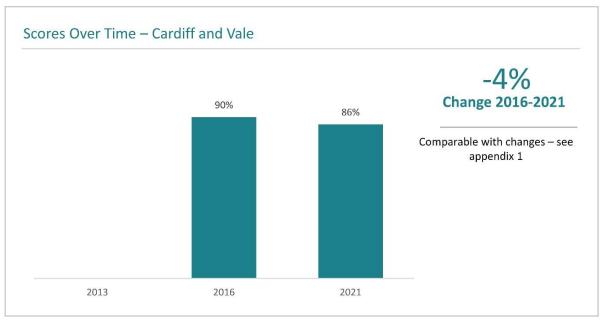




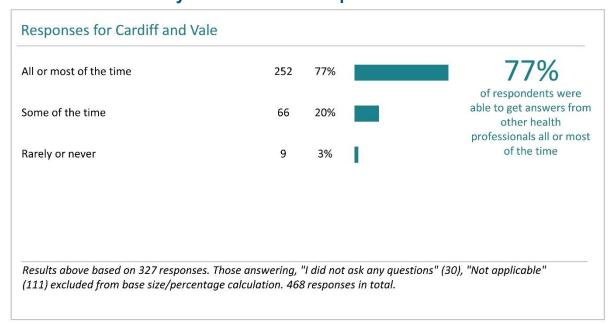
Question 23b: "When you had questions to ask, how often did you get answers you can understand from your... CNS?"

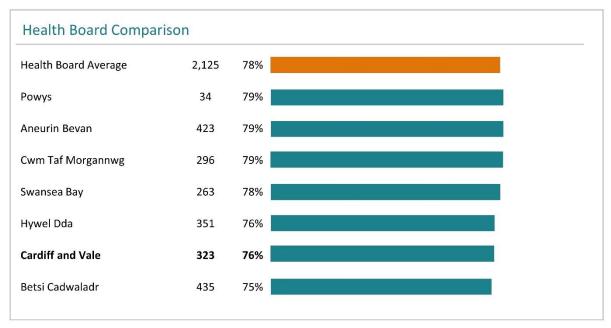




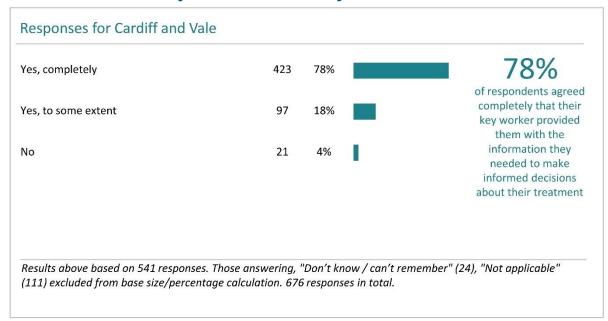


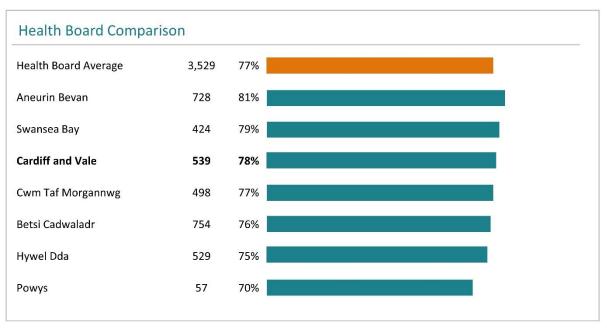
Question 23c: "When you had questions to ask, how often did you get answers you can understand from your... Other health professional?"



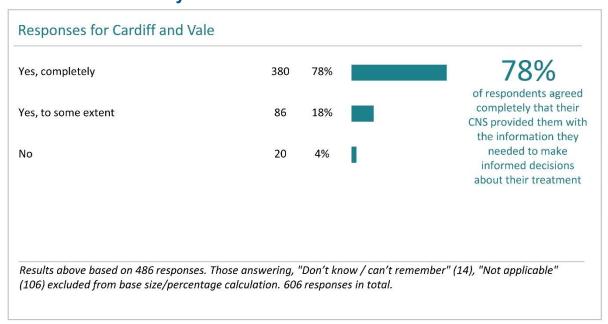


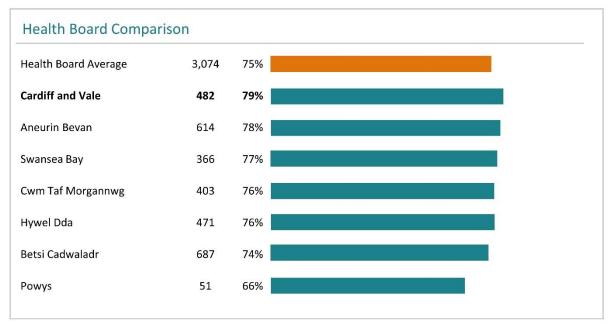
Question 24a: "Did they provide you with the information you needed to make informed decisions about your treatment? Key Worker"

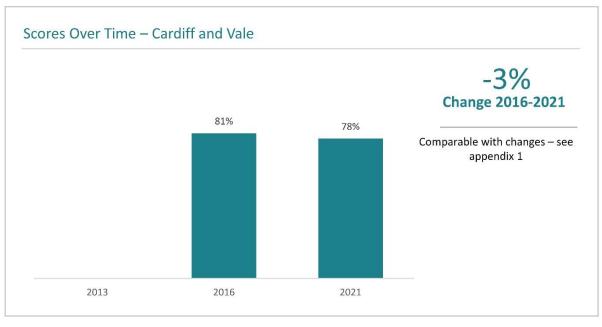




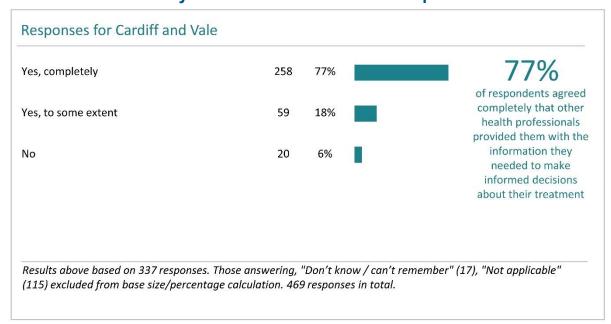
Question 24b: "Did they provide you with the information you needed to make informed decisions about your treatment? CNS"

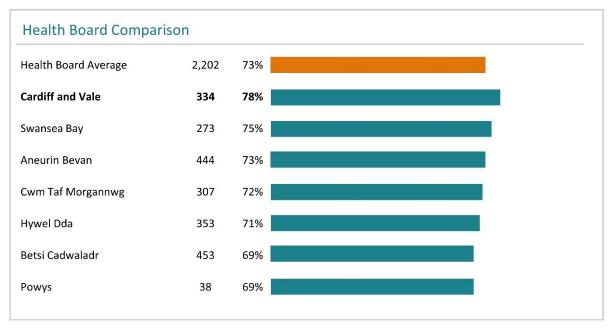




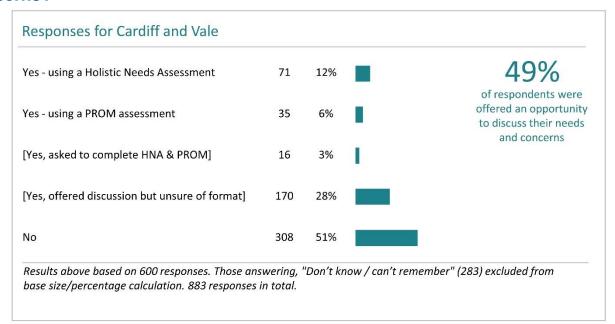


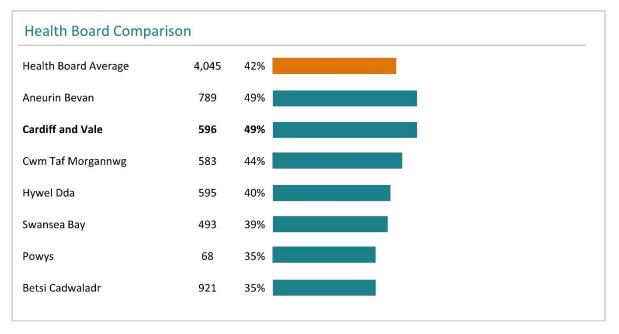
Question 24c: "Did they provide you with the information you needed to make informed decisions about your treatment? Other health professional"





