National Report

Wales Cancer Patient Experience Survey 2016

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picker.org

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Section one:

Foreword

Foreword

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Susan Morris, Head of Services, Wales, Macmillan Cancer Support

The Welsh Government and Macmillan Cancer Support are pleased to report the results of the second Cancer Patient Experience Survey (CPES) in Wales. We must express our gratitude to the thousands of people who took part in the survey for providing such detailed feedback on their experiences of cancer diagnosis, treatment and care.

The Cancer Delivery Plan recognises the importance of seeking people's views about their treatment and care. This year's survey results indicate a positive experience of cancer care in Wales and there are many areas to celebrate. People's overall experience is very positive, with 93% rating their care overall as seven or more out of ten, only 1% rating their care overall as poor – between nought and three out of ten – and 89% of people stating they were always treated with dignity and respect whilst in hospital.

The hard work and commitment of the health professionals caring for people with cancer was endorsed by the many comments left at the end of the survey. The care and support provided by such a highly skilled workforce is clearly making a real difference to people's experience of having cancer.

The survey results confirm that having a named Clinical Nurse Specialist (CNS), who is often the Key Worker, provides a more positive experience for patients and their family both during and after their treatment. The Cancer Delivery Plan clearly requires health boards/trust to offer people timely, high quality and accessible information about their cancer and treatments. Improving access to this support must be a focus for the future, as for some patients, contacting both the CNS and Key Worker was difficult, and one in seven people reported not having a named Key Worker at all. Providing patients with the opportunity to discuss their needs to develop a personalised care plan also had a significant positive impact on their overall experience. We must improve on the fact that less than half of people surveyed were offered this discussion and that only one out of five people were offered a written care plan.

Evidence suggests that people generally receive a cancer diagnosis in a timely and sensitive manner, and the great majority of people see their GP with their initial symptoms or concerns. However, the results indicate there is further work to do, as more than one in five patients (21%) felt their GP did not "completely" take their initial symptoms seriously. Patient comments illustrate the distress this can cause, and the negative impact this can have on health outcomes. These results underline the need to support professionals in primary care to identify early signs and symptoms of cancer to enhance earlier diagnosis and improve overall outcomes and experiences.

Information is key to improving patient experience. While treatment options were well explained, the survey highlights that further work is required to provide all patients with written information about their specific type of cancer, in a format that is easy to understand. Individuals also often face increased costs and reduced income as a result of their cancer diagnosis, and many are not aware of the benefits they are entitled to. In recognition of this we need to ensure the commitment made within the Cancer Delivery Plan to provide access to welfare benefits advice is achieved. Of those patients who indicated that information about financial help or benefits would be relevant to them, over half said they had not received enough of this.

People have reported varying experiences according to their type of cancer. The Cancer Delivery Plan confirms that tackling variation is at the heart of service quality improvement[1]. Given the previous survey had identified patients with lung cancer as being the least positive about their care, it is encouraging to report that this was not the case in 2016: patients with lung cancer are now similarly likely to report positive experiences as patients with cancers from other tumour groups. However, variation in the experiences of care for people with different types of cancer still remain, and those with breast, head and neck, prostate and skin cancer reported more positive experiences of care on average than those with rarer cancers such as sarcoma, urological or brain cancer. The results also show that people with other long-term health needs or mental health conditions also continue to see variation in their experiences of care.

The results of the survey confirm we must continue to strengthen the integration of services beyond hospital, as only two thirds of people felt they were given enough care and support from health or social services after leaving hospital.

Overall, the views of the 6,714 people with cancer surveyed show that there is much to celebrate about cancer care in Wales. However, with one in two people predicted to be diagnosed with cancer[2] and over 19,000[3] people diagnosed with cancer in

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[1] NHS Wales Cancer Network, *Cancer Delivery Plan for Wales 2016-2020,* November 2016, p.1

[2] Ahmad, A, S. Ormiston-Smith, N. and Sasieni, P, D (2015) Trends in the lifetime risk of developing cancer in Great Britain: comparison of risk for those born from 1930 to 1960. British Journal of Cancer. 112, p943–947 http://www.nature.com/bjc/journal/v112/n5/full/bjc2014606a.html

[3] WCISU, Cancer in Wales A summary report of the population cancer incidence, mortality and survival, February 2015 (http://www.wcisu.wales.nhs.uk/sitesplus/documents/1111/WCISU%20Official%20Stats%20Report%20Final%20English.pdf)

Wales every year, we need to listen to the voices of patients. They are the experts on their care and how it can be improved, and we need to put them at the centre of decisions to get the best possible outcomes. Person centred care is not an optional extra, it is core to delivering safe, effective and high quality care services. Access to a Clinical Nurse Specialist and an assigned Key Worker, facilitating routine holistic discussions about needs, and offering a written plan of care will help reduce the variation that exists across Wales and decrease the inequalities that exist in the experience of patients with different cancers.

We believe that the feedback received, which comes directly from patients and covers 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 that this should be harnessed to drive service improvements where needed. People in Wales deserve nothing less.

Section two:

Executive summary

Preface

The results presented here are from the second Wales Cancer Patient Experience Survey (WCPES). The survey was conducted by Picker in 2016, on behalf of the NHS Wales Cancer Implementation Group and Macmillan Cancer Support.

This survey has been designed to measure and understand patient experience of cancer care and treatment in Wales to help drive improvement both nationally and locally. The findings of this national report, and the accompanying local health board and NHS trust reports, will help celebrate what is working well and inform ongoing improvements in cancer care throughout Wales by highlighting areas of importance, raised by patients across Wales, and their associated findings.

Key results

Overall, 11,000 cancer patients were invited to take part in this survey. Over 6,700 responded, representing a response rate of 65%[3]. The number of respondents answering each question is reported in Appendix 8: Frequency tables.

This survey has highlighted many positive aspects of cancer care in Wales. These include:

- 93% of respondents rated their overall experience as seven out of ten or more.
- 97% of respondents who had a choice of treatments said that their treatment options were explained to them.
- 90% of respondents rated the overall administration of their care as “good” or “very good”.

Of patients who had had an operation or stayed overnight in hospital for cancer care in the last 12 months:

- 95% said that they “always” had enough privacy when being examined or treated; and
- 89% of inpatients reported that they were “always” treated with respect and dignity while in hospital.

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[3] For full details of response rate calculations and completion methodology see Section five: Survey respondents

However, there are some areas in which cancer care in Wales could be improved, such as:

- 48% of respondents were "offered the opportunity to discuss" their needs and concerns as part of the development of a care plan.
- 18% of respondents said that they had been "offered a written care plan".
- 44% of respondents said that hospital staff had "completely" discussed with them or given them information about the impact cancer could have on their day-to-day activities.
- 52% of respondents who wanted information about financial help and benefits that they may have been entitled to said that they would have liked information or more information.
- 57% of respondents who needed it felt that they had "definitely" received enough care and help from their general practitioner (GP) after leaving hospital.

Overall, patients reported having a positive experience of cancer care in Wales. Respondents used the opportunity to praise staff and suggested that their care and treatment, particularly within hospitals, was to a very high standard. However, the results of this survey would suggest that there is room for improvement, particularly with regards to home support and the development and provision of care plans.

Tumour group analysis

The level of variation in the experiences of patients with different tumour groups differed considerably between questions. For some items, differences were minimal: for example, between 92% and 97% of patients with cancers from all tumour groups said that they were "always" given enough privacy when being examined or treated in hospital. In other cases, the experiences reported by patients with different tumour groups varied considerably. For example, 73% of patients with lung cancer said that they were told about voluntary or charity support, compared to only 27% of patients with urological cancers.

Where differences were apparent, patients with breast, head and neck, prostate, and skin cancers typically reported the most favourable experiences of care and support. There is room for improvement in the experiences of patients with rarer cancers, for example sarcomas and urological cancers, as these patients report below average experiences on a majority of items across the care pathway. Patients with blood cancers also reported poorer experiences in some areas. For example, they were markedly less likely than most other groups to say that they "completely" understood the explanation of what was wrong that was given to them when their cancer was diagnosed: 56% of patients with blood cancers said this, compared to between 69% and 82% in all other groups.

Patients with lung cancer were similarly likely to report positive experiences as were patients with cancers from other tumour group: this contrasts with a finding from a 2013 survey that showed patients with lung cancer to be amongst those least likely to report good experiences of care.

Effect of Clinical Nurse Specialists (CNS) allocation

Overall, 81% of respondents reported that their care included access to a Clinical Nurse Specialist (CNS). In most cases – 69% of all patients, or 84% of those with access to a CNS – the CNS was designated as the patient's Key Worker.

Throughout the care pathway, patients with access to a CNS reported having a significantly better experience. This was true for 73 out of 74 questions, even covering areas of care where a CNS might not traditionally be expected to have an involvement: for example, within the very early diagnostic phase or in community care. This could suggest that the provision of a CNS can improve a patient's perception of their overall care, or that CNSs are more likely to be available in areas where the standard of care is generally high.

Access to a CNS appeared particularly important in providing support and information for people with cancer: of patients with access to a CNS, 67% received information about voluntary and charity support compared to only 29% of those without a CNS, and 52% "completely" discussed the possible impact of cancer on their day-to-day activities compared to 23% of others.

Effect of Key Worker allocation

In total, 86% of respondents reported that they were given the name and contact details of their Key Worker. As noted above, this will most often have been a CNS. As with access to a CNS, patients who had the name and contact details of their Key Worker reported significantly more favourable experiences of care than those who did not – again, this was true across the care pathway, including in areas of care and support where there was no direct involvement of a Key Worker. As with the provision of a CNS, this suggests that having the name and contact details of a Key Worker is associated with more positive experiences of care; this may be because the involvement of a Key Worker helps to improve people's perception of their cancer care, or because Key Workers are more likely to be available when care is well organised and of a good standard.

Offer of a written care plan

Similarly, patients who had the "opportunity to discuss their personal needs and concerns in order to put together a care plan" reported having a significantly better experience than those who did not. Again, differences were evident across the care pathway, although the biggest differences were in questions related to receiving information and support, including home support.

Patients who were offered a written care plan were also more positive about their experiences than those who were not offered a written care plan, but were not significantly more positive than those who had had the opportunity to discuss their personal needs and concerns. This indicates that the opportunity to discuss a care plan is a critical factor in creating a more positive experience, rather than whether or not it is formally written. However, only 48% of respondents had the opportunity to discuss their needs and concerns in order to put together a care plan, so this is an area for improvement.

Results from patients who completed their survey in Welsh

Respondents were given the opportunity to complete the survey either in English or in Welsh, and 2% opted to complete the Welsh language version. Respondents completing the survey in Welsh were significantly more likely to be 60 years of age or older compared to those completing the survey in English (88% compared to 77%) and were significantly more likely to say that they had no long-standing conditions (71% compared to 60%). The small number of people (126) responding in Welsh, along with the variation in the demographic characteristics of this group, mean that further comparison of the experiences of these groups should be interpreted cautiously – other background characteristics are likely to influence observed differences. However, respondents answering the Welsh language version of the questionnaire were generally more positive where significant differences were detected. An exception is that they were significantly less likely to say that they “completely” received the information they needed about their care in the preferred language – 44% compared to 97% for patients completing the questionnaire in English. Despite this, they were consistently more likely to say that they received written information and that it was easy to understand. This suggests that a lack of information in these patients’ preferred language did not necessarily undermine their understanding of the information that they were given.

Results from those who completed their survey online

Respondents were invited to participate in the survey via a letter and questionnaire posted to their home address. This included instructions on how to complete the survey online if individuals preferred this, and 3% of respondents chose to complete the questionnaire in this way. Online respondents were significantly more likely to be male (59% compared to 48%); under 60 years of age (35% compared to 22%); and in full-time employment (20% compared to 14%). As above, the small overall number of online respondents (200) and the demographic differences between groups mean that further comparisons need to be interpreted with caution. Few significant differences were detected, but online respondents found written information easier to understand and were less likely to feel that they were as involved as they wanted to be in decisions about their care and treatment. This could be interpreted as suggesting a higher demand for involvement amongst this group, but demographic and socioeconomic characteristics may have important influences. Further research is required to explore this.

Written comments from respondents

Each questionnaire included space for respondents to write additional comments in their own words under three question prompts: “Was there anything particularly good about your care?”, “Was there anything that could be improved?” and “Any other comments?.” These free text comments provide further and sometimes deeper insight into patients’ personal experiences of care.

Leaving comments was optional. Respondents who chose to write additional comments tended to be older than average, with more than half of all comments (51%) coming from people over the age of 70. Slightly more comments were made by women than by men. This is similar to the profile of survey respondents overall.

The majority of the comments received (61%) were positive. Positive comments most commonly focussed on the quality of care and treatment provided by staff, notably their compassion, professionalism and commitment, sometimes in circumstances that were recognised to be challenging due to workload pressures. The organisation of services was recognised, particularly the speed and efficiency with which diagnosis was made and treatment was begun. Patients also sometimes commented that they felt care from different services was well co-ordinated. Where this was the case, it instilled confidence that the outcomes of care would be as good as possible. A large number of positive comments also referred to specific aspects of treatment, or expressed thanks and appreciation for the care they had received.

Around two in five comments (38%) were negative and reflected problems in care or support. Themes within the negative comments included difficulties in accessing primary care when respondents first became aware of signs and symptoms due to long waiting times and unaccommodating appointments systems. They also referred to experiences of staff in primary care not taking their symptoms sufficiently seriously: in some cases patients said that they felt this led to delays to diagnosis and treatment. A related theme was the length of time it sometimes took for a referral to specialist services to be made. These delays caused anxiety and stress. An additional negative theme was provision of information. Information about the disease itself, treatment and prognosis were most commonly mentioned. The availability and quality of information were the main concerns. Some wanted better information about what they should expect after treatment, particularly what is “normal” and what should be treated as a cause for concern and further care. The fourth dominant subject of comments related to support provided at home, including physical and emotional support.

Results overview

The results provide a useful indication of how cancer care in Wales is measuring up to the ambitions laid out in the new Cancer Delivery Plan 2016/20. This sets out several important areas of focus for preventing cancer; detecting cancer earlier; delivering fast, effective treatment and care; meeting the needs of people with cancer; improvement in cancer information; caring for people with cancer at the end of life; and targeting cancer research. It highlights the need for person-centred care and the creation of a more equal relationship between patients and healthcare professionals.

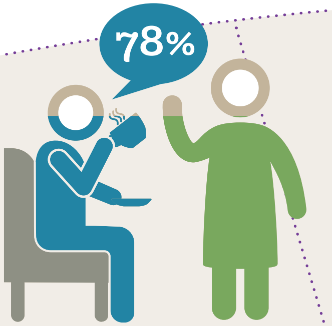
The results show that whilst the majority of patients consider the transitions between primary and secondary care to be good, it is worth noting that the care and help given by GPs after people left hospital was highlighted as a potential area of improvement. Efficiency of moving from diagnosis to treatment is praised both in the quantitative results and in the written comments patients provided. Patients report strong relationships with healthcare professionals, particularly Clinical Nurse Specialists and Key Workers, reflecting a commitment to person-centred care.

The survey results also highlight some areas for potential improvement when looked at in the context of the Cancer Delivery Plan. The discussion leading to the offer of a care plan is clearly very important in facilitating person-centred care, but the majority of patients report not being offered a written care plan. It is also clear that there are some inconsistencies in the delivery of care, with those with sarcoma, urological and brain cancer reporting more negative experiences of care.

Lastly, the results also highlight the importance of information, particularly in written form, throughout the patient journey. Results show us that the provision of accessible and appropriate written information is a key area for targeted improvement across Wales.

CPES: All Wales executive summary

Involvement



said they were definitely involved as much as they wanted in decisions about their care and treatment.

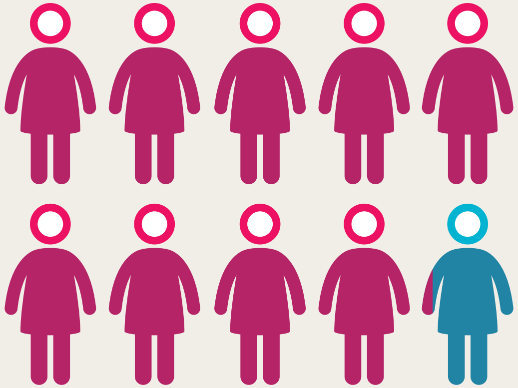
Care plan

said they were offered the opportunity to discuss their needs and concerns to put together a care plan.

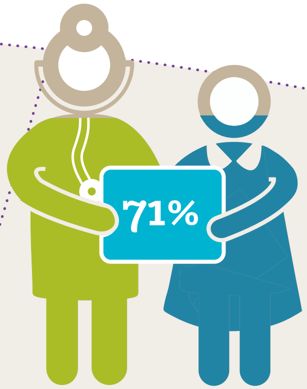
said they weren't offered a written care plan.

Rating of care

93% said they would rate their care 7 out of 10 or better.



Coordination

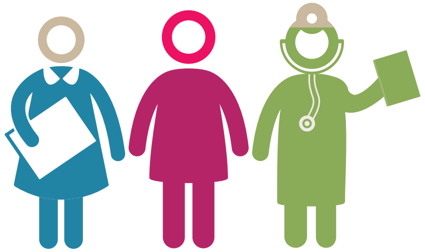


said different healthcare professionals worked well together to give them the best possible care.

"Set of symptoms"

81% said they felt they were treated as a person rather than a "set of cancer symptoms".

Doctors and nurses



81% had confidence/trust in all ward nurses treating them.

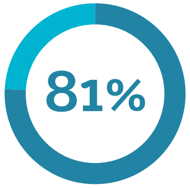
89% had confidence/trust in all doctors treating them.

Key Workers

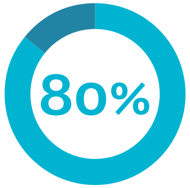
86% said they were given the name and contact details of their Key Worker.

said their Key Worker helped them to get answers to important questions all or most of the time.

Clinical Nurse Specialist (CNS)



said their care included access to a CNS.



said their CNS provided information to make informed decisions about treatment and care.

Community setting

59% said after leaving hospital, they were given enough care and help from health or social services.

56% said they were given enough care and help from their GP and the GP surgery.

Wales Cancer Patient Experience Survey 2016. Survey of 6,714 adults who received cancer care in Wales in 2015 (65% response rate).

CPES: Patient pathway summary – All Wales

WE ARE MACMILLAN. CANCER SUPPORT

NI YW MACMILLAN. CYMORTH CANSER

Llywodraeth Cynulliad Cymru
Welsh Assembly Government

GIG CYMRU NHS WALES

Picker

Diagnosis

55% said they saw a GP or other doctor within three months from first thinking something might be wrong.

25% said they were unaware something might be wrong.

Beforehand **90%** said staff completely explained what would be done during the test(s).

82% said test results were explained to them in a way they could understand.

Side effects

Before they started their treatment, **56%** said they were told about any side effects of treatment that could affect them in the future rather than straight away.

Dignity and respect

89% said they were treated with dignity and respect while in hospital.

Post treatment

92% said hospital staff told them who to contact if they were worried about their condition or treatment after they leave hospital.

Communication

84% said they were told sensitively about cancer.

77% said they understood the explanation of what was wrong with them.

Pain management

87% said hospital staff did everything they could to help control their pain.

86% said while being treated as an outpatient/day case, hospital staff did everything they could to help control the pain.

Financial support

48% said hospital staff gave information about how to get financial help or any benefits they might be entitled to.

Care at home

61% said doctors or nurses gave their family or someone close to them all the information they needed to help care for them at home.

All Wales results. Wales Cancer Patient Experience Survey 2016. Survey of 6,714 adults who received cancer care in Wales in 2015 (65% response rate).

Section three:

Introduction

Background to Wales Cancer Patient Experience Surveys

In November 2016 the Welsh Government refreshed the Together for Health – Cancer Delivery Plan, reflecting the progress and ongoing commitment the Welsh Government has to delivering "the best possible care and support to everyone affected by cancer". It sets out its vision for services and outcomes for patients to match the best in Europe and emphasises a commitment to deliver the highest standard of care for everyone with cancer.

The plan outlined a strategy for driving improvement in cancer services throughout Wales. One of the critical outcomes of this plan was a pledge to put "people at the heart of cancer care" and the 2012 Cancer Delivery Plan committed to develop and undertake a national patient experience survey programme. The first survey of this kind in Wales was launched in 2013.

Key findings of the 2013 survey

A total of 7,352 patients responded to the first Wales Cancer Patient Experience Survey, a response rate of 69%. Overall, the findings indicated that cancer services were well regarded by patients across Wales.

The national report published in 2014 found that:

- Patients with more rare forms of cancer were less likely to respond positively than those with more common cancers, with the least positive experiences being reported from lung, urology and sarcoma tumour groups.
- There was considerable variation in the coverage of Key Workers and Clinical Nurse Specialists across Wales. The facilitation of these resources were strongly associated with improved perceptions and reporting of quality care.
- The provision of CNS was particularly impactful to the over 75 age group.
- Poorer patient experience was reported with respect to information about condition, treatment and care.
- Throughout Wales only a minority (one in five) of patients were being offered written care plans.
- Some patients reported a breakdown in care during the transition between hospital and local health/social services.

For full results and analysis from the 2013 survey, please visit:

http://gov.wales/topics/health/publications/health/reports/report13/?skip=1&lang=en

http://gov.wales/topics/health/publications/health/reports/report13/?skip=1&lang=cy

Changes for the 2016 survey

Ahead of the second Welsh Cancer Patient Experience Survey, the methodology of the previous survey was reviewed and feedback was sought from a wide range of stakeholders, including through an NHS engagement workshop. Following this process, several changes were made to the methodology.

The first change was in how patients are attributed to health boards/trust in the reporting of the results. After careful consideration of the advantages and disadvantages of the approaches available, approval for residency based reports was provided by the Steering Group that oversaw the programme. It was decided that rather than being attributed based on discharge, a reporting method that led to many boards having reports in some instances based on very few responses, patients' results would be assigned to their board of residence.

For the first time, the survey was also able to be completed online, through a unique ID provided on the cover of the questionnaire. The online survey replicated the 'look and feel' of the paper version and, like the paper version, could be completed in English or Welsh.

While the questionnaire itself is based on the 2013 survey, significant revisions took place with the intention of making the data it produces more useful to health boards/trust staff and policy makers. Questions were included or removed based on feedback from NHS, third sector organisations and patients. Changes were tested with participants across Wales, in both the Welsh and English languages to ensure validity.

After reviewing the methodology, it was decided that in order to make comparisons between health boards as fair as possible the data would be standardised. Standardising the data ensures that when health boards are being compared, the proportions of certain types of patients at these health boards are not having an undue bearing on the comparison. This is covered in greater detail in the following section.

Section four:

Survey overview

Survey methodology

Sample process

All seven health boards and one NHS trust participated in the survey, covering acute and specialist cancer care throughout Wales. All centres provided full lists of all eligible patients who had been admitted as an inpatient or day case. Eligible patients were defined as adults (aged 16 and over at the time of discharge) with a *confirmed* primary diagnosis of cancer, with an International Classification of Disease (ICD-10) code of C00-99 (excluding C44 and 84) or D05.

Lists, validated by Picker staff, were combined to form a national sample, which was de-duplicated to ensure that only the latest patient record remained. Following this process the most recent 11,000 records were taken, compiled of patients who were discharged between June and December 2015.

Questionnaire distribution

Participation was encouraged using a three-mailing approach. Respondents could either return the paper questionnaire (Freepost), reply over the telephone via the Freephone helpline or complete online using a unique login code.

All survey materials were printed in both Welsh and English. Patients were initially sent a complete survey pack including questionnaire, covering letter inviting them to take part, a multiple language sheet (offering help with the survey for those who felt more comfortable responding in another language), and a Freepost envelope to return questionnaires. Non-responders were sent up to two reminders; the first a reminder letter and the second a complete survey pack.

Assignment of respondents to a health board/trust

In 2013, individual health board/trust scores were produced by assigning patients to the health board/trust they had most recently attended. In response to feedback and learnings from this, patients were assigned to their health board of residence for 2016 regardless of where they were treated (including patients attending Velindre NHS Trust for part or all of their care). Approval of this approach was provided by the steering group that oversaw the programme. The only exception to this is Velindre NHS Trust, a specialist cancer and blood centre, under which no patients reside. Reporting for this trust is based on patients discharged most recently from this trust – as in the 2013 survey.

For this reason, as well as the fact that it is a specialist cancer centre within a trust, Velindre NHS Trust is treated separately in this report. It is not compared to the seven health boards in Wales.

Standardisation (adjusted data)

Traditionally, cancer patient experience surveys have been reported using unadjusted data, or data that has not been standardised. This changed in 2016 when standardisation (case-mix adjustment) was introduced for the National 2015 Cancer Patient Experience Survey in England.

Standardisation is used in many national patient surveys when comparisons between healthcare providers are made. This is not only the case in established patient experience measures in the UK – such as the national patient survey programme – but also worldwide – including, for example, in the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) in the United States. The purpose of standardisation is to make comparisons in data fairer. 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 provider.

After extensive analysis, it was determined that the WCPES 2016 data would be adjusted by age, ethnicity, deprivation and tumour group when health board performance is compared.

When health boards are not being compared, unadjusted data will be used.

Board average score and All Wales score

This report uses both adjusted and unadjusted data. Adjusted data is data that has been standardised to make comparisons between health boards fairer, accounting for demographic factors beyond the health board's control. Unadjusted data has not been changed in any way – it is an exact reflection of the responses patients provided after anonymisation.

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

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

Tumour groups

Data is displayed within this report by tumour group type. Each patient's ICD-10 code of their primary diagnosis field has been grouped into one of these 13 tumour group types.

Please note, that where Urology is referred to, this does not include Prostate tumour groups, which are reported on separately.

