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Wales Cancer Patient Experience Survey 2021/22

National Report

IQVIA

Part 1:
National Quantitative Report

Contents - Part 1: Quantitative Report

Foreword

Macmillan Cancer Support and the Wales Cancer Network are delighted to present the third Wales Cancer Patient Experience Survey (WCPES). The survey is the culmination of a long-standing partnership between Macmillan and the Wales Cancer Network that has an unwavering focus on meeting the needs of people living with cancer in Wales and delivering sustainable service changes, based on high-quality evidence and insight.

We are incredibly grateful to the thousands of people who gave their time to complete this survey, at what may have been a very challenging period in their lives. Their insights, stories and experiences will be essential in guiding cancer services forward in Wales as we recover from the Covid-19 pandemic.

Over the past two years, we have all faced unprecedented challenges from the pandemic. Our NHS in Wales has worked tirelessly and selflessly to continue service provision in the most difficult circumstances. However, the impact on cancer services has been severe and a full recovery will potentially take years to realise. This third survey provides essential insights into the experiences of how people living with cancer were diagnosed and supported throughout their care during 2020.

This latest survey continues to demonstrate people with cancer have generally high levels of satisfaction with their care and treatment, with 91% of respondents rating their overall care as seven or more out of ten. However, we recognise that the results show a far more nuanced picture of the advice and support offered to people following their diagnosis.

The results from this survey suggest that Wales continues to be a leader in delivering person-centred care, with 90% of respondents given the name and contact details of a Key Worker, an improvement on the previous survey. A further 84% of people were able to get answers they could understand from their Key Worker all or most of the time. Despite this, 58% of people said they were not offered an opportunity to discuss their needs and concerns, and this is something that must be addressed as a result of this rich feedback.

With the cost-of-living crisis affecting people in Wales, access to high-quality signposting and advice has never been more important. 53% of respondents said they were given enough information on how to access financial support or any benefits they were entitled to. Significantly, 36% said they were not offered this and would have liked more information. 54% of respondents were told about support from the voluntary sector during their care.

Follow up care and support by the GP following discharge from hospital has sadly showed a decline between surveys, with only 31% of respondents reporting they were “definitely given enough care and help from their GP and the GP practice”, in 2016, this was 56%, an overall deterioration of 25%. The pandemic had a significant impact on Primary Care and this an area which needs focus and support.

The survey also highlighted that 80% of respondents reported they had not had a discussion about the opportunity to take part in cancer research, which is a continuing trend from the previous two surveys. This suggests that this is an area that requires ongoing focus.

We believe the feedback received, which comes directly from patients and covers all stages of the cancer pathway from presentation and diagnosis to the care they received during and after treatment, provides vital insight into what is working well and areas that need improvement. This information must be harnessed to drive service developments in cancer care where needed.

We are grateful to the Welsh Government for continuing to support this survey and for their ongoing commitment to putting the voice of patients at the heart of policy development and service change in Wales.

Richard Pugh Head of Partnerships, Wales & South West England	**Claire Birchall** Network Manager
Macmillan Cancer Support	Wales Cancer Network

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 this 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.

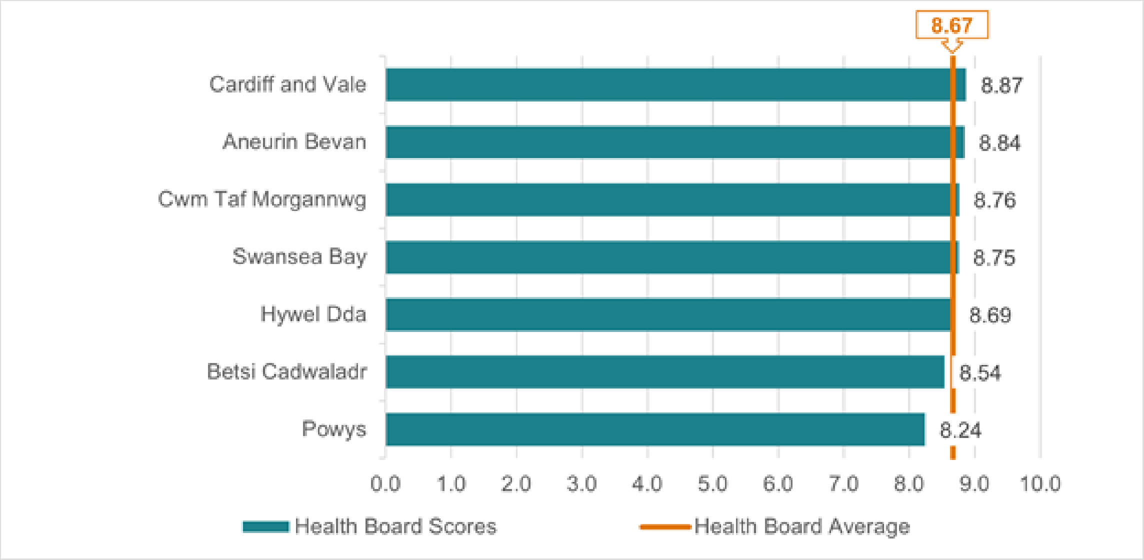
The impact of the pandemic varied across Health Boards and Velindre at different times depending on the numbers of COVID cases, services, and workforce capacity. As primary care (e.g. access to GP and pharmacy), community services (e.g. health and social care), secondary care (e.g. hospitals and specialist 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 overall are positive. **91%** of patients rated their overall care as 7 or more out of 10 (a slight drop from **93%** 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). The chart below shows the overall average rating out of 10 across the Health Boards.



90% said they were always treated with dignity and respect while they were in hospital (**89%** in 2016).

Other positive scores in the survey include:

- **94%** of patients said they were always given enough privacy when they were being examined or treated
- **93%** of patients said they were given all the information they needed about their operation
- **93%** of patients said they were given all the information they needed about their test
- **92%** of patients 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:

- **42%** were offered the opportunity to discuss their needs and concerns
- **37%** of patients 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 patients said their family or someone else close to them definitely had enough opportunity to talk to a healthcare professional
- **31%** of patients said that, after leaving hospital, they were definitely given enough care and help from their GP and the GP practice
- **30%** of patients said they had been offered a written care plan
- **20%** of patients 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]

90% of patients said they were given the name and contact details of their Key Worker. **69%** 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, **89%** of respondents said their care included access to a CNS, (**81%** reported that their CNS was also their Key Worker, **8%** said their CNS was not their Key Worker). **68%** of the respondents who had access said it was easy to contact them. **85%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **76%** said their CNS provided them with all the information they needed to make informed decisions about their treatment.

72% 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. **61%** of respondents who had contacted their other health professional said that it was easy to do so. **78%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **73%** 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 **55%**.

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. 1,283 respondents who answered this question (**21%**) indicated that they needed to speak to staff in Welsh; of these, **39%** agreed 'Yes, completely' that they were able to do so.

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[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 24 scores have worsened and 7 have improved.

The 3 largest improvements related to CNSs and Key Workers:

- **88.9%** of respondents in 2021/22 reported their care included access to a CNS – **81.4%** in 2016 (**+7.5%**)
- **68.4%** of respondents in 2021/22 reported it was easy for them to contact their CNS – **63.4%** in 2016 (**+5.0%**)
- **90.0%** of respondents in 2021/22 reported they were given the name and contact details of their Key Worker – **85.9%** in 2016 (**+4.1%**)

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

- **31.0%** 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 – **55.6%** in 2016 (**-24.6%**)
- **46.2%** 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 – **58.6%** in 2016 (**-12.4%**)
- **50.0%** of respondents in 2021/22 reported that after leaving hospital, they were definitely given enough care and help from health or social services – **59.5%** in 2016 (**-9.4%**)

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 Statement[6]. 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 Wales[7]. 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.

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[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.

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 raw data has not been changed in any way – it is an exact reflection of the responses patients provided after anonymisation.

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

3.5 Health 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 the survey was **11,184** cancer patients. Of these **664** 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 (**544**), had moved address (**65**) or had informed the helpline they were ineligible for another reason (**55**).

The eligible sample size was therefore calculated as **10,520** patients. A total of **6,259** questionnaires were returned completed, giving an overall response rate of **59.5%**

Completed questionnaires were received by post from **5,124** respondents (**81.9%** of responses); and **1,045** (**16.7%**) chose to complete their questionnaires on-line. **89** respondents called IQVIA's Freephone helpline to give their responses over the telephone; and just **1** used IQVIA's translation/interpreting services to give their responses.

75 patients responded using the Welsh version of the questionnaire.

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	**81.9%**
Online	**16.7%**
Telephone	**1.4%**
Translation	**<1%**

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

Health Board	Number of respondents	Percentage of total respondents
Aneurin Bevan University Health Board	1233	20%
Betsi Cadwaladr University Health Board	1,395	22%
Cardiff and Vale University Health Board	935	15%
Cwm Taf Morgannwg University Health Board	895	14%
Hywel Dda University Health Board	925	15%
Powys Teaching Health Board	103	2%
Swansea Bay University Health Board	773	12%

Trust	Number of respondents	Percentage of total respondents
Velindre Cancer Centre	1793	29%

Tumour Group	Number of respondents	Percentage of total respondents
Breast	1452	23.2%
Other cancers[8]	877	14.0%
Colorectal / lower gastrointestinal	679	10.8%
Haematological	658	10.5%
Urological (excluding prostate)	632	10.1%
Prostate	619	9.9%
Gynaecological	388	6.2%
Lung	314	5.0%
Head and neck	242	3.9%
Upper gastrointestinal	194	3.1%
Skin	138	2.2%
Sarcoma	41	<1%
Brain / central nervous system (CNS)	25	<1%

Sex of respondents	Number of respondents	Percentage of total respondents
Female	3474	56%
Male	2785	44%

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[8] The list of codes that make up the Other cancers category are detailed in Appendix 2.

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 White[9], 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.

We also recognise the small number of respondents in the younger age groups, and those who do not identify as heterosexual.

Age of respondents	**Number of respondents**	**Percentage of total respondents**
16-24	22	<1%
25-34	40	<1%
35-44	190	3%
45-54	550	9%
55-64	1,312	21%
65-74	2,219	35%
75-84	1,620	26%
85+	306	5%

Ethnicity of respondents	**Number of respondents**	**Percentage of total respondents**
Asian background	45	<1%
Black / African / Caribbean background	9	<1%
Mixed / multiple ethnic background	40	<1%
Other ethnic group	9	<1%
White background	5890	94%
Not available	266	4%

Sexual orientation of respondents [10]	**Number of respondents**	**Percentage of total respondents**
Heterosexual	5,596	89.4%
Bisexual	16	<1%
Gay or lesbian	45	<1%
Other sexuality	19	<1%

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[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, 2.3% of respondents said they preferred not to answer this question, and a further 6.9% 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 at the national level. It also includes comparisons between Health Boards at a question level, a summary of Velindre Cancer Centre's results, and a brief summary of comparisons by key variables (age, sex, sexual orientation, ethnicity, deprivation.

Alongside this report, a qualitative analysis report has been published, along with individual reports for each participating Health Board and Velindre Cancer Centre.

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 national 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.

The national results 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.

As the patients allocated to Velindre Cancer Centre are assigned by discharge rather than by residence, it is not appropriate to compare its performance to the Health Boards in Wales. For this reason, Velindre Cancer Centre’s results are reported in a separate section of this document.

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 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% is 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.

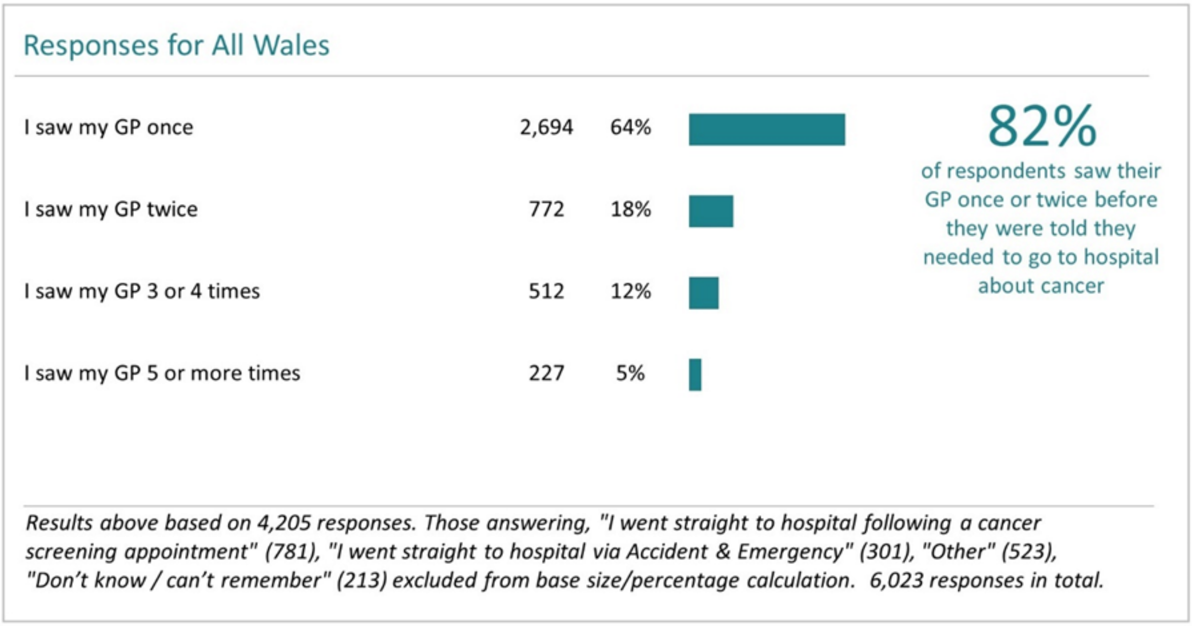
This process for presenting the data will result in the All Wales scores and the Health Board average scores showing as different in the reporting charts.

Evaluative patient experience questions

The 58 evaluative patient experience questions have been charted in 4 ways:

1. 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?”



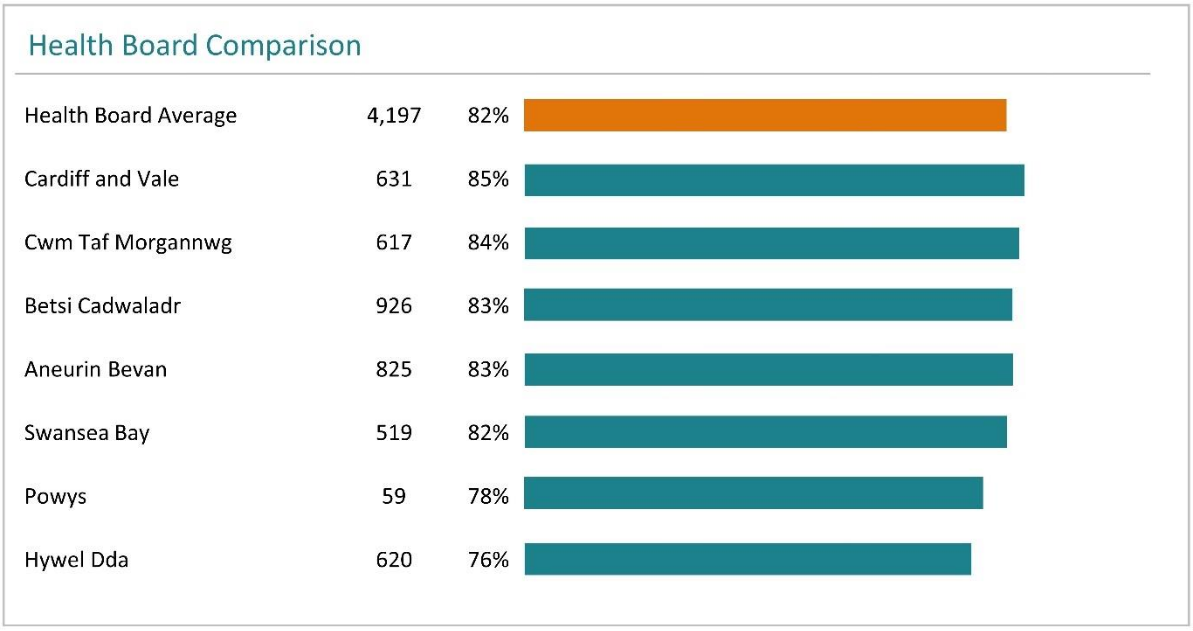
82% of respondents saw their GP once or twice before they were told they needed to go to hospital about cancer

Results above based on 4,205 responses. Those answering, "I went straight to hospital following a cancer screening appointment" (781), "I went straight to hospital via Accident & Emergency" (301), "Other" (523), "Don’t know / can’t remember" (213) excluded from base size/percentage calculation. 6,023 responses in total.

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**.

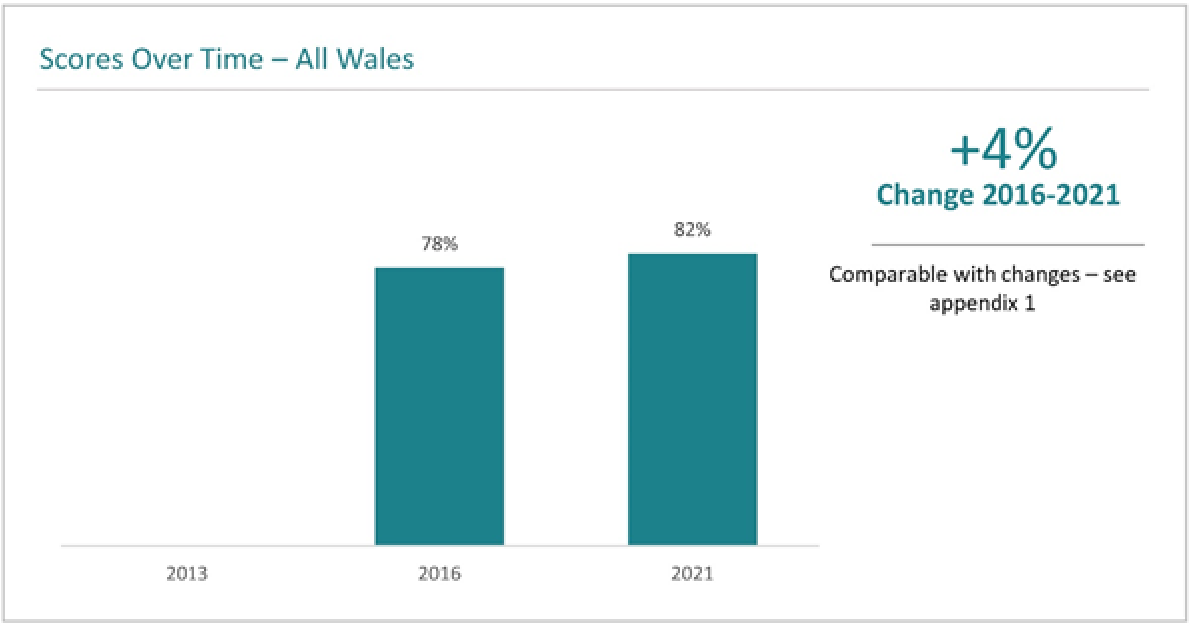
The percentage scores shown in the Health Board Comparison Charts will differ from those in the other charts because standardised data is being used.

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?”

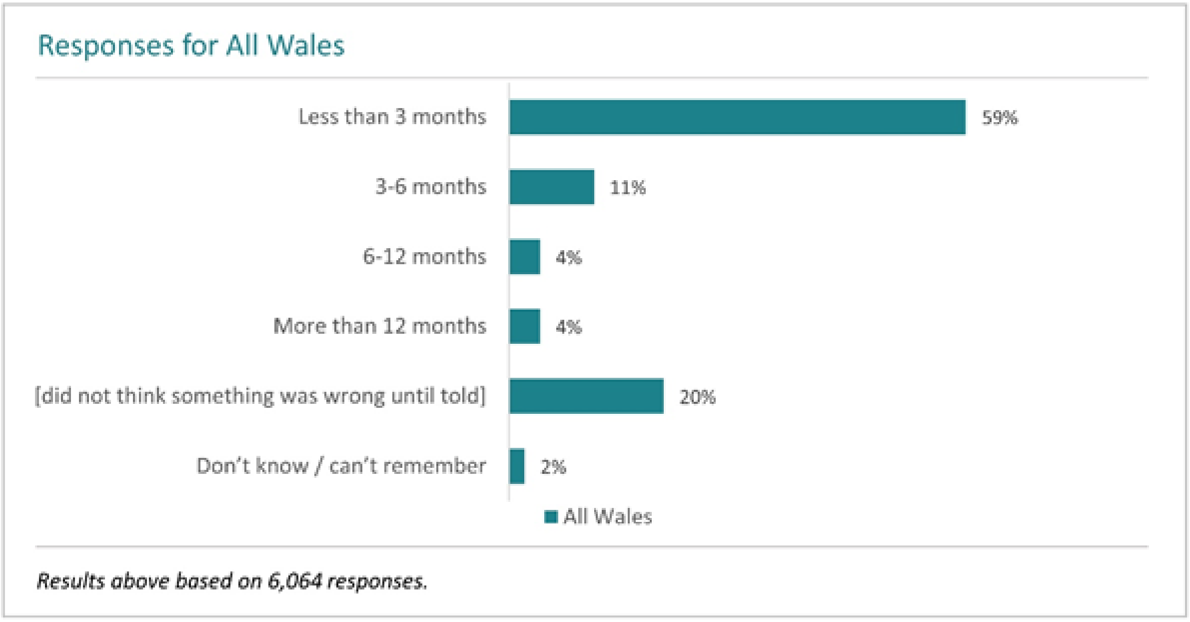


Informational (non-evaluative) questions

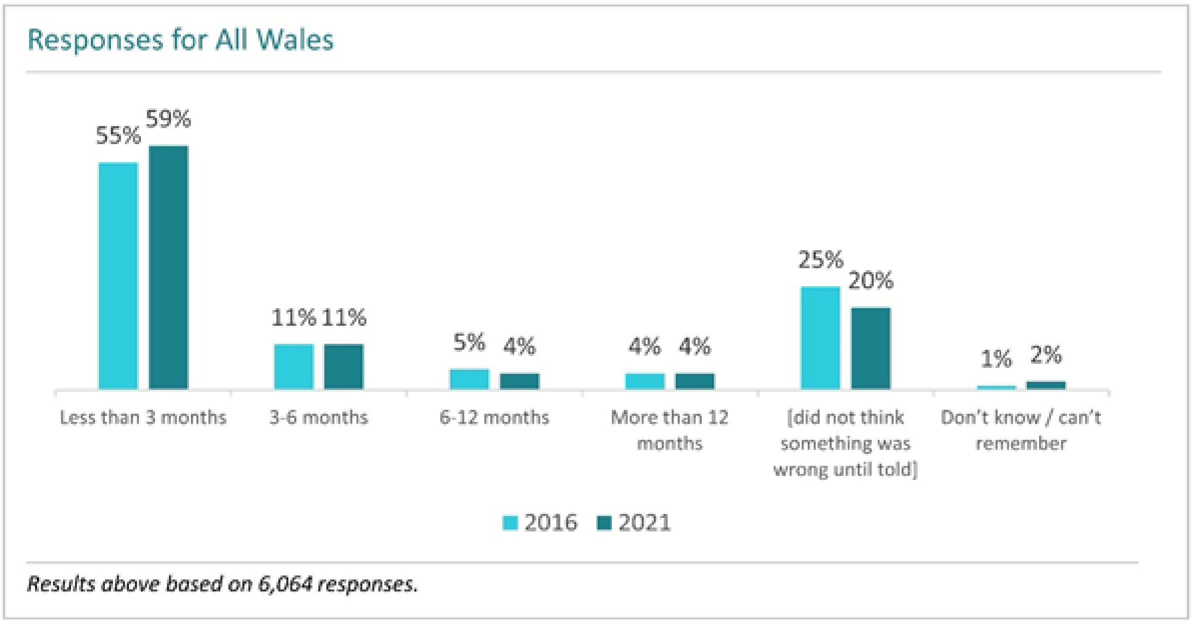
Despite not being assigned a score, 2 of the informational questions (Q02 and Q13) were deemed to contain important data.

The results for these 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?”



Results above based on 6,064 responses.

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

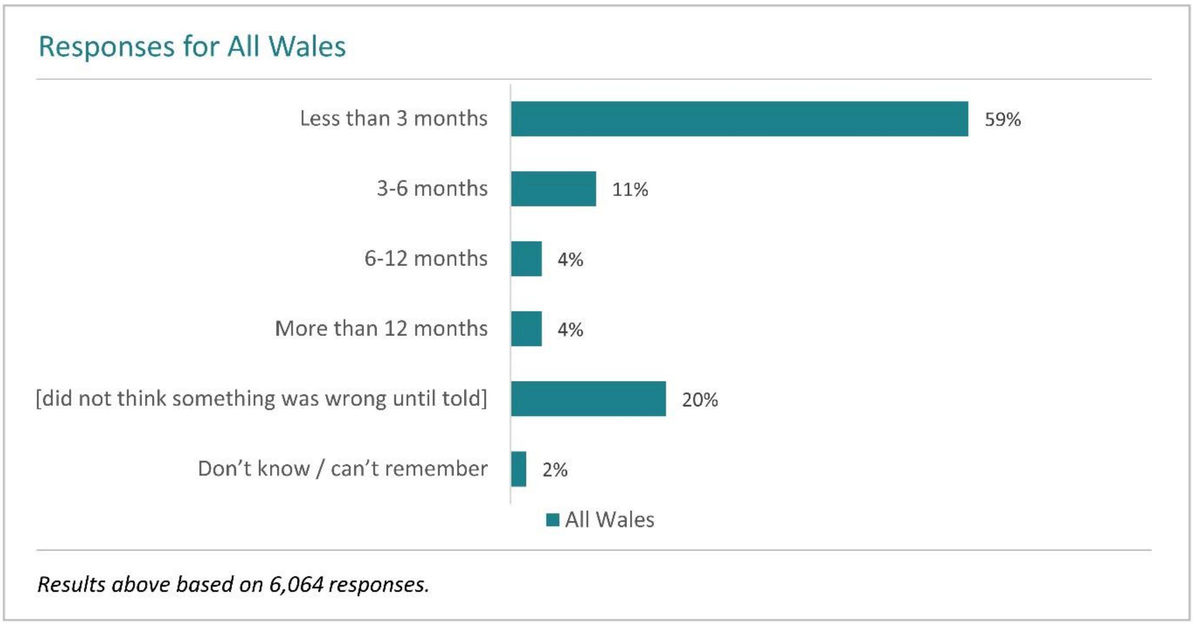
Full details on the standardisation and scoring is included in the Technical Document for this survey, which is published separately at https://wcpes.co.uk/library

8. National results

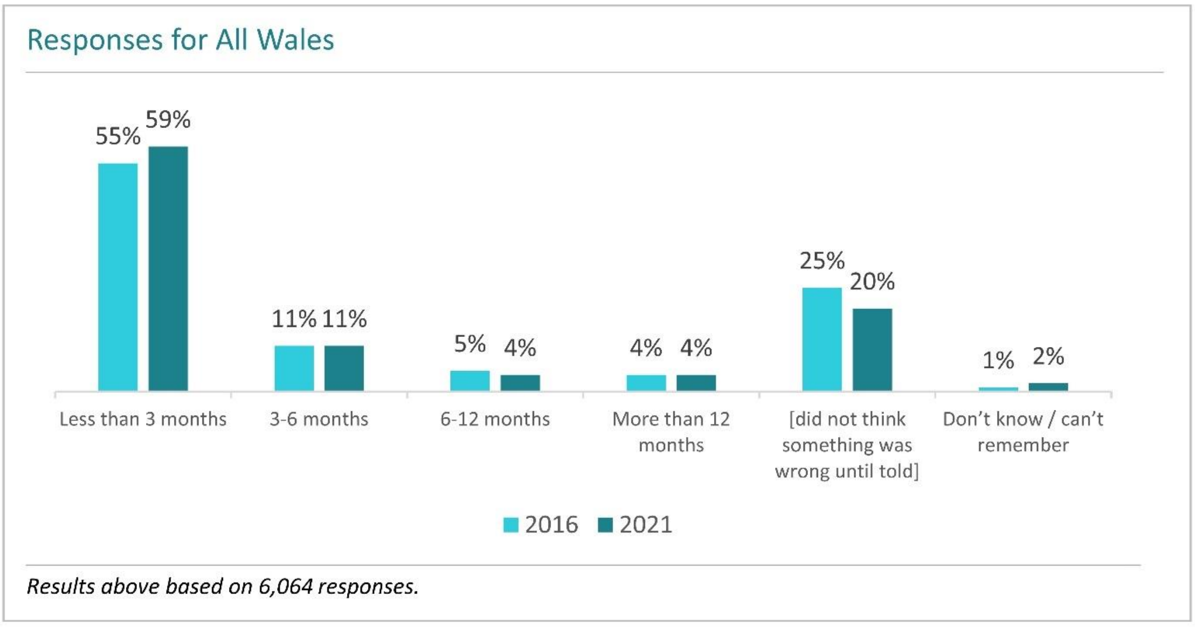
This section contains charts for each of the 58 evaluative questions, plus 2 informational questions that were deemed to contain important data. For this reason, not every question in the survey has been charted.

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?” [11]



Results above based on 6,064 responses.



Results above based on 6,064 responses.

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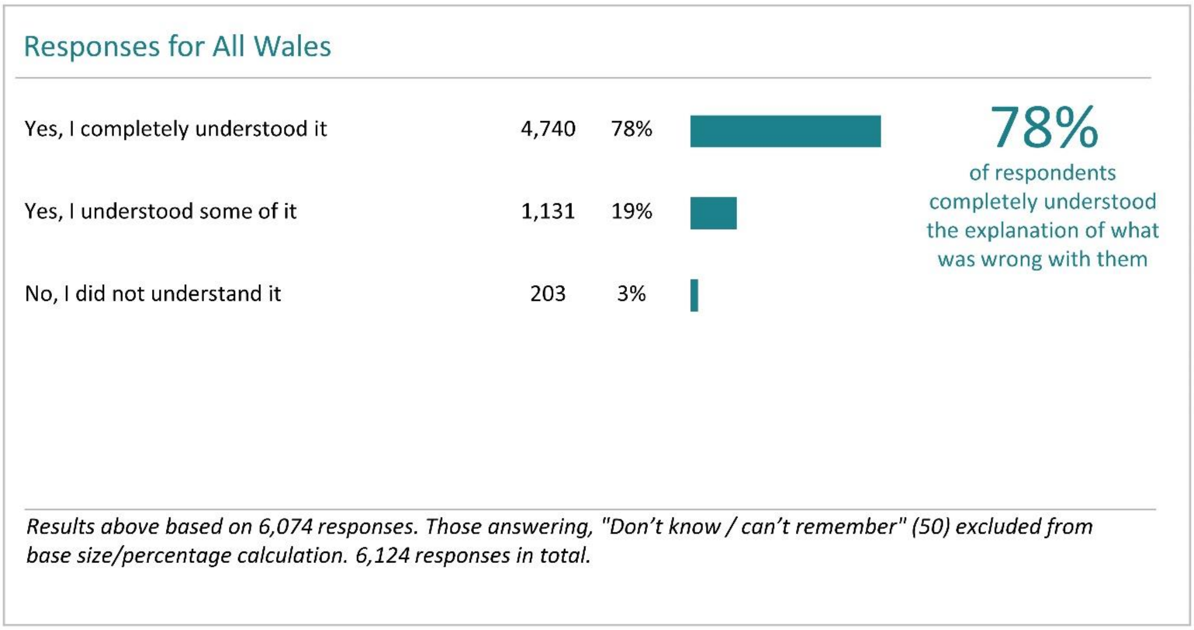
[11] Unabridged answer wording for ‘[did not think something was wrong until told]’ is ‘I did not think something was wrong with me until I was told’

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



Responses for All Wales

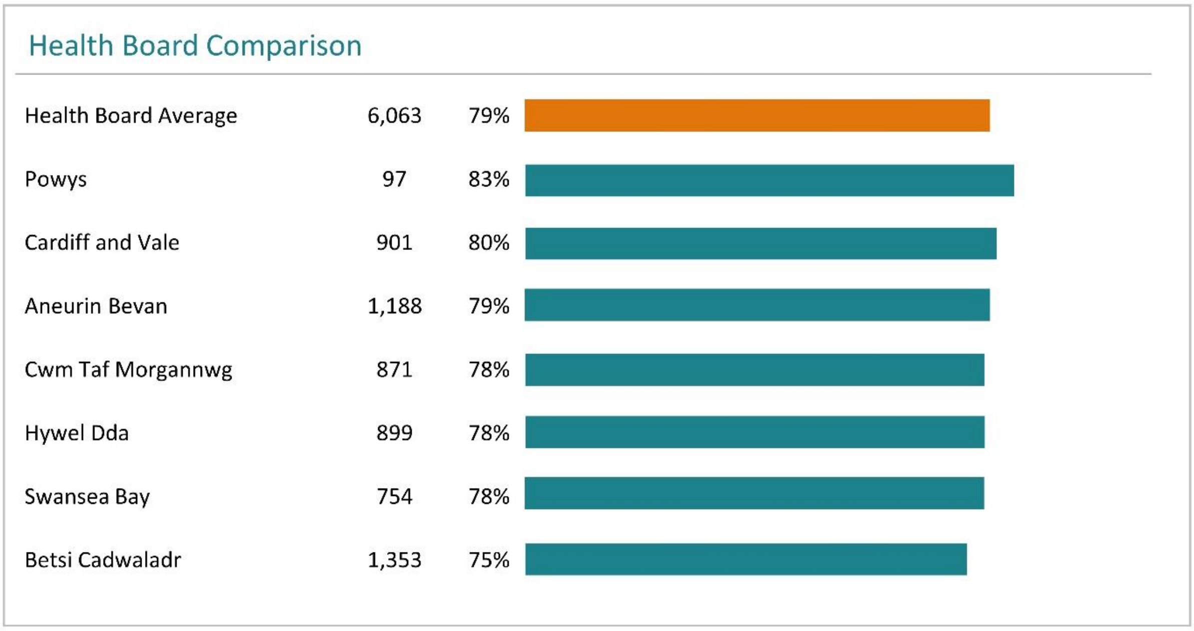
Yes, I completely understood it	4,740	78%	
Yes, I understood some of it	1,131	19%	
No, I did not understand it	203	3%	

78%
of respondents completely understood the explanation of what was wrong with them

Results above based on 6,074 responses. Those answering, "Don’t know / can’t remember" (50) excluded from base size/percentage calculation. 6,124 responses in total.

Survey respondent:

“I do think that my condition could be explained to me in more detail.”

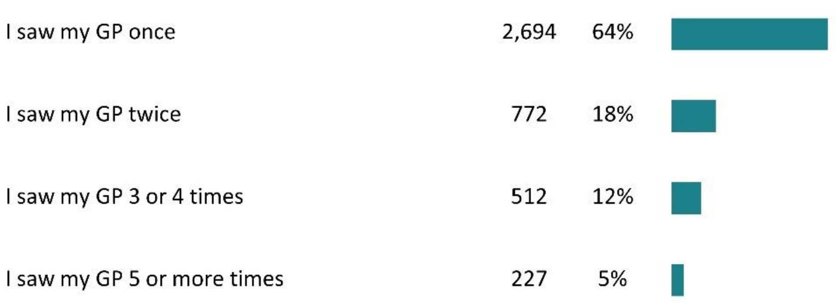


Health Board Comparison

Health Board Average	6,063	79%
Powys	97	83%
Cardiff and Vale	901	80%
Aneurin Bevan	1,188	79%
Cwm Taf Morgannwg	871	78%
Hywel Dda	899	78%
Swansea Bay	754	78%
Betsi Cadwaladr	1,353	75%

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?”

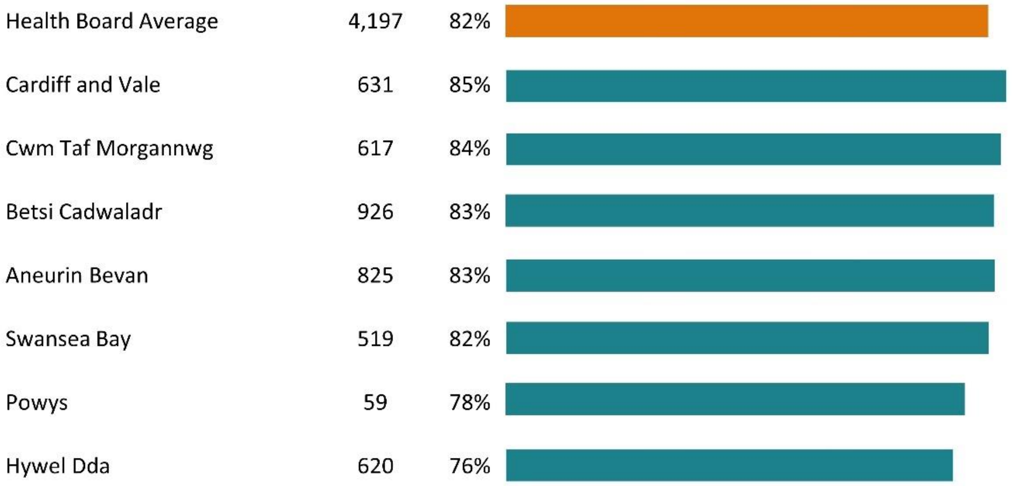
Responses for All Wales



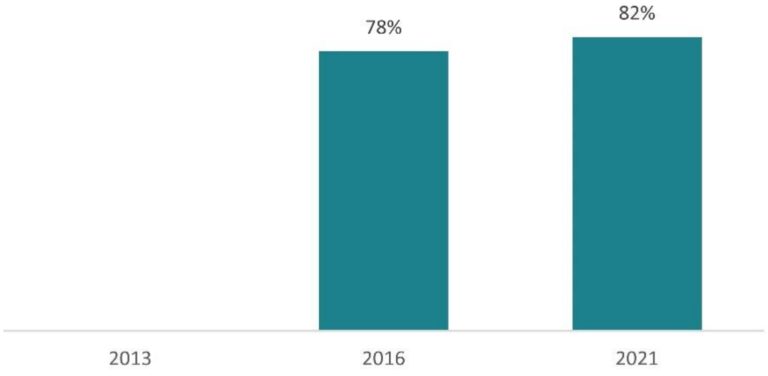
82%
of respondents saw their GP once or twice before they were told they needed to go to hospital about cancer

Results above based on 4,205 responses. Those answering, "I went straight to hospital following a cancer screening appointment" (781), "I went straight to hospital via Accident & Emergency" (301), "Other" (523), "Don’t know / can’t remember" (213) excluded from base size/percentage calculation. 6,023 responses in total.

Health Board Comparison



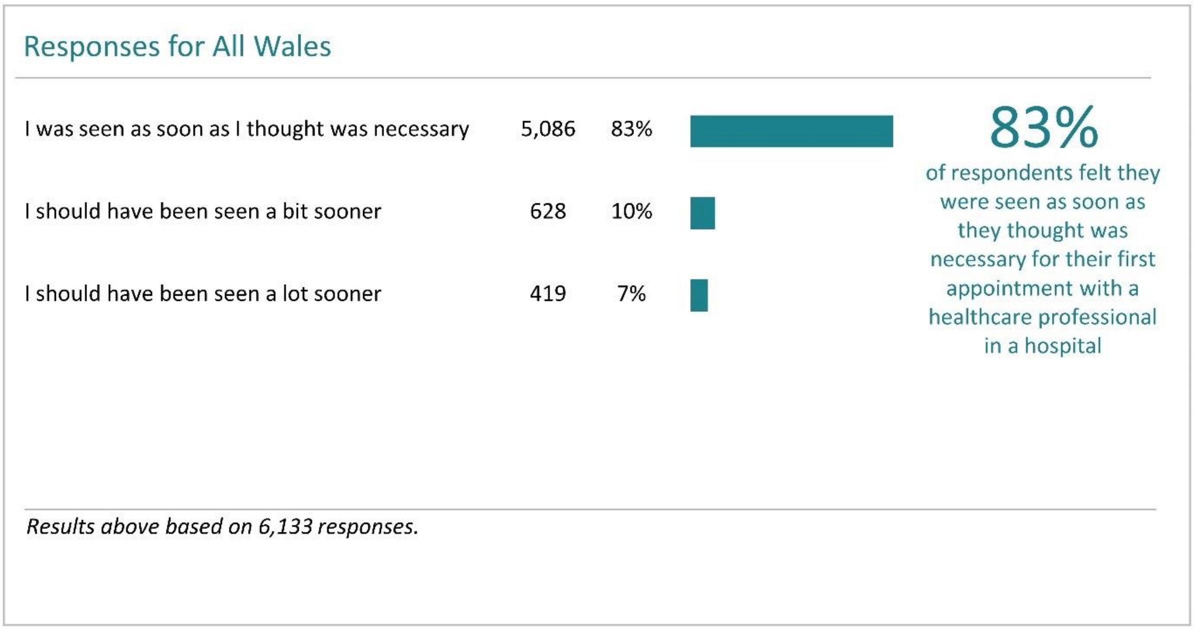
Scores Over Time – All Wales



+4%
Change 2016-2021

Comparable with changes – see appendix 1

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?”



Responses for All Wales

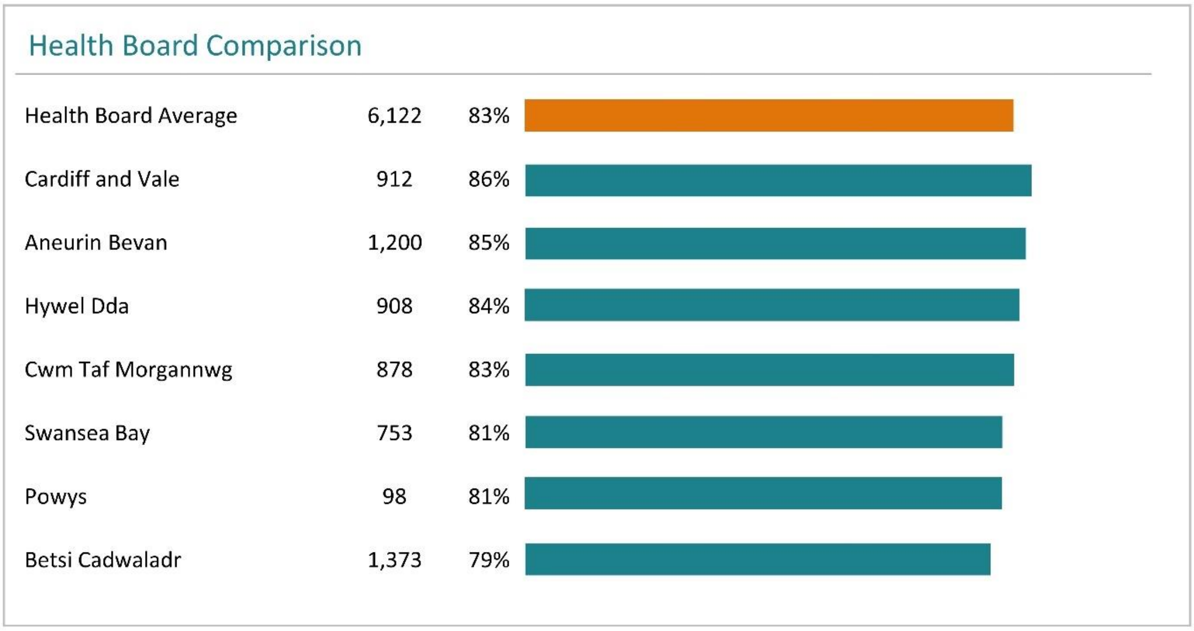
I was seen as soon as I thought was necessary	5,086	83%	
I should have been seen a bit sooner	628	10%	
I should have been seen a lot sooner	419	7%	

83%
of respondents felt they were seen as soon as they thought was necessary for their first appointment with a healthcare professional in a hospital

Results above based on 6,133 responses.

Survey respondent:

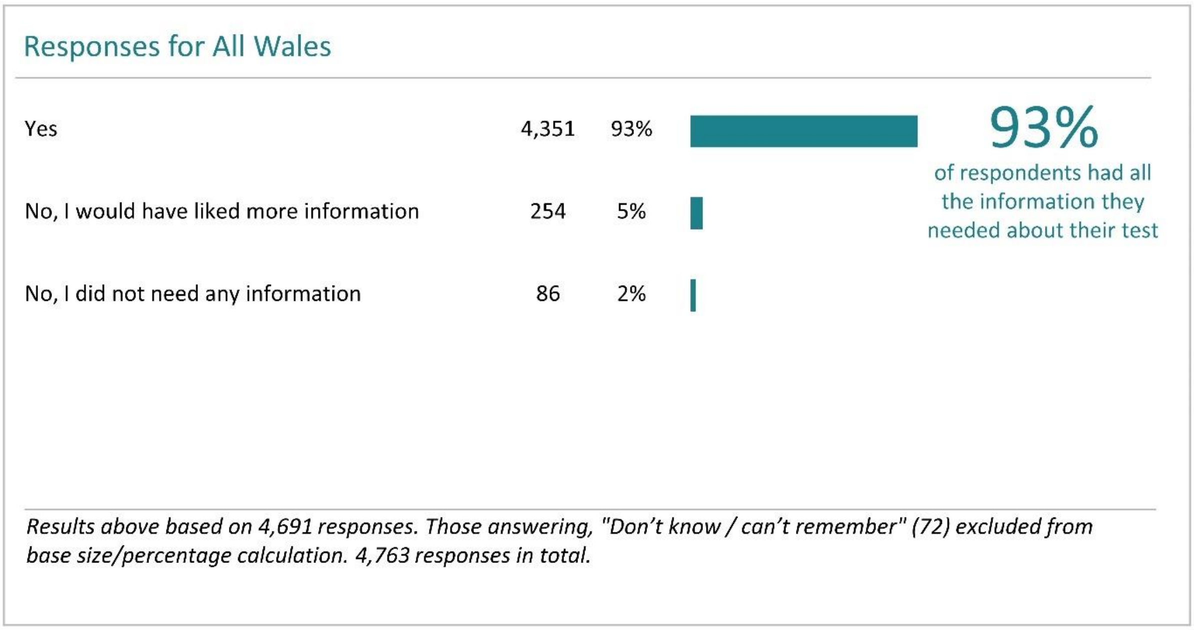
“Due to COVID I did not see my GP, but a telephone discussion resulted in my GP referring me straight to gynaecology, where a scan and taking a tissue sample was done in a timely period.”



Health Board Comparison

Health Board Average	6,122	83%
Cardiff and Vale	912	86%
Aneurin Bevan	1,200	85%
Hywel Dda	908	84%
Cwm Taf Morgannwg	878	83%
Swansea Bay	753	81%
Powys	98	81%
Betsi Cadwaladr	1,373	79%

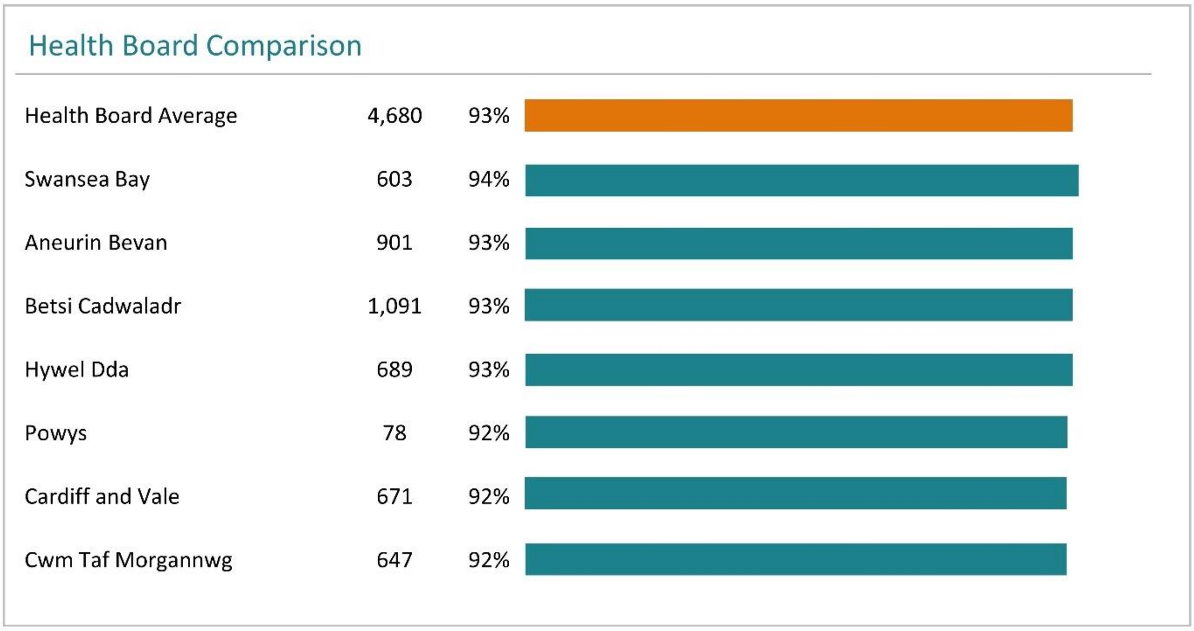
Question 8: "Beforehand, did you have all the information you needed about your test?”


Responses for All Wales

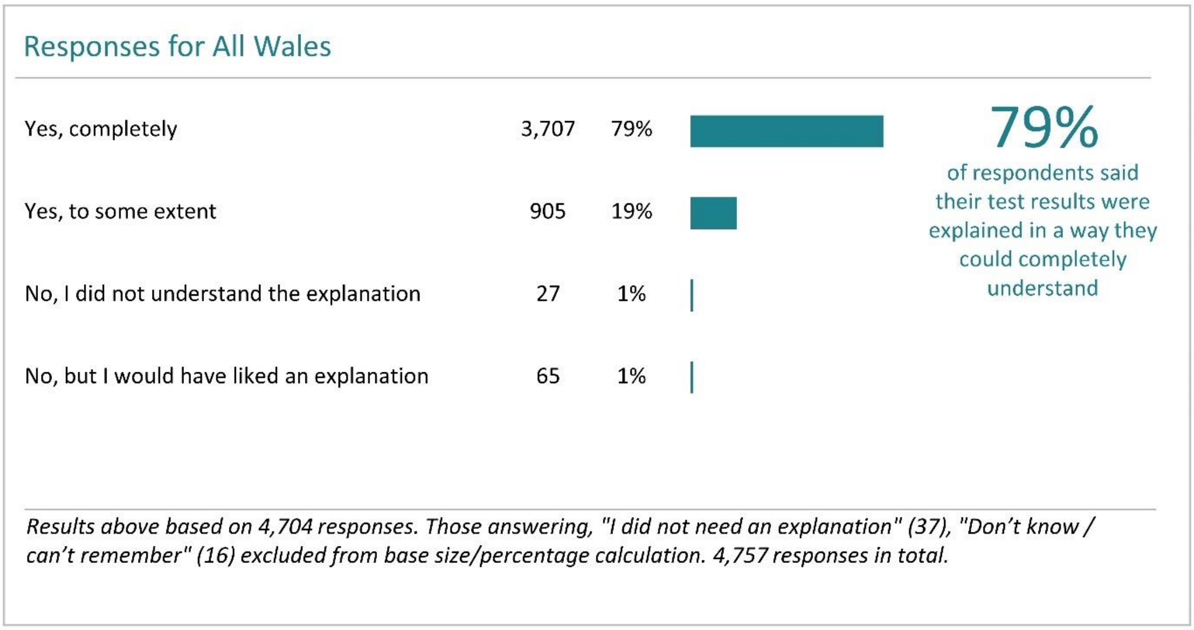
Results above based on 4,691 responses. Those answering, "Don’t know / can’t remember" (72) excluded from base size/percentage calculation. 4,763 responses in total.

Survey respondent:

“The first appointment I had to tell me of my diagnosis was not explained very well but I doubt he was the usual consultant. The following day I had a telephone call from the specialist nurse, and she explained my diagnosis and was very reassuring which was a huge relief.”


Health Board Comparison

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

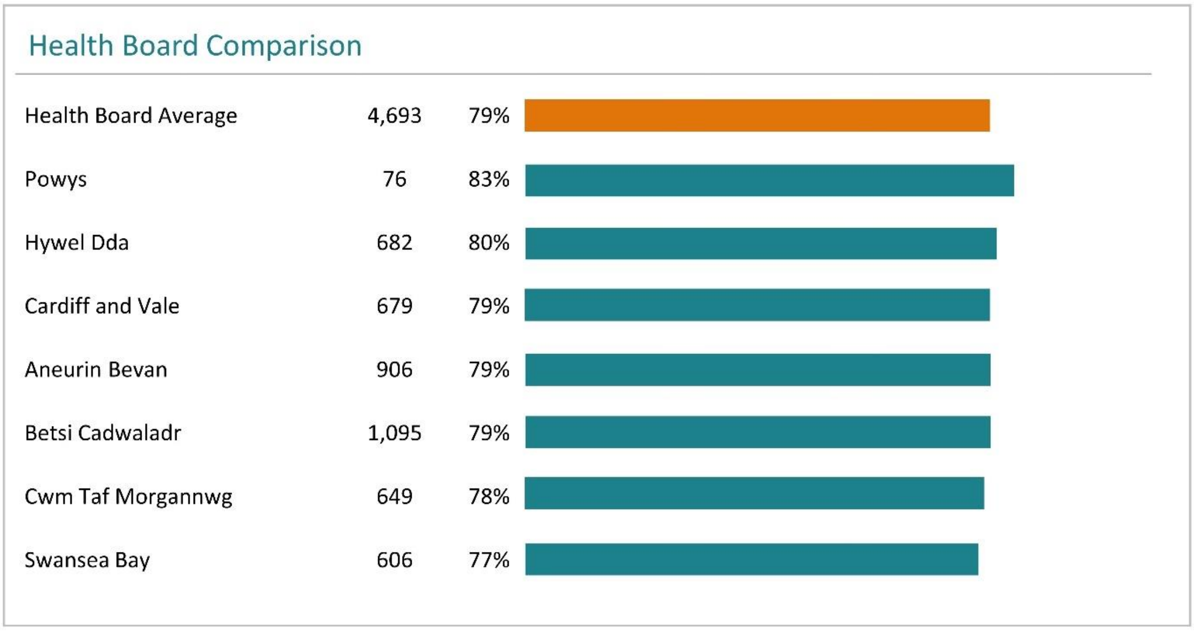


Responses for All Wales

Yes, completely	3,707	79%	
Yes, to some extent	905	19%	
No, I did not understand the explanation	27	1%	
No, but I would have liked an explanation	65	1%	

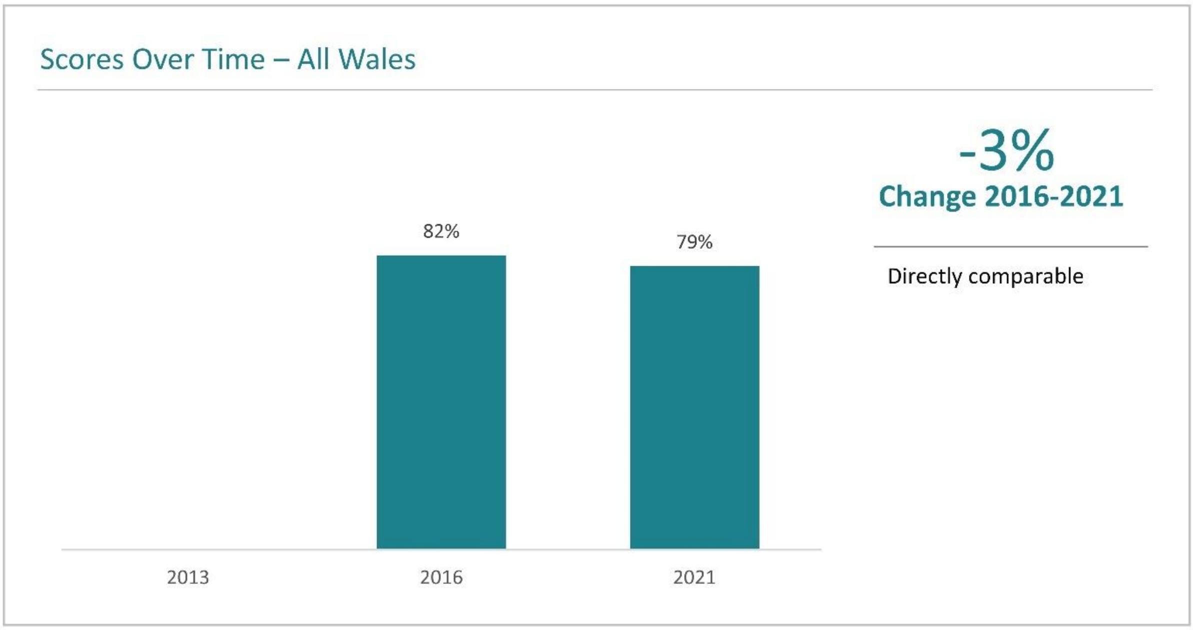
79% of respondents said their test results were explained in a way they could completely understand

Results above based on 4,704 responses. Those answering, "I did not need an explanation" (37), "Don't know / can't remember" (16) excluded from base size/percentage calculation. 4,757 responses in total.



Health Board Comparison

Health Board Average	4,693	79%
Powys	76	83%
Hywel Dda	682	80%
Cardiff and Vale	679	79%
Aneurin Bevan	906	79%
Betsi Cadwaladr	1,095	79%
Cwm Taf Morgannwg	649	78%
Swansea Bay	606	77%



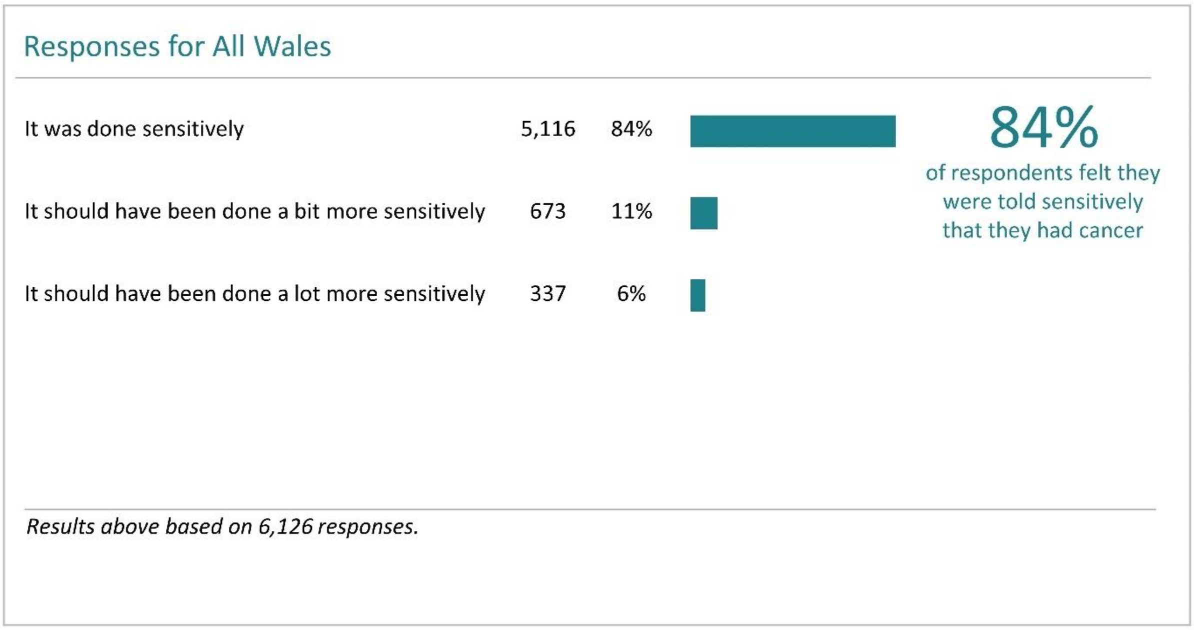
Scores Over Time – All Wales

-3%
Change 2016-2021

Directly comparable

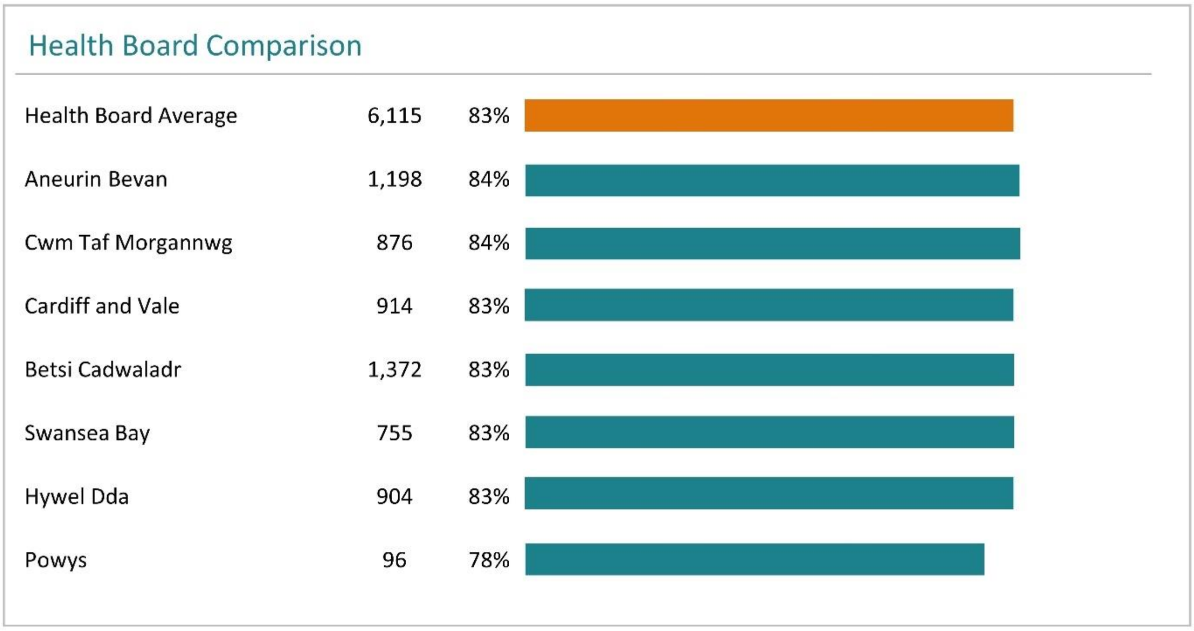
8.2 Finding out you had cancer

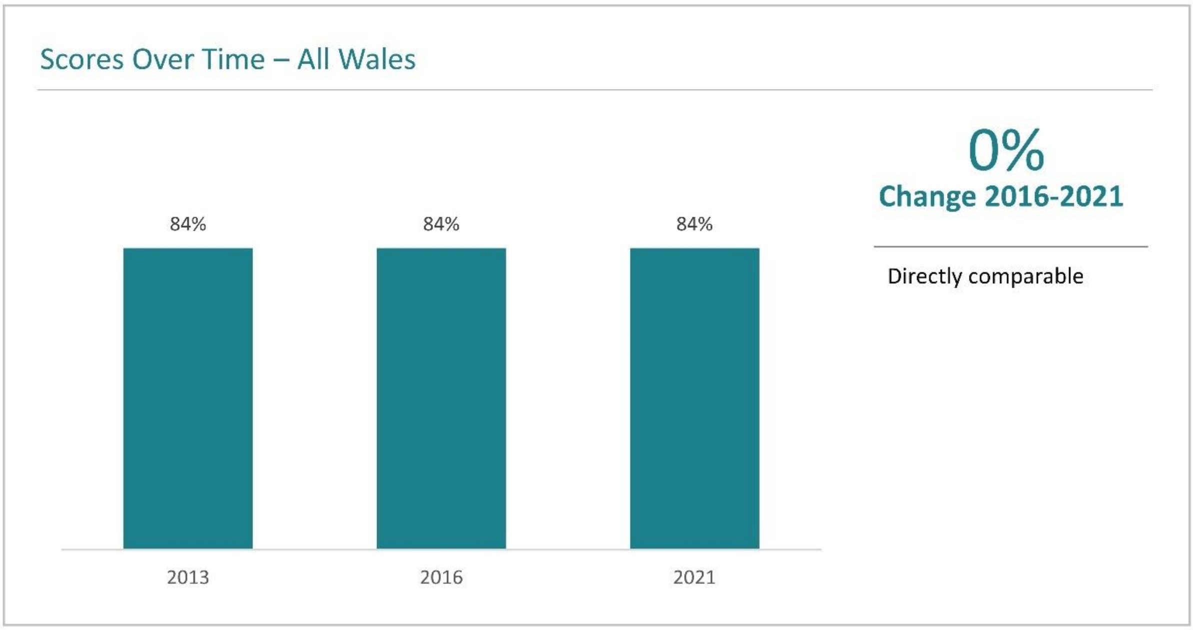
Question 10: "How do you feel about the way you were told you had cancer?”