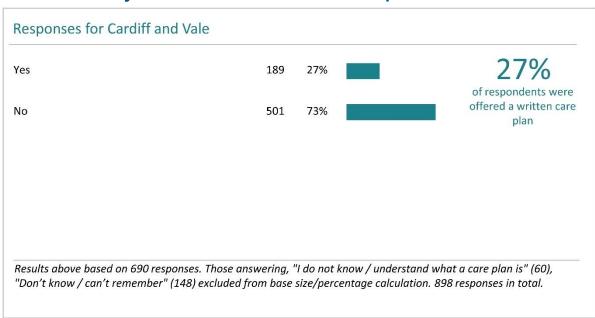
Question 25: "Were you offered the opportunity to discuss your needs and concerns?" 11

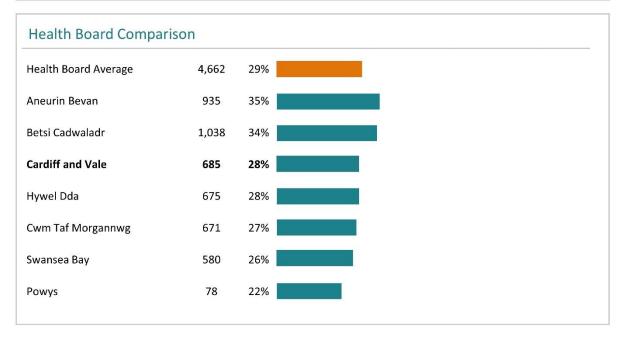




¹¹ A HNA is a Holistic Needs Assessment. Patient-Reported Outcome Measures (PROMs) are questionnaires that have been designed and tested with patients and clinicians for either specific diseases or for general health or quality of life.

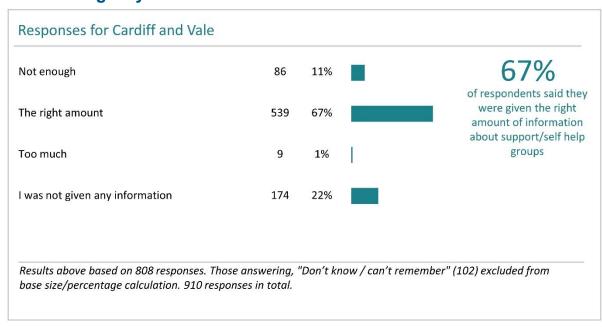
Question 26: "Have you been offered a written care plan?"

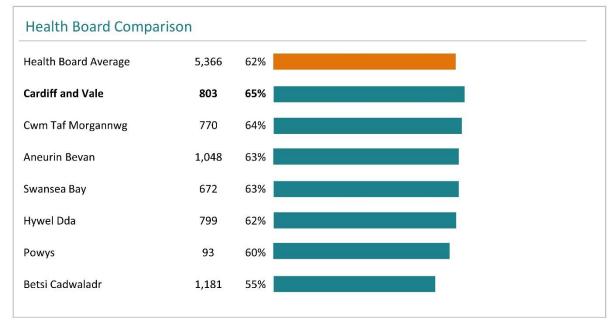




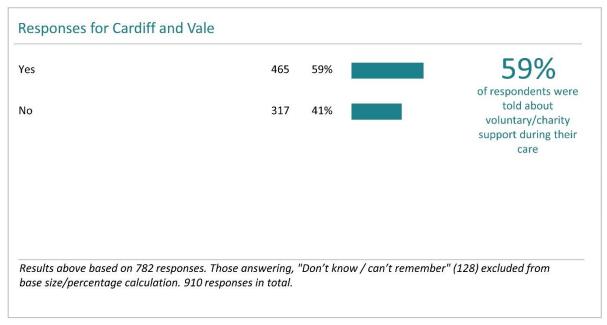
8.5 Support for people living with cancer

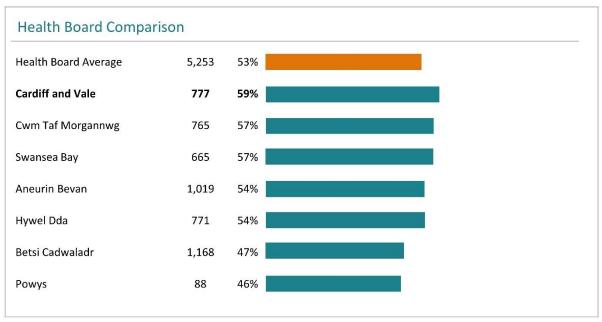
Question 27: "How much information about support or self-help groups did your healthcare team give you?"

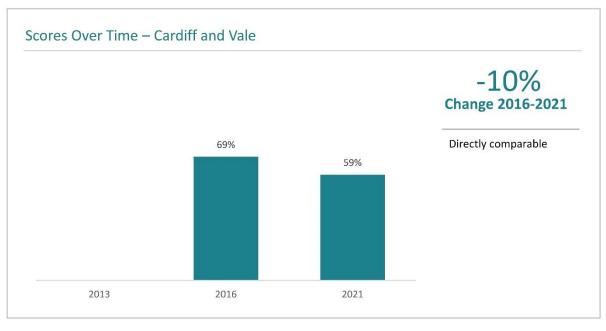




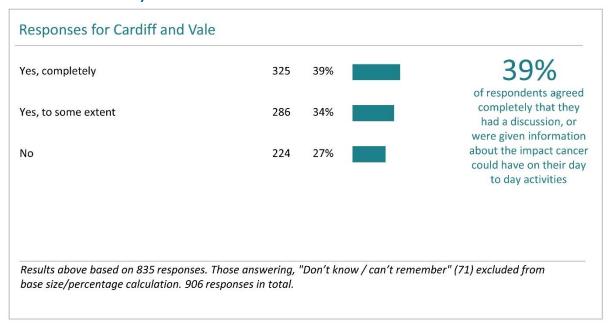
Question 28: "During your care, were you told about voluntary or charity support?"

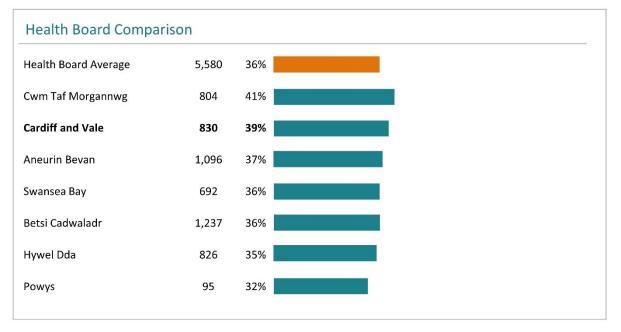




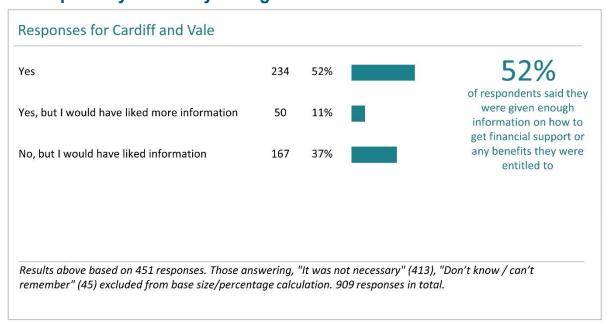


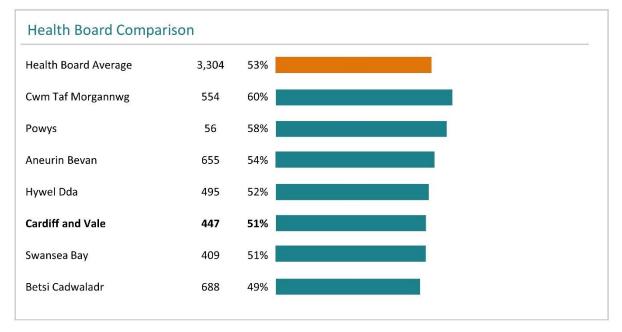
Question 29: "Did your healthcare team discuss with you or give you information about the impact cancer could have on your day-to-day activities (for example, work life or education)?"





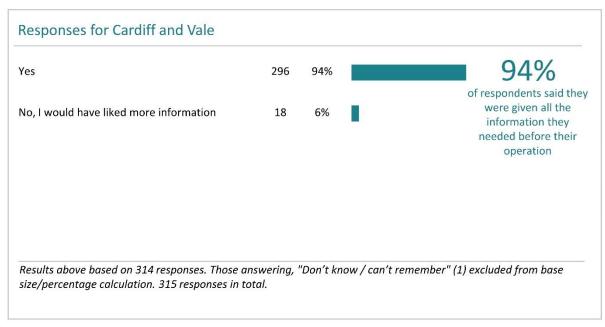
Question 30: "Did your healthcare team give you information about how to get financial help or any benefits you might be entitled to?"