Understanding your results

There are certain practices which we have adopted at Picker in the interests of accuracy and to help draw attention to the most meaningful results. In addition to the overarching policies below, each analysis section opens with a brief explanation as to how to interpret the results within.

Positive scores

Throughout this report, positive scores are used as a summary measure and comparative tool. A positive score shows the percentage of respondents for each question who have given an optimal response. Therefore, a higher positive score indicates better performance.

To see which response options have been included in positive score calculations, please see Appendix eight: Frequency tables.

Targeted questions

Some questions include response options that allow respondents to indicate that a question is not applicable to them, for example: "I have not had any side effects'', or "I did not need an explanation". To make the results as easy to interpret as possible, we use derived questions, which exclude any response options where the respondent has indicated that the question should not apply to them. The new calculation is illustrated in an additional "+" question (e.g. Q10+).

No replies

To achieve greater accuracy in the positive scores, all non-respondents for each question are removed from the calculation. This ensures that all performance indicators have been provided by survey respondents only.

For full frequency tables for the All Wales sample, please see Appendix eight. For health board and trust results, please see individual reports.

Low numbers of respondents

The questionnaire included some filter questions to ensure that only relevant questions are asked of respondents. For example, respondents who indicate that they have not had chemotherapy will not be asked subsequent questions about their experiences of chemotherapy treatments. This means that fewer people will answer some questions, and where the number of respondents is fewer than 50 the result should be treated with caution. Where there are fewer than 20 respondents, results have been suppressed.

Base sizes

As described above, not all respondents answer every question either due to questionnaire directive or by choice. This means that many questions will have a different number of respondents, or base size. For details on base sizes, please refer to Appendix eight.

Significant differences

Throughout this report, we have noted questions where there are significant differences between scores. By ‘significant’ difference, we mean that the finding is statistically reliable and that the difference is ‘real’ and not due to chance. The calculation used to test statistical significance is a Z test to a significance level of $p<0.05$[4].

Confidence intervals

This survey involved only a sample of patients. As the survey was not of all patients, the results may not be completely accurate. However, we can estimate the level of confidence we should have in the results as shown in the table below.

Number of respondents	Confidence interval (+/-)
50	12.0%
100	8.5%
200	6.0%
300	4.9%
400	4.2%
500	3.8%
600	3.5%

Example: For a particular question, 300 patients responded, of which 25% answered “yes”. From the table above, we can see that for 300 respondents the confidence interval would be +/- 4.9%. We would therefore estimate that the true results could be between 20.1% and 29.9%. However, if only 50 patients responded, and 25% answered “yes”, the confidence intervals would be +/- 12% so the true result could be between 13% and 37%.

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[4] The meaning of $p=0.05$ is that there is a 1 in 20 chance of observing a difference of this magnitude in a sample when there is no difference in the population.

Using this report

In this report, we have considered the typical patient care pathway, highlighting variation in patient experience across Wales, indicating areas of good practice and where there is room for improvement. This report should be recognised as a summary overview of patient perception of cancer services in Wales.

For an insight into cancer services at a local level, please see individual health board/trust reports.

Further information

This All Wales report, alongside the local health board and NHS trust reports, presents the results of respondent perception of cancer care in Wales in a number of ways to provide an analysis that we at Picker hope is as engaging and accessible as possible. If you would like any further information or help in understanding your results, please contact the Picker Patient Feedback Team at:

PatientFeedbackTeam@PickerEurope.ac.uk

Section five:

Survey respondents

Dates of fieldwork

Fieldwork ran from 27th July 2016 – 26th October 2016, with two reminders sent during this time.

Survey activity

The response rate for the WCPES was 65%. Across all health boards/trust the response rate ranged from 64% to 71%.

	All Wales
Initial mailing	**11,000**
Total eligible patients	**10,383**
Total completed	**6,714**
Hardcopy	6,514
Online	200
Response rate	**65%**

Figure 3: Survey activity

This was a dual language survey and respondents could reply by returning a paper questionnaire, online, or by telephone. This option also included a language line service.

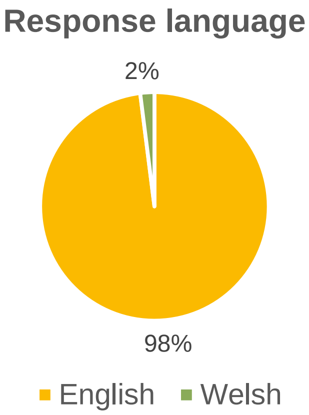


Figure 4: Response language

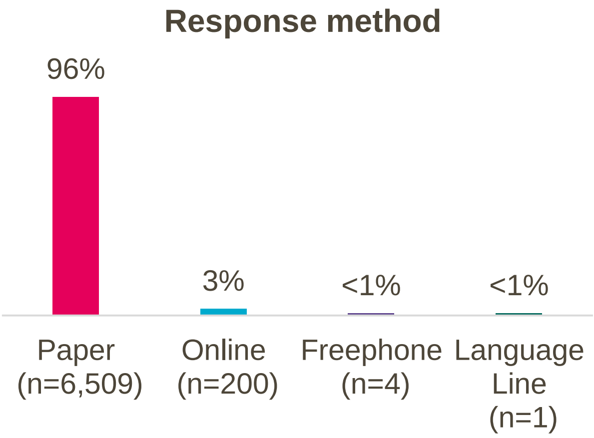
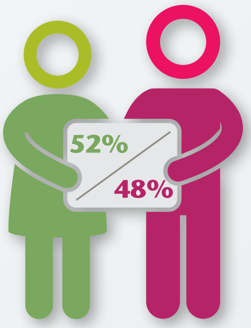


Figure 5: Response method

Demographics of Respondents

All Wales

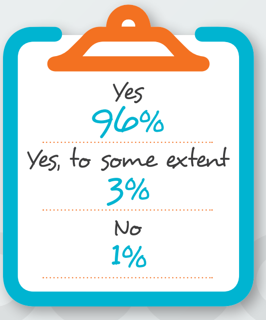
Gender


52%
48%

Sexual orientation


Heterosexual/Straight **96%**
Gay or Lesbian **1%**
Other **1%**
Prefer not to answer **2%**

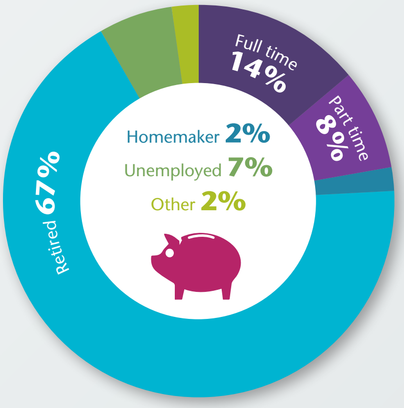
Received information in preferred language


Yes 96%
Yes, to some extent 3%
No 1%

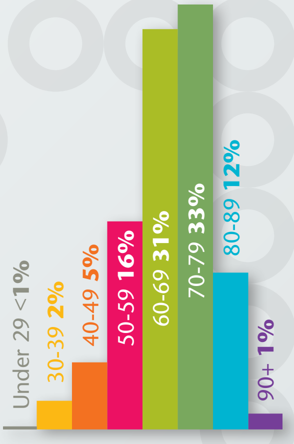
Ethnic group


Asian background **0.4%**
Mixed/multiple ethnic background **0.1%**
White background **99.2%**
Black / African / Caribbean background **0.2%**
Other ethnic group **0.1%**

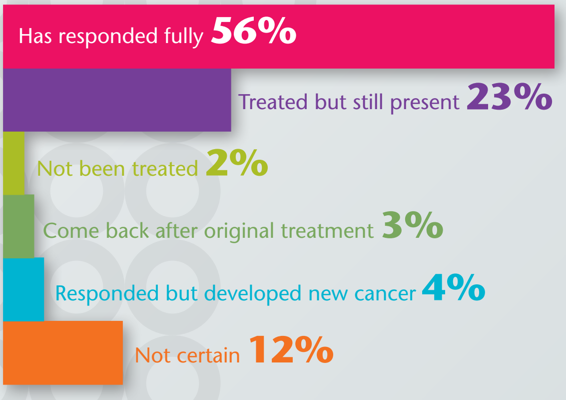
What is your main employment status?


Full time **14%**
Part time **8%**
Retired **67%**
Homemaker **2%**
Unemployed **7%**
Other **2%**

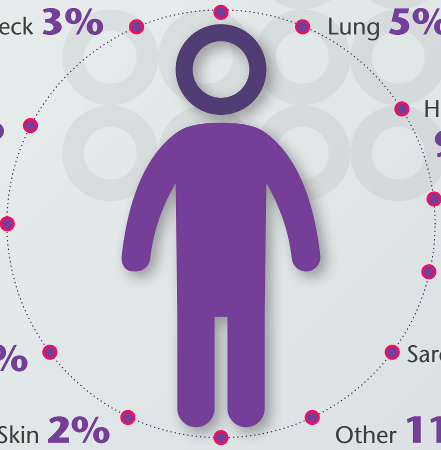
Age


Under 29 **<1%**
30-39 **2%**
40-49 **5%**
50-59 **16%**
60-69 **31%**
70-79 **33%**
80-89 **12%**
90+ **1%**

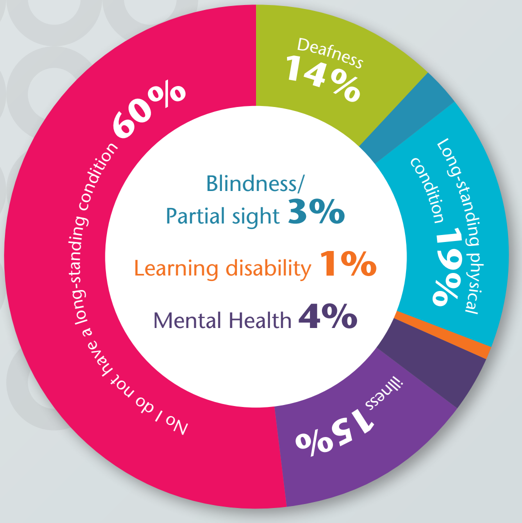
How has your cancer responded to treatment?


Has responded fully **56%**
Treated but still present **23%**
Not been treated **2%**
Come back after original treatment **3%**
Responded but developed new cancer **4%**
Not certain **12%**

Tumour groups


Brain/CNS **1%**
Head and neck **3%**
Lung **5%**
Breast **23%**
Haematological **9%**
Prostate **14%**
Upper GI **4%**
Urological **10%**
Colorectal/ Lower GI **12%**
Sarcoma **1%**
Skin **2%**
Other **11%**
Gynaecological **5%**

Do you have any of the following long term conditions?


Deafness **14%**
Long-standing physical condition **19%**
illness **15%**
No I do not have a long-standing condition **60%**
Blindness/ Partial sight **3%**
Learning disability **1%**
Mental Health **4%**

* percentages include multiple responses

Percentages may not add up to 100% due to rounding

Section six:

Main findings

Main findings

Introduction

The Cancer Delivery Plan for Wales 2016–2020[5] acknowledges the challenges ahead. In time, the demand for health and care services is likely to increase as half of people currently under the age of 65 are predicted to develop cancer[6]. The refreshed Cancer Delivery Plan sets out several important areas of focus for preventing cancer; detecting cancer earlier; delivering fast, effective treatment and care; meeting the needs of people with cancer; improvement in cancer information; caring for people with cancer at the end of life; and targeting cancer research. Person-centred care and the creation of a more equal relationship between patients and healthcare professionals, where treatment and care are co-produced, are central to the plan.

The 2016 WCPES was commissioned to continue monitoring patients' experiences of their cancer treatment and care. Understanding these experiences is crucial to improving and enhancing the design, delivery and quality of cancer services in Wales.

As with the results from the 2013 WCPES[7], the 2016 survey results were largely positive. Most patients provided high ratings of their overall care – 93% gave a rating of seven or above out of ten – and 90% (nine out of ten) said that the overall administration of their care (including getting letters at the right time, doctors having the right notes and results, and so on) was "very good". Further, there was much positive feedback about many specific aspects of the care pathway.

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[5] Wales Cancer Network (2016) Cancer Delivery Plan for Wales 2016-2020. The highest standard of care for everyone with cancer. Retrieved on 18 Feb. 17 from: http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf

[6] Ahmad, A, S. Ormiston-Smith, N. and Sasieni, P, D (2015) Trends in the lifetime risk of developing cancer in Great Britain: comparison of risk for those born from 1930 to 1960. British Journal of Cancer. 112, 943–947.

[7] Quality Health (2013) Wales Cancer Patient Experience Survey.

Positive score chart for patient's overall experience of care

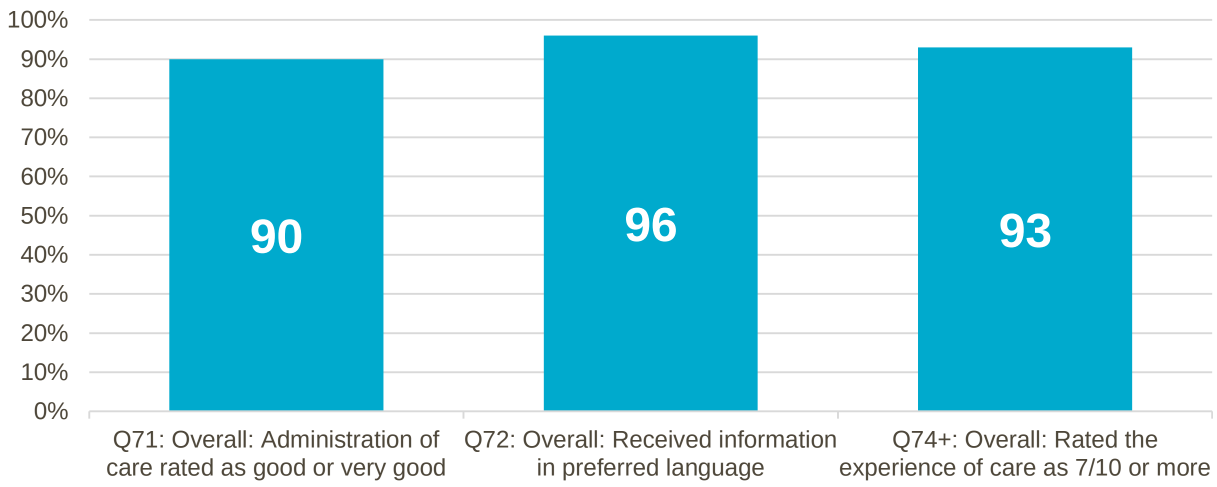

Figure 7: Positive score chart for patient's overall experience of care (Q71 – Q74+)

The wide scope of the survey provides the opportunity to identify differences in care and areas for targeted improvement. The questionnaire covered people's experiences with a range of health service settings, asking patients to answer questions on each aspect of their cancer care within both primary and secondary care.

Within the context of the Cancer Delivery Plan for Wales 2016–2020, we provide an overview of the survey results in relation to five of the seven key areas of focus – early detection; fast delivery and effective treatment and care; meeting people's needs; improving information; and targeting research[8].

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[8] 'Preventing cancer' and 'End of life' are excluded here as no data from the 2016 patient experience survey were collected on this.

Positive score chart for the early detection of cancer

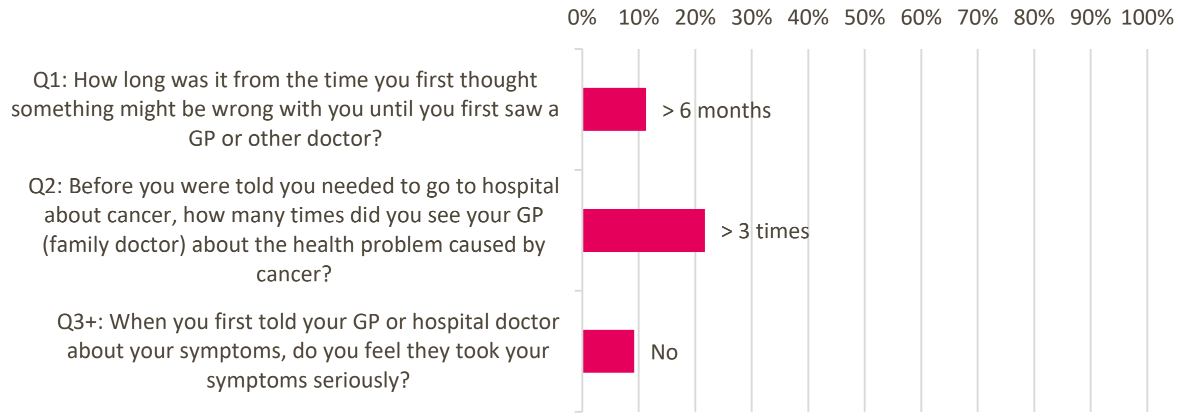

Figure 8: Chart for early detection of cancer results

There were few direct questions relating to early detection in the 2016 survey. However, several questions provide some indication of the time it took for patients to detect any signs or symptoms, and what happened next. Just under a fifth of patients (19%) took at least three months between realising something was wrong and seeing a doctor for the first time; and a quarter (25%) were completely unaware of their cancer until told about it by a health professional. Improving symptom awareness and encouraging people to attend screening programmes will need to continue as actioned in the current cancer delivery plan.

Encouragingly, only a minority of patients (4%) went straight to hospital via Accident & Emergency to seek treatment for the health problem caused by their cancer. Most patients (61%) saw their GPs once or twice before going to hospital showing that primary care remains an important gateway into secondary cancer services and appears to be doing this in a timely way. More than one in six (18%) were referred to hospital following a cancer screening appointment. Together, these results suggest that referral from primary care to secondary cancer services is working well.

Despite this, a minority (6%) did say that they had seen their GP five times or more prior to being referred to hospital. Some respondents also felt that their GP had not taken their symptoms seriously: of those who presented with symptoms, 9% said that their GP did not take these seriously and 12% said they took them seriously only “to some extent”. The importance of referral from primary care was highlighted in written comments from patients; delays to referral from primary care were noted as a theme amongst the minority of negative comments, and in some cases patients felt that this was attributable to GPs not treating their symptoms with adequate importance. Enhancing co-production between GPs and patients, as highlighted in the current primary care service plan, will be beneficial[9]. Multi-disciplinary teams may also be helpful in supporting GPs with this, while seeking to better engage with primary care as the current Cancer Delivery Plan recommends[10].

> *"GPs often too reluctant and too slow to refer patients for cancer tests despite showing probable symptoms. This needs to be improved & GP's need to refer patients to a hospital for checks if they show any cancer like symptoms. In my case I was told that my tumour was non-malignant by my GP despite having a hard lump which turned out to be breast cancer." – Female, 76*[11]

> *"My GP would not have referred me to the specialist if I hadn't pushed. Even at my lowest points, the GP still made me wait days to see them." – Female, 49*

Delivering fast, effective treatment and care

The current Cancer Delivery Plan flagged excellent service quality to be of major importance. Included within this are referral to treatment times. The latest plan specifies that no patient should wait more than 62 days from the point of when cancer is first suspected to the start of treatment.

The survey results revealed generally positive experiences regarding timely referral and in receiving their first hospital appointment. The majority of patients (81%) felt they were seen "as soon as [they] thought necessary"; only 8% of patients felt they should have been seen "a lot sooner" for their first hospital appointment.

One of the fundamental principles of person-centred care is for patients to have the opportunity to be involved in decisions about their care and treatment[12]. Many patients (78%) said that they were "definitely" involved in decisions about their treatment and care – but more than one in five (22%) indicated that they were not

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[9] Our plan for a primary care service for Wales up to March 2018. February 2015.

[10] Wales Cancer Network (2016) Cancer Delivery Plan for Wales 2016-2020. The highest standard of care for everyone with cancer. Retrieved on 18 Feb. 17 from: http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf, p10

[11] All quotes within this section are presented as verbatim.

[12] eg Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (Eds.). (1993). Through the Patient's Eyes: Understanding and Promoting Patient-Centred Care. San Francisco: Jossey-Bass.

involved as much as they wanted to be. This shows that care is person-centred for many people with cancer, but not for all.

Similarly, most patients reported very positive relationships with health professionals. Of patients who had an operation or were treated overnight in hospital in the last 12 months, 89% said that they had confidence and trust in “all” of the doctors caring for them, and 81% said that they had confidence and trust in “all” of the ward nurses. This is important because trust in healthcare professionals is highly important to patients and is generally accepted to be a fundamental component of the relationships between patients and healthcare professionals[13]. But there remains scope for improvement: of people treated in hospital, around one in five (22%) said that they did not receive enough emotional support and only two in three (67%) said that they were able to discuss their worries or fears with staff as much as they wanted. Similarly, almost one in five of all respondents (19%) said that they felt that they “sometimes” or “often” felt that they were “treated as ‘a set of cancer symptoms’, rather than a whole person”, suggesting more could be done to provide personalised, responsive care in line with the Cancer Delivery Plan[14].

Positive score chart for patient’s confidence in staff

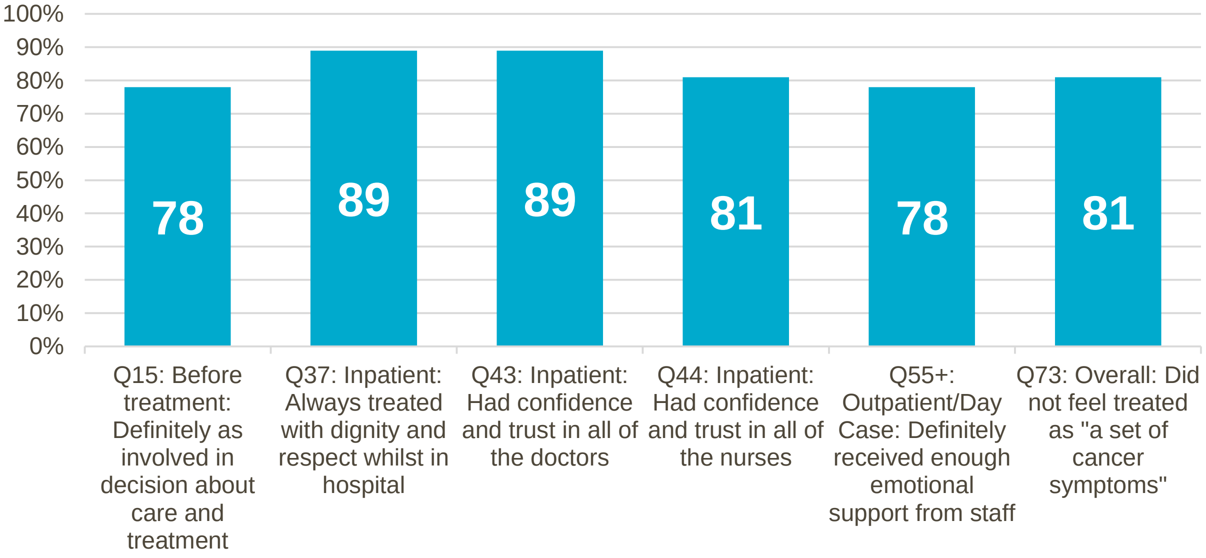

Figure 9: Positive score chart for patient confidence in staff (Q15, Q37, Q43, Q44, Q55+, Q73)

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[13] eg Rolfe, A., Cash-Gibson, L., Car, J., Sheikh, A., & McKinstry, B. (2014). *Interventions for improving patients’ trust in doctors and groups of doctors*. In Cochrane Database of Systematic Reviews. John Wiley & Sons, Ltd. https://doi.org/10.1002/14651858.CD004134.pub3

[14] *Op cit,* p13-14

Another area for improvement in hospital care was enabling patients' families to be able to speak to a health professional. Only two thirds of respondents (66%) said that their family or someone close to them "definitely" had enough opportunity to talk to a healthcare professional.

Positive score chart for inpatient interactions with staff

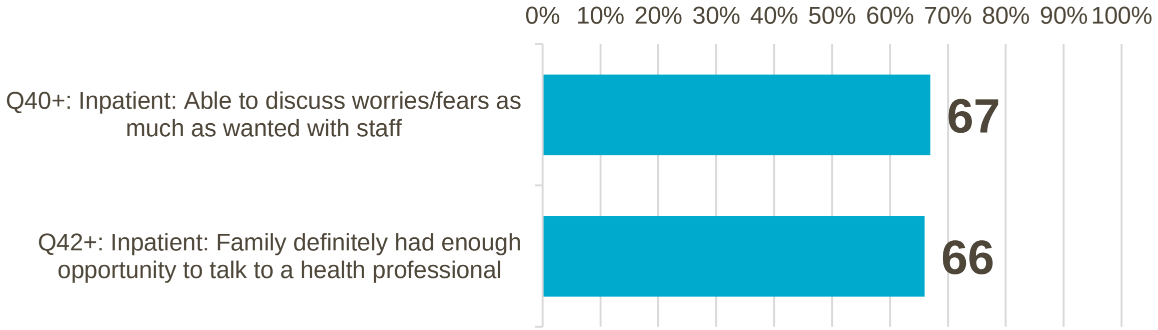

Figure 10: Positive score chart inpatient interaction with staff (Q40+, Q42+)

Meeting people's needs

Having a named Key Worker, usually the Clinical Nurse Specialist (CNS), is an important means by which to enhance a patient's experience of cancer services. The guidance for Key Workers of patients with cancer states, "all cancer patients must have an allocated Key Worker… and must be contactable and responsive"[15]. Their role, among many other things, includes providing information to patients and signposting to local support groups.

The majority (81%) of patients said that they had been given the name and contact details of a Key Worker. Likewise, 81% of respondents said that they had access to a CNS as part of their care – including 69% who said that this person was their Key Worker.