Responses for All Wales

84%
of respondents felt they were told sensitively that they had cancer

Results above based on 6,126 responses.


Health Board Comparison

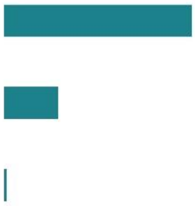

Scores Over Time – All Wales

0%
Change 2016-2021

Directly comparable

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

Responses for All Wales



Yes, I completely understood it	4,739	77%
Yes, I understood some of it	1,340	22%
No, I did not understand it	90	1%

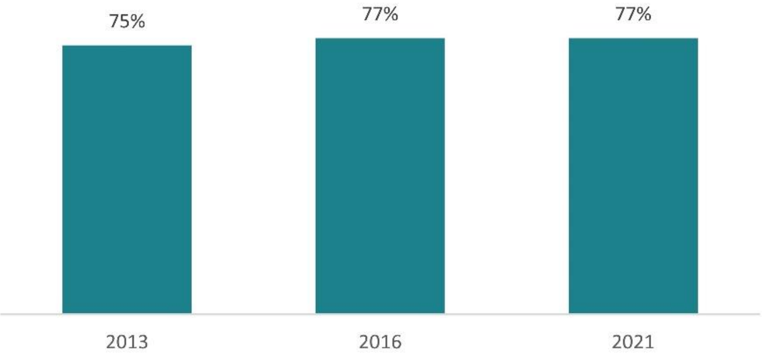
77%
of respondents completely understood the explanation of what was wrong with them

Results above based on 6,169 responses. Those answering, "Don’t know / can’t remember" (18) excluded from base size/percentage calculation. 6,187 responses in total.

Health Board Comparison

Health Board Average	6,158	78%
Powys	100	82%
Swansea Bay	759	79%
Aneurin Bevan	1,215	79%
Cardiff and Vale	922	78%
Cwm Taf Morgannwg	879	77%
Hywel Dda	908	75%
Betsi Cadwaladr	1,375	75%

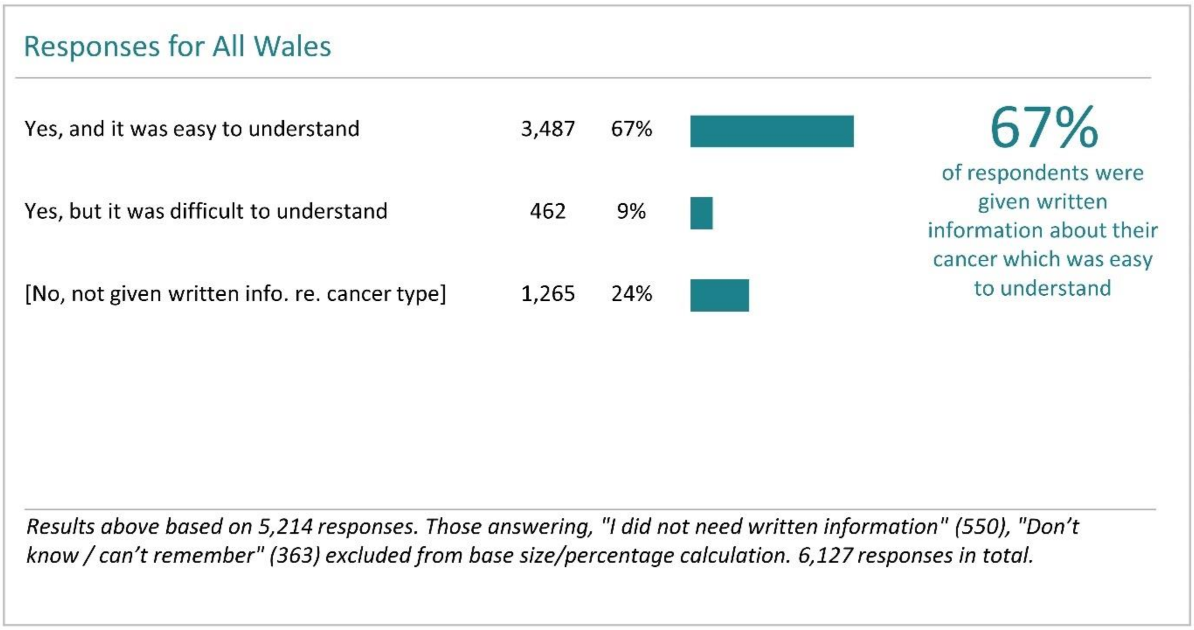
Scores Over Time – All Wales



0%
Change 2016-2021

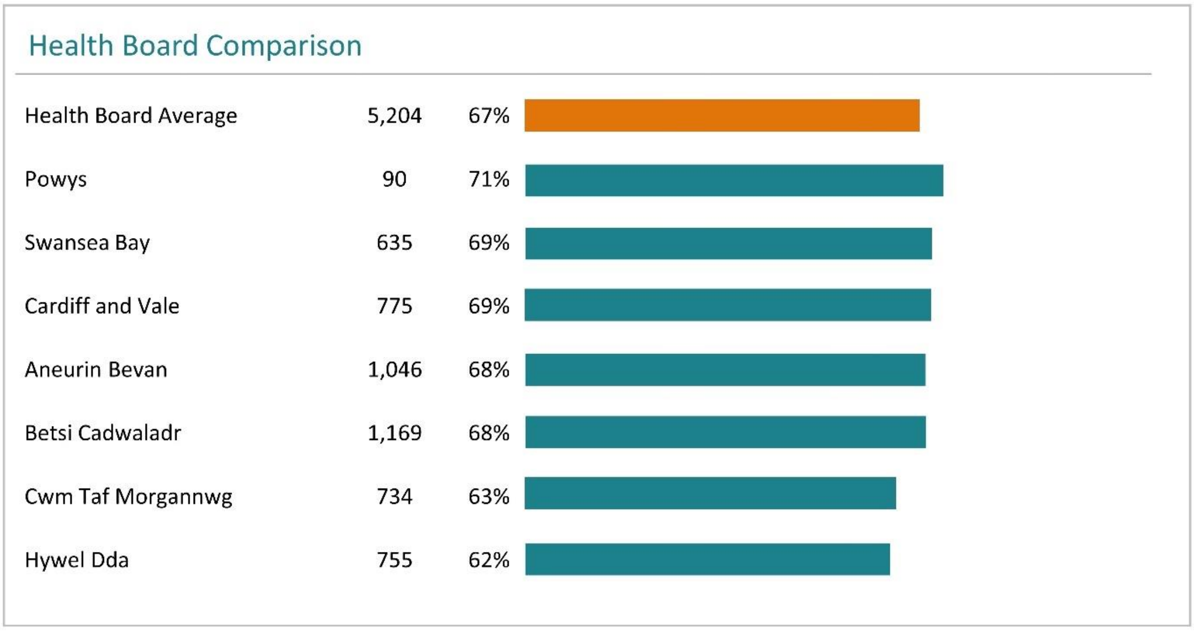
Directly comparable

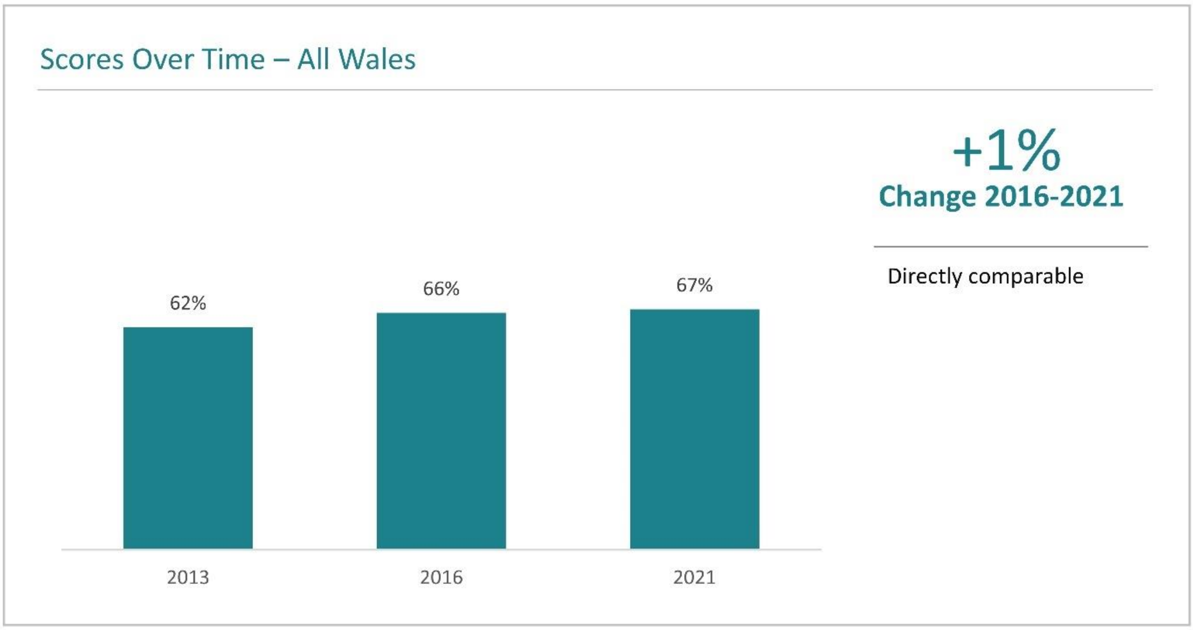
Question 12: "When you were told you had cancer, were you given written information about the type of cancer you had?"[12]



67% of respondents were given written information about their cancer which was easy to understand

Results above based on 5,214 responses. Those answering, "I did not need written information" (550), "Don't know / can't remember" (363) excluded from base size/percentage calculation. 6,127 responses in total.





+1% Change 2016-2021

Directly comparable

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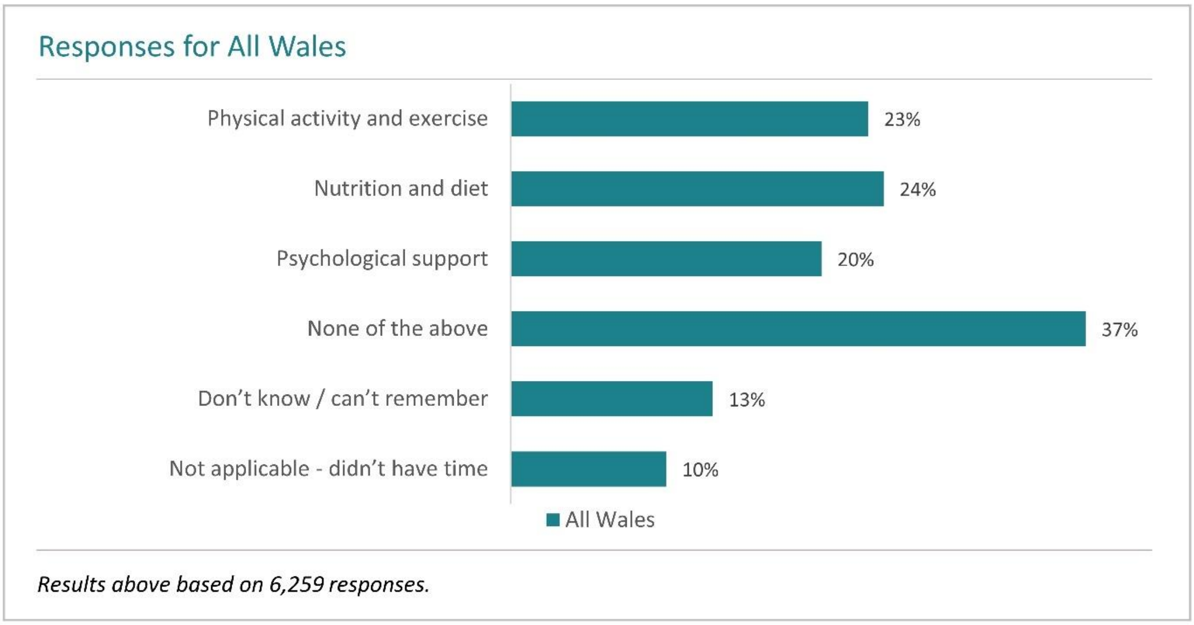
[12] Unabridged answer wording for '[no, not given written info. re. cancer type]' is 'No, I was not given written information about the type of cancer I had'

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

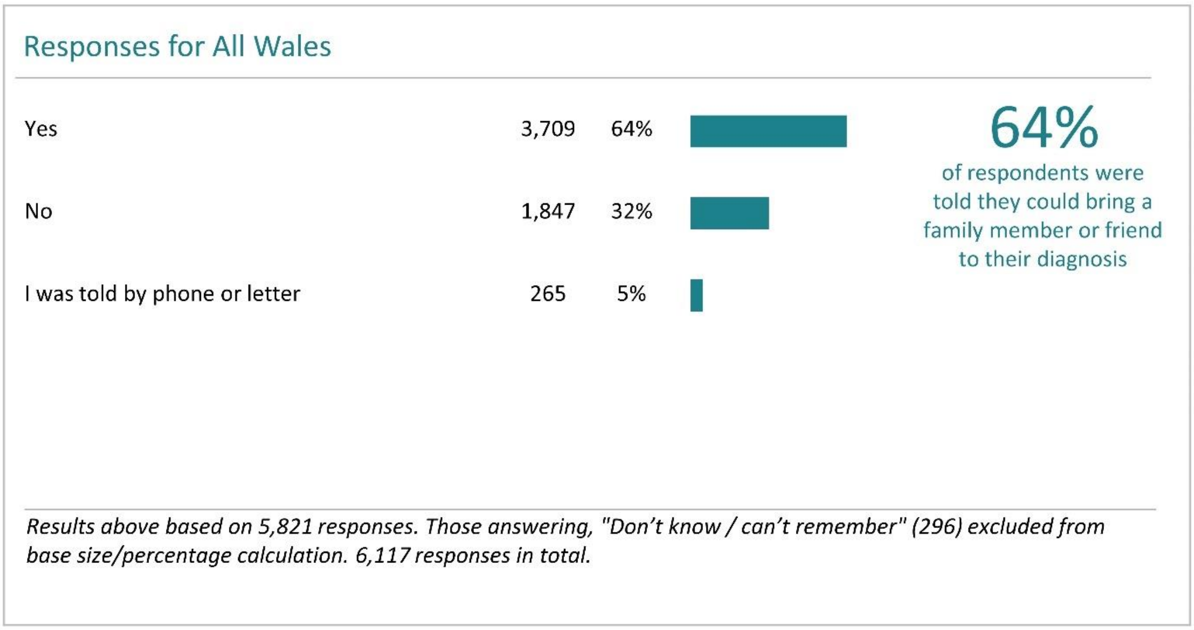


Results above based on 6,259 responses.

Survey respondent:

“No advice prior to hospital or after discharge on exercise, diet, rehabilitation, etc.”

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?"



Responses for All Wales

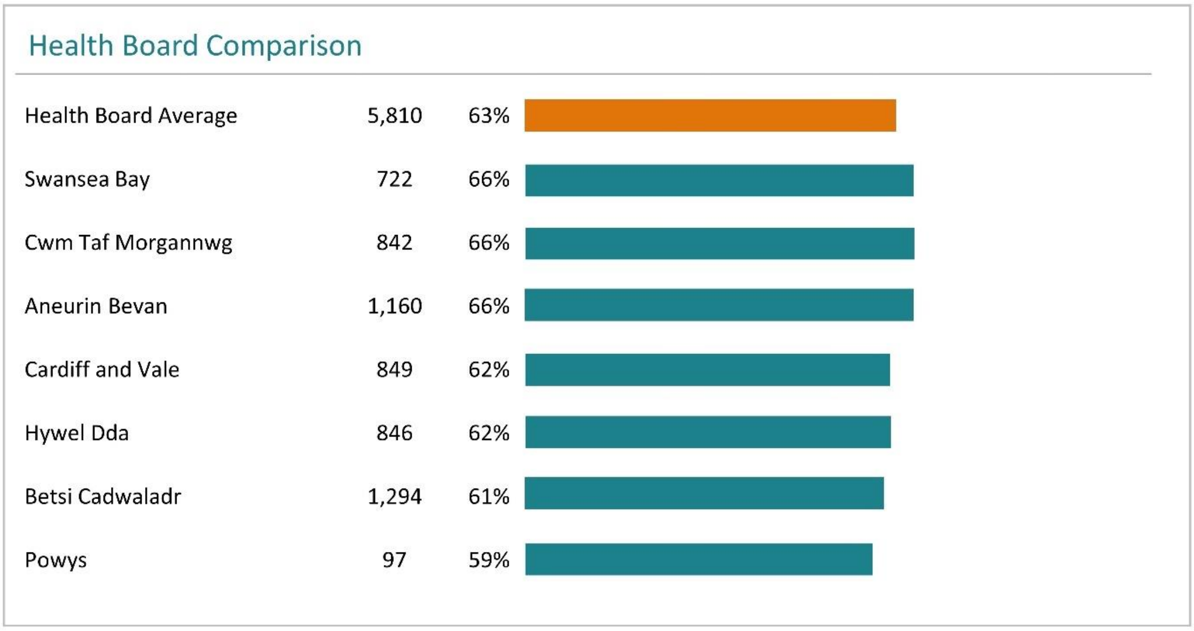
Yes	3,709	64%	
No	1,847	32%	
I was told by phone or letter	265	5%	

64%
of respondents were told they could bring a family member or friend to their diagnosis

Results above based on 5,821 responses. Those answering, "Don't know / can't remember" (296) excluded from base size/percentage calculation. 6,117 responses in total.

Survey respondent:

"Receiving a Cancer diagnosis during the pandemic was incredibly difficult due to the restrictions in place. Not having a family member with me at diagnosis or admission to hospital ward, follow up appointment etc. Saying that the superb care and empathy that I received from all staff involved was outstanding. I can't thank all staff involved enough for making a very traumatic experience manageable."

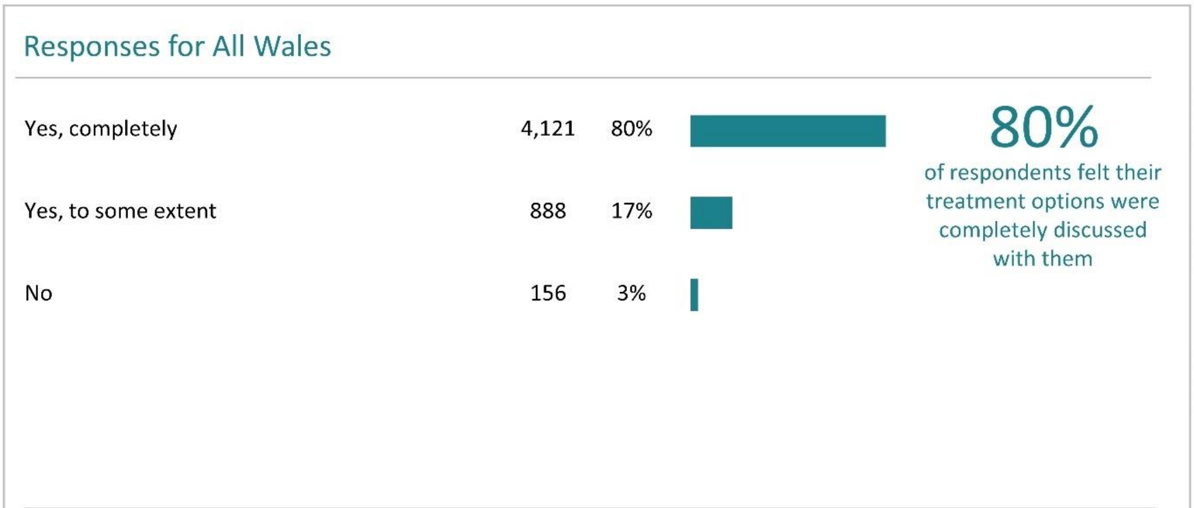


Health Board Comparison

Health Board Average	5,810	63%
Swansea Bay	722	66%
Cwm Taf Morgannwg	842	66%
Aneurin Bevan	1,160	66%
Cardiff and Vale	849	62%
Hywel Dda	846	62%
Betsi Cadwaladr	1,294	61%
Powys	97	59%

8.3 Deciding the best treatment and / or care for you

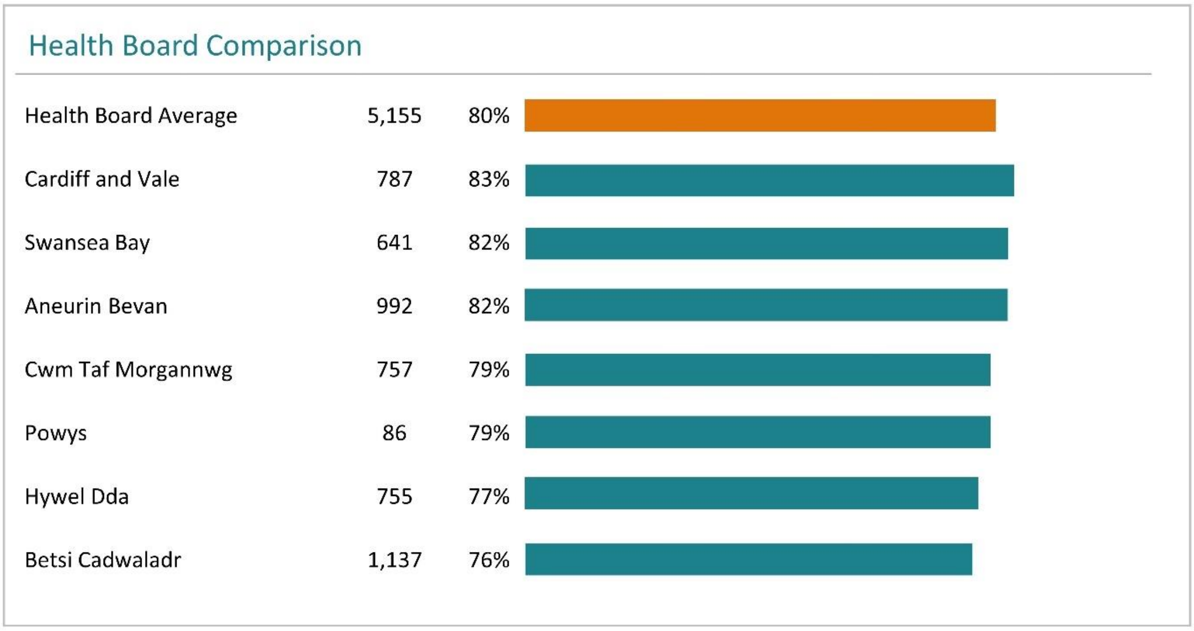
Question 15: "Before your cancer treatment started, were your treatment options discussed with you?”



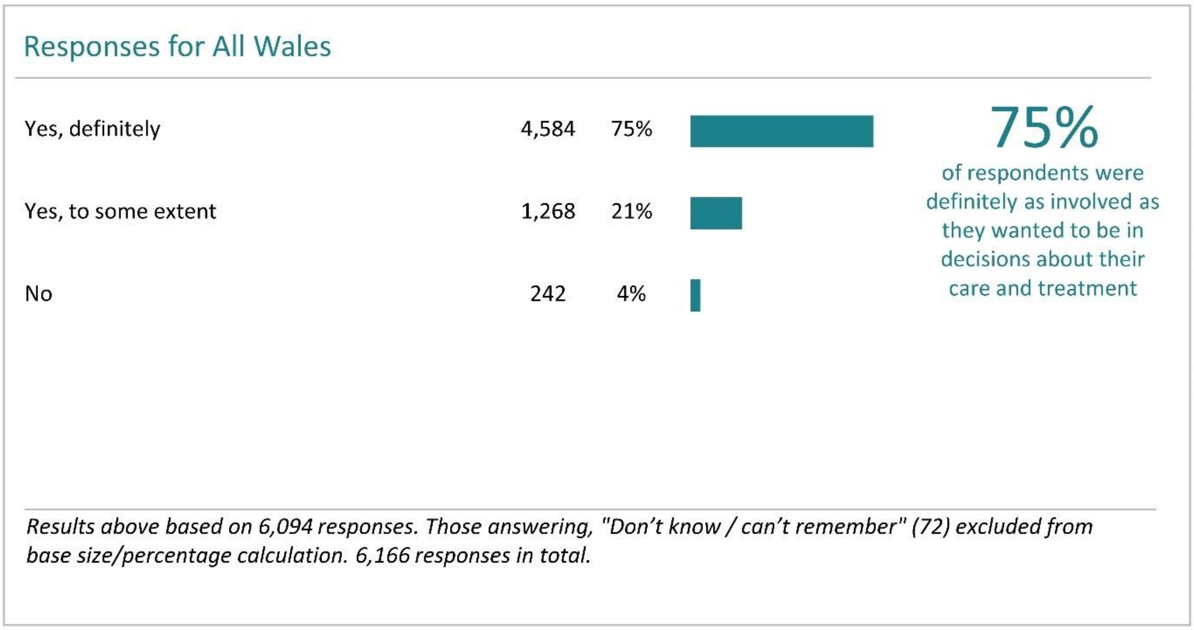
Results above based on 5,165 responses. Those answering, "There was only one type of treatment that was suitable for me" (870), "Don’t know / can’t remember" (65) excluded from base size/percentage calculation. 6,100 responses in total.

Survey respondent:

“The course of treatment was outlined at this appointment and the time I was to get a hysterectomy also given and all the pre-op blood test, etc. done and what I should expect. Due to COVID no one was with me, but I coped better on my own, some may not. The Macmillan nurse contacted me regularly pre-op, but I was confident of a good outcome from their comprehensive explanation.”



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



Responses for All Wales

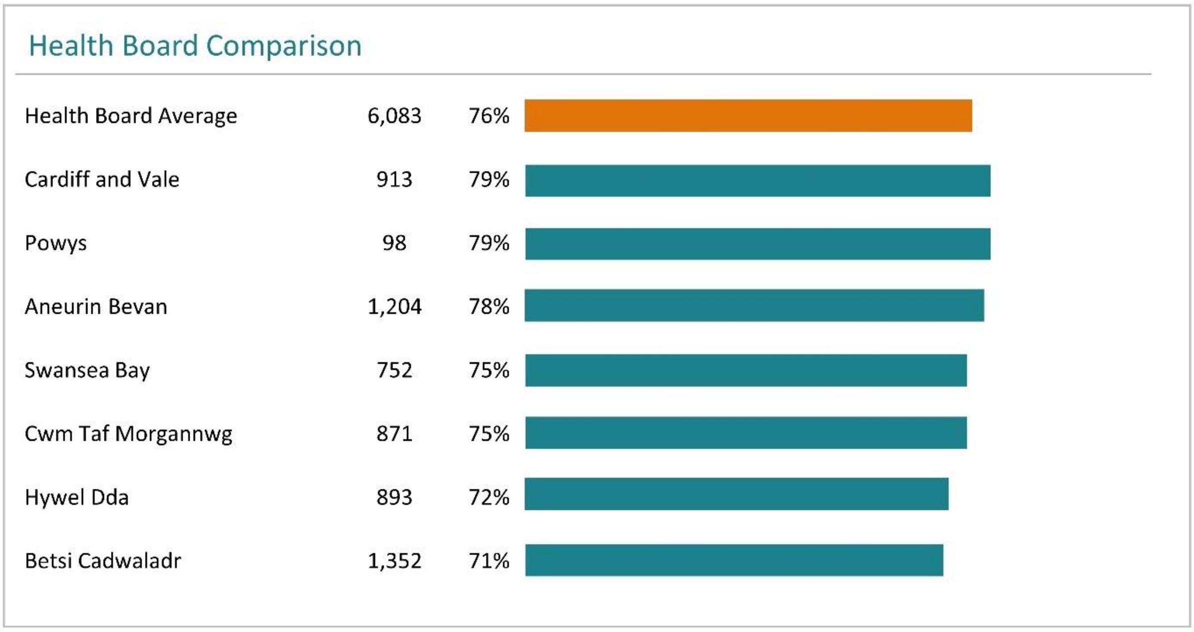
Yes, definitely	4,584	75%	
Yes, to some extent	1,268	21%	
No	242	4%	

75%
of respondents were definitely as involved as they wanted to be in decisions about their care and treatment

Results above based on 6,094 responses. Those answering, "Don’t know / can’t remember" (72) excluded from base size/percentage calculation. 6,166 responses in total.

Survey respondent:

“Although I have been offered a full range of treatment for my cancer, I have not been given any advice as to which is the most suitable treatment for my case. I do not know what would be best for me!”

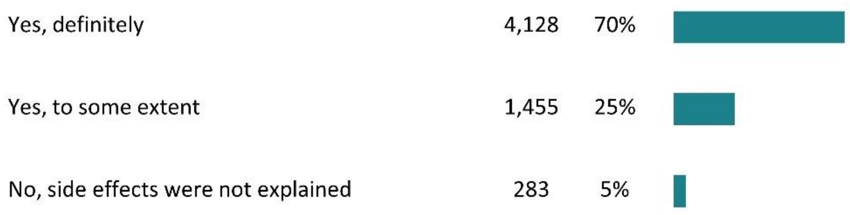


Health Board Comparison

Health Board Average	6,083	76%
Cardiff and Vale	913	79%
Powys	98	79%
Aneurin Bevan	1,204	78%
Swansea Bay	752	75%
Cwm Taf Morgannwg	871	75%
Hywel Dda	893	72%
Betsi Cadwaladr	1,352	71%

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

Responses for All Wales

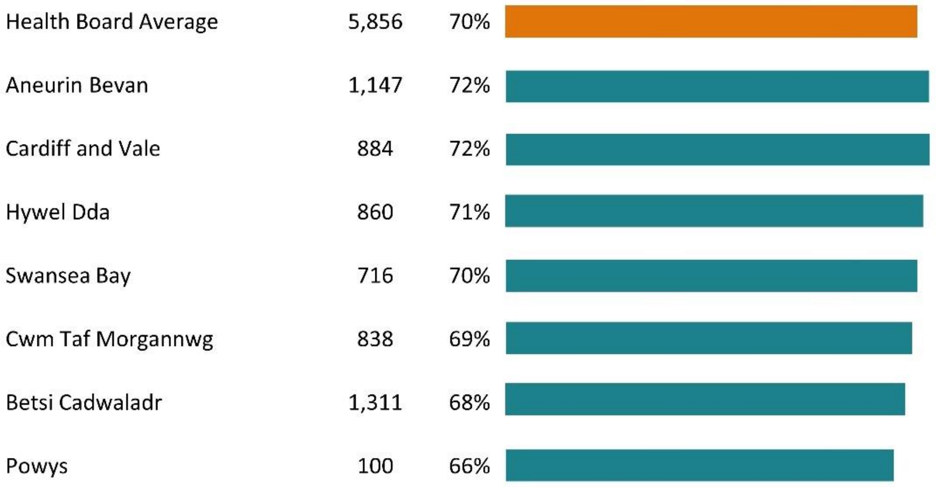


70%

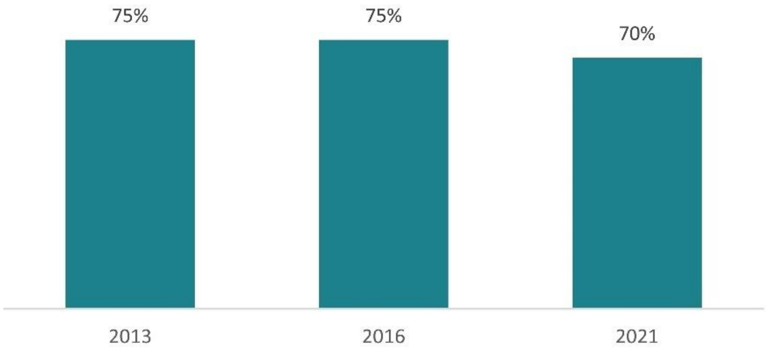
of respondents said that possible side effects of treatment were definitely explained in a way they could understand

Results above based on 5,866 responses. Those answering, "I did not need an explanation" (217), "Don't know" (51) excluded from base size/percentage calculation. 6,134 responses in total.

Health Board Comparison



Scores Over Time – All Wales

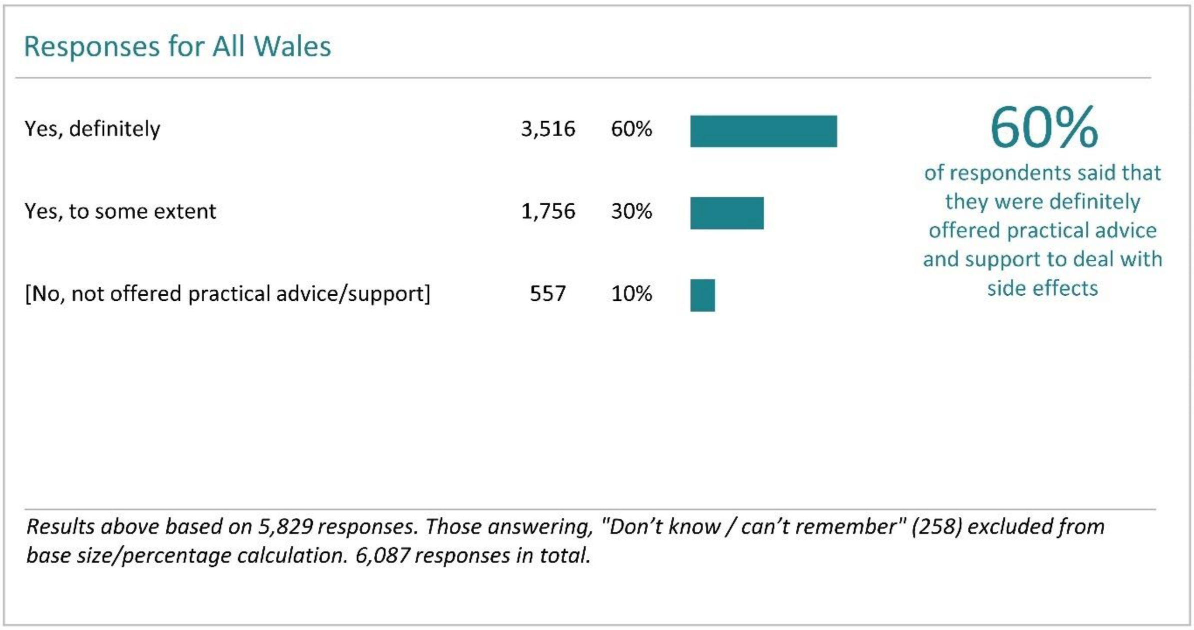


-5%

Change 2016-2021

Comparable with changes – see appendix 1

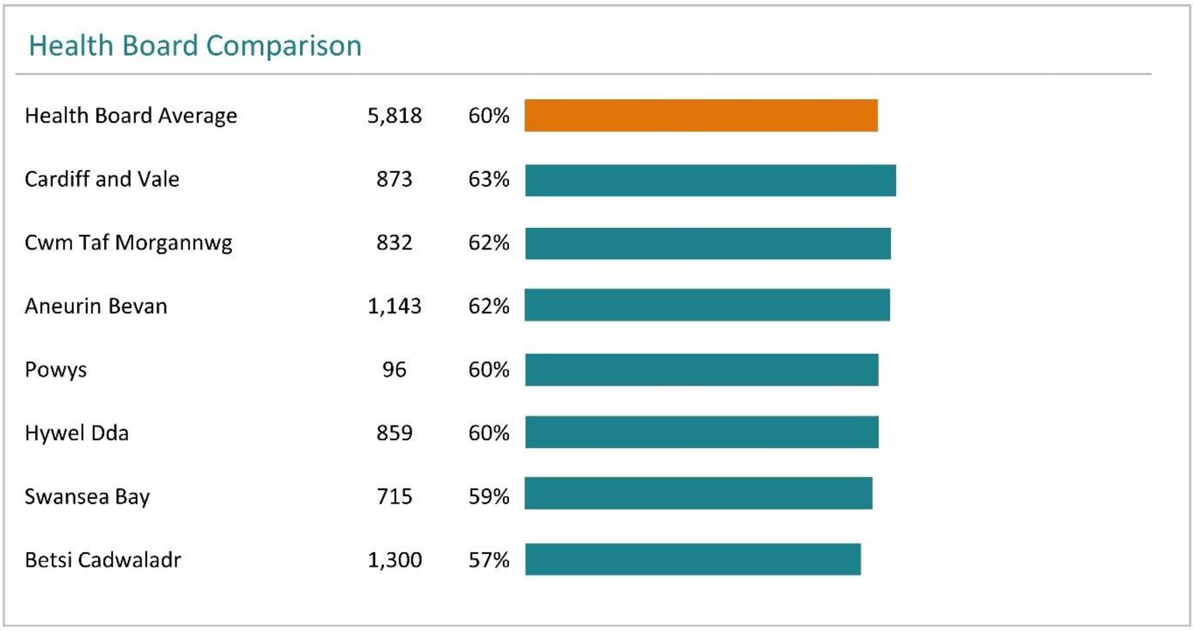
Question 18: "Were you offered practical advice and support in dealing with the side effects of your treatment(s)?"[13]



Results above based on 5,829 responses. Those answering, "Don't know / can't remember" (258) excluded from base size/percentage calculation. 6,087 responses in total.

Survey respondent:

"I wasn't given any practical information about life after treatment e.g. diet, exercise, alcohol consumption or how to get back to normal."



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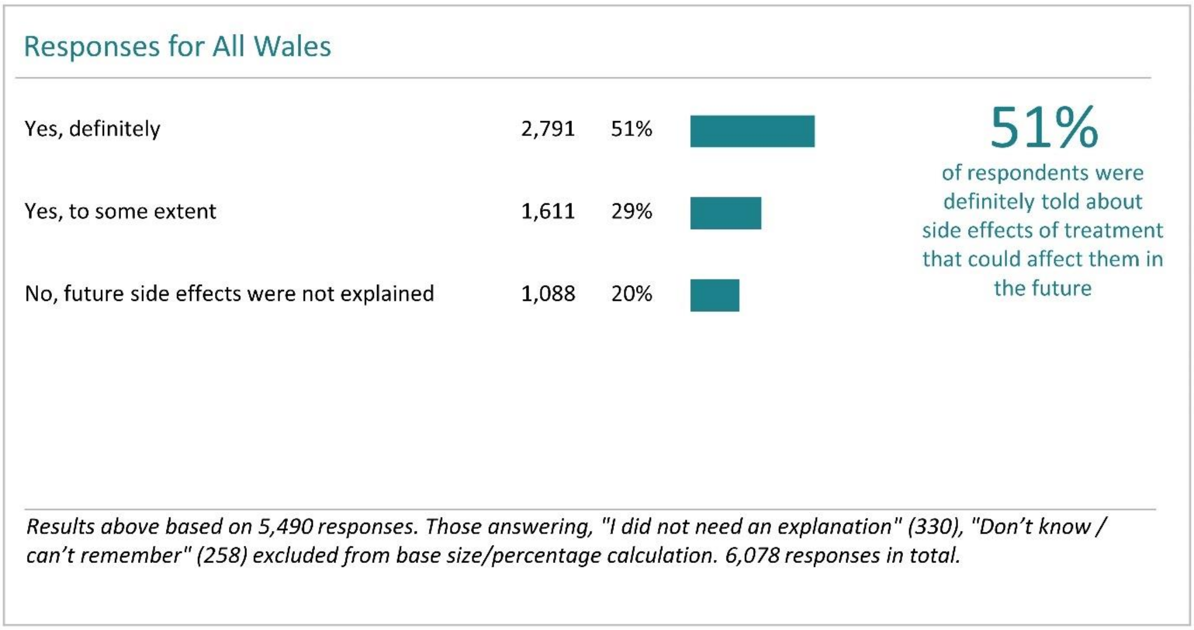
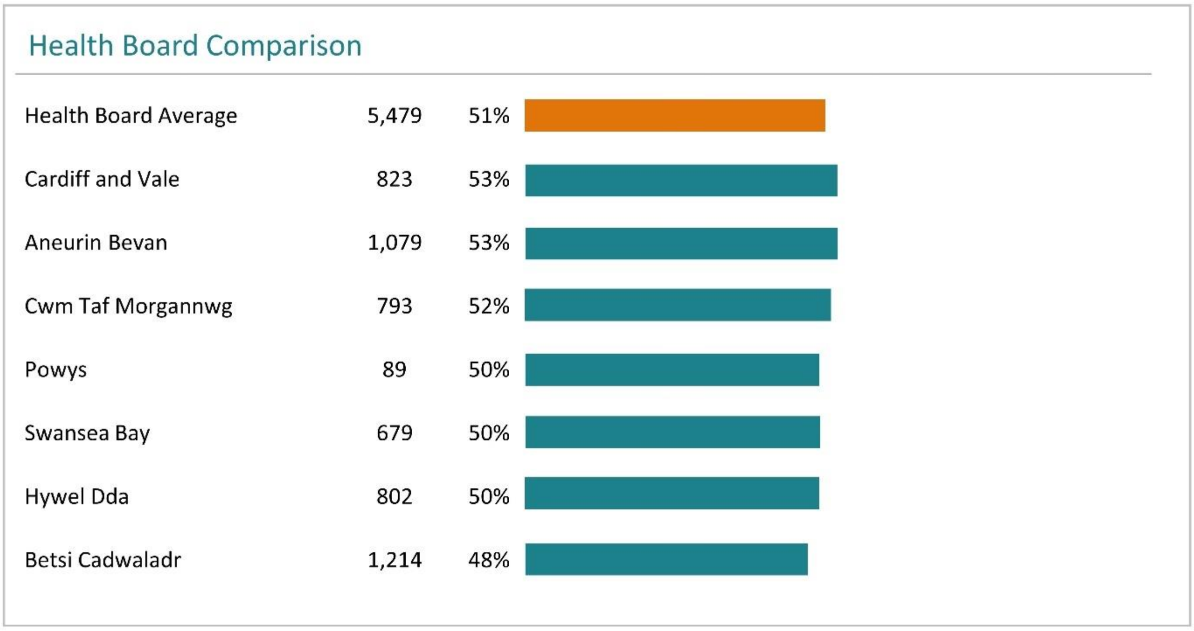
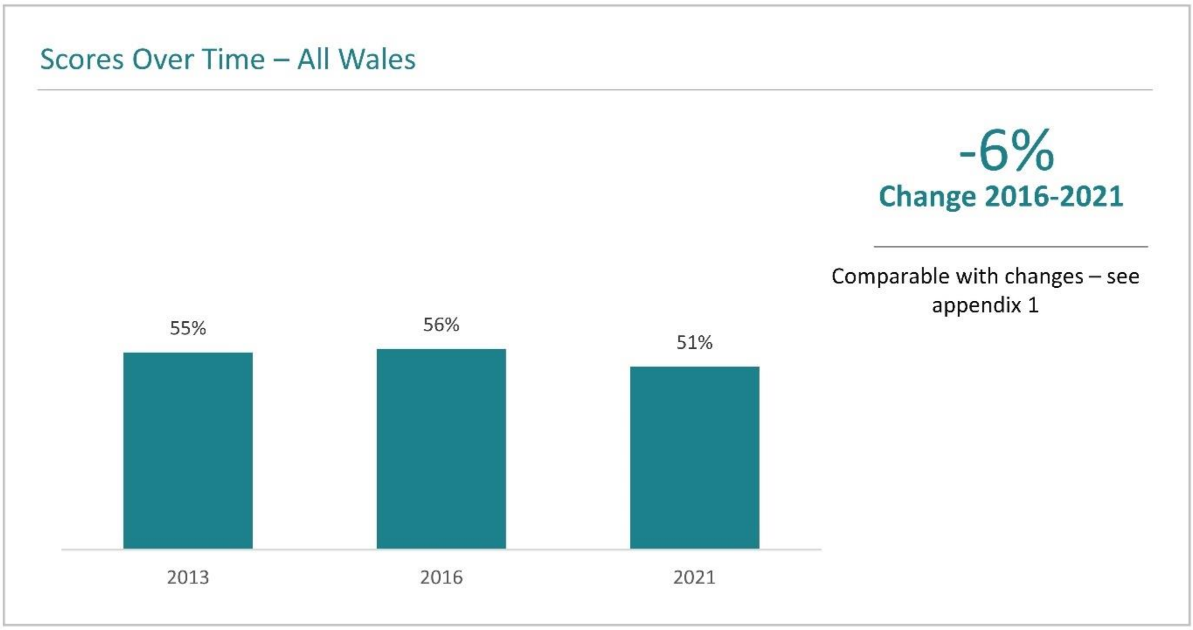
[13] Unabridged answer wording for '[no, not offered practical advice/support]' is 'No, I was not offered any practical advice or support'

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?”


Responses for All Wales

Results above based on 5,490 responses. Those answering, "I did not need an explanation" (330), "Don’t know / can’t remember" (258) excluded from base size/percentage calculation. 6,078 responses in total.

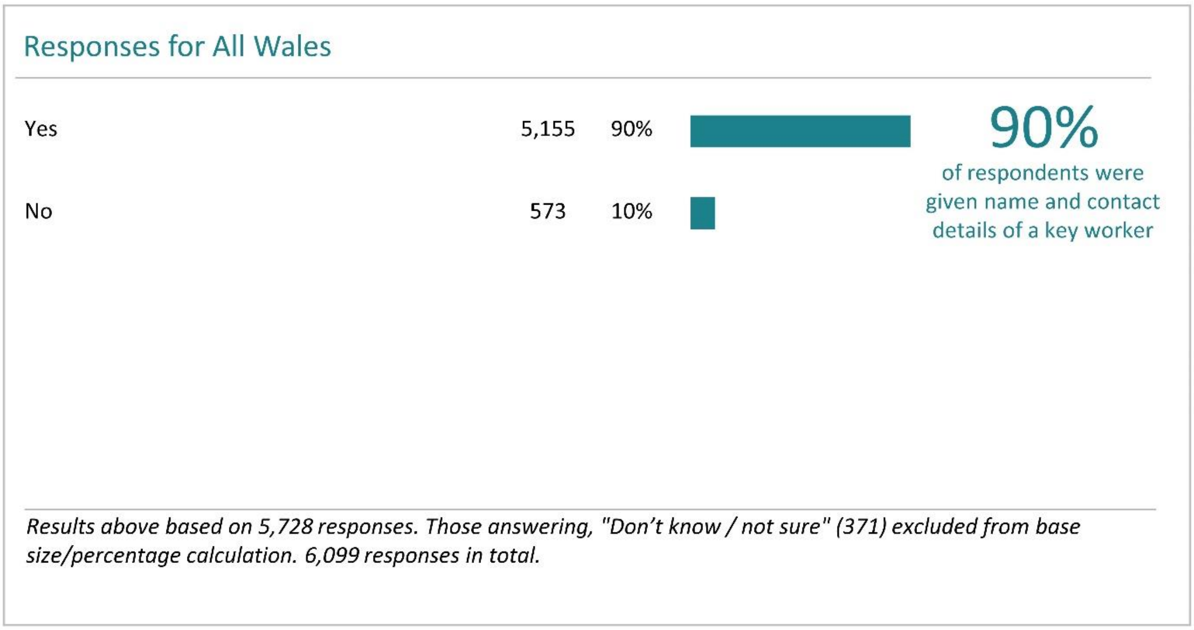

Health Board Comparison


Scores Over Time – All Wales

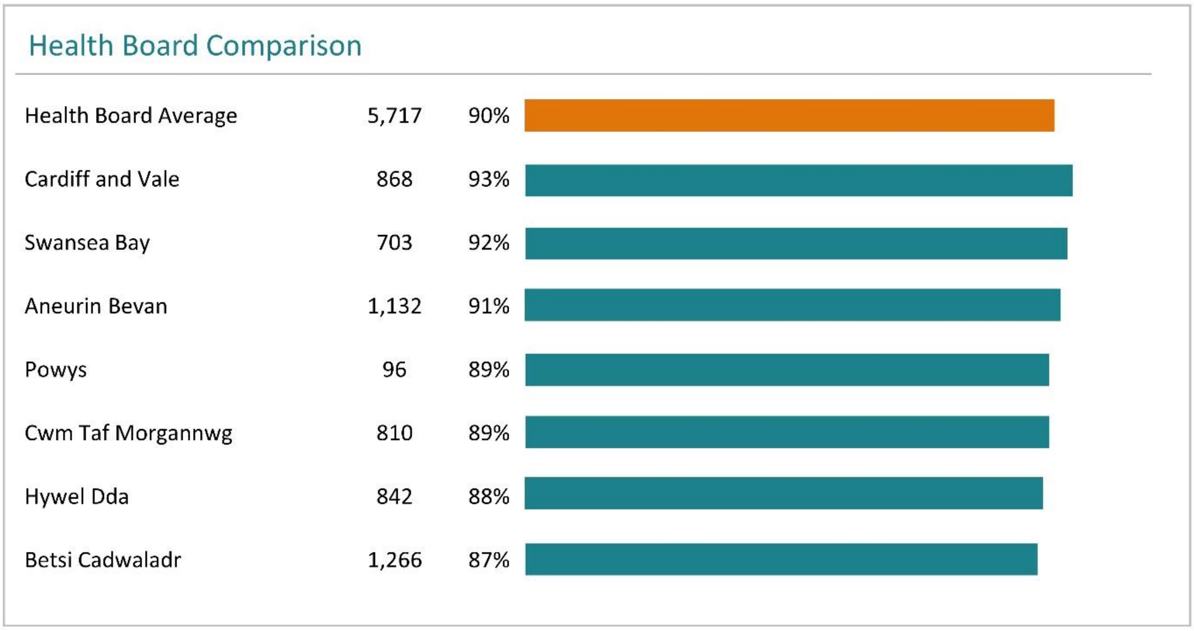
Comparable with changes – see appendix 1

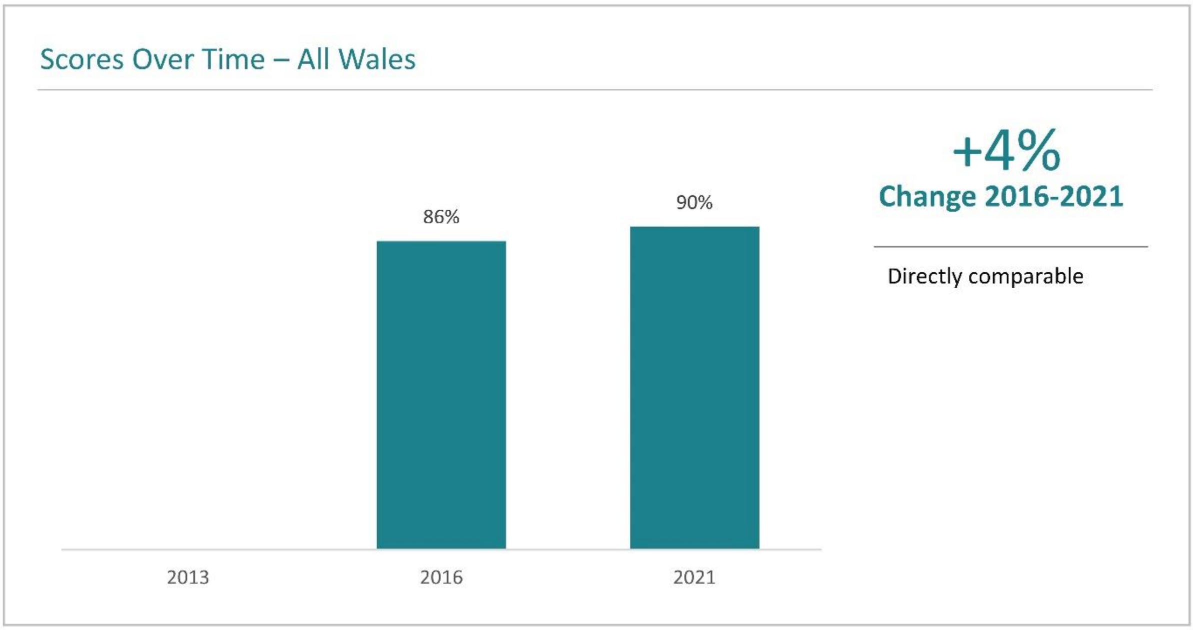
8.4 Healthcare professionals

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



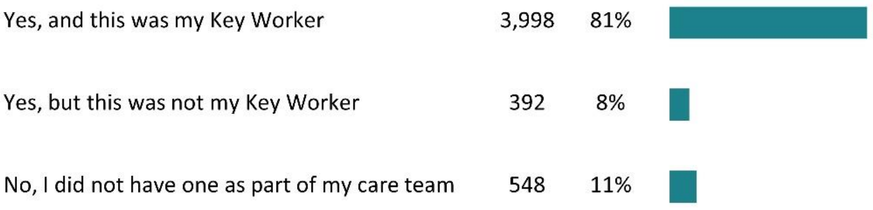
Results above based on 5,728 responses. Those answering, "Don’t know / not sure" (371) excluded from base size/percentage calculation. 6,099 responses in total.





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

Responses for All Wales

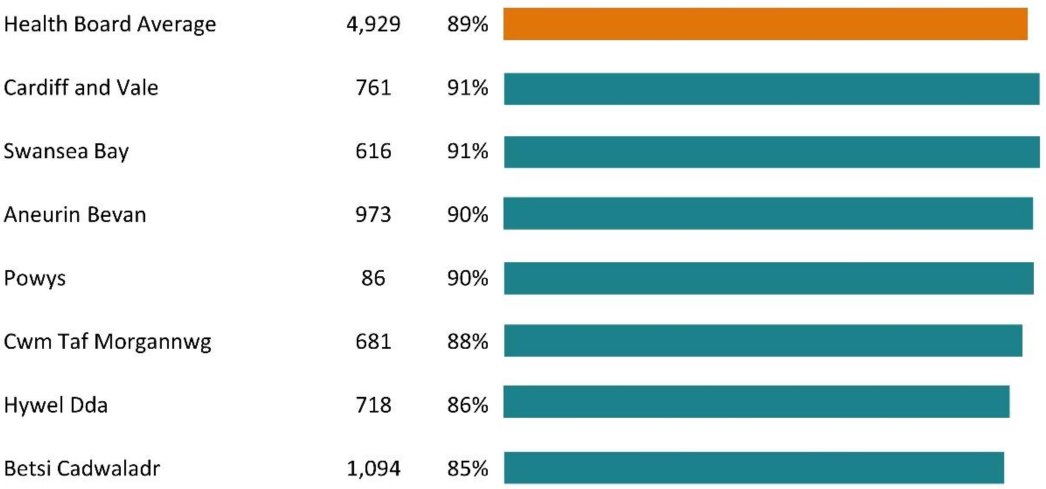


Yes, and this was my Key Worker	3,998	81%	
Yes, but this was not my Key Worker	392	8%	
No, I did not have one as part of my care team	548	11%	

89%
of respondents had access to a CNS

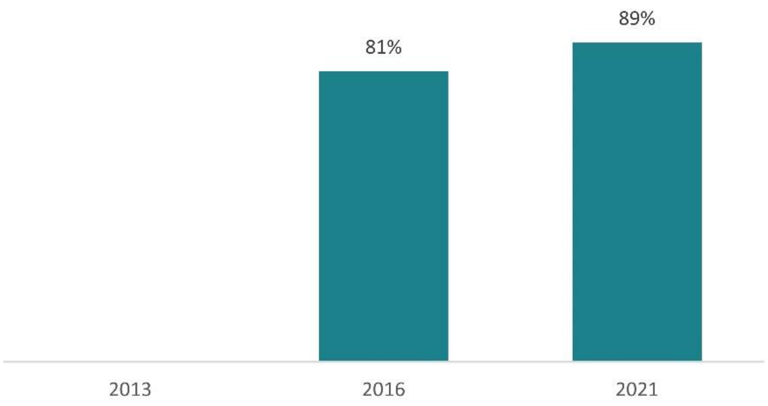
Results above based on 4,938 responses. Those answering, "Don't know / can't remember" (685) excluded from base size/percentage calculation. 5,623 responses in total.

Health Board Comparison



Health Board Average	4,929	89%	
Cardiff and Vale	761	91%	
Swansea Bay	616	91%	
Aneurin Bevan	973	90%	
Powys	86	90%	
Cwm Taf Morgannwg	681	88%	
Hywel Dda	718	86%	
Betsi Cadwaladr	1,094	85%	

Scores Over Time – All Wales

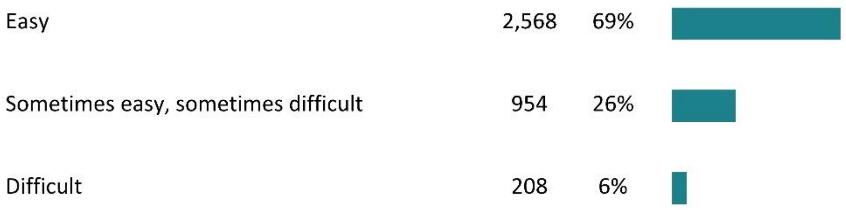


+8%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for All Wales

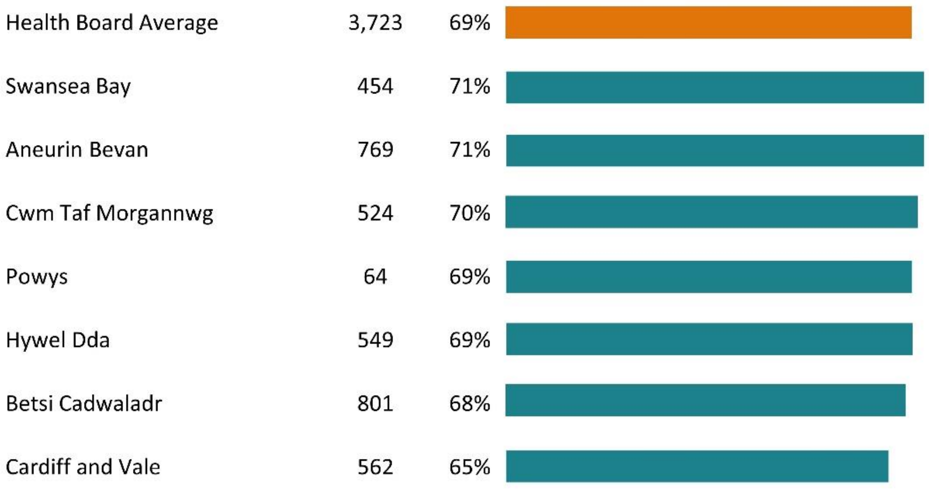


Easy	2,568	69%
Sometimes easy, sometimes difficult	954	26%
Difficult	208	6%

69%
of respondents said it was easy to contact their key worker

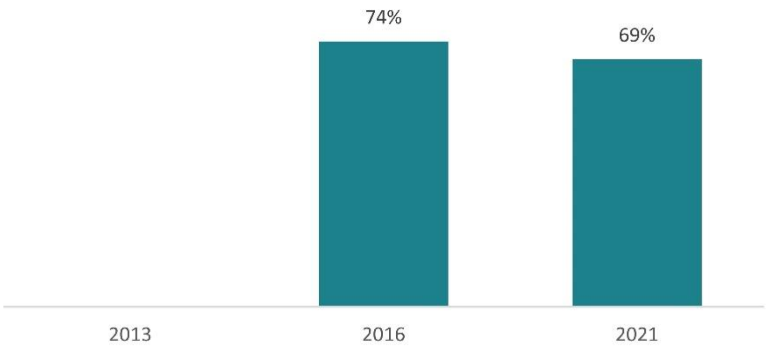
Results above based on 3,730 responses. Those answering, "I have not tried to contact them" (516), "Not applicable" (568) excluded from base size/percentage calculation. 4,814 responses in total.

Health Board Comparison



Health Board Average	3,723	69%
Swansea Bay	454	71%
Aneurin Bevan	769	71%
Cwm Taf Morgannwg	524	70%
Powys	64	69%
Hywel Dda	549	69%
Betsi Cadwaladr	801	68%
Cardiff and Vale	562	65%

Scores Over Time – All Wales

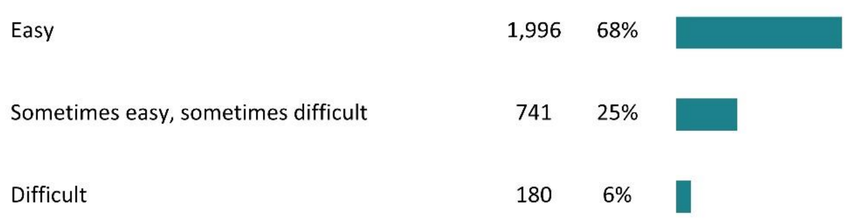


-5%
Change 2016-2021

Comparable with changes – see appendix 1

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

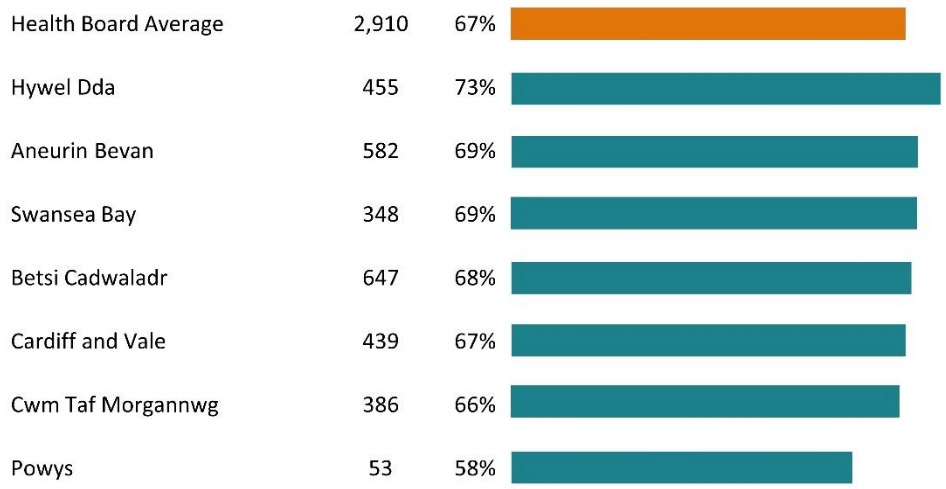
Responses for All Wales



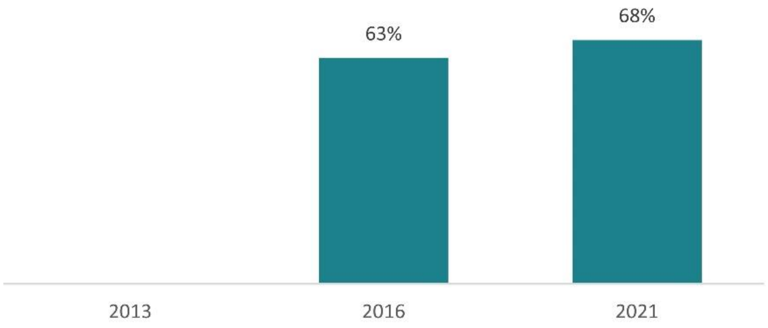
68%
of respondents said it was easy to contact their CNS

Results above based on 2,917 responses. Those answering, "I have not tried to contact them" (371), "Not applicable" (501) excluded from base size/percentage calculation. 3,789 responses in total.