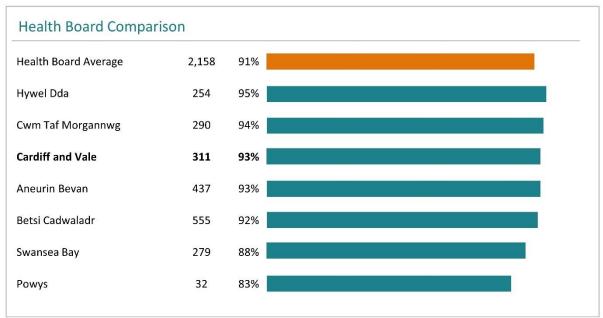




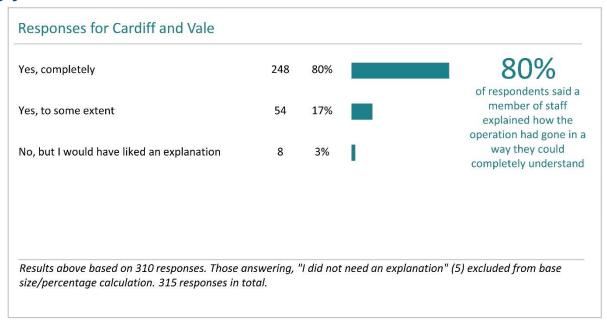
8.6 Operations

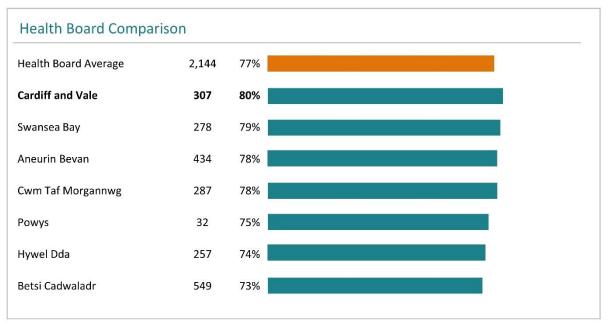
Question 32: "Beforehand, did you have all the information you needed about your operation?"

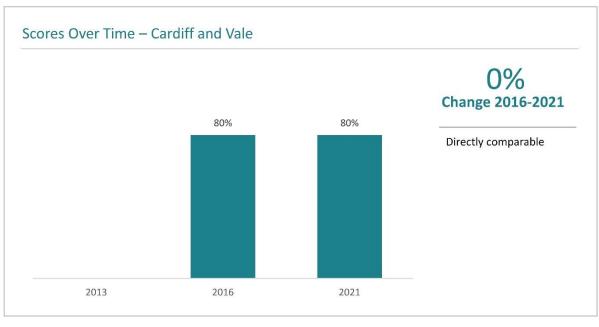




Question 33: "After the operation, did a member of staff explain how it had gone in a way you could understand?"

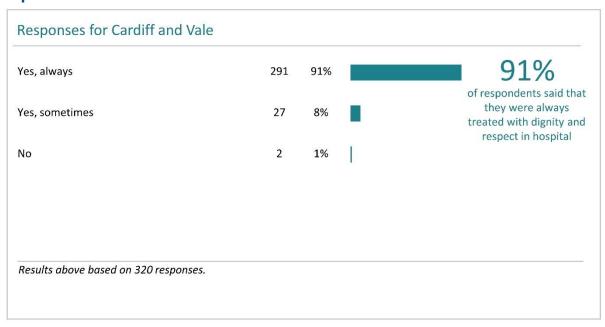


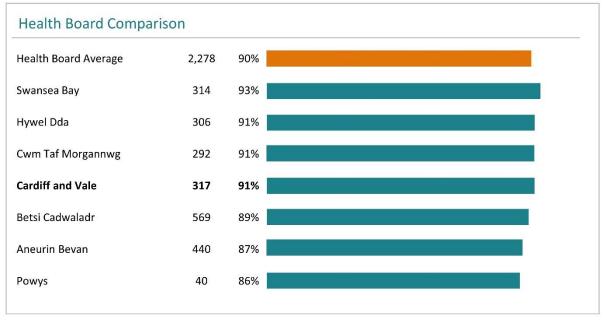


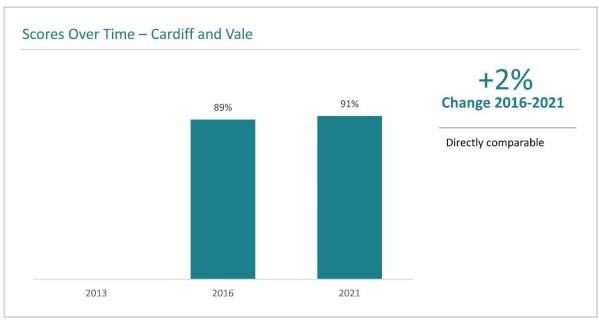


8.7 Hospital care as an inpatient

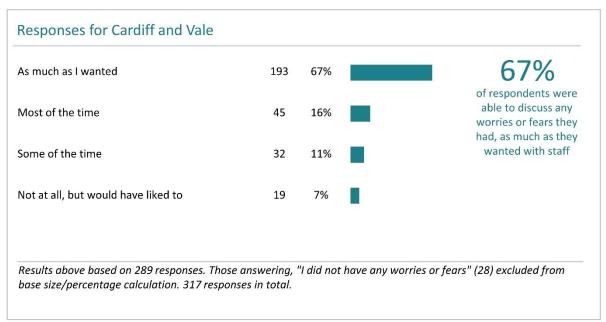
Question 35: "Overall, while you were in hospital, were you treated with dignity and respect?"

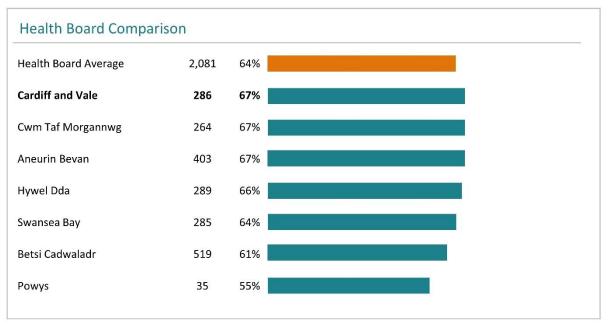


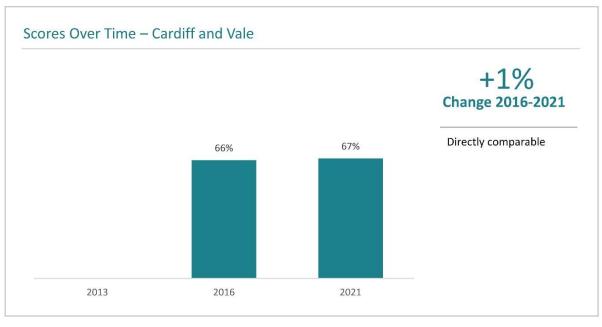




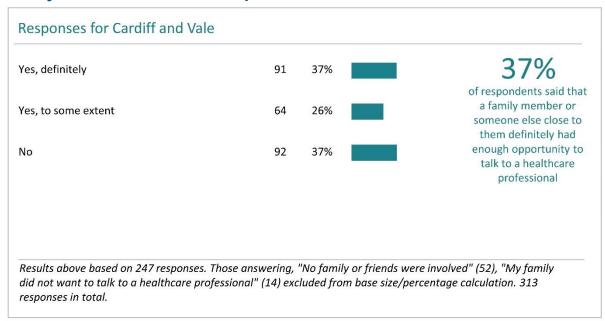
Question 36: "Were you able to discuss any worries or fears with staff during your hospital visit?"

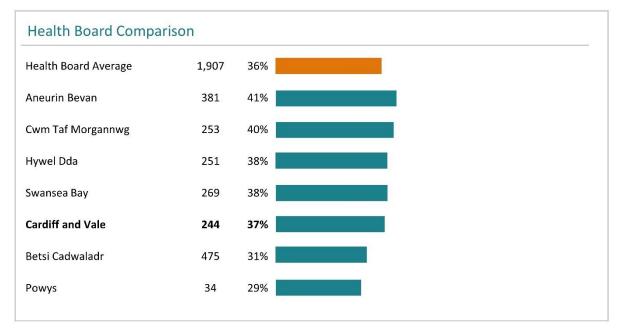




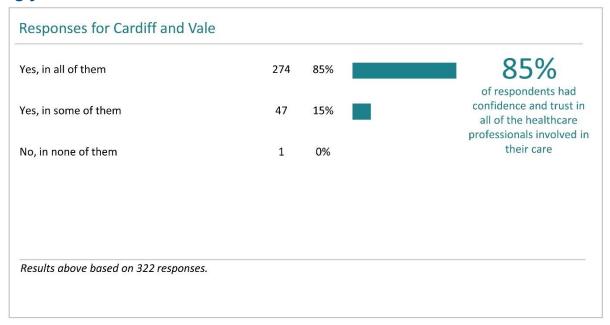


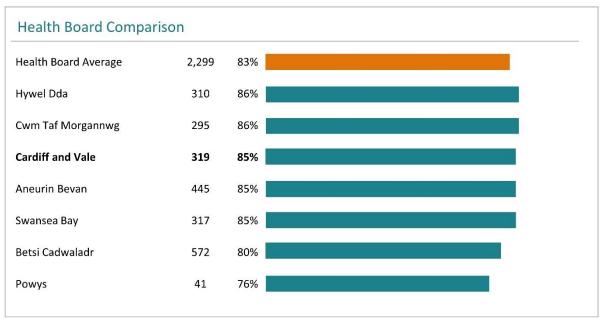
Question 37: "Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?"