> *"The care I received from the CNS nurses at [Hospital], and from the CNS nurses from [Hospital] has been second to none. I just cannot fault any of it."* – Age, gender unknown

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[15] Welsh Government. (2014 September). *Principles and Guidance – Key Workers for Cancer Patients*. http://gov.wales/docs/dhss/publications/141120whc001en.pdf p1-2.

“I have been particularly lucky in having a "key worker" who has explained in detail everything I have questioned.” – Female, 86

While this is positive, it is short of the 100% aspired to within the Key Worker guidance. Patients also reported sometimes experiencing difficulties in contacting their Key Worker and CNS; of those who had tried, this was reported to be “sometimes” or generally difficult for 26% of patients in relation to Key Workers and 36% in relation to the CNS. When they were able to get in contact, the vast majority of patients always or mostly received understandable answers to any important questions from their CNS (91%) and found that their Key Worker helped them to get answers (87%). Four in five (80%) said that their CNS gave them the information they needed to make informed decisions about treatment and care.

Positive score chart for Key Worker provision

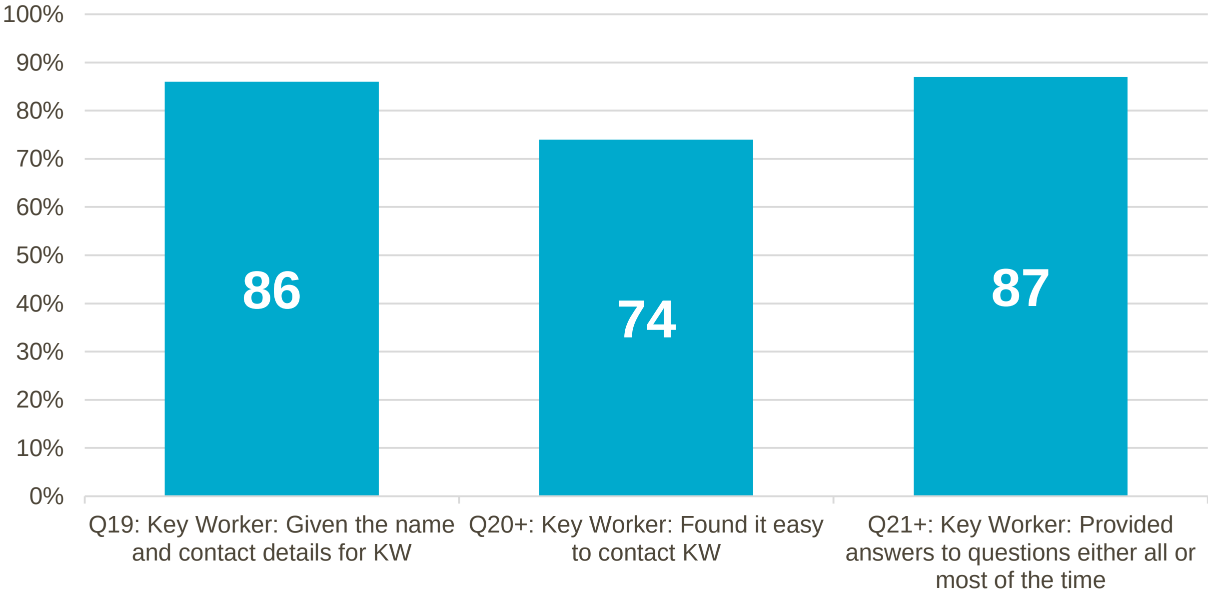

Figure 11: Positive score chart for Key Worker provision (Q19 – Q21+)

Positive score chart for Clinical Nurse Specialist provision

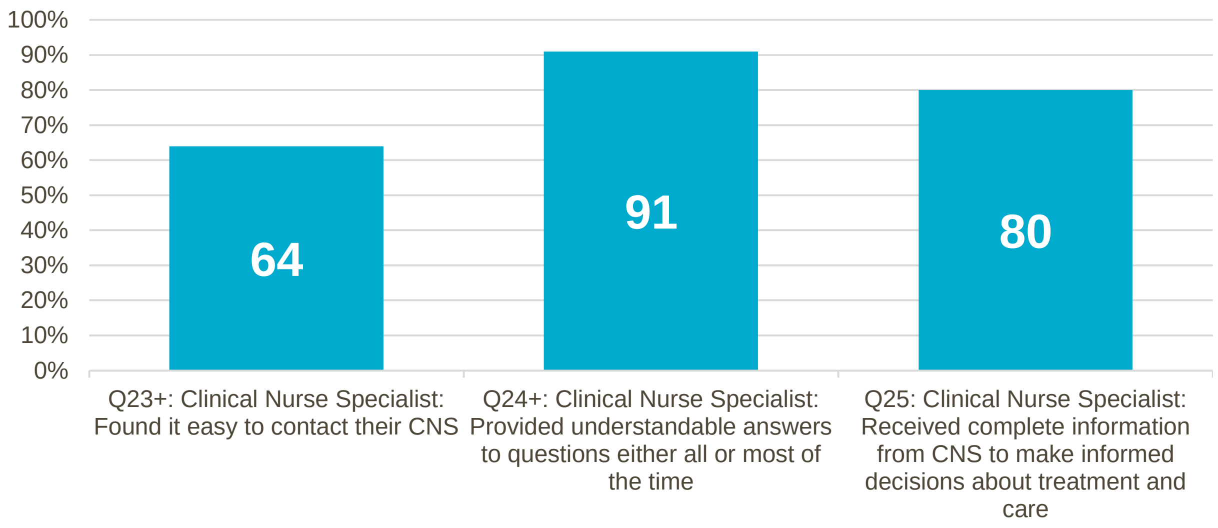

Figure 12: Positive score chart for Clinical Nurse Specialist provision (Q22 – Q25)

The positive impact of a Key Worker/CNS was undoubtedly clear. When compared to those without this support, patients with access to a Key Worker and/or CNS reported more favourable experiences to *all* relevant questions regarding information, treatment and care, arranging home support and their overall NHS care.

The importance of post treatment support and preventing patients feeling unsupported once their treatment ends were key learning points from the 2013 WCPES. However, in the 2016 survey, people's experiences of arranging home support remained less positive overall when compared to the experience of being in hospital. Hospital staff did provide the majority of patients (89%) with a contact number to use if they were worried about their condition or treatment after discharge, but two in five patients (41%) felt that they did not get enough practical advice and support in dealing with side effects of treatment at home – including 15% who were not offered any practical advice or support.

The transition from hospital to home can be a particularly vulnerable phase for patients, as the current Cancer Delivery Plan acknowledges. As noted above, the Key Worker/CNS was usually able to help facilitate and arrange home support, and is ideally placed to ensure this is done effectively. The integration of care pathways, for example, between secondary cancer services and primary care at this discharge/home support phase appeared very good, insofar as most respondents (91%) felt their GP was well informed about the treatment and care provided. However, of those patients who needed help or care from the GP and GP surgery after leaving hospital, only 56% said that they "definitely" received this.

Positive score chart for home support being arranged for a patient

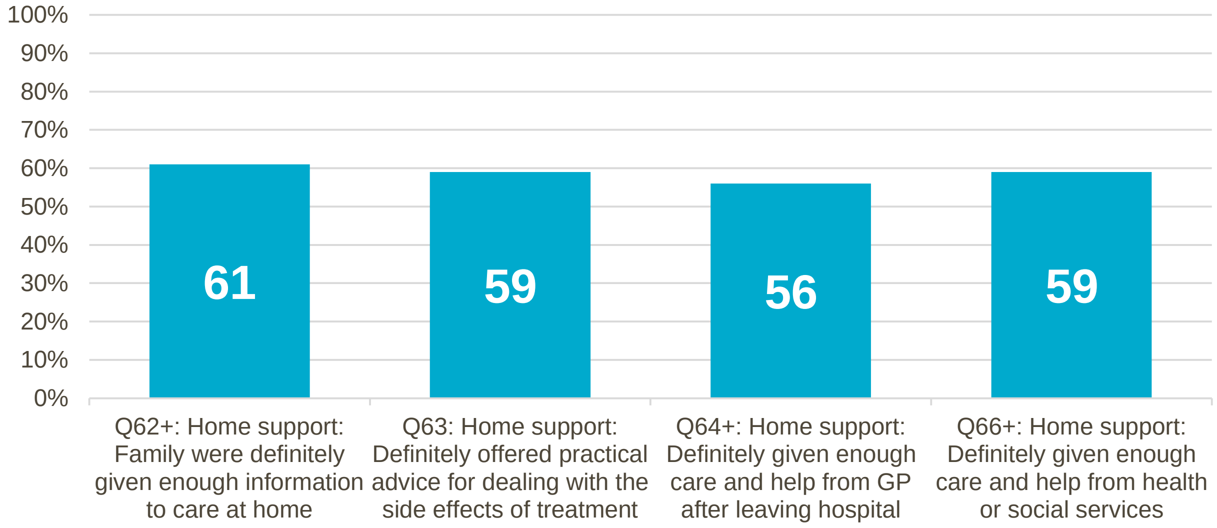

Figure 13: Positive score chart for home support being arranged for a patient (Q62+ – Q66+)

However, even though patients' experiences were positive overall, only three in five (61%) patients with family or friends involved in their care reported that these people were "definitely" given enough information to help with care at home. One in five (19%) said that this information was not given at all.

As well as the support offered by family members and close friends, many people with cancer find assistance from self-help groups, voluntary sector organisations, and charities, to be beneficial. Two thirds of respondents (65%) said that hospital staff gave them "the right amount" of information about support and self-help groups, and 58% said that they were told about voluntary or charity support. But for many others this information was missing: more than one in five (21%) were not given any information about support or self-help groups, and 42% were not told about voluntary or charity support. This is important in terms of supporting self-management of care and encouraging co-production. Of those patients who thought that information about financial help or benefits was necessary, more than half (52%) said that they would have liked more information from hospital staff: this includes 41% who did not get any information as well as 10% who got some but "would have liked more". Overall, 23% of *all* respondents (including those who said that they did not need this kind of information, did not know, or could not remember) indicated that they received no information on financial help or benefits from hospital staff but would have liked some. This is a concern as these respondents may have been experiencing some form of financial difficulties as a result of their cancer. The refreshed Cancer Delivery Plan commits to *all* people getting information on how to access welfare benefits advice following a cancer diagnosis. Whilst it is possible that some patients are able to access this information from other sources, the fact that nearly one in four (23%) of all respondents said that they wanted more information about financial help from hospital staff is a concern.

Positive score chart for the level of information received by patients

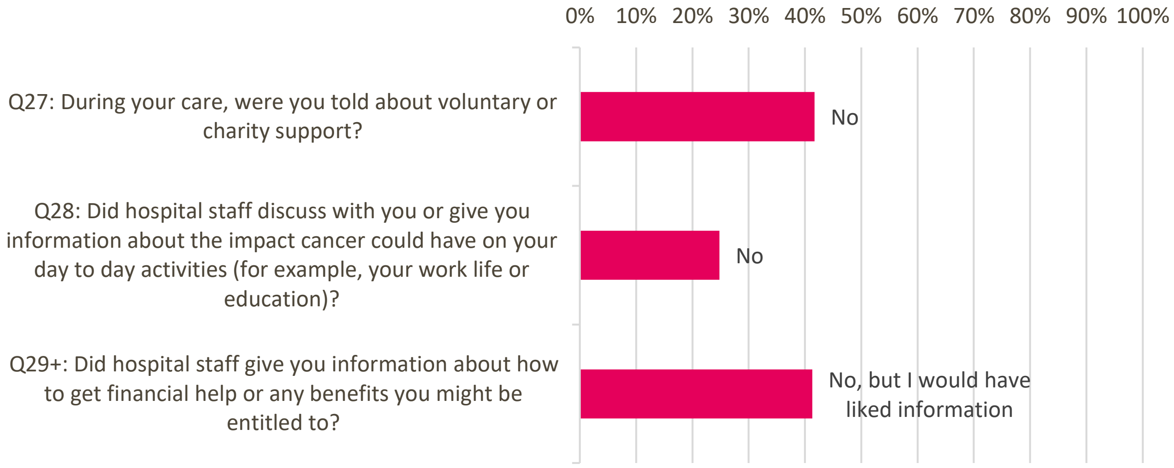

Figure 14: Positive score chart for level of information received by the patient (Q27, Q28, Q29+)

A major area for targeted improvement is the patient's individualised care plan. Care plans are an essential means by which patients' needs, options and preferences for treatment and care. They also signpost patients and their loved ones to appropriate support for their needs. It is a fundamental component of person-centred care and enables a more equal relationship between patients and healthcare professionals to be created.

Positive score chart for patient access to care plan

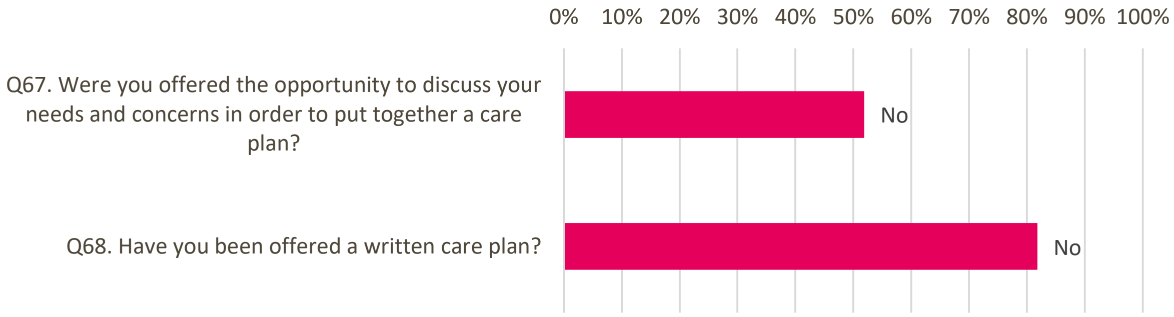

Figure 15: Positive score chart for patient access to care plan (Q67, Q68)

Just under half of patients (48%) reported having had the opportunity to discuss their needs and to develop a care plan, this means that the majority did not. An even smaller proportion of patients were offered a written care plan – only 18% reported this.

The absence of involvement in developing care plans for most patients is worrying not just because of the importance of good involvement for person-centred care, but also because of the differences in the wider experiences of people who were and were not given this opportunity. Patients who were given the opportunity to discuss their needs and concerns in order to put together a care plan reported more positive experiences of their treatment and care across every phase of the patient journey compared to those without. A care plan, therefore, not only promotes the opportunity for better involvement and shared decision-making in the delivery of treatment and care, but is associated with improved patient experience of it. This may be because involvement in developing care plans has a positive impact on people's experiences overall, or alternatively it may be that people who have better experiences in general are also more likely to be offered this involvement – for example because both better experiences and offers of involvement may result from good organisation of care.

Again the Key Worker/CNS is in prime position to develop and offer a written care plan to all patients receiving secondary cancer services. It is critical that every patient has the opportunity to be involved in developing a care plan and is offered the choice of receiving a written copy if they desire. Indeed, ensuring an appropriate care plan is agreed with a patient is well within the Key Workers remit, as described in the principles and guidance of Key Workers of cancer patients[16]. Similarly, the refreshed Cancer Delivery Plan commits to every person diagnosed with cancer having their needs assessed and being offered a care plan – the fact that less than one in five respondents to this survey reported receiving such an offer shows that there is an urgent need for improvement if this commitment is to be met.

> *"My key worker/specialist nurse was great she was always there for me getting back to me with answers to my many questions."* – Male, 68

> *"The clear care plan clearly explained so I had no doubt about what treatment I would receive and when."* – Female, 54

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[16] *Ibid.*

Improving cancer information for patients

According to the Cancer Delivery Plan, providing clear and accessible information to patients is fundamental to delivering a high quality service and patient experience. A number of questions in the survey asked about the information given to people who had undergone diagnostic tests in the previous 12 months. Verbal communication by staff to explain any tests or procedures patients would undergo was generally positively received by most patients: 90% said that they received complete explanations of what would be done during diagnostic tests. So too were explanations of test results: 82% said that these were “completely” explained in a way they could understand. Less than 2% said that they did not receive or understand an explanation, although of course it remains troubling for any patient to receive no explanation of the results of an important diagnostic investigation.

Finding out that they have cancer can itself represent a major life event for patients, and can naturally be a difficult and concerning time. Providing good information and support at this point – and providing it sensitively – is vital for high quality care. Most respondents (84%) said that they were told that they had cancer in a sensitive way, but 6% said this information should have been given “a lot more sensitively”. Moreover, more than one in five patients (23%) said that they did not or only partially understood the explanation of what was wrong with them.

> *“No sensitivity in the diagnosis: the doctor had assumed I'd already been told and was clearly surprised I hadn't so misinformation. At the time he had a trainee doctor with him and it was embarrassing all around.”* – Male, 55

It is very encouraging that of patients who had choices about their treatment, almost all (97%) said that their treatment options were explained to them, but only three quarters (75%) of patients said that possible side effects were “definitely” explained to them. Similarly, fewer than three in five patients (56%) said that they were “definitely” told about potential side effects that might arise in the future.

Giving clear information about potential side effects is important to allow patients to make informed decisions about their care, and evidence shows that it can have a long term impact on behaviours – for example, long-term medicines adherence has been shown to be higher amongst breast cancer patients given information about medicines side effects prior to commencing treatment[17].

> *"More explanation regarding different options of treatment would have been welcomed…"* – Male, 72

> *"I felt that although I was involved in the discussions about my treatment options the surgeon had already decided what he was going to do and either did not listen to or disregarded some of my wishes."* – Male, 60

> *"Side effects to treatment could have been better explained."* – Male, 56

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[17] eg Kahn, K. L., Schneider, E. C., Malin, J. L., Adams, J. L., & Epstein, A. M. (2007). Patient Centered Experiences in Breast Cancer. *Medical Care*, *45*(5), 431–439. https://doi.org/10.1097/01.mlr.0000257193.10760.7f

Positive score chart for what happened before treatment

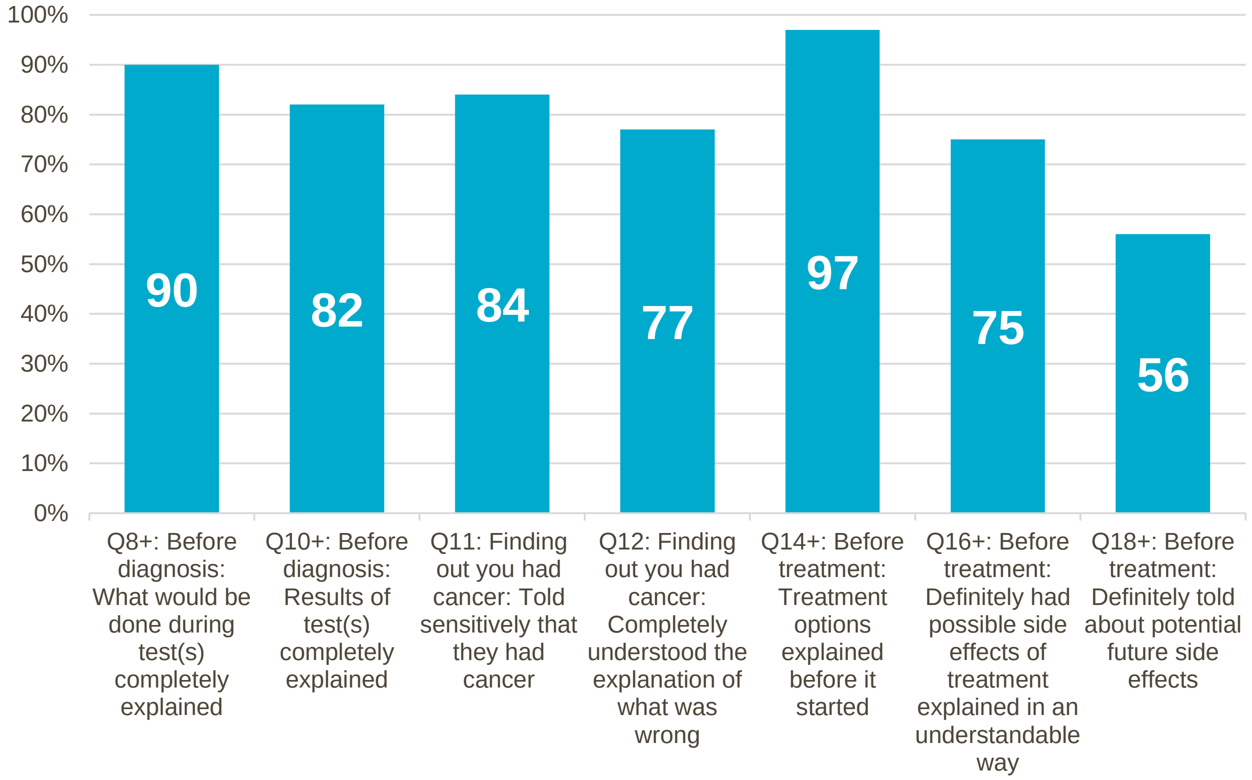

Figure 16: Positive score chart for what happened before treatment (Q8+, Q10+, Q11, Q12, Q14+, Q16+, Q18+)

The provision of accessible and appropriate written information is a key area for targeted improvement. Excluding those patients who said that they did not need written information, two in three (66%) patients said that they were given written information about the type of cancer they had and that this was easy to understand. More than a quarter (27%), however, did not receive any such written information.

Targeting cancer research

Clinical and health services research is pivotal to improving the quality of patient care in the future – for example through the development of new and improved methods, interventions, and medicines. Cancer research is no different, but only a relatively small proportion of patients (23%), had had discussions about taking part in cancer research.

This perhaps represents a missed opportunity for cancer services and patients to develop more cost-effective treatments and identify best practice. This is, however, reflective of the current situation.

Tumour group analysis

The level of variation in the experiences of patients with different tumour groups differs considerably between questions. For some questions, differences were minimal. For others, there were wide differences in the experiences reported by different groups. There was, predictably, a strong association between how positive respondents were on average for a question and the range in results between different tumour groups: that is, there was generally less variation in questions where most patients gave favourable responses. For example, 95% of all patients and between 92% and 97% of patients within each tumour group said that they were "always" given enough privacy when being examined or treated in hospital. By contrast 51% of all respondents said that they were told about voluntary or charity support: within tumour groups, this figure varied from 73% for patients with lung cancer to only 27% for patients with urological cancers.

Tumour group	Number of respondents
Brain/CNS	37
Breast	1546
Colorectal/Lower GI	823
Gynaecological	348
Haematological	611
Head and Neck	230
Lung	318
Prostate	959
Sarcoma	60
Skin	142
Upper GI	242
Urological	678
Other	720

Figure 17: Base size of respondents for each tumour groups

Positive score chart for those respondents who rated their experience of care as 7/10 or higher by tumour group

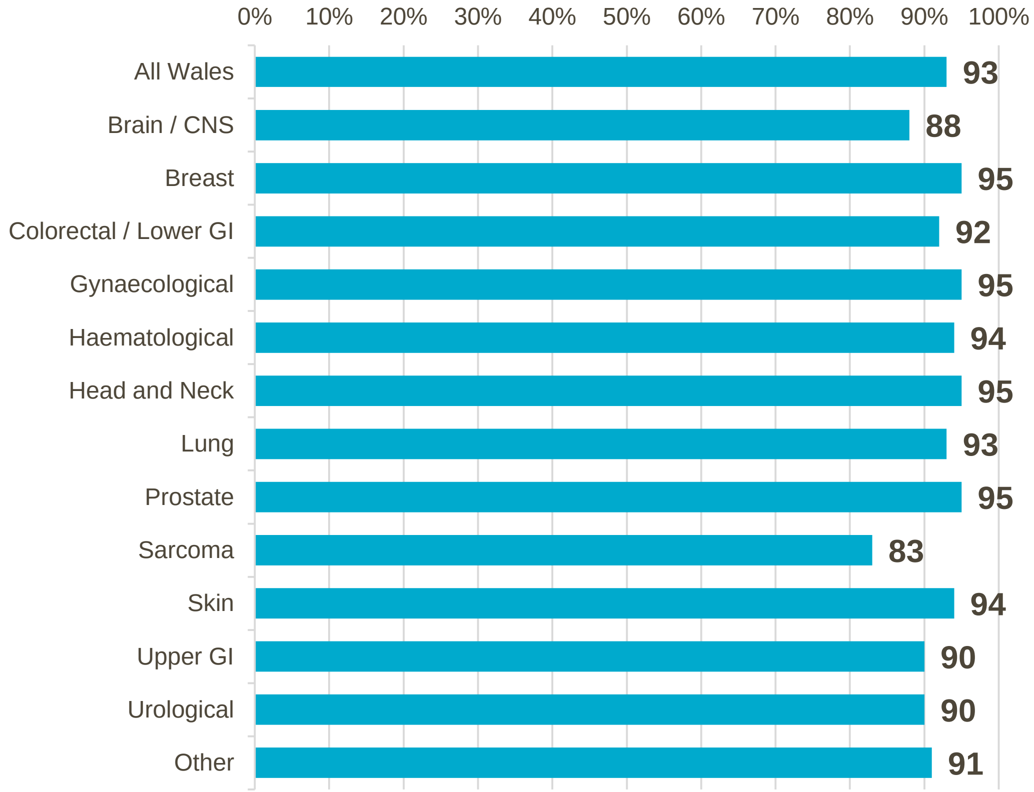

Figure 18: Q74+ respondents who rated the experience of care as 7/10 or more broken down by tumour group

For questions where differences were more readily apparent, some trends were visible. Several groups had particularly positive experiences across a number of questions: for example, patients with breast, head and neck, prostate and skin cancer. Patients with breast and prostate cancer in particular reported positive experiences about many aspects of their treatment and care across all phases of their cancer care.

Some tumour groups appear to have relatively less positive experiences with their treatment and care. Three tumour groups stand out in particular – patients with sarcoma, urological and brain/central nervous system cancers[18]. Patients with blood cancers also reported poorer experiences in some areas.