Health Board Comparison



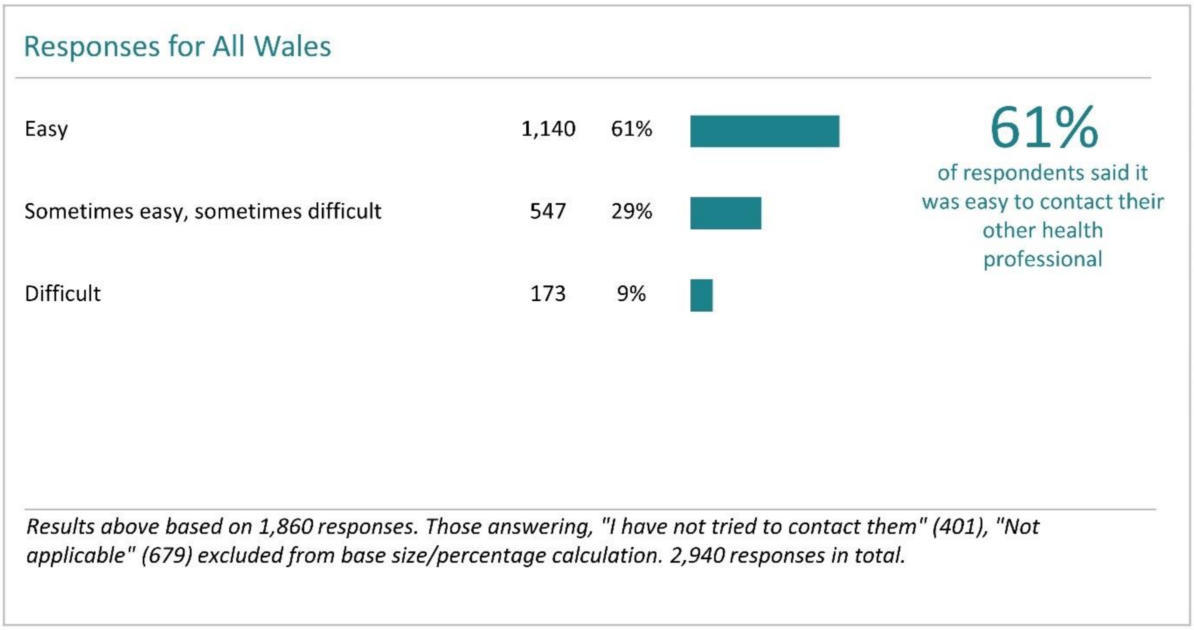
Scores Over Time – All Wales



+5%
Change 2016-2021

Comparable with changes – see appendix 1

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



Responses for All Wales

Easy	1,140	61%	
Sometimes easy, sometimes difficult	547	29%	
Difficult	173	9%	

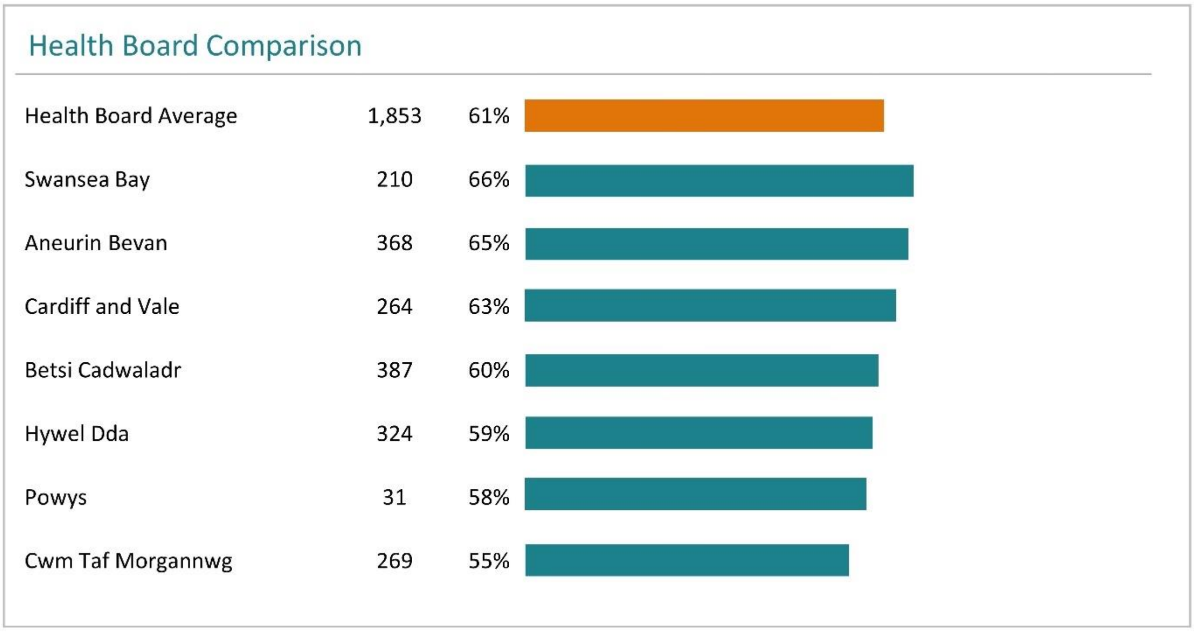
61%

of respondents said it was easy to contact their other health professional

Results above based on 1,860 responses. Those answering, "I have not tried to contact them" (401), "Not applicable" (679) excluded from base size/percentage calculation. 2,940 responses in total.

Survey respondent:

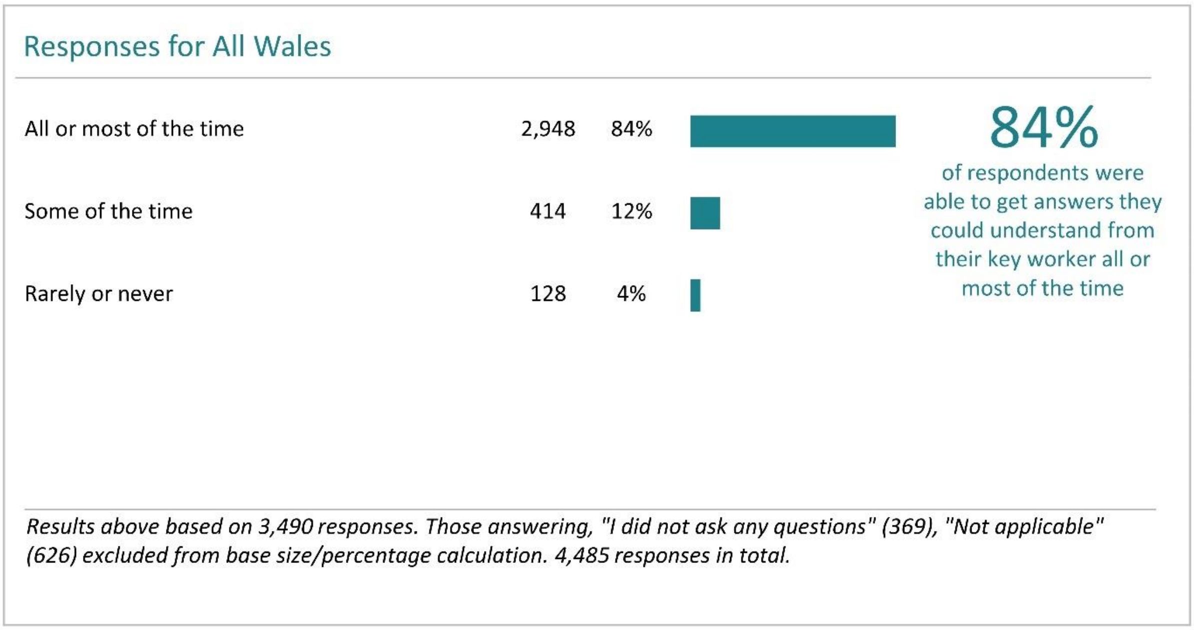
“I was very happy with the support team at [location removed]. They were easy to contact and always seemed glad to answer my questions, whatever they were.”



Health Board Comparison

Health Board Average	1,853	61%
Swansea Bay	210	66%
Aneurin Bevan	368	65%
Cardiff and Vale	264	63%
Betsi Cadwaladr	387	60%
Hywel Dda	324	59%
Powys	31	58%
Cwm Taf Morgannwg	269	55%

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



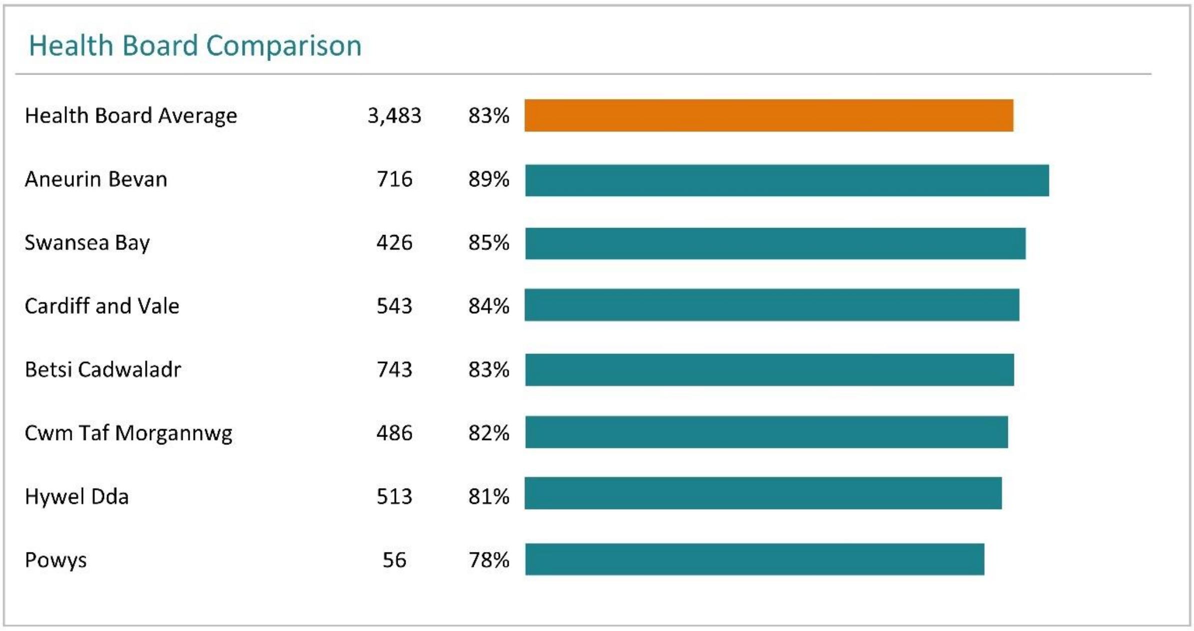
Responses for All Wales

84%
of respondents were able to get answers they could understand from their key worker all or most of the time

Results above based on 3,490 responses. Those answering, "I did not ask any questions" (369), "Not applicable" (626) excluded from base size/percentage calculation. 4,485 responses in total.

Survey respondent:

"Doctors, key workers and nursing staff were informative and explained every step of my treatment."



Health Board Comparison

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

Responses for All Wales

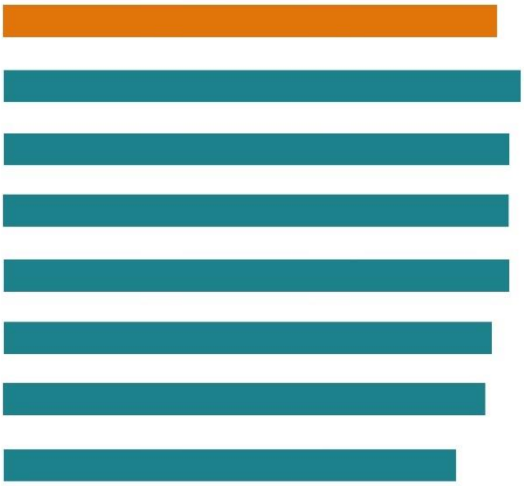
All or most of the time	2,591	85%
Some of the time	353	12%
Rarely or never	98	3%

85%
of respondents were able to get answers from their CNS all or most of the time

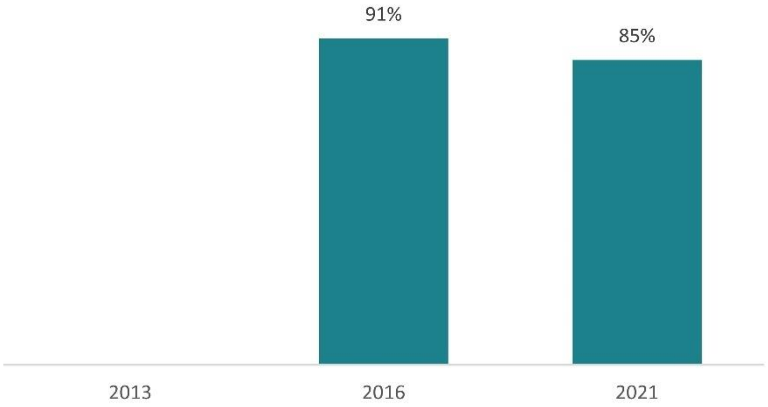
Results above based on 3,042 responses. Those answering, "I did not ask any questions" (270), "Not applicable" (559) excluded from base size/percentage calculation. 3,871 responses in total.

Health Board Comparison

Health Board Average	3,035	84%
Aneurin Bevan	608	88%
Hywel Dda	473	86%
Cardiff and Vale	478	86%
Swansea Bay	355	86%
Cwm Taf Morgannwg	387	83%
Betsi Cadwaladr	680	82%
Powys	54	77%



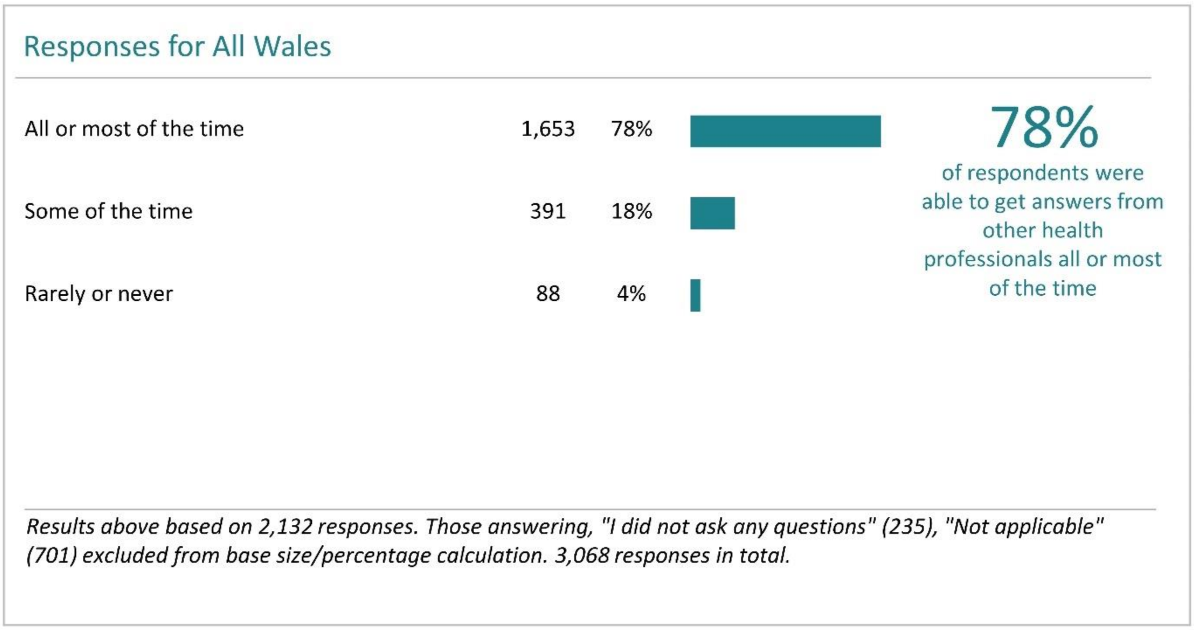
Scores Over Time – All Wales



-6%
Change 2016-2021

Comparable with changes – see appendix 1

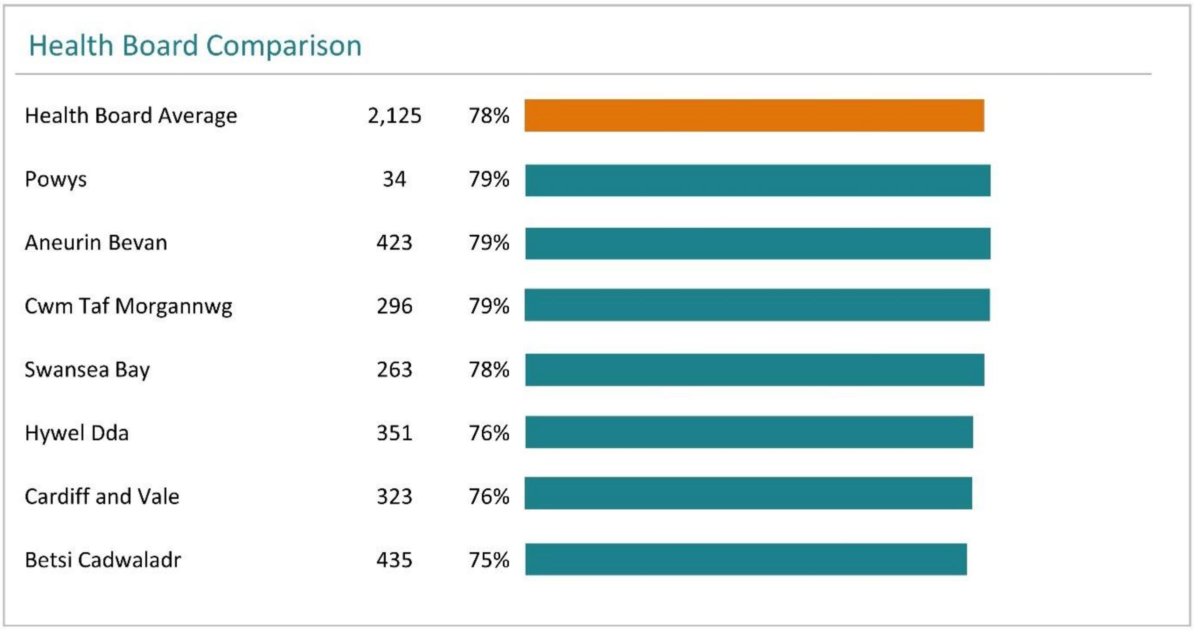
Question 23c: "When you had questions to ask, how often did you get answers you can understand from your... Other health professional?”



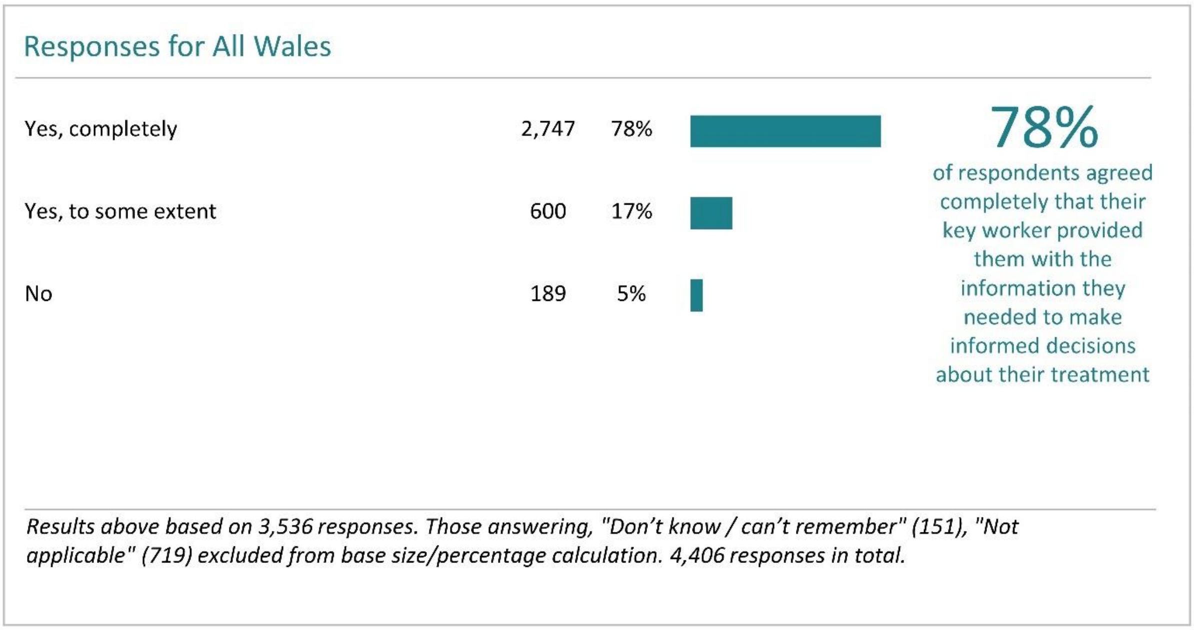
Results above based on 2,132 responses. Those answering, "I did not ask any questions" (235), "Not applicable" (701) excluded from base size/percentage calculation. 3,068 responses in total.

Survey respondent:

“The care from the specialists, surgeon, oncologist, chemotherapy and radiotherapy nurses was incredible.”



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

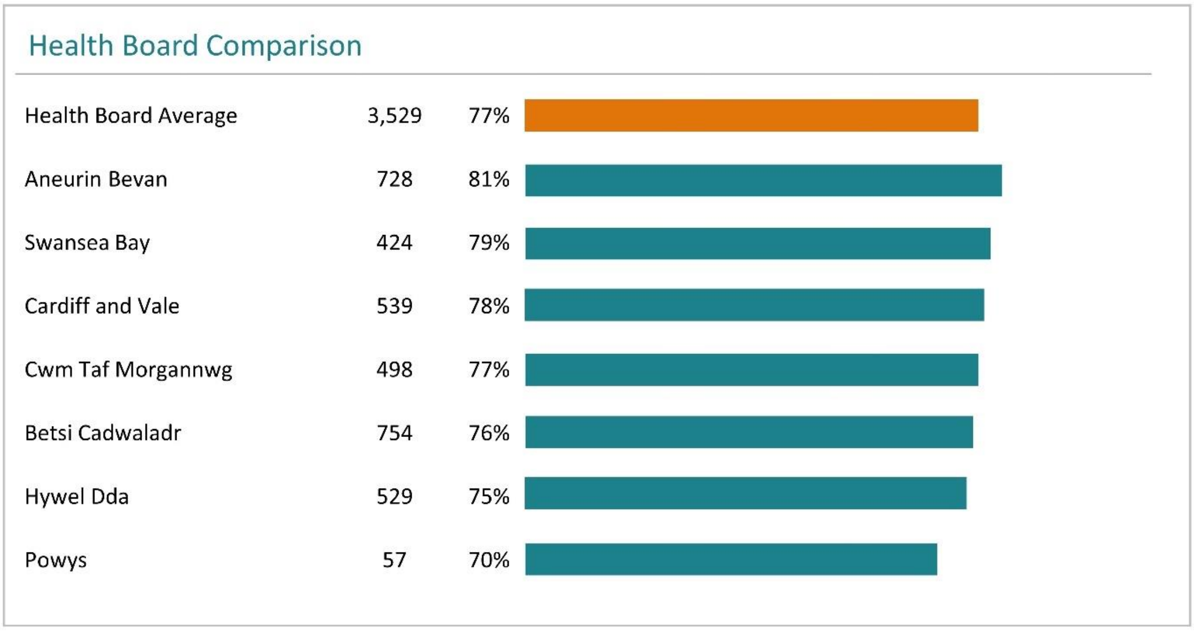

Responses for All Wales

78% of respondents agreed completely that their key worker provided them with the information they needed to make informed decisions about their treatment

Results above based on 3,536 responses. Those answering, "Don’t know / can’t remember" (151), "Not applicable" (719) excluded from base size/percentage calculation. 4,406 responses in total.

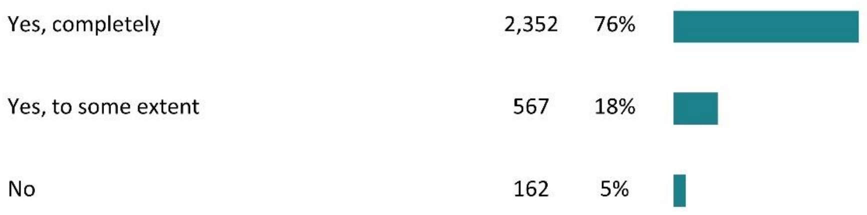
Survey respondent:

“My support/key worker and Macmillan nurse has been amazing and really supportive. I've had advice and financial help. Also, my diagnosis and treatment have been explained in a way I understand.”


Health Board Comparison

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

Responses for All Wales

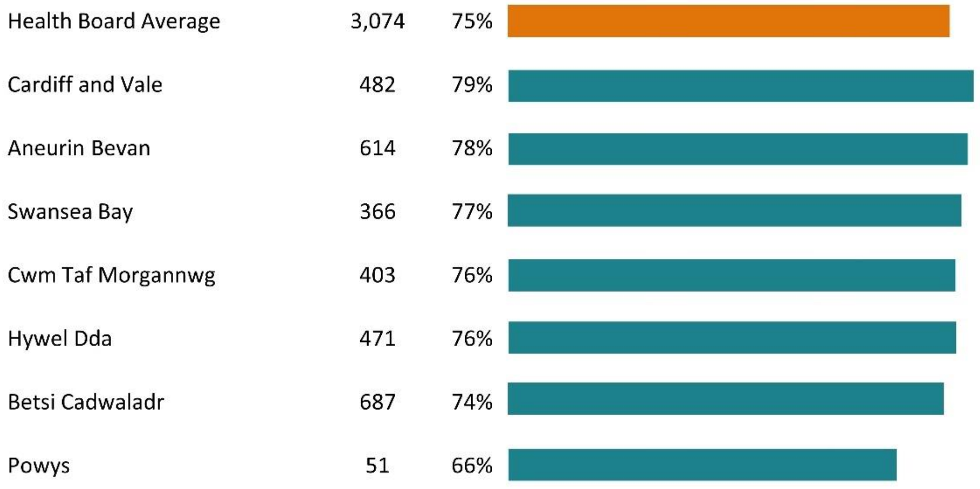


76%

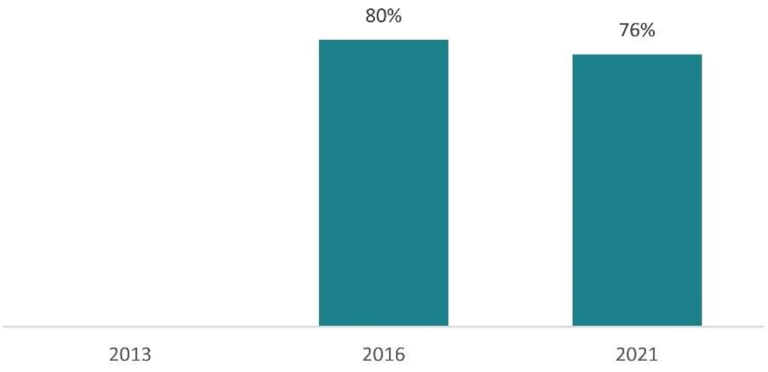
of respondents agreed completely that their CNS provided them with the information they needed to make informed decisions about their treatment

Results above based on 3,081 responses. Those answering, "Don't know / can't remember" (121), "Not applicable" (650) excluded from base size/percentage calculation. 3,852 responses in total.

Health Board Comparison



Scores Over Time – All Wales

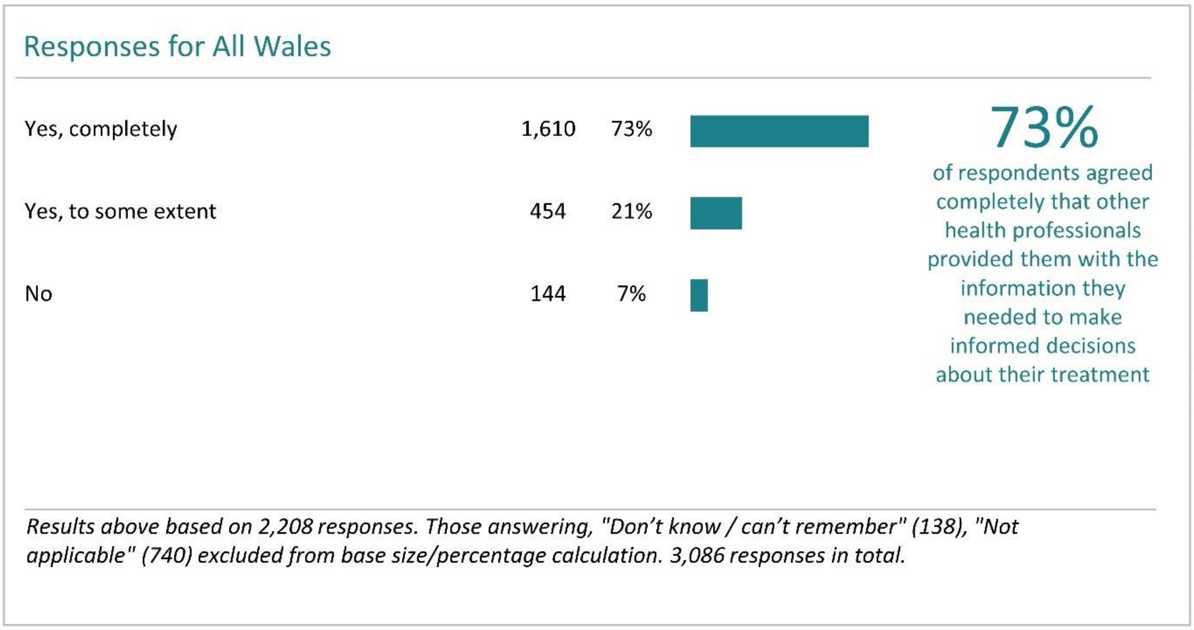


-4%

Change 2016-2021

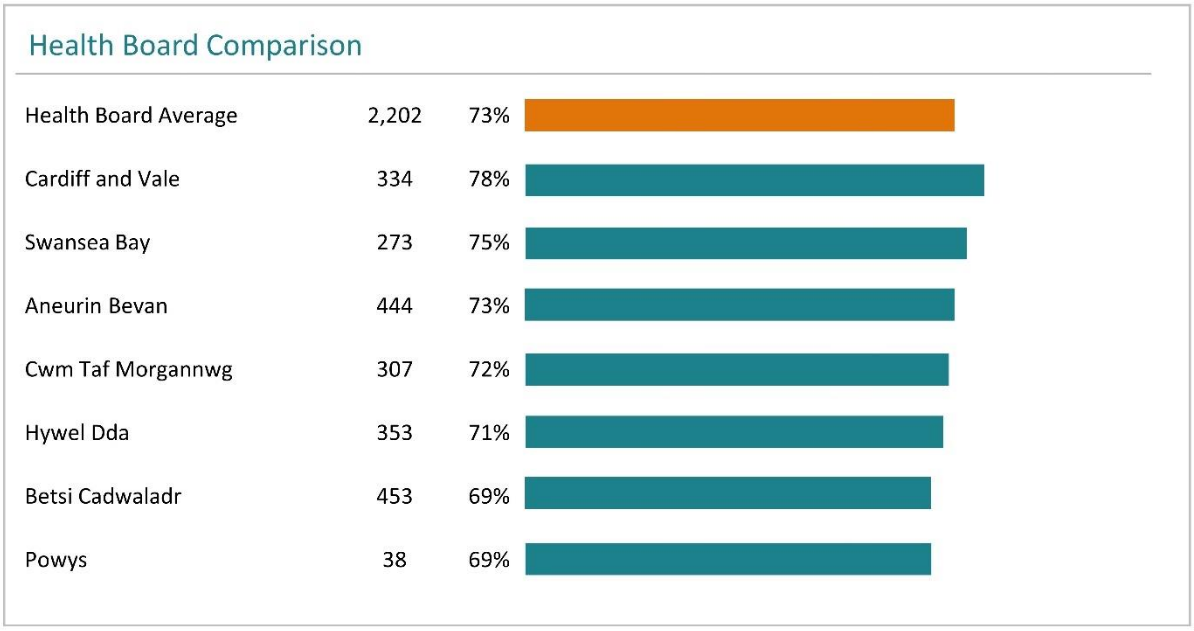
Comparable with changes – see appendix 1

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

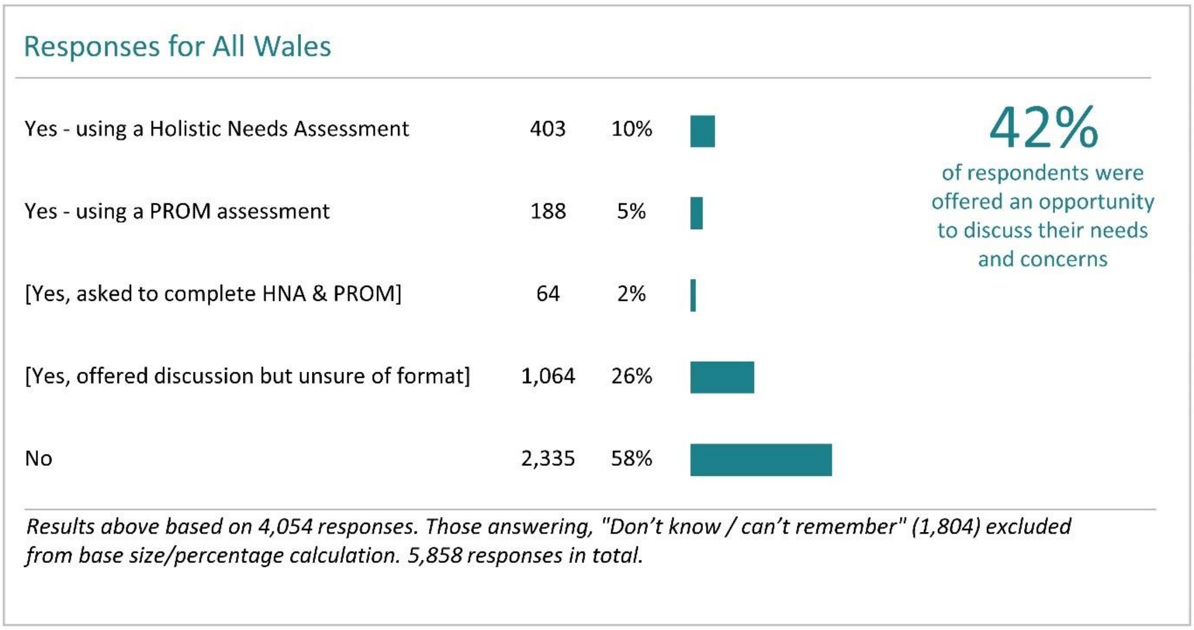


73% of respondents agreed completely that other health professionals provided them with the information they needed to make informed decisions about their treatment

Results above based on 2,208 responses. Those answering, "Don’t know / can’t remember" (138), "Not applicable" (740) excluded from base size/percentage calculation. 3,086 responses in total.



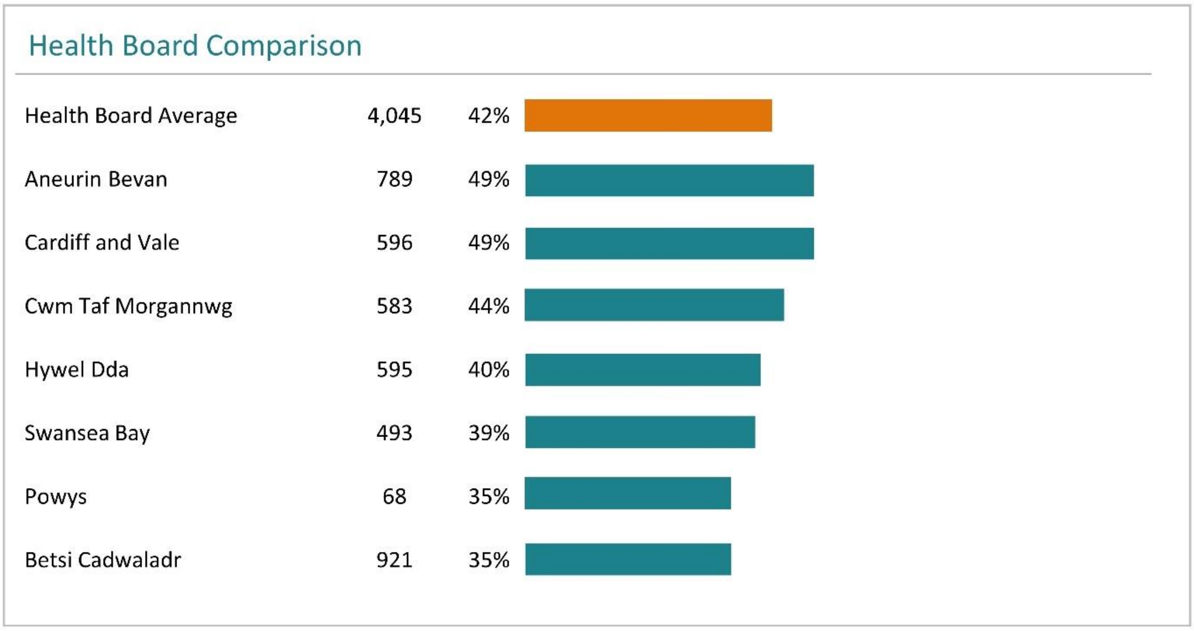
Question 25: "Were you offered the opportunity to discuss your needs and concerns?”[14,15]



Results above based on 4,054 responses. Those answering, "Don’t know / can’t remember" (1,804) excluded from base size/percentage calculation. 5,858 responses in total.

Survey respondent:

“No mental health support, no benefits or financial referral or support. In my experience there was no holistic care looking at me as an individual and what I and my family might need given I had a terminal metastatic breast diagnosis.”



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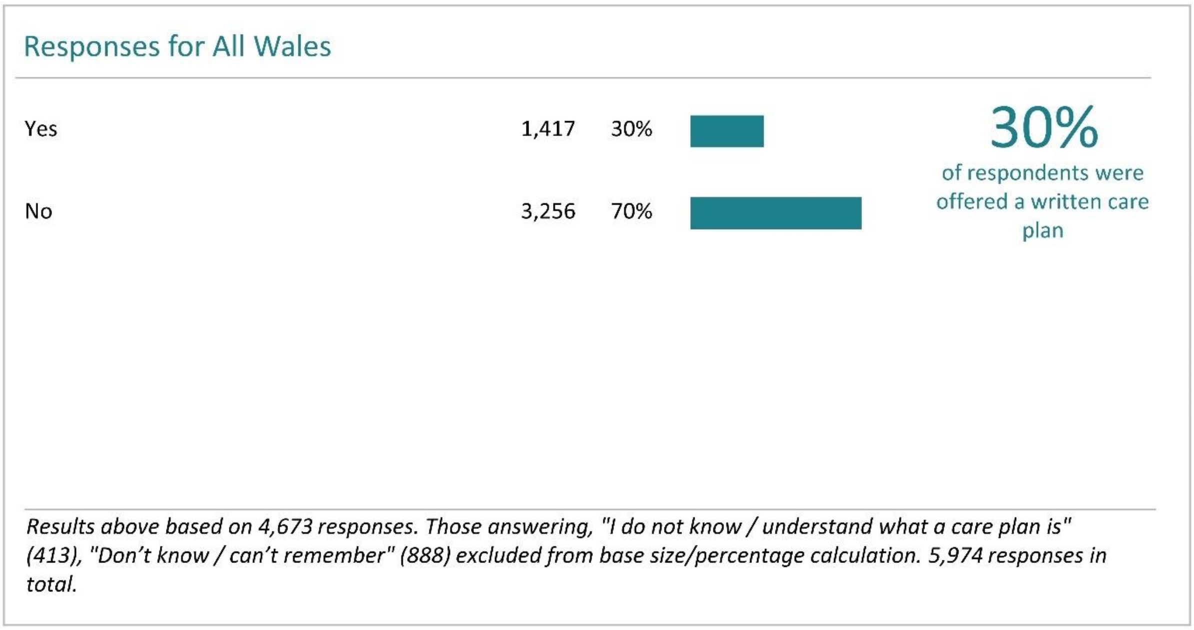
[14] Unabridged answer wording for ‘[yes, asked to complete HNA & PROM]’ is ‘Yes - I was asked to complete a Holistic Needs Assessment and a PROM’. Unabridged answer wording for ‘[yes, offered discussion but unsure of format]’ is ‘Yes - I was offered a discussion about my needs and concerns but unsure of the format'.

[15] 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?"

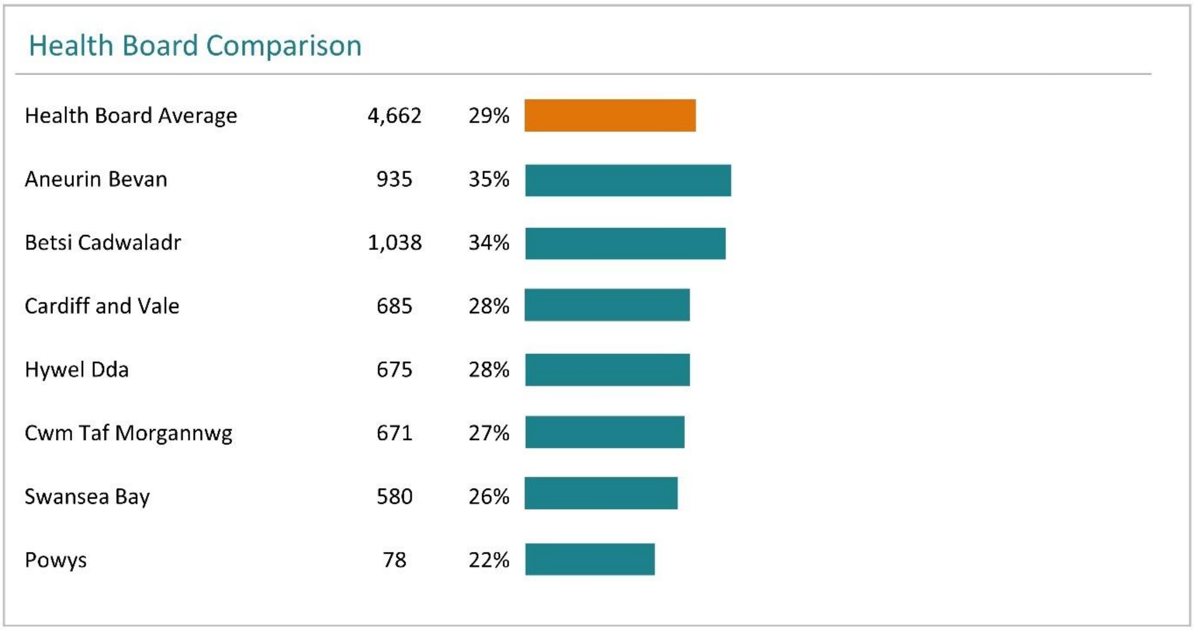


Responses for All Wales

Yes	1,417	30%
No	3,256	70%

30% of respondents were offered a written care plan

Results above based on 4,673 responses. Those answering, "I do not know / understand what a care plan is" (413), "Don't know / can't remember" (888) excluded from base size/percentage calculation. 5,974 responses in total.

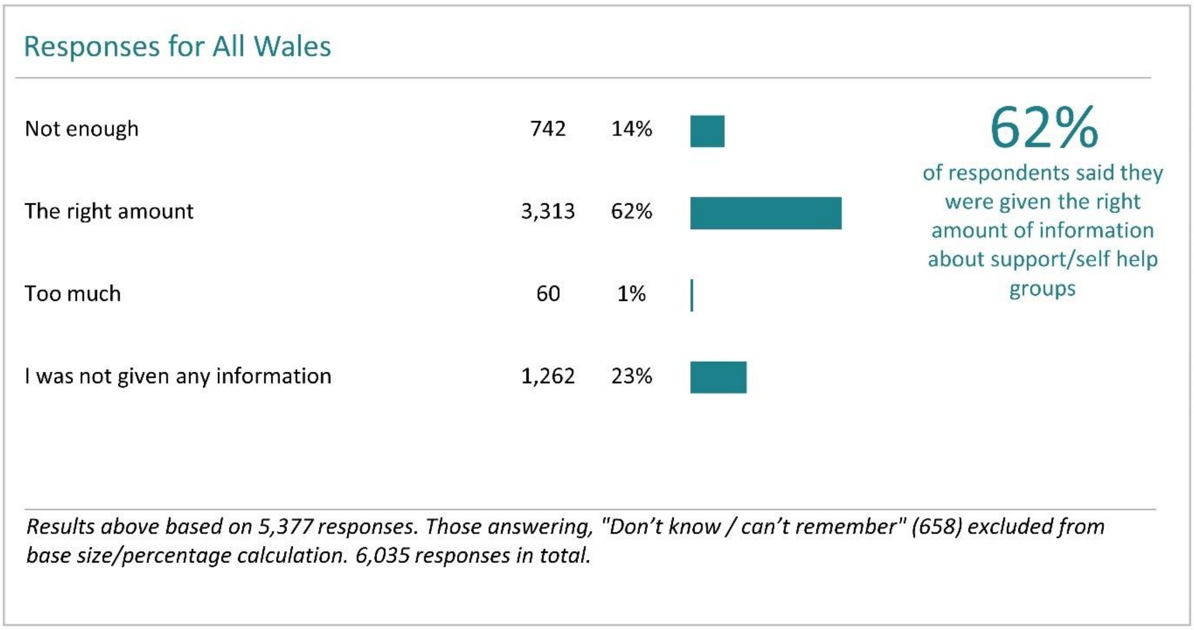


Health Board Comparison

Health Board Average	4,662	29%
Aneurin Bevan	935	35%
Betsi Cadwaladr	1,038	34%
Cardiff and Vale	685	28%
Hywel Dda	675	28%
Cwm Taf Morgannwg	671	27%
Swansea Bay	580	26%
Powys	78	22%

8.5 Support for people living with cancer

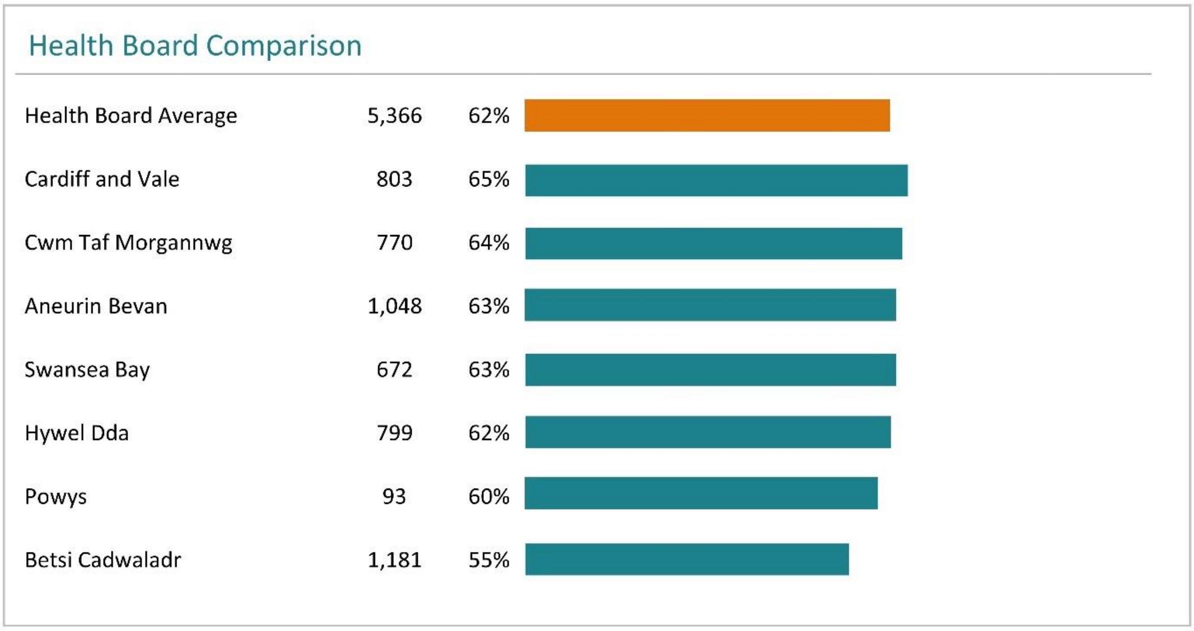
Question 27: "How much information about support or self-help groups did your healthcare team give you?”



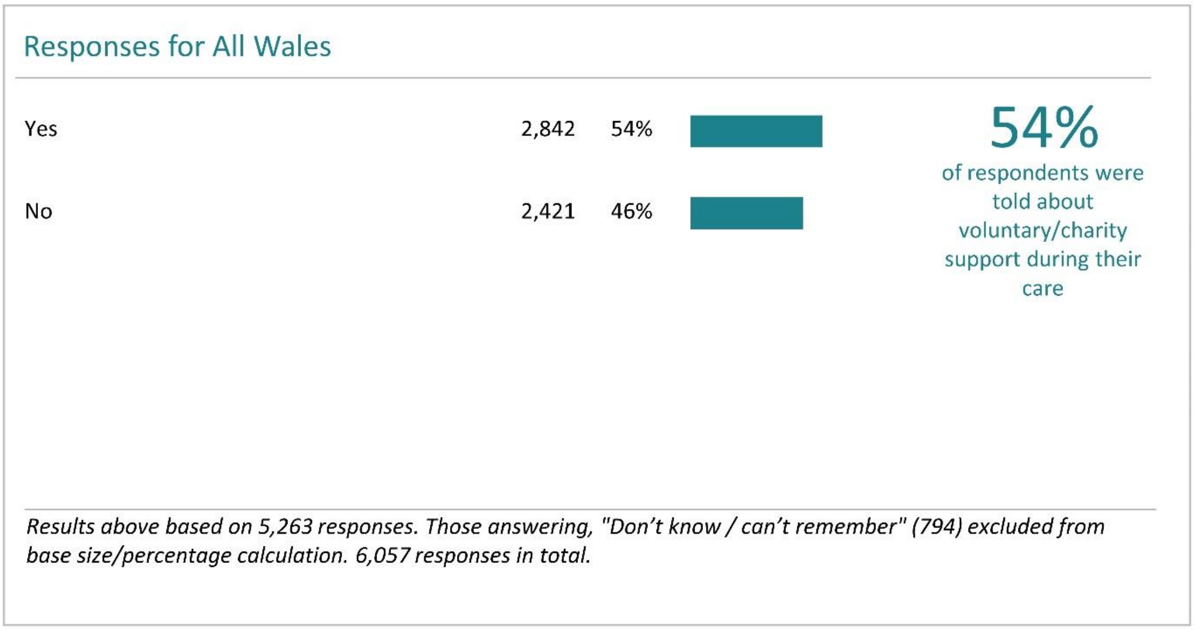
Results above based on 5,377 responses. Those answering, "Don’t know / can’t remember" (658) excluded from base size/percentage calculation. 6,035 responses in total.

Survey respondent:

“COVID restrictions did not allow any type of group meetings after treatment where it would have been useful to be able to meet up with patients having similar treatment and diagnosis.”



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

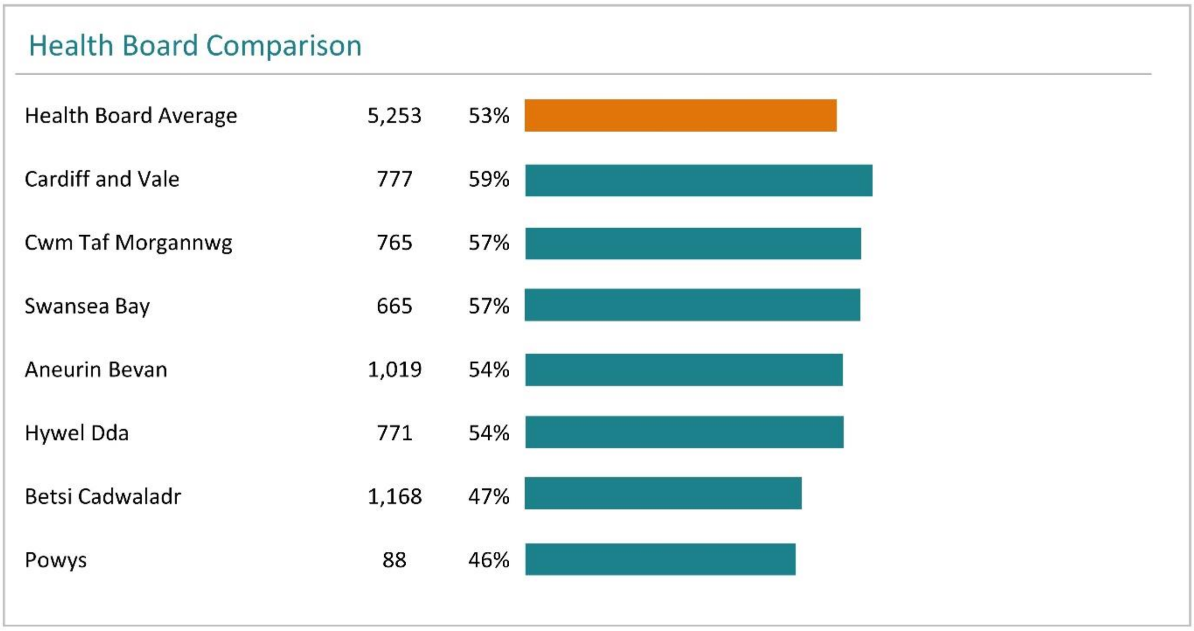


Responses for All Wales

Yes	2,842	54%
No	2,421	46%

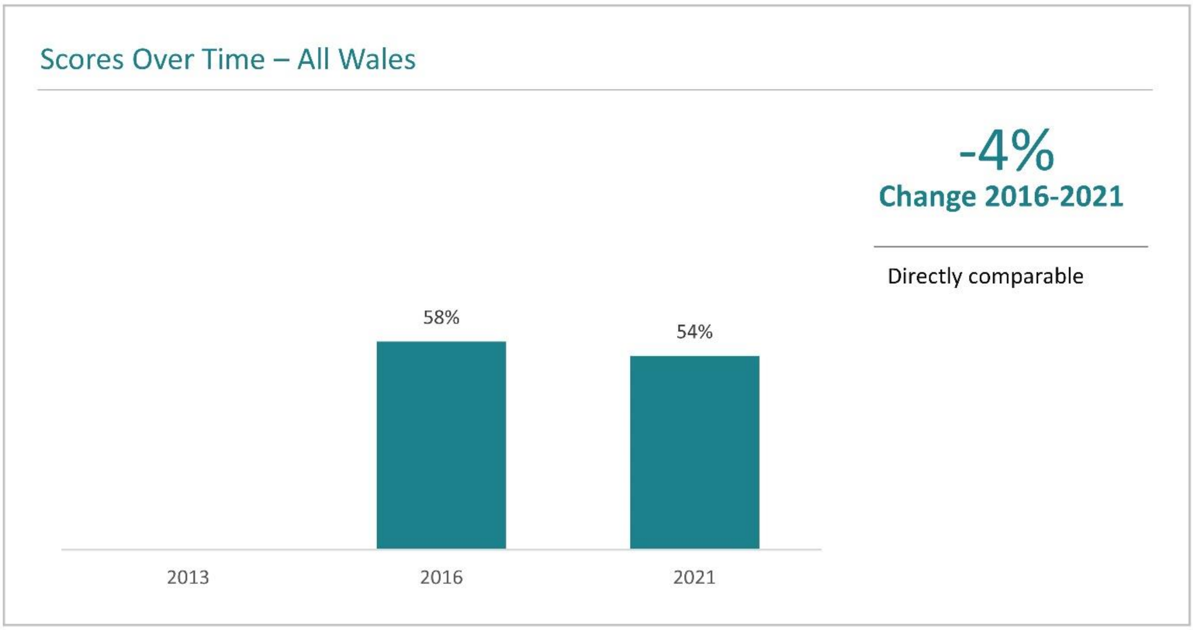
54%
of respondents were told about voluntary/charity support during their care

Results above based on 5,263 responses. Those answering, "Don’t know / can’t remember" (794) excluded from base size/percentage calculation. 6,057 responses in total.



Health Board Comparison

Health Board Average	5,253	53%
Cardiff and Vale	777	59%
Cwm Taf Morgannwg	765	57%
Swansea Bay	665	57%
Aneurin Bevan	1,019	54%
Hywel Dda	771	54%
Betsi Cadwaladr	1,168	47%
Powys	88	46%

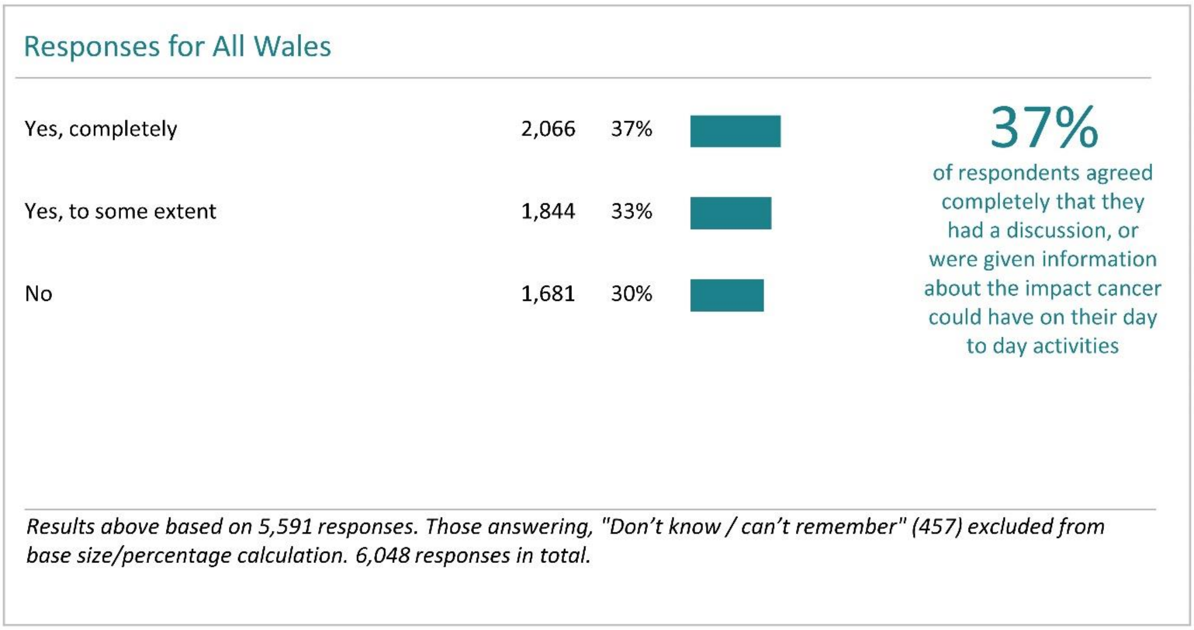


Scores Over Time – All Wales

-4%
Change 2016-2021

Directly comparable

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)?"



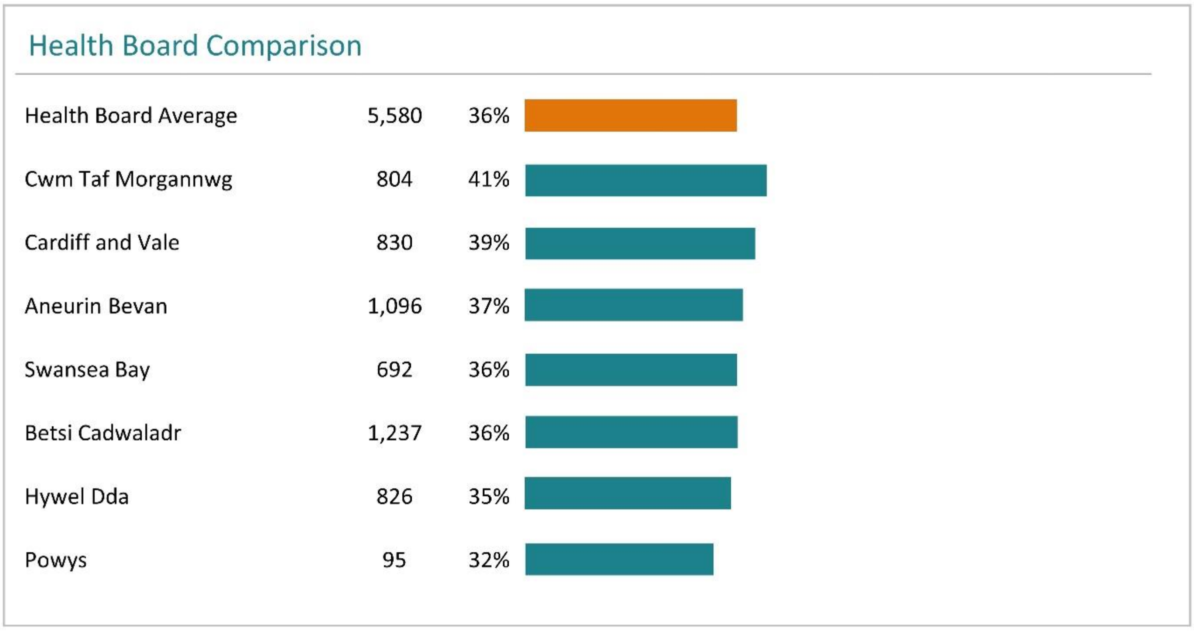
Responses for All Wales

Yes, completely	2,066	37%
Yes, to some extent	1,844	33%
No	1,681	30%

37%

of respondents agreed completely that they had a discussion, or were given information about the impact cancer could have on their day to day activities

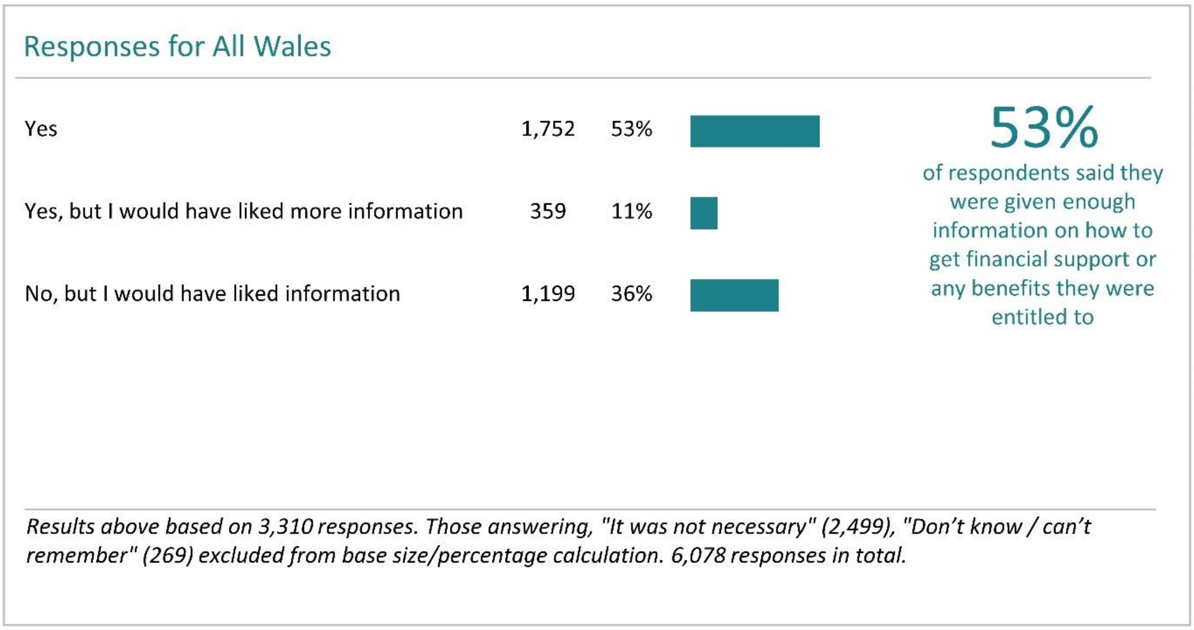
Results above based on 5,591 responses. Those answering, "Don't know / can't remember" (457) excluded from base size/percentage calculation. 6,048 responses in total.