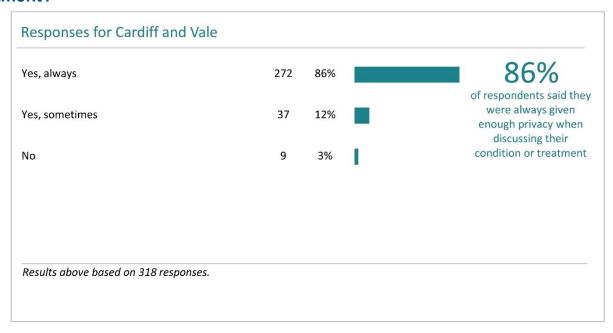


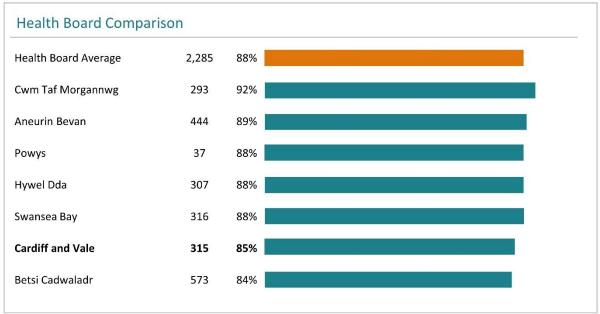
Question 38: "Did you have confidence and trust in the healthcare professionals treating you?"

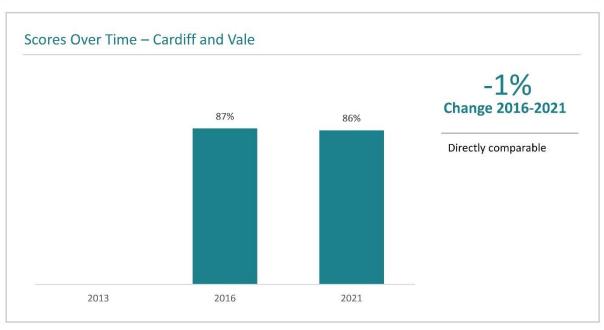




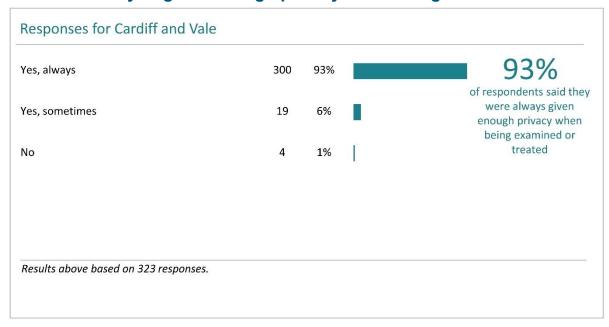
Question 39: "Were you given enough privacy when discussing your condition or treatment?"

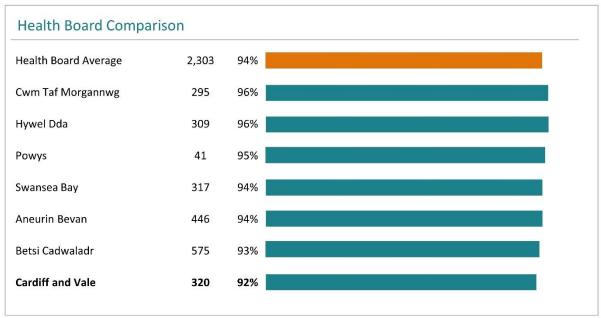


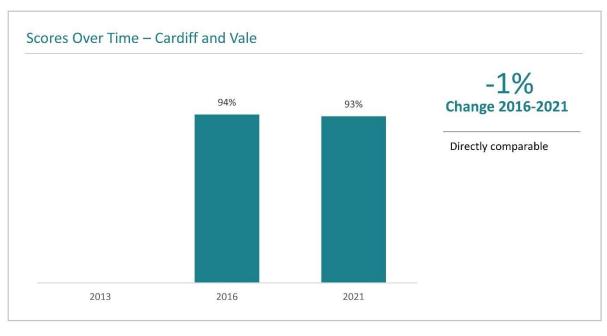




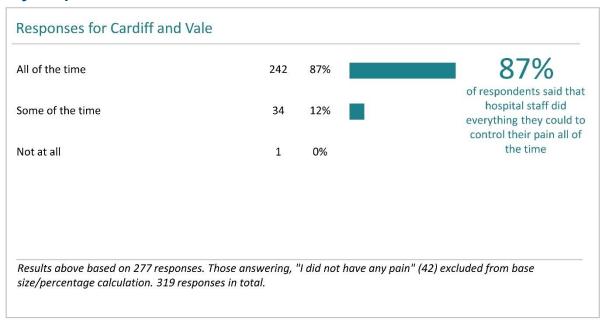
Question 40: "Were you given enough privacy when being examined or treated?"

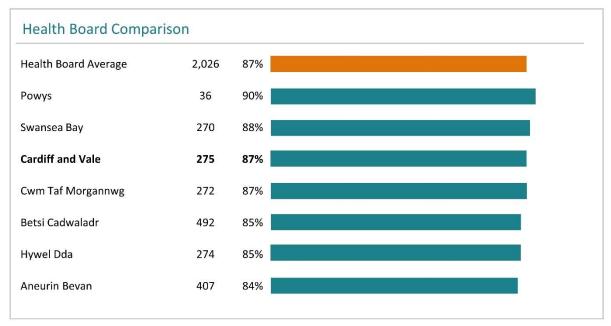


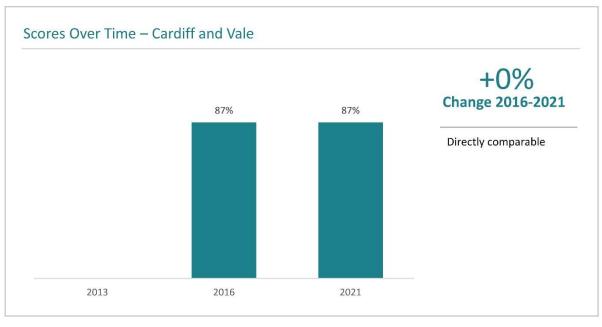




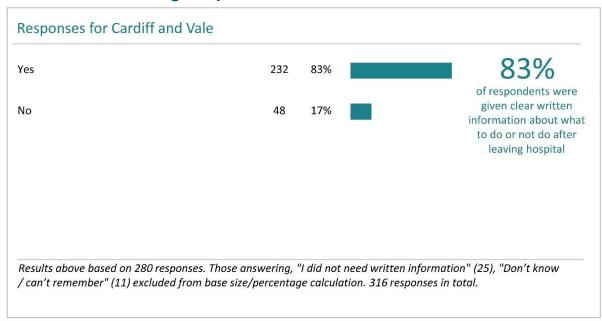
Question 41: "Do you think the hospital staff did everything they could to help control your pain?"