Patients with sarcoma had the least positive experience of all the tumour groups examined: they gave the least favourable aggregate responses of any tumour group on almost half of all questions in the survey. This spanned across all phases of their treatment and care and requires prompt action to understand both the underlying reasons and how this can be improved. The relatively small number of survey respondents with sarcoma means that there is a possibility that some observed differences may be down to chance – however, the consistency with which this group reported less favourable experiences certainly merits further investigation. For example, only 83% of patients with sarcoma rated their care as seven out of ten or higher, compared to between 88% (brain and central nervous system) and 95% (breast, gynaecological, head and neck, and prostate) amongst other tumour groups.

Positive score chart for the lowest sarcoma scores

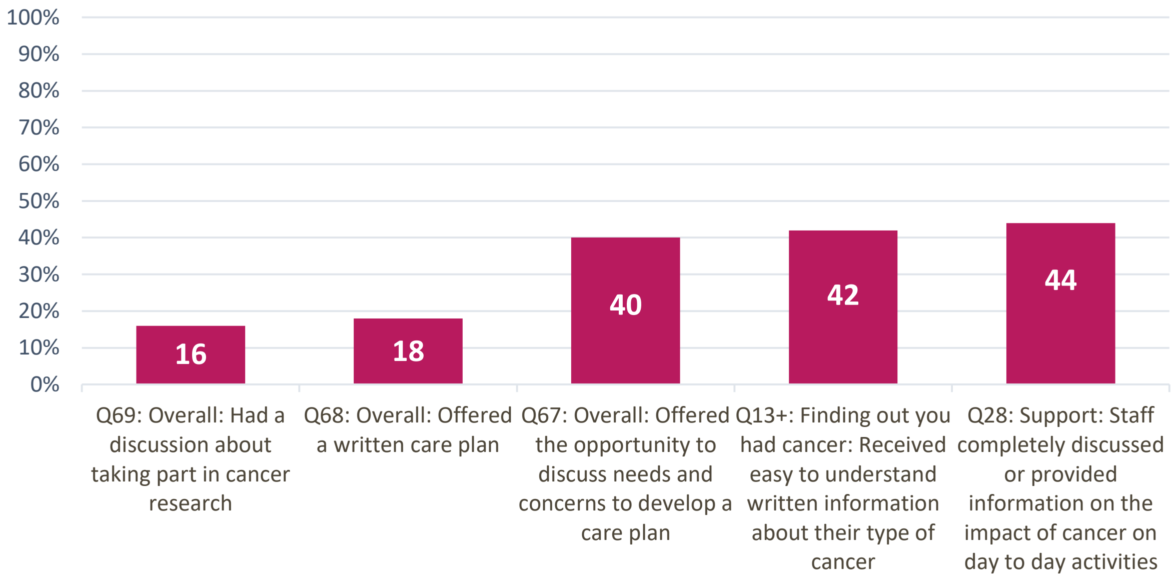

Figure 19: Positive score chart for lowest sarcoma scores (Q69, Q68, Q67, Q13+, Q28)

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[18] Relatively wide confidence intervals on most questions for patients with brain/central nervous system cancer and sarcoma were identified. This means the sample size for each of these tumour groups were comparatively small, so some caution is needed in interpreting these findings and the conclusions drawn from them. However, as these tumour groups had consistently less positive experiences across many of the areas examined they do therefore warrant attention.

Patients with urological cancer also had less positive experiences of treatment and care. This, however, tended to be more focused on support, such as receiving the right amount of information about self-help groups, voluntary and charity support, discussing the impact of cancer on daily activities, and receiving information regarding financial help. For example, only 27% of patients with urological cancers were told about voluntary and charity support, compared to between 36% (skin) and 73% (lung) in other groups.

Positive score chart for lowest urological scores

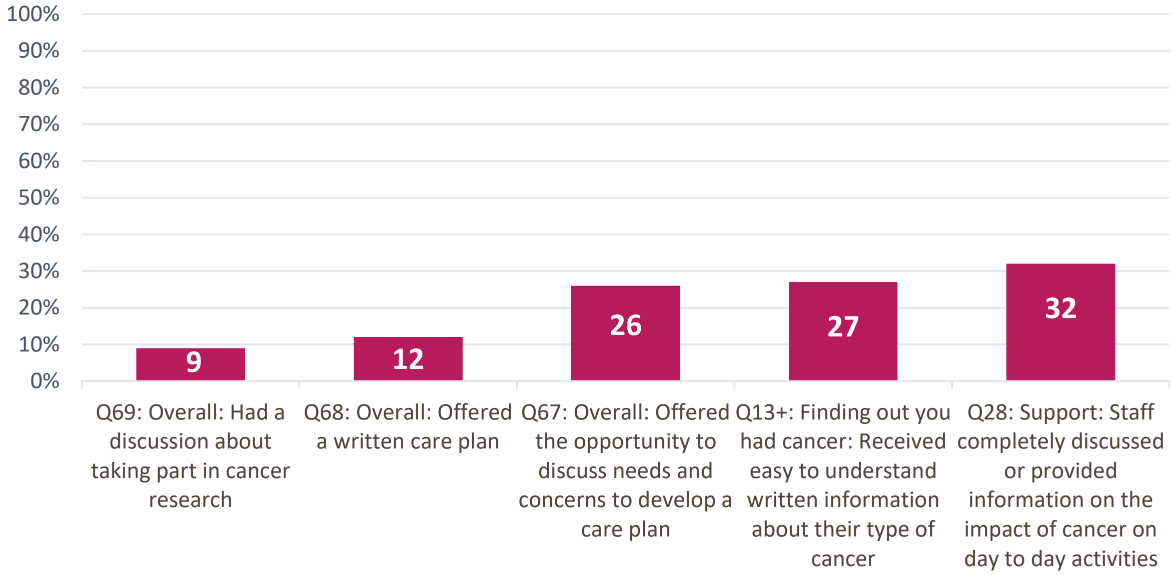

Figure 20: Positive score chart for lowest urological scores (Q69, Q68, Q67, Q13+, Q28)

Although not as marked, patients with brain/central nervous system cancer had less positive experiences of their care, most notably in contacting their Key Worker and in being given enough care and help from their GP following discharge from hospital.

As noted above, patients with blood cancers also reported poorer experiences in some areas. For example, they were markedly less likely than most other groups to say that they “completely” understood the explanation of what was wrong that was given to them when their cancer was diagnosed: 56% of patients with blood cancers said this, compared to 69% to 82% in all other groups.

In a previous survey conducted in 2013, patients with lung cancer were reported to be amongst those least likely to give positive reports of their experiences. This finding was not replicated in 2016, where patients were generally similarly likely to the average of all patients to report positive experiences. Patients with lung cancer were still the least likely to say that they did not feel that they were treated as “a set of cancer symptoms”, with 76% saying this compared to 81% on average: but this was the only question where lung cancer patients where the group least likely to report good experiences. For most questions, people with lung cancer were similarly likely to those with other tumour groups to report positive experiences, and for four questions they were the most positive. For example, patients with lung cancer were the most likely to say that they had been seen as soon as necessary by a hospital doctor before their diagnosis (88% compared to an average of 81%) and to say that they were told about charitable and voluntary support (73% compared to an average of 58%).

Long-standing conditions

It is recognised that many patients with cancer also live with at least two or more other long-standing conditions[19]. Two in five (40%) patients surveyed disclosed having at least one long-standing condition, predominantly a long-standing physical health condition (19%).

The experience of care for these respondents was positive for the majority. In some areas the positive experiences reported by respondents with long-standing conditions exceeded those without a long-standing condition; and in others fell marginally short of it.

There were comparatively fewer positive experiences for people who reported having a long-standing condition to discuss their needs and concerns to develop a care plan compared to those without, with the exception of respondents with a learning disability.

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[19] Welsh Government. (2014 September). *Principles and Guidance – Key Workers for Cancer Patients*. http://gov.wales/docs/dhss/publications/141120whc001en.pdf p1-2.

Positive score chart for patients who were offered the opportunity to discuss needs and concerns by long-term conditions

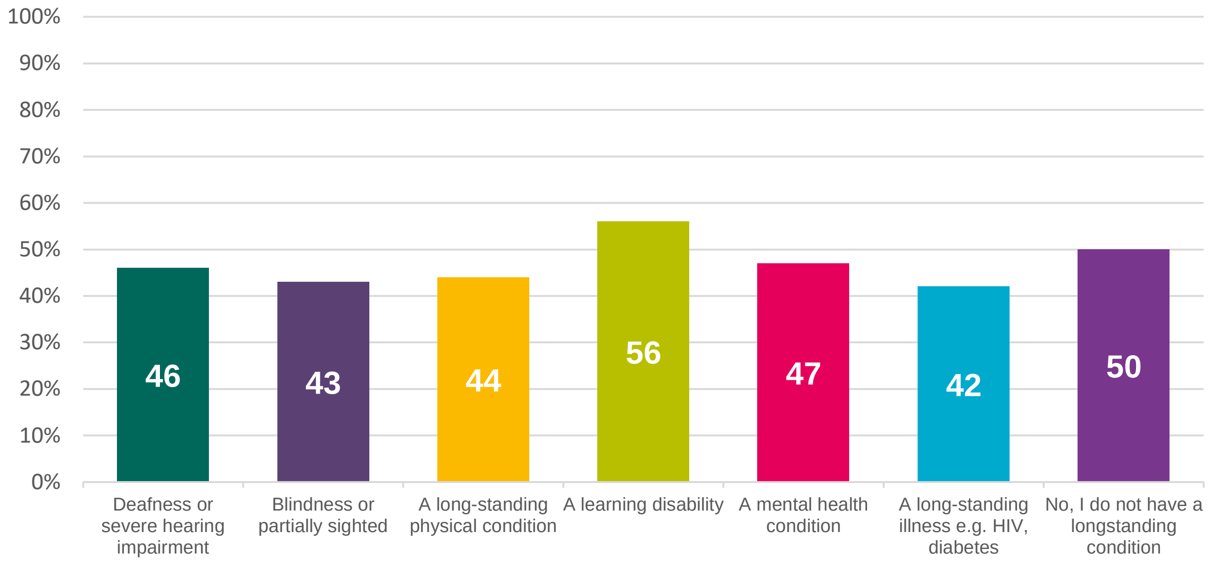


Figure 21: Positive score chart for patient opportunities to discuss concerns by long-term condition (Q67)

Experiences of those with learning disabilities

Respondents with a learning disability reported very positive experiences in a range of areas. Their positive experiences exceeded both those reporting other long-standing conditions and those without, for example, when presenting their symptoms to their GP, explanations of what tests would be carried out and how their operation had gone.

However, patients with a learning disability reported a positive experience with how their cancer was explained, either verbally or through written information that was easy to understand. This included understanding responses from the Clinical Nurse Specialist (CNS) to any questions asked by those with a learning disability.

Nevertheless, findings need to be interpreted with caution as only a smaller number of respondents – fewer than 50 – reported having a learning disability. This means that there is a relatively wide margin of error for estimates about the experiences of this group. Furthermore, a self-completion questionnaire may lead to under-representation of people with severe learning difficulties, so further research focussed on the experiences of people with learning difficulties and cancer is recommended to better understand this area.

Experiences of those with mental health conditions

The lowest proportion of respondents who reported positive experiences for several aspects of their cancer care were those with a mental health problem. This largely related to their experience of inpatient care, for example, in being able to discuss their concerns or worries with staff as much as they would have liked (56% compared to an average of 67%, and 70% of those who said that they did not have a long-standing condition).

Positive score chart for patients able to discuss worries/fears by long-term conditions

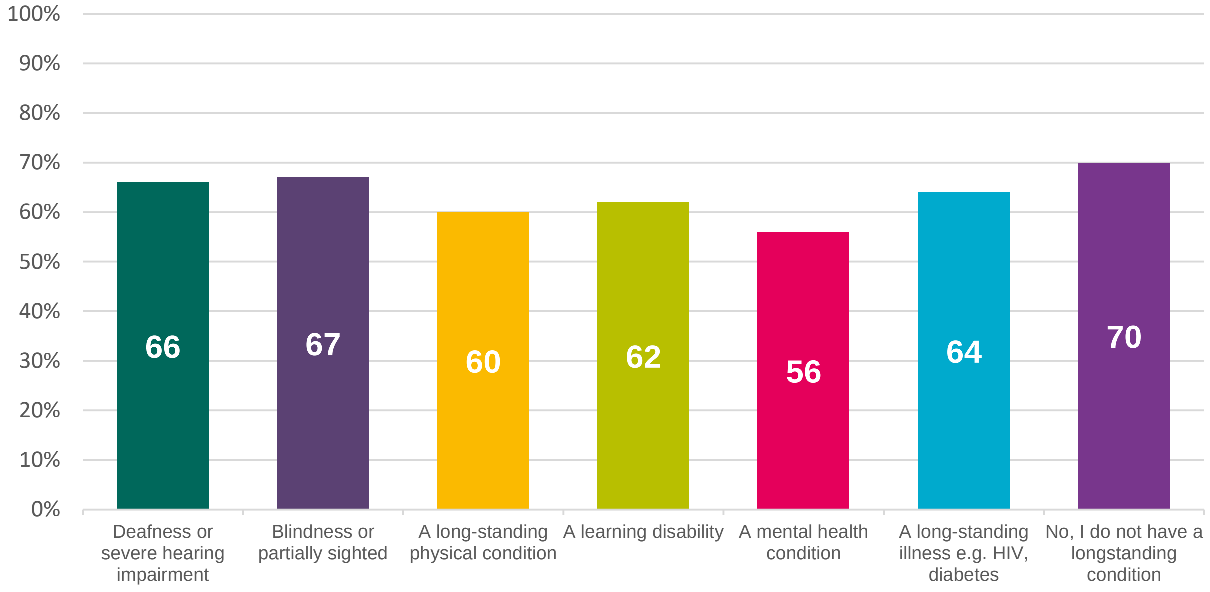


Figure 22: Positive score chart for patients able to discuss fears with staff by long-term condition (Q40+)

Respondents with a mental health problem reported the most positive experiences of being told about voluntary and charity support (61% compared to an average of 58%, and 61% of those who said that they did not have a long-standing condition), but not with receiving enough care and help from health or social services (48% compared to an average of 59%, and 63% of those without a long-standing condition).

As with the learning difficulties group, the number of people self-reporting mental health conditions was comparatively low – fewer than 250 respondents. Again, this means that findings should be interpreted with caution.

Experience of those with other long-standing conditions

Access to a CNS was comparatively lower for visually impaired respondents (73%), who also reported fewer positive responses for their CNS providing information to make informed decisions about their treatment and care (75%), self-help and support groups, voluntary sector/charity support (42%) and financial support (36%).

Positive score chart for patients who had access to a Clinical Nurse Specialist by long-term conditions

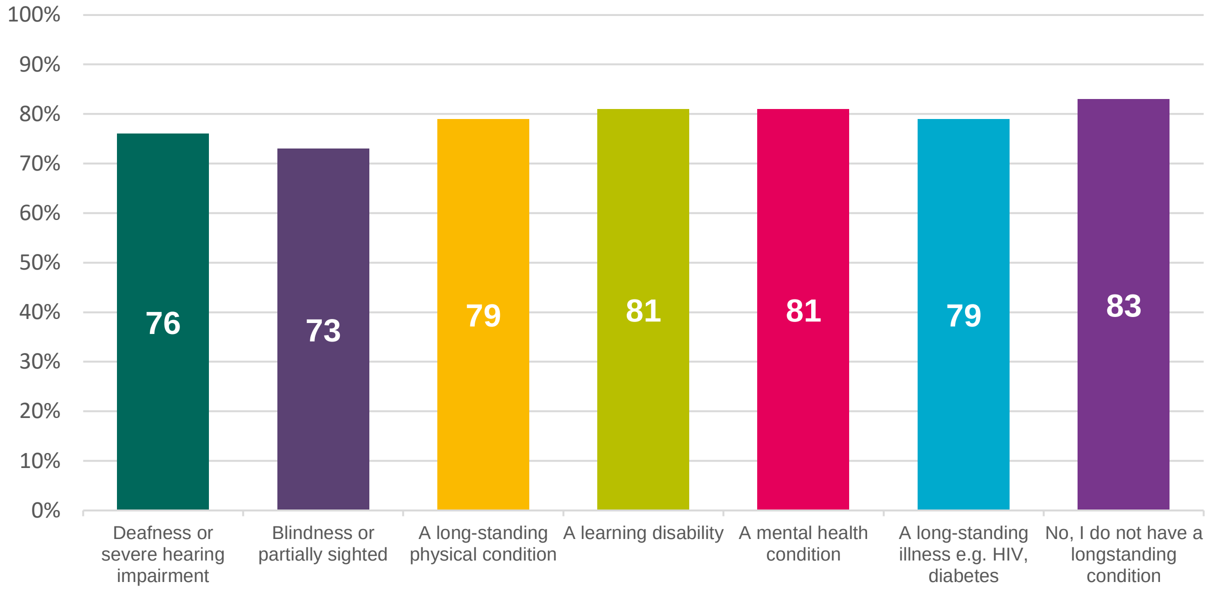


Figure 23: Positive score chart for patient access to Clinical Nurse Specialist by long-term condition (Q22)

For patients with a long-standing illness (for example HIV or diabetes) home support and receiving enough information for their family to care at home was comparatively low in terms of positive experience (56% compared to an average of 61% and 62% of those who said that they did not have a long-standing condition); and for those with a long-standing physical condition (57%).

Positive score chart for families who were given enough information to care at home by long-term conditions

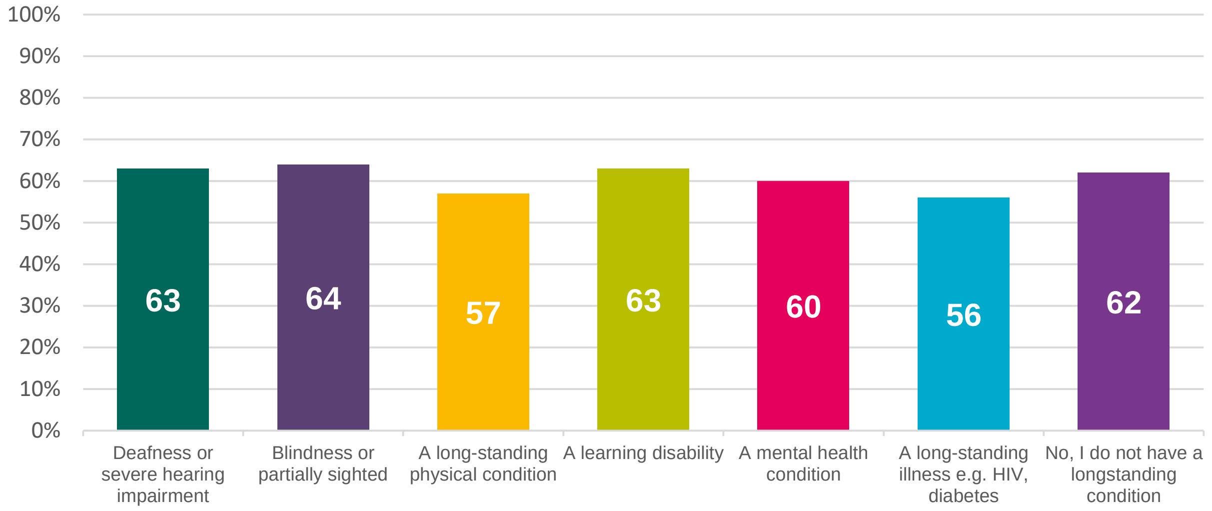


Figure 24: Positive score chart information given to family by long-term condition (Q62+)

Experiences of respondents completing the Welsh language version of the questionnaire

Respondents were given the opportunity to complete the survey either in English or in Welsh, and 2% opted to complete the Welsh language version. This amounts to a relatively small number of respondents overall – fewer than 150 – but this nevertheless affords the ability to look at the experiences of people who preferred to complete the survey in Welsh. This analysis can only realistically be done nationally, as the number of people responding in Welsh is too small to allow any analysis of subgroups.

There were some demographic differences between people who chose to complete the survey in English and in Welsh. Respondents completing the survey in Welsh were significantly more likely to be 60 years of age or older compared to those completing the survey in English (88% compared to 77%) and were significantly more likely to say that they had no long-standing conditions (71% compared to 60%). They were also far more likely to live in the north and west of Wales – with the overwhelming majority residing in the catchment area of Betsi Cadwaladr University Health Board or Hywel Dda Health Board. The combined number of Welsh language respondents from the remaining five health boards was fewer than 20.

This is important in considering the meaning of any other observed differences between the groups, as these other characteristics may confound or influence these. It is possible that observed differences between people completing the Welsh and English language versions of the survey may be partly or wholly attributable to people in the survey being typically older and with fewer reported long-standing conditions.

Nevertheless, review of the responses from people completing the survey in Welsh and in English highlights some interesting variances. Where there were differences, people responding in Welsh typically reported more favourable experiences. For example, respondents completing the survey in Welsh were significantly more likely to say that their GP or hospital doctor took their symptoms “completely” seriously when they first discussed these – 92% of people responding to the Welsh version said this compared to 79% of others. They were also more likely to say that they had their first appointment with a hospital doctor “as soon as… necessary”: 88% compared to 81%. Amongst those treated in hospital, people responding in Welsh were also significantly more likely to say that they had confidence and trust in “all” ward nurses (90% compared to 80%) and that doctors and nurses communicated effectively (also 90% compared to 80%).

One particularly interesting finding relates to written information. People responding in Welsh were much less likely to say that they “completely” received information in their preferred language – only 44% of those responding in Welsh said this, compared to 97% of those responding in English. Despite this, people responding in Welsh were consistently more likely to report that they found written information easy to understand. For example, 79% said that they received written information about the type of cancer they had and that it was easy to understand, compared to 66% of people responding in English. This suggests that a lack of information in these patients’ preferred language did not necessarily undermine their understanding of the information that they were given.

As noted above, caution is needed in interpreting these findings. The relatively small number of people responding in Welsh and the difference in demographic characteristics of the two groups are both important considerations. Moreover, it is important to acknowledge that a person’s choice to respond in Welsh or in English is not sufficient to make any further inference about the languages respondents speak. Most Welsh language respondents will be bilingual, therefore there may be many Welsh speakers amongst the population of people responding to the survey in English. People may also have different language preferences when completing a patient survey – which deliberately uses very simple language wherever possible – compared to when they are given information about their cancer or treatment, which may be unavoidably more complex. Nevertheless, it is reasonable to hypothesise that the results show room for improvement in the provision of information about cancer in Welsh.

Experiences of respondents completing the survey online

Respondents were invited to participate in the survey via a letter and a questionnaire posted to their home address. This included instructions on how to complete the survey online if individuals preferred this, and 3% of respondents chose to complete the questionnaire in this way. As with Welsh language respondents, this represents a relatively low number of responses overall – 200 – but some comparison of the online and postal response groups is possible.

As with choice of language, there were demographic differences between the groups responding online and by post. Online respondents were significantly more likely to be male (59% compared to 48%); under 60 years of age (35% compared to 22%); and in full-time employment (20% compared to 14%). Again, these differences may represent confounding factors.

For most questions, there were no significant differences in the experiences reported by people who responded by post or online. However, online respondents were more likely to report receiving understandable information, answers to questions.

For example, 88% of online respondents compared to 81% of people responding by post said that they were given written information about possible treatment side effects and that this was “easy to understand”, and similarly 95% of online compared to 87% of postal respondents said that their Key Worker helped them to get answers to important questions “all or most of the time”. However, they were also significantly less likely to say that they were “definitely” as involved as they wanted to be in decisions about their care and treatment (71% compared to 79%), and were less likely to say that it was easy to contact their Key Worker if they had tried to do this (66% compared to 74%). Amongst patients who had an operation, they were also more likely to say that they did not receive an explanation of how this had gone, but would have liked one (8% compared to 4%).

One possible interpretation of these findings relates to what is sometimes called ‘patient activation’. Online respondents appeared confident in understanding the information that they were given and seeking information from the healthcare professionals involved in their care, but they also expressed greater problems with involvement and easy access to Key Workers. It could be hypothesised that these patients may have broadly higher expectations about involvement in their care. However, this might equally be related to patients’ age (online respondents were generally younger) and socioeconomic status. Further research is needed to explore this in greater detail.

Conclusions

The results from the 2016 WCPES were generally very positive. Patients gave positive accounts of their care and treatment, with the vast majority rating their overall experience as seven or above out of ten. Similarly, most respondents felt that health professionals generally worked well together and that care was well administered. This reflects broadly positive experiences from the point at which patients first sought help to their diagnosis, treatment, and care at home. However, there were aspects of care at each stage that showed room for improvement.

Most respondents in the survey were referred to hospital after seeing a GP about symptoms caused by their cancer on one or two occasions. Referral from cancer screening programmes was also a common route into secondary care. Referral from primary care to secondary cancer services appeared smooth for the majority of patients, and the support that people received around diagnosis and referral was generally of a good standard. However, some patients had less positive experiences – around one in twenty (5%) saw their GP five or more times before being referred, and one in five of those presenting with symptoms (21%) felt that their GP or hospital doctor did not take these "completely" seriously.

Good relationships with trusted health professionals are an important part of people's experiences of person-centred care. There was evidence in the survey that patients had strong relationships with health professionals, including their Key Worker/CNS, whom they trusted to provide their cancer treatment and care. Indeed, access to a Key Worker/CNS was associated with significantly more positive experiences across the survey. This may indicate access to Key Workers or CNSs can improve people's experiences of their care, or it may be that provision of access to these professionals is a feature of generally good care. In either case, it is of some concern that a minority of patients do not have access to these professionals – 14% said that they were not given the name and contact details of a Key Worker and 19% (nearly one in five), did not have access to a CNS. Based on the evidence of the survey, and in line with the Cancer Delivery Plan's recognition of the importance of these roles, increasing provision of Key Workers and CNSs could be an important step in improving people's experiences of cancer care in Wales in the future.