Health Board Comparison

Health Board Average	5,580	36%
Cwm Taf Morgannwg	804	41%
Cardiff and Vale	830	39%
Aneurin Bevan	1,096	37%
Swansea Bay	692	36%
Betsi Cadwaladr	1,237	36%
Hywel Dda	826	35%
Powys	95	32%

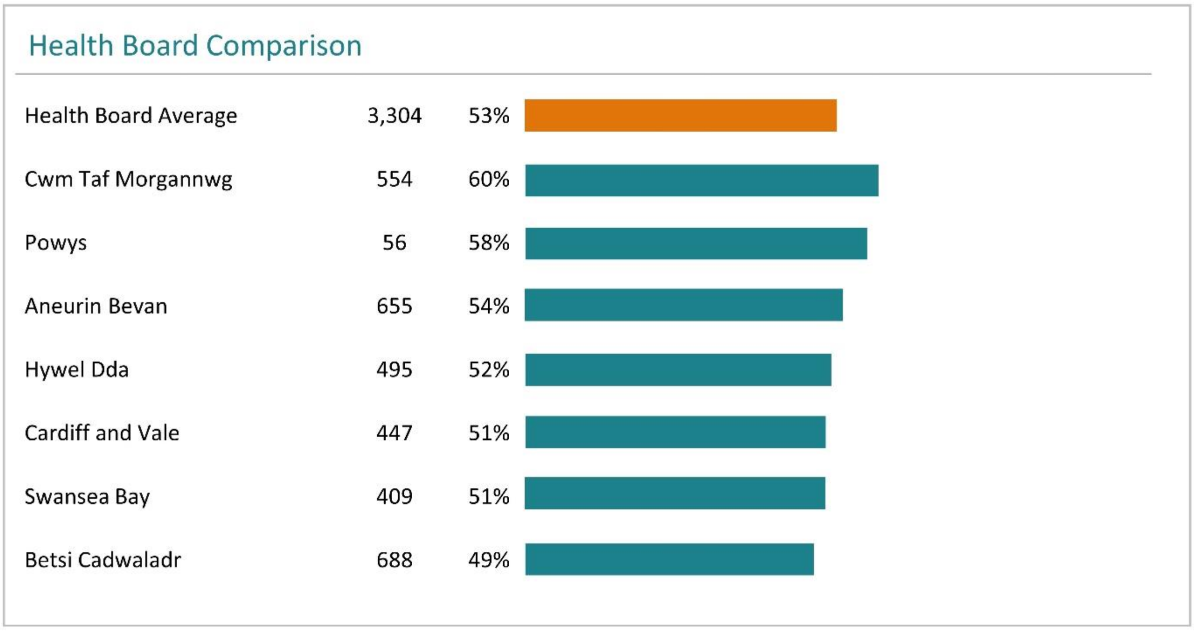
Question 30: "Did your healthcare team give you information about how to get financial help or any benefits you might be entitled to?”



Results above based on 3,310 responses. Those answering, "It was not necessary" (2,499), "Don’t know / can’t remember" (269) excluded from base size/percentage calculation. 6,078 responses in total.

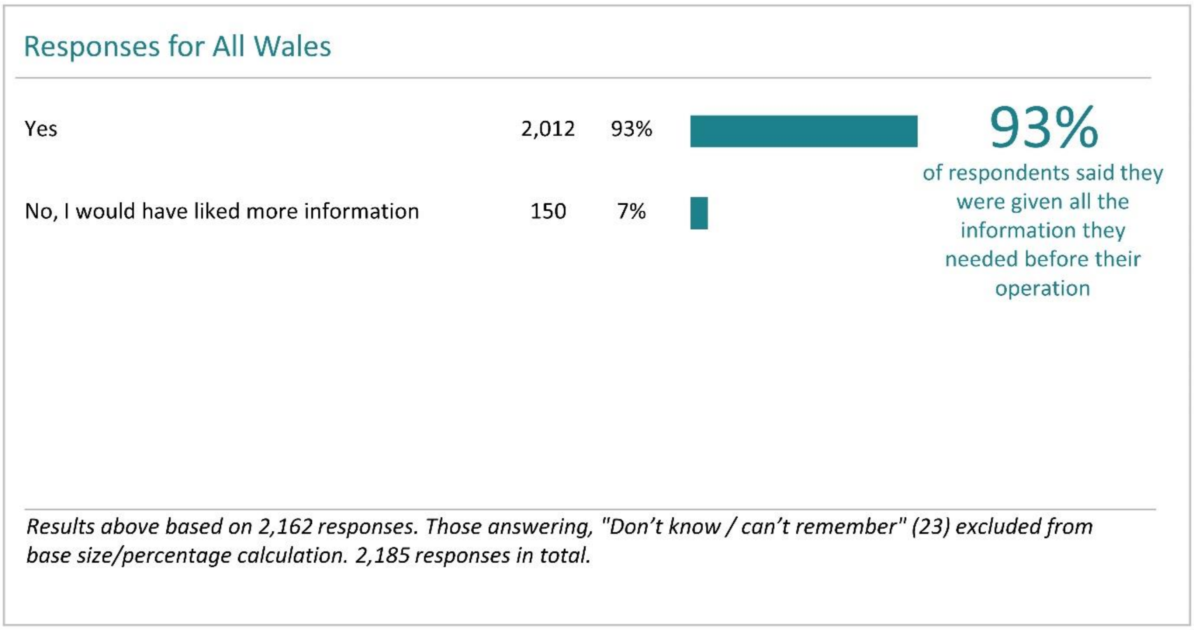
Survey respondent:

“More information about any possible financial care and support. Unable to carry out daily chores and now have to employ help.”



8.6 Operations

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



Responses for All Wales

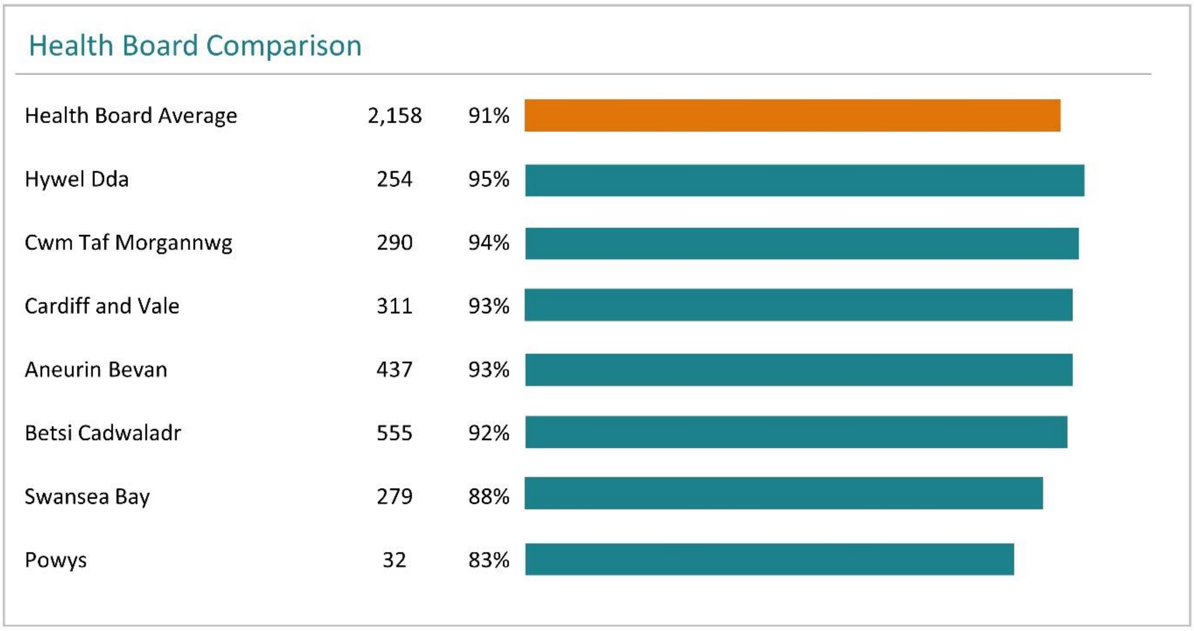
Yes	2,012	93%	
No, I would have liked more information	150	7%	

93%
of respondents said they were given all the information they needed before their operation

Results above based on 2,162 responses. Those answering, "Don’t know / can’t remember" (23) excluded from base size/percentage calculation. 2,185 responses in total.

Survey respondent:

“My surgeon took time to explain things well and answered my questions. He was always kind and clear when conveying information.”



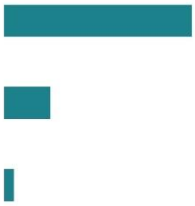
Health Board Comparison

Health Board Average	2,158	91%
Hywel Dda	254	95%
Cwm Taf Morgannwg	290	94%
Cardiff and Vale	311	93%
Aneurin Bevan	437	93%
Betsi Cadwaladr	555	92%
Swansea Bay	279	88%
Powys	32	83%

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

Responses for All Wales

Yes, completely	1,648	77%
Yes, to some extent	409	19%
No, but I would have liked an explanation	91	4%



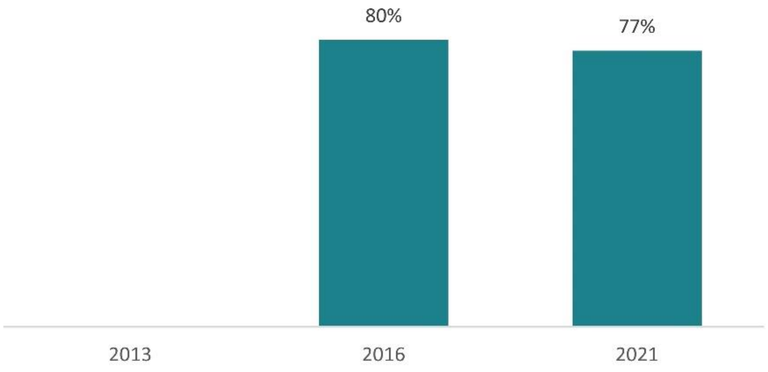
77%
of respondents said a member of staff explained how the operation had gone in a way they could completely understand

Results above based on 2,148 responses. Those answering, "I did not need an explanation" (27) excluded from base size/percentage calculation. 2,175 responses in total.

Health Board Comparison

Health Board Average	2,144	77%
Cardiff and Vale	307	80%
Swansea Bay	278	79%
Aneurin Bevan	434	78%
Cwm Taf Morgannwg	287	78%
Powys	32	75%
Hywel Dda	257	74%
Betsi Cadwaladr	549	73%

Scores Over Time – All Wales

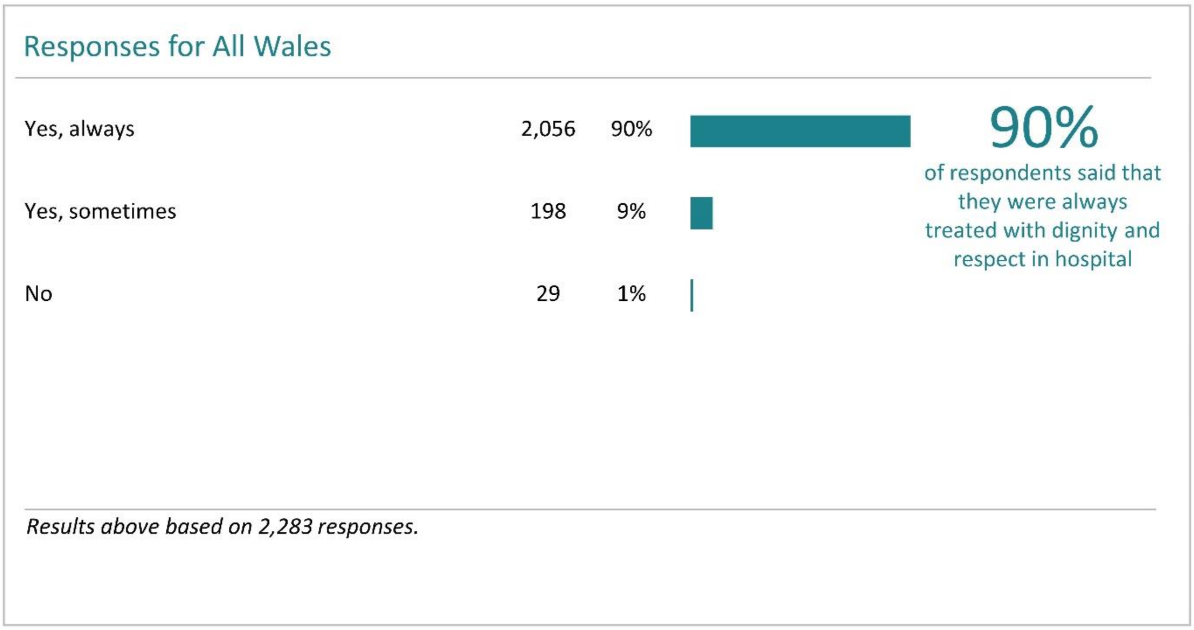


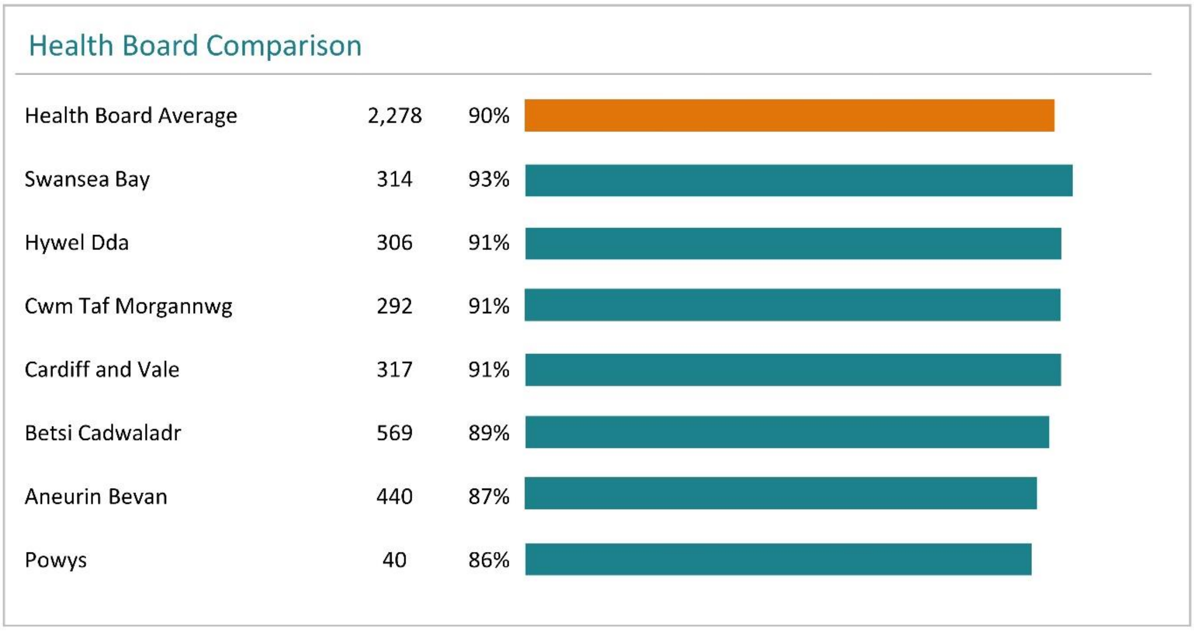
-3%
Change 2016-2021

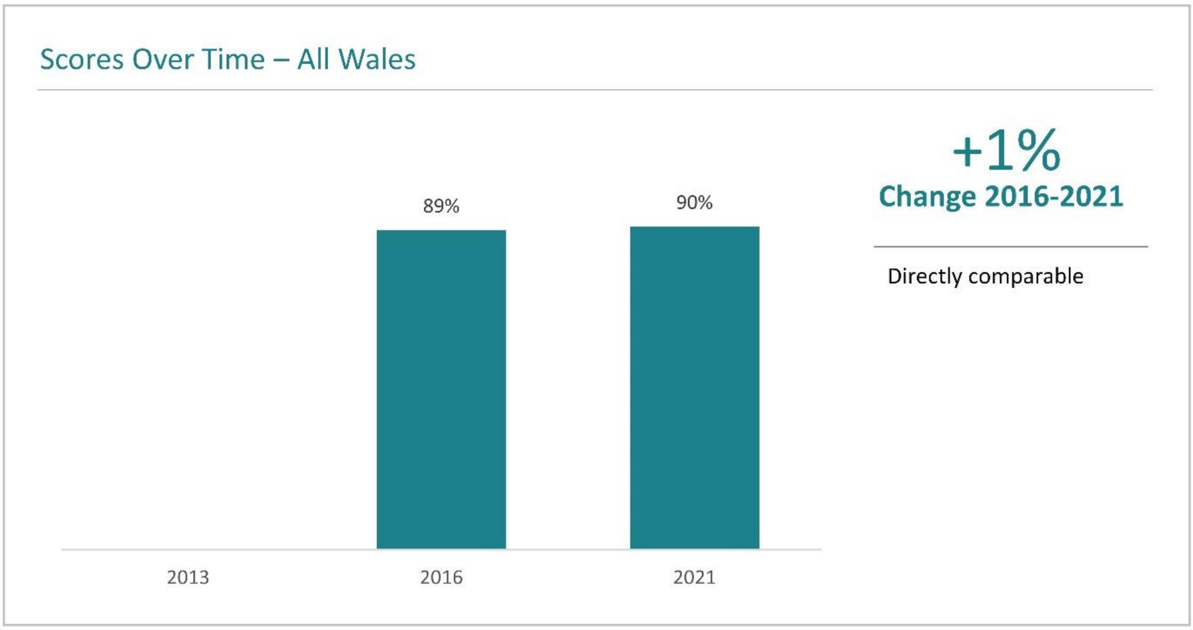
Directly comparable

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?”

Responses for All Wales

As much as I wanted	1,347	65%
Most of the time	358	17%
Some of the time	242	12%
Not at all, but would have liked to	139	7%

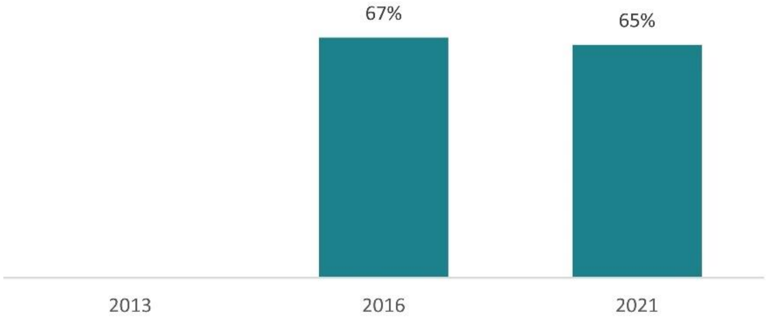
65%
of respondents were able to discuss any worries or fears they had, as much as they wanted with staff

Results above based on 2,086 responses. Those answering, "I did not have any worries or fears" (183) excluded from base size/percentage calculation. 2,269 responses in total.

Health Board Comparison

Health Board Average	2,081	64%
Cardiff and Vale	286	67%
Cwm Taf Morgannwg	264	67%
Aneurin Bevan	403	67%
Hywel Dda	289	66%
Swansea Bay	285	64%
Betsi Cadwaladr	519	61%
Powys	35	55%

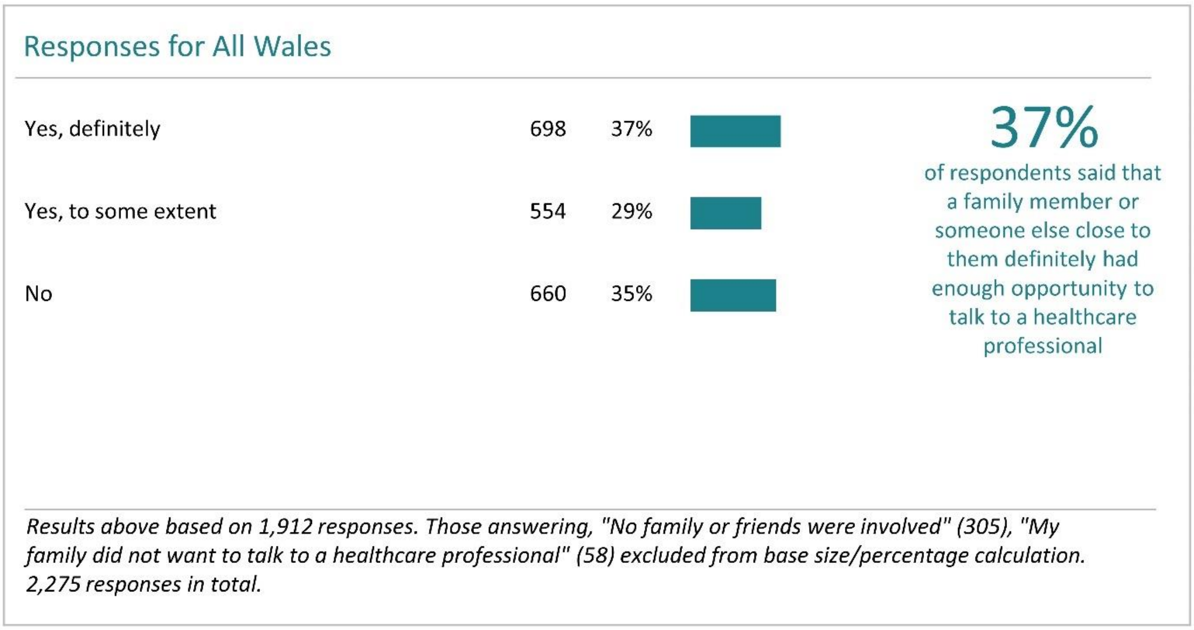
Scores Over Time – All Wales



-3%
Change 2016-2021

Directly comparable

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



Responses for All Wales

Yes, definitely	698	37%	🟦
Yes, to some extent	554	29%	🟦
No	660	35%	🟦

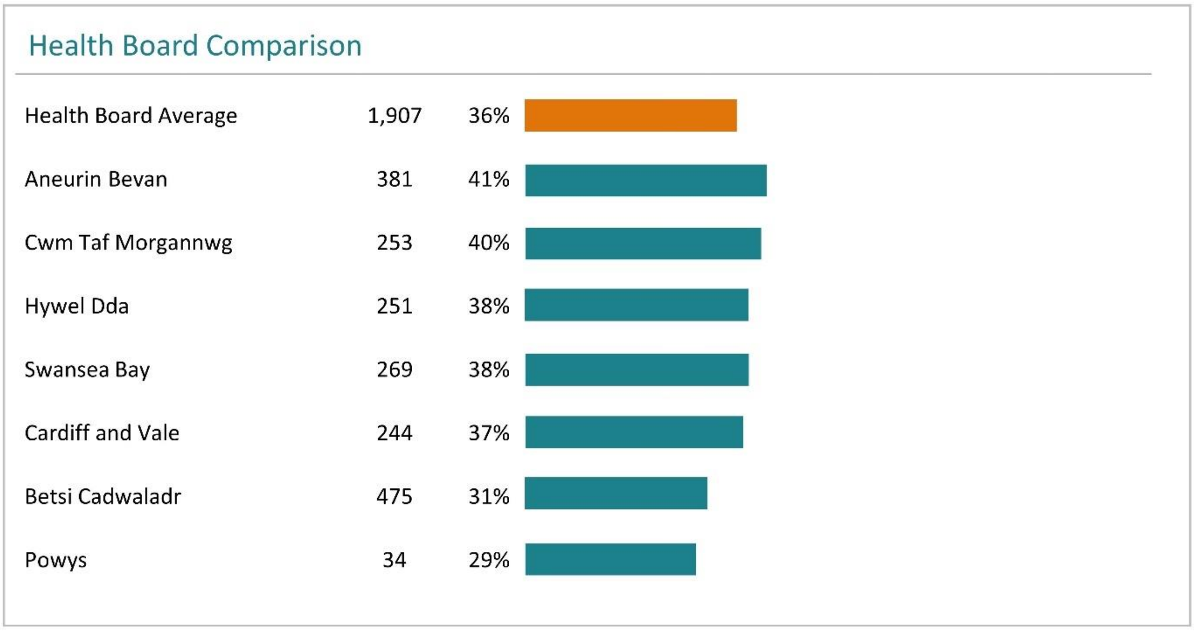
37%

of respondents said that a family member or someone else close to them definitely had enough opportunity to talk to a healthcare professional

Results above based on 1,912 responses. Those answering, "No family or friends were involved" (305), "My family did not want to talk to a healthcare professional" (58) excluded from base size/percentage calculation. 2,275 responses in total.

Survey respondent:

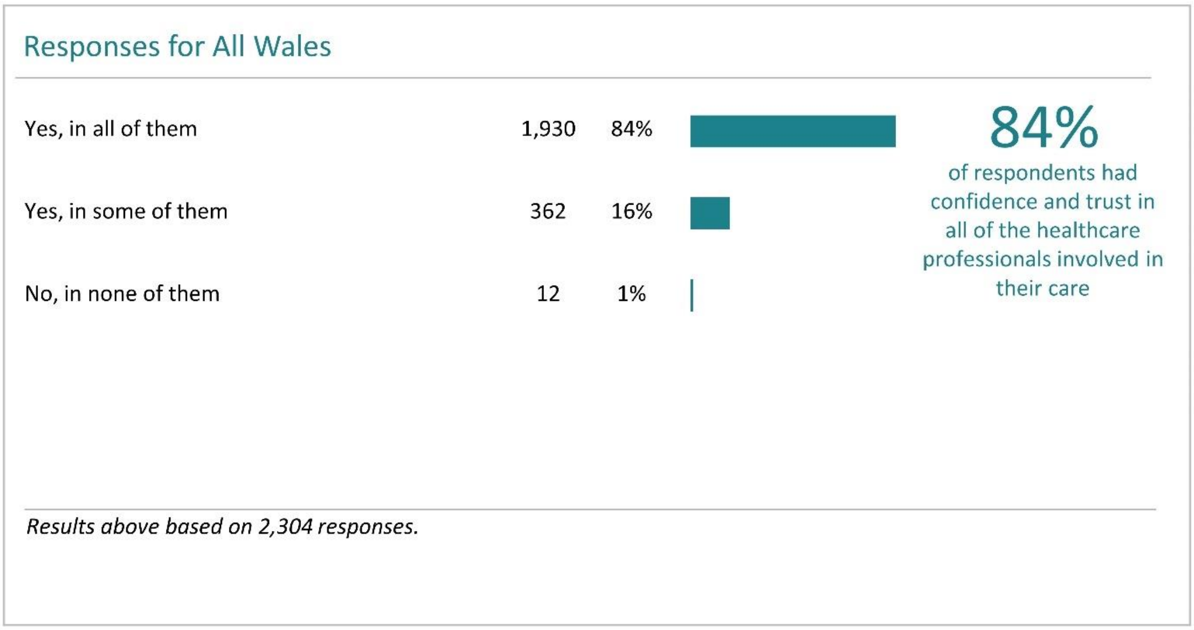
"The surgeon, who actually performed the operation, rang my [family member] and spent time with him for about half an hour, explaining how everything had gone."



Health Board Comparison

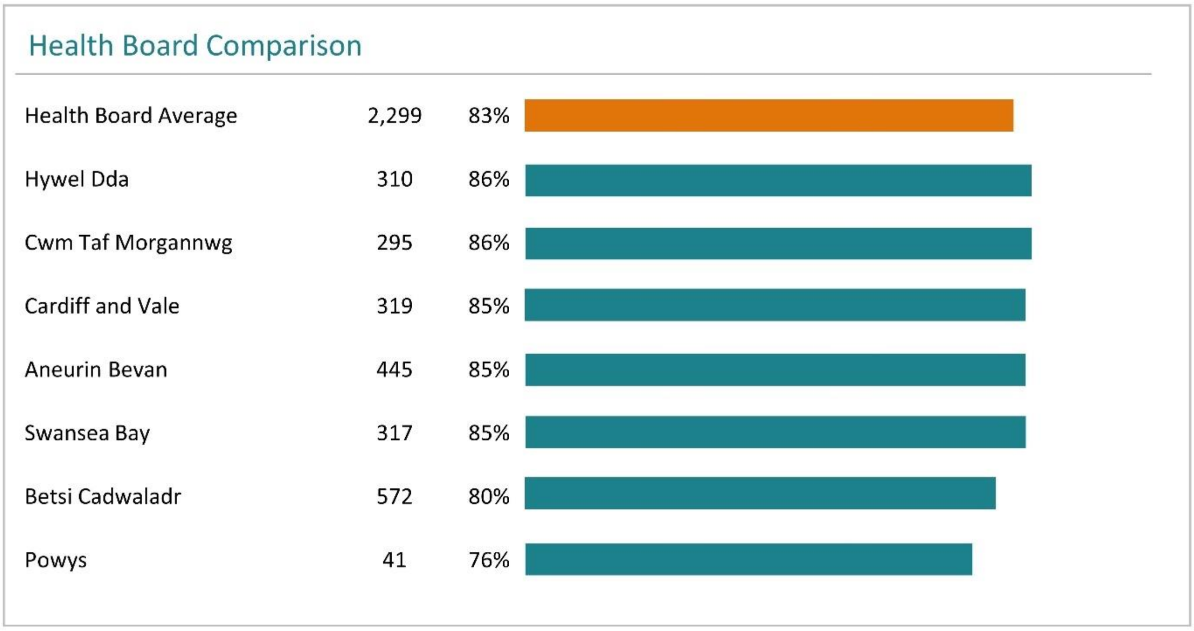
Health Board Average	1,907	36%
Aneurin Bevan	381	41%
Cwm Taf Morgannwg	253	40%
Hywel Dda	251	38%
Swansea Bay	269	38%
Cardiff and Vale	244	37%
Betsi Cadwaladr	475	31%
Powys	34	29%

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

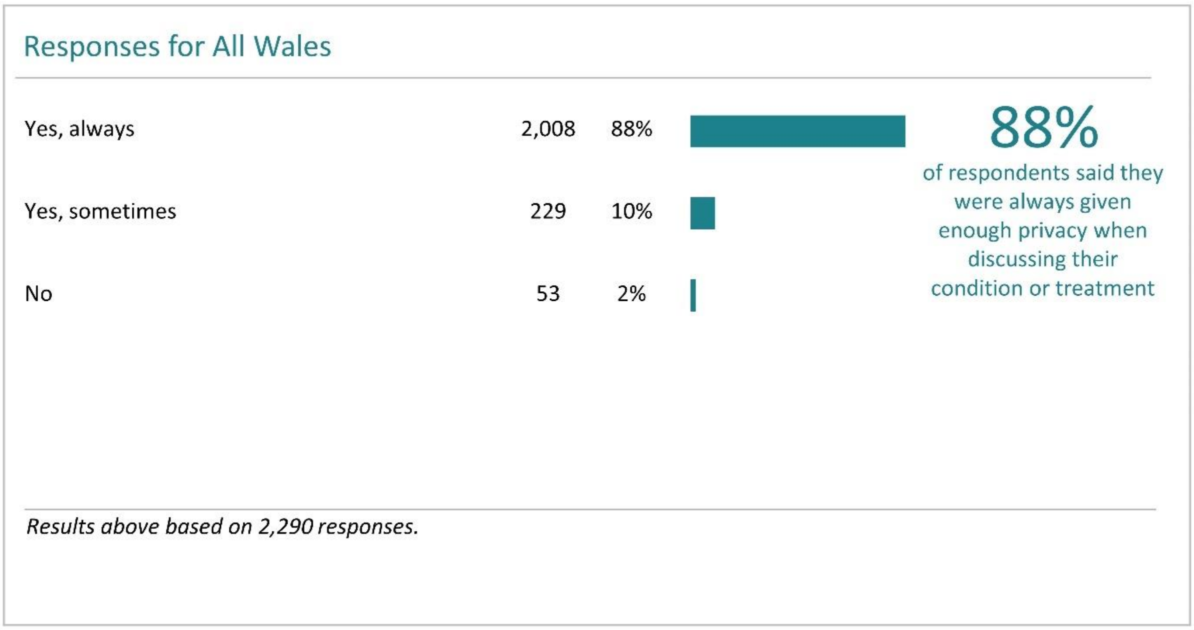


Survey respondent:

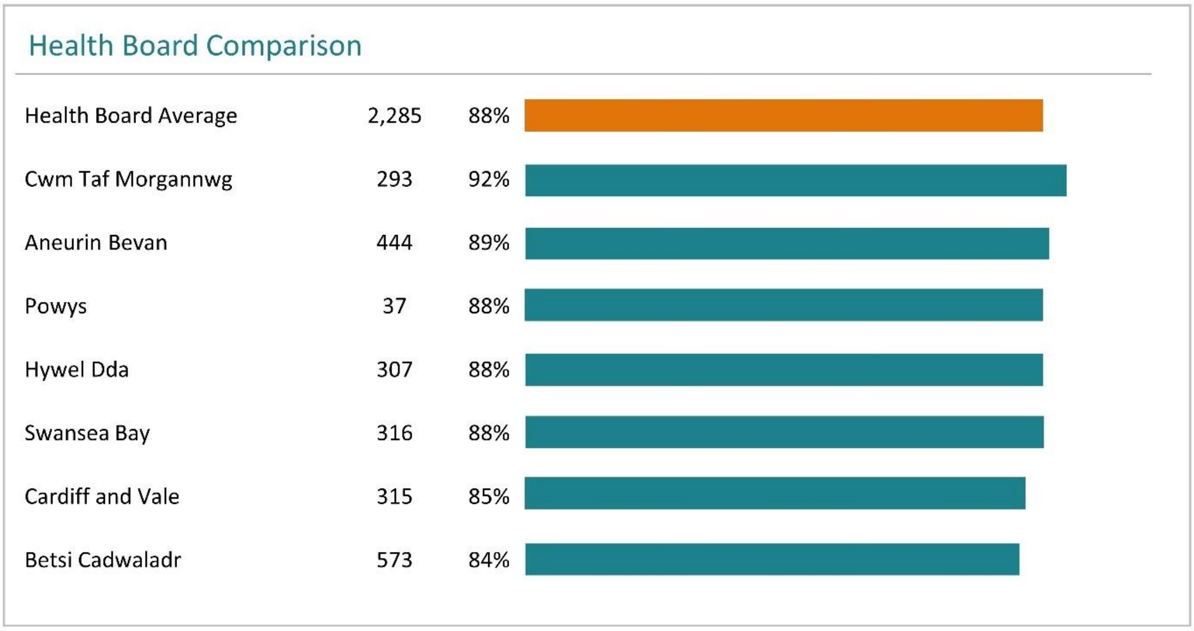
“Just would like to thank the NHS staff. I had complete trust in them.”

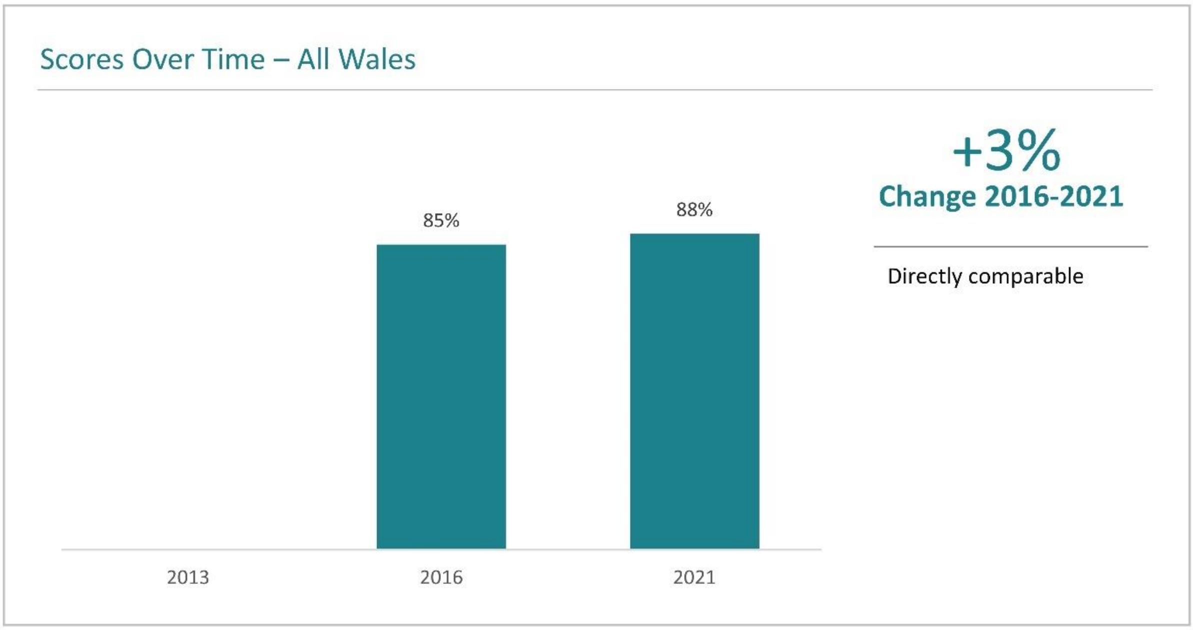


Question 39: "Were you given enough privacy when discussing your condition or treatment?”


Responses for All Wales

Results above based on 2,290 responses.

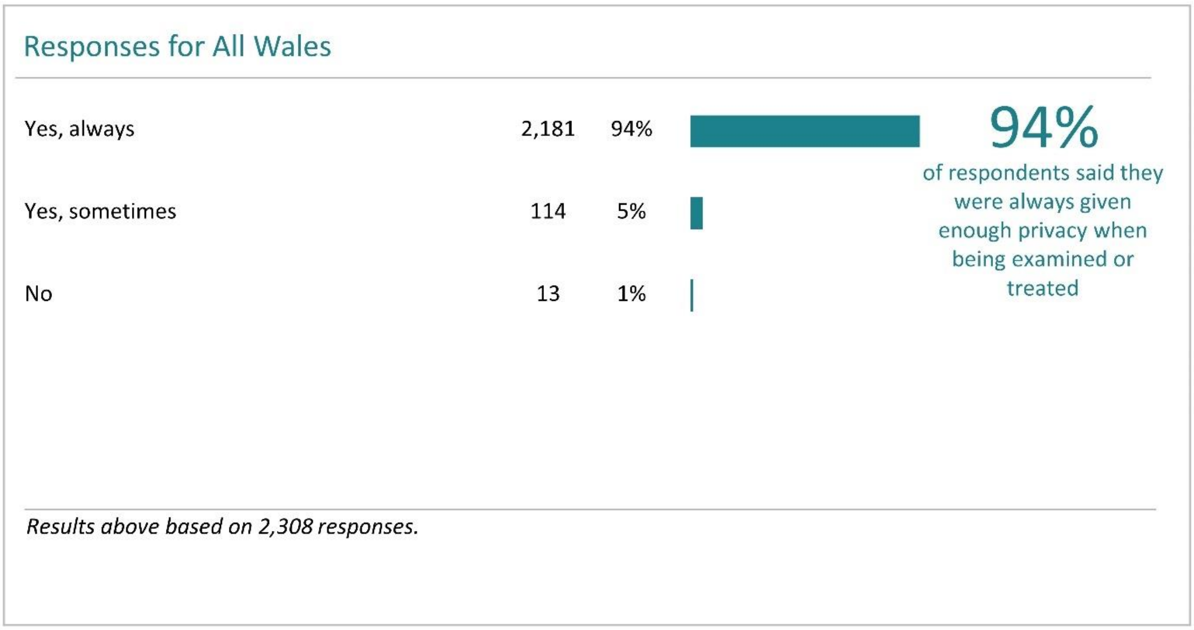

Health Board Comparison

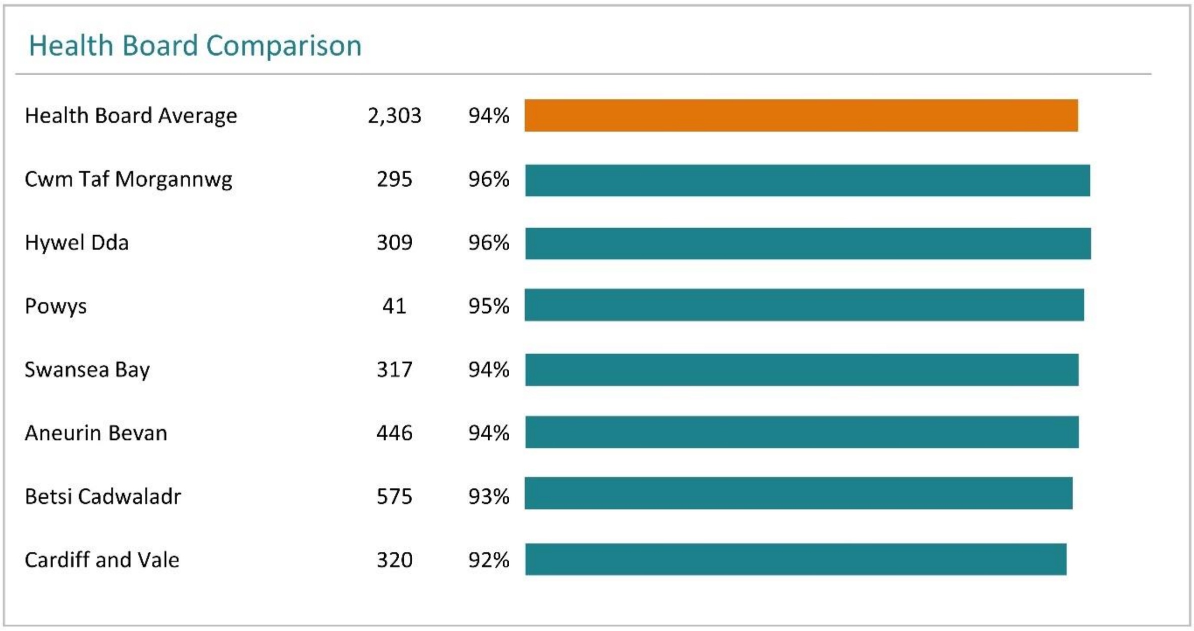

Scores Over Time – All Wales

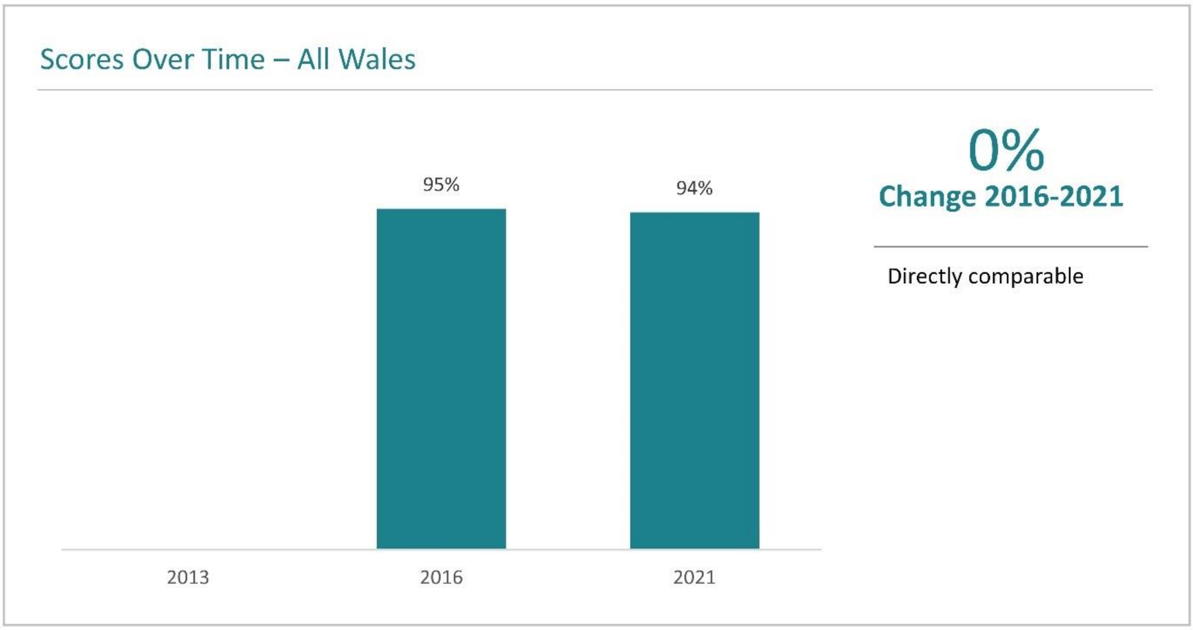
+3%
Change 2016-2021

Directly comparable

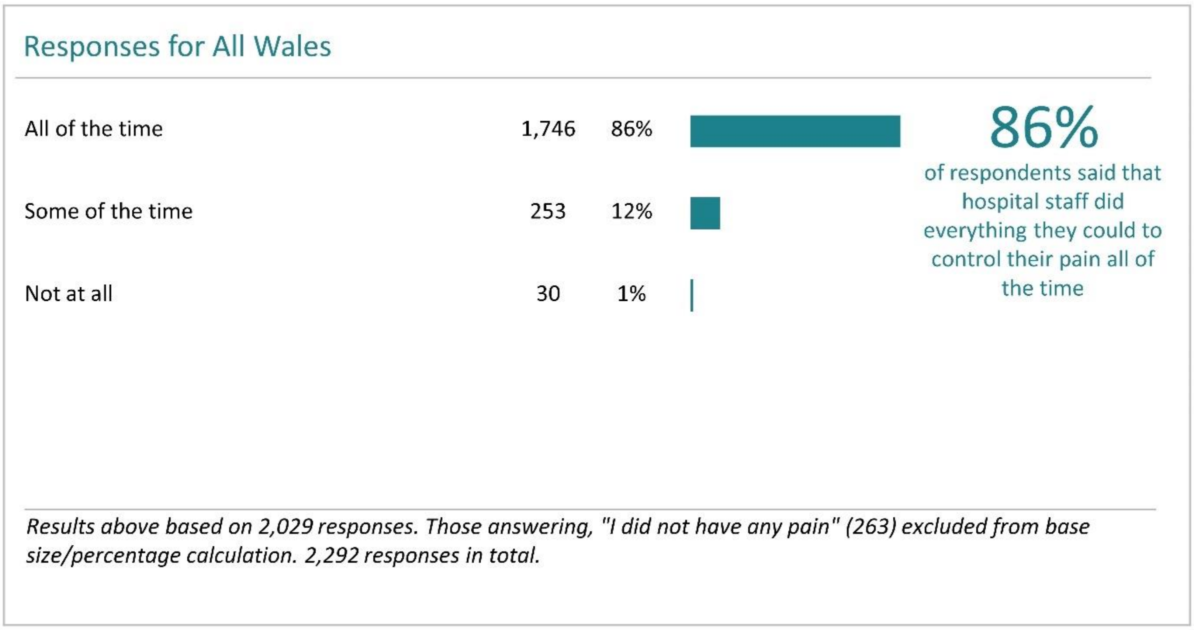
Question 40: "Were you given enough privacy when being examined or treated?”







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

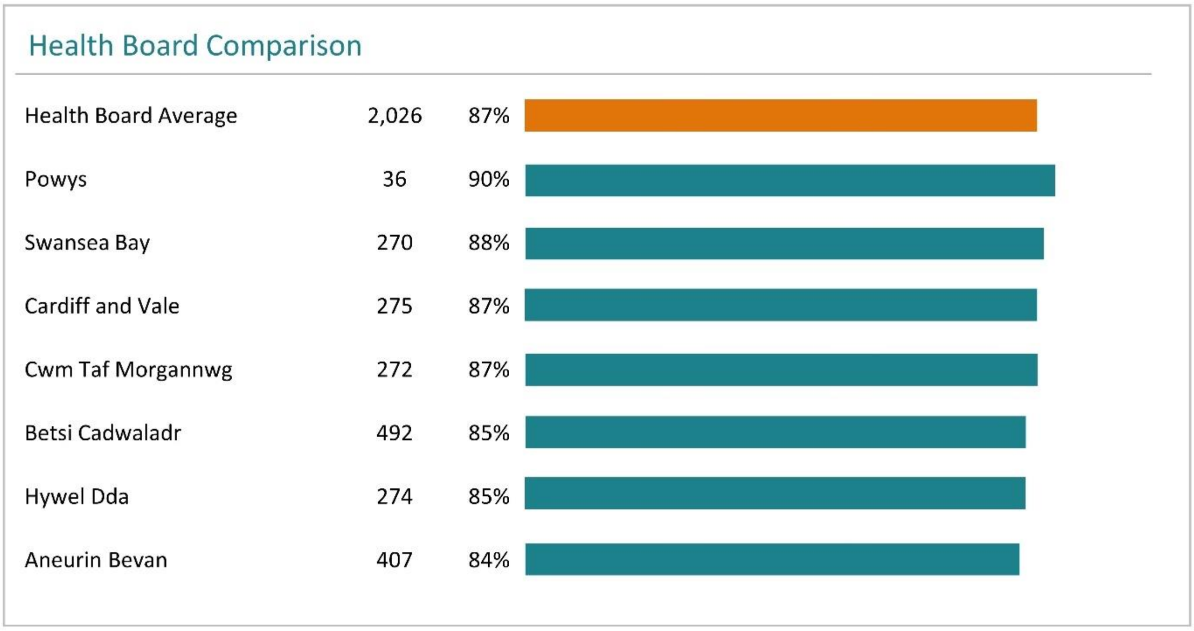


Responses for All Wales

All of the time	1,746	86%
Some of the time	253	12%
Not at all	30	1%

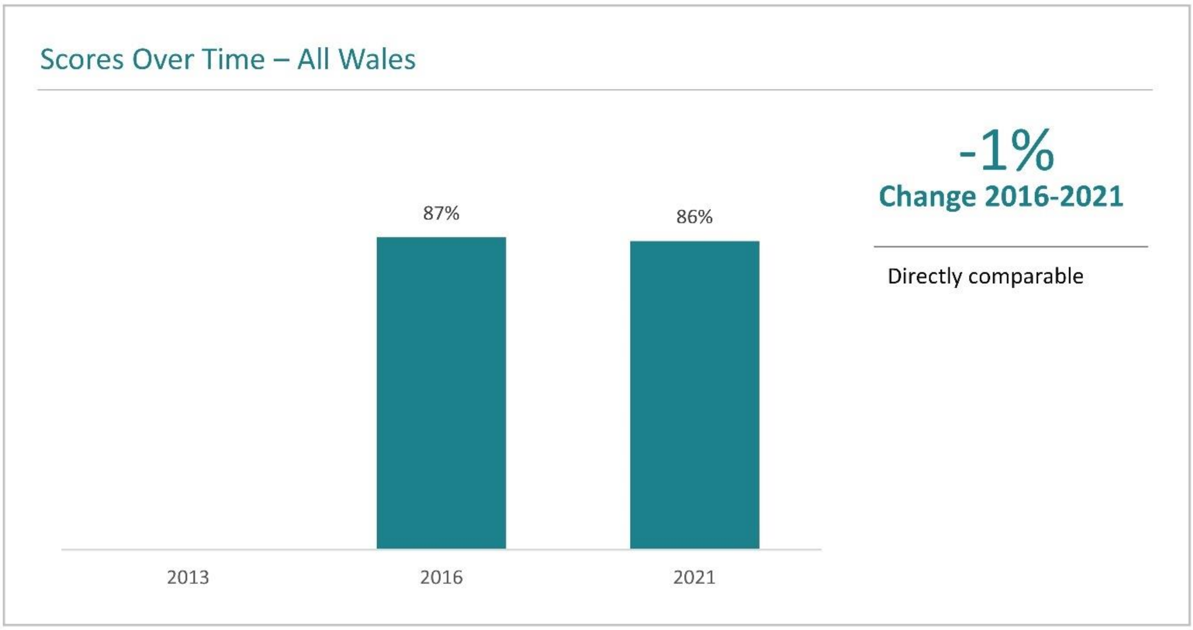
86%
of respondents said that hospital staff did everything they could to control their pain all of the time

Results above based on 2,029 responses. Those answering, "I did not have any pain" (263) excluded from base size/percentage calculation. 2,292 responses in total.



Health Board Comparison

Health Board Average	2,026	87%
Powys	36	90%
Swansea Bay	270	88%
Cardiff and Vale	275	87%
Cwm Taf Morgannwg	272	87%
Betsi Cadwaladr	492	85%
Hywel Dda	274	85%
Aneurin Bevan	407	84%

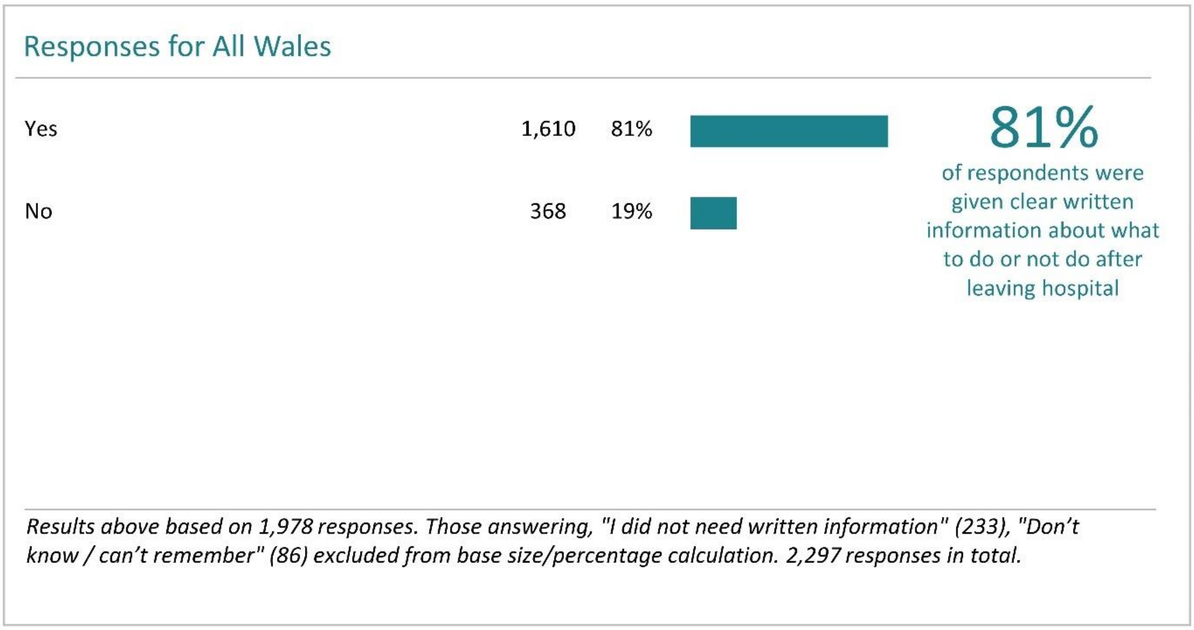


Scores Over Time – All Wales

-1%
Change 2016-2021

Directly comparable

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

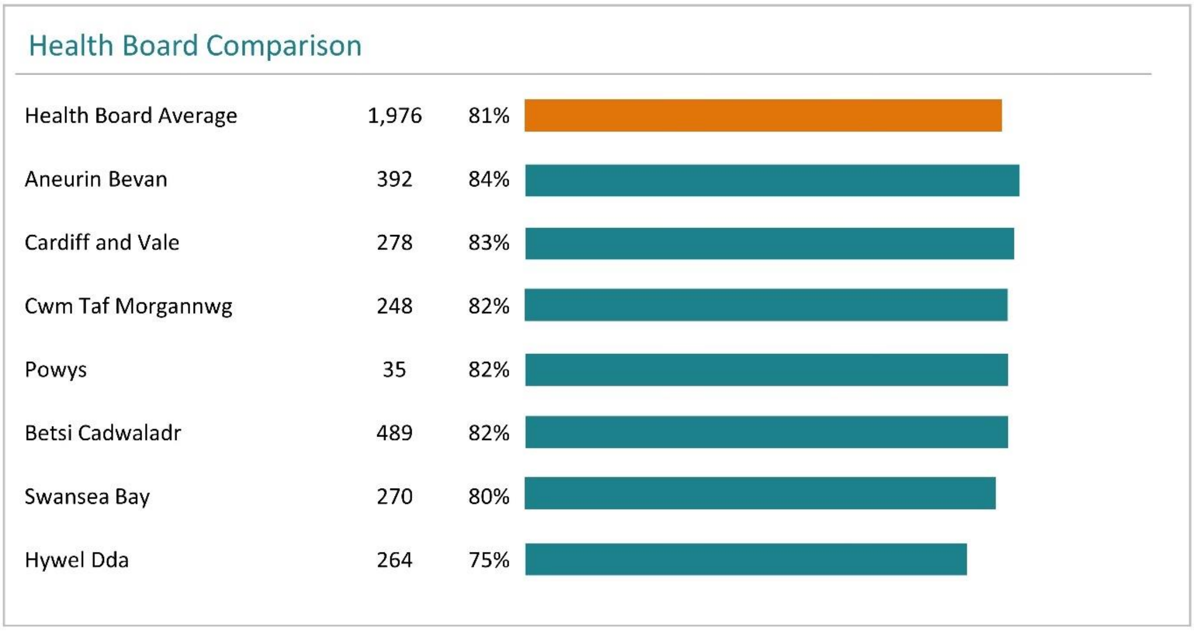


Responses for All Wales

Yes	1,610	81%
No	368	19%

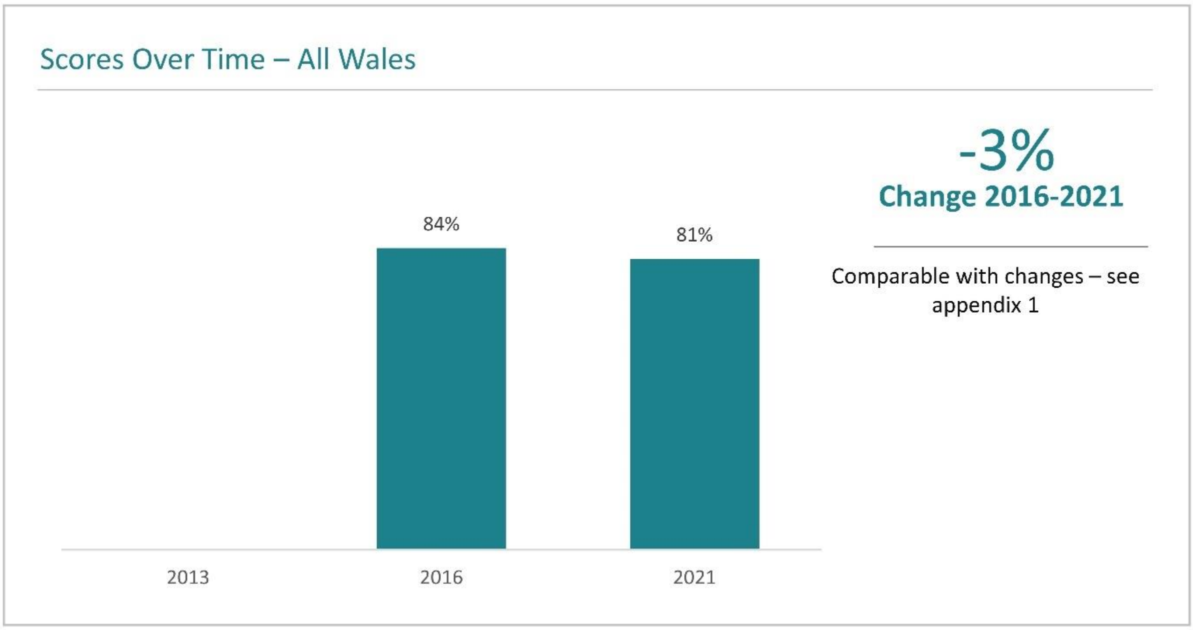
81%
of respondents were given clear written information about what to do or not do after leaving hospital

Results above based on 1,978 responses. Those answering, "I did not need written information" (233), "Don't know / can't remember" (86) excluded from base size/percentage calculation. 2,297 responses in total.



Health Board Comparison

Health Board Average	1,976	81%
Aneurin Bevan	392	84%
Cardiff and Vale	278	83%
Cwm Taf Morgannwg	248	82%
Powys	35	82%
Betsi Cadwaladr	489	82%
Swansea Bay	270	80%
Hywel Dda	264	75%



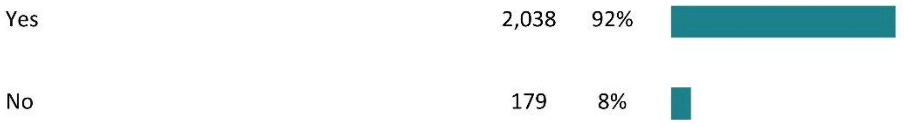
Scores Over Time – All Wales

-3%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for All Wales

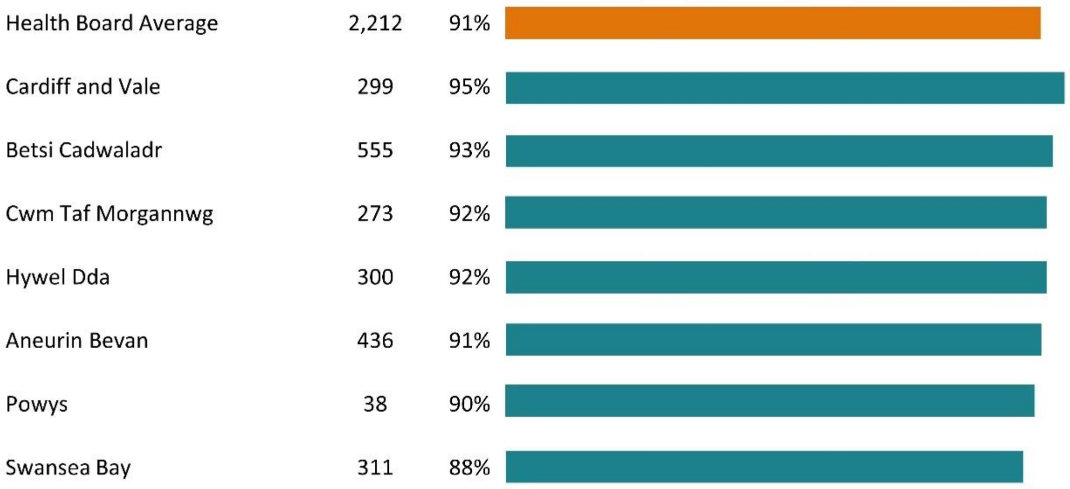


92%

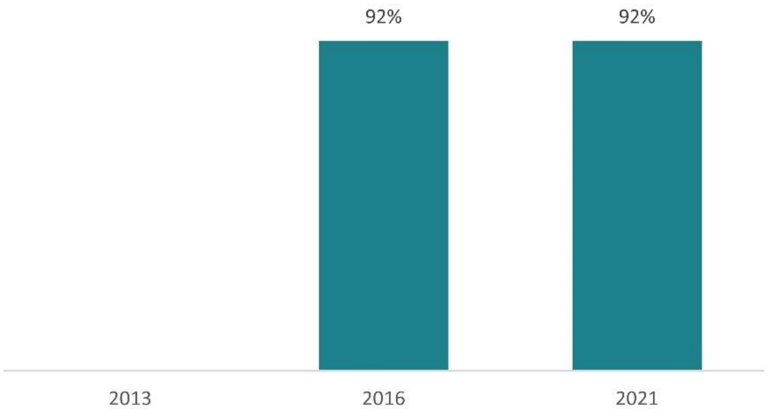
of respondents were told by hospital staff who to contact if worried after leaving hospital

Results above based on 2,217 responses. Those answering, "Don’t know / can’t remember" (99) excluded from base size/percentage calculation. 2,316 responses in total.