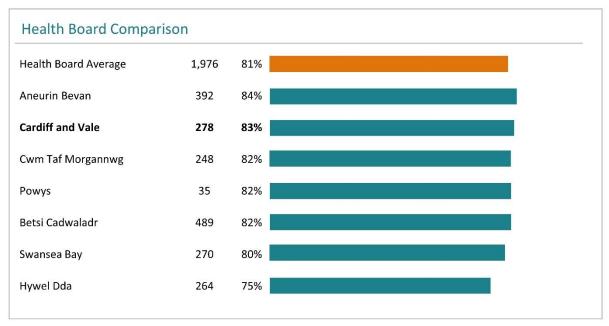


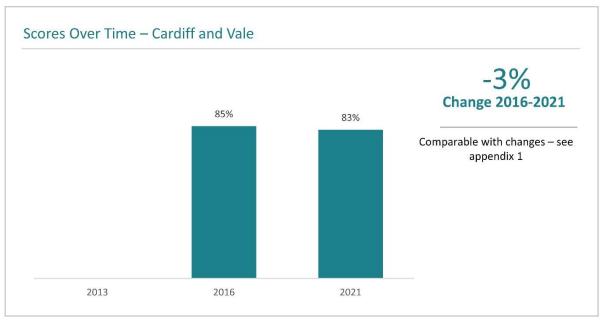




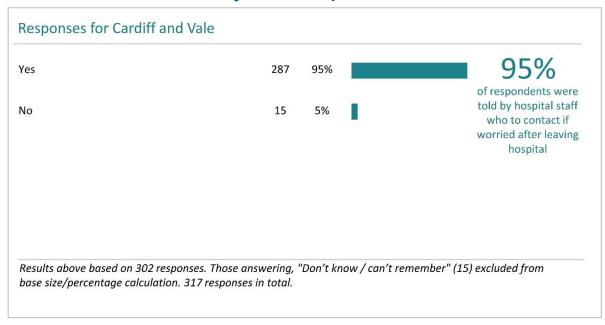
Question 42: "Were you given clear written information about what you should or should not do after leaving hospital?"

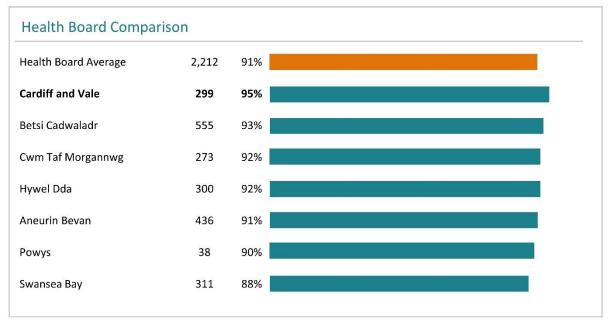


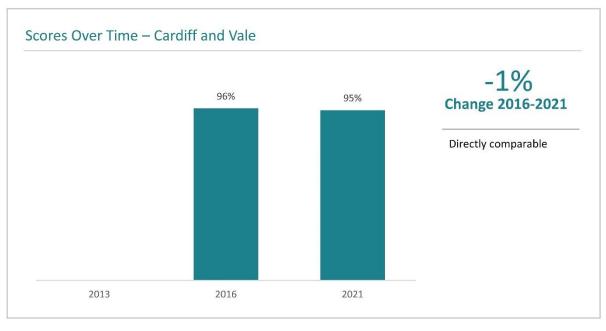




Question 43: "Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?"

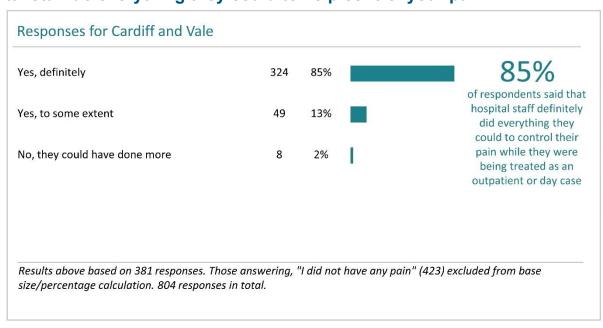


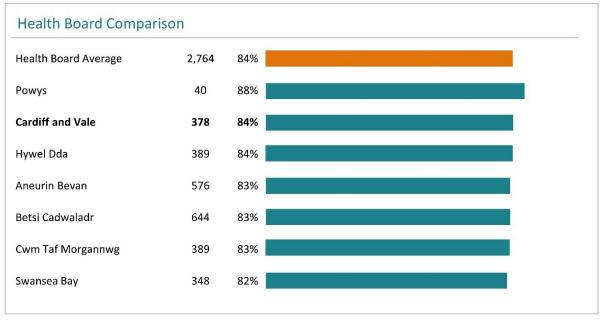


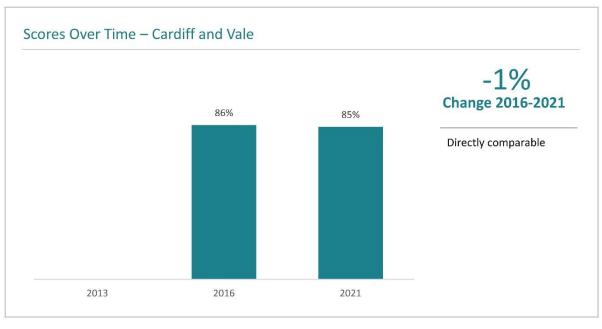


8.8 Outpatients / day case appointments

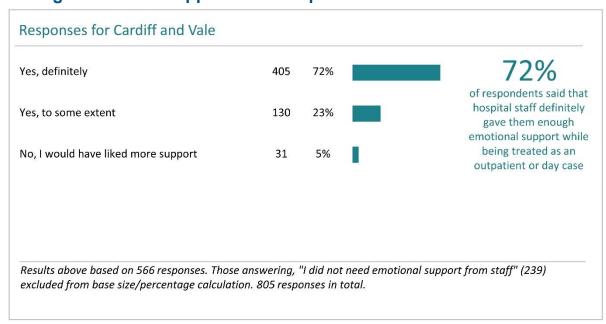
Question 45: "While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?"

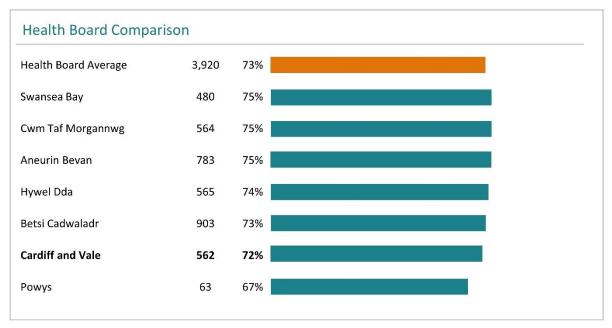


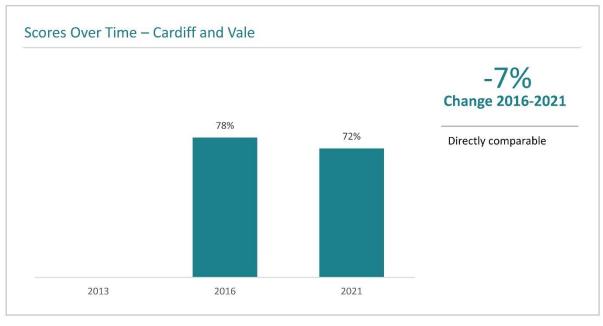




Question 46: "While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?"

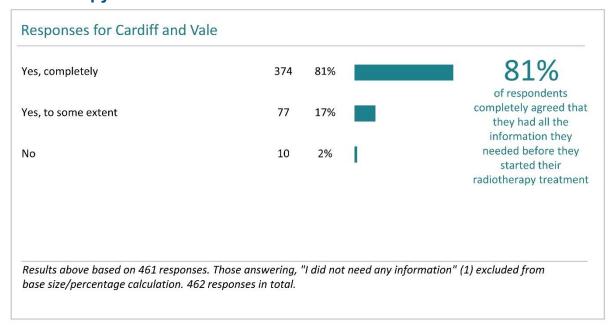


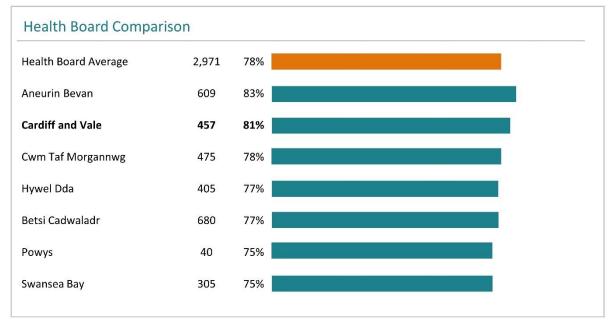




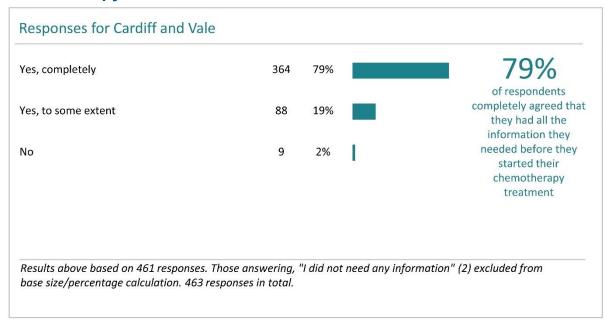
8.9 Radiotherapy / chemotherapy

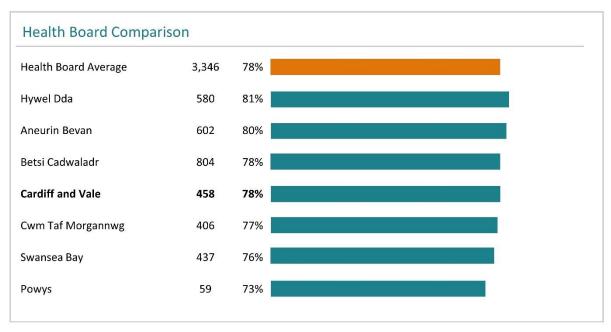
Question 48: "Beforehand, did you have all of the information you needed about your radiotherapy treatment?"