Hospital care, both for inpatient and outpatient treatment, was also described favourably by the majority of respondents. 89% (nine out of ten) said that they were "always" treated with respect and dignity in hospital, and most patients said that they were able to get understandable answers from staff when they had important questions. However, we found room for improvement in the emotional support offered to people in hospital: 33% (one in three) would have liked more opportunity to discuss their worries or fears with hospital staff, and, of those who needed it, more than 22% (one) in five indicated that they were "definitely" not given enough emotional support.

Results from the survey also provide direction for targeted improvements to wider care in the future. Perhaps the most notable is the opportunity to develop and be given a written care plan. The Cancer Delivery Plan commits to all cancer patients in Wales being offered a copy of their care plan, and evidence from this survey shows that people involved in discussions about their care plan reported more positive experiences of their care. There is a need to improve on the rate at which this involvement and offers of care plans are provided: in 2016, 48% (less than half) of patients said that they had the opportunity to discuss their needs and concerns as part of the development of a care plan, and less than 18% (one in five) were offered a written care plan.

Another area where provision is generally low is around the opportunity to be asked to be involved in cancer research when appropriate. Less than one in four reported being asked about this, indicating missed opportunities to involve patients in important cancer research. Targeted improvement on providing additional information, including written information about their cancer, treatment and care, and support groups after discharge from hospital, is also required. For example, only 48% of people who felt that they needed information about financial help or benefits reported receiving this. Analysis of differences in the experiences of people with different tumour groups indicates that there is a need for further work to understand and improve patient experience for those with sarcoma, urological and brain/CNS cancer. However, additional research may be needed to fully understand their experiences and how these can be improved. Although the current survey provides valuable insight on differences between groups, the size of the groups and the reliability of data means that some differences need to be interpreted with caution. There is also potential for results to be confounded by other factors, including demographics and socioeconomic status, which may influence people's experiences of care. Equally, it should be recognised that 'cancer' is actually a broad range of many related diseases – it cannot necessarily be assumed that the elements of care that are important to people with, say, prostate cancer are also those most important to people with, say, cancer of the brain or central nervous system.

The experience of patients with other long-standing conditions was also very positive. Having a greater awareness of these patients' needs and by providing additional support where necessary will ensure that their experience is as good as it can possibly be.

Overall, the results from the survey show a mix of findings, illustrating where there is good practice and where things are working well, but also where there are areas for improvement. In general, people treated for cancer in Wales report positive experiences, and there are undoubtedly many positives to be celebrated. But there are also areas for improvement in the future. The findings should be informative for professionals and policy makers alike in reviewing the current state of care for people with cancer in Wales and in planning future changes, whether nationally or locally, which may lead to better health services for all.

Section seven:

Results

Positive score summary

This section outlines the national, All Wales, positive scores. These scores indicate the percentage of respondents who gave the most positive responses to each question, indicating a perception of an excellent patient experience. Targeted questions are indicated with a "+" this indicates that non-applicable respondents have been removed from the positive score calculation.

For an explanation of the All Wales score and more information about the calculation of positive scores and targeted questions, please see relevant parts of Section four: Survey overview.

For a full list of results, including base sizes, percentage and numerical breakdowns, and positive score calculations, please see Appendix eight.

Positive score chart: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

Q3+ – Q5: All respondents

Q8+ – Q10+: Respondents who had a diagnostic test

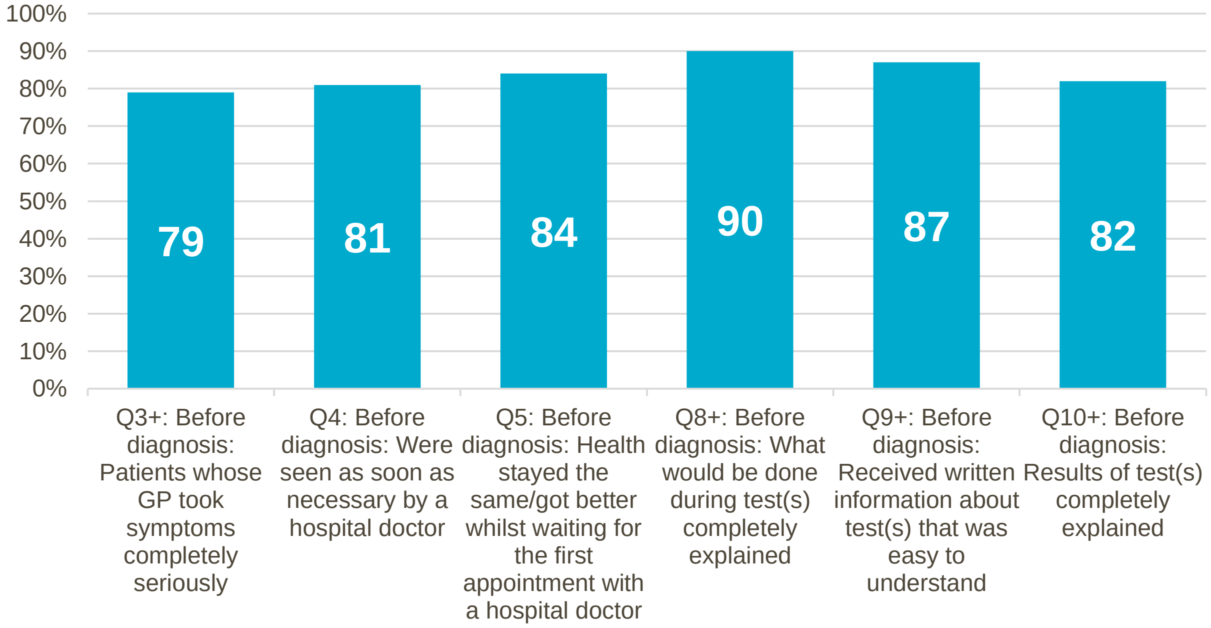


Figure 25: Positive score chart for what happened before patients found out they had cancer (Q3+ – Q10+)

Positive score chart: Finding out you had cancer

These questions are about what happened when patients found out they had cancer.

All respondents

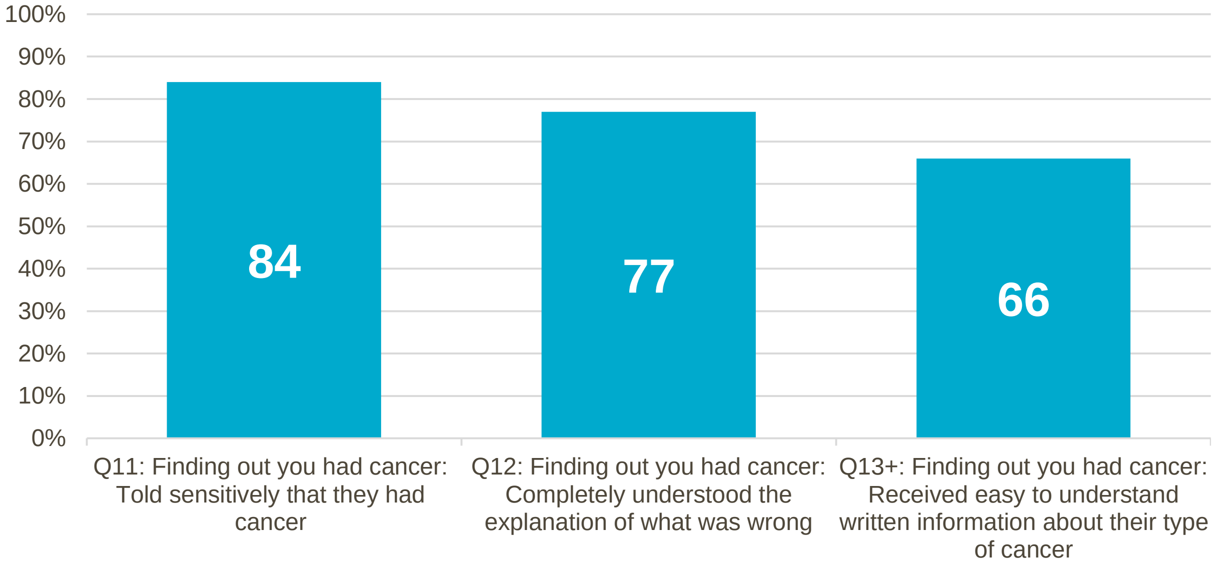


Figure 26: Positive score chart for what happened when patients found out they had cancer (Q11 – Q13+)

Positive score chart: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

All respondents

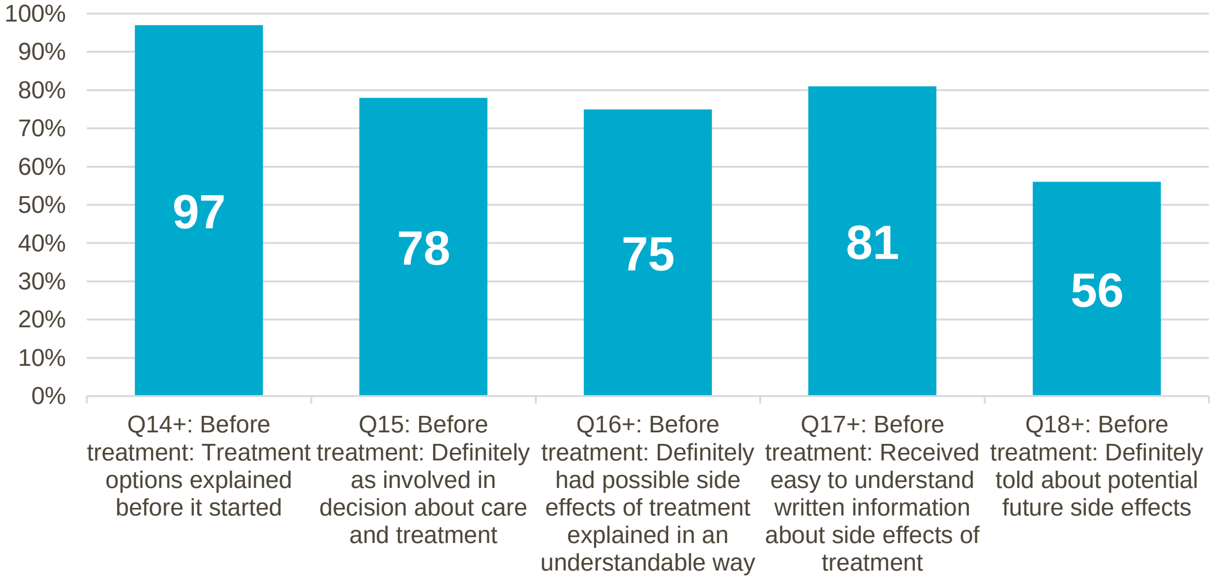


Figure 27: Positive score chart for decisions made about the best treatment or care (Q14+ – Q18+)

Positive score chart: Key Worker

These questions are about Key Workers.

Q19: All respondents

Q20+ – Q21+: Respondents who had the name and contact details of a Key Worker

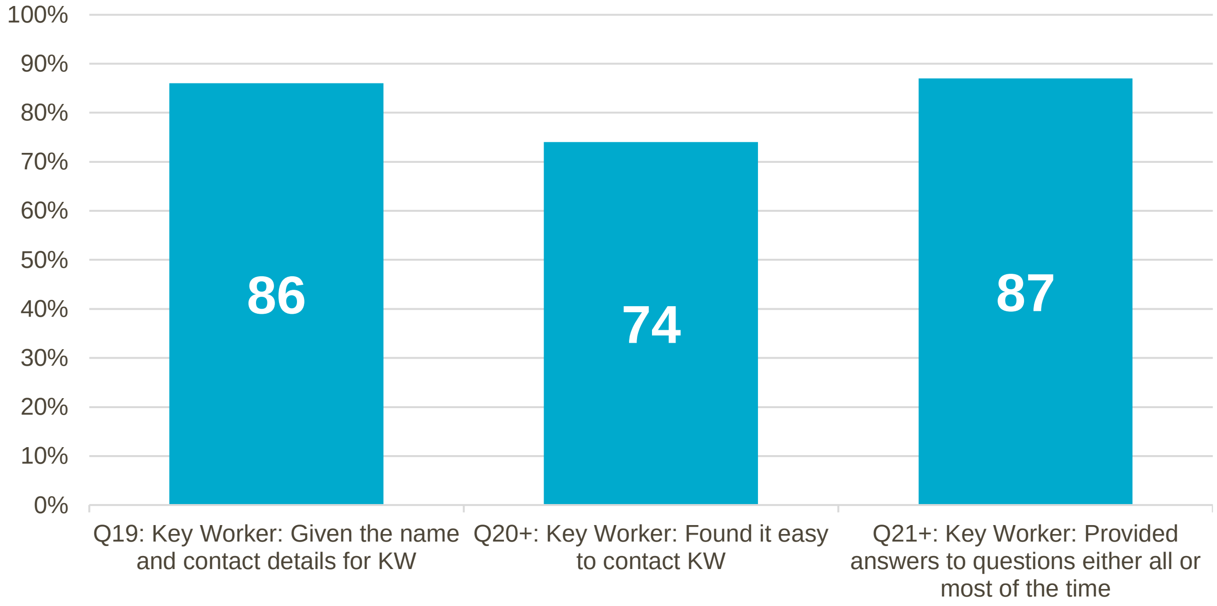


Figure 28: Positive score chart for Key Workers (Q19 – Q21+)

Positive score chart: Clinical Nurse Specialist

These questions are about Clinical Nurse Specialists.

Q22: All respondents

Q23+ – Q25: Respondents who had the name and contact details of a Clinical Nurse Specialist

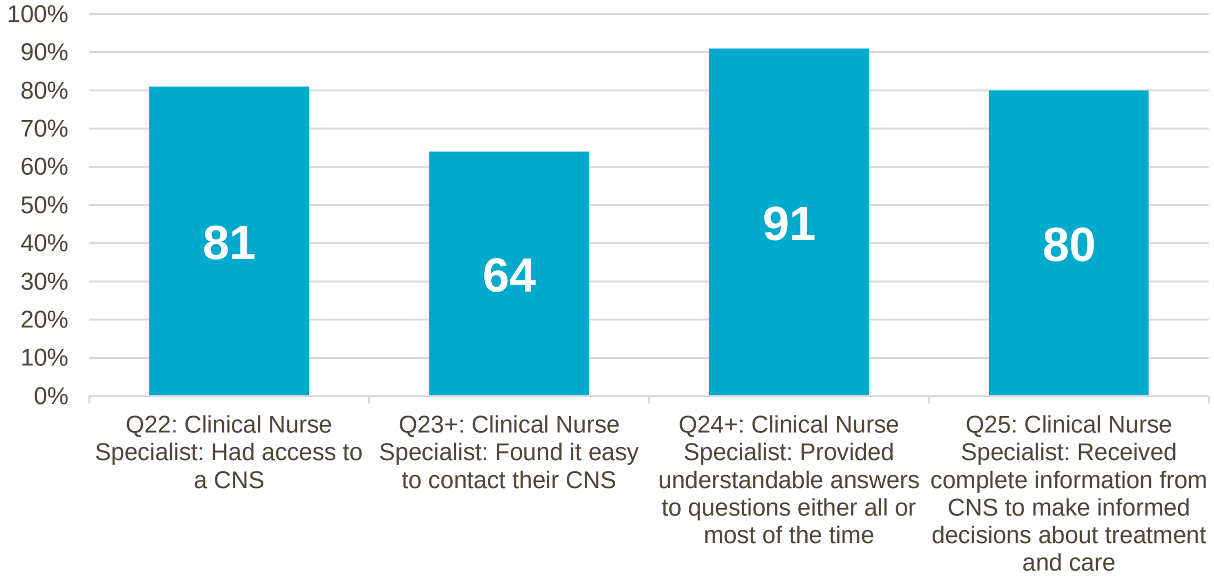


Figure 29: Positive score chart for Clinical Nurse Specialists (Q22 – Q25)

Positive score chart: Support for people with cancer

These questions are about support for a patient when their cancer first started.

All respondents

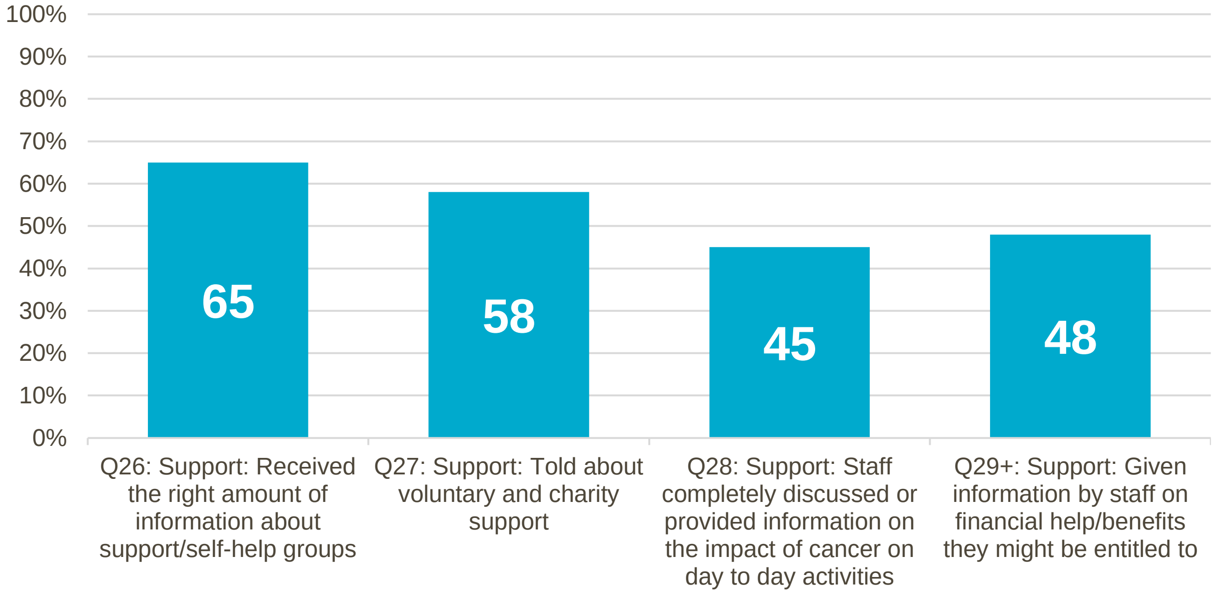


Figure 30: Positive score chart for what support is available for patients when starting treatment (Q26 – Q29+)

Positive score chart: Operations

These questions are about support for a patient when their cancer treatment first started.

Respondents who had an operation for their cancer

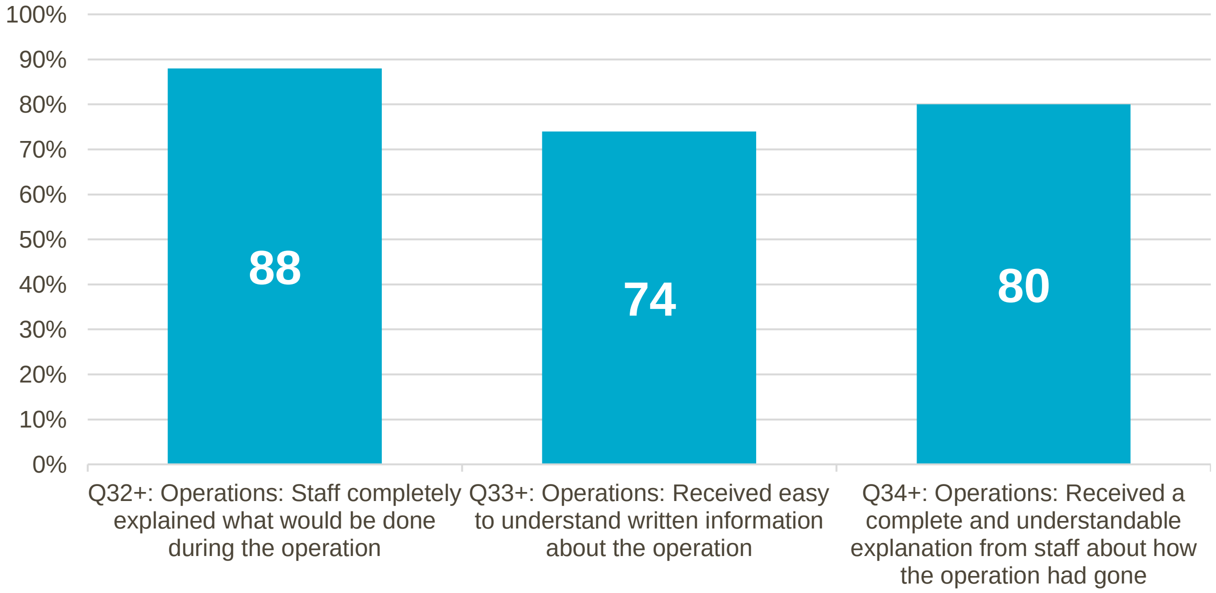


Figure 31: Positive score chart for operations a patient may have had (Q32+ – Q34+)

Positive score chart: Hospital care as an inpatient

These questions are about any inpatient stay in hospital related to cancer treatment.

Respondents who had an operation or stayed overnight for their cancer care

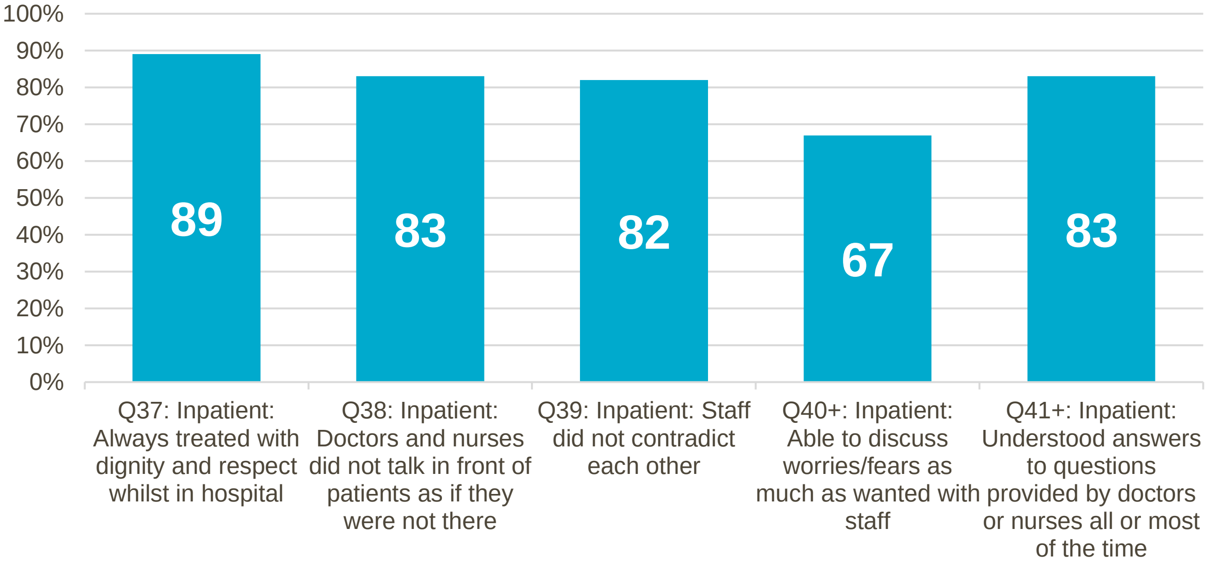


Figure 32: Positive score chart for an inpatient stay in hospital (Q37 – Q41+)

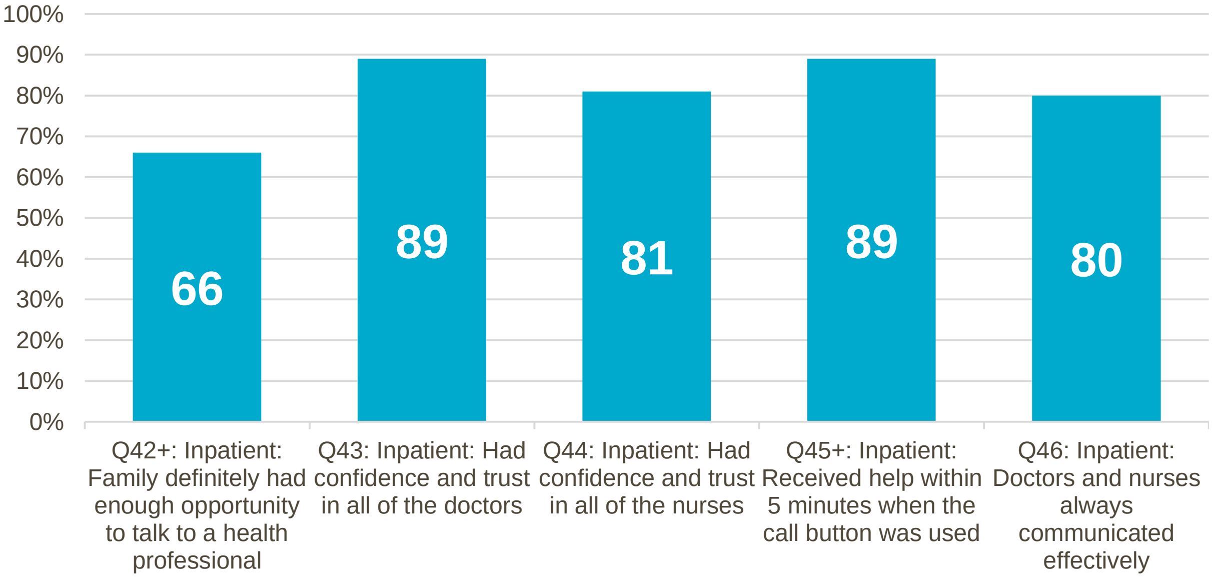


Figure 33: Positive score chart for an inpatient stay in hospital (Q42+ – Q46)