Health Board Comparison



Scores Over Time – All Wales



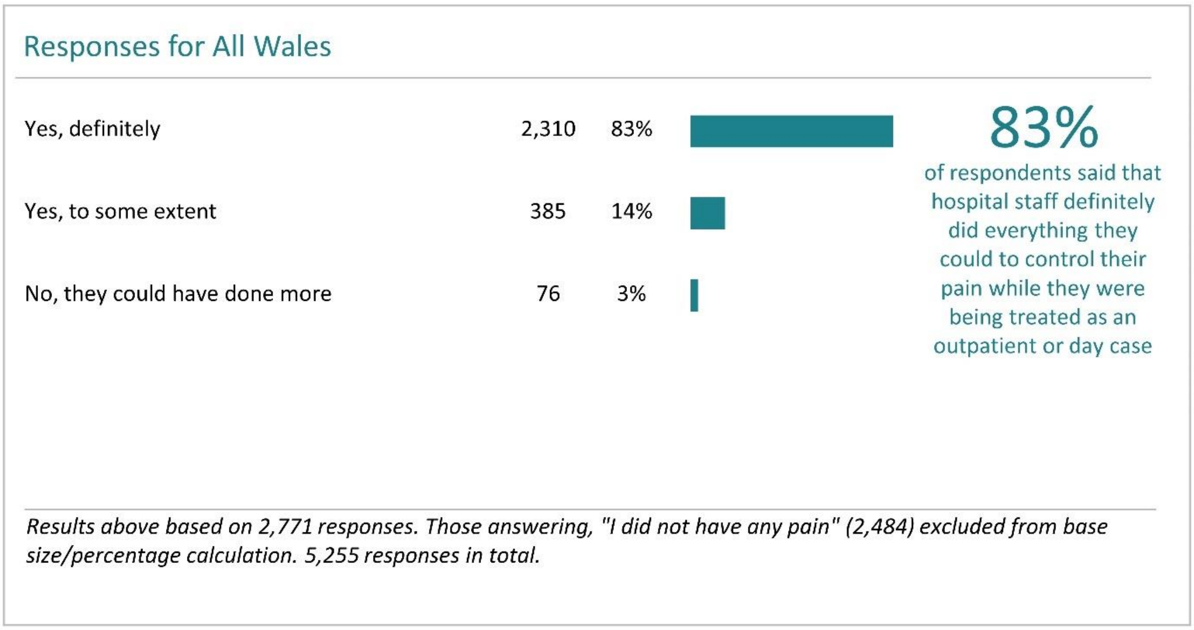
0%

Change 2016-2021

Directly comparable

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?”

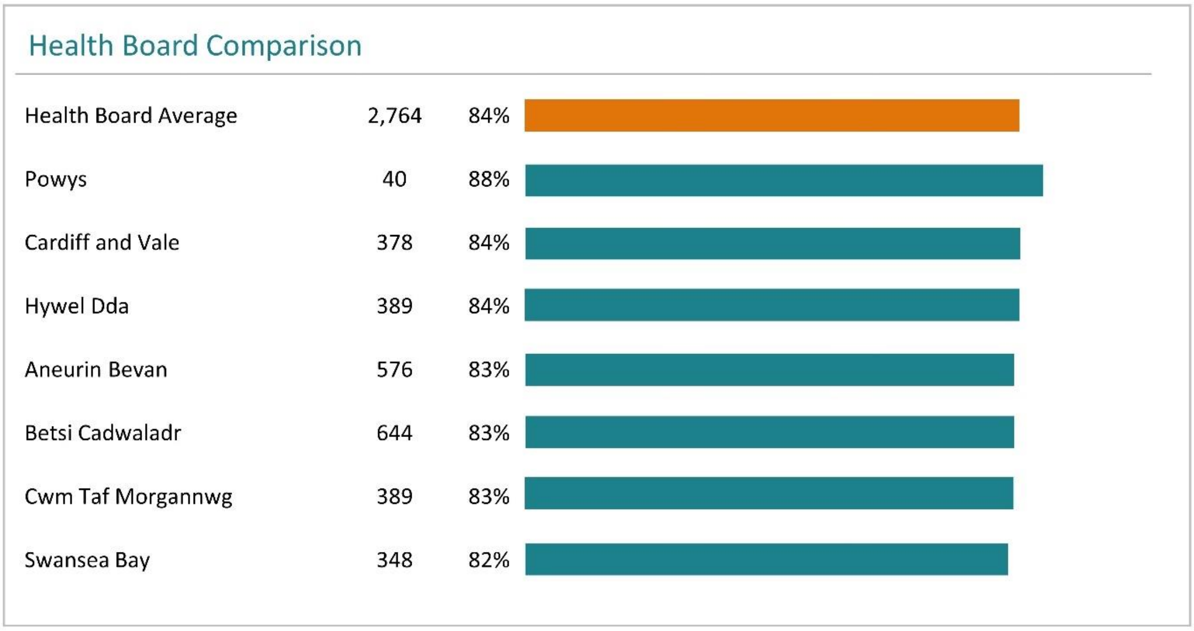


Responses for All Wales

Yes, definitely	2,310	83%	
Yes, to some extent	385	14%	
No, they could have done more	76	3%	

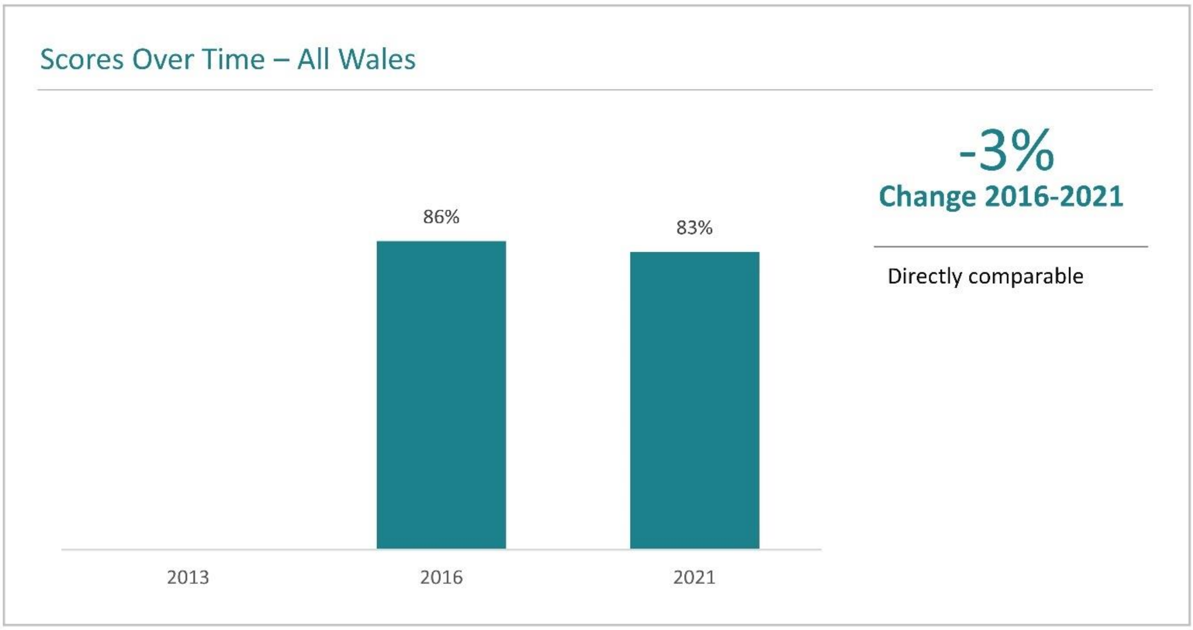
83%
of respondents said that hospital staff definitely did everything they could to control their pain while they were being treated as an outpatient or day case

Results above based on 2,771 responses. Those answering, "I did not have any pain" (2,484) excluded from base size/percentage calculation. 5,255 responses in total.



Health Board Comparison

Health Board Average	2,764	84%
Powys	40	88%
Cardiff and Vale	378	84%
Hywel Dda	389	84%
Aneurin Bevan	576	83%
Betsi Cadwaladr	644	83%
Cwm Taf Morgannwg	389	83%
Swansea Bay	348	82%

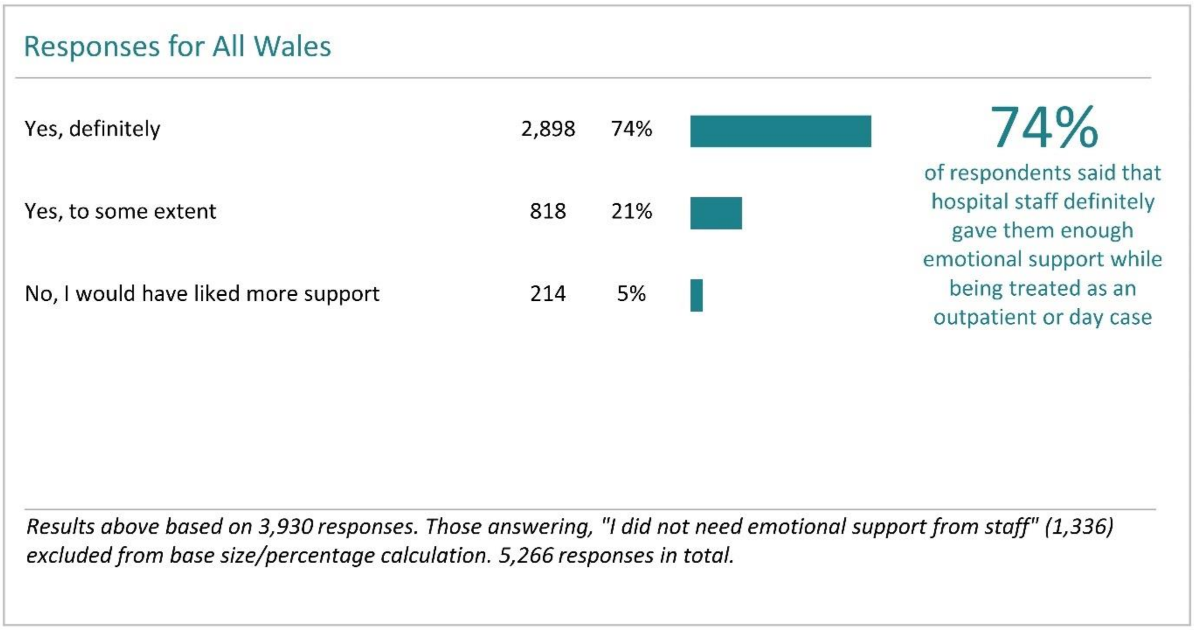


Scores Over Time – All Wales

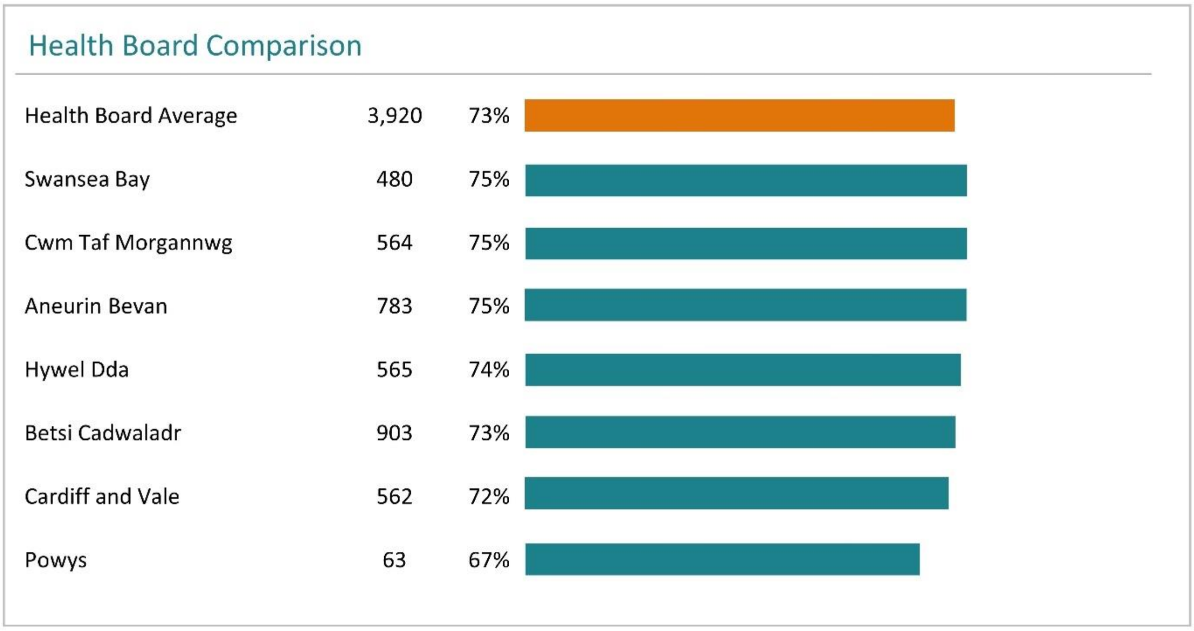
-3%
Change 2016-2021

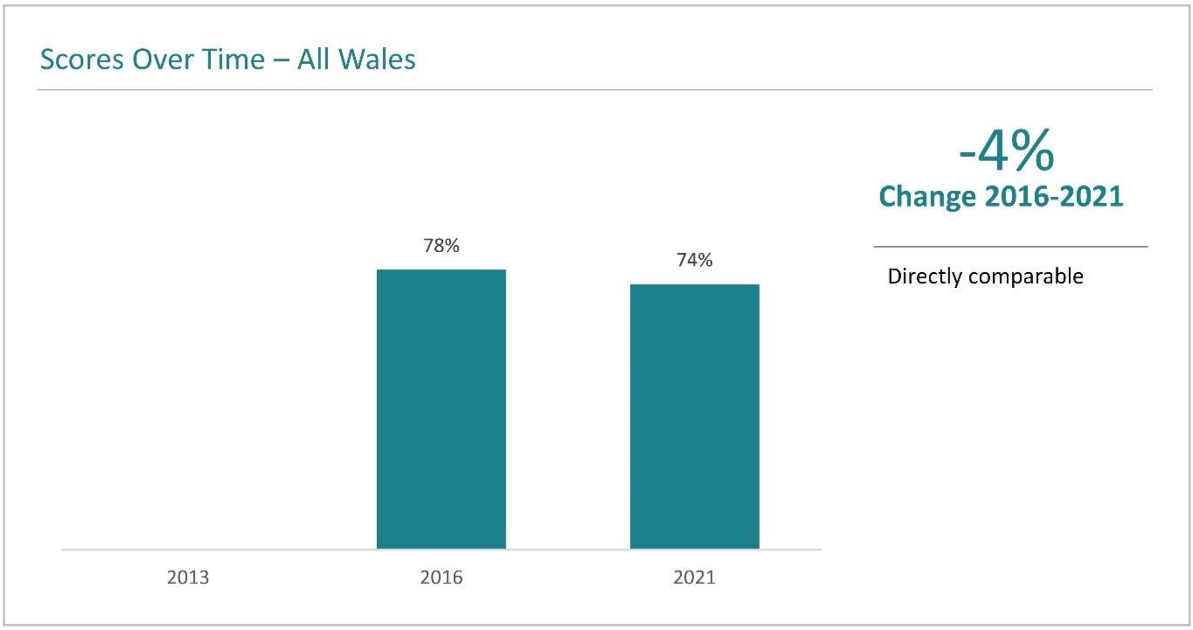
Directly comparable

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



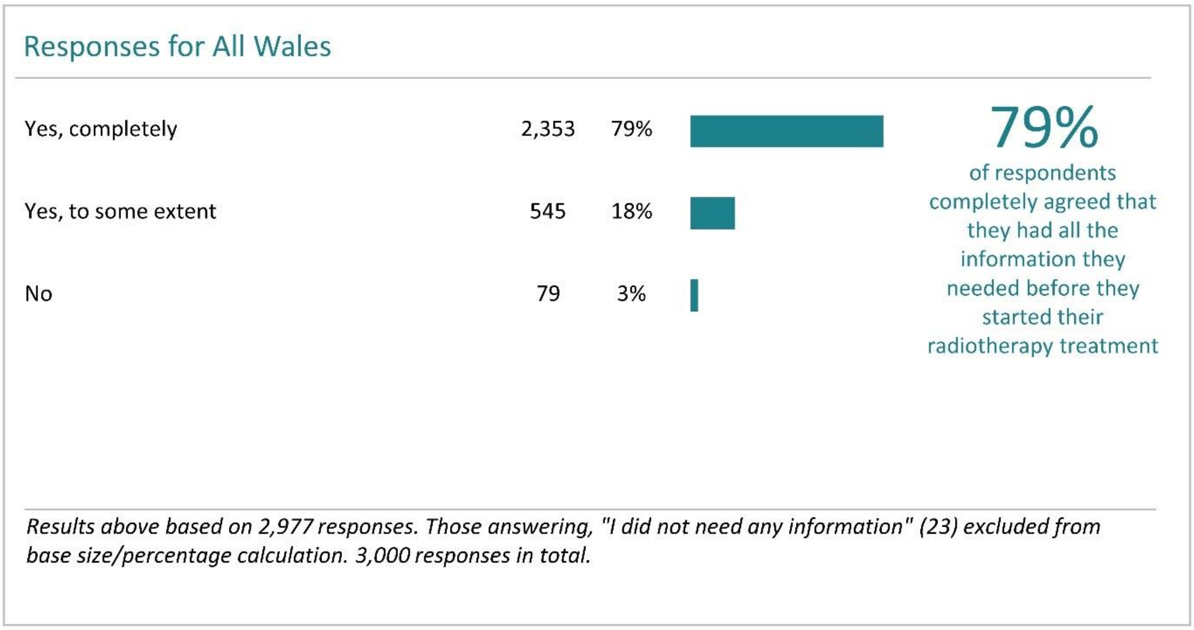
Results above based on 3,930 responses. Those answering, "I did not need emotional support from staff" (1,336) excluded from base size/percentage calculation. 5,266 responses in total.





8.9 Radiotherapy / chemotherapy

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

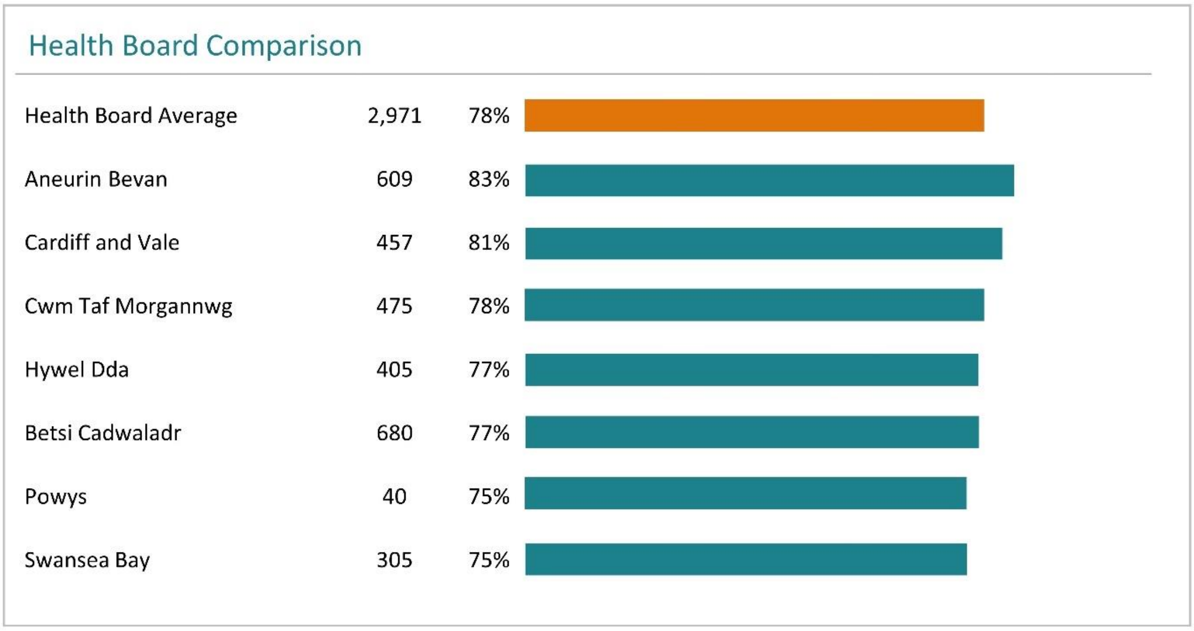


79% of respondents completely agreed that they had all the information they needed before they started their radiotherapy treatment

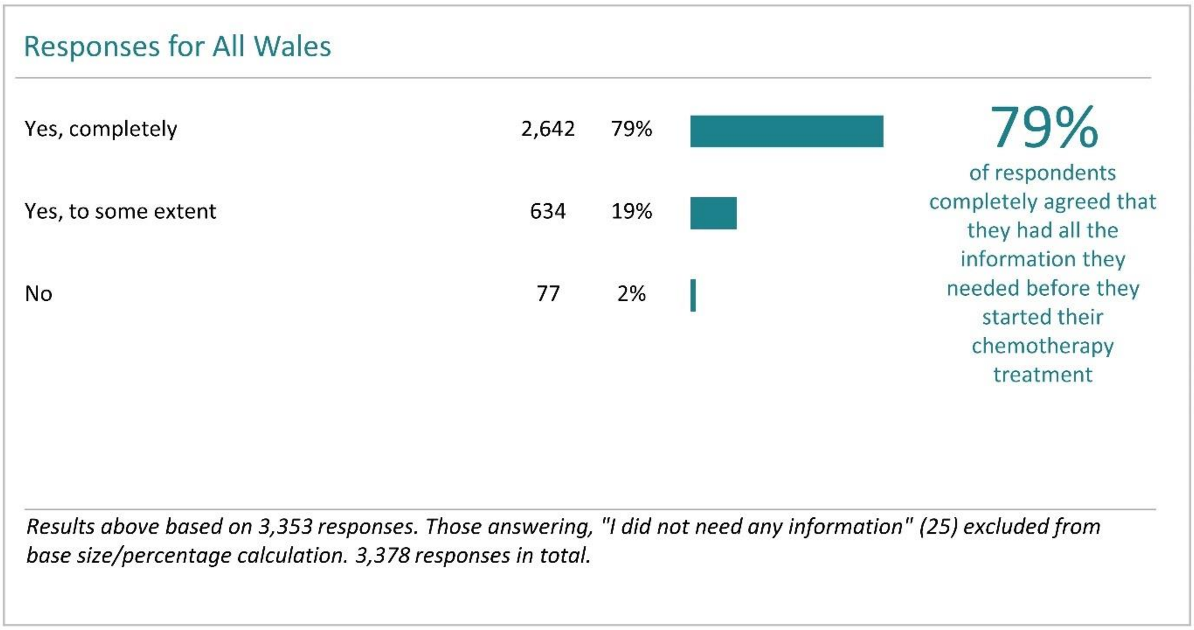
Results above based on 2,977 responses. Those answering, "I did not need any information" (23) excluded from base size/percentage calculation. 3,000 responses in total.

Survey respondent:

“I thought that all the staff who dealt with me from diagnosis to surgery, outpatient care, radiotherapy and follow up have all been very professional, helpful and caring. I received prompt treatment and was given full and helpful information and support at every stage.”



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



Responses for All Wales

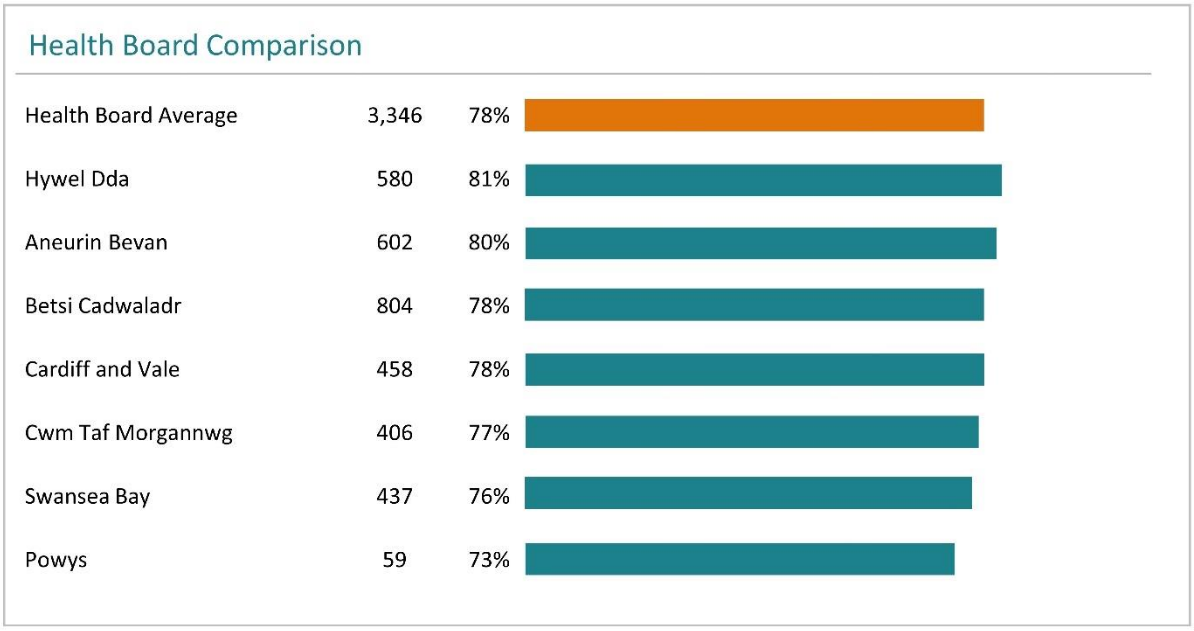
Yes, completely	2,642	79%
Yes, to some extent	634	19%
No	77	2%

79% of respondents completely agreed that they had all the information they needed before they started their chemotherapy treatment

Results above based on 3,353 responses. Those answering, "I did not need any information" (25) excluded from base size/percentage calculation. 3,378 responses in total.

Survey respondent:

"Good information on the 3 weekly oncology call pre-chemotherapy. Excellent support when calling the number on the chemotherapy alert card."

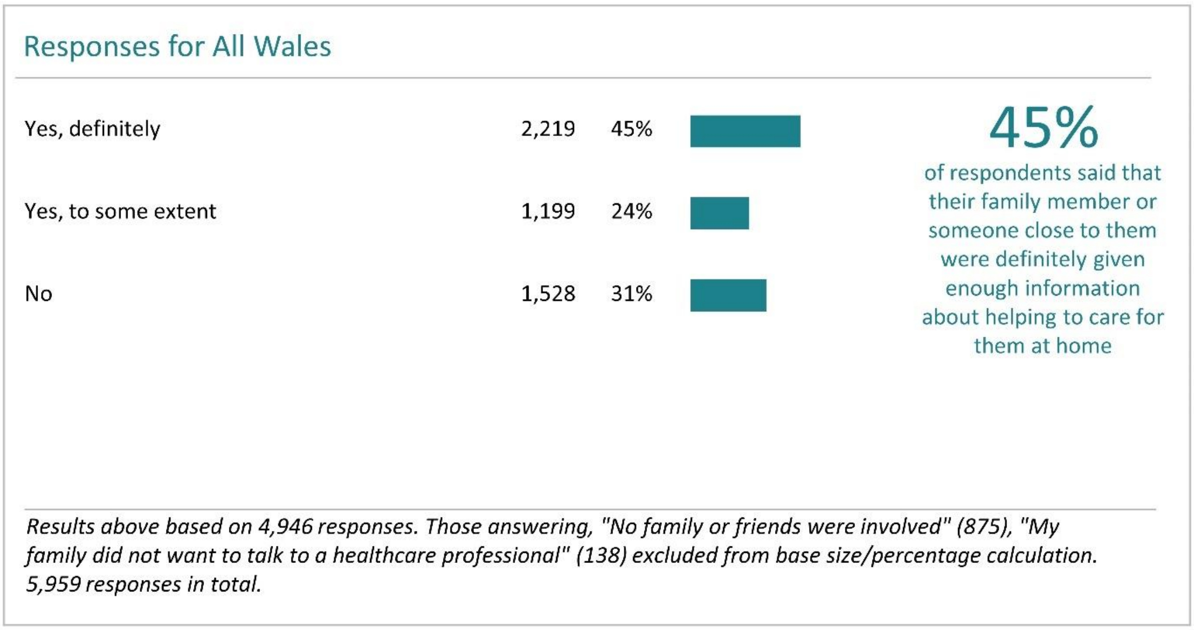


Health Board Comparison

Health Board Average	3,346	78%
Hywel Dda	580	81%
Aneurin Bevan	602	80%
Betsi Cadwaladr	804	78%
Cardiff and Vale	458	78%
Cwm Taf Morgannwg	406	77%
Swansea Bay	437	76%
Powys	59	73%

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?”



Responses for All Wales

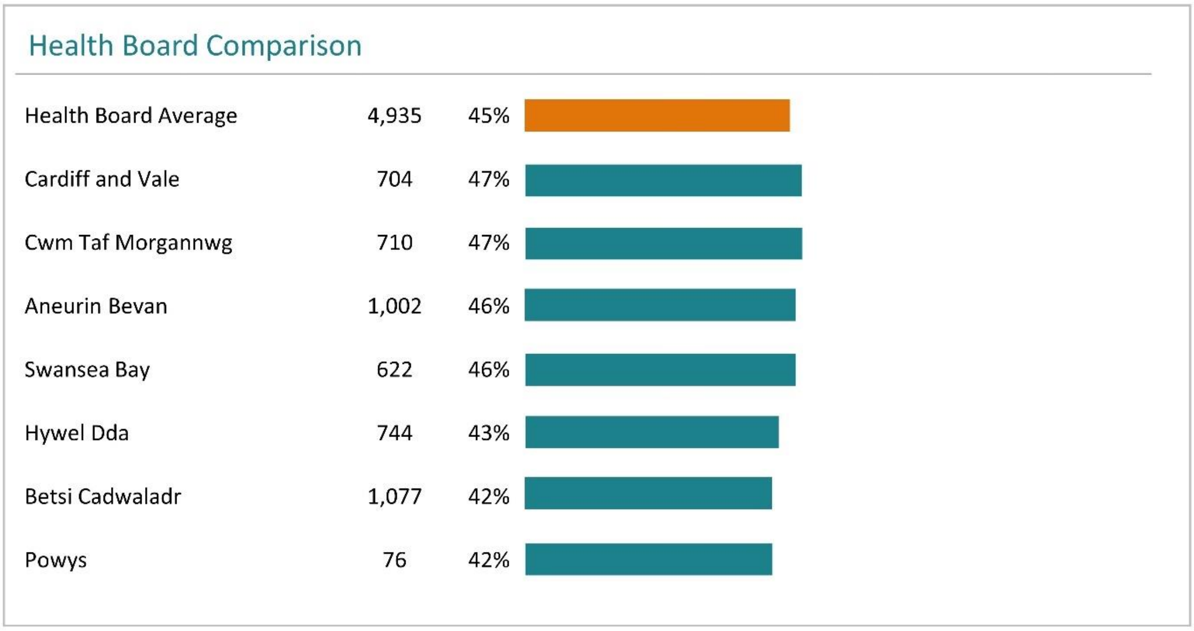
Yes, definitely	2,219	45%
Yes, to some extent	1,199	24%
No	1,528	31%

45%
of respondents said that their family member or someone close to them were definitely given enough information about helping to care for them at home

Results above based on 4,946 responses. Those answering, "No family or friends were involved" (875), "My family did not want to talk to a healthcare professional" (138) excluded from base size/percentage calculation. 5,959 responses in total.

Survey respondent:

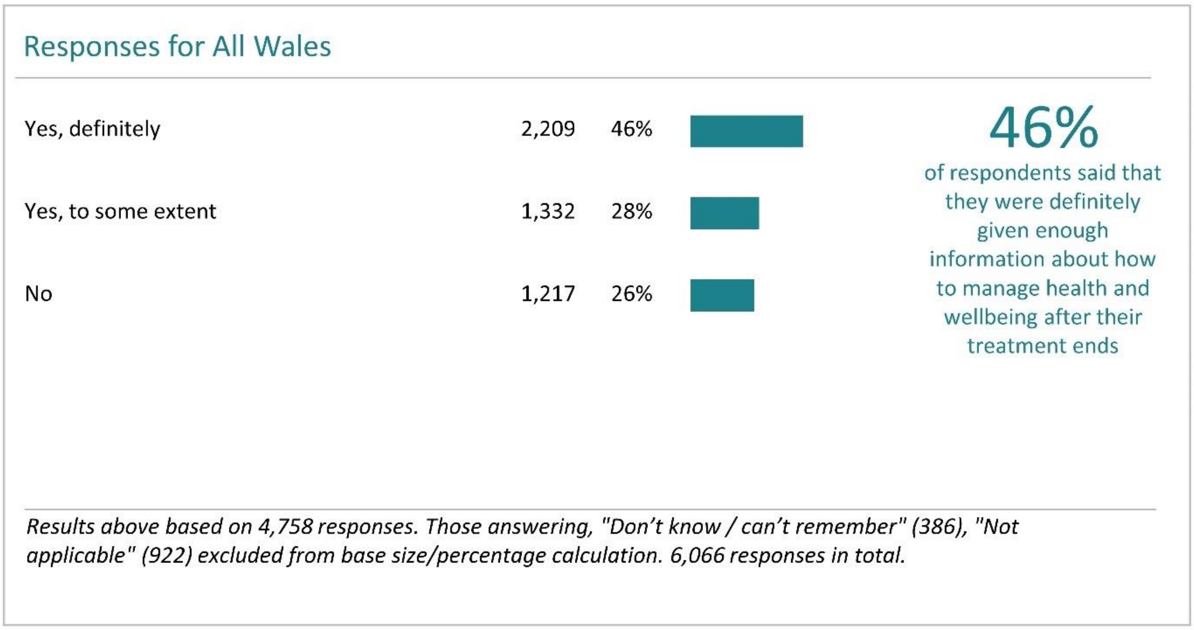
“When I had a previous cancer, I was given a sheaf of paperwork and booklets describing the treatment and after-effects. I was not given any such documentation during the second cancer and felt that this would have been beneficial to both myself and my spouse, who cared for me throughout my recovery.”



Health Board Comparison

Health Board Average	4,935	45%
Cardiff and Vale	704	47%
Cwm Taf Morgannwg	710	47%
Aneurin Bevan	1,002	46%
Swansea Bay	622	46%
Hywel Dda	744	43%
Betsi Cadwaladr	1,077	42%
Powys	76	42%

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



Responses for All Wales

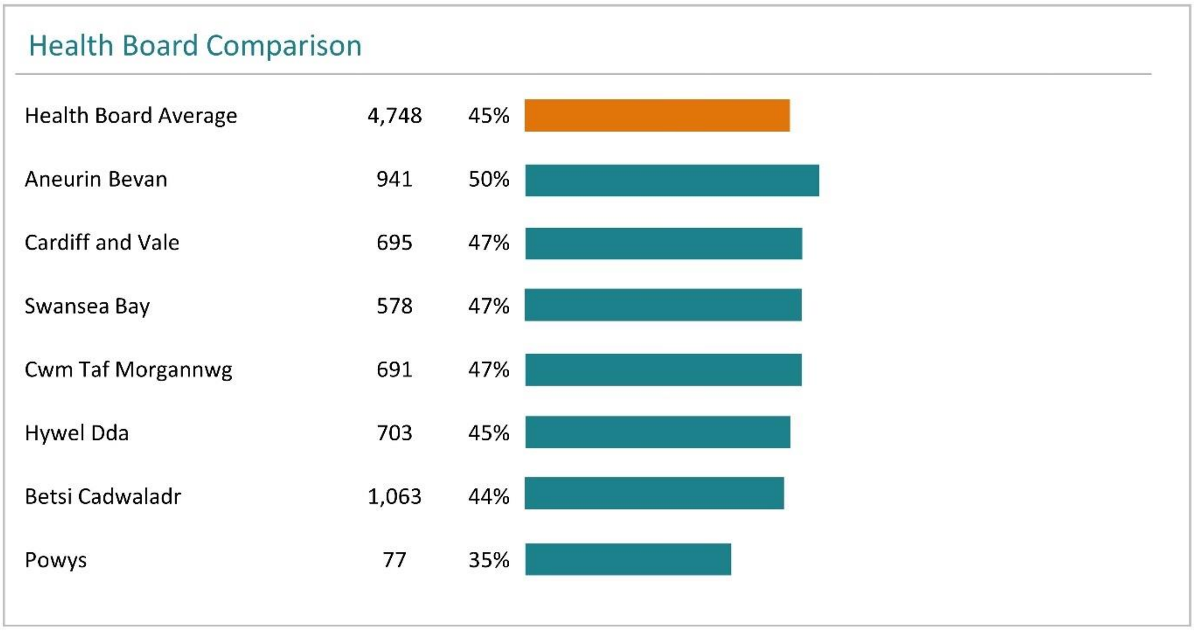
Yes, definitely	2,209	46%
Yes, to some extent	1,332	28%
No	1,217	26%

46%
of respondents said that they were definitely given enough information about how to manage health and wellbeing after their treatment ends

Results above based on 4,758 responses. Those answering, "Don't know / can't remember" (386), "Not applicable" (922) excluded from base size/percentage calculation. 6,066 responses in total.

Survey respondent:

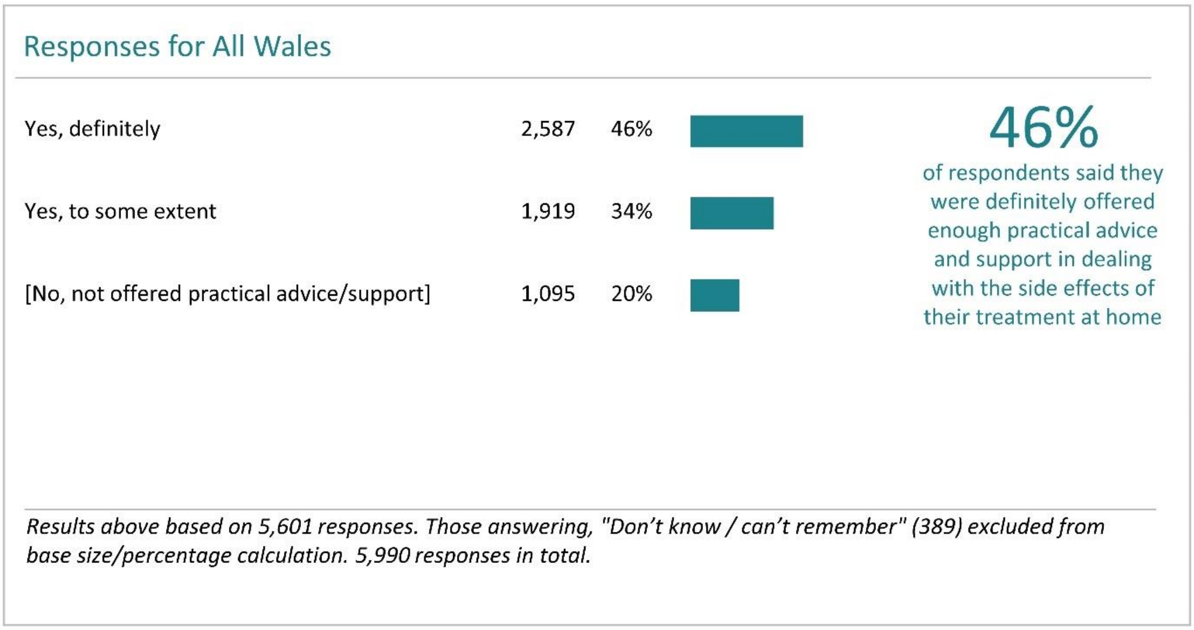
> ***"It was not until my treatment finished and I was left to get on with life I went into a kind of shock. I broke down approximate two months after felt lost, alone, and did not know what to expect. This did shock me as I am a very strong person. I have spoken to others with cancer and have found this is quite common, it is only then you realise you have cancer."***



Health Board Comparison

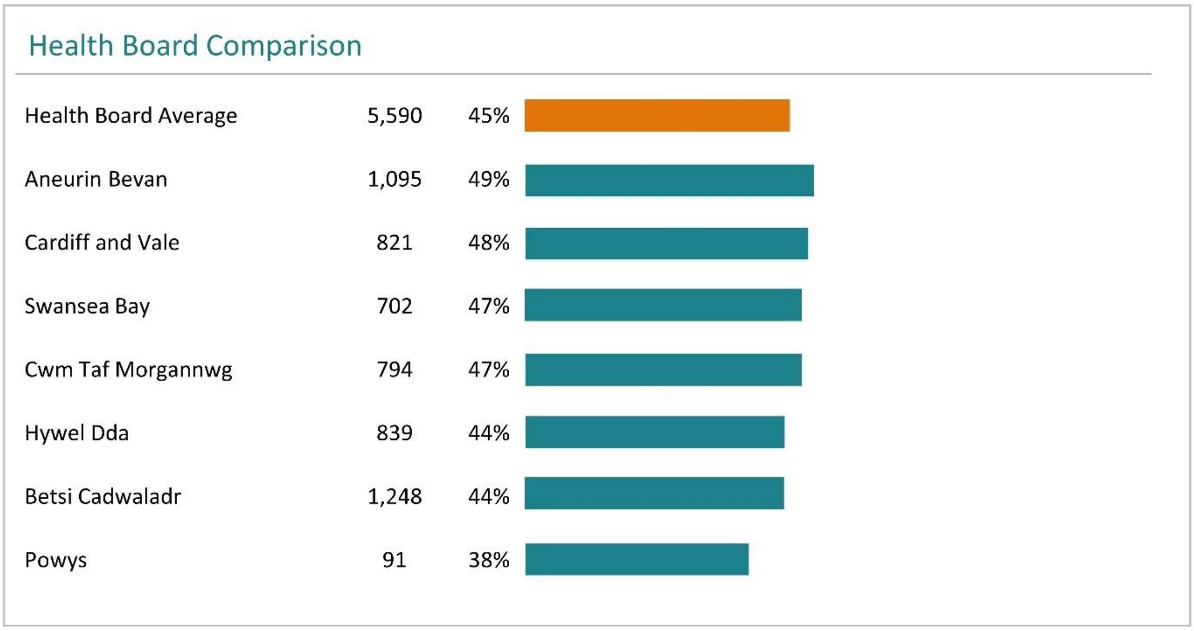
Health Board Average	4,748	45%
Aneurin Bevan	941	50%
Cardiff and Vale	695	47%
Swansea Bay	578	47%
Cwm Taf Morgannwg	691	47%
Hywel Dda	703	45%
Betsi Cadwaladr	1,063	44%
Powys	77	35%

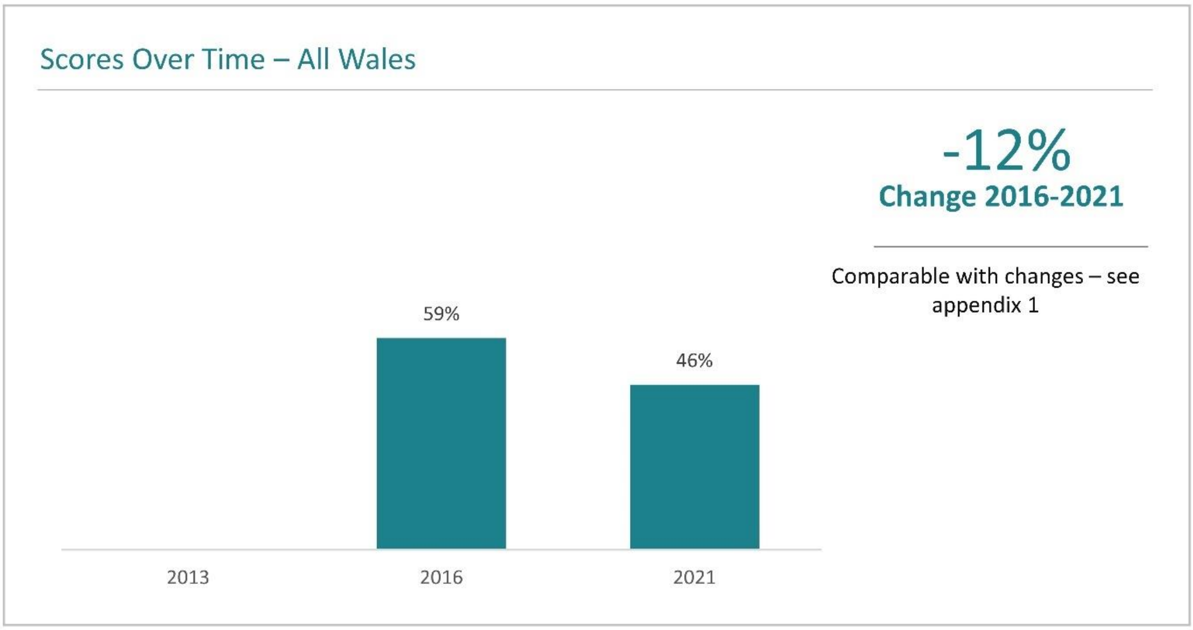
Question 53: "Were you offered practical advice and support in dealing with the side effects of your treatment(s) at home (such as physical activity advice, how to manage diet and fatigue)?”[16]



46%
of respondents said they were definitely offered enough practical advice and support in dealing with the side effects of their treatment at home

Results above based on 5,601 responses. Those answering, "Don’t know / can’t remember" (389) excluded from base size/percentage calculation. 5,990 responses in total.





-12%
Change 2016-2021

Comparable with changes – see appendix 1

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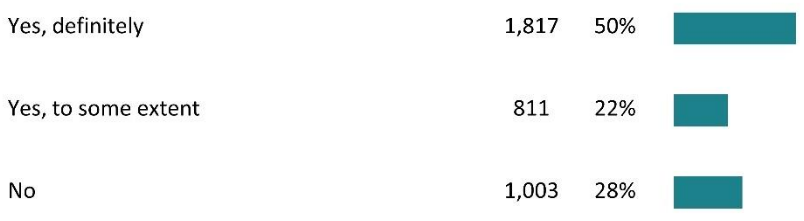
[16] Unabridged answer wording for ‘[no, not offered practical advice/support]’ is ‘No, I was not offered any practical advice or support’

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)?”

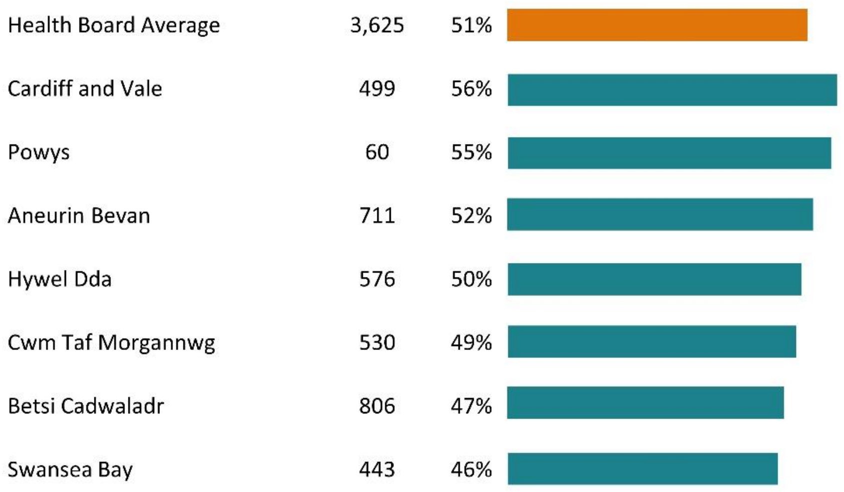
Responses for All Wales



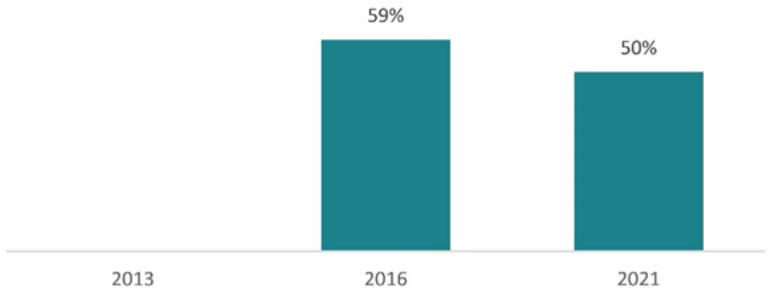
50%
of respondents said they were definitely given enough care and help from health or social services after leaving hospital

Results above based on 3,631 responses. Those answering, "I did not need help" (2,324), "Don’t know / can’t remember" (48) excluded from base size/percentage calculation. 6,003 responses in total.

Health Board Comparison



Scores Over Time – All Wales



-9%
Change 2016-2021

Directly comparable

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?”

Responses for All Wales

Yes, definitely	1,285	31%
Yes, to some extent	1,145	28%
No	1,715	41%

31%

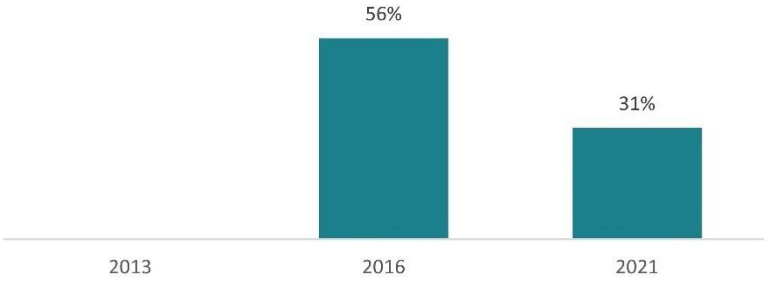
of respondents said they were definitely given enough care and help from their GP and GP practice after leaving hospital

Results above based on 4,145 responses. Those answering, "I did not need help" (1,846), "Don’t know / can’t remember" (55) excluded from base size/percentage calculation. 6,046 responses in total.

Health Board Comparison

Health Board Average	4,138	31%
Hywel Dda	637	34%
Aneurin Bevan	829	33%
Powys	68	31%
Swansea Bay	534	31%
Betsi Cadwaladr	914	30%
Cardiff and Vale	558	29%
Cwm Taf Morgannwg	598	28%

Scores Over Time – All Wales

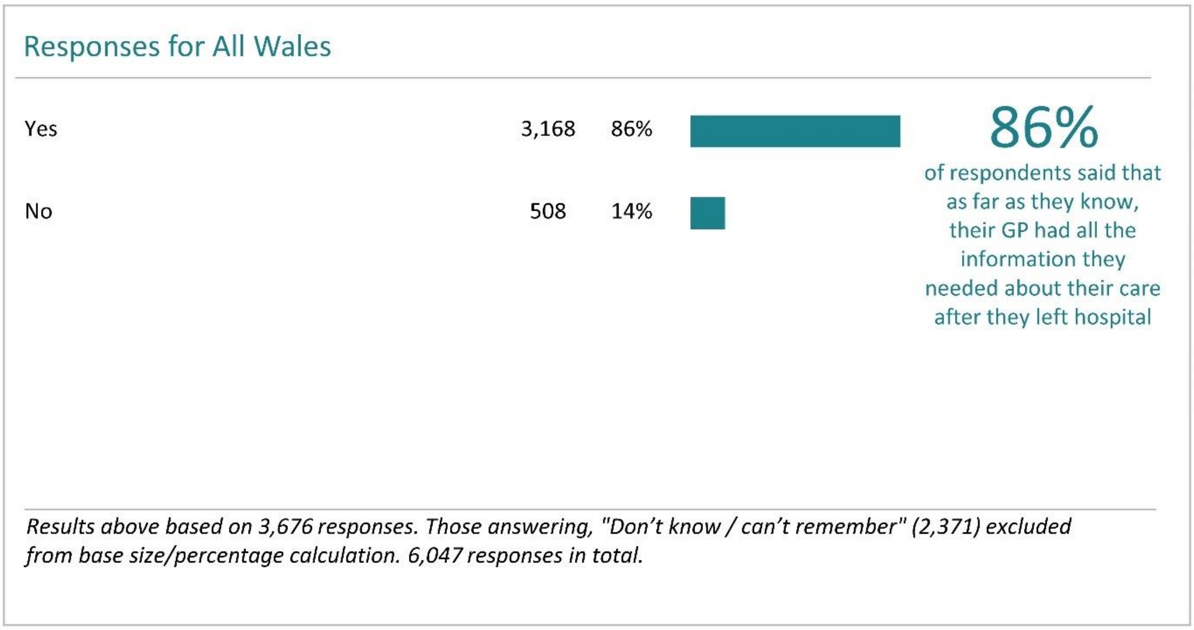


-25%

Change 2016-2021

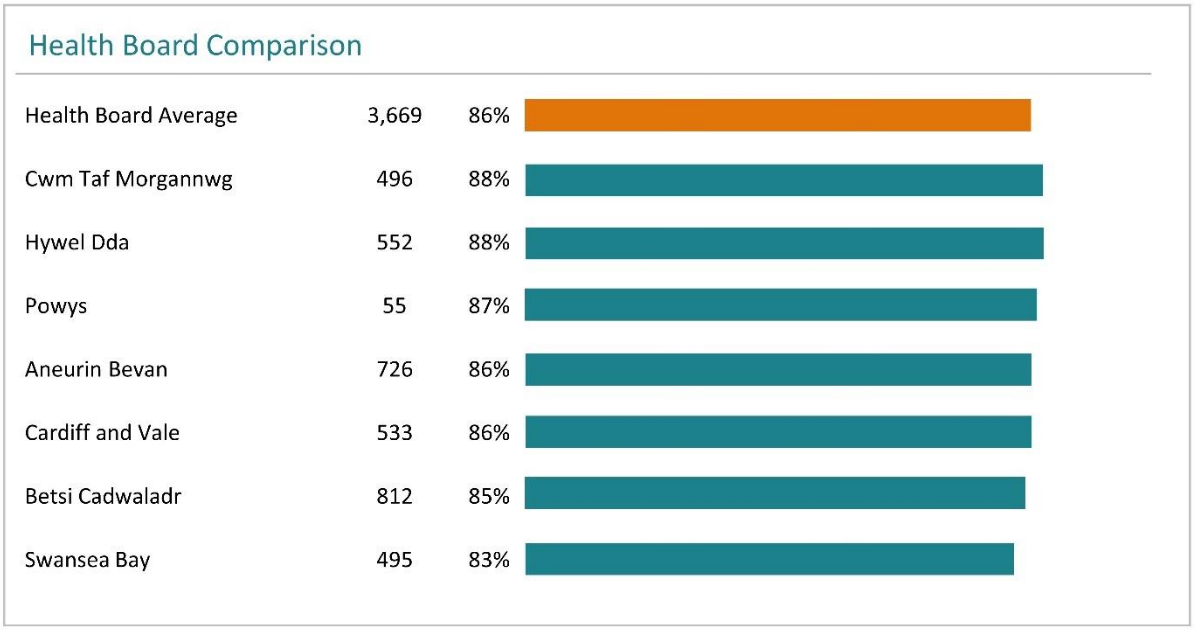
Comparable with changes – see appendix 1

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



86% of respondents said that as far as they know, their GP had all the information they needed about their care after they left hospital

Results above based on 3,676 responses. Those answering, "Don't know / can't remember" (2,371) excluded from base size/percentage calculation. 6,047 responses in total.



8.12 Your overall NHS care

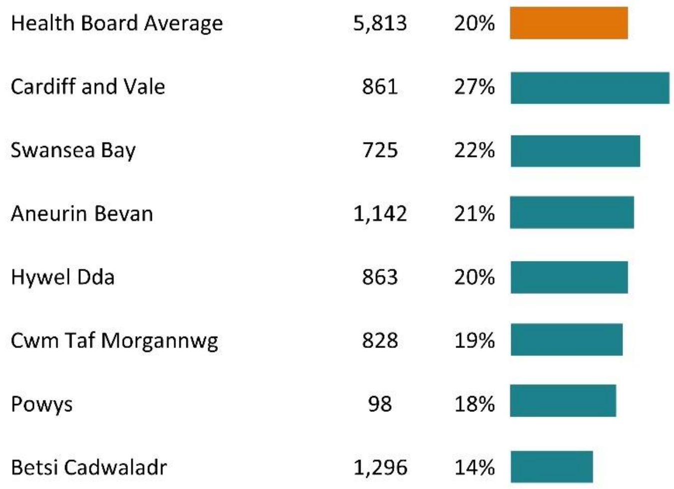
Question 57: "Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?"

Responses for All Wales

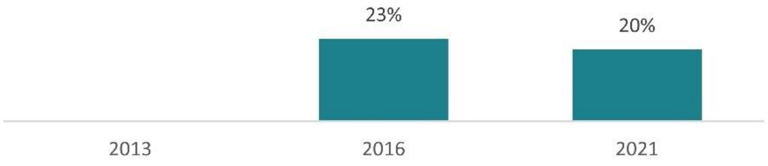
20%
of respondents said they have had a discussion about taking part in cancer research

Results above based on 5,824 responses. Those answering, "Don't know / can't remember" (316) excluded from base size/percentage calculation. 6,140 responses in total.

Health Board Comparison



Scores Over Time – All Wales



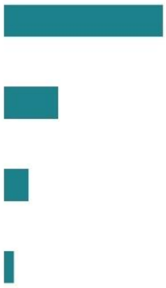
-3%
Change 2016-2021

Directly comparable

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

Responses for All Wales

Yes, always	3,800	65%	
Yes, most of the time	1,292	22%	
Yes, some of the time	565	10%	
No, never	208	4%	



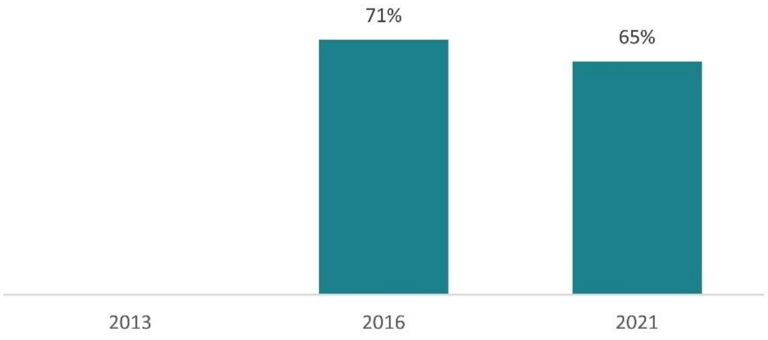
65%
of respondents said the different professionals treating and caring for them have worked well together all of the time

Results above based on 5,865 responses. Those answering, "Don’t know / can’t remember" (239) excluded from base size/percentage calculation. 6,104 responses in total.

Health Board Comparison

Health Board Average	5,854	64%	
Aneurin Bevan	1,158	69%	
Cardiff and Vale	884	66%	
Swansea Bay	722	65%	
Cwm Taf Morgannwg	831	65%	
Hywel Dda	868	64%	
Powys	93	61%	
Betsi Cadwaladr	1,298	61%	

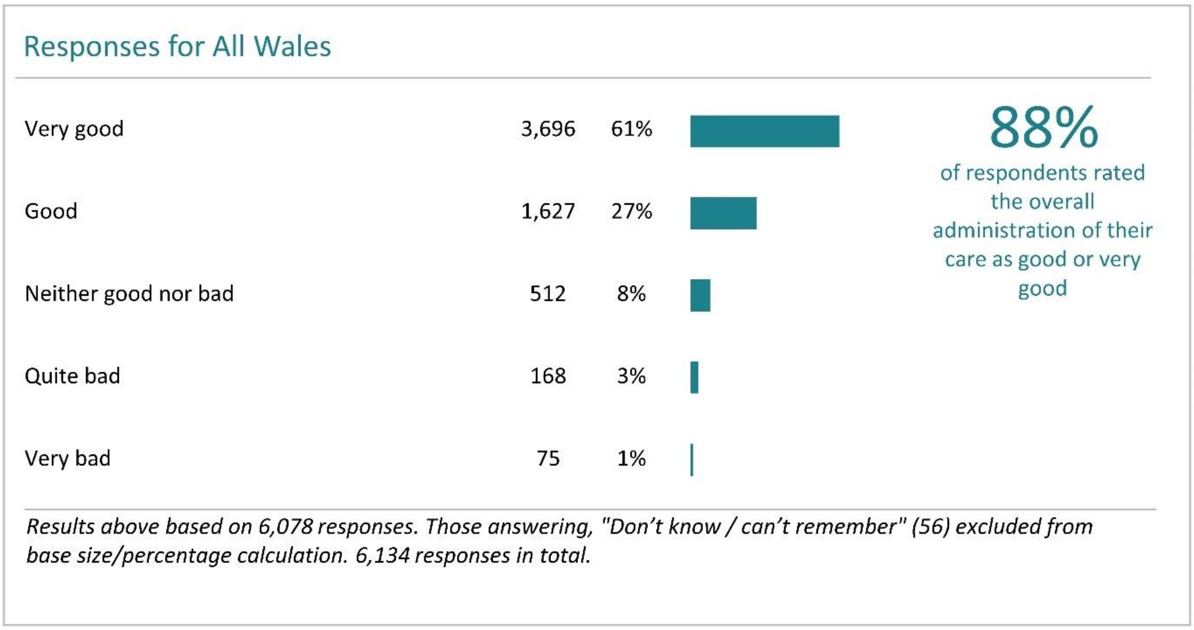
Scores Over Time – All Wales



-6%
Change 2016-2021

Comparable with changes – see appendix 1

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.)?”

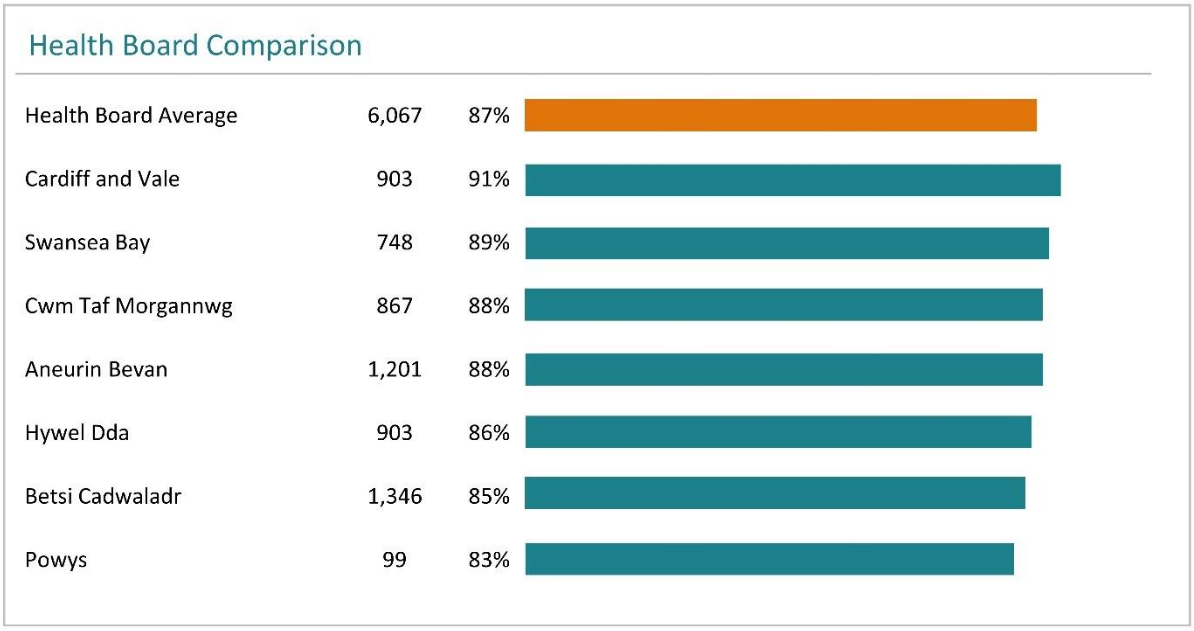


Responses for All Wales

Very good	3,696	61%	
Good	1,627	27%	
Neither good nor bad	512	8%	
Quite bad	168	3%	
Very bad	75	1%	

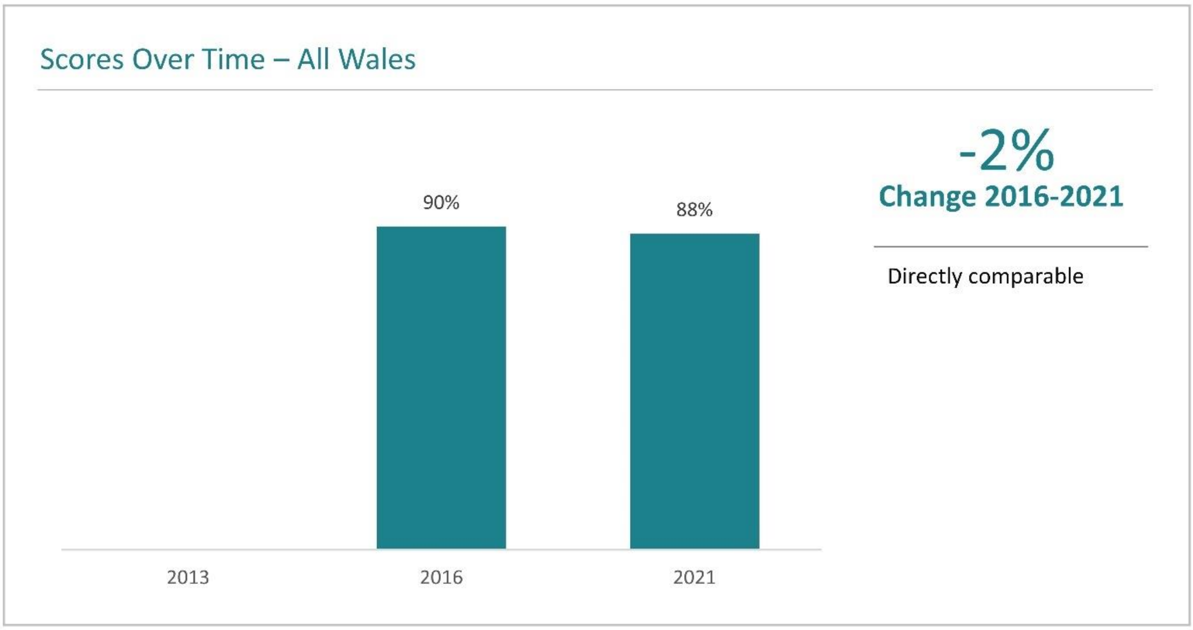
88%
of respondents rated the overall administration of their care as good or very good

Results above based on 6,078 responses. Those answering, "Don’t know / can’t remember" (56) excluded from base size/percentage calculation. 6,134 responses in total.