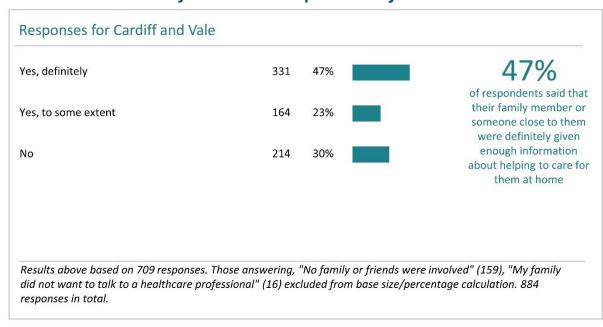
Question 50: "Beforehand, did you have all of the information you needed about your chemotherapy treatment?"

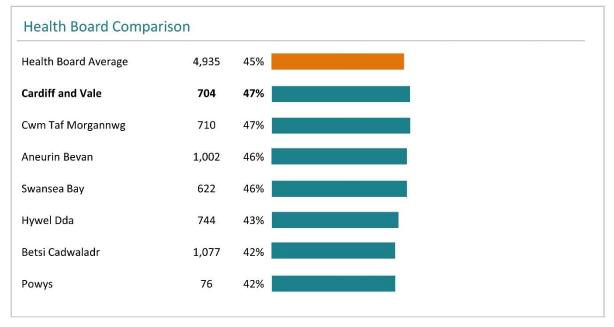




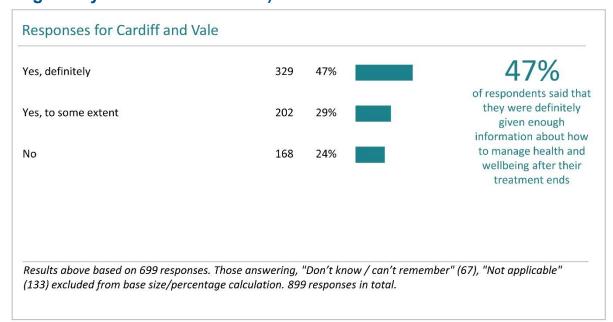
8.10 Arranging home support

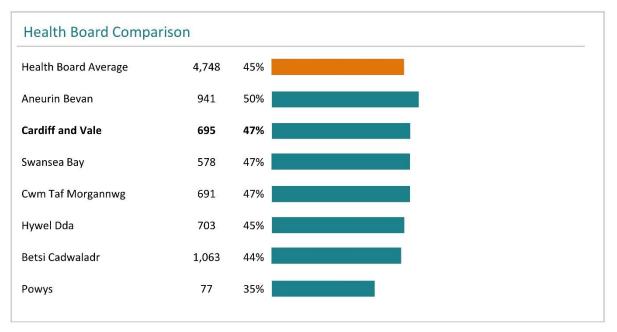
Question 51: "Did healthcare professionals give your family or someone close to you all the information they needed to help care for you at home?"



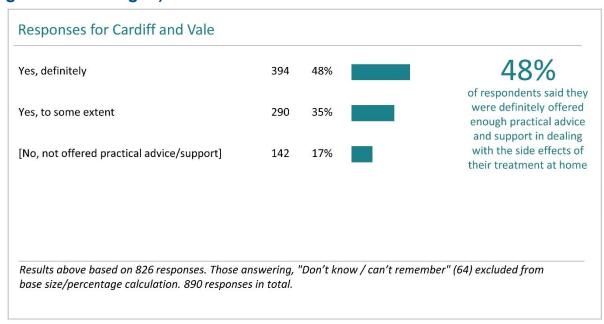


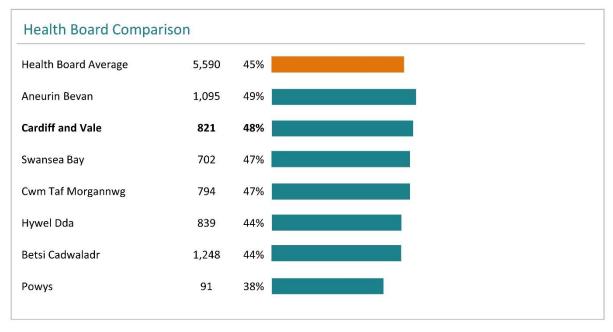
Question 52: "Were you given information about how to manage your health and wellbeing after your treatment ends?)"

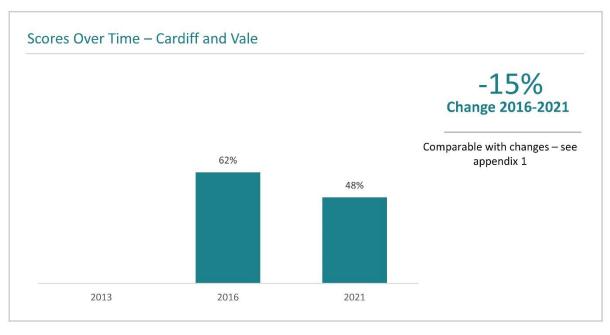




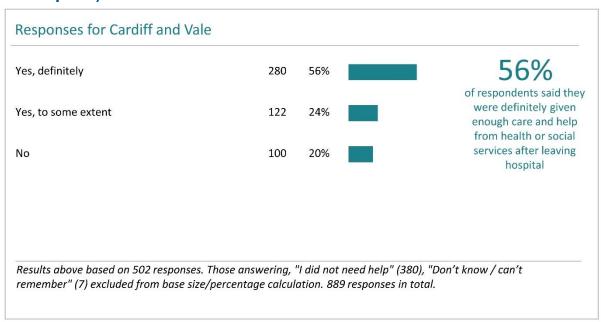
Question 53: "Were you offered practical advice and support in dealing with the side effects of your treatment(s) at home (such as physical activity advice, how to manage diet and fatigue)?"

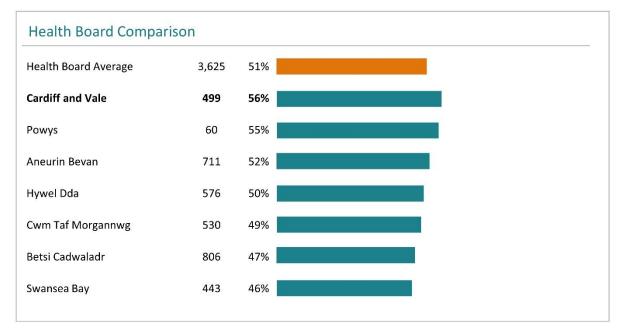


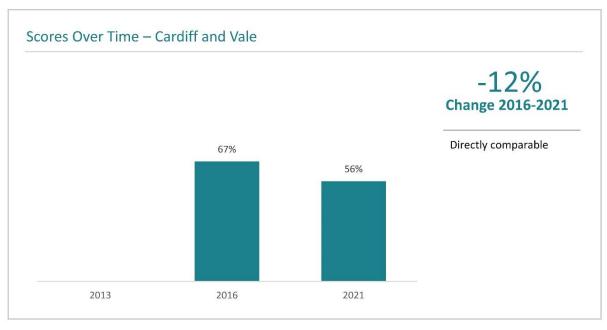




Question 54: "After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?"