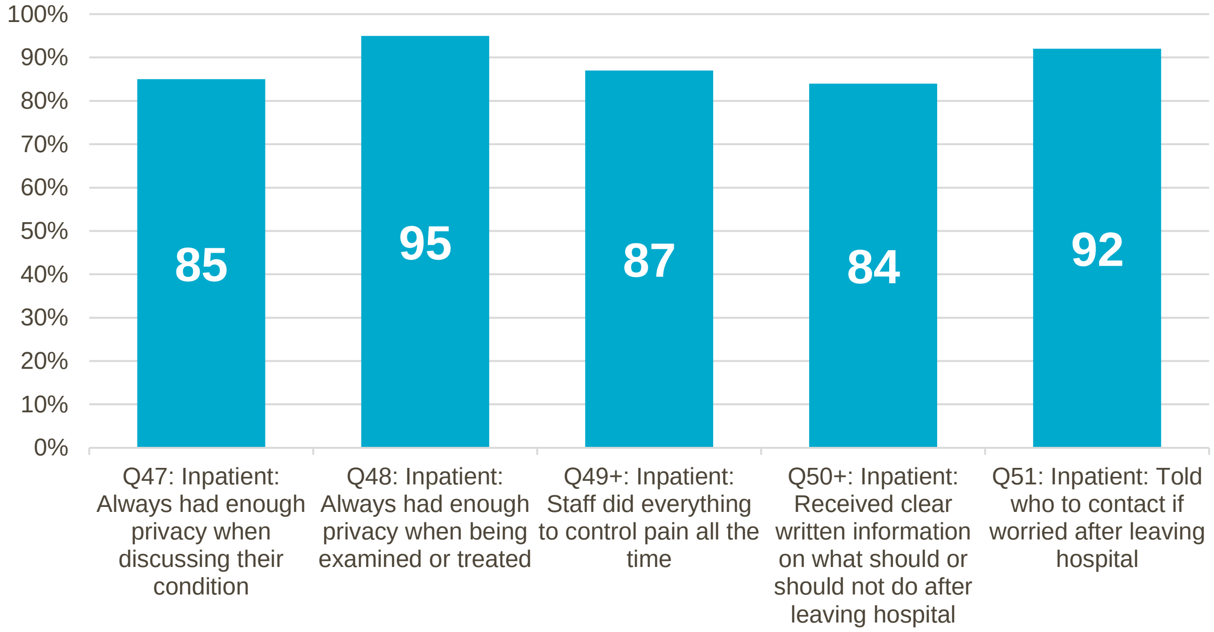


Figure 34: Positive score chart for an inpatient stay in hospital (Q47 – Q51)

Positive score chart: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

Respondents who had an outpatient or day case appointment

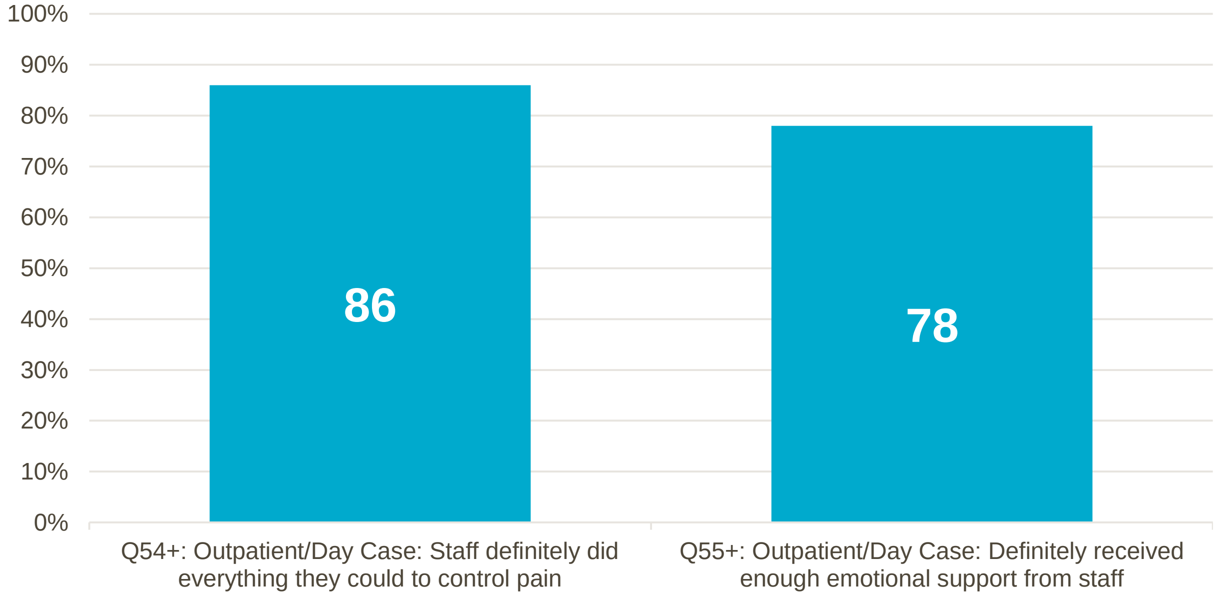


Figure 35: Positive score chart for an outpatient or day case appointment (Q54+ – Q55+)

Positive score chart: Radiotherapy/chemotherapy

These questions relate to any radiotherapy or chemotherapy patients may have had.

Q58+: Respondents who had radiotherapy

Q61+: Respondents who had chemotherapy

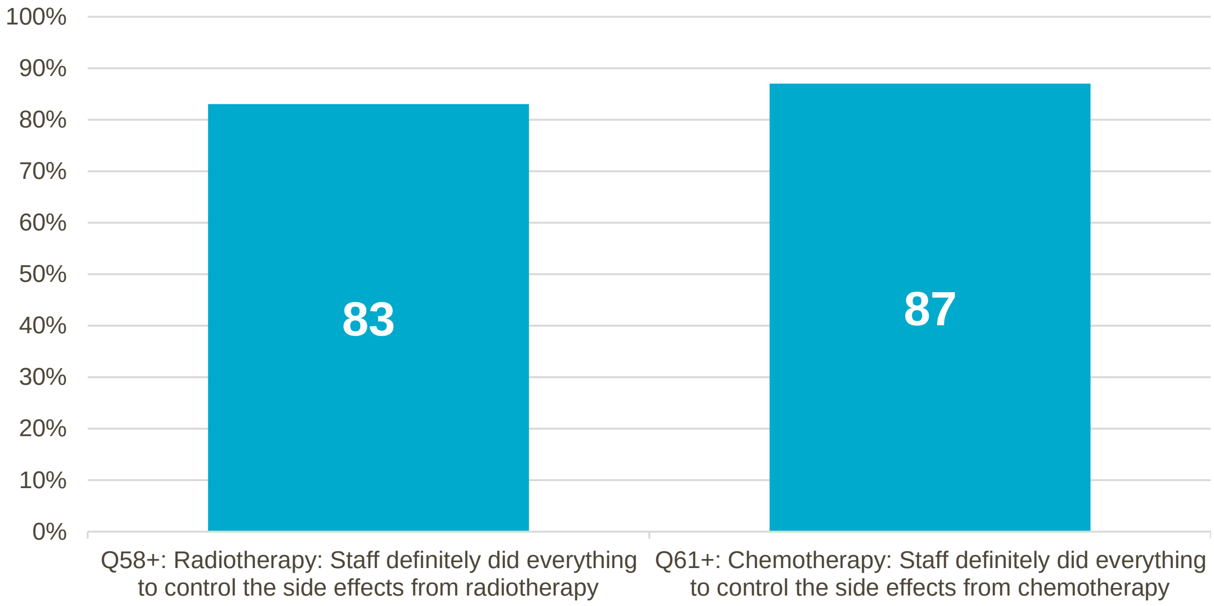


Figure 36: Positive score chart for radiotherapy/chemotherapy (Q58+ – Q61+)

Positive score chart: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for their cancer.

All respondents

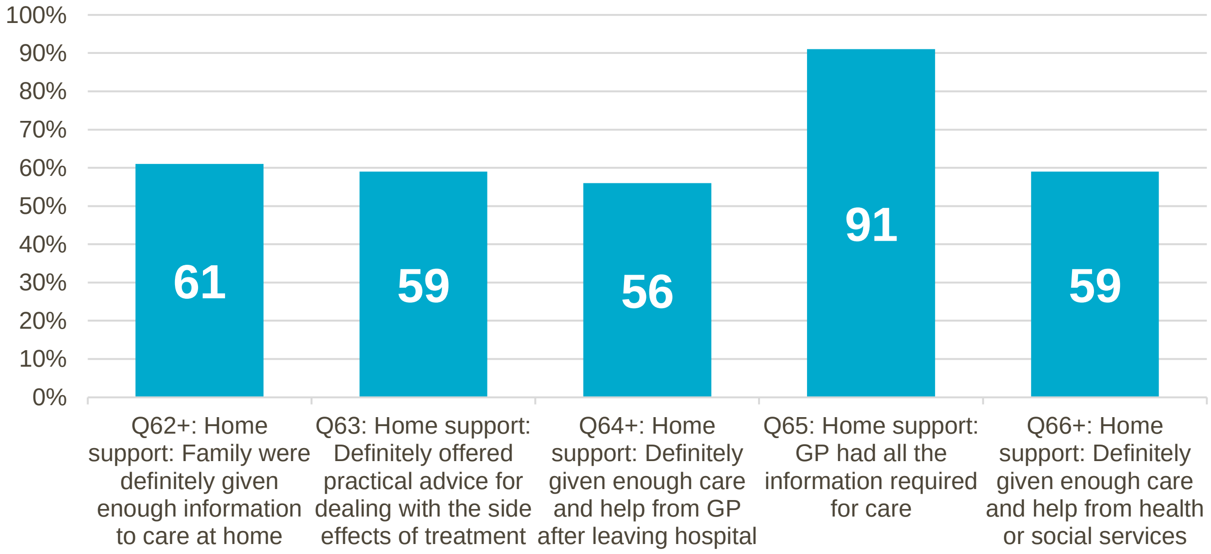


Figure 37: Positive score chart for home support being arranged for a patient (Q62+ – Q66+)

Positive score chart: Your overall NHS care

These questions relate to patients' overall experience of the care they received from the NHS.

All respondents

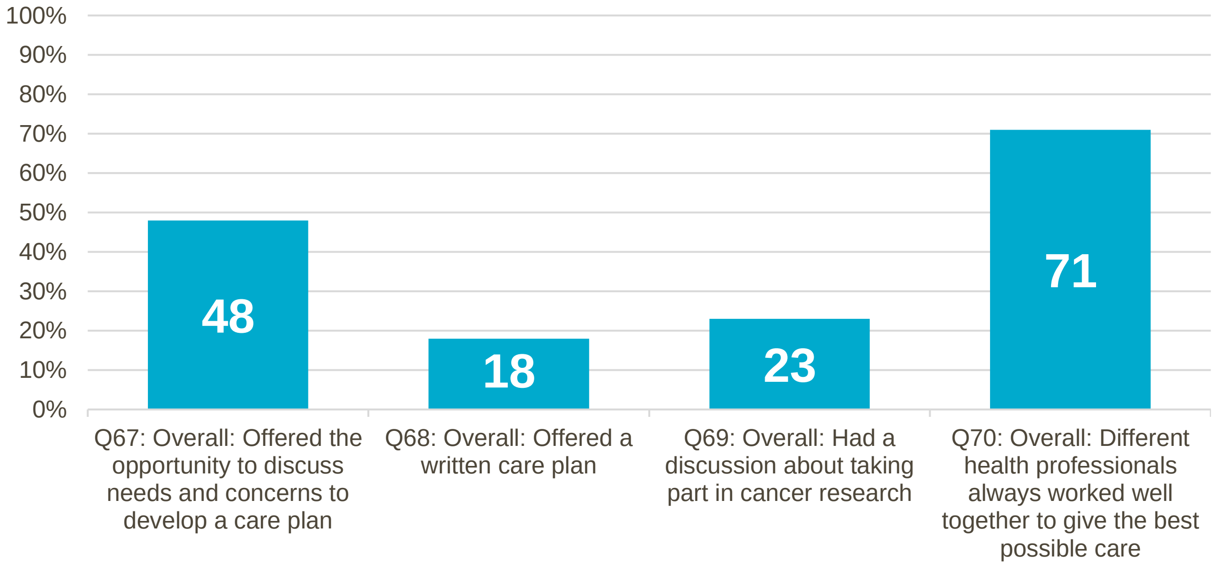


Figure 38: Positive score chart for patients' overall experience of care (Q67 – Q70)

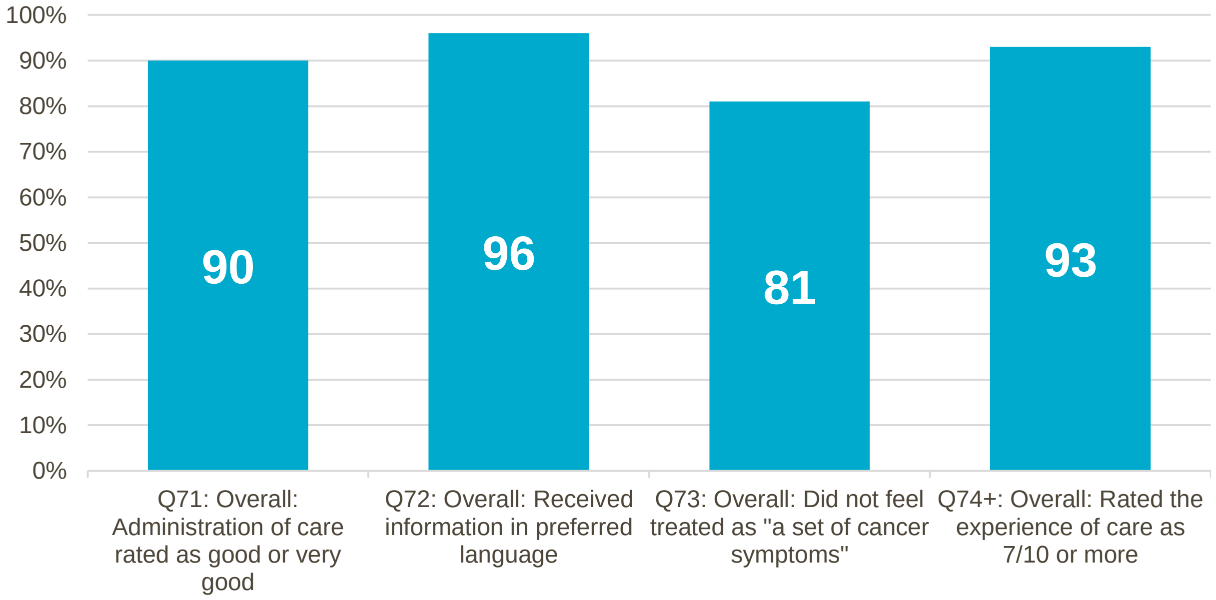


Figure 39: Positive score chart for patients' overall experience of care (Q71 – Q74+)

Health board analysis

This section compares respondents' perception of their cancer care relative to their health board of residency. Positive scores were used as a comparative tool and the data was adjusted in order to make comparisons fairer. For more information regarding data adjustment and standardisation please see Section four: Survey overview. For a comprehensive look at all questions by health board please see Appendix one: Health board analysis.

Findings were generally very positive with most patients rating their overall experience as seven out of ten or more (the health board average is 93%).

There was little variance in positive scores across health boards, suggesting that experience of care in Wales is not greatly impacted by the health board in which a patient resides. However, some areas did show some significant differences.

The questionnaire is broken down into many different sections, inviting the patient to give feedback on different aspects of their care. Some areas showed very little difference across health boards. For example, there were no instances where significant differences were detected between the result for any individual health board and the health boards' average in either of the two scored questions relating to outpatients or day case appointments. Similarly, there were few questions with significant differences between individual health boards and the health boards' average in a number of other sections. This included three differences across five questions in the "Before your diagnosis" section; three differences across three questions relating to "Finding out you had cancer"; two differences in three questions about "Operations"; and one from two questions on "Radiotherapy". There were three significant differences between health boards and the average in four questions related to "Clinical Nurse Specialists"; all of these related to whether patient care included access to a Clinical Nurse Specialist.

Where a greater number of significant differences between health boards and the average are found, however, a trend is apparent: Cardiff & Vale University Health Board residents report the most positive experience, followed by Powys Teaching Health Board residents, Aneurin Bevan University Health Board residents and Cwm Taf University Health Board residents. In contrast, Abertawe Bro Morgannwg University Health Board residents usually reported an experience in line with or slightly below the health board average. Residents of Betsi Cadwaladr University Health Board and Hywel Dda University Health Board generally reported the least positive experience.

The section with the most significant differences is the "Your Overall NHS Care" section. In this section residents of Cardiff & Vale UHB report a significantly more positive experience on four questions; discussing a care plan, having a discussion about taking part in cancer research, receiving information in the preferred language and rating their care as seven out of ten more. Cwm Taf UHB residents also report a higher than average positive score on one question in this section: the rating of the overall administration of care.

By contrast residents of Hywel Dda UHB report a significantly poorer experience on six questions in this overall care section. This includes questions on being given the opportunity to discuss needs and concerns to put together a care plan; having a discussion about taking part in clinical research; reporting that different professionals involved in care and treatment had worked well together; rating of the overall administration of care; receiving information in a preferred language; and being treated as a whole person rather than a set of symptoms. Betsi Cadwaladr UHB residents report a more negative than average experience on two questions; rating of the overall administration of care and receiving information in the preferred language. Most of those who responded in the Welsh language live in the catchment area of Betsi Cadwaladr UHB or Hywel Dda UHB.

Outside of the “Overall” section the questions are usually more specific, discouraging respondents from collating several experiences – as they are asked to do in the overall rating question for example. Significant differences in these questions can therefore give a more detailed impression of where care across Wales differs based where they reside. Some of the most striking differences occur in these areas:

- Explanation of side effects in the section “Deciding the best treatment and/or care for you”. A significantly smaller proportion of residents of Hywel Dda UHB report being told about the possible side effects of treatment and of the potential future side effects. By contrast, a significantly greater proportion of residents of Aneurin Bevan UHB reported having side effects explained to them.
- Being given the name and contact details for a Key Worker: Residents of Aneurin Bevan UHB and Cwm Taf UHB were significantly more likely than average to say they were given the contact details of a Key Worker. Residents of Hywel Dda UHB and Betsi Cadwaladr UHB were significantly less likely than average to say this.
- Access to Clinical Nurse Specialist. Residents of Cardiff & Vale UHB and Aneurin Bevan UHB were more likely than average to report that they had access to a Clinical Nurse Specialist. Residents of Hywel Dda UHB were significantly less likely to report this.
- Difference in the section “Support for people with cancer”. Residents of both Cardiff & Vale UHB and Cwm Taf UHB were more likely than average to report that they received the right amount of information about self-help groups, that they were told about voluntary and charity support and that they were given information by staff on financial help/benefits they might be entitled to. By contrast, residents of Hywel Dda UHB were significantly less likely to report a positive experience on two questions (receiving the right amount of information about self-help groups

and discussing with a member of staff the impact cancer would have on their day to day life), and Betsi Cadwaladr UHB residents were significantly less likely to report a positive experience than average on two questions (receiving the right amount of information about self-help groups and being told about voluntary and charity support).

- Receiving easy-to-understand information about an operation. Residents of Aneurin Bevan UHB were significantly more likely to report this, whereas residents of Cwm Taf UHB were significantly less likely to do so.
- Receiving information when leaving hospital after an inpatient stay. Residents of Abertawe Bro Morgannwg UHB and Betsi Cadwaladr UHB were significantly less likely than average to feel that they were given clear written information about what they should or should not do after leaving hospital, whereas residents of Aneurin Bevan UHB were significantly more likely to feel this way. Similarly, residents of Abertawe Bro Morgannwg UHB were significantly less likely to feel that they were told who to contact if they were worried after leaving hospital, whereas the results of Cardiff & Vale UHB and Aneurin Bevan UHB residents were significantly higher than average for this question.
- Doctors and nurses talking in front of inpatients as if they weren’t there. Residents of Hywel Dda UHB were significantly more likely to feel that doctors and nurses talked in front of them as if they weren’t there compared to the average. Residents of Aneurin Bevan UHB were significantly less likely to feel this way.
- GP being given all the information required to care for a patient. Residents of Hywel Dda UHB and Cwm Taf UHB were significantly less likely than average to feel this way. Residents of Cardiff & Vale UHB were significantly more likely.

Radiotherapy within Wales

There are two questions in the section of the questionnaire concerned with radiotherapy. One asks respondents to identify where they had radiotherapy – if at all – and the other asks them to report if they felt that hospital staff did everything they could to control the side effects of that radiotherapy. Of the three sites in Wales where patients reported they had radiotherapy, those that went to Singleton Hospital were significantly less likely than average to report that they felt staff did all they could to control their side effects.

Positive score chart for staff controlling side effects from radiotherapy by site

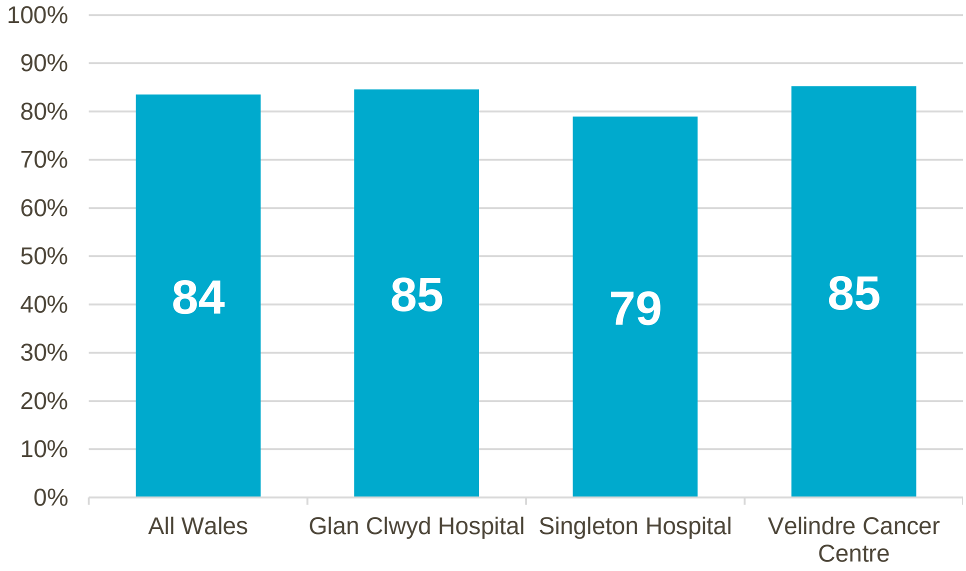


Figure 40: Q58 – Staff definitely did everything to control the side effects from radiotherapy by hospital site

Velindre NHS Trust

As a specialist cancer centre treatment centre, Velindre NHS Trust has no residents. The Trust treated many patients that will be assigned to the health boards in the previous section. The findings in this section look at patients most recently discharged from Velindre.

The data used here is unadjusted. For more information on data adjustment and standardisation, please see relevant parts of Section four: Survey overview.

For full details of the breakdown, please see Appendix two: Velindre NHS Trust.

Velindre NHS Trust generally received very positive feedback:

- Almost all patients (99%) who had an operation or were treated as an inpatient at Velindre said that they had “always” enough privacy when being examined or treated.
- The overwhelming majority of patients (97%) reported that their treatment options were explained to them before their cancer treatment started.
- Overall rating: 5% of patients (one in twenty) did not rate their overall care as seven or more out of ten.
- Information on discharge: almost all (95%) patients said they were told who to contact if they were worried after they had left the hospital.
- Of patients who had an operation or were treated as an inpatient, the vast majority said that they had confidence and trust in all of the doctors (95%) and all of the nurses (93%) treating them.

However, the scores also showed two areas where the Trust could look to improve.

- Only 20% of patients (one in five) reported that they were offered a written care plan. Less than three in five patients said that they were offered the opportunity to discuss their needs and concerns in order to put together a care plan.
- Support: 50% of patients (half) reported that hospital staff had “completely” discussed with them or given them information about the impact that cancer could have on their day-to-day activities.

The number of patients that attended Velindre and completed the survey (1,780) allows for internal breakdowns by tumour group. Highlighting where there are significant differences in the experiences of patients allows the trust to target areas for improvement.

For a full breakdown of results a report has been produced for Velindre. Some of the most striking variances across tumour group are listed here:

- Prostate cancer patients generally report a more positive experience of care than average, with scores significantly higher on eight questions in the survey and lower in just one. The question on which this patient group reports a more negative experience is the one that asks if the patient had access to a CNS.
- Breast cancer patients seemed to fare well on questions relating to support. They were significantly more likely than average to be given the name and contact details of a Key Worker and significantly more likely than average have access to a CNS – with a positive score of 95% on both of these questions. They were also significantly more likely than average to report receiving the right amount of information about support/self help groups and significantly more likely to be told who to contact if worried after leaving hospital as an inpatient.

Tumour group analysis

This section compares respondents’ perception of their cancer care relative to their diagnosed tumour group.

Please note that positive scores have once again been used as a comparative tool.

The data used here is unadjusted. This means, unlike the data used when health board comparisons are made, the data has not been standardised.

Where the number of responses is below 20 results have been supressed, indicated by an asterisk (*).

For a full list of results, including base sizes, percentage and numerical breakdowns, please see Appendix nine.