Health Board Comparison

Health Board Average	6,067	87%
Cardiff and Vale	903	91%
Swansea Bay	748	89%
Cwm Taf Morgannwg	867	88%
Aneurin Bevan	1,201	88%
Hywel Dda	903	86%
Betsi Cadwaladr	1,346	85%
Powys	99	83%

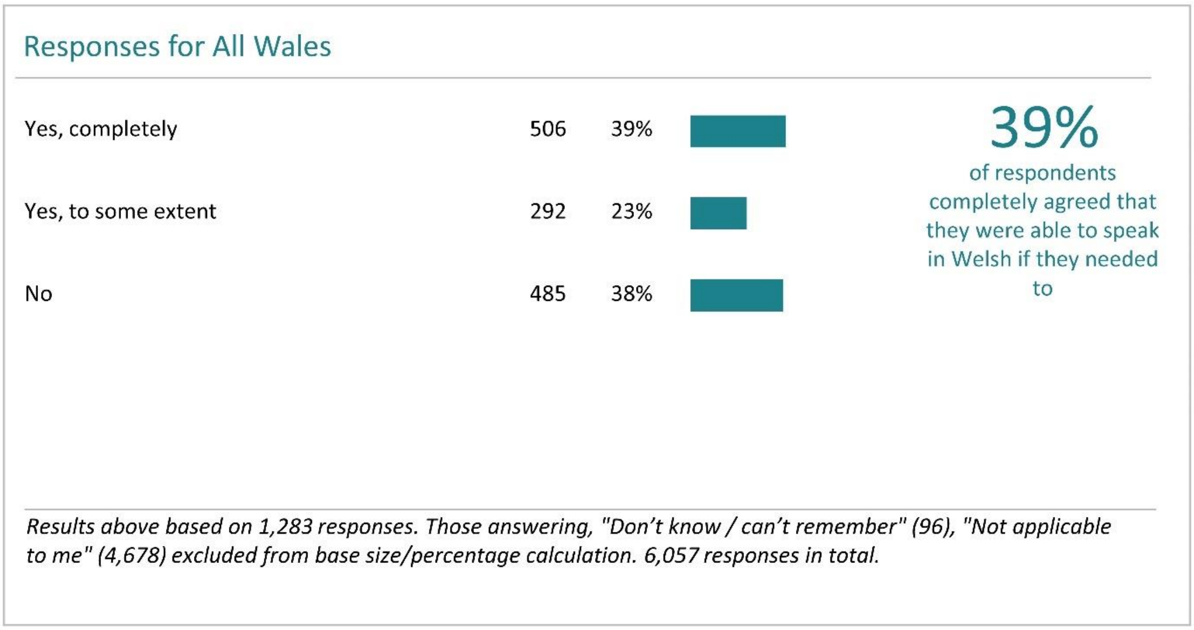


Scores Over Time – All Wales

-2%
Change 2016-2021

Directly comparable

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

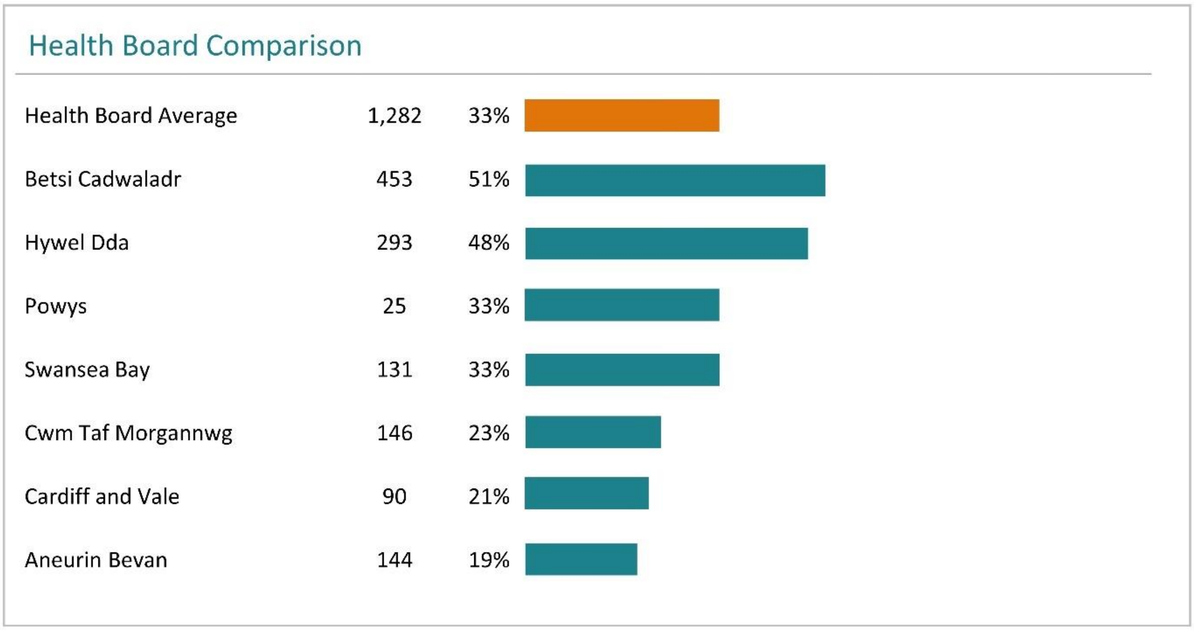


39% of respondents completely agreed that they were able to speak in Welsh if they needed to

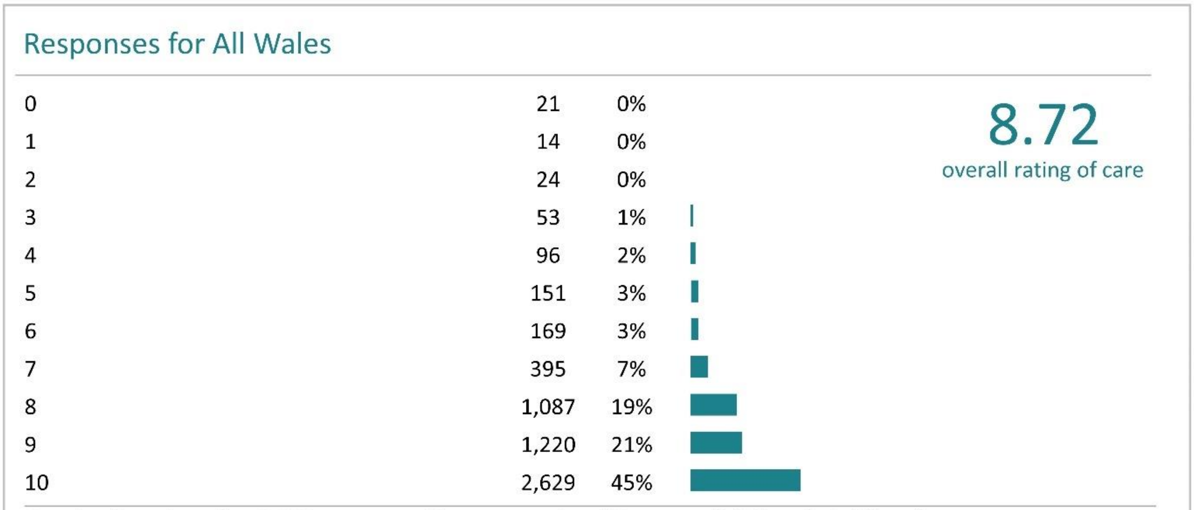
Results above based on 1,283 responses. Those answering, "Don’t know / can’t remember" (96), "Not applicable to me" (4,678) excluded from base size/percentage calculation. 6,057 responses in total.

Survey respondent:

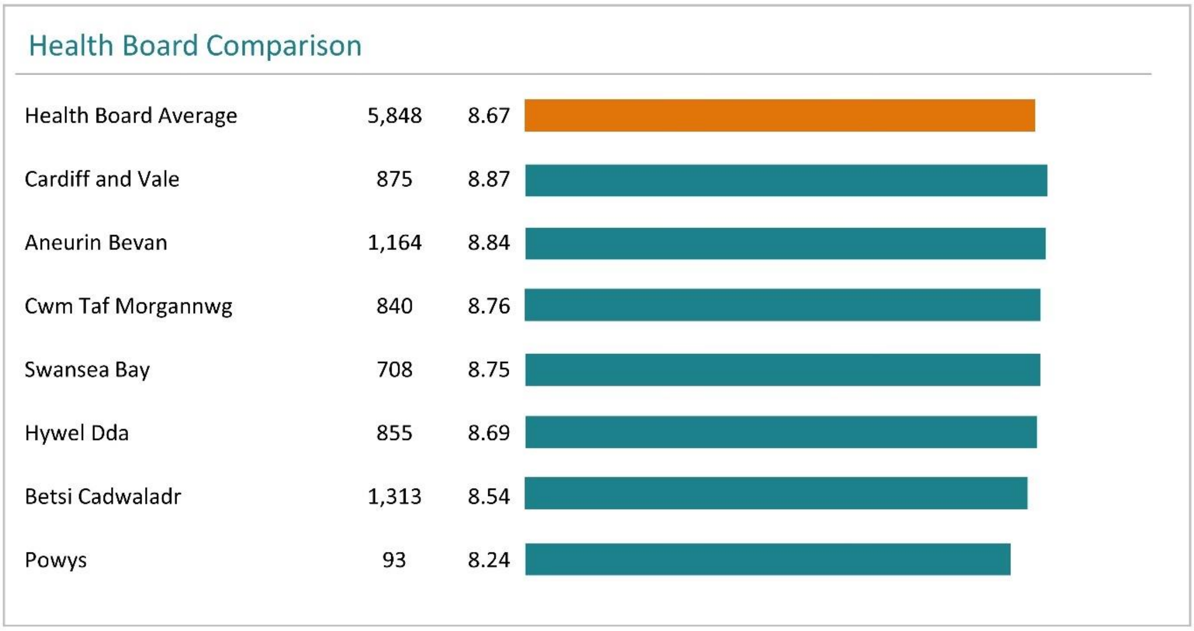
“The staff at [hospital name removed] were fantastic - it was a breath of fresh air to be able to speak the Welsh language whilst I was there.”

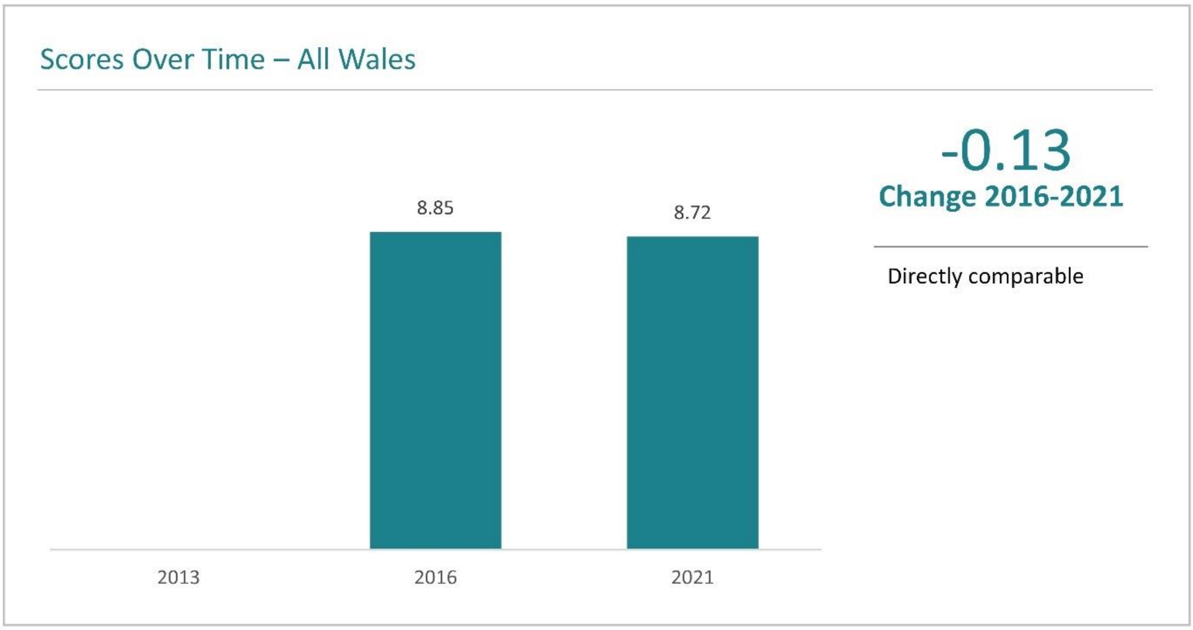


Question 61: "Overall, how would you rate your care? 0 is I had a very poor experience and 10 is I had a very good experience”[17]



Results above based on 5,859 responses. Those answering, "No answer" (43) excluded from base size/percentage calculation. 5,902 responses in total.





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[17] Question 61 asks respondents to rate their overall care on a scale of 0 to 10. Scores are the average of this scale.

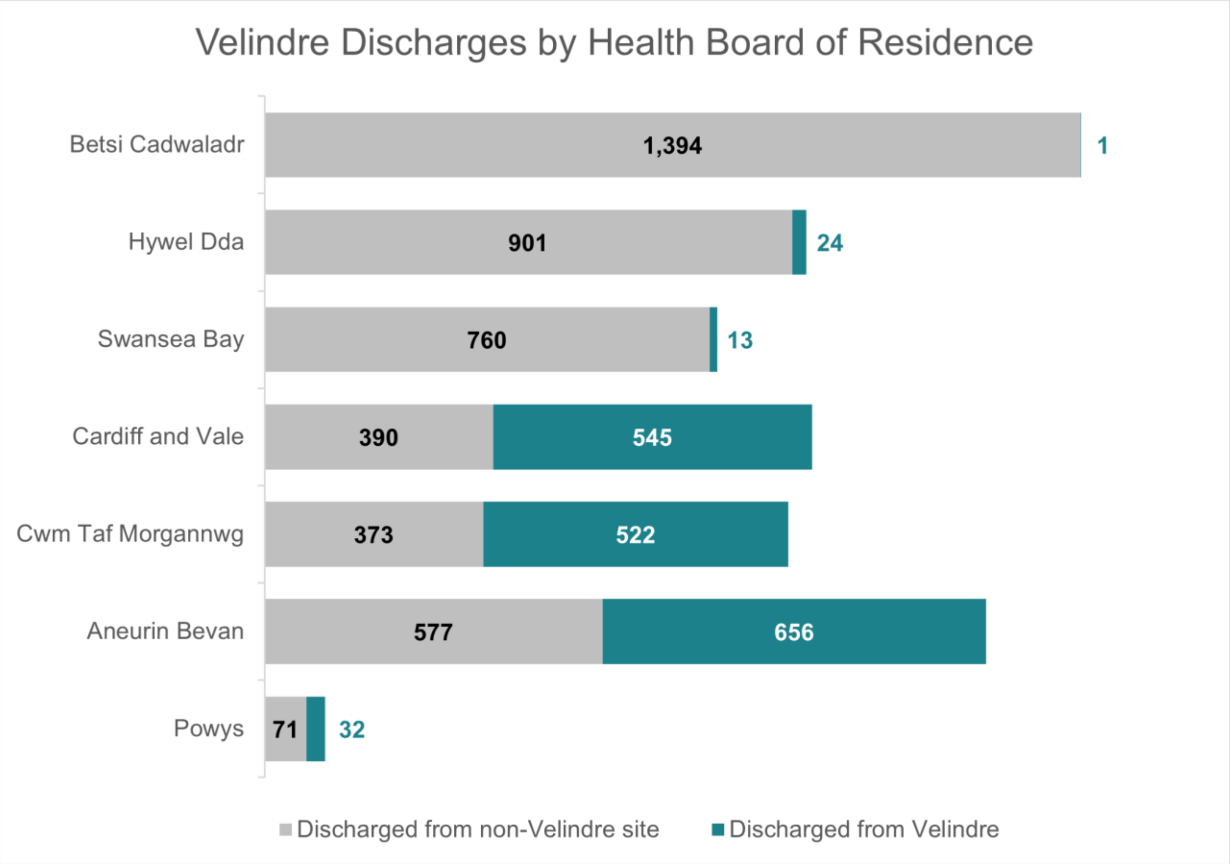
9. Understanding the results for Velindre Cancer Centre

Velindre Cancer Centre is part of Velindre University NHS Trust.

Velindre Cancer Centre delivers specialist cancer services for South East Wales, within the cancer centre and in outreach clinics in some Health Boards. Velindre Cancer Centre treat patients with including chemotherapy, immunotherapy and other Systemic Anti-Cancer Treatments (SACT), radiotherapy and related treatments.

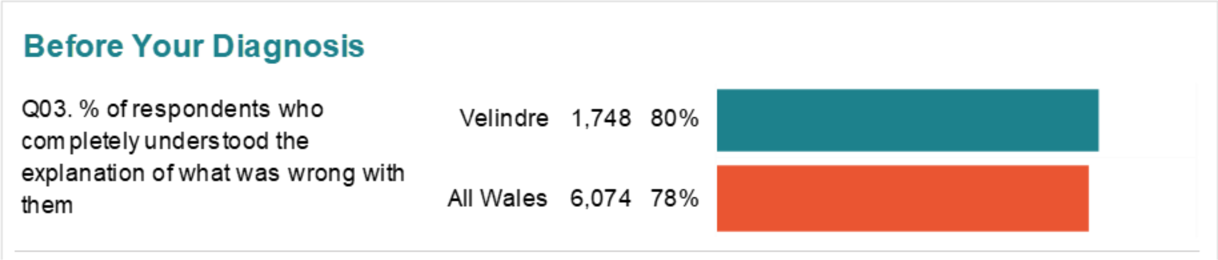
The majority of patients completing the CPES from Velindre Cancer Centre, would have had part of their care delivered by their Health Board of residence e.g. diagnostics and surgery.

The chart below shows how many respondents from each Health Board (of residence) were discharged from Velindre.



When interpreting Velindre Cancer Centre’s results, the reported experience will reflect the whole patient pathway which may span multiple Health Boards. As the patients allocated to Velindre Cancer Centre are assigned by discharge rather than by residence, it is not appropriate to compare its performance to the Health Boards in Wales. For this reason, Velindre Cancer Centre’s results are reported separately in the following section of this document.

Velindre Cancer Centre results section contains scored charts for each of the 58 evaluative questions. These charts illustrate the scored result for each question using unadjusted raw data, with Velindre Cancer Centre's data compared to the All Wales Score. An example chart is shown below.



Please see sections 3.3, 3.4 and 7 for further information on the methodology.

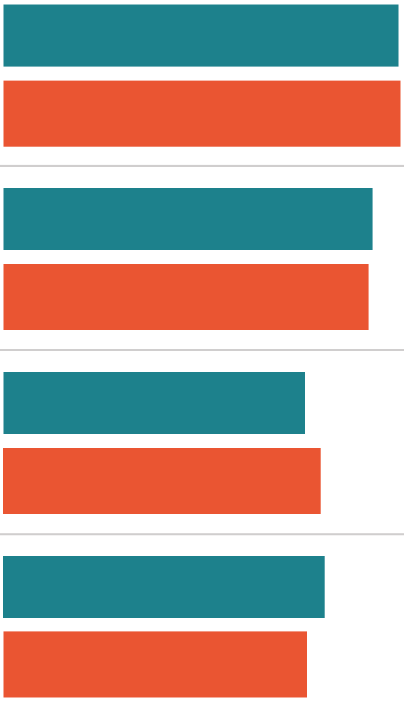
10. Velindre Cancer Centre results

Before Your Diagnosis

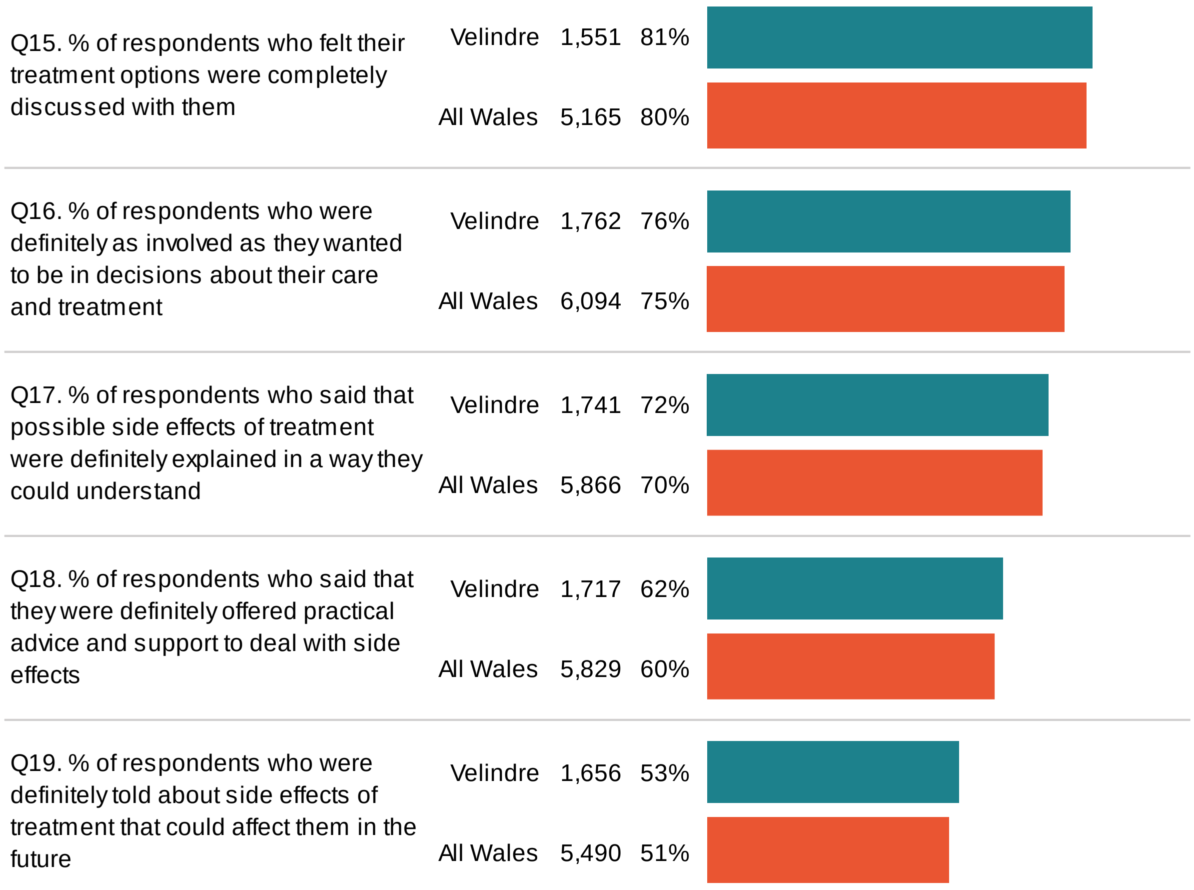
Q03. % of respondents who completely understood the explanation of what was wrong with them	Velindre	1,748	80%
	All Wales	6,074	78%
Q04. % of respondents who saw their GP once or twice before they were told they needed to go to hospital about cancer	Velindre	1,223	84%
	All Wales	4,205	82%
Q06. % of respondents who felt they were seen as soon as they thought was necessary for their first appointment with a healthcare professional in a hospital	Velindre	1,761	84%
	All Wales	6,133	83%
Q08. % of respondents who had all the information they needed about their test	Velindre	1,335	92%
	All Wales	4,691	93%
Q09. % of respondents who said their test results were explained in a way they could completely understand	Velindre	1,344	78%
	All Wales	4,704	79%

Finding Out You Had Cancer

Q10. % of respondents who felt they were told sensitively that they had cancer	Velindre	1,760	83%
	All Wales	6,126	84%
Q11. % of respondents who completely understood the explanation of what was wrong with them	Velindre	1,775	78%
	All Wales	6,169	77%
Q12. % of respondents who were given written information about their cancer which was easy to understand	Velindre	1,501	63%
	All Wales	5,214	67%
Q14. % of respondents who were told they could bring a family member or friend to their diagnosis	Velindre	1,678	67%
	All Wales	5,821	64%

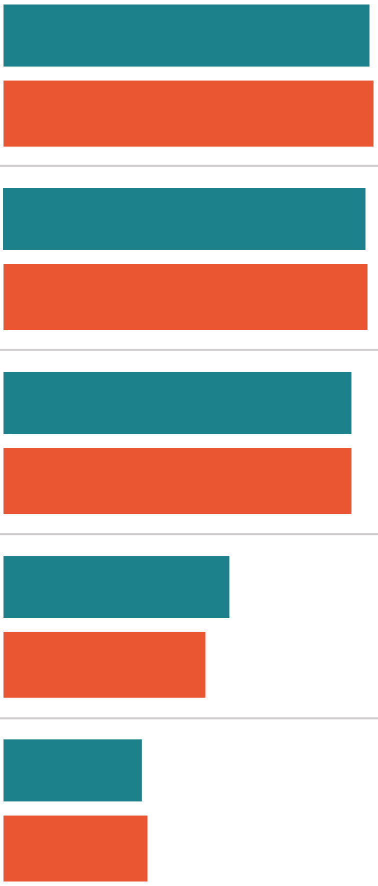


Deciding The Best Treatment And/Or Care For You



Healthcare Professionals - Part 1

Healthcare Professionals - Part 2



Q24a. % of respondents who agreed completely that their key worker provided them with the information they needed to make informed decisions about their treatment	Velindre	1,043	77%
	All Wales	3,536	78%
Q24b. % of respondents who agreed completely that their CNS provided them with the information they needed to make informed decisions about their treatment	Velindre	925	76%
	All Wales	3,081	76%
Q24c. % of respondents who agreed completely that other health professionals provided them with the information they needed to make informed decisions about their	Velindre	661	73%
	All Wales	2,208	73%
Q25. % of respondents who were offered an opportunity to discuss their needs and concerns	Velindre	1,144	48%
	All Wales	4,054	42%
Q26. % of respondents who were offered a written care plan	Velindre	1,343	29%
	All Wales	4,673	30%

Support For People With Cancer

Q27. % of respondents who said they were given the right amount of information about support/self help groups	Velindre	1,565	66%
	All Wales	5,377	62%
Q28. % of respondents who were told about voluntary/charity support during their care	Velindre	1,516	64%
	All Wales	5,263	54%
Q29. % of respondents who agreed completely that they had a discussion, or were given information about the impact cancer could have on their day to day activities	Velindre	1,624	40%
	All Wales	5,591	37%
Q30. % of respondents who said they were given enough information on how to get financial support or any benefits they were entitled to	Velindre	1,052	60%
	All Wales	3,310	53%

Operations

Question			
Q32. % of respondents who said they were given all the information they needed before their operation	Velindre	375	94%
	All Wales	2,162	93%
Q33. % of respondents who said a member of staff explained how the operation had gone in a way they could completely understand	Velindre	368	74%
	All Wales	2,148	77%

Hospital Care As An Inpatient

Question			
Q35. % of respondents who said that they were always treated with dignity and respect in hospital	Velindre	413	88%
	All Wales	2,283	90%
Q36. % of respondents who were able to discuss any worries or fears they had, as much as they wanted with staff	Velindre	377	63%
	All Wales	2,086	65%
Q37. % of respondents who said that a family member or someone else close to them definitely had enough opportunity to talk to a healthcare professional	Velindre	348	39%
	All Wales	1,912	37%
Q38. % of respondents who had confidence and trust in all of the healthcare professionals involved in their care	Velindre	417	82%
	All Wales	2,304	84%
Q39. % of respondents who said they were always given enough privacy when discussing their condition or treatment	Velindre	414	88%
	All Wales	2,290	88%
Q40. % of respondents who said they were always given enough privacy when being examined or treated	Velindre	418	93%
	All Wales	2,308	94%
Q41. % of respondents who said that hospital staff did everything they could to control their pain all of the time	Velindre	377	85%
	All Wales	2,029	86%
Q42. % of respondents who were given clear written information about what to do or not do after leaving hospital	Velindre	355	78%
	All Wales	1,978	81%
Q43. % of respondents who were told by hospital staff who to contact if worried after leaving hospital	Velindre	397	92%
	All Wales	2,217	92%

Outpatients / Day Case Appointments

Q45. % of respondents who said that hospital staff definitely did everything they could to control their pain while they were being treated as an outpatient or day case	Velindre	753	84%
	All Wales	2,771	83%
Q46. % of respondents who said that hospital staff definitely gave them enough emotional support while being treated as an outpatient or day case	Velindre	1,105	72%
	All Wales	3,930	74%

Radiotherapy / Chemotherapy

Q48. % of respondents who completely agreed that they had all the information they needed before they started their radiotherapy treatment	Velindre	1,310	82%
	All Wales	2,977	79%
Q50. % of respondents who completely agreed that they had all the information they needed before they started their chemotherapy treatment	Velindre	990	78%
	All Wales	3,353	79%

Arranging Home Support

Q51. % of respondents who said that their family member or someone close to them were definitely given enough information about helping to care for them at home	Velindre	1,428	44%
	All Wales	4,946	45%
Q52. % of respondents who said that they were definitely given enough information about how to manage health and wellbeing after their treatment ends	Velindre	1,396	45%
	All Wales	4,758	46%
Q53. % of respondents who said they were definitely offered enough practical advice and support in dealing with the side effects of their treatment at home	Velindre	1,632	47%
	All Wales	5,601	46%
Q54. % of respondents who said they were definitely given enough care and help from health or social services after leaving hospital	Velindre	1,045	52%
	All Wales	3,631	50%

Care From Your General Practice

Q55. % of respondents who said they were definitely given enough care and help from their GP and GP practice after leaving hospital	Velindre	1,191	31%
	All Wales	4,145	31%
Q56. % of respondents who said that as far as they know, their GP had all the information they needed about their care after they left hospital	Velindre	1,020	86%
	All Wales	3,676	86%

11. Comparisons between different groups of respondents

All of the national level data for the survey has been analysed across different respondent groups, to establish whether there are any significant differences in their experience of cancer care. Specifically, we have looked at the impact of age, ethnicity, IMD quintile (deprivation), sex and tumour group.

For almost all scored questions in the survey, where there are sociodemographic factors with only two points of comparison (e.g. sex) a proportional statistical test has been applied. Where there are multiple groups to be compared (e.g. age groups) a chi-squared test has been used.

The exception to this is Q61 - the overall experience question for which an average score is calculated rather than a “percent positive” score. For this question t-tests have been used to identify significant differences between specific sub-groups of respondents.

The full detail is available at https://wcpes.co.uk/library

As a summary, we have looked in this report at the following questions:

- Q11 Did you understand the explanation of what was wrong with you?
- Q16 Were you involved as much as you wanted to be in decisions about your care and treatment?
- Q20 Were you given the name and contact details of your Key Worker?
- Q21a Did your care include access to a CNS?
- Q22a How easy was it for you to contact your Key Worker?
- Q22b How easy was it for you to contact your CNS?
- Q25 Were you offered the opportunity to discuss your needs and concerns?
- Q26 Have you been offered a written care plan?
- Q35 Overall, while you were in hospital, were you were treated with dignity and respect?
- Q43 Did the hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
- Q54 After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?
- Q55 After leaving hospital, were you given enough care and help from your GP and the GP practice?
- Q60 Were you able to speak in Welsh to staff if you needed to?
- Q61 Overall, how would you rate your care?

Analysis by **sex.** There are significant differences between scores for males and females on 8 of the fourteen selected questions.

Male respondents reported significantly better experiences than females for 6 of the selected questions:

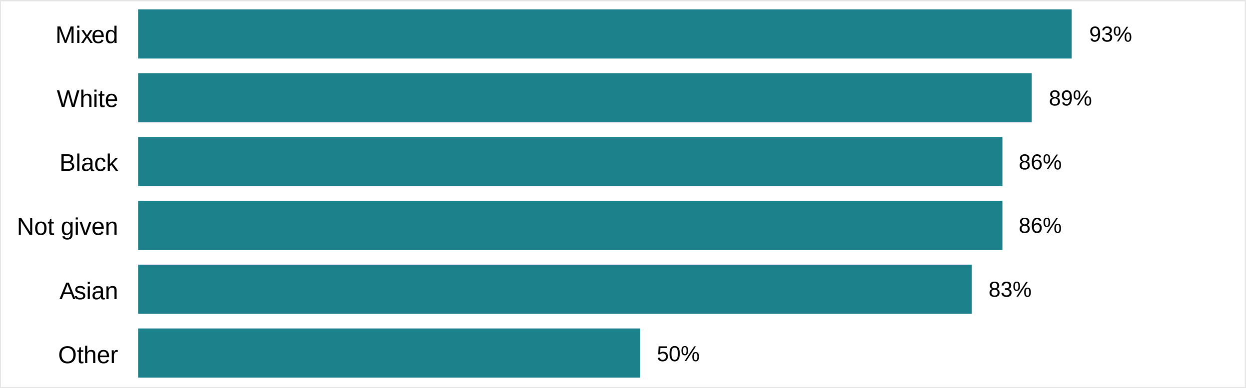
Question	Male	Female
Q22b How easy was it for you to contact your CNS?	71%	67%
Q25 Were you offered the opportunity to discuss your needs and concerns?	46%	39%
Q35 Overall, while you were in hospital, were you were treated with dignity and respect?	92%	89%
Q54 After leaving hospital, were you given enough care and help from health or social services?	52%	48%
Q55 After leaving hospital, were you given enough care and help from your GP and the GP practice?	33%	29%
Q60 Overall, how would you rate your care?	8.8	8.6

Female respondents reported significantly better experiences than males for 2 of the selected questions:

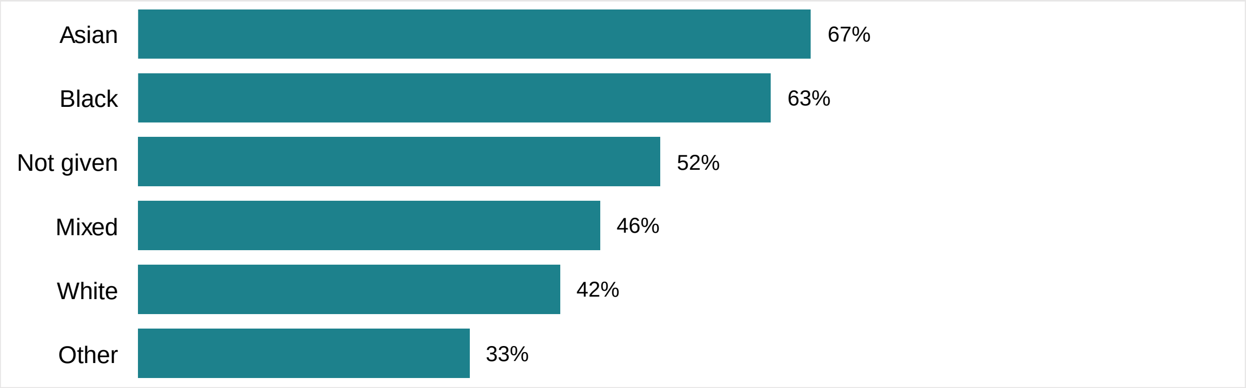
Question	Male	Female
Q20 Were you given the name and contact details of your Key Worker?	89%	91%
Q21a Did your care include access to a CNS?	87%	90%

Analysis by **ethnicity**. **There are significant differences across the different ethnic groups on 3 of the fourteen selected questions**, which are illustrated below.

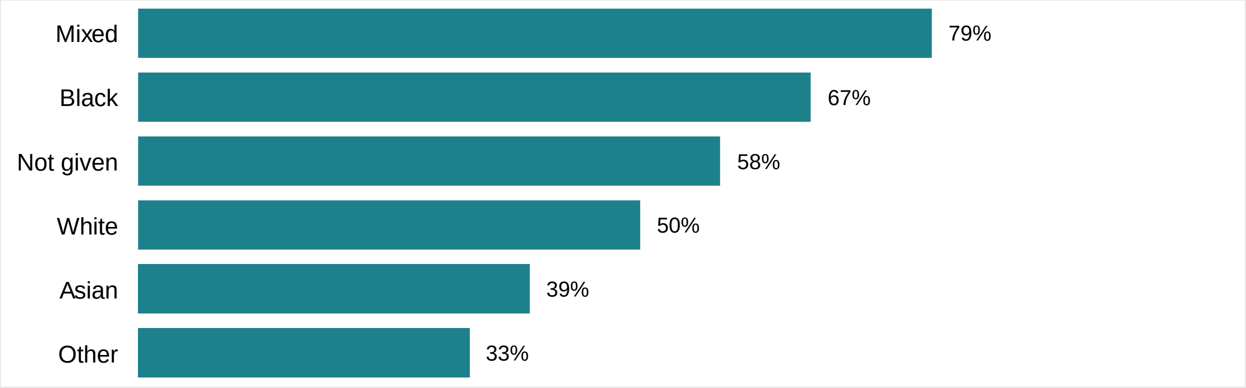
Respondents from a Mixed background reported most positively that their care included access to a CNS (Q21a).



Respondents from an Asian background reported most positively that they were offered the opportunity to discuss their needs and concerns (Q25).

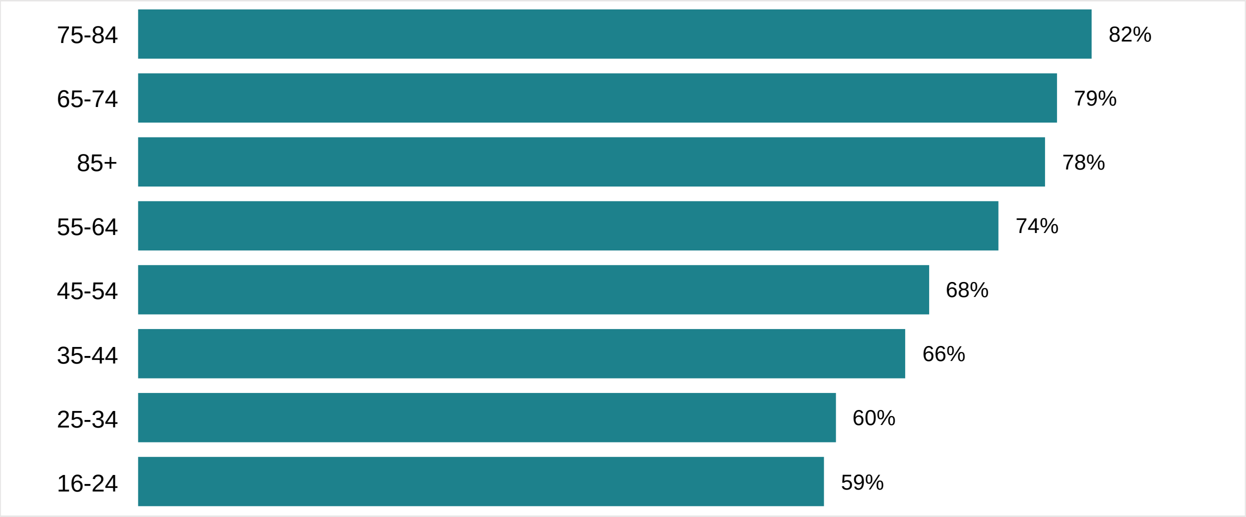


Respondents from a Mixed background reported most positively that after leaving hospital, they were given enough care and help from health or social services (Q54).



Analysis by **age**. **There are significant differences across the different age groups on 6 of the fourteen selected questions,** these are illustrated below.

Respondents from the 75-84 age group reported most positively that they understood the explanation of what was wrong with them (Q11).

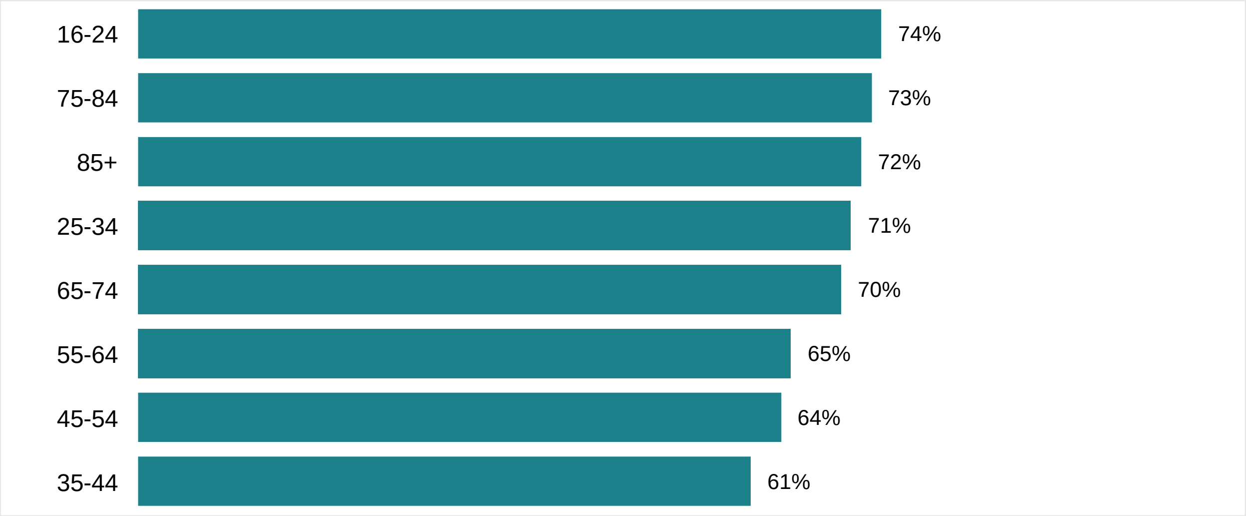


Respondents from the 75-84 age group reported most positively that they were involved as much as they wanted to be in decisions about their care and treatment (Q16).

Respondents from the 16-24 age group reported most positively that they were given the name and contact details of their Key Worker (Q20).

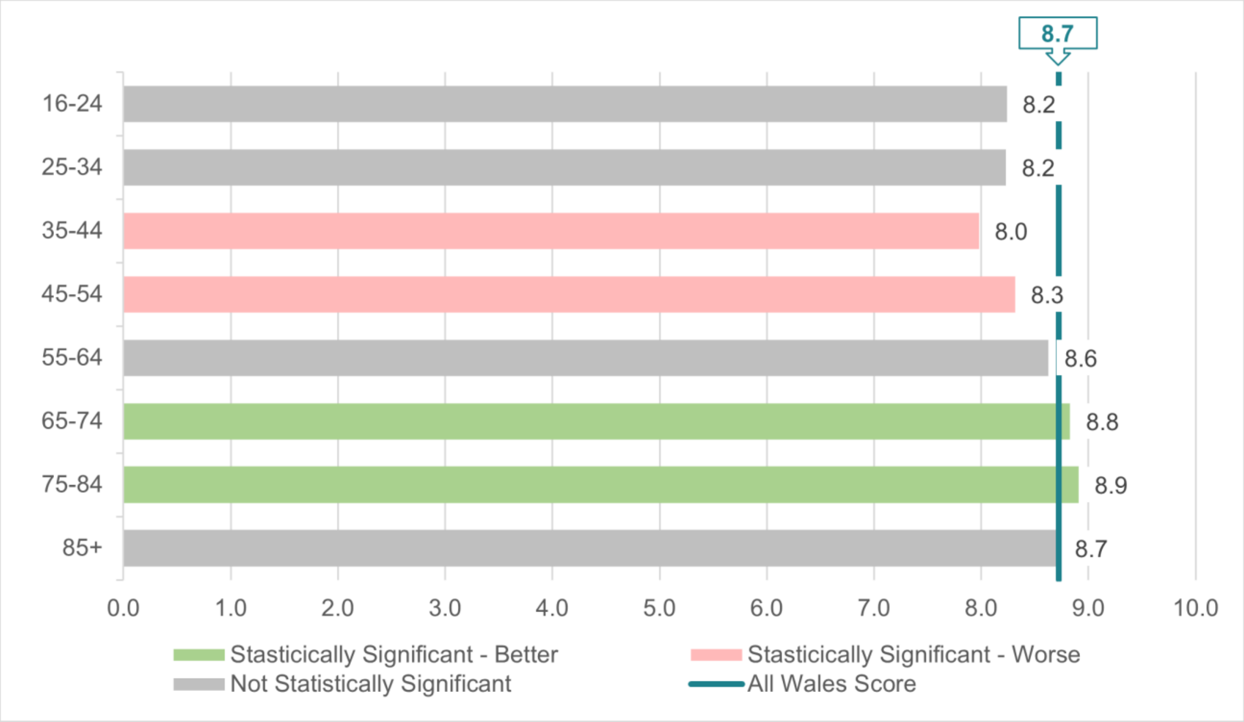
Respondents from the 16-24 age group reported most positively that their care included access to a CNS (Q21a).

Respondents from the 16-24 age group reported most positively that it was easy for them to contact their Key Worker (Q22a).



Respondents from the 16-24 age group reported most positively that hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital (Q43).

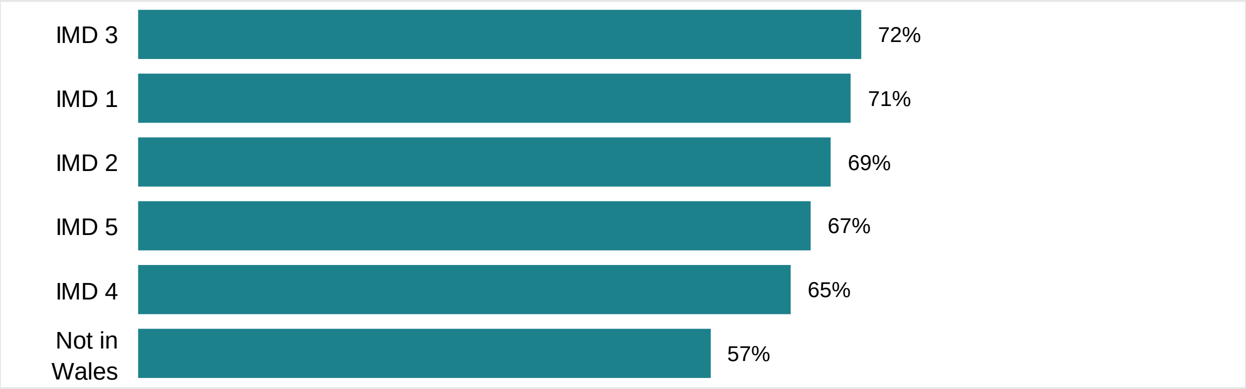
Respondents in the 65-74 and 75-84 age groups scored statistically higher for their overall rating of care (Q61), when compared to the All Wales score, while the 35-44 and 45-54 age groups tested significantly lower.



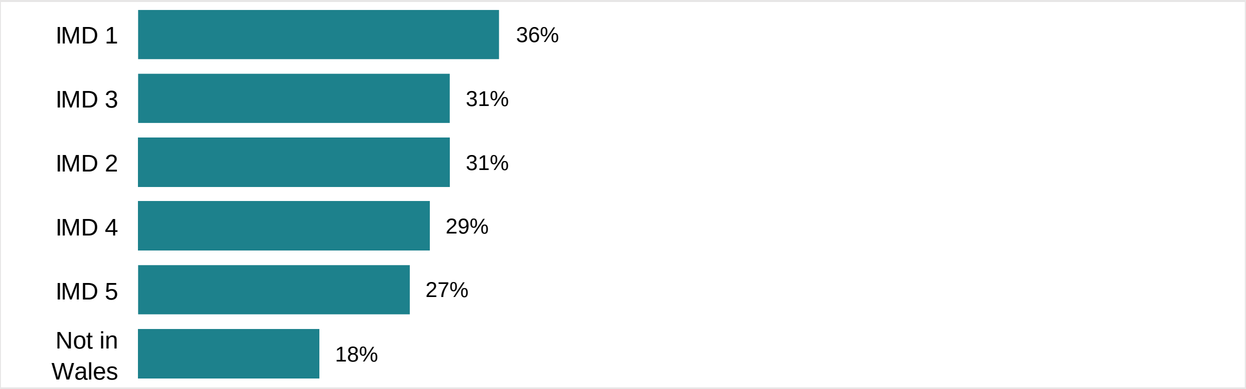
Analysis by **IMD quintile (deprivation)**. Indices of Multiple Deprivation (IMD) classifies geographic areas in Wales into five quintiles based on relative disadvantage. Quintile 1 are the most deprived areas, while quintile 5 are the least deprived areas.[18]

There are significant differences across all the groups on 4 of the fourteen selected questions, which are illustrated below.

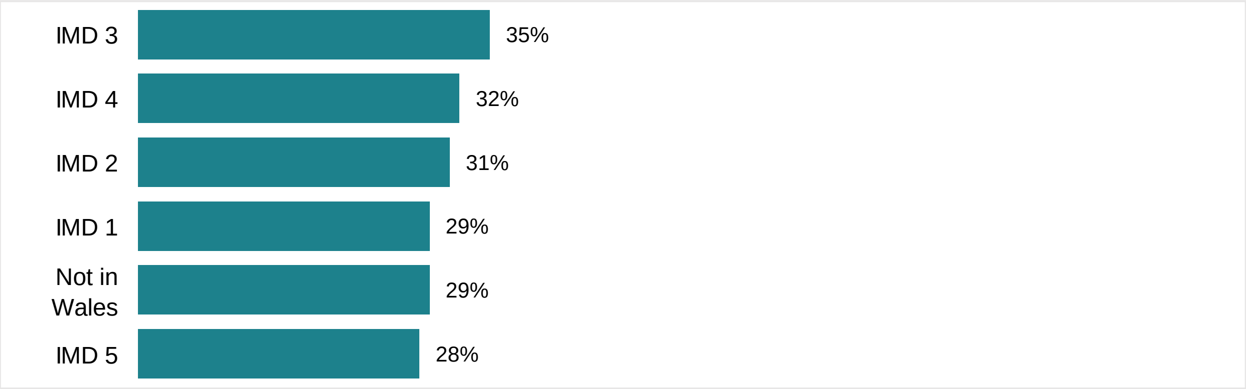
Respondents from the IMD 3 group reported most positively that it was easy for them to contact their Key Worker (Q22a).



Respondents from the IMD 1 group reported most positively that they had been offered a written care plan (Q26).



Respondents from the IMD 3 group reported most positively that they were given enough care and help from their GP and GP practice after leaving hospital (Q55).



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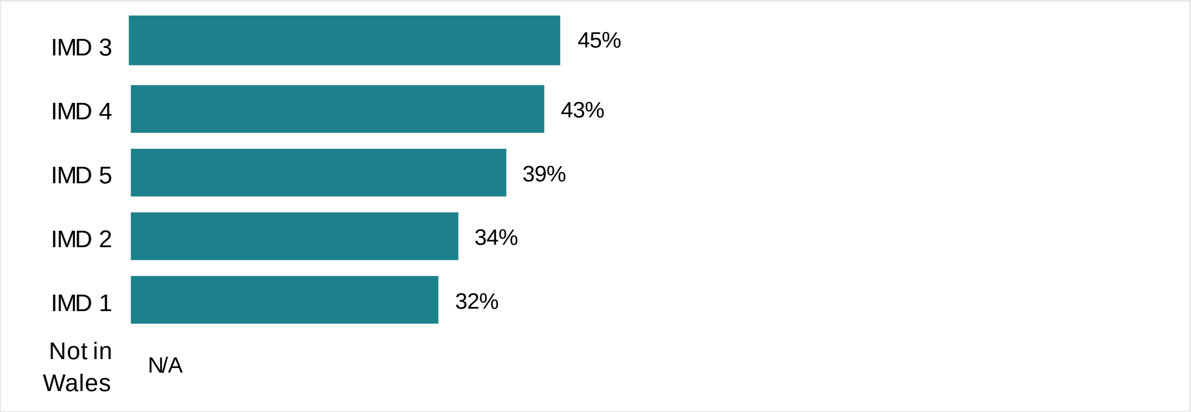
[18] A small number of respondents had postcodes from outside Wales and are classified as 'Not in Wales for the purpose of this analysis

Respondents from the IMD 3 group reported most positively that they were able to speak in Welsh to staff if they needed to (Q60).



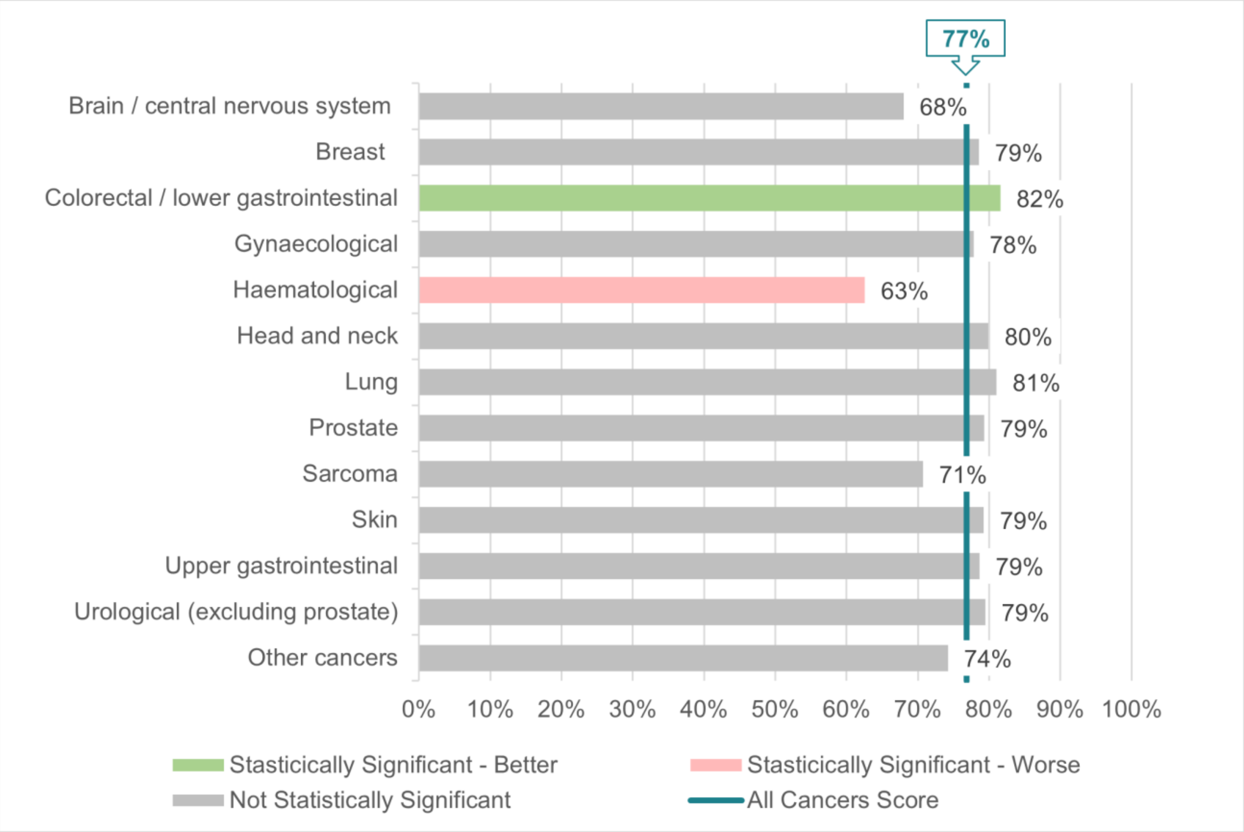
There were 2 questions where there was a significant difference between the most (IMD 1) and least (IMD 5) deprived areas. **The most deprived group reported higher scores on both questions**.

Question	IMD 1	IMD 5
Q25 Were you offered the opportunity to discuss your needs and concerns?	48%	42%
Q26 Have you been offered a written care plan?	36%	27%

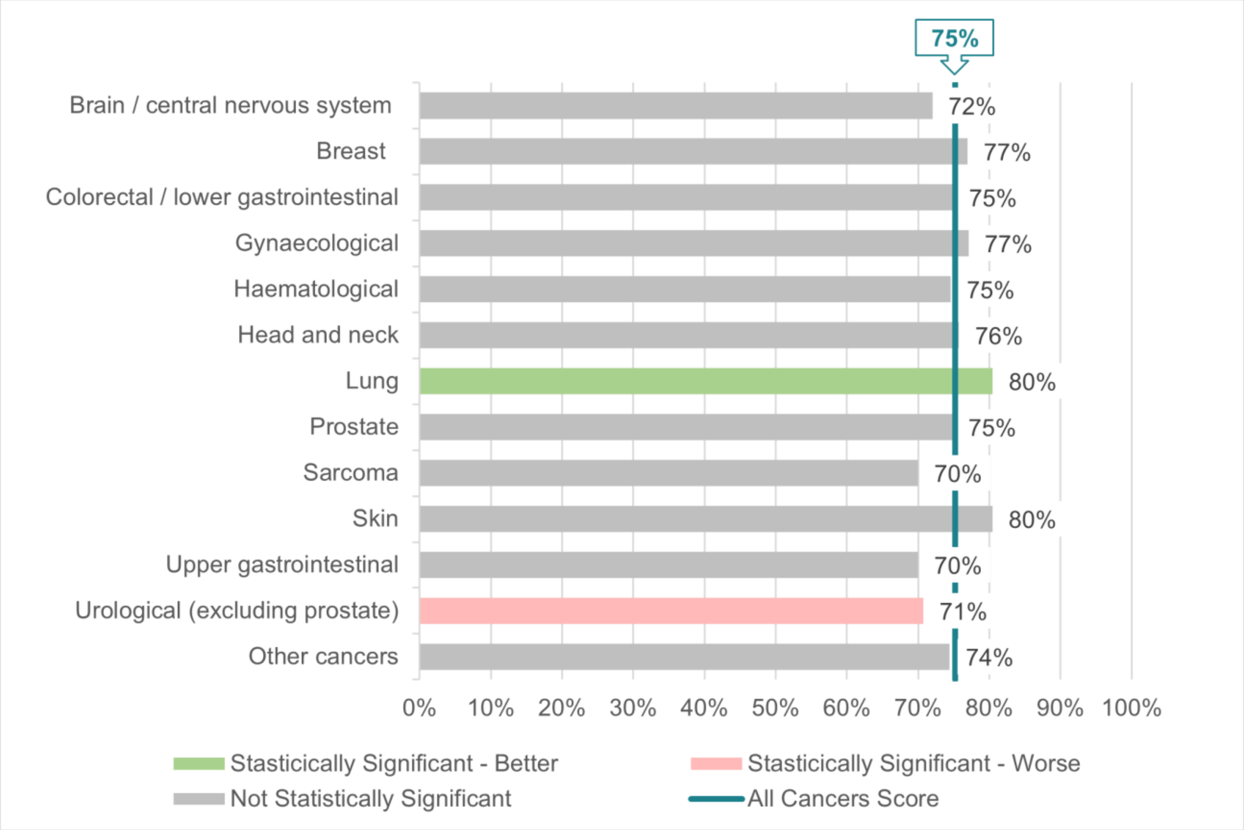
Analysis by **tumour group**. **There was only one question, from the 14 selected questions where no tumour group score significantly deviated from the All Wales average**, this was question 35 ‘Overall, while you were in hospital, were you were treated with dignity and respect?’.

Of the other 13 questions, 1 or more tumour groups showed significant difference to the All Wales average, these are illustrated below.

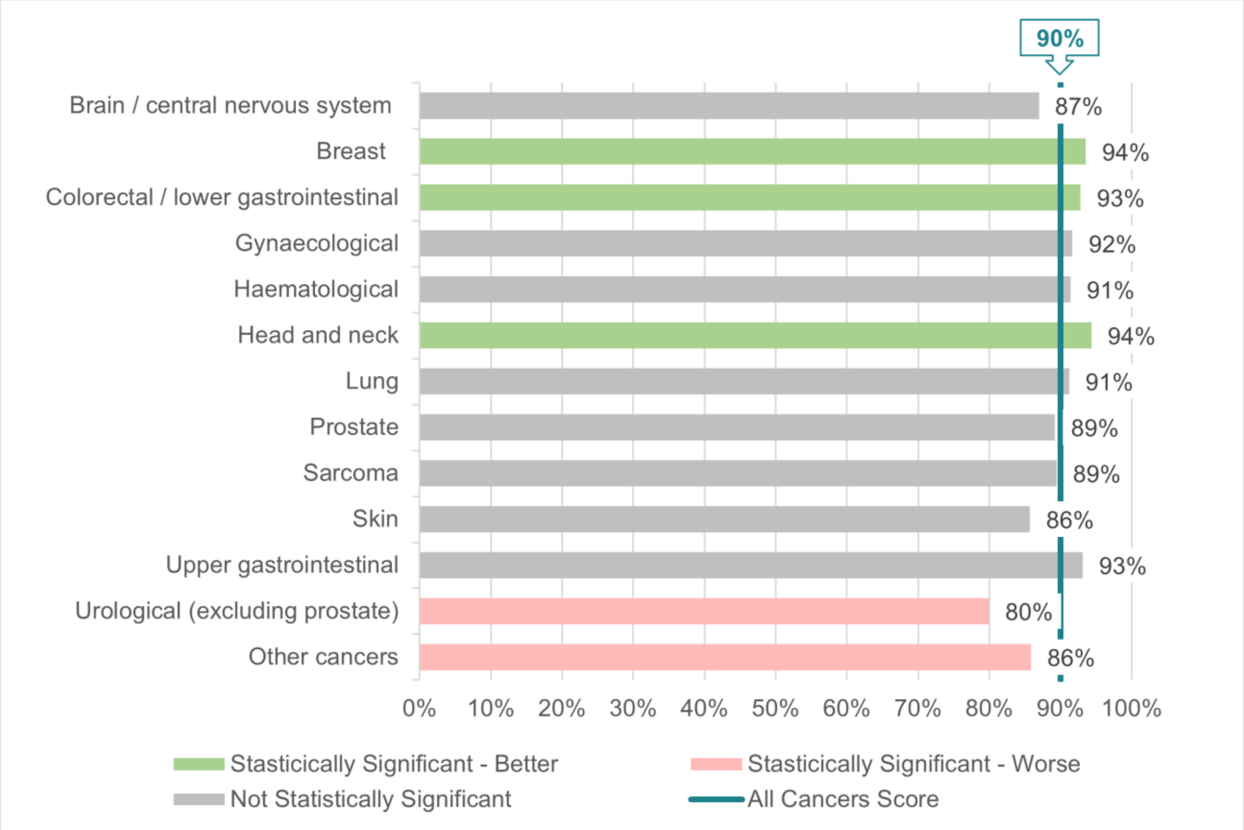
Respondents within the Colorectal / lower gastrointestinal group scored statistically higher for understanding the explanation of what was wrong with them (Q11), while the Haematological group was statistically lower.