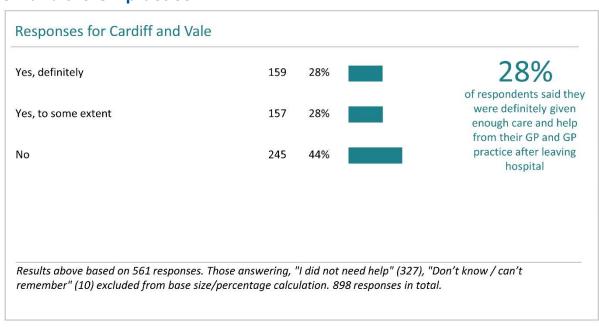


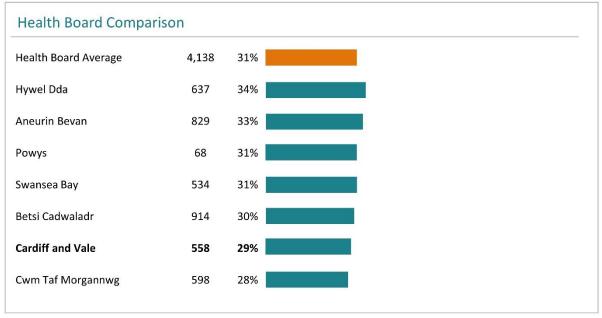


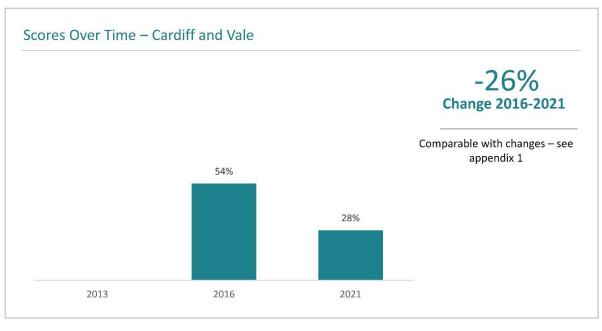


8.11 Care from your General Practice

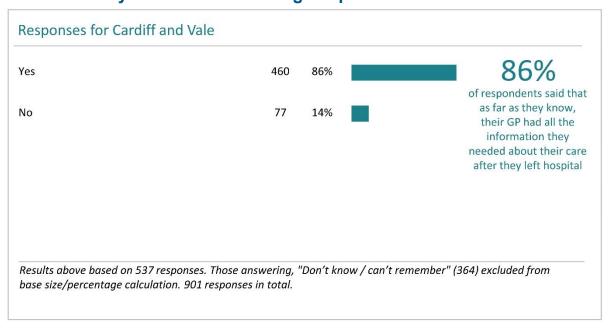
Question 55: "After leaving hospital, were you given enough care and help from your GP and the GP practice?"

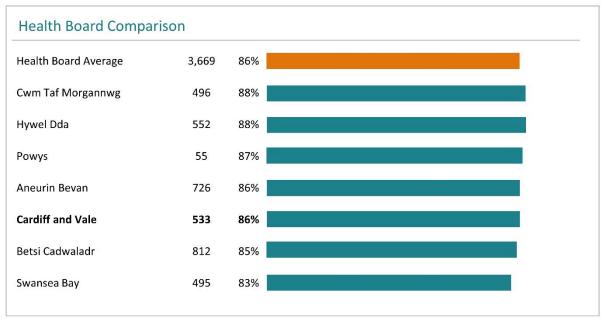






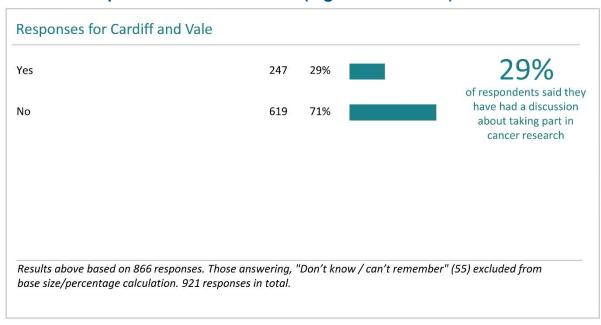
Question 56: "As far as you know, did your GP practice have all the information they needed about your care after leaving hospital?"

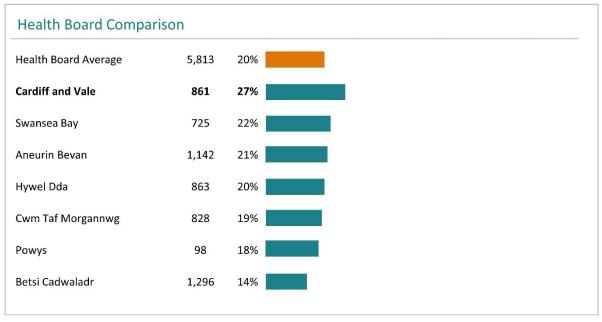


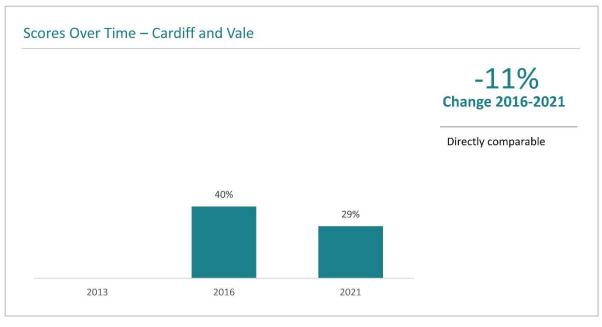


8.12 Your overall NHS care

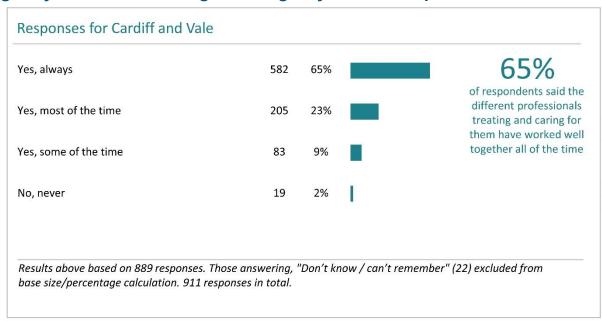
Question 57: "Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?"

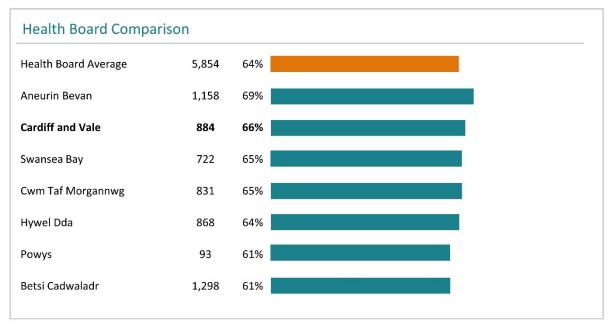


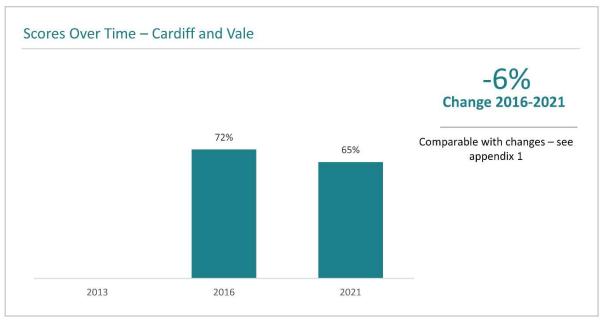




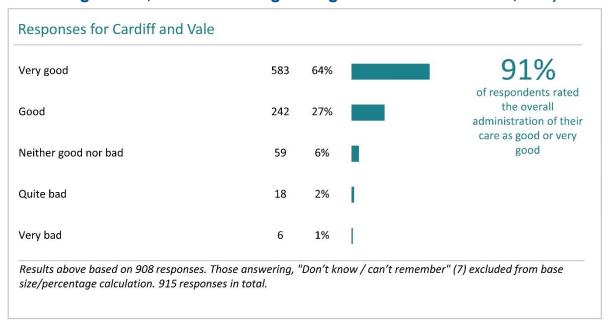
Question 58: "Since your diagnosis, have the different professionals treating and caring for you worked well together to give you the best possible care?"