Tumour group table: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

Q3+ – Q5: All respondents

Q8+ – Q10+: Respondents who had a diagnostic test

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q3+: Before diagnosis: Patients whose GP took symptoms completely seriously	79	69	**88**	77	79	**69**	72	74	**84**	**56**	85	74	81	**72**
Q4: Before diagnosis: Were seen as soon as necessary by a hospital doctor	81	69	83	78	83	79	79	**88**	83	68	82	74	83	**75**
Q5: Before diagnosis: Health stayed the same/got better whilst waiting for the first appointment with a hospital doctor	84	69	**94**	**80**	79	**71**	79	82	**93**	**66**	**96**	**70**	84	**76**
Q8+: Before diagnosis: What would be done during test(s) completely explained	90	96	91	90	86	89	88	92	92	88	85	89	88	87
Q9+: Before diagnosis: Received written information about test(s) that was easy to understand	87	82	86	90	84	80	84	88	**91**	75	91	92	85	83
Q10+: Before diagnosis: Results of test(s) completely explained	82	73	**86**	85	80	77	82	82	82	74	83	80	81	**76**

Figure 41: Tumour group table for what happened before patients found out they had cancer (Q3+ – Q10+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Finding out you had cancer

These question are about what happened when patients found out they had cancer.

All respondents

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q11: Finding out you had cancer: Told sensitively that they had cancer	84	75	**88**	84	80	79	88	85	84	78	91	**75**	81	81
Q12: Finding out you had cancer: Completely understood the explanation of what was wrong	77	69	**82**	81	74	**56**	79	78	81	76	76	78	82	73
Q13+: Finding out you had cancer: Received easy to understand written information about their type of cancer	66	52	69	62	**57**	68	62	60	**80**	**42**	75	61	67	**52**

Figure 42: Tumour group table for what happened when patients found out they had cancer (Q11 – Q13+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

All respondents

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic- al	Other
Q14+: Before treatment: Treatment options explained before it started	97	**100**	97	96	98	98	99	96	97	88	99	96	96	96
Q15: Before treatment: Definitely as involved in decision about care and treatment	78	78	80	79	80	74	77	79	80	69	79	78	78	76
Q16+: Before treatment: Definitely had possible side effects of treatment explained in an understandable way	75	86	76	78	80	70	76	75	77	70	74	77	72	73
Q17+: Before treatment: Received easy to understand written information about side effects of treatment	81	77	**86**	82	81	**75**	78	79	**85**	67	72	87	**75**	78
Q18+: Before treatment: Definitely told about potential future side effects	56	68	58	57	58	**45**	57	55	**66**	52	60	56	52	51

Figure 43: Tumour group table for decisions made about the best treatment or care (Q14+ – Q18+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Key Worker

These questions are about Key Workers

Q19: All respondents
Q20+ – Q21+: Respondents who had the name and contact details of a Key Worker

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q19: Key Worker: Given the name and contact details for KW	86	84	**94**	88	89	**78**	**92**	**93**	85	78	75	**92**	**67**	84
Q20+: Key Worker: Found it easy to contact KW	74	56	75	74	78	**80**	69	76	71	74	73	78	68	69
Q21+: Key Worker: Provided answers to questions either all or most of the time	87	70	88	87	85	86	87	91	89	82	86	87	84	86

Figure 44: Tumour group table for Key Workers (Q19 – Q21+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Clinical Nurse Specialist

These questions are about Clinical Nurse Specialists

Q22: All respondents
Q23+ – Q25: Respondents who had the name and contact details of a Clinical Nurse Specialist

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q22: Clinical nurse specialist: Had access to a CNS	81	86	**93**	84	83	**75**	86	87	79	71	**65**	87	**57**	79
Q23+: Clinical nurse specialist: Found it easy to contact their CNS	63	*	59	65	68	75	45	55	70	*	*	*	59	64
Q24+: Clinical nurse specialist: Provided understandable answers to questions either all or most of the time	91	80	92	92	90	88	90	91	92	82	89	92	90	89
Q25: Clinical nurse specialist: Received complete information from CNS to make informed decisions about treatment and care	80	86	83	80	82	79	82	79	81	68	78	78	80	**73**

Figure 45: Tumour group table for Clinical Nurse Specialists (Q22 – Q25)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups

Tumour group table: Support for people with cancer

These questions are about support for a patient when their cancer treatment first started.

All respondents

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic- al	Other
Q26: Support: Received the right amount of information about support/self–help groups	65	69	**76**	65	68	**58**	72	65	**71**	58	**50**	67	**43**	60
Q27: Support: Told about voluntary and charity support	58	66	**69**	59	62	53	**68**	**73**	56	52	**36**	**68**	**27**	58
Q28: Support: Staff completely discussed or provided information on the impact of cancer on day to day activities	45	49	**51**	43	44	43	54	45	47	44	43	49	**32**	**38**
Q29+: Support: Given information by staff on financial help/benefits they might be entitled to	48	47	53	51	58	**39**	**60**	**63**	**40**	46	30	56	**26**	49

Figure 46: Tumour group table for what support is available for patients when starting treatment (Q26 – Q29+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Operations

These questions are about any operation a patient may have had related to cancer treatment.

Respondents who had an operation for their cancer

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q32+: Operations: Staff completely explained what would be done during the operation	88	86	90	85	86	82	90	87	89	82	88	90	90	86
Q33+: Operations: Received easy to understand written information about the operation	74	57	78	69	71	67	64	63	**88**	**46**	72	73	79	66
Q34+: Operations: Received a complete and understandable explanation from staff about how the operation had gone	80	79	82	78	81	70	84	82	81	68	87	85	76	78

Figure 47: Tumour group table for operations a patient may have had (Q32+ – Q34+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Hospital care as an inpatient

These questions are about any inpatient stay in hospital related to cancer treatment.

Respondents who had an operation or stayed overnight for their cancer care

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q37: Inpatient: Always treated with dignity and respect whilst in hospital	89	93	**93**	86	86	89	87	87	92	84	94	92	88	84
Q38: Inpatient: Doctors and nurses did not talk in front of patients as if they were not there	83	74	**91**	79	86	78	85	74	87	73	83	84	79	78
Q39: Inpatient: Staff did not contradict each other	82	74	**86**	80	82	79	78	78	88	67	85	77	83	**74**
Q40+: Inpatient: Able to discuss worries/fears as much as wanted with staff	67	72	72	65	69	66	71	62	**78**	56	71	66	64	**56**
Q41+: Inpatient: Understood answers to questions provided by doctors or nurses all or most of the time	84	79	**89**	83	81	82	85	77	87	71	88	85	78	79
Q42+: Inpatient: Family definitely had enough opportunity to talk to a health professional	66	81	69	64	62	69	67	64	70	70	72	73	**57**	62
Q43: Inpatient: Had confidence and trust in all of the doctors	89	85	92	89	90	90	90	86	92	82	94	89	89	**82**

Figure 48: Tumour group table for an inpatient stay in hospital (Q37 – Q43)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q44: Inpatient: Had confidence and trust in all of the nurses	81	85	**85**	77	74	79	80	81	**88**	74	**92**	79	79	74
Q45+: Inpatient: Received help within 5 minutes when the call button was used	89	*	**93**	87	85	89	85	91	91	89	*	94	86	85
Q46: Inpatient: Doctors and nurses always communicated effectively	80	81	**86**	80	78	80	77	77	85	78	88	80	74	75
Q47: Inpatient: Always had enough privacy when discussing their condition	85	74	**89**	83	82	83	84	82	90	84	87	87	85	79
Q48: Inpatient: Always had enough privacy when being examined or treated	95	96	96	95	95	95	92	93	94	93	94	97	95	92
Q49+: Inpatient: Staff did everything to control pain all the time	87	80	**93**	87	81	85	85	83	92	83	93	89	82	84
Q50+: Inpatient: Received clear written information what should or should not do after leaving hospital	84	84	**91**	82	83	79	87	80	89	76	**95**	79	80	77
Q51: Inpatient: Told who to contact if worried after leaving hospital	92	96	**96**	93	88	95	96	93	94	88	96	89	**87**	**87**

Figure 49: Tumour group table for an inpatient stay in hospital (Q44 – Q51)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

Respondents who had an outpatient or day case appointment

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q54+: Outpatient/Day Case: Staff definitely did everything they could to control pain	86	*	87	87	85	91	91	81	88	75	85	88	81	85
Q55+: Outpatient/Day Case: Definitely received enough emotional support from staff	78	70	79	78	80	77	80	76	81	69	83	78	74	75

Figure 50: Tumour group table for an outpatient or day case appointment (Q54+ – Q55+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Radiotherapy/chemotherapy

These questions relate to any radiotherapy or chemotherapy patients may have had.

Q58+: Respondents who had radiotherapy
Q61+: Respondents who had chemotherapy

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q58+: Radiotherapy: Staff definitely did everything to control the side effects from radiotherapy	83	81	83	89	90	-	85	81	84	77	75	81	81	79
Q61+: Chemotherapy: Staff definitely did everything to control the side effects from chemotherapy	87	72	87	89	91	89	87	84	82	81	*	90	78	85

Figure 51: Tumour group table for radiotherapy/chemotherapy (Q58+ – Q61+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for their cancer.

All respondents

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic- al	Other
Q62+: Home support: Family were definitely given enough information to care at home	61	62	61	64	61	63	**72**	60	59	57	65	60	56	57
Q63: Home support: Definitely offered practical advice for dealing with the side effects of treatment	59	58	**63**	62	58	57	**72**	56	58	56	54	62	**49**	**52**
Q64+: Home support: Definitely given enough care and help from GP after leaving hospital	56	38	56	58	59	55	52	60	58	44	68	52	54	50
Q65: Home support: GP had all the information required for care	91	89	94	93	90	90	89	90	92	88	93	88	91	90
Q66+: Home support: Definitely given enough care and help from health or social services	59	*	63	**70**	55	**50**	62	54	56	52	66	61	**48**	57

Figure 52: Tumour group table for home support being arranged for a patient (Q62+ – Q66+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Tumour group table: Your overall NHS care

These questions relate to patients’ overall experience of the care they receive from the NHS.

All respondents

	All Wales	Brain/ CNS	Breast	Colorectal/ Lower GI	Gynaecol -ogical	Haematol -ogical	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urologic-al	Other
Q67: Overall: Offered the opportunity to discuss needs and concerns to develop a care plan	48	50	**53**	51	48	43	**69**	47	47	40	37	53	**34**	46
Q68: Overall: Offered a written care plan	18	13	**24**	19	16	16	**34**	20	**14**	18	**8**	15	**12**	18
Q69: Overall: Had a discussion about taking part in cancer research	23	24	20	24	26	**34**	23	**32**	25	16	**7**	20	**9**	**30**
Q70: Overall: Different health professionals always worked well together to give the best possible care	71	61	71	70	69	75	73	71	75	57	74	67	70	67
Q71: Overall: Administration of care rated as good or very good	90	88	**93**	89	91	91	91	89	89	84	89	86	**85**	88
Q72: Overall: Received information in preferred language	96	97	96	96	94	96	98	95	96	92	98	97	96	97
Q73: Overall: Did not feel treated as "a set of cancer symptoms"	81	82	82	82	81	83	86	76	84	78	**91**	78	82	**76**
Q74+: Overall: Rated the experience of care as 7/10 or more	93	88	95	92	95	94	95	93	95	83	94	90	90	91

Figure 53: Tumour group table for patients’ overall experience of care (Q67 – Q74+)

Figures marked in green indicate that the score is significantly better than the overall score across all tumour groups.
Figures marked in red indicate that the score is significantly worse than the overall score across all tumour groups.

Section eight:

Improvement opportunities

Focusing improvement

The intention of the WCPES programme is to drive improvements to cancer services on both a local and national level. The information in this section indicates areas where respondents are reporting that cancer services in Wales are particularly good and where they feel there may be scope for improvement.

- **Ranked positive scores**

  This considers patient experience across the care pathway to determine the best and worst national results, highlighting where patients are reporting a more or a less positive experience.

- **Historical comparisons**

  This survey has gone through an extensive redesign process since it was last run in 2013, so historical analysis is limited. However, there are a few topics where direct comparisons can be made.

- **Themes in respondent comments**

  The questionnaire contained three free text questions where respondents could provide qualitative data on subjects that are important to them. Here, we recognise recurrent themes to gain an insight into respondent treatment priorities.

For further information or help in understanding your results, please contact the Picker Patient Feedback Team at: PatientFeedbackTeam@PickerEurope.ac.uk.

Ranked positive scores

This section highlights the questions to which respondents had the most and the least positive response. Focusing on areas with lower positive scores could improve the patient experience for a large proportion of your patients. For a complete list of ranked positive scores, please see Appendix six. Please note this is **unadjusted data**.

Ten most positive scores

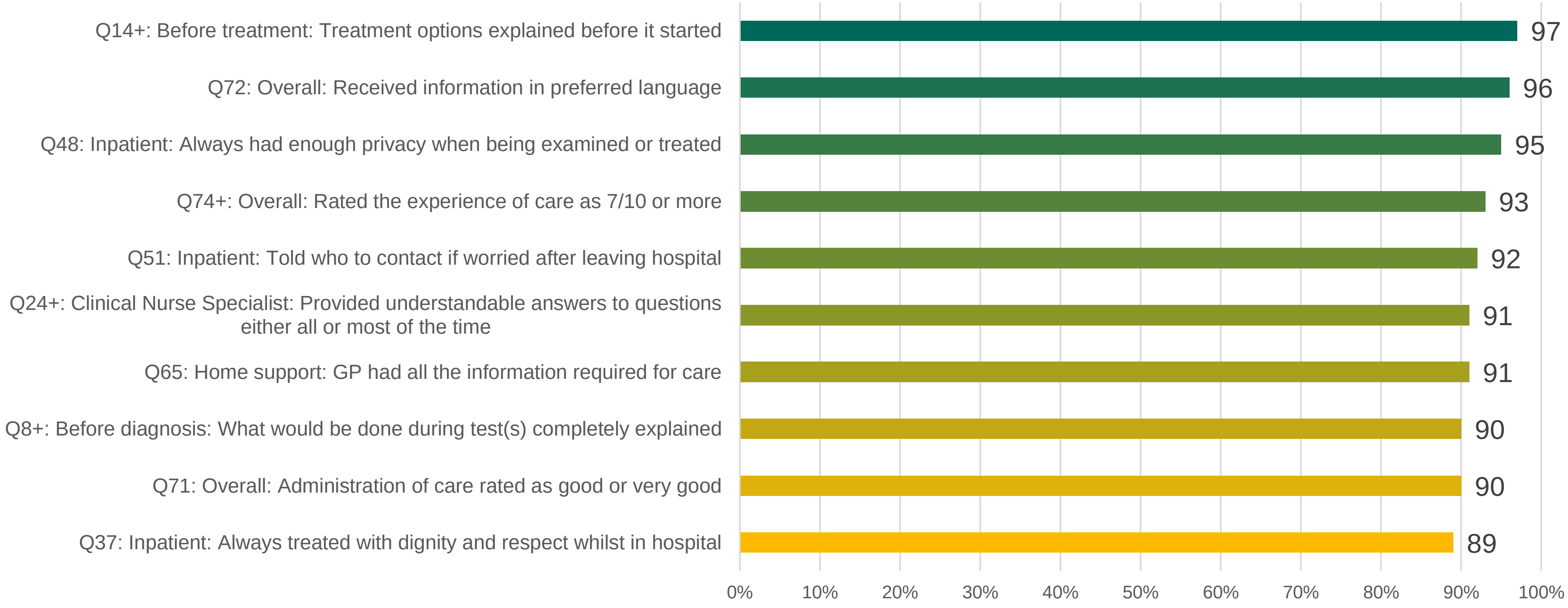


Figure 54: Ten most positive scores

Ten least positive scores

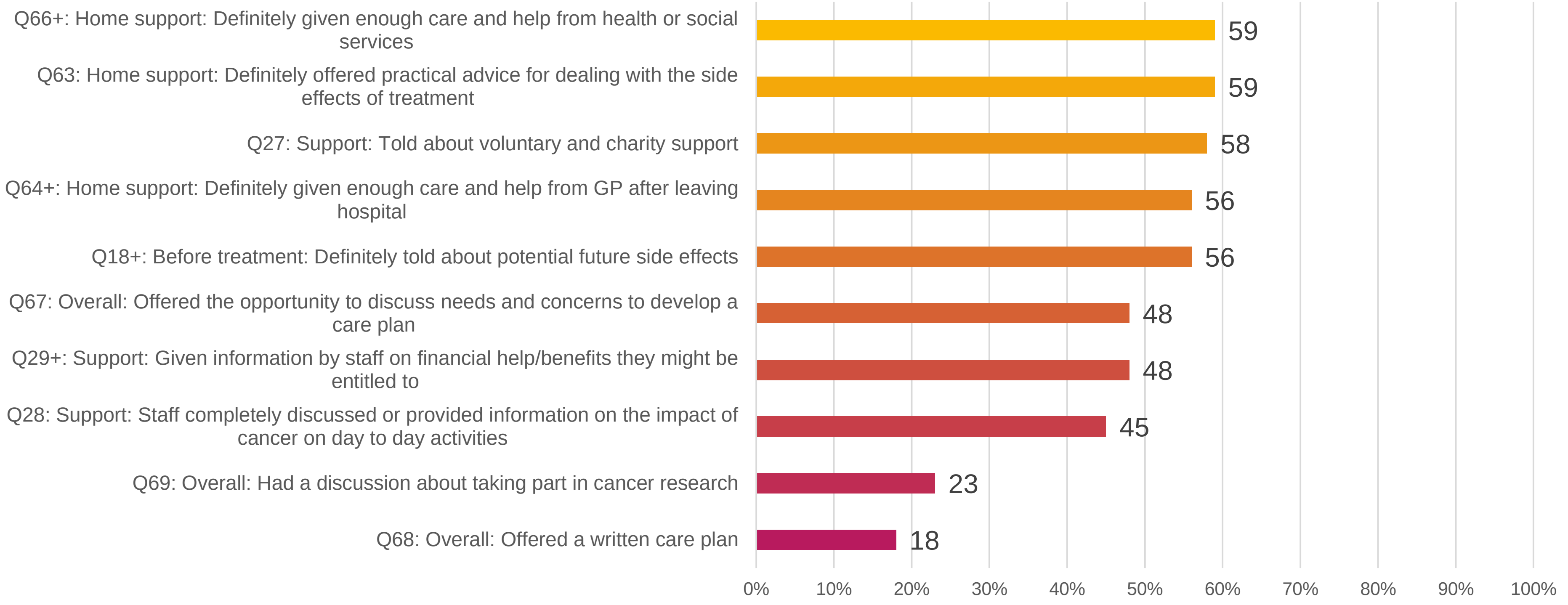


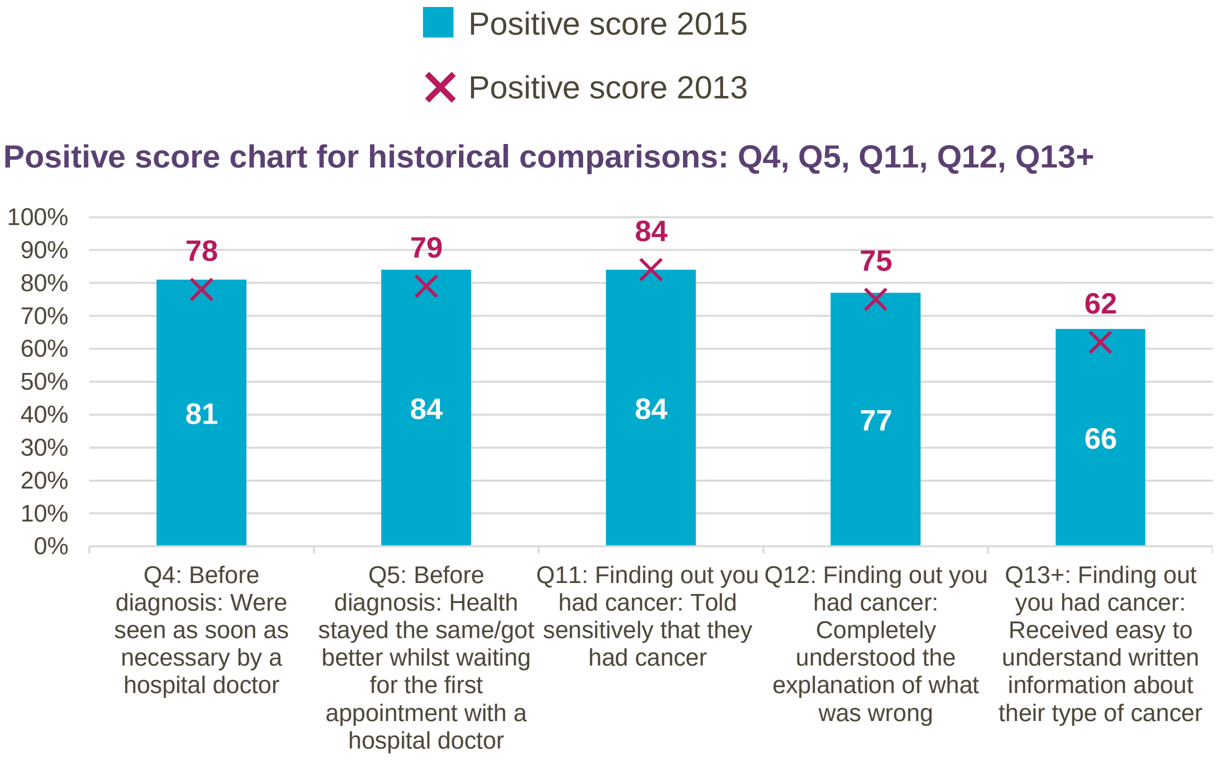
Figure 55: Ten least positive scores

Historical comparisons

Performance across different surveys cannot be compared unless the questions are identical because any change to the question text or response options will influence how respondents answer it. The purpose of comparing questions over time is to see if there has been any change in performance over that time. But comparing the scores of altered questions will not be comparing just the change in performance at the two different points in time, but also the impact of this change, making it impossible to accurately measure performance.

This applies not only to the wording of the question but also the cohorts answering it. For example, if previously a question was answered by all those responding to a questionnaire, but now comes after a routing question, the group answering the question has changed and so the results cannot be compared.

Only ten of the questions retained from the 2013 survey have seen no alterations of this kind, and so can be compared. However, any conclusions drawn from these comparisons must still be treated with caution. While those questions are the same as in 2013, they are featured in a questionnaire that has largely changed. It is difficult to measure the effect that this will have on respondents but will likely influence how the questions are answered.



Positive score chart for historical comparisons: Q4, Q5, Q11, Q12, Q13+

Figure 56: Positive score chart for historical comparison (Q4, Q5, Q11, Q12, Q13+)

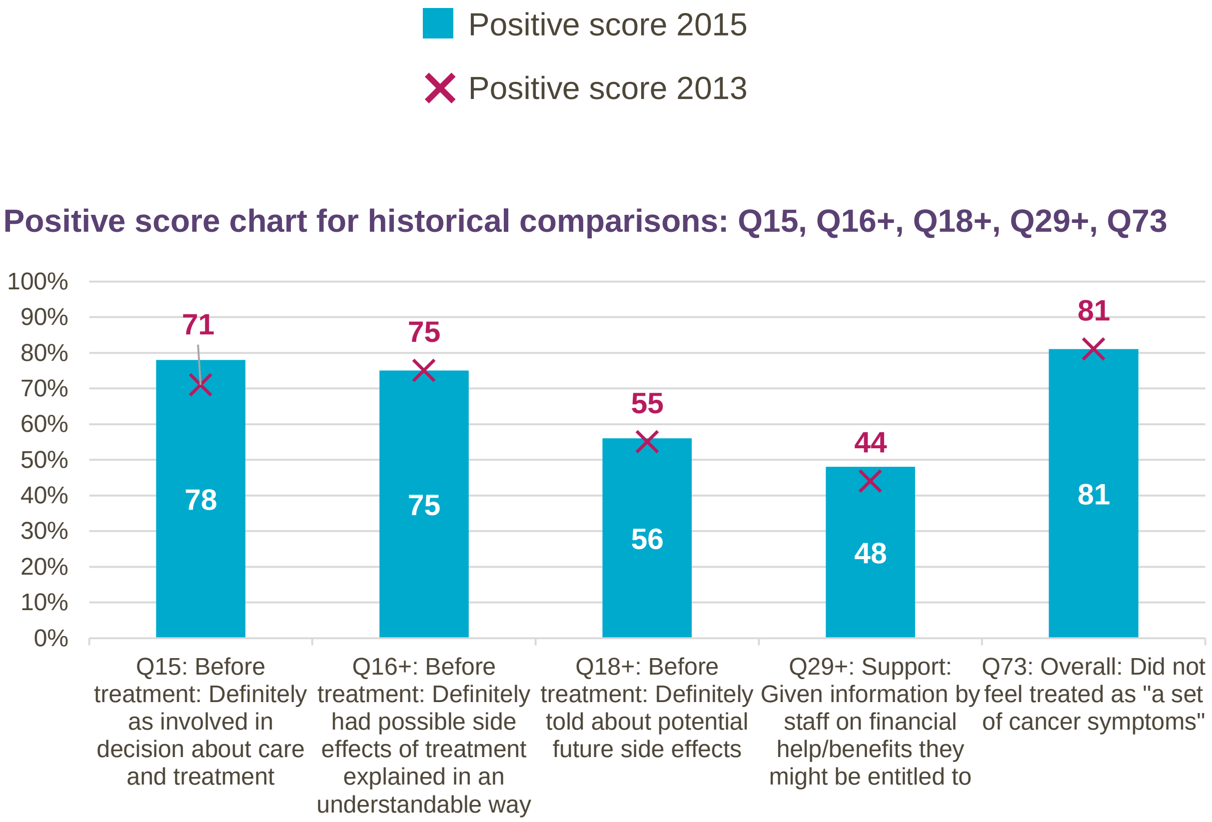


Figure 57: Positive score chart for historical comparison (Q15, Q16+, Q18+, Q29+, Q73)

Themes in respondent comments

Open-ended survey questions give respondents the opportunity to elaborate on aspects of their experience of cancer care in Wales. Their free text comments are a rich data source that can complement and offer additional insight into the quantitative findings of the survey.