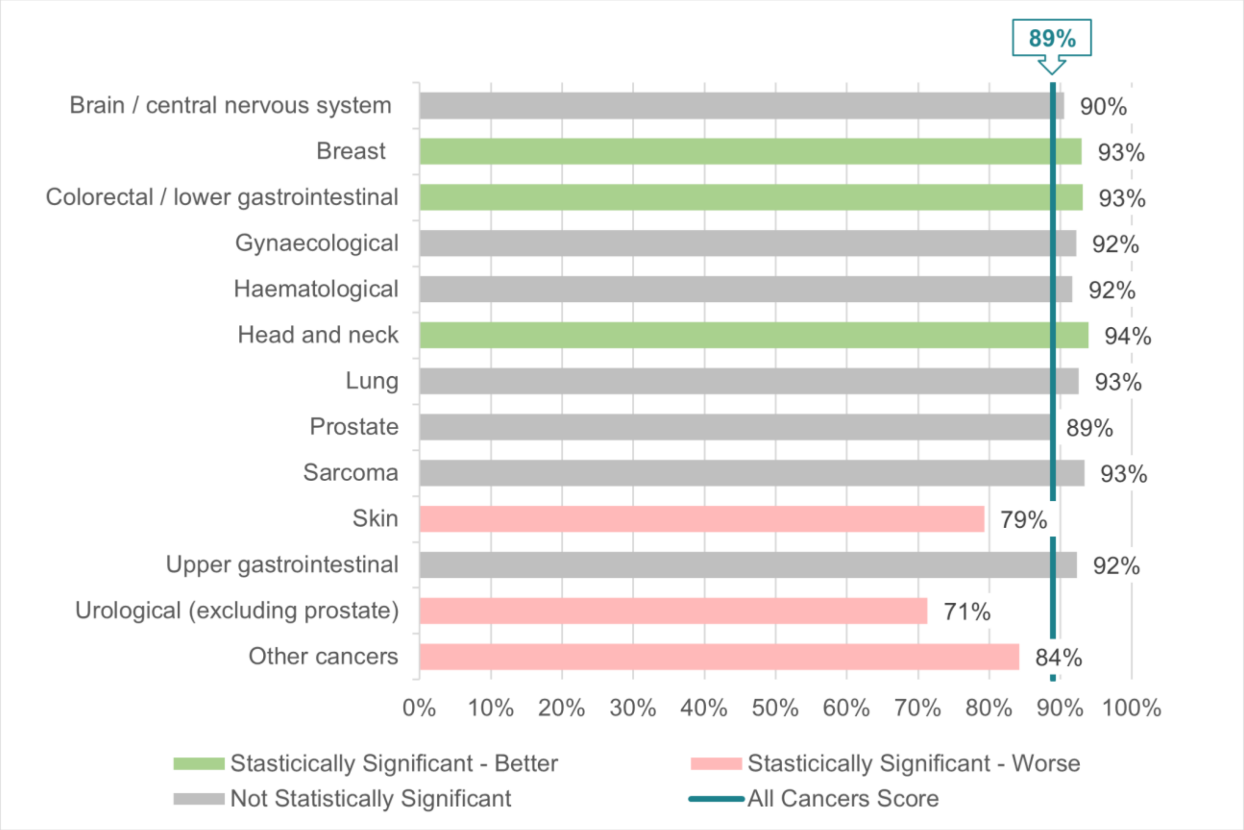
Respondents within the Lung tumour group scored statistically higher when asked if they were involved as much as they wanted to be in decisions about their care and treatment (Q16), while the Urological group was statistically lower.



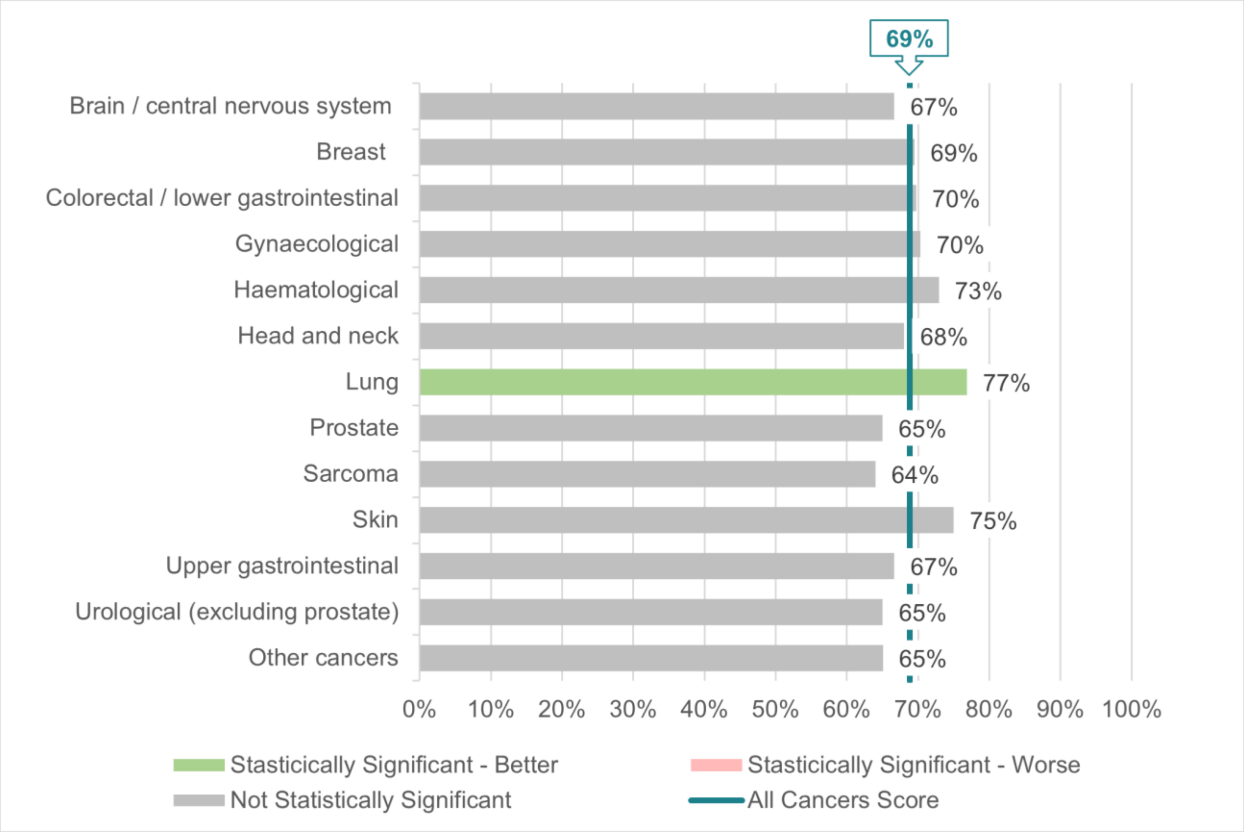
Respondents within the Breast, Colorectal / lower gastrointestinal and Head and neck tumour groups scored statistically higher for saying they were given the name and contact details of their Key Worker (Q20), while the Urological and Other cancers groups were statistically lower.



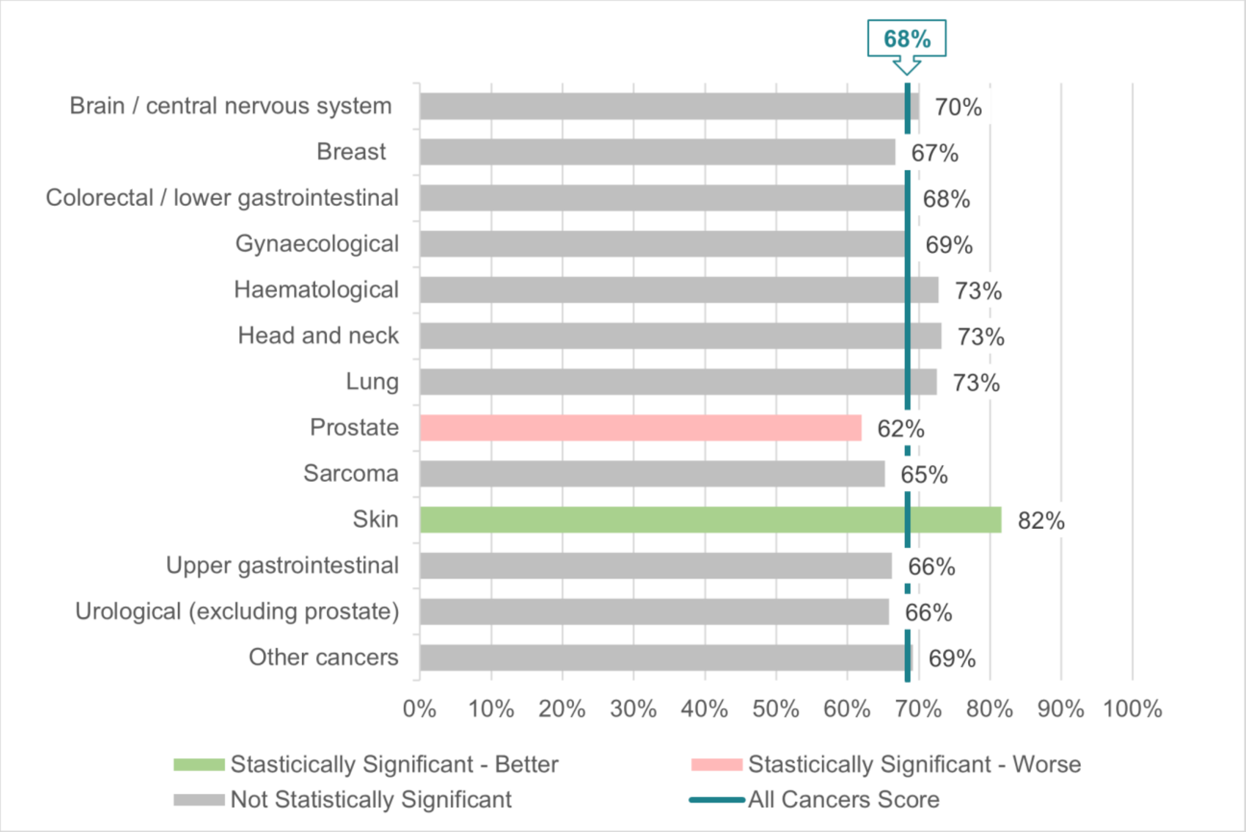
Respondents within the Breast, Colorectal / lower gastrointestinal and Head and neck tumour groups scored statistically higher for saying their care included access to a CNS (Q21a), while the Skin, Urological and Other cancers groups were statistically lower.



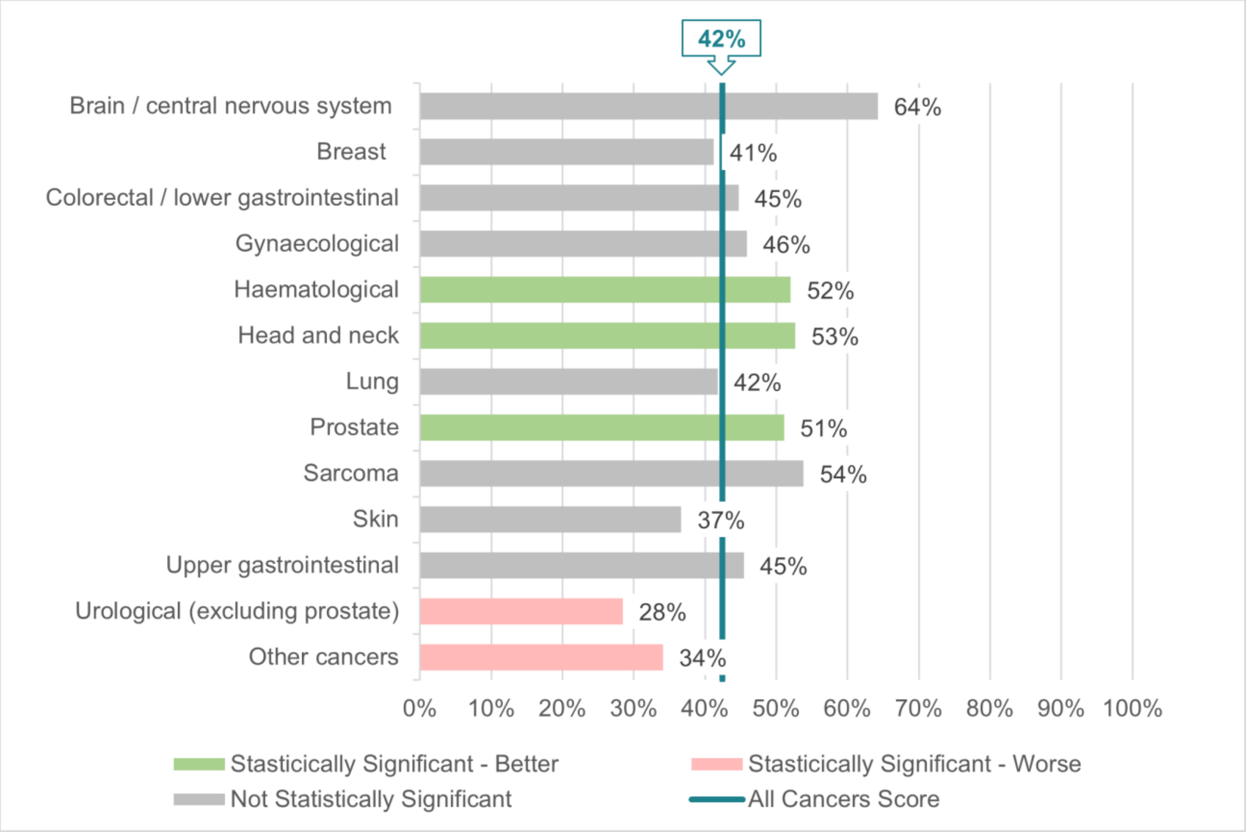
Respondents within the Lung tumour group scored statistically higher for saying it was easy for them to contact their Key Worker (Q22a).



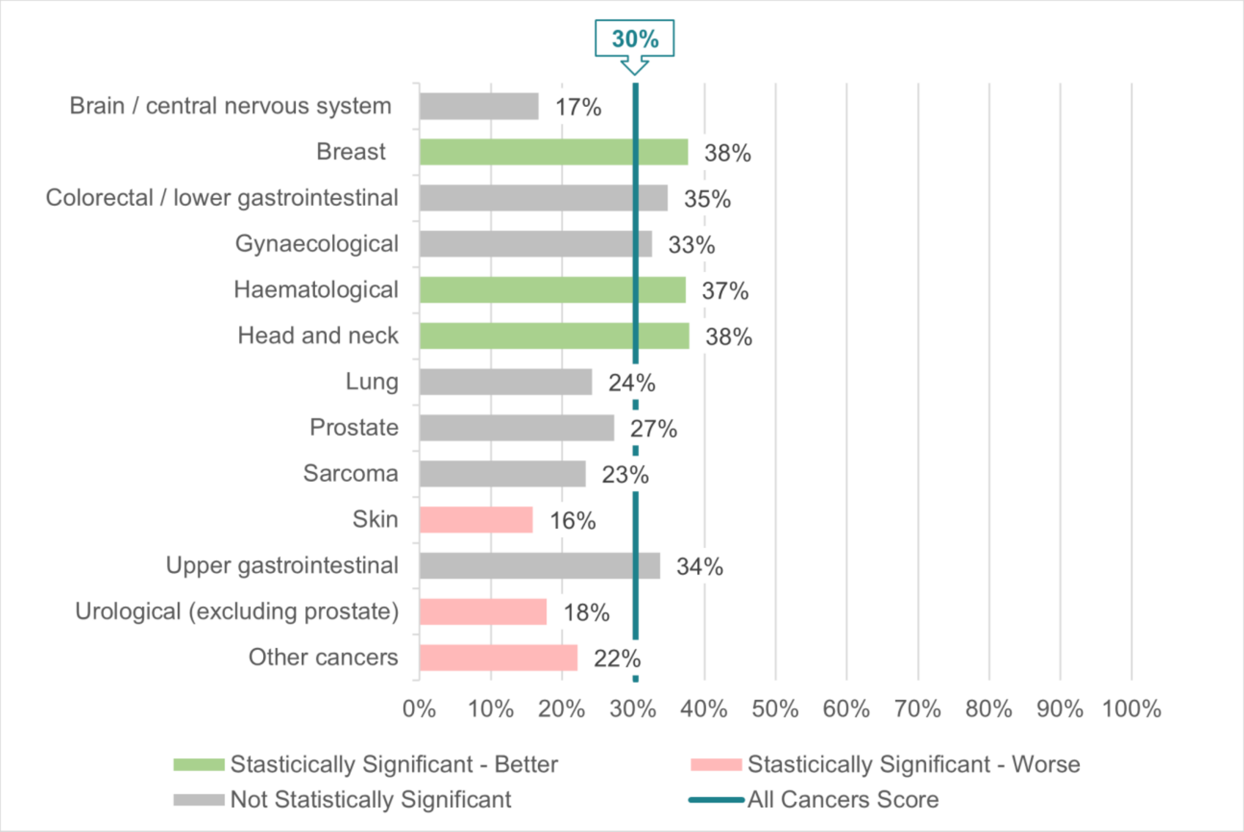
Respondents within the Skin tumour group scored statistically higher for saying it was easy for them to contact their CNS (Q22b), while the Prostate group was statistically lower.



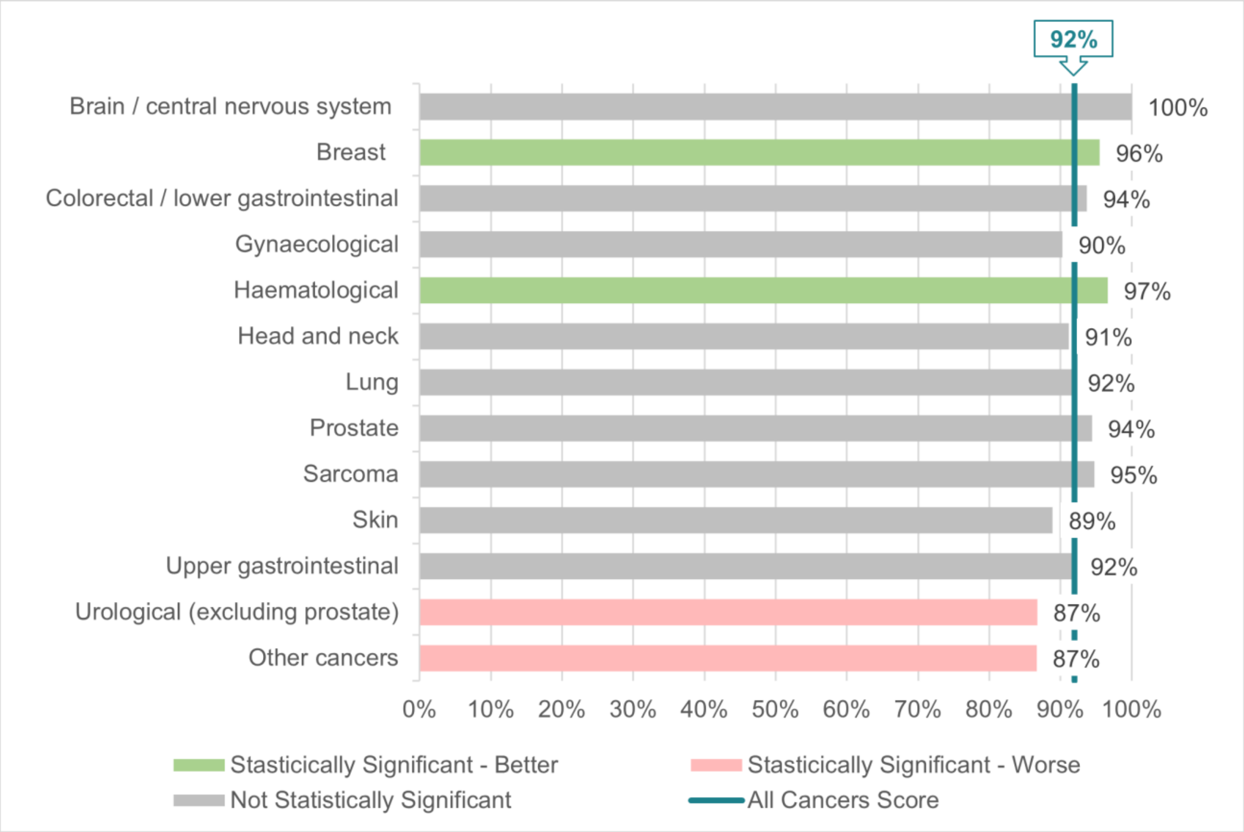
Respondents within the Haematological, Head and neck, and Prostate tumour groups scored statistically higher for saying they were offered the opportunity to discuss their needs and concerns (Q25), while the Urological and Other cancers groups were statistically lower.



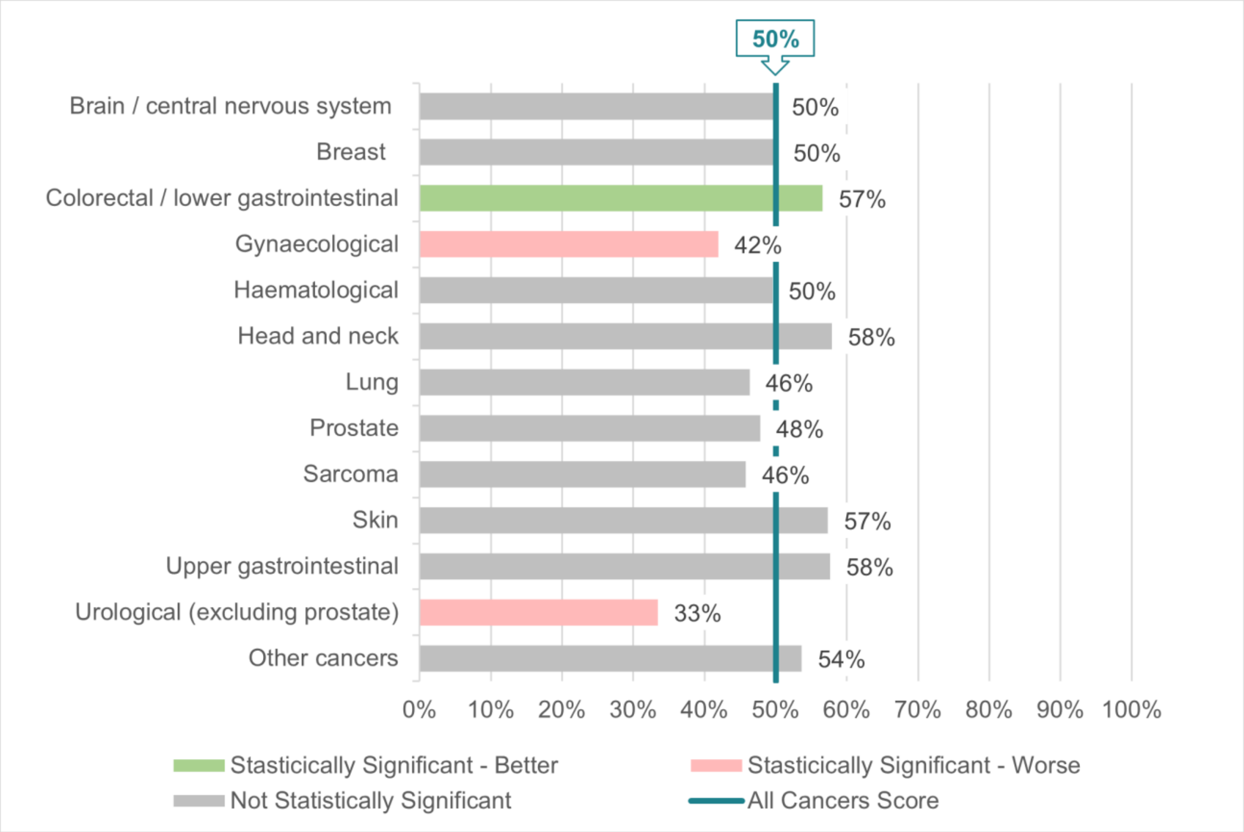
Respondents within the Breast, Haematological and Head and neck tumour groups scored statistically higher for saying they had been offered a written care plan (Q26), while the Skin, Urological and Other cancers groups were statistically lower.



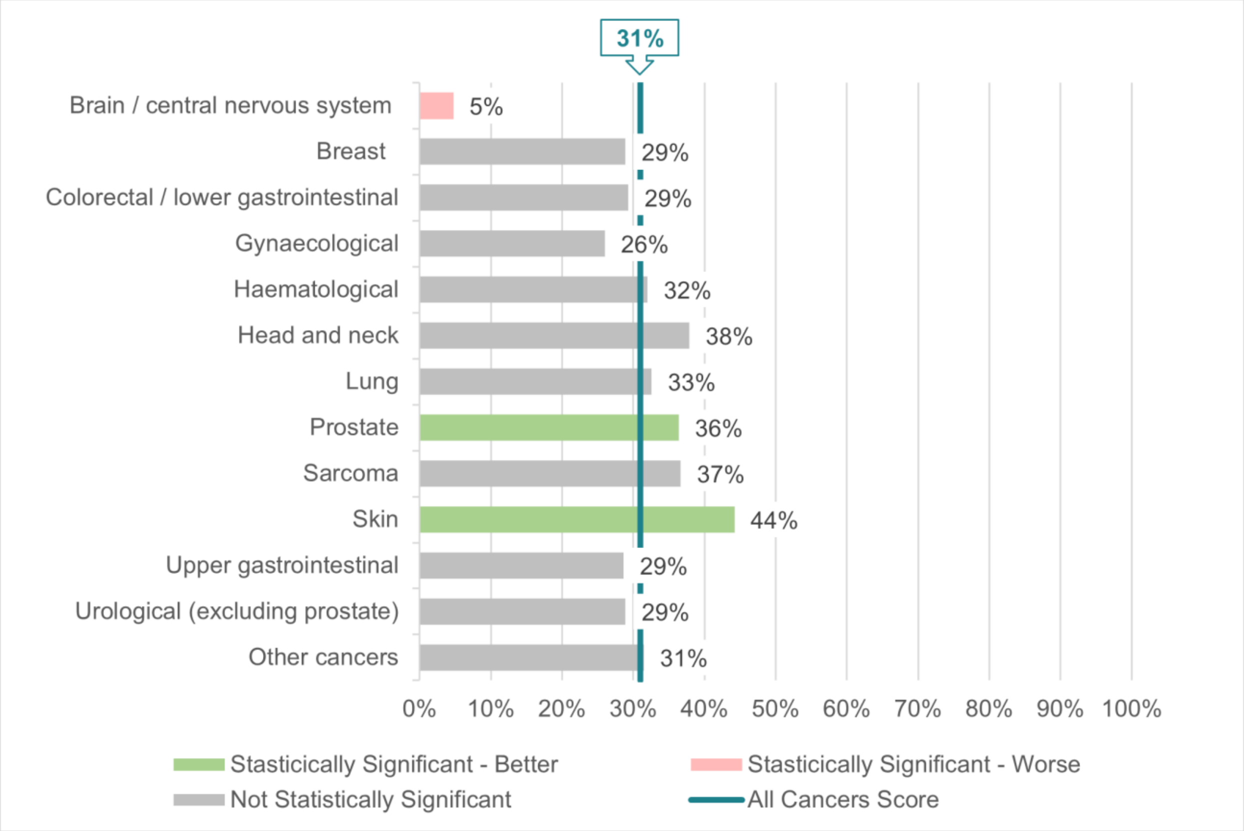
Respondents within the Breast and Haematological tumour groups scored statistically higher for saying that hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital (Q43), while the Urological and Other cancers groups were statistically lower.



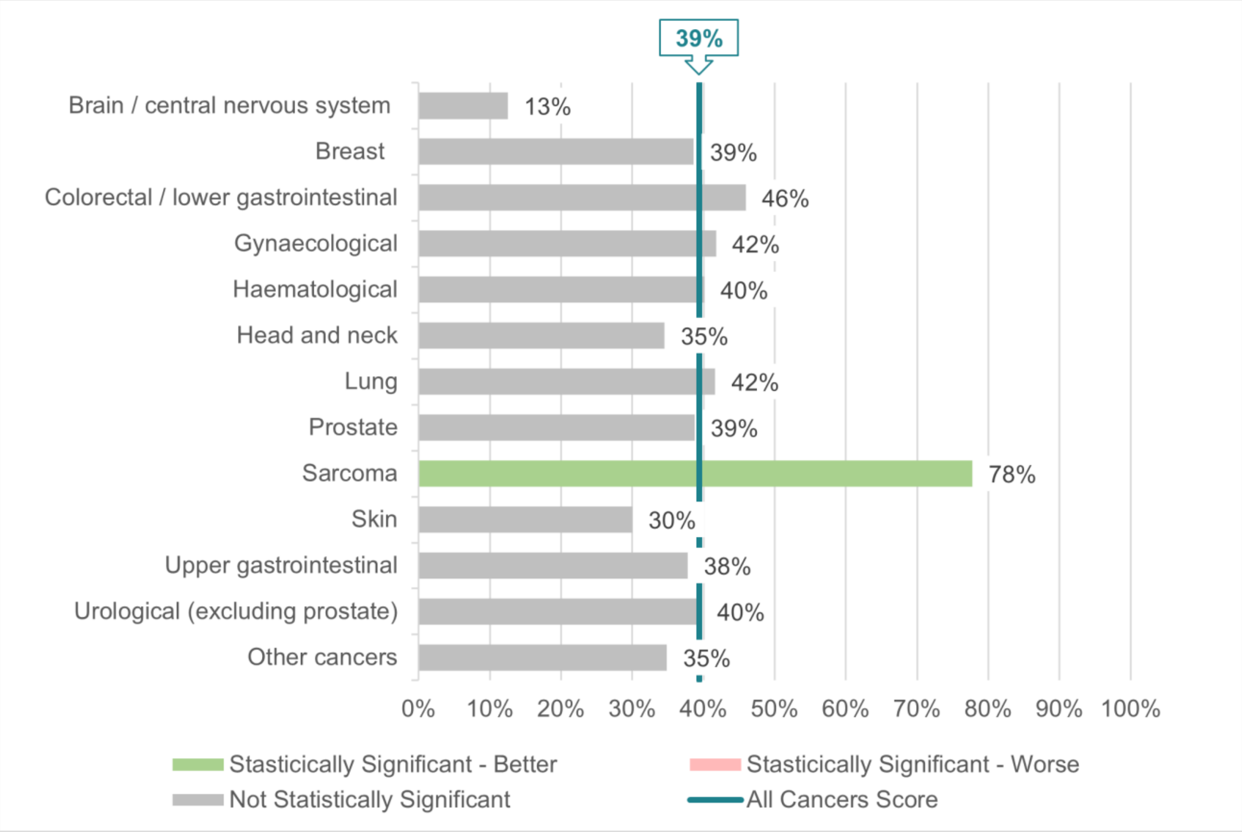
Respondents within the Colorectal / lower gastrointestinal tumour group scored statistically higher for saying that they were given enough care and help from health or social services after leaving hospital (Q54), while the Gynaecological and Urological groups were statistically lower.



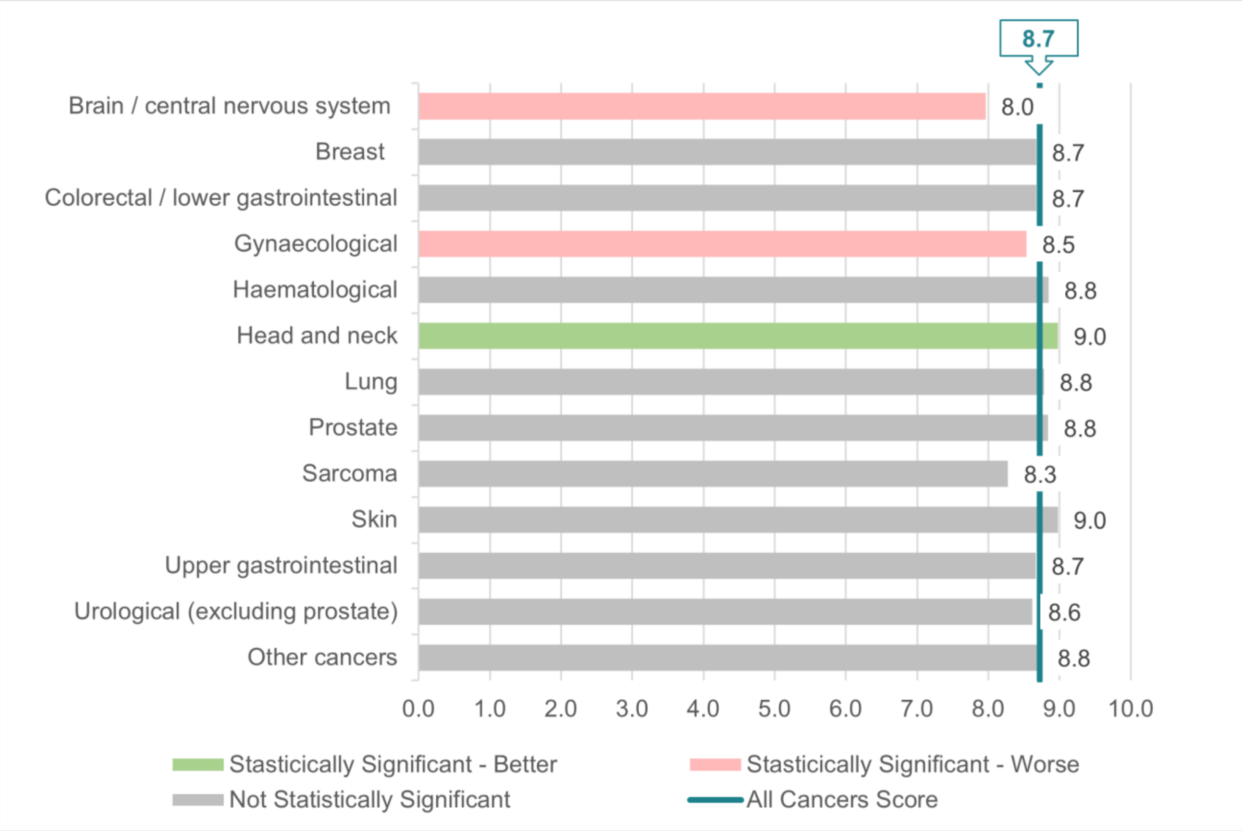
Respondents within the Prostate, and Skin tumour groups scored statistically higher for saying they were given enough care and help from their GP and the GP practice after leaving hospital (Q55), while the Brain / central nervous system group was statistically lower.



Respondents within the Sarcoma tumour group scored statistically higher for saying they were able to speak in Welsh to staff if they needed to (Q60).



Respondents within the Head and neck tumour group scored statistically higher for their overall rating of care (Q61), while the Brain / central nervous system and Gynaecological groups were statistically lower.



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	Secondary and unspecified malignant neoplasm of lymph nodes (C77), of respiratory and digestive organs (C78) and of other and unspecified sites (C79)
C78	
C79	

Any other

C00	Malignant neoplasm of lip
C05	Malignant neoplasm of palate
C11	Malignant neoplasm of oropharynx
C12	Malignant neoplasm of pyriform sinus
C13	Malignant neoplasm of hypopharynx
C14	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
C26	Malignant neoplasm of other and ill-defined digestive organs
C30	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

Part Two:
Qualitative Report

Contents - Part 2: Qualitative Report

1. 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)[19], Cancer Delivery Plan (2016-2020)[20] and most recently in 2021 through the Cancer Quality Statement[21]. 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 Wales[22]. 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 is responsible for designing, implementing, and analysing the survey.

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[19] https://www.iccp-portal.org/system/files/plans/120613cancerplanen.pdf

[20] http://www.walescanet.wales.nhs.uk/sitesplus/documents/1113/161114cancerplanen.pdf

[21] https://gov.wales/quality-statement-cancer-html

[22] https://gov.wales/national-optimal-pathways-cancer-whc2022021

2. Methodology

Overview

This report sets out an analysis of the free text comments to provide a high-level insight to the qualitative feedback.

This report is designed to be read alongside the National Quantitative Report and, as such, includes some references to particular questions when they relate to emerging themes in the qualitative data.

There were 4 open-ended questions at the end of the questionnaire, to give respondents the opportunity to share more about their experiences in their own words:

1. Is there anything you would like to tell us about how your care and treatment was affected by the COVID-19 pandemic?
2. Was there anything particularly good about your care?
3. Was there anything that could be improved?
4. Any other comments?

The first question was added for this year to understand how the COVID-19 pandemic had impacted the experiences of those receiving cancer care in Wales. The remaining questions were as they were in 2016 and did not focus on a particular part of the pathway so respondents could choose what to comment on.

There were 6,259 respondents to the survey overall, although not every person left a comment.

A count of respondents to the open-ended questions broken down by language of completion, mode, Health Board and tumour group is included as Appendix 1 of this report.

Open ended question	Number of respondents	Percentage of total respondents
Is there anything you would like to tell us about how your care and treatment was affected by the COVID-19 pandemic?	3,121	50%
Was there anything particularly good about your care?	3,629	58%
Was there anything that could be improved?	2,322	37%
Any other comments?	1,734	28%

Preparation and sanitisation of comments

Following the close of fieldwork, all handwritten comments were scanned and typed up. Where needed, comments were translated for analysis, and all comments were sanitised. The sanitisation process includes the removal of identifiable details, such as names and dates, to protect the confidentiality of respondents.

Approach

An analysis was undertaken of the free text comments to complement and enrich the understanding behind why people have responded in the way they have to the closed ended questions. The aim of this analysis was also to identify areas of interest that were not included in the question set. An inductive thematic approach was used for the analysis, this is a process of analysis used to uncover patterns across the data and is further detailed below.

Question 1 was treated as one item for analysis, while questions 2-4 were treated as another. The reason for the merging of questions 2-4 is that, while questions 2 and 3 prompted respondents to think about what was particularly good or what could be improved, sometimes respondents would leave, for example, a constructive/negative comment for question 2 or a positive comment in question 3. By treating the general questions as one, the comments can be more accurately grouped together as the themes overlapped between the two. While there was overlap with the question about the impact of the COVID-19 pandemic, the themes were considered different enough to justify the separate treatment of this question.

There were 3629 responses to the question about what was good and 2322 responses to the question about what could be improved. Often, comments about what was good were shorter and put in more general terms, whereas comments about what could be improved were longer and more specific.

Comments were inductively coded by researchers which ensured that the codes were driven by the data. A coding framework was created after an initial review of the comments, the codes were subsequently applied to all comments and the data was organised using NVivo (qualitative analysis software). Individual comments often included multiple sub-comments, where more than one code can be applied to each ‘whole’ comment. The codes were grouped into sub-themes and then into overarching main themes and these were developed and reviewed throughout coding and analysis. The main themes describe central concepts common across the data with subthemes demonstrating different facets of each theme.

Quotes are included to illustrate the themes throughout this report. All quotes included in this report are verbatim (with the exception of any identifiable information that has been removed) and therefore some have spelling and grammar errors. Some quotes are part of a ‘whole’ comment where multiple sub-comments were identified within a whole comment.

3. Analysis of COVID-19 question

This section addresses the comments to the question:

Is there anything you would like to tell us about how your care and treatment was affected by the COVID-19 pandemic?

The comments were organised into eight themes:

- **Minimal impact**
  When given the opportunity to talk about how COVID-19 affected their care and treatment, some respondents described how they did not believe it had an effect.
- **Being alone**
  One of the most spoken about consequences of COVID-19 were the restrictions in place that required many people to be unaccompanied by family or friends during their cancer journey. This section summarises the key areas where respondents felt this this happened and the impact that it had.
- **Virtual communication**
  One of the major impacts of COVID-19 people spoke about was the move from face-to-face to virtual appointments. This section summarises the challenges and successes of virtual communications described by respondents.
- **Quality of care**
  Many people chose to speak about their care during the COVID-19 pandemic in terms of the overall quality (i.e. good/bad) as well as the overall care delivered by healthcare professionals or “staff”.
- **Delays and cancellations**
  Respondent’s comments revealed how COVID-19 caused delays at multiple points within the cancer pathway, including the rescheduling and cancellation of operations.
- **Personal Protective Equipment (PPE) and other precautions**
  When talking about the effect of COVID-19 many respondents talked about the practical impact of the protocols and restrictions in place and how these made them feel.
- **Support and information**
  Many respondents used the opportunity to comment on the support and information they received throughout the COVID-19 pandemic and how this met or differed from their expectations.
- **Reduced service**
  Within many of the comments there was a strong theme of respondents experiencing a reduction of cancer services and treatment during the COVID-19 pandemic. This section outlines examples of where this happened and how people said it had affected them.

Key areas within each theme, along with illustrative comments, are explored over the next chapter.

3.1. Minimal impact

When given the opportunity to talk about how COVID-19 affected their care and treatment some respondents described how they did not believe it had had an effect.

No impact

Many people responded to this question with comments explaining that they did not think the COVID-19 pandemic had impacted on their experience or that they thought it had had little impact on their experience. Some respondents stated they felt lucky that it had not affected them or that they were impressed with how staff managed.

“I do not believe my cancer care was unduly affected by COVID. I was seen very promptly and received a very positive outcome.”

“It seemed to me that the staff coped with the COVID-19 situation impeccably and at no time did I feel I was receiving a lesser service as a result.”

“I was fortunate to have continuous care, surgery, appointments etc. throughout the COVID-19 pandemic.”

“Doesn't seem to have had any great impact on hospital care.”

“At no time did I have a procedure or operation cancelled because of COVID for which I am very grateful.”

“Since COVID-19, I have been impressed by how my treatment has continued without interruption.”

“Procedures necessary were still carried out during the COVID-19 pandemic, which I thought was excellent.”

“I do not feel like the COVID-19 pandemic has had any negative impact upon my cancer care.”

“There has been no impact to my care during the COVID-19 pandemic.”

“By the time the pandemic had started I was already having immunotherapy treatment as part of a trial, this continued as normal, fantastic!”

“There has been very little difference in the care provided by [hospital name removed] before COVID-19. They have been excellent. I have received all my usual appointments and treatments.”

“My case has not in any way been impeded by COVID-19.”

“My care and treatment has not suffered or been deferred at any point during the COVID-19 pandemic.”

No delays

Many people who spoke about the minimal impact of the pandemic on their care put this specifically in terms of not experiencing any delays or being satisfied with the speed at which things moved.

“I don't think my treatment was delayed by COVID. I was very fortunate that my treatment could go ahead as soon as possible.”

“Delays in hospital treatment due to COVID-19 are often on the news, but in my experience from diagnosis to now I was dealt with promptly and quickly.”

“I was diagnosed after COVID-19 struck and am extremely grateful for the swift and efficient was at which I was treated.”

“The speed of treatment was very quick and I was surprised especially with COVID-19.”

“I'm pleased that my treatment/therapy/operation were not affected by the pandemic in respect of being delayed.”

“My care during this time was never interrupted. I carried on as normal. I think patients were very lucky.”

“Considering the circumstances of the lockdown, I received the best and quickest service that the NHS could provide.”

“Even though this was in COVID times the response I got from first seeing my GP to getting my treatment was within a few weeks. I have no complaints whatsoever regarding my treatment provided by the NHS.”

“I was lucky to get the surgery and treatment in a timely fashion.”

“I don't think my treatment was delayed by COVID. I was very fortunate that my treatment could go ahead as soon as possible.”

“My treatment and diagnosis was excellent. It was immediate and quick and, after the colonoscopy and diagnosis, the operation was within two/three weeks and not affected by COVID-19, brilliant.”

“I was diagnosed at the start of COVID-19 and was concerned that it would delay my treatment but, fortunately I was very pleased with the speed at which I was seen and the treatment I received.”

“COVID has not affected my treatment. The team have always tried to ensure my treatment has had no delays.”

3.2. Being alone

One of the most spoken about consequences of COVID-19 were the restrictions in place that required many people to be unaccompanied by family or friends during their cancer journey. This section summarises the key areas where respondents felt this happened and the impact it had.

Appointments and Treatment

Many respondents told us that COVID-19 affected them in that they had to attend appointments or go through treatment alone, without being allowed to have a friend or family member accompany them, or to have visitors during hospital stays. Most people reported that this was a negative part of their experience, citing it was hard, difficult or lonely even if they did understand the reason behind it.

“COVID did not allow my spouse to attend hospital on day of operation and during my stay afterwards, or during my radiotherapy treatment. Feeling alone in what was a very traumatic time.”

“The only issues I had was not being able to attend appointments with my spouse (apart from the initial diagnosis), they too found this very difficult to cope with. I felt very isolated and having to go through cancer treatment alone is very scary.”

“My husband was not able to accompany me to any of my chemo treatments or to see me during a hospital admission.”

“Going through treatment without anyone being able to attend appointments and treatment with me was very difficult.”

“Difficult not having family support when having treatment.”

“COVID-19 - Made from the beginning of my treatment a lonely journey without any family member being allowed to attend with me, except my spouse when admitted to the hospital to explain what would happen and that. That would be the only time they could accompany me.”

“The COVID 19 pandemic made treatment for cancer a very lonely time. Having no support from family and friends during treatments was hard for lots of people.”

“Due to COVID, a family member couldn't come with me during my treatments nor during my appointments. This was difficult.”

“Not having visitors was very hard.”

“It was difficult not to be able to have any visitors and the Wi-Fi connection was not always good enough for video calls.”

“The only period that was difficult for me was when I had radiotherapy at the beginning of the pandemic. I stayed there at [location removed] for 2 weeks and I wasn't able to welcome family members as visitors, nor was I able to chat with other patients.”

“I know there is no easy way of saying this but I think someone should have been with me- there were no visitors (COVID) no company at all, only a clock on the wall ticking away my life.”

“Being an inpatient without any visitors can be lonely.”

“It was very difficult not to be able to receive any visitors during my hospital stays.”

“Due to COVID-19 I was unable to have family support at any of my treatments, diagnosis, etc. I totally understand and accepted the situation.”

“Because of COVID-19 family wasn't allowed to visit me.”

Being alone at diagnosis

The quantitative survey results tell us that 64% of respondents were told they could bring a family member or friend to their diagnosis. Where people spoke about receiving their diagnosis alone, this was typically spoken about as a difficult experience.

“Was on my own when attending my treatment and when I received my diagnosis, I was very upset and did not understand what was being said to me.”

“Having the diagnosis and having to go to every appointment on my own was difficult because of COVID.”

“Receiving a cancer diagnosis during the pandemic was incredibly difficult due to the restrictions in place. Not having a family member with me at diagnosis.”

“Awful to go through diagnosis and treatment alone due to COVID. Needed someone with me to help absorb information but wasn't allowed.”

“I found it very lonely not being able to have my spouse with me at diagnosis and treatment.”

“Not being able to bring someone at my first diagnosis appointment was difficult mentally.”

“Not being able to take my spouse with me to any of my appointments was very stressful, especially the one when I was that I had cancer. I can fully understand during the COVID-19 pandemic that restrictions need to be made but having to deal with this on your own, I think allowances need to be made.”

“My diagnosis and surgery were both during lockdown from COVID-19 pandemic. I felt a bit like a rabbit in headlights. After finding a breast lump my doctor appointment, hospital appointment, biopsy and results were all given to me alone.”

“The only thing I wished was that someone could have been with me for the diagnosis. I was given a lot of information which I found hard to take in, after I was told I had cancer. Without COVID-19 I am very sure things would have been different.”

“COVID 19 meant that I was completely alone in hospital when diagnosed and operated on. No visitors and no one with me when I was told of my cancer. Very difficult for me and my family.”

Impact on mental wellbeing

Many people gave us further detail on how their mental wellbeing was negatively impacted due to being alone whilst on the cancer pathway. These comments described the impact both generally and specifically, including references to being scared, frightened, anxious, stressed and depressed.

“My mental health was impacted massively by my cancer diagnosis and having to go through the experience alone.”

“Mental health suffered by not being able to have visitors in hospital, particularly to be told on my own that I had cancer while in hospital.”

“Prohibition of family member visits affected my mental ability to fully cope with my rehabilitation following procedure and chemotherapy.”

“Greatly effected in terms of family support. Being young I needed family and friends to help me mentally and physically and many situations were extremely lonely and scary without this.

Having [procedure removed] alone and being without seeing family for 20 + days has greatly affected me mentally.”

“The inability to have family with you on appointments and surgery really impacted on my mental health. To have to face such things alone has led to depression and anxiety, which hasn't improved since treatment finished.”

“These procedures were all new to me and I was frightened. It would have helped with anxiety and worry if I was not alone.”

“I had 2 stays in hospital during COVID-19, it was frightening and sad not seeing the ones closest to you.”

“Felt alone, frightened and isolated.”

“I had to go through it all alone as my spouse was not allowed in hospital with me, which was frightening and then they do not fully understand what you have been through.”

“Found having to go alone for mammogram results etc. Very stressful. But the staff were very aware of this.”

Information available to family and retaining information

The quantitative data tell us that 37% of respondents that had family who wanted to talk to healthcare professionals, reported their family definitely had enough opportunity to do so. In the comments, some respondents spoke about how family members were not able to get information about their cancer diagnosis or care because they were not allowed to attend appointments with them.

In addition, respondents told us that attending appointments alone meant that they had no-one to help them retain or process the information they were given.

“Obviously, the fact that no visitors were allowed made receiving information about my condition and care very difficult for my family.”

“The main comment is the lack of information shared with family members i.e. main carer (wife). My wife had to insist that she be allowed into hospital and attend briefings, meetings and consultations. At one point I was sent home with chemotherapy drugs without adequate information. This was a policy of the hospital, no one else allowed in!”

“Due to COVID-19 restrictions it was not possible for my wife to attend the chemotherapy unit so when I was discharged after my final treatment she was not given any information on my future care.”

“I had to receive very distressing news on more than one occasion during this stay while I was on my own. I then had to relay this information to my family while I was still trying to take it in myself. I don't think this is conducive to the recovery of patients in hospital; it put a lot of stress on me at a time when I didn't feel strong enough to be able to cope with it. This quite possibly has been one of the worst and most stressful experiences of my life.”

“I understand that the pandemic meant that I couldn't bring someone with me to appointments a lot of the time, but it was hard for me to try and remember and relay information to my family. It would have been helpful to have more contact between my doctors and my family.”

“Having all your meetings on your own, while being diagnosed with two cancers at the same time, was hard. Not just emotionally but actually remembering all the information and asking the right questions.”

“My care was dramatically affected by COVID 19. Al but 1 of my appointments was done alone which made it very difficult to process all of the information.”

“Awful to go through diagnosis and treatment alone due to COVID. Needed someone with me to help absorb information but wasn't allowed.”

“It was difficult as no visitors were allowed to visit during my stay in hospital not even my spouse. Also no one was allowed to attend O/P clinics either which was difficult as I do not always retain information given to me or ask the appropriate questions.”

“Had to attend all appointments on my own which I found difficult especially if there was a lot of information involved.”

“I was unable to take anyone with me for my appointments. The initial time when I was told I had cancer even though the pandemic was here I think I should have been allowed to have someone with me to help me take the information in.”

Positive experience of restrictions

There were some respondents who felt that attending alone was a positive. In addition, some people told us that staff helped them to feel that they were not alone.

“I think it's actually been quite nice to not have the waiting room rammed by patients. Although it's sad that patients are sat there having chemo on their own, I think it actually works better and makes for a better environment for the ward, plus it reduces the amount of people you have to come into contact with.”

“I preferred not to have anyone with me and having to deal with their emotions so again COVID restrictions suited me.”

“Due to COVID there was no visitors on the ward as inpatient, a fact that I found very enjoyable! It allowed post op patient proper rest and no crowds.”

“Not having visitors was awesome. Time on my own with no one coming into see me gave me time to recover and get home sooner.”

“My treatment was affected all the way through because I had to go to every appointment, chemo/radio and surgery on my own. In my own case, I think this worked well. I am an independent private type person and I think sometimes it's easier to deal with my own emotions on my own.”

“I thought that not having visitors when I went into hospital for the operation was better for both myself to come round and not have to be sociable.”

“I attended all appointments on my own voluntarily to avoid unnecessary exposure.”

“Visitors were not allowed which was correct.”

“The only way COVID-19 affected things was by going to appointments alone but this could not be helped as everyone had to try and stay as safe as possible and I fully agree with the rules.”

“Was very pleased with my treatment and the care because I did not feel alone the staff were very good”

“Considering the enormous strain all staff are under. I never felt alone during my care.”

“Had my treatment while we were on lockdown so I went on my own to my appointments the staff at the hospital were wonderful and when I had my radiotherapy.”

3.3. Virtual communication

One of the major impacts of COVID-19 people spoke about was the move from face-to-face to virtual appointments. This section summarises the challenges and successes of virtual communications as described by respondents.

Challenges of virtual appointments

Some people questioned if it was possible to receive the same service in a virtual appointment as they would in person, whether this was because they felt an in-person examination was required or because they found communication less effective virtually, particularly for those with impaired hearing. As with attending appointments alone, there were many who acknowledged that they understood why this change was implemented.

“Telephone appointments were understandable at the beginning of the pandemic. Routine telephone appointments monthly are convenient but should be interspersed with face to face as this would help my understanding of the progression of my cancer and might help to improve my care.”

“Most follow up done by telephone, which is understandable and worked for me, but not the ideal way to discuss health matters.”

“Given useless telephone appointments instead of face to face. How can a surgeon on the phone give you your 5th year physical examination? How can you have a mammogram over the telephone? Absolutely ridiculous!”

“The telephone appointment were a real struggle, as I find it hard to absorb the information when speaking on the phone. After the call I could not be able to tell my spouse the details and what was happening next.”

“I would have liked to have face to face appointments and a doctor or a nurse to check my breasts. A telephone appointment wasn't effective. A chat isn't the same as a physical examination. Of course, I fully understand why this didn't happen.”

“I have had monthly telephone appointments with a healthcare professionals but it's not like seeing your consultant and being able to discuss things in person. I've found that in telephone calls, I've forgotten to ask questions and felt more anxious.”

“Because of COVID 19 the only people I've seen are for my radiotherapy and mammogram. Everything else was done over the phone. Because I have hearing loss I found this quite difficult on time didn't know if I fully understood the information and I'm not the kind of person to question things”

“I'm not enjoying having my consultant appointment on the screen. I would prefer to go back to face to face (I already have to travel to go inside the hospital for the scan so wouldn't be much more risk to see the doctor I think).”

Receiving diagnosis over the phone

A point that people particularly pulled out when discussing virtual appointments was receiving their diagnosis virtually, with many expressing dissatisfaction with this.

“Being told that you have cancer on the phone is not acceptable, didn't hear anything from my key worker even though I phoned and emailed. Very disappointed.”

“When I was first diagnosed, it was on the phone, Oncology phoned to invite me to start treatment. I hadn't been informed by consultant, I had cancer so it was a shock. There was a lot of missed communication between the hospitals.”

“Was told about cancer over the phone because of COVID GP wouldn't see me in person.”

“Albeit there was very little support as a result I was given one diagnosis over the phone which is not the best.”

“I was told that it was incurable stage 4 cancer over the phone by my oncologist and again this was as a result of COVID. This was a very devastating phone call and would have been better done face to face. I understand why it had to be done on the phone, but receiving an incurable cancer diagnosis on the phone is not ideal.”

“Not happy being told over phone my diagnosis.”

“The initial video diagnosis from my GP wasn't easy to do alone.”

“GP has never asked how I am since diagnosis. Would have been good to have received diagnosis in person rather than a phone call.”

“I found it very unprofessional that I was told this diagnosis over the telephone. Despite COVID-19 this should have been handled face to face by GP I have not raised complaint but made feelings known.”

“Obviously COVID had a massive effect my diagnosis came by phone while I was supermarket shopping I was shocked and distressed that a tiny mole could have this outcome.”

“Being told you have a cancer over the telephone is devastating.”

Convenience of virtual appointments

Although they were not in the majority, some people told us that they were pleased with their virtual appointments or expressed a preference for this. The reasons included the convenience of not having to travel for a face-to-face appointment and the reassurance of feeling safe.

“Some of my appointments have taken place over the telephone, due to pandemic.   This is not an issue and I think this something that should continue in the future, where appropriate, as I am sure it makes time management sense for staff. It also makes things easier for patients, who are able to receive information in the comfort of their own home.”

“Video appointments were really helpful - it was useful to see the nurse, be able to show her my scars and get advice without having to go into the hospital.”

“I have had no need for 'face to face' meetings, but my needs have been met by very positive telephone consultations.”

“I had telephone reviews which I found very helpful and had a positive effect on my wellbeing not having to wait at the outpatients for a long time definitely has a positive effect.”

“During the pandemic my regular check ups took place over the phone, which worked out very well for me. I was always able to have any concerns I may have dealt with, to keep my visits to the hospital as few as possible. I am able to phone them any time I have any concerns at all.”

“Service offered on Zoom and medication delivered at home. You cannot ask more than this.”

“During COVID-19, many of the appointments were over the phone and more convenient than the travelling back and forth. Blood tests were also done locally without the hassle of tiredness that travel brings (40 miles) also quicker.”

“Due to COVID post first face to face consultation update with team are via phone appointments these have worked very well providing regular updates on blood test and CT scan results, as well as ensuring my ongoing treatment is effective and continuing any adjustments required.”

“Understanding there were some delays, but overall the care I received was excellent. The telephone consultations were a very good way of communicating without the need to attend hospital.”

“More phone contact was welcome instead of F2F appointments due to distances to travel.”

3.4. Quality of care

Many people chose to speak about their care during the COVID-19 pandemic in terms of the overall quality (i.e. good/bad) and also about the overall care delivered by healthcare professionals or “staff”.

Positive experience of care

The majority of people were positive about the quality of their care – unlike the ‘minimal impact’ theme, many of these comments expressed that the care they received was good despite the impact of the pandemic. Other comments simply spoke about how good the care was and did not mention the perceived impact of the pandemic at all.

The quantitative survey results tell us that:

- The average rating of care is 8.72 (where respondents were asked to rate their care from 0 to 10).
- 90% of respondents said they were always treated with respect and dignity in hospital.

“Under the circumstances I had excellent treatment.”

“The care I have received has be A1, could not have asked for better even though all the COVID 19 problems.”

“The hospital cancer care was excellent during a very difficult period for the NHS.”

“My operation was at the start of the pandemic in 2020. I was fortunate that everything was handled very well.”

“My treatment following diagnosis was good overall, especially as it was during the first month of a pandemic.”

“My treatment despite COVID-19 has been 100%. I can't praise the NHS enough for everything they have done and continue to do for me and my family.”

"I am lucky to live in Wales and have received the best care, attention and treatment both for the cancer and for my well-being. Thank you NHS."

"The treatment I received at [hospital name removed] was so good you would not know there was a pandemic going on. Top notch care from the [hospital name removed] staff."

"My treatment has been excellent during the pandemic. Better than I hoped for. Thank you."

Care from healthcare professionals

The quantitative survey results tell us that 84% of respondents had confidence and trust in all of the healthcare professionals involved in their care.
Often quality of care specifically referred to the support of the healthcare professionals involved, and how hard they worked to make the difficult situation manageable.

"I had a hysterectomy during the first lockdown. The staff were amazing, working under difficult circumstances, but always making their patients their priority."

"I had fantastic treatment by all the staff and under very difficult conditions as COVID was very active at the time, they acted promptly and professionally at all times."

"I feel very strongly that nearly all health professionals I came into contact with did their best in very difficult circumstances. I realise that my treatment would have been very different if it hadn't been for COVID."

"During all of these visits every staff member I met was so welcoming, kind, compassionate and caring and it helped a lot that I was treated so well by them all."

"Due to COVID 19, nurses were unable to sit and chat. Short staffing due to some nurses getting COVID. They all did their best for everyone and I am very grateful to how they looked after me considering the circumstances."

"During that time all surgeons, doctors and nurses have treated me with care and compassion during some difficult times having been a regular patient or cancer since [date removed] no praise is adequate to explain how well I have been treated (and still am). The NHS is very fortunate to have these members of staff."

Negative experience of care

A minority of people spoke about their care in a negative way, with some speaking in general terms and others specifically linking this with a perception that COVID-19 was given priority above cancer care. This included some comments where people indicated they were disappointed with the aftercare or care from their GP practice.

In terms of aftercare, the quantitative data tells us:

- 46% of respondents said that they were definitely given enough information about how to manage their health and wellbeing after their treatment ends
- 46% of respondents said they were definitely offered enough practical advice and support in dealing with the side effects of their treatment at home
- 50% of respondents said they were definitely given enough care and help from health or social services after leaving hospital
- 31% or respondents said they were definitely given enough care and help from their GP and GP practice after leaving hospital

"Yes COVID was given priority. Why is this? A life is a life and should be treated equally."

"Discharged after operation sooner than I expected or felt ready for as I live alone and no family near."

"The questionnaire answers all appear negative, however I believe that my experience was adversely affected by COVID. Interactions with health care professionals was not possible to meet my needs. I felt very isolated and my care was not as good as my spouse when they had cancer. My experience in hospital was very isolating too."

"However, from the day I left my final radiotherapy appointment, COVID-19 had caused lockdowns etc. and I received no further care or support at all for over a year. My BCN [breast cancer nurse] was never available as she had been assigned to a COVID ward or doing vaccinations and I even had to push for my first annual check up. I felt totally abandoned by the NHS and the care was simply not good enough."

"Any negative responses in my answers can be attributed to COVID. Due to COVID I have felt abandoned, after my surgery, a mastectomy and lymph node removed, early last year just before the first lockdown. Patients like myself were left to themselves to care for after surgery dressings in my case in total isolation. This was a trauma in itself, and quite scary."

3.5. Delays and cancellations

Respondent's comments revealed how COVID-19 caused delays at multiple points within the cancer pathway, including the rescheduling and cancellation of operations.

Delayed diagnosis

The quantitative survey results tell us that:

- 59% of respondents waited less than 3 months between first thinking something was wrong with them, until they first saw a GP or other doctor
- 82% of respondents saw their GP once or twice before they were told they needed to go to hospital about cancer
- 83% of respondents felt they were seen as soon as they thought was necessary for their first appointment with a healthcare professional

Comments relating to delayed diagnosis included not seeing their GP quickly (some by choice and some because this was not available), needing to visit multiple times, delayed tests and subsequent results, and delayed referrals

"COVID prevented me receiving a diagnosis of cancer for nine months."

"Delay in diagnosis (primarily on my part) - I would have contacted my GP 3 months earlier than I did if COVID had not been a factor."

"I didn't do anything about my symptoms at first because of the COVID-19 pandemic."

"I delayed going to my GP after I noticed worrying signs because of the pandemic. As soon as I did phone my GP he fast tracked for diagnostic tests which I will always be grateful for."