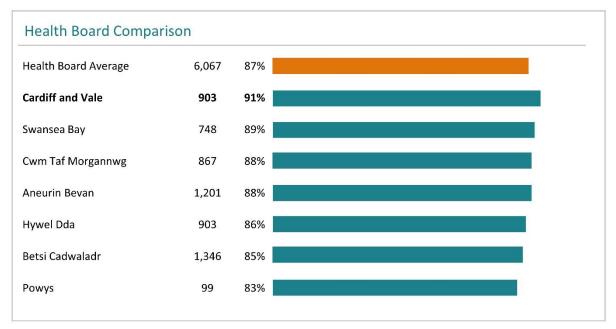


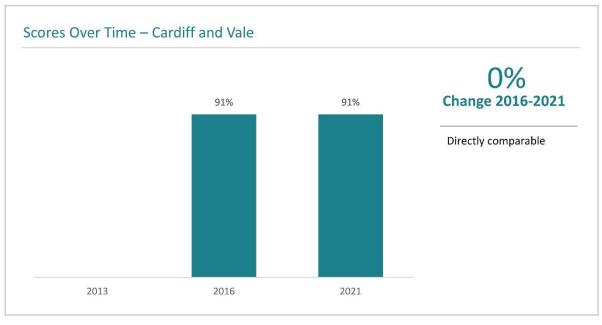




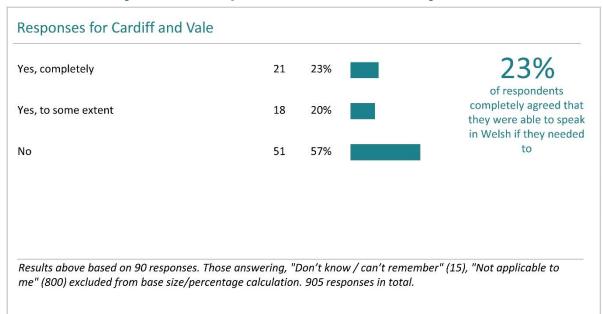
Question 59: "Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?"

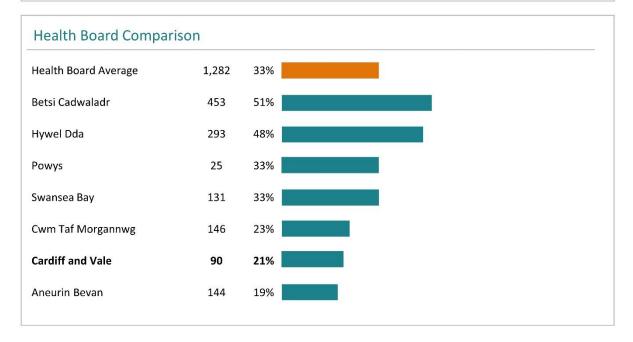




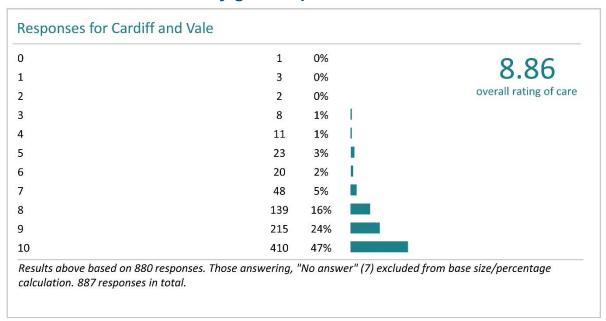


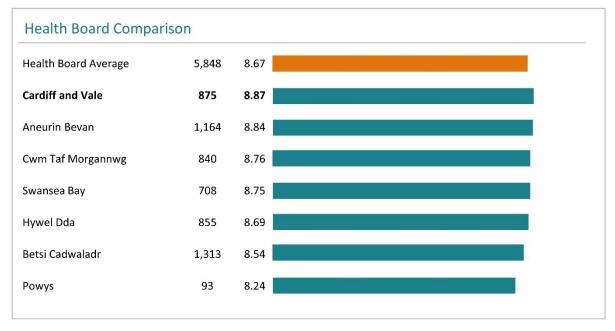
Question 60: "Were you able to speak in Welsh to staff if you needed to?"

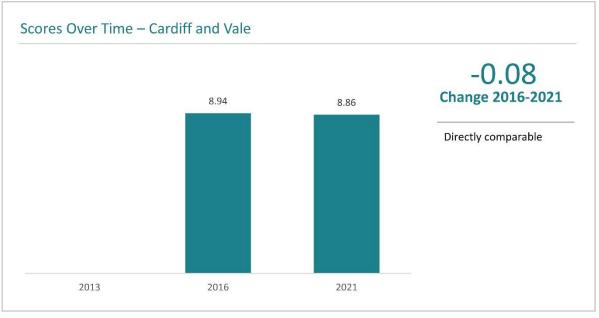




Question 61: "Overall, how would you rate your care? 0 is I had a very poor experience and 10 is I had a very good experience" 12







 $^{^{12}}$ Question 61 asks respondents to rate their overall care on a scale of 0 to 10. Scores are the average of this scale.

Appendix 1

Where questions are not directly comparable with previous iterations of the survey but the question meaning remains the same, questions are marked as 'comparable with changes'. These changes are outlined below. Full record of changes is available at https://wcpes.co.uk/library

Q04	Comparable - but additional response option added 'Other'
Q17	Comparable - but response option changed from 'Not sure/can't remember' to 'Don't know/can't remember'
Q19	Comparable - but response option changed from 'Not sure/can't remember' to 'Don't know/can't remember'
Q21a	Comparable - but question changed from 'Did your care include access to a Clinical Nurse Specialist ' to 'Did your care include access to a CNS '; change to the response options from 'No I did not have a clinical nurse specialist as part of my care team' to 'No I did not have one as part of my team' and 'Don't know/not sure' to 'Don't know/can't remember'
Q22a	Comparable - but question changed from 'How easy is it for you to contact your Key Worker' to 'How easy was it to contact your Key Worker'; change to the response options from 'I have not tried to contact her/him' to 'I have not tried to contact them' and additional response of 'Not applicable'
Q22b	Comparable- but question changed from 'How easy is it for you to contact your clinical nurse specialist' to 'How easy was it to contact your CNS'; change to response options from 'I have not tried to contact her/him' to 'I have not tried to contact them' and additional response of 'Not applicable'
Q23b	Comparable - but question text changed from 'When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?' to 'When you had questions to ask, how often did you get answers you can understand from your CNS'; response option changed from 'I do not ask any questions' to 'I did not ask any questions' and additional response 'Not applicable'.
Q24b	Comparable - but question text changed from 'Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?' to 'Did they provide you with the information you needed to make informed decisions about your treatment ? CNS' and additional response: 'Not applicable'
Q42	Comparable - but response option changed from 'Can't remember' to 'Don't know/Can't remember'
Q53	Comparable - but response option changed from 'Not sure / can't remember' to 'Don't know/can't remember'
Q55	Comparable - but question text changed from 'After leaving hospital, were you given enough care and help from your GP and the GP surgery ?' to 'After leaving hospital, were you given enough care and help from your GP and the GP practice ?'
Q58	Comparable - but response option changed from 'Don't know' to 'Don't know/can't remember'

Appendix 2

The Other cancer category is comprised of codes below. This has been used throughout the reporting of the 2021 results and is consistent with the last survey in 2016, as well as the most recently published CPES in both England and Northern Ireland.

Secondary

C77 C78	Secondary and unspecified malignant neoplasm of lymph nodes (C77), of respiratory and digestive organs (C78) and of other and unspecified sites (C79)	
C79		
Any other		
C00	Malignant neoplasm of halate	
C05	Malignant neoplasm of palate	
C11	Malignant neoplasm of oropharynx	
C12	Malignant neoplasm of pyriform sinus	
C13	Malignant neoplasm of hypopharynx	
C14 C24	Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx	
C24	Malignant neoplasm of other and unspecified parts of biliary tract	
C30	Malignant neoplasm of other and ill-defined digestive organs Malignant neoplasm of nasal cavity and middle ear	
C31	Malignant neoplasm of accessory sinuses	
C37	Malignant neoplasm of thymus	
C38	· · · · · · · · · · · · · · · · · · ·	
	Malignant neoplasm of heart, mediastinum and pleura	
C39	Malignant neoplasm of other and ill-defined sites in the respiratory system and intrathoracic organs	
C47	Malignant neoplasm of peripheral nerves and autonomic nervous system	
C57	Malignant neoplasm of other and unspecified female genital organs	
C58	Malignant neoplasm of placenta	
C63	Malignant neoplasm of other and unspecified male genital organs	
C68	Malignant neoplasm of other and unspecified urinary organs	
C69	Malignant neoplasm of eye and adnexa	
C70	Malignant neoplasm of meninges	
C72	Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system	
C74	Malignant neoplasm of adrenal gland	
C75	Malignant neoplasm of other endocrine glands and related structures	
C76	Malignant neoplasm of other and ill-defined sites	
C80	Malignant neoplasm, without specification of site	
C86	Other specified types of T/NK-cell lymphoma	
C88	Malignant immunoproliferative diseases	
C96	Other and unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue	
C97	Malignant neoplasms of independent (primary) multiple sites	

Acknowledgments

This report would not have been possible without the thousands of responses from people living with cancer in Wales, we are indebted to the time they gave us to deliver this report.

The third Wales Cancer Patient Experience survey was produced by a tripartite partnership between IQVIA, the Wales Cancer Network and Macmillan Cancer Support. This group dedicated a large amount of professional time to ensuring this report was delivered. We also thank all others who have previously contributed to this project.