"My diagnosis was delayed due to COVID 19 as my GP surgery were not seeing patients so they had diagnosed me over the phone with IBS."

"During COVID 19 I found myself with abdominal pains. I had two phone consultations over two weeks of being ill. In the end I went to A&E where I was diagnosed with a perforated tumour in bowel and had to have an emergency colostomy and was told if I had left it another twenty four hours they would not like to say what may have happened to me. I have since had an apology from a senior GP at my surgery as the second time I called I should have been physically examined at surgery. Unfortunately, I think GPs have put patients at a higher risk of something serious by doing phone consultations during COVID 19."

"I feel like my GP was blinded with COVID and didn't think of what else it could be. I was told three times it may be a false negative, do another PCR."

"Without doubt the time taken from visits to my GP and tests were longer due to COVID-19 pandemic."

"My bone marrow biopsy was delayed due to COVID 19, which delayed my leukaemia diagnosis."

"The diagnosis of bladder cancer was spotted as a result of a delayed follow up test due to COVID restrictions."

"The diagnostic tests were delayed due to COVID-19."

"I think I should have been referred at the previous appointment but wasn't."

"I had to wait longer than usual after being referred to the hospital by my GP. I could not see my GP in person and found that the image quality of the pics I sent to him on my skin cancer were not sufficient to ensure a visual diagnosis. This delayed things and I felt I was slow to see my dermatologist."

"I was originally refereed to Haematology in February 2020 as a urgent care and should have had an appointment in around April 2020 and this was delayed by the pandemic."

"I first went to my GP in early 2020 with PMB and I was not referred until I went back 2 months later! I believe I was let down by my primary care practice."

Delayed appointments, scans and tests

Many respondents spoke about delays they experienced to appointments in general follow-ups, and tests/scans related to their cancer. Generally, the tone of the comments was factual or negative.

"COVID-19 caused delays with my appointments in hospital and with my local GP."

"Some appointments have been delayed by the pandemic."

"During COVID some hospital appointments have been delayed."

"Since diagnosis, almost 12 months ago, there has not been any communication/follow up appointments to review my condition"

"As expected, there have been delays in my follow up appointments."

"My yearly monogram was delayed by about 4 months."

"Check ups delayed by COVID."

"Because of the COVID-19 situation the biopsy that I needed was delayed for some time, this should not be the case in cancer verses pandemic."

"Also following my discharge from the hospital, I have had a very long delay to have my scan and endoscopy done, more than a year."

"Scans and appointments were delayed because of it."

Delayed treatment

Many respondents spoke about the delays they experienced to their treatment in general terms, although some specifically mentioned chemotherapy and radiotherapy. Delays to initial treatment starting were also described here. There were some people who further explained how the delay to treatment impacted on their cancer and prognosis.

Due to how often people speaking specifically about delays to their operations, or treatment being suspended, these are addressed as separate sub-themes within this report

"My cancer treatment was delayed."

"Treatment delayed because of COVID-19."

"Some of my treatment was delayed by 6 months due to COVID-19."

"My original appointment to start radiotherapy was cancelled due to COVID 19."

"I am still waiting for my radiotherapy. I have been waiting since [date removed] operation. I am told this was because of COVID-19 back log."

"Due to lockdown my chemotherapy was delayed."

"Chemotherapy was delayed during COVID-19."

"Stem cell transplant postponed and the cancer returned while waiting for the transplant. I then had to start treatment again from scratch."

"I had to wait longer before I started my treatment."

"Initial treatment delayed due to early impact of COVID-19."

"COVID-19 had a direct impact on my treatment it caused a four month delay between original diagnosis and the commencement of treatment."

"Treatment was very delayed, resulting in my tumour doubling in size."

"I have had no treatment only the biopsy which confirmed prostate cancer, I now have 3 monthly blood tests to monitor the situation. My family member had the same cancer and when they died it was it had spread throughout their body. My worry is my treatment delayed because of COVID-19 and the meantime my cancer is spreading."

"My bone infusion was deferred a few months at the beginning of the pandemic. This had no negative impact."

Delayed or cancelled operations

Many respondents spoke about the impact COVID-19 had on their cancer related operations. People described the delays, rescheduling and cancellations they experienced. Delays were reported varying from weeks to months, and some people also told us how the waits made them feel stressed or worried.

"Womb cancer/hysterectomy. Five week wait for hysterectomy from diagnosis due to COVID."

"I waited 11 months for my cancer operation due to the pandemic."

"The surgeon was extremely helpful with regard to operating as soon as possible, but in the end operation was postponed twice."

"Yes, everything was delayed due to COVID. I don't think cancer patients should take a back seat to COVID. I had to wait twelve weeks for my operation which was the worst time. Very, very stressful."

"It was very stressful when surgery was postponed with the onset of the first lockdown."

"Due to COVID-19 the operation was cancelled."

"My surgery was withheld due to COVID."

"My operation had to be postponed due to COVID-19. I was due to have operation, was told cancelled due to COVID-19, devastated."

"3 operations cancelled due to COVID."

"Pandemic caused six month delay in surgical procedure from February 2020 to July 2020 which allowed tumour to progress to stage three causing potential spread to major organs and subsequent complications in treatment."

"At the beginning, following the diagnosis there was some considerable stress and worry as the clinicians involved could not provide even an approximate time scale as to when surgery could be carried out, due to the impact of COVID at that time.(i.e. March 2020). However, surgery restarted after approximately three weeks, which was relatively prompt under the circumstances, but very worrying, in the meantime."

3.6. Personal protective equipment (PPE) and other precautions

When talking about the effect of COVID-19, many respondents talked about the practical impact of the protocols and restrictions in place, and how these made them feel.

Hospital COVID-19 safety precautions

Many respondents spoke in general terms about precautions or restrictions in place. Generally, the tone of the comments was positive/satisfied, although some people had mixed experiences or were dissatisfied with the safety measures or lack thereof.

"All care was done through safety measures."

"I had no difficulty in complying with the COVID-19 regulations at [hospital name removed]."

"I always felt the hospital had put in place enough measures to keep me safe during treatment."

"The hospital arrangements because of COVID-19 have been very thorough
COVID precautions were always explained to me in full."

"[Hospital name removed] had all the COVID-19 things under strict control."

"Precautions taken at hospital very good."

"Myself and the staff at [hospital name removed] took every care possible in order to avoid my having COVID."

"COVID struck as I began my treatment and great care was taken to protect me by everyone at all times."

"I found very stringent measures were in place in all my appointed clinics which was reassuring."

"The hospital followed strict COVID 19 regulations, staff tried their best to provide the care and support given the situation."

"The precautions taken at hospital have been very good."

"In early 2020 I was admitted just as COVID-19 was identified as a pandemic that required special protective measures. My operation was literally on the weekday and the new arrangements were explained to me and fellow patients. All staff were very conscientious and particularly aware of the problems to be faced."

"Treatment received (surgery) was not compromised by COVID-19 issues, all appropriate precautions were taken and no delay experienced."

"I felt safe with the additional precautions taken whilst attending for Chemotherapy."

"Every precaution taken in [hospital name removed] Chemotherapy Unit and the same for the [hospital name removed]. Cannot fault the care and precautions put in place. Excellent."

"My treatment commenced a week before the outbreak of COVID. All precautions were taken to protect me and my treatment went ahead as planned."

“Think everything has been done to keep me from COVID - 19. Everything from the letters to self isolate, to the way hospital staff and the staff at chemo have done the most to protect us.”

“The fact that the hospital is not checking everyone at the entrance for COVID-19 symptoms, temperature and face masking wearing makes me feel less safe to go in for blood tests or other scans, though this is very well done at the cancer day unit during the past few months (not from the beginning), I really hope the health board can reinforce on these to minimise the potential risks of COVID-19 virus spread in the hospital, which will put cancer patients on the extremely dangerous position.”

“COVID made treatment very difficult especially during Chemotherapy treatment. Hospital staff seemed pre-occupied with COVID procedures and neglected some of my care and treatment as a result.”

“My treatment started [date removed] at the beginning of COVID-19. [Hospital name removed] was adapting in the beginnings regarding safeguarding. The health security at the [name removed] department was excellent.”

“The hospital had been physically divided between red and white zones. I felt that the adherence to strict infection control had not been embedded in the white zone, and understood to wipe down the two bed ward several times a day. I felt that I was sometimes at risk of infection - in the few nights in hospital, the staff charged every day, most were very careful, a few were not.”

“Poor infection control during COVID e.g. no working thermometer on ward to check patients.”

“Radiotherapy treatment process changed daily due to the evolving COVID 19 response and staff appeared confused about infection control process as they were changing daily, it felt quite scary.”

“Found that the precaution in place at the [hospital name removed] in [date removed] 2020 at the height of the pandemic was not good at all visiting here numerous times.”

“From my perspective, hospital stays at [hospital name removed] have been very stressful with no visitors allowed and my perception is that COVID-19 controls have been weak. Hospital stays at [hospital name removed] are far superior, with much higher standards of care and COVID-19 controls in place.”

PPE

Many respondents described how PPE was worn either by themselves or staff during their care and treatment. Masks were frequently referenced, although there was criticism of how they impacted care, especially communication.

“Masks used everywhere.”

“Was especially impressed by the endoscopist and his assistant who had to work so hard while wearing full person protective equipment!”

“Due to my treatment I was advised by my consultant to isolate during pandemic only to go to the chemo unit, fully masked and gloved.”

“Not affected other than PPE, distancing and wearing of masks on hospital transport in the hospital and hand sanitising at key areas.”

“It must have been awful for the staff having to wear face masks/should at all time but they did so without exception. I have such respect for them all.”

“All the health professionals were always wearing masks and protective gear.”

“All staff wore masks.”

“The pandemic improved the care and outcome for me due to everyone wearing masks during the period where I was neutropenic.”

“All face to face contact was done wearing masks, which was distressing for everyone.”

“The surgeon told me after my mastectomy that he had difficulty seeing what he was doing as his mask kept steaming up. That was not very reassuring.”

“Communication difficulties due to my deafness and having to wear face masks - impossible! I do wear hearing aids.”

“I did feel it inhumane that the HCPs wore masks and it lacked the empathy I needed because I couldn't see their faces.”

“Not being able to understand doctors or read facial expressions due to the mask made it hard.”

“Having hearing problems on some occasions when being talked to by staff I had difficulty in understanding what was being said via a face mask.”

“I was often unable to make out clearly what was being said to me due to the wearing of facemasks combined with my hearing loss.”

“Wearing of masks made hearing difficult with my hearing loss.”

“It is a bit of a pain having to walk in and out of the hospital with the masks and people cant hear you and my glasses steam up but if you have to do it you.”

“Please, please, please consider giving a see-through mask to workers who speak to patients of all ages. It would make such a difference. Nothing worse than saying 'pardon', 'sorry?' every other sentence.”

“Outpatients appointments were difficult because you had to wear mask.”

“However my operation was very scary with staff in full COVID-19 PPE.”

“I continued to have Herceptin injections at home. The nurses who attended me at home to deliver these were somewhat unhappy about their PPE so were not always in a very good mood but they undertook their job professionally.”

Social distancing

Respondents spoke about the social distancing or dedicated isolation procedures put in place. Most people described this in general terms but there were some who specifically mentioned having to wait outside (in cars) to be called in. There were also some respondents who talked about their dissatisfaction with lack of social distancing.

“Foyer area seemed empty.”

“The patients were spread out more due to the restrictions.”

“The unit coped really well during the pandemic enduring social distancing etc.”

“The homeliness had to go, pictures plants etc. disappeared. Everything became more clinical. Spacing meant chat with other patients (in masks) difficult.”

“We were confined to the ward in [hospital name removed] to minimise contact.”

“Ward isolation was a good thing as a secure ward was very reassuring as catching COVID-19 post operation was unthinkable.”

“When in hospital having surgery had limited contact from doctors, nurses, anyone due to the COVID situation. Had to walk to theatre and get on operating table to be put under because not doing it in the anaesthetic room, this was very traumatic and something I will never forget all because of COVID.”

“The hospital treatment I received was second to none as the ward was completely isolated. My surgery was in 2021 so COVID very much playing a major part in our lives, and the way the ward conducted isolation was simply excellent protecting myself and others from COVID.”

“The isolated Hospital ward was very well organised.”

“Less people were able to have chemotherapy on the ward - social distancing was necessary.”

“Social distancing in the waiting areas.”

“I was able to collect my medication in the hospital's car park at a pre-arranged appointment with the nurse's.”

“The only impact on my care was I had to wait in my car outside and be called in for treatment.”

“I had 20 sessions of radiotherapy in 2020 where I sat and waited in my car to be called in.”

“The pandemic caused some set back's as I had to travel to a safe house for my treatment and medication. If unable to attend my support nurse would deliver my medication.”

“I had several weeks of radiotherapy during cold weather. I regularly had to wait outside in my car for more than an hour before being allowed to enter the hospital. I got very cold at times and had to ask to be allowed inside.”

“I occasionally had to stand outside the hospital during my Chemo due to space issues. When it was cold (this was over winter) it could be pretty painful.”

“When I went for my radiotherapy they asked patients to stay outside in their cars if possible before treatments.”

“COVID lockdown occurred after 2 sessions of radiotherapy. I was very worried that it would be discontinued. [Hospital name removed] managed it well with stopping the use of the waiting room and sitting in cars until they were ready to treat you.”

“Good system allowing me to wait in car until appointment then they phone me to go in.”

“Then had to wait in car for phone call before entering hospital.”

“Had to change treatment from [hospital name removed] to [hospital name removed] and found it scary that so many non-patients were allowed in the department. The pandemic changed this and I now feel reassured from talking with staff that the safeguards for immuno-comprised patients will be retained, with restrictions on the numbers accompanying a patient.”

“As an immunotherapy patient have been alarmed at length of time held in assessment units, latest waiting time was [timeframe removed]. The unit was overcrowded and most patients not wearing masks. Had to take bloods prior to insulin injection, there was nowhere to go and had to do it in waiting room.”

“Unfortunately, I have had to attend A&E for the treatment of side effects of immunotherapy and found their care to be lacking of social distancing for immunocompromised patients, for example being placed in a general waiting area then moved to a trolley bay designed for 1 with 7 other patients in chairs with IV infusions which meant 0 social distancing.”

“The entry area was always far too busy with too many people walking in different queues to be weighed, for the receptionist for ambulance, etc. All packed into the cramped area in front of reception. It was poorly organised.”

“As someone with [condition removed] and a compromised immune system, I would have anticipated better isolation/protection while I awaited admission in the A&E waiting area.”

Feeling safe

The vast majority of people who spoke about safety during the COVID-19 pandemic told us how they felt safe and protected, with particular references to treatment and attending hospitals.

“I was always made to feel safe through the COVID-19 pandemic.”

“Hospital appointments were always introduced in a safe manner.”

“I still continued to have treatment and felt very safe doing so at [hospital name removed].”

“I felt very safe throughout all treatments.”

“In a few months later I had robotic surgery to remove my prostate, when you think we had COVID-19 all around us it was a very dangerous time and still from my experience all the NHS staff I met were outstanding and kept you safe at all times.
“I was always made to feel safe through the COVID-19 pandemic.”

“Given all the help and information needed to keep me safe as a vulnerable person, undergoing cancer treatment. Couldn't ask for more, vaccination and follow up vaccinations have followed automatically without need to ring around.”

“I felt very safe on ward before and after my operation.”

“Ward feels absolutely safe and secure.”

“I felt safe and reassured every time I entered the hospital. I witnessed all the healthcare professionals going above their utmost to make all patients feel secured and safe.”

“Generally felt reassured that the hospital outpatients, treatment centre and wards were as COVID safe as possible.”

“Think everything has been done to keep me from COVID - 19. Everything from the letters to self isolate, to the way hospital staff and the staff at chemo have done the most to protect us.”

“As a patient I felt safe and protected by staff at [hospital name removed] during the pandemic.”

“Felt safe on the ward in hospital, I was given my own room and all care was given with COVID in mind. PPE was always worn by nurses and doctors and every effort was made to protect me from catching the virus.

“[Hospital name removed] have respond to the COVID-19 pandemic in a way that protects patients, so that I and all the patients (I am sure) full safe.”

“Think everything has been done to keep me from COVID - 19. Everything from the letters to self isolate, to the way hospital staff and the staff at chemo have done the most to protect us.”

Protecting self through shielding/isolating

There were respondents who specifically spoke about the impact of COVID-19 being that they had to protect themselves through shielding or isolating. As well as telling us the ways that this happened, some people specifically described the negative effect it had on them.

“I was told to shield during lockdown so was wary about going to my appointments.”

“COVID did mean that I had to self isolate pre op and then had to shield whilst I was having chemo (although I would have had to be careful of infection risks anyway).”

“Because myeloma keeps my immune system low, I have more or less kept myself in isolation.”

“Am still shielding and only going out to hospital appointments.”

“I did feel isolated as I needed to shield and not having contact with others going through similar situation.”

“It affected me terribly, as I was stuck in the house, couldn't go out and I had nobody in the house to talk to.”

“I had to isolate before surgery due to COVID-19, was hard not to see family and friends”

“Had to self isolate for the two weeks before my operation and the two weeks after so a month in total. I fully understand the necessity of this, however it took a real toll on my mental well being which I was not offered any support for.”

“Shielding and having to attend chemotherapy, radiotherapy and follow up appointments alone with no family or friend support has been quite difficult.”

“As I am clinically extremely vulnerable the isolation has made me very miserable and depressed.”

“Having a cancer diagnosis was hard, harder due to COVID-19 and need to isolate from friends and family at a time when I needed to see them for support.”

“Outside of hospital visits, social isolation during my treatment was awful because of restrictions due to COVID-19.”

“Massive financial impact on having to isolate prior to elective surgery as my company does not pay sick pay.”

“Having cancer came at the worse time for me, COVID 19 made my life hell! I couldn't have any family or friends around, it made my house my jail.”

“Self isolation for 1 week before the cancelled operation and for 2 weeks prior to the two operations that I did have. Self isolation for me involved being on my own in one room of the house, as I have children and it was the only way to prevent possible exposure. This had a profound effect on my whole family.”

“Had letter informing me that I could finish shielding but had no letter to inform me to shield in the first place.”

3.7. Support and information

Many respondents used the opportunity to comment on the support and information they received throughout the COVID-19 pandemic and how this met or differed from their expectations of what they wanted.

Lack of support and information

Comments about support and information often attributed a lack of it to the COVID-19 pandemic, although not all directly made this link. The types of support that people spoke about were wide ranging, but at times comments here linked with topics within other themes identified, such as dissatisfaction with reduced communication or a perceived lack of aftercare. Some people spoke about a lack of information in relation to the changing circumstances and restrictions.

“Felt very lonely as had no one to talk to apart from my spouse and children. No professionals spoke with me or offered me support. Would of been nice to talk to a professional as felt isolated.”

“The staff who were able to provide care was given as best as possible under the COVID restrictions. However, I feel the information before, during and after my surgery etc was limited and rushed.”

“I feel that my lack of full support was due to the pandemic at the time. I didn't feel the odd phone call was good enough or reassuring.”

“Support wasn't always forthcoming, had to chase with regards to benefits.”

“The main reception was very public and there was no privacy when having to give personal information. No instruction or guidance was given on arrival at the hospital so patients just sat or stood in the outside, exposed temporary shelter not realising that they need to book in at reception first.”

“In addition, there has been no information on COVID and treatment, when to have vaccines in relation to treatment etc. I have had to find this out by looking at guidance issued by NHS.”

“I was told I had cancer on my own in the hospital immediately following the cystoscopy, told to wait outside the room on my own and sent to walk to the other end of the hospital on my own for bloods. I had no support at all and was given no information.”

“None of the support groups were running or were virtual which I wasn't comfortable with, so it was a bit isolating, due to COVID.”

“All support and follow up ceased for some months gradually restarting.”

“Due to COVID-19 I did not receive a lot of the information or support I needed before my treatment. I was approximately 1/2 way through treatment when I receive all the paperwork which included a booklet for you to document each day how you were feeling.”

Charity support

A major sub-theme is charity support. The comments included those that spoke about how valuable they found the charity support, as well as some who reported a reduced charity offer to lockdown restrictions. The types of support referenced included (but were not limited to): financial guidance, support groups, and emotional support.

“COVID also cut of support with no drop in centres like Maggie's available”

“Macmillan staff have been excellent, thank you so much.”

“The Macmillan support was brilliant, I was helped with forms that had to be filled in and travel expenses, many thanks to them.”

“Also a team of welfare from Macmillan were helpful in sorting my financial worries and emotional supports. Thank you.”

“I was hugely impressed by the support given by the nurses, and most particularly by the Macmillan staff. They went to great lengths to help and support me in so many different ways. They are nothing short of magnificent.”

“I found that many of the suggestions for alternative therapies mentioned in the Macmillan booklets were not available during the lockdowns.”

“My diagnosis and treatment happened immediately before and during the COVID-19 pandemic, which affected the experience adversely at no fault of the hospital or treatment team. There was no Macmillan etc. in person support available during the first lockdown.”

“Although some online support groups available to known charities such as Macmillan and Breast Cancer Now, not the same as face to face and not for me personally.”

“Due to COVID restrictions, a lot of the support groups, e.g. Maggie's, were closed, although emergency help would have been available.”

“There was no f2f support from Macmillan, only and answer phone message and call back service.”

“COVID affected the opportunity to take part in clinical trials, if I was able to take part my treatment plan might of been different to hat I received. It also impacted the opportunity to access the Maggie's centre for support for myself and family.”

“The Macmillan nurses have been our lifeline at times.”

3.8. Reduced service

Within many of the comments there was a strong theme of respondents experiencing a reduction of cancer services and treatment during the COVID-19 pandemic. This section outlines examples of where this happened and how people said it affected them.

Reduced choice or availability of treatment

Respondents described how they felt that COVID-19 had impacted on their experience by reducing, restricting or removing the treatment options they had available to them.

“I wanted a completed dual mastectomy but because of COVID-19, I wasn't able to. I also wanted to be tested for the cancer gene but that still hasn't been offered to me”

“My original preferred treatment was to be the removal of my [details removed]. This was cancelled due to the COVID 19 pandemic. Chemotherapy and radiotherapy was carried out instead.”

“I had to have my Kidney removed radically, as this was the only surgery they could perform, keyhole surgery had been suspended.”

“My treatment and diagnosis was just as COVID-19 started, there may have been other treatment options but due to COVID-19 I was treated with an intensive course of chemoradiotherapy.”

“There is no doubt that COVID has put a great deal of strain and restrictions on treatment.”

“My 3rd chemo session was due in 2020. This was halted and I was informed that I would be having a mastectomy on and not the lumpectomy that was planned. It was hard to adjust to this new plan at short notice.”

“Due to COVID I was not able to receive the treatment that the doctors recommended. However the treatment I received seemed adequate and I have follow up treatment every 4 months.”

“All my choices were taken away from me during COVID. The [hospital name removed] tried to make me have an operation I was not happy with without even speaking to my doctor.”

“My Radiotherapy treatment consisted of five rather fifteen sessions i.e. triple doses I still suffer side effects and I wonder to what degree, these are due to the intensive Radiotherapy. I live in fear of cancer returning especially as I have recently read that it usually returns after this treatment.”

“COVID affected the opportunity to take part in clinical trials, if I was able to take part my treatment plan might of been different to what I received.”

“My treatment coincided with the onset of COVID lockdown. The trials I had signed up to were cancelled.”

Change to existing treatment

Many respondents spoke about COVID-19 causing changes to their existing treatment. People referred to treatments being paused, stopped for a period of time or having their treatment sessions cut short or reduced in number.

"They stopped my chemo tablets for nearly a year but was put on Tamoxifen instead, not really effected enough."

"Cancelled my treatment for six months because of COVID."

"My treatment was suspended for a couple of months. I was then able to attend for my Immunotherapy on a 6 weekly basis."

"Treatment was stopped for 3 months. In that time the cancer started to grow again."

"I had to stop my chemotherapy for 11 weeks because of COVID".

"My zoledronic acid treatment was deferred because of the COVID-19 situation."

"It was very badly affected the only treatment I was having was Dexa bone treatment which was delayed for a short time."

"Chemotherapy suspended."

"My immunoglobulin infusions which are every 3 weeks were discontinued for several months."

"Had two of my chemotherapy's stopped due to COVID which I thought was completely unnecessary and upsetting.

"My chemotherapy treatment was stopped due to COVID-19. I was supposed to have eight cycles, put when the pandemic started it was stopped because of the risk. I had only four cycles."

"Due to COVID, after the discussion with my consultant I reduced the number of chemo treatments from a maximum of ten to if I remember it rightly 7. The reason being at the risk involved of any infection would have on me, due to reduced resistance factor."

"Received only 5 chemotherapy treatment instead of 6."

"COVID has made a huge impact as I could not complete my chemo."

"My chemotherapy was stopped midway through because the risk of catching COVID whilst immuno-compromised (in March 2020) outweighed potential benefits. However, I did only have half the treatment intended which may change my future prognosis."

Travelling for available treatment

Tying into the availability of treatment, there were respondents who also described how they had to travel to alternate hospitals to get the treatment they needed, and many spoke about the negative impact this had on them.

"To make matters worse, I would have to travel from [area name] by public transport (in the middle of the pandemic) as [hospital name removed] was not carrying out operations."

"The treatment I had was not available from [name removed] Health Board and so it took place at [hospital name removed], which involved having to be taken by taxi and an overnight stay before the day of the operation.   Post operation the return journey, was distinctly uncomfortable."

“I also used to get my jab done at the clinic hospital which was much more convenient for me. Due to COVID it is done from [hospital name removed], which has awful parking and long waits in the treatment unit.”

“COVID-19 meant [hospital name removed] had ceased operations and I had to travel to [hospital name removed] on the morning of my operation, which added a bit more to the anxiety levels.”

“Due to the COVID-19 pandemic I had to travel to other hospitals further away for my treatments, rather than having my treatment my local hospital.”

“COVID tests before surgery and some other hospital appointments were frustrating as not particularly local.”

“The only problem about my treatment of COVID-19 was the distance I had to travel to have a simple injection. Over 50 miles round trip.”

Reduced contact with healthcare services

An emergent theme was the reduced contact respondents felt they had with certain services or elements of their care. Check-ups and follow-up care were seen as happening less frequently, alongside conversations with surgeon/oncologists. and people also spoke about a lack of face-to-face conversations. Some people specifically referenced the level of contact from their GP.

“There has been no face to face contact since leaving hospital. Services which should have been in contact have only sent leaflets, which don't help when dealing with some of the trauma from major surgery”

“I haven't had any check-ups due to the pandemic”.

“In eighteen months of treatment, surgery, chemotherapy and radiotherapy I have only seen my consultant face to face once.”

“Unfortunately, my check-ups have been delayed, my first three months check-ups was not until five months later than should have been. Still waiting for my second check-up, which should have been six months later. Have phoned and have been told if I don't hear within a month to phone back, this has happened twice, still waiting to hear I haven't been discharged as yet.”
“It was not being seen by the surgeon or Oncologist, that made me feel a little bit low sometimes. The phone call I had from the Oncologist was very informative and reassuring, and the surgeon was just lack of human contact generally. That did affect me and I'm sure countless other patients who experience the same, I am usually a very positive person, but was affected by this.”

“I had my operation in March 2020. I have met my consultant once when I was diagnosed but have not seen him face to face since. I know it was a problem with COVID but I have never been examined to make sure my scar is ok. I have a rare cancer and I feel let down as I have no follow up examination. I think this is too long not to be seen.”

“No face to face with cancer team.”

Reduced contact with GP services

The quantitative data tells us that 31% of respondents said that they were definitely given enough care and help from their GP and GP practice after leaving hospital.
In their comments people gave details of their dissatisfaction with the contact they were able to get from their GP during the COVID-19 pandemic. References were made to being unable to get appointments or access to GPs and lack of assistance with follow-up or ongoing care.

“I was unable to speak to my GP and now I can't get to speak with my GP when needed haven't had a face to face for nearly two years.”

“During the COVID-19 pandemic access to my GP surgery has been almost impossible and I have been very disappointed at times.”

“My G.P has pretty much opted out of my care and other than blood tests I have not heard from them since COVID-19 began.”

“GP services have not been all that good; difficult to contact, often unhelpful in trying to get to speak to or see a GP regarding problems associated with medication.”

“My G.P did not contact me after surgery with regard to further surveillance at the surgery despite me requesting.”

“Some of my treatment was given at home instead of at hospital dur to the COVID-19 pandemic. I have not seen my GP at all for the past 22 months due to the pandemic I have only had about 3 telephone consultations in that time. It is very hard to get a telephone consultation.”

“No contact ever from GP to find out how I was or to monitor the drugs I was advised by secondary care. I eventually did go and ask for a blood test and BP check as advised but they did not seem to know much about me.”

“Lack of face to face support following operation, removing dressings and checking on scar and bruising. No consultations or support from my GP practice.”

“Because of COVID I have not been able to see my GP since my operation, and have not had a check up.”

“GP - GP staff (nightmare to get hold of a doctor or pharmacist). Had to get prescriptions from the hospital. Fight to get injections as GP frontline staff have caused barriers.”

4. Analysis of general questions

This section addresses the comments to the questions:

2. Was there anything particularly good about your care?
3. Was there anything that could be improved?
4. Any other comments?

The comments were organised into six themes:

- **Care experience**

This section summarises the comments respondents made relating to their general experience of care, what was positive and what they felt could be improved.

- **Healthcare professionals and other staff encountered**

This section summarises the comments respondents made regarding healthcare professionals and the other staff they encountered what was positive and what they felt could be improved.

- **Diagnosis**

Many respondents gave feedback relating to their experience of receiving their cancer diagnosis. This section summarises the key areas people spoke about.

- **Communication & administration**

This section describes the areas around communication and administration where respondents felt that improvements could be made.

- **Wider hospital experience**

Beyond their direct care and treatment, some respondents spoke about their wider experience whilst in hospital. This section describes the areas where people felt that improvements could be made.

- **Support & advice**

Through review of the comments, it became apparent that there was a wide variety in the understanding of what the term ‘support’ meant to people. This section summarises key areas of support that respondents spoke about.

Key areas within each theme, along with illustrative comments, are explored over the next chapter.

4.1. Care experience

This section summarises the comments respondents made relating to their general experience of care, what was positive and what they felt could be improved.

Positive experience of care

Many comments were people speaking positively in general terms about their experience of care or their experience in general. Lots of people used this as an opportunity to express their gratitude to the NHS and the most-used adjective here was ‘excellent’. Some of these comments acknowledged that their care was particularly good when considered in light of the pandemic.

The quantitative survey results tell us that:

- The average rating of care is 8.72 (where respondents were asked to rate their care from 0 to 10).
- 90% of respondents said they were always treated with respect and dignity in hospital.

“I received an excellent care beyond my expectation.”

“The care I have received was of the highest calibre. My heartfelt thanks to all concerned.”

“Under the extremely difficult circumstances of the pandemic I was impressed with the care I received at all the hospitals I attended.”

“Wonderful care - that's why I'm still alive!”

“I think that in hindsight the care given was of a good standard. Everyone did the best they could in this COVID pandemic.”

“From the first diagnosis to present, the care I received was second to none.”

“I cannot fault the care and attention I would receive when I was staying in hospital or as a day patient receiving chemotherapy.”

“I can only speak well of the care I received. As far as I am concerned my treatment overall was second to none.”

“[Hospital name removed] have provided outstanding support/care. Thank you! Forever grateful!”

“Just a big thankyou, without all the expert care I have received I may not be here today. So, very, very grateful.”

“Nobody wants or likes being diagnosed with cancer. The overall experience has been totally transferred from a horror to a manageable state, due to the care received. Thank you.”

Aftercare and follow up

One of the areas that some people mentioned could be improved was aftercare and follow up. When people used these terms, they encompassed a wide range of ways they would have felt more supported after returning home or after treatment ends.

The quantitative survey results tell us that:

- 46% of respondents said that they were definitely given enough information about how to manage their health and wellbeing after their treatment ends
- 46% of respondents said that they were definitely offered enough practical advice and support in dealing with the side effects of their treatment at home
- 50% of respondents said they were definitely given enough care and help from health or social services after leaving hospital
- 31% or respondents said they were definitely given enough care and help from their GP and GP practice after leaving hospital

“Unfortunately, I can't say the aftercare once left hospital was good.”

“I found the care following discharge from hospital to be disappointing.”

“I think the aftercare could be improved and explained better, I would have like to have received support on checking breasts correctly and about support groups where I could identify with people going through the same thing. All I was given was lots of booklets to read.”

“Follow up appointments with consultant could be better.”

“My GP was not involved with my care after returning home. It would have been good to see someone I live alone!”

“Aftercare appeared to be non existent. My GP should have been informed and should have taken an interest in me and my condition. I accept that this was probably because of the COVID and pandemic but the occasional call would have helped.”

"Post operation aftercare and moving forward after treatment ends. Face to face consultants/surgeons appointments are very important to continue after treatment has ended from the reassurance and examination which helps to keep your mind at rest. This can only be partly done via telephone.”

“Aftercare however, virtually non existence. Breast Care Nurse very difficult to contact, lack of example got the impression she really didn't know who I was when I rang. Lack of information on reconstruction, only told my weight was an issue when I had a virtual appointment.”

“Access to help and advice after treatment finished was poor and non-existent after the pandemic started.”

“Follow up care could be improved as it is non existent. I am taking tablets but I have not been seen for Osteoporosis tests.”

4.2. Healthcare professionals and other staff encountered

This section summarises the comments respondents made regarding healthcare professionals and the other staff that they encountered, what was positive and what they felt could be improved.

Excellence of staff

Often, when people spoke in general terms about what was good about their care, they spoke about the staff that they encountered. Some people spoke about a whole team while others singled out individuals. This was not only clinical staff, but many other people were also referenced, for example, cleaners and porters.

“Nursing/caring staff were excellent during my initial hospital stay which led to my diagnosis, during my chemotherapy and during my radiotherapy.”

“The surgical consultant care was excellent, could not fault it. Oncology consultant was good and caring. [Hospital name removed] staff nurses kept me going whilst I was in hospital they were my angels I don't know how I would have coped without them and the junior doctors did their best to help me when the people that should have been there to help weren't.”

“I thought that all the staff who dealt with me from diagnosis to surgery, outpatient care, radiotherapy and follow up have all been very professional, helpful and caring.”

“All front line people - surgeons, doctors, post op nursing staff, ward nursing staff, porters were all ultra-professional but at the same time human.”

“The specialist nurses are brilliant, also the health cares are very knowledgeable in their jobs and very understanding.”

“So many of the medical and non medical staff were friendly, kind and helpful over and above the call of duty. This certainly helped me cope better with the whole experience.”

“All the healthcare professionals that were involved in my care, were all very good and gave me everything I needed.”

“Super professional care by the cancer care surgeon, doctors, nurses, PAs and staff at chemotherapy and radiology, all made you feel like family, not a patient. 10/10.”

“The nursing staff were all friendly and personable. My surgeon took time to explain things well and answered my questions. He was always kind and clear when conveying information.”

Staffing levels

Although people were generally positive about their encounters with healthcare professionals. A number of people spoke about how busy staff were or commented on staff workloads and many responded to what could be improved, with ‘more staff’. Sometimes respondents linked this to funding, and sometimes this was put alongside comments that investment was also needed in other hospital resources.

“There are obvious shortage of professional staff, from very experienced GP who can screen the cancer patients from the first visit , to specialist cancer doctors, diagnostics tests staff, to equipment, there is great need of further investment on both staff and facility.”

“A lot of my issues were probably due to staffing levels.”

“The only improvement to be made is by making all staff workloads and hours, easier and better.”

“Despite shortage of staff, they treated everyone with great respect and dignity.”

“There was nowhere near enough staff and the ones that are there do their best with what they are given. Staff are leaving because they are under so much stress - even before the pandemic.”

“I think the cancer facility at [hospital name removed] is well run, but I feel the staff were stretched and they could do with more space and equipment.   Particularly noticed not enough radiotherapy equipment. Some appointments had to be postponed due to maintenance issues.”

“The nurses in the clinic are over worked and needed more staff. The wait to see them sometimes was 2-3 hours, in a room full of germ ridden human beings!”

“I feel sorry for the nurses and staff, they are so busy.”

“Unable to comment as nursing staff were under a lot of pressure due to staffing.”

“The majority of the nurses, healthcare assistants, doctors etc. do an amazing job under an immense amount of pressure. They provided an excellent level of care despite being stretched very thinly.”

4.3. Diagnosis

Many respondents gave feedback relating to their experience of receiving their cancer diagnosis. This section summarises the key areas people spoke about.

Slow diagnosis

When people spoke about their diagnosis, the speed of diagnosis was of great importance. Where people felt there were delays, they often spoke about this as an area that could have been improved. These comments sometimes made reference to being misdiagnosed before receiving a cancer diagnosis.

“The wait time between referral and my first appointment was 6 weeks when I was told by my GP I should be seen in 2 weeks. The GP requested I should be seen urgently but I had to wait six weeks regardless.”

“I think GPs should listen to their patient’s concerns, especially when they are going back and forth with the same symptoms which don't appear to get better. I believe my diagnosis could have been a lot sooner than 11 months had I been sent to the hospital prior to the last GP I saw who sent me straight to the hospital.”

“My only concern is that I felt my GP was slow from when I saw them to first in arranging tests and before test dates were met, I was an emergency admission. Perhaps referral times from the GP could be quicker.”

“The first appointment following GP referral was 3-4 weeks, which is a long time when one is anxious.”

“Poor GP initial handling and time taken for NHS for diagnosis.”

“The gap between doctor appointment and screening/biopsy was the most stressful time. Waiting to find out whether I had cancer or not.”

“My doctor followed NHS guidelines when I first reported symptoms, which meant a time-consuming (3months) series of tests for other conditions before cancer was identified. I believe my doctor would have preferred to have ordered a colonoscopy earlier, hence identifying the cancer.”

“I believe the GP practice could have been more sensitive to the amount of time my symptom had been occurring and to contact me on the results of my urine samples. The cancer may not have been stage 3 as they would have caught it sooner. I understand that most of this time was during the first COVID-19 lockdown and things were really difficult, but as my symptom started well before this time, I am surprised I was not contacted earlier for assessment and treatment.”

“I feel my cancer could have been spotted earlier had I been sent for an x-ray because I was in so much pain and the painkillers were not killing the pain.”

“I feel that my illness could have been diagnosed earlier with face to face consultations and examinations with my GP but because of COVID restrictions they were initially by phone.”

“An earlier understanding by the GP practice that my symptoms could be caused by prostate cancer, so I could have started treatment sooner.”

Quick diagnosis

For some people the experience around their diagnosis was good and many spoke about how quickly they were diagnosed, with some linking this to their quick transition into care and treatment. In these cases, many people expressed gratitude for their GP taking prompt action.

“The prompt diagnosis and care I had from my GP and the breast cancer clinic undoubtedly saved my life! Cannot thank them enough.”

“I phoned breast care nurse because of a rash. I was seen very quickly, which led to an early diagnosis. This was an early diagnosis due to brilliant teamwork of doctors and breast nurses.”

“My treatment was greatly improved by the early diagnosis by my GP.”

“Speed of tests once they knew something was wrong with me was impressive, they just kept coming one after another.”

“No delays in diagnosis or treatment.”

“My GP was very good. He got my scans and tests done very quickly and was very sensitive breaking the news that my biopsy was positive.”

“Prompt diagnosis and treatment.”

“From first seeing the doctor to being seen at the hospital for tests, diagnosis and treatments, was impressively quick.”

“Speedy diagnosis and prompt dealing with the cancer.”

“I felt very fortunate to have been diagnosed so quickly.”

“Almost everything from my GPs immediate referral to all of my treatment. I can not praise them enough and they saved my life, for which I will be forever grateful.”

“My GP [name removed] was extremely quick with his diagnosis that I might have cancer and I was swiftly seen by a consultant at the [hospital name removed].”

“The speed in which tests were done and diagnosis given and treatment started, was exceptional.”

“Due to the prompt GP referral, I was treated more efficiently through early diagnosis.”

“My GP was amazing and I got my referral done extremely quickly and has been a fantastic support.”

“My diagnosis was very quick. Following a referral from my GP, I was seen very quickly.”

Screening

Another key area that people spoke about when pulling out something that was particularly good in terms of diagnosis, was that cancer was picked up via a screening programme. In these cases, many people acknowledged that they had not experienced any symptoms or that it otherwise would have been picked up later.

“I consider myself very lucky that my cancer was picked up very early on a routine mammogram. I was diagnosed at the end of November and my operation took place in early January.”

“I would not have known I had bowel cancer if it wasn't for the bowel screening Wales test. I had no blood or pain or any other indicators. Everybody should avail themselves of the screening.”

“I am grateful for the bowel screening in Wales, at how easy it was to participate and how quickly subsequent tests (endoscopy and scans) were arranged and the bowel operation performed.”

“I was diagnosed from the resort of a routine mammogram and referred to Breast Health Wales.”

“The mammogram screening program picked up my cancer before I was aware of it so that is really positive.”

“I had my diagnosis purely down to luck after having a routine mammogram.”

“The screening test brought the concern to light. Very grateful for that.”

“Yes, I was diagnosed through screening and was very impressed with how rapidly my cancer treatment was commenced.”

“My cancer was spotted through the bowel cancer screening test and a problem had been found.”

“Screening process via Breast Care Wales also excellent.”

Delivery of diagnosis

As well as references to the speed of diagnosis, another key area of importance was the delivery of diagnosis and, in particular, the sensitivity of this delivery. The quantitative survey results tell us that 16% of respondents felt the way they were told they had cancer could have been done a bit, or a lot more sensitively.

Some comments here referred to people being told their diagnosis when they were by themselves or diagnosis being delivered over the phone.

“I felt the way I was told about my diagnosis was that I was lucky because they had caught it early and I had had the best news of the day. At the time I was smiling as I thought this was good news. Once reality sinks in I realised the lucky ones are the ones that walk out with no diagnosis! I have since learnt that I am thankful and not lucky that it was caught early. Maybe it's just a choice of words.”

“I was told I had a very rare cancer immediately after my operation - I was not fully awake. It was in the middle of a six bedded ward and very busy; I felt everybody was listening.”

“The way I was given my diagnosis was very upsetting, waiting two hours before I saw the doctor, I was on my own told quite bluntly what was going to happen then had to go outside to tell my husband and family.”

“Due to the pandemic, everything was done, although when you are alone when given your diagnosis it becomes more of a blow than if you had someone with you.”

“Being told you have cancer and will have life changing operation was extremely difficult to hear especially with no support by my side. I wish my spouse could have been with me.”

“Diagnosis of cancer should have been given to me personally by medical staff, not for me to hear staff talking at nurses station. I felt because I worked at the hospital for a considerable amount of years my condition and treatment was not private.”

“It would have been nicer to be told face to face like I have said before.”

“When I received my diagnosis in [hospital name removed] - it all felt quite rushed. I wasn't ready to talk about various options for reconstruction at that stage, as I was coming to terms with the diagnosis and the added information about reconstruction options from the surgeon was a little overwhelming.”

“The way I was told I had cancer. I was told as a matter of fact by a surgeon and a Gynaecologist with no-one else present not even my partner as I was a patient in hospital at the time.”

“When I was asked to see the consultant, I was not told I could bring someone for support, even when they knew I was being given this devastating news.”

“When I was first told that I had cancer, I think this should have been done in a more sensitive manner.”

“To be told over the phone that I had cancer by a nurse was very upsetting.”

4.4. Communication & administration

This section describes the areas around communication and administration where respondents felt that improvements could be made.

Joined-up communication

The quantitative data tell us that 65% respondents said the different professionals treating and caring for them worked well together to give them the best possible care together all of the time.

While many respondents simply told us that communication could be improved, a strong theme emerged around the communication between the services organising and delivering their care. People described how this caused confusion and possible delays around their treatment.

“Better communication between departments and professionals, i.e. there was an incident when medication was not given due to breakdown in communication.”

“Continuity of care - lack of communication between departments, causes confusion at [hospital name removed].”

“When the nurse practitioner who has responsibility for my case wrote to my GP surgery to provide them with information about my condition, the details of both the surgery and the GP were incorrect…I do not believe that this error was in any way the fault of the nurse practitioner, but rather that there may not be a clear pathway for the provision of up to date information between hospitals and GP surgeries. In that regard, I found it rather strange that the information was apparently provided to the surgery by a hard copy letter rather than by email. I wonder whether this is an area which could benefit from scrutiny to ensure that communication between primary and secondary care is as efficient and effective as possible.”

“Lack of communication between hospitals, my notes were requested more than once, this prolonged appointment which resulted in starting treatment.”

“I am surprised at the lack of communication between various departments involved in my treatment i.e. urology and cardiology, which has caused delay.”

“Communication between specialists. Twice I went for very worrying symptoms and the Doctor I saw did not know why I was there.”

“There could be better communication with GP's from different hospitals.”

“Administration and communication with the different health care professionals with my care.”

Administration

The quantitative data tell us that 88% respondents rated the overall administration of their care as very good or good.

However, in their comments some respondents told us the administration could be improved, in particular the accuracy and timeliness of communication around appointments.

“A smoother transition referral system between NHS Wales and England, to avoid unnecessary delays, admin errors, communication errors. Very disappointed with the amount of anxiety caused prior to my treatment.”

“The period of time from being referred by was very protracted and stressful. Waiting to hear whether funding was approved, caused great anxiety. There are great communication admin problems when being treated outside of Wales, errors originating in Wales.”

“Cancelled appointments not being re-booked for me. Hospital cancelled appointment.”

“After my initial diagnosis the team were very disorganised and unprofessional in mislaying notes etc. The consultant did not give me confidence and I was glad to transfer my care after my operation. My operation was delayed because of this.”

“Referring people to other hospitals to then being told we can't treat you and refer me back. Lost documents, appointments being delayed.”

“Appalling backup of the many areas of 'supporting' administration.”

“Also had a letter for a clinic appointment that should have been a phone consultation - meant we turned up at clinic when we should have been phoned.”

“Two referrals for physiotherapy was lost/not actioned.”

“The administration side of things is very poor. I often spend ages on the phone trying to get through to sort out appointments.”

“Administrative side could be improved. I was receiving letters for appointments after the actual day of the appointment. And receiving letters for appointments after they had been cancelled. Was very confusing.”

4.5. Wider hospital experience

Beyond their direct care and treatment, some respondents spoke about their wider experience whilst in hospital. This section describes the areas where people felt that improvements could be made.

Hospital environment and facilities

Some people chose to raise specific improvements they felt could be made to issues relating to hospital environment and facilities. This included comments on hospital parking, cleanliness and room/ward conditions.

“Car parking can be difficult at the moment. No park and ride, etc., due to COVID.”

“Car parking, especially for disabled.”

“Parking availability”

“Cleanliness of ward, frankly was filthy.”

“Hospital bathroom and toilet were really not very clean.”

“Not much organisation on the ward- rows full of bed pans in the toilets left over 24 hours.”

“Condition of the wards. The roof leaked and splashed rain water over the beds. Patients had to be taken to other wards.”

“As I was in isolation the hospital room was poor no ventilation during a hot summer.”

“On a very hot day there was no way of cooling the ward, although nursing staff were very good in providing ice packs to cool me down.”

Food

Food emerged as an area that respondents felt could be improved upon, with particular reference to the quality, although choice and suitability were also mentioned.

“I believe the food was dreadful and an improvement could be made.”

“The food in the hospital was too salty and couldn't be eaten.”

“Inpatient food at [hospital name removed] - if my food had been better I would undoubtedly recovered at least a week sooner. That is fact.”

“The food at the [hospital name removed], the evening snack was very poor. Dreadful soup. White roll and grated cheese. Restricted to one yoghurt a day. One hot meal a day. Food at [hospital name removed] was very good.”

“Food at [hospital name removed] was very poor. Same menu week in week out. Staff didn't care to cater for patients needs. Basic food sometimes unavailable.”

“As a vegan I had no choice of food, if it wasn't for a nurse going out to buy me soy milk out of her own money I would not have eaten as I only had rice crispies to choose.”

“Food offered me after the operation was not always what I was allowed.”

“Appropriate food was not offered directly after surgery, I had to ask for soft foods even though my surgery was planned it was not prearranged and the nurses struggled to get it for me. It is common, I have since discovered, in most hospitals. I feel that this is important and more should be done to assist patients.”

“I was given food that was specifically banned whilst an inpatient in [hospital name removed] due to being at risk for bowel obstruction.”

4.6. Support & advice

Through review of the comments, it became apparent that there was a wide variety in the understanding of what the term ‘support’ meant to people. In this section we have summarised key areas of support that respondents spoke about.

Satisfaction with support

A large number of respondents used the comments to describe in general terms their satisfaction with support and how it was a positive aspect of their care. They described the how members of their healthcare team, such as their consultant, the nurses, staff or the hospital were supportive or gave them support during their care and treatment.

“Full support from all staff.”

“The care and support from staff during treatments.”

“[Hospital name removed] have provided outstanding support/care.

The consultant and her team have been very caring and are supporting me through a very difficult life change.”

“Very happy with all support.”

“The support of all health professionals I have met.”

“All staff very supportive and very kind.”

Emotional support

One of the areas where people expressed that support was needed was emotional support. Often this crossed over with comments about charity support or other support they felt was required. The quantitative survey results tell us that:

- 65% of respondents were able to discuss any worries or fears they had, as much as they wanted with staff during their hospital visit
- 74% of respondents said that hospital staff definitely gave them enough emotional support while being treated as an outpatient or day case

Where people did receive emotional support, they often cited how beneficial they found this. Sometimes this was in a ‘formal’ setting like counselling, and sometimes comments were about clinical staff being emotionally supportive.

“My struggle following treatment has been getting access to emotional support. I now have contact with the psychology department but have had a long wait. There seems to be no package of emotional care offered after treatment and although I have access to CNS, she is not a counsellor and there is a limit to what she can offer in a phone call. She is spread very thinly.”

“I have never been offered emotional support.”

“More information on cancer charity support and to be signposted to local support available. I approached Maggie's Cancer Centre direct after researching support online. More emphasis on what to expect in the future after treatment in particular your emotional state and coming to terms with adapting to life after cancer.”

“There was no information on lifestyle changes such as diet, exercise, supplements, emotional support or spiritual consideration. I found it was one box fits all no matter what age/ weight and personal beliefs the patient has.”

“I also found out about holistic and emotional support myself, no one offered the information.”

“I was probably in need of more emotional and mental health support.”

“I have had cancer 4 times. I feel I would have benefitted from more emotional support & specialised counselling at times, as it has been traumatic, but I was very impressed with the level of care.”

“I feel strongly that I had no support emotionally and visited my GP and am now on anti-depressants. I thought I would have had maybe some support relating to dietary needs, exercise and emotional support but I have received none and have found things very difficult.”

“Once started my surgery and treatment was good and my breast care nurse excellent. However, emotional support was non existent, no one to hug or put a supportive arm around my shoulder.”

“Good explanations and support at each stage of treatment. I never felt rushed when asking questions when emotionally distressed early on, was given access to counselling which made a huge difference to my mental wellbeing.”

“My care in hospital was outstanding and I felt very safe. I believe I have had the best treatment available. I can't emphasise enough the importance of being given time to talk face to face and that has been made difficult by COVID. The radiotherapy team were excellent and gave emotional support when they could see patients struggling.”

“I was treated with care and respect by the healthcare professionals all the way though my treatment - they paid attention to my emotional state as well as physical.”

“I came to rely on the Macmillan nurses to help not only with medical questions but also with psychological support. I think that the management of my treatment which was right at the start of the pandemic was exemplary and went remarkably well considering the circumstances and is a great tribute to the NHS and Macmillan team.”

Information provided about side effects

The quantitative survey results tell us that:

- 70% of respondents said that possible side effects of treatment were definitely explained to them in a way they could understand
- 51% of respondents were definitely told about side effects of treatment that could affect them in the future

In their comments, respondents told us that there could be improvement in the amount and delivery of information given on side effects.

“More information should be given on chemo side effects, a nurse told me I would be fine on my first visit after I asked her how I was likely to be over the week to come. Obviously I was not fine; I had never felt so ill in my life.”

“It consisted of the consultant reading a tick-list of side effects to me, and I received no written information.”

“I feel more information regarding side effects and treatment of Peripheral Neuropathy post Chemotherapy should be available. In particular, balance and swollen legs and feet. This should include use of compression stockings.”

“I would liked more information about after effects of treatment. It was written in the booklet but someone to talk to would have been nice.”

“I was unprepared for the other side effects, as I was not given a great deal of information about this prior to treatment.”

“Better information regarding possible later side effects of radiotherapy would have been helpful. I believe these were not explained enough.”

“I have lots of questions unanswered about side effects and future.”

“Yes, tell us more about the side effects of the tablets we are given.”

“Would have liked more information regarding side effects, risks of sepsis etc.”

Information provided for side effects

Respondents spoke about wanting improvements to the practical advice around diet, exercise and how to manage their side affects

The quantitative survey results tell us that:

- 60% of respondents said that they were definitely offered practical advice and support to deal with side effects
- 46% of respondents said that they were definitely offered enough practical advice and support in dealing with side effects of their treatment at home (such as physical activity advice, how to manage diet and fatigue)

“Maybe some physiotherapy advice about dealing with side effects of the Letrozole tablets (aching joints, stiffness etc).”

“The one thing that would improve the service would be some much better advice on diet and nutrition following a cancer diagnosis and during chemotherapy. I have asked many time during my treatment if there are any supplements I can take or if there is a specific diet that is beneficial and the answer has always been 'eat what you like as you normally would' and having read numerous books and now paid for private advice this is totally not true. Diet and nutrition can really help with the side effects of chemotherapy and also in the fight against recurrence and more advice should be given.”

“There was no advice or support on exercise, there is a wealth of knowledge and evidence for this but no support/advice. I was offered [word unreadable] /reflexology/massage which there is no evidence for. Please can support be in place for evidence based treatment.”

“I would have welcomed more information on how to deal with side effects, diet and exercise.”

“More education around diet and nutrition.”

“When I mentioned side effects, especially my ability to eat - no help was offered.”

“Maybe more structured advice about diet and appropriate exercise.”

“I feel is now I need the support. I live with chronic pain mental health and various other issues. I would like to have support for these issues and be able to talk to someone about them.”

“Also, more information given on post operation exercise as no physio given.”

Practical and financial support

The quantitative survey results tell us that 53% of respondents were given enough information on how to get financial support and any benefits they were entitled to.

In their comments a few people described how they were able to access financial support through help provided by charities. However, most respondents spoke about how they were not given support or help in this area or suggested that more information could be provided.

“Marie Curie also contacted financial help and future arrangements when needed.”

“My spouse attended Maggie's, who helped us with Care Allowance and a blue badge; also helped my spouse with support.”

“Macmillan sorted my financial problems due to my inability to work.”

“The Macmillan benefits worker, was very efficient and helped me with my claim for PIP, which was successful.”

“City Hospice were brilliant sorting out financial.”

“Having a Macmillan/DWP person at the unit to advise financially.”

“I don't know if there is any financial help I can get.”

“Have financial advisors visit the day care units to help with terms.”

“Could not be bothered to help me with financial help neither, absolutely a joke.”

“Had no financial help or guidance from Macmillan even though I enquired about it.”

“More information about any possible financial care and support.”

“Help to be told what, if any benefits we were entitled to while having treatment i.e. costs of taxis to and from hospital appointments.”

“I feel more should be available i.e. financially to help especially with all that's happened lately with COVID. They gave furlough to people but people who need help through illness.”

“Also it would have been very helpful to have been told about the PIP claim I was eligible for. I was eventually told 1 year after having to stop work, having already had a re-mortgage refused because of our low income.”

“I would have liked information regarding radar key and blue badge, have now obtained both.”

“I need help with benefits and was offered no help with this at all.”

“More support on what you can claim for, no information or support given at time, really poor in fact would be ignored.”

Support from charities

The quantitative data tell us that 54% of respondents were told about voluntary/charity support during their care.

Often, the comments made about the support given by charities speak highly of the support received, and how they were able to 'step in' and help them access more of the benefits/services they were entitled to.

"I have also had some excellent support and advice from Macmillan support centre"

"Family accessed support form Macmillan support on several occasions and I did too - excellent."

"Macmillan sorted my financial problems due to my inability to work."

"After two years of treatment, my spouse attended Maggie's, who helped us with Care Allowance and a blue badge; also helped my spouse with support."

"Macmillan supported me to access PIP - this has been a life saver financially."

"Macmillan staff were able to expediate appoinments and provided me with excellent support."

"I must say the Rowen Tree Cancer Charity voluntary transport was 10 out of 10."

"I also receive help from the Bracken Trust, they have been amazing, every time I need to talk to someone they are always there."

"It was good to have Macmillan nurse on hand to discuss things with."

"Marie Curie were contacted by oncologist, who are excellent and arranged for NHS nurses to call regularly"

"The support I and my spouse have received from Maggie's has been so helpful in my progress."

Support groups

One area where some people expressed disappointment with a lack of support was the lack of availability of support groups, typically because of the COVID-19 restrictions.

The quantitative survey data tell us that 62% of people were given the right amount of information about support / self-help groups.

"When cancer is said some people think the worse as I did, it affected my mental health really badly. I know support groups were unable to open which was very unfortunate."

"Although COVID-19 was raging I was able to have all of my treatments. However, no home visits, no charity help, no self help groups, meant that I was isolated and lonely."

"Access to support groups and therapies was not possible due to COVID. This definitely impacted on my mental health and coping with the diagnosis."

"There is also a lack of support groups in my area. I know my cancer comes under the [details removed] but there are not a lot of people to talk to that have been through the same treatment plan as I had."

"It would have been good to be offered more support and told about any local groups/advice on headwear/wigs after losing my hair to Chemotherapy."

Support received from Key Workers and Clinical Nurse Specialists (CNSs)

The quantitative survey results tell us that:

- 84% of respondents were able to get answers they could understand from their Key Worker all or most of the time
- 85% of respondents were able to get answers they could understand from their CNS all or most of the time
- 78% of respondents agreed completely that their Key Worker provided them with the information they needed to make informed decisions about their treatment
- 76% of respondents agreed completely that their CNS provided them with the information they needed to make informed decisions about their treatment

Many people made specific reference to their Key Worker or CNS (and sometimes referred to specialist nurses e.g., breast nurse) being a positive element of their care, giving them support and information when needed.

“The clinical nurse specialist at [hospital name removed] was excellent in advising me about treatment options. When deciding on surgery and operation and being referred, they were excellent in forwarding information and then carrying out the operation and arrangements.”

“My CNS has been extremely helpful and supportive”

“CNS was very prompt in replying to concerns.”

“I continue to receive telephone calls on a regular basis from CNS to check on my progress. This greatly appreciated.”

“My CNS team have been excellent and always get back to me when I need information.”

“Clinical nurse specialists and cancer specialists were approachable, friendly and gave clear explanations.”

“Clinical nurse specialist, excellent support and communication.”

“The support that I had from the clinical nurse specialist both before and after the operation, she gave me loads of information and was always ready to answer any questions.”

“My breast care nurse specialist was very helpful and encouraging. A font of useful knowledge.”

“I could contact my breast care nurse during the working week to discuss concerns and advice; if unavailable, would ring back the same day.”

“Key worker excellent.”

“My key worker/breast nurse was fantastic especially in the early part of days of care and treatment.”

“My key worker is fantastic! She understands me and what kind of support I need, whether that is a hug, a joke, or a kick up the butt!”

“My key worker/nurse was really helpful and kind, I was really upset when she finished seeing me after the drain was removed, I felt that she was so much support for me.”

Access to support from Key Workers and Clinical Nurse Specialists (CNSs)

Some respondents indicated dissatisfaction with Key Workers or their CNS which mainly related to not being provided a Key Worker or CNS, or not being able to contact them.

The quantitative survey results tell us that:

- 90% of respondents were given the name and contact details of a Key Worker
- 89% of respondents had access to a CNS
- 69% of respondents said it was easy to contact their Key Worker
- 68% of respondents said it was easy to contact their CNS

“Provide a key worker for breast cancer patients who are under care of oncology.”

“My keyworker was impossible to get hold of and never followed up any of my calls which was disappointing.”

“I didn't have a single named key worker/CNS but a group of CNSs - getting in touch with them was difficult and no-one seemed to follow up on phone messages left. I gave up in the end.”

“At our initial appointment a key worker was present, and we were given a card. However, they were based in two hospitals and contacting them was not easy. We tried once and left a message but received no response. Fortunately, we had no further need to contact them. You probably could use more staff!”

“I don't recall having a key worker or having one keep in touch.

“I was NEVER appointed a Clinical Nurse Specialist for my initial primary cancer, would have been good if I could have one.”

“Could never get hold of key worker, consultant or clinical nurse and stopped trying at an early stage as a result”.

“Support from clinical nurse very poor! Not return call for three days!”

5. Additional analysis

A full set of sanitised comments has been passed to Macmillan Cancer Support and the Wales Cancer Network to enable more detailed analysis of the comments/ themes that have arisen. Health Boards have also received sanitised comments from respondents residing in those Health Boards, to support improvement.

This report is designed to be read alongside the National Quantitative Report. Quantitative reports for Health Boards and Velindre Cancer Centre are also available alongside an online reporting platform, which displays data tables and enables breakdowns by key variables. The other reports and supporting documents can be found at https://wcpes.co.uk/library

Appendix 1

Response counts to open ended questions

There were 4,515 respondents to the qualitative questions. This is 72% of the total respondents to the survey (6,259).

Language

	Number of respondents	Percentage of total qualitative respondents
English	4446	98%
Welsh	69	2%

Mode

Trust	Number of respondents	Percentage of total qualitative respondents
Online	813	18%
Paper	3702	82%

Health Board

In 2016, individual Health Board scores were produced by assigning patients to their Health Board of residence, regardless of where they were treated (including patients attending Velindre Cancer Centre for part or all of their care). Feedback confirmed that this was the preferred approach for interpreting the results again in 2021/22.

The exception to this is Velindre Cancer Centre, which is a specialist cancer centre within Velindre University NHS Trust, under which no patients reside. Rather than being reported on by place of residence, Velindre is reported on by place of discharge – as in the 2013 and 2016 surveys. [23]

Health Board	Number of respondents	Percentage of total qualitative respondents
Aneurin Bevan University Health Board	860	19%
Betsi Cadwaladr University Health Board	1025	23%
Cardiff and Vale University Health Board	699	15%
Cwm Taf Morgannwg University Health Board	627	14%
Hywel Dda University Health Board	678	15%
Powys Teaching Health Board	80	2%
Swansea Bay University Health Board	546	12%

1287 of these respondents (29% of total respondents to the qualitative questions) were also discharged most recently from Velindre Cancer Centre, under which no patients reside.

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[23] For full details please see section 3.3 of the of the Quantitative report.

Tumour group

Tumour Group	Number of respondents	Percentage of total respondents
Brain / CNS	17	<1%
Breast	1098	24%
Colorectal / LGT	497	11%
Gynaecological	282	6%
Haematological	472	10%
Head and Neck	163	4%
Lung	219	5%
Other[24]	611	14%
Prostate	443	10%
Sarcoma	30	<1%
Skin	108	2%
Upper Gastro	145	3%
Urological	430	10%

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[24] The list of codes that make up the Other cancers category are detailed in Appendix 2.

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	Secondary and unspecified malignant neoplasm of lymph nodes (C77), of respiratory and digestive organs (C78) and of other and unspecified sites (C79)
C78	
C79	

Any other

C00	Malignant neoplasm of lip
C05	Malignant neoplasm of palate
C11	Malignant neoplasm of oropharynx
C12	Malignant neoplasm of pyriform sinus
C13	Malignant neoplasm of hypopharynx
C14	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
C26	Malignant neoplasm of other and ill-defined digestive organs
C30	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.

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