The WCPES 2016 allowed patients to consider all aspects of their cancer care, from before diagnosis to treatment and aftercare. The free text section posed three questions: “Was there anything particularly good about your care?”; “Was there anything that could be improved?”; and “Any other comments?”. These questions were not directly connected to any specific part of the cancer care pathway and respondents could independently choose whether to focus on a specific aspect or provide insight on the process overall.

The results reported below provide a high-level analysis that highlights the major themes across all respondent comments. For a more detailed localised insight, please see individual health board and trust reports.

All quotes within this section are presented as verbatim.

Please see Appendix seven for details of the methodological approach used when theming the respondent comments.

Demographics of respondents

68% of respondents (4,588 people) replied to at least one of the free text questions. A slightly greater percentage of women (53%) provided a free text response than men (47%). The majority of comments were provided by an older cohort with 51% being over 70 years of age.

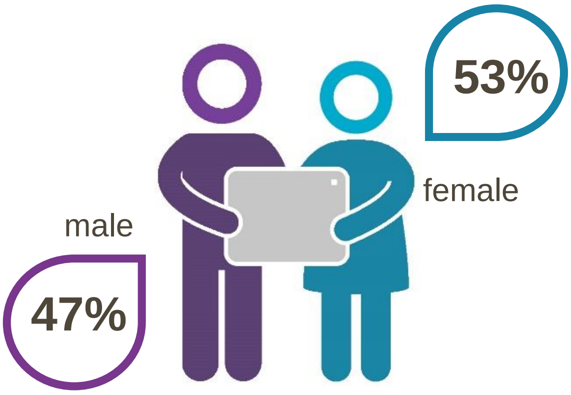


Figure 58: Free text gender split

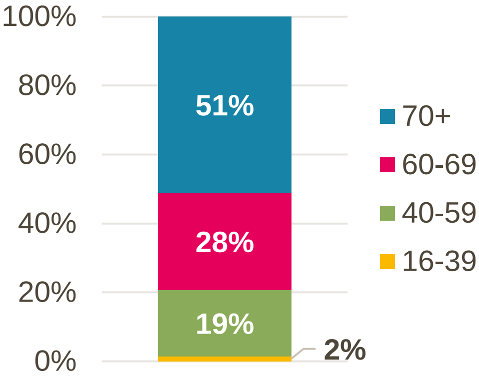


Figure 59: Free text age split

Key themes

4,588 people provided 8,893 comments containing 16,549 individual remarks. The majority of remarks (10,025, 61%) were positive. These positive remarks, while often effusive, tended to be short and generalised in their praise of cancer services across Wales.

Just over a third (6,324, or 38%) of remarks were negative, indicating dissatisfaction with some element of treatment or care, and these comments were generally more specific in their criticism. They tended to express dissatisfaction with a particular incident of care or procedure. Very few criticised their entire experience. 115 (1%) chose to offer suggestions for improvement, which can be found in individual health board and trust reports. 85 remarks (1%) were neutral.

Discussion of the themes is accompanied by example comments from respondents: these are reproduced verbatim to best reflect the voice of individual respondents.

Positive themes

Analysis of the positive comments made by patients in relation to their cancer care and treatment highlighted four dominant themes:

1. The quality of care and treatment from staff
2. How services were organised and co-ordinated
3. Experiences of care relating to specific aspects of treatment
4. Expressions of recognition and thanks.

1. Quality of care and treatment from staff

The majority of positive comments related to patients’ overall experience and commended the care and treatment provided by staff. In particular, comments highlighted the overall standard of care and the professionalism and commitment of staff; further discussion of comments within these themes is presented below.

> *“All the hospital staff treated me with empathy, as if I was a member of their own family. Couldn't have wished for better treatment. I was made to feel nothing was too much trouble for them.”* – Female, 52
>
> *“The staff of the NHS were exceptional, I cannot praise them enough.” –* Female, 63

Overall experience

Comments reflected patients’ sense that their experience of hospital care had met, and often exceeded, their expectations. They reflected a general sense that the system worked well. They included often enthusiastic praise for the quality of treatment and care they had received and demonstrated confidence that they had been in safe hands.

> *“I felt that the total care I received was superb & a credit to the healthcare system*.” – Male, 59
>
> *“All the health professionals I saw have been excellent and I’m very impressed with the level of aftercare provided.”* – Male, 54
>
> *“[Name removed], his staff, student, the pharmacist in [name removed] hospital could not have been more helpful and informative. Always patient, reassuring. [Name removed] has continued to telephone regularly - much appreciated.”* – Male, 78

> *"Found the treatment and staff at [name removed] excellent. Everything was very positive and upbeat."* – Female, 68

Professionalism and commitment of staff

Comments frequently referred to the compassion and care that was shown to patients and their family, and how they felt the staff had "gone the extra mile." There was a recognition that staff were often under considerable pressure but were nonetheless dedicated to providing the best care possible.

> *"Every person I encountered, from porters and receptionists to nurses and doctors, was extremely kind and sensitive and I was always made to feel I could ask any questions. I can't fault the care I've received."* – Female, 46

> *"The staff at [name removed] breast care and the radiotherapy dept were excellent although under pressure from the number of patients."* – Female, 68

> *"I cannot fault the way I have been treated by all hospital staff from consultants to cleaners since I have been diagnosed with cancer."* – Male, 83

> *"The staff have all been excellent, without fault - helpful, compassionate and caring. Thankyou."* – Male, 55

> *"All of the care received by the entire staff at [name removed] is absolutely excellent which helps you to feel safe & secure and that you are getting the best all round treatment available. Everyone at [name removed] definitely goes the extra mile for their patients."* – Female, 55

Many respondents emphasised the high level of kindness and empathy they experienced, underlining the importance of compassion from staff supporting patients with cancer. Often, key staff members were commended for playing a vital role in ensuring patients felt cared for as individuals.

> *"From initial diagnosis at [name removed] the care was exceptionally brilliant. There were no delays the staff at all levels were friendly and compassionate."* – Male, 74

> *"The care and attention given by the nursing staff during chemo and radiotherapy was excellent whenever I needed to use the chemo pager. My concerns were dealt with sympathetically and advice given. The oncologist nurse was superb showing empathy and ready with answers to any of my many concerns."* – Female, 76

> *"The care I received, and am still receiving, has been first class in every aspect, I cannot fault any part of the treatment process. All the medical staff involved, consultants, nursing staff and my Macmillan key worker have treated me with the utmost respect, kindness and above all care, and I cannot sing their praises highly enough."* – Male, 71

> *"My treatment was amazingly good practically. Initial mammography, blood tests, ultrascan, biopsy all done within a couple of hours at breast test Wales [name removed]. I was very cold after surgery nursing staff responded immediately with extra blankets hot drinks and hot buttered toast to excellent effect. All staff made me feel special and related to me totally appropriately. Well done."* – Female, 74

2. Organisation of services

Speed and efficiency of process

Many respondents indicated that once their cancer had been diagnosed, the overall treatment process was quick and felt efficient.

> *"The speed with which matters progressed from confirmed diagnosis to operation to remove the cancer."* – Male, 74

> *"The speed and professionalism I received were excellent. I was kept informed at every stage and also allowed my own input."* – Female, 64

> *"At all times I was treated promptly and efficiently and with total respect and dignity."* – Male, 63

> *"I was treated quickly. All health professionals involved told me the next step in my treatment. Any outcomes were communicated to me as they occurred. They saved my life."* – Female, 54

Prompt and efficient care was reassuring for many respondents. Receiving a diagnosis and treatment quickly instilled confidence that the best treatment outcomes would be achieved.

> *"Bladder cancer treated speedily and followed up 6 monthly, now yearly. Gives one peace of mind."*– Female, 80

> *"The promptness of the diagnosis to having my operation was about a month. I feel so lucky."* – Female, 63

> *"Prompt, caring treatment that makes me feel confident in the care, treatment and follow-ups I receive."* – Female, 69

> *"The length of time from the first treatment to the last was quite short which greatly relieved stress and anxiety."* – Female, 69

> *"The speed and professionalism with which I was treated gave me great confidence that I was in the right hands to deal with my cancer."* – Male, 62

> *"From the start seeing my doctor to the operation and hospital care I was treated very well and with dignity. The process from discovery to operation was very quick and helped to ease my initial fears."* – Female, 59

‘Joined up’ care

Respondents who commented on this noted that treatment appeared ‘connected’ and ‘joined up’. Patients who attended a number of services, hospitals and departments for different aspects of diagnosis and treatment appreciated clear and prompt communication and co-ordination between them.

> *“I have never known a more professional workplace… They work so hard and are so well informed. The team work is phenomenal. I feel in safe hands.”* – Female, 55

> *“Pathway from GP to treatment was excellent, and very quick. Staff at GP surgery, radiology and urology team were all excellent.”* – Female, 57

> *“Well coordinated and personable.”* – Male, 72

> *“On the whole I had a long series of different tests (in 3 hospitals) within a comparatively short time, and I did not have a long wait before the surgery.”* – Male, 73

> *“At [name removed], I felt the team were totally joined up - whoever I spoke to you was happy to engage with any issues I raised. I felt human, not a set of symptoms.”* – Female, 61

3. Care relating to specific incidents of treatment

High quality of overall care during specific procedures (particularly in relation to chemotherapy, radiotherapy and operations) was stressed repeatedly. These treatments can be particularly traumatic for patients, but respondents frequently praised the care and attention provided by staff. Aftercare in regards to these specific aspects of care, particularly within the hospital setting, was also applauded.

> *“My overall care during treatment was good, very well organised and efficient.”* – Female, 53

> *“The surgery and reconstruction to my breast is excellent, which was carried out at [name removed]. The surgeon went to great lengths to minimise the impact, which I am extremely grateful for.”* – Female, 59

> *“Yes, through having 3 monthly skin chemo my tumour in groin was picked up on. Through having CT scans a cancerous lymph node was found too, which I'm now receiving treatment for... Without these procedures I probably would not be here now.”* – Female, age unknown

> *“Went for one op ended up having two. Everyone must have done a good job. I'm here to tell the tale.”* – Female, 68

"My surgeon was excellent. Saved my life by cutting out the cancer along with part of my lung. No other therapy needed. My consultant [name removed] in [name removed] went beyond normal requirements to ensure the best care possible was given to me." – Male, 63

"I had a melanoma … but was due to [travel internationally] shortly afterwards. The care related to this was exemplary and very supportive in that my immediate follow up (wound treatment) was undertaken by the hospital (not local services) and I was given antibiotics to ensure I did not get an infection. There was a real interest in me as a person and they ensured that I went on my holiday - I was very grateful." – Female, 67

"[Name removed] and team at [name removed] have to be extremely praised for their expertise and care when I had my operation for removal of the oesophagus." – Male, 62

4. Recognition and thanks

A large number of patients commented on the high quality of care they experienced despite pressures on staff. They believed staff numbers were low and their workload heavy, and praised the quality of their performance despite these challenges. In particular, many patients took the opportunity to express their thanks and many stressed that their lives had been saved as a result of the high quality service and treatment they had received.

"The kindness, care and expertise of the surgeons, doctors, nurses and everyone who works on the wards is second to none in the hospital where I had my two cancer operations, they saved my life." – Female, 50

"I would like to say thank you very much, in this difficult time for me. I was lucky to meet great people." – Female, 44

"The dedication of the team of nurses & doctors looking after me was unbelievable. They got me well, I can't thank them enough." – Female, 78

"I had excellent treatment at all hospitals I attended especially [name removed] there are no words I can find to express my appreciation of the staff there." – Male, 66

"A huge thanks to everyone I met along the journey who always treated me with tender loving care. The hospital was like a 5 star hotel as was the care, something I will always remember." – Female, 55

Negative themes

A minority of patients (360, or 5%) reported that they were dissatisfied with their overall experience and offered no positive feedback within the free text section. One question specifically asked if there was anything that could be improved, and overall just over a third of remarks indicated the patient was unhappy with an aspect of care. Patients' negative comments tended to focus on specific aspects in their cancer journey, and focused largely on the following areas:

1. Difficulty accessing primary care.
2. Time taken for referral to specialist services and for diagnosis.
3. Insufficient or inappropriate information.
4. Lack of support at home.

> *"Follow up very poor, constantly cancelled was told I would have 3 /12 follow up appointments have been seen only twice in appointments 1yr. Improvement much needed here."* – Female, 65
>
> *"More needs to be done in explaining long-term effects of radiotherapy - nerve damage to legs for example!"* – Female, 74

1. Access to primary care

Access to care was the problem most frequently raised within the free text section. One frequently-raised issue was difficulties accessing a GP appointment. Other comments centred on the time it took from when the respondent had initially noticed symptoms and visited a GP until they obtained a diagnosis. Another concern for some, particularly those living in rural areas, was distance to hospital.

> *"Living very rural, there were large distances to travel to hospital for surgery & radiotherapy."* – Male, 53
>
> *"I am far less impressed…by the considerable distances patients in this rural area [location] have to travel for appointments and treatment."* – Male, 82

Making a GP appointment

GP practices' appointment systems and availability of appointments was reportedly a major barrier for some to access a GP. In some cases this caused serious delays to a diagnosis being made. Occasionally, patients described how they had had such great difficulty getting an appointment that they had opted for private treatment. In some cases, delays led to a spread of the cancer with very serious consequences.

> *"My GP could have picked this up sooner. I had been to the GP 3 times before they actually refer me to the breast centre to have a biopsy"* – Female 54

> *"Original GP took too long to refer me due to my age - I knew I was ill and kept insisting but had to pay private to see specialist... Overall the care I have received has been very good."* – Female, 38

> *"I had great difficulty in getting appointment for GP. When I had first sign something was wrong I phoned GP surgery several times only to be told by receptionist that appointments had all gone and to phone at 8.30 next morning. I gave up. I then had another symptom that something was wrong. I tried again to have appointment to be told again the appointments had gone. I eventually had appointment with asthma nurse 3 months later and she got me an appointment with the GP. It was almost too late for me as I was told the tumour was trying to press through a muscle. Appointment system needs to be changed."* – Female, 70

> *"GP support was non-existent. I could not get an appointment when I first discovered a lump so I went private."* – Female, 55

> *"On initial finding a problem it took three weeks to get an appointment with a female doctor. I still experience long delays with getting GP appointments."* – Female, 46

Symptoms being taken seriously

Some respondents reported that when they did see a GP or nurse in primary care, it took a long time before they recognised that their symptoms were serious and merited further investigation or a referral. Patients felt this to have been responsible for serious consequences, including their condition worsening and/or cancer spreading.

> *"My dealings with my GP practice have poor. Appointments difficult to arrange, and a lack of interest when I first thought something was wrong."* – Male, 72

> *"When I originally went to doctors to see about my lungs … the GP couldn't fit me in for 3 weeks so they suggested I see the nurse. The nurse listened to my chest and I explained my symptoms …she said … to come back if cough didn't get better. It seemed to get better for a few months so I didn't go back until it came back again ... The GP took me seriously straight away & sent me for an X-ray but by the time the diagnosis finished … the cancer had spread to my left lung so they could not operate. Had the nurse taken me seriously initially I feel I could have been saved. I have never smoked but feel if I had I would have been taken more seriously."* – Female, 43

> *"I should have had immediate referral [from GP] instead of being put on an eight month waiting list. The GP should have red flagged my symptoms and took into*

consideration my age and what was happening. Instead my condition became worse and three times I went to my GP. The third time I asked to be seen sooner at the hospital as I knew because of the pain etc something was seriously wrong." – Female, 64

2. Time taken for referral to specialist services and for diagnosis

Many patients who made comments expressed concerns about the amount of time that passed before diagnosis. Respondents suggested that there were delays in receiving that first hospital appointment; both due to delay in referral but also waiting times once an appointment with specialist services had been requested. These long waits caused great anxiety and worry. A few commented that it could take some time before initial test results were communicated.

> *"It took far too long to be seen for initial scans, biopsies etc, particularly as I had a previous history of cancer. I don't think it is appreciated the effect this has on your emotional well-being."* – Female, 63
>
> *"Waiting times for consultation or treatment were emotionally draining."* – Male, 75
>
> *"Despite a fast track referral by my GP to the breast clinic I had to wait 6 weeks for an appointment. I feel this was too long and found the wait very stressful. Following a definite diagnosis of bilateral breast cancer. It was a further 7 weeks before I could have surgery I had to change consultants to be operated on this quickly."* – Female, 61
>
> *"I should have started my treatment within 62 days but it was well over 100 days even taking account of accepted delays such as waiting for MRI scan etc. Had to write to MP etc or may have had to wait even longer! Not very impressive. It greatly added to my concern and stress."* – Male, 75
>
> *"The time from the first appointment with the GP and the surgery after the diagnosis was very long – 5 months - and it is possible that I would not be still receiving chemotherapy (expensive and ineffective to date) without this delay. It is possible that the surgery would have been effective and that the cancer would not have spread further in my body had the diagnosis and the surgery been quicker and more effective."* – Female, 60
>
> *"Every appointment and waiting for scan results etc takes weeks, bad enough having the stress of cancer."* – Male, 53

Distance to hospital

In a similar vein, some patients commented that the distance to hospital could be too far, especially when receiving daily treatments. However, again, it should be noted that these comments seem to be predominately localised to patients who reside under a comparatively rural health board. Some offered the suggestion that transport links could look to be improved.

> *“Shame that the radiotherapy was in [name removed]. It would be wonderful if [name removed] had one machine instead of 4 in [name removed].”* – Female, 58

3. Information

The importance of being adequately informed about their diagnosis, care and treatment was stressed by patients who felt improvements were required. Information at the time of diagnosis about the disease and prognosis were important, as was information about procedures and treatment. Information about hospital processes and about follow-up care were also sometimes said to be lacking. Some patients complained that they did not feel involved enough in decisions about their care. Others suggested that at times they may have received contradicting or even incorrect information.

Information about diagnosis and prognosis

Free text comments showed how some patient felt inadequately informed about what their cancer diagnosis meant in terms of the treatment they needed and their health, now and in the future.

> *“One would say one thing the other something else. Some point they scarred me and said I might have it in my neck. They couldn't of read notes, as I have thyroid trouble.” – Female, 54*
>
> *“More information regarding prognosis and life expectancy.”* – Male, 58
>
> *“Due to the nature of my diagnosis I did/do not have access to the relevant specialist cancer/ tumour doctor. My doctor often has to have the information from someone else and I get it third hand. When I have questions there is no way of me accessing the answers because I have no actual person who has care responsibility for me as far as I can make out… I have no idea to this day of the operation has removed the whole tumour or how it will be monitored in the future.”* – Female, 36
>
> *“I was informed that I was suffering with bone cancer. Since then I have no information of how this will affect my future. What will it affect my future or life expectancy?”* – Female, 72

> *"Consistent terminology eg. I was told I had a large cyst which then became a tumour. To me they have different meanings, so I was shocked to be given a probable cancer diagnosis."* – Female, 65

Some patients wanted more written information, while some wanted information that was more closely tailored to their own situation. Some respondents would have liked literature that was easier to understand and others wanted information that gave more detail. Some would prefer to have been given information about the emotional and psychological effects of having cancer.

> *"I wasn't told what type of cancer I had until I saw my Oncologist and I didn't have any written information on this type of cancer. I didn't even know there was more than one different type of breast cancer. I had to look online for info about my type of cancer."* – Female, 42

> *"The literature I was given some was too simple as though written for an idiot and some was too complicated."*– Female, 75

> *"At the first appointment I was given leaflets, booklets etc with information relating from lumpectomy through to double mastectomy. I found this frightening and inappropriate as I could not compare my grade 1, slow growing, tiny lump to my daughter who had died after having a double mastectomy."* – Female, 71

> *"More reading materials, more advice on how this can affect you emotionally. A booklet on the different stages & types of melanoma would have been useful and re-assuring."* – Female, 43

Information about aftercare and follow-up

Access to information appeared to be a particular issue in relation to aftercare and follow up. People would have liked more information about how they might expect to feel after treatment or operations, what is ‘normal’ and when it was necessary to seek further advice or care.

> *“More information needs to be given to patients when they leave hospital. Before your operation you are given too much information (although I understand why - due to insurance purposes). However when you leave hospital you should be given a rough guide of what to expect (eg:- when your pain is likely to subside/end). Unless you ask really no information is given to you.”* – Female, 62
>
> *“Admin after leaving hospital. I asked for a letter detailing my diagnosis & treatment. It was promised on 2 occasions, it took 4 months to get.”* – Female, 59
>
> *“Information regarding the aftercare required from the operation. I did not know if I was doing the right things and if the pain and discomfort I felt was normal. Eventually went to GP who reassured me.”* – Female, 61
>
> *“In the post-operation literature I was given there was no mention of the possibility of post-operative pain due to the inflammation of the body by gas. Had I realised how severe this pain could be, I would have started painkillers earlier. It might be helpful to have this mentioned in the literature.”* – Male, 73
>
> *“Would have liked a patient information leaflet with advice on recovering following bowel cancer surgery and what to expect.”* – Female, 75
>
> *“Conflicting information about what I should be eating. One person said one thing, another another thing.”* – Female, 34

4. Support at home

When patients returned home after episodes of care, their needs for support were not always met. These needs took various forms: aftercare from district nurses, support for their mental health, Macmillan Cancer Support, and information about financial support available.

A sense of isolation seemed to pervade comments regarding dissatisfaction with support at home across the national landscape. However, there do appear to be pockets across the country where patients are reporting high quality home support. Patients across the board praised receipt of care and support from third sector cancer organisations.

Many remarked that there was too long a delay before any follow-up appointments, with some indicating that this could leave people feeling isolated and alone.

Aftercare

Patients who had returned home sometimes felt they were inadequately informed and supported.

> *"Post operative information was poor. No information provided to support (emotionally and mentally) eg [name removed] no nominated key worker or CNS provided."* – Female, 57

> *"I left [name removed] with no care plan, it was left completely to my daughter to care for my needs and to have facilities put in her house i.e. shower and toilet."* – Male, 93

Community/district nurses

Responses indicated that some people felt they lacked support from community nurses. In some cases, the availability of staff was a problem. In some cases, when district nurses visited them at home, comments suggested that they were not adequately skilled. This meant that sometimes patients had to carry out procedures themselves that they expected to be undertaken by clinical staff.

> *"My district nurse was a disaster during treatment. There were 3 or 4 occasions where she didn't turn up."* – Female, 51

> *"District nurses need regular practice on PICC line care did not appear to be familiar with them."* – Male, 77

> *"The aftercare with the district nurses were non-existent. They came out twice and no more and I am living on my own and had to change the dressings and the draining bags by myself."* – Female, 61

> *"District nurses could be allocated based on experience. I administered my own Clexane but needed query answered by district nurse re administration of medicines and she didn't know. Left it to me to continue as I seemed competent and sensible."* – Female, 63

> *"I had to move a PICC line. On first visit district nurse didn't know what she was doing regarding flushing/changing dressing. They refused to finish the line on a chemo week - which made me very anxious and I always ended up feeling very stressed in those 3 days leading to my chemo. They gave me wrong info. When the oncologist reduced the strength the nurses were v. vocal in telling me I'd need more chemo. When my treatment finished I was constantly told by them to get the line taken out, to the point that one rang the day before and asked why I hadn't had it removed. I felt bullied in my own home. I felt that some nurses*

> *on team should have more cancer related knowledge in order to deal with patients going through this."* – Female, 48

Emotional and psychological support

A number of comments referred to an unmet need for psychological and emotional support following treatment for cancer. Patients themselves felt that they needed help to cope with the emotional effects of their treatment and the implications of the prognosis for their future, both for themselves and for family members, particularly where they had dependents.

> *"The aftercare e.g. mental health. Cancer messes with your state of mind. When treatment ended I seemed to be in limbo and still am."* – Male, 72

> *"As a single mum [removed] I wish there is someone I could talk to about dying etc what would happen at the end etc this is what frightens me the most! Not knowing."* – Female, 49

> *"I do feel that the emotional side of cancer is the most difficult issue to deal with. Not only as a patient but for close family (ie) husbands, young children and parents. Perhaps there is something that could be done to address this."* – Female, 41

> *"Although my physical needs were catered for, as I suffer with anxiety and depression I feel that my cancer took main stage - as it should - but my mental state ignored."* – Female, 58

Financial assistance

Many commented that they did not have adequate information about/provision of financial assistance. When this was cited, it was sometimes in relation to decisions regarding employment and the importance that this kind of information would play in such a decision.

> *"Support for people who are living on their own. More financial support."* – Female, 57

> *"I felt that certain information was given well after I returned to work eg [name removed] said that there was possible help with money worries, but it was too late by then. My return to work was due to money worries and I know my care nurse would have preferred I waited longer."* – Female, 53

Section nine:

Appendices

Appendix one: Health board analysis

This section compares respondent’s perception of their cancer care relative to their health board of residency. Please note that positive scores have once again been used as a comparative tool.

The data in this section is standardised data. This means that it has been adjusted to make comparisons between health boards as fair as possible.

The graphs in this section show the adjusted score for each of the seven health boards compared to the health board average score.

For more information about standardisation or the health board average, please see the relevant parts of Section four: Survey overview.

■ Health board positive score

— Health board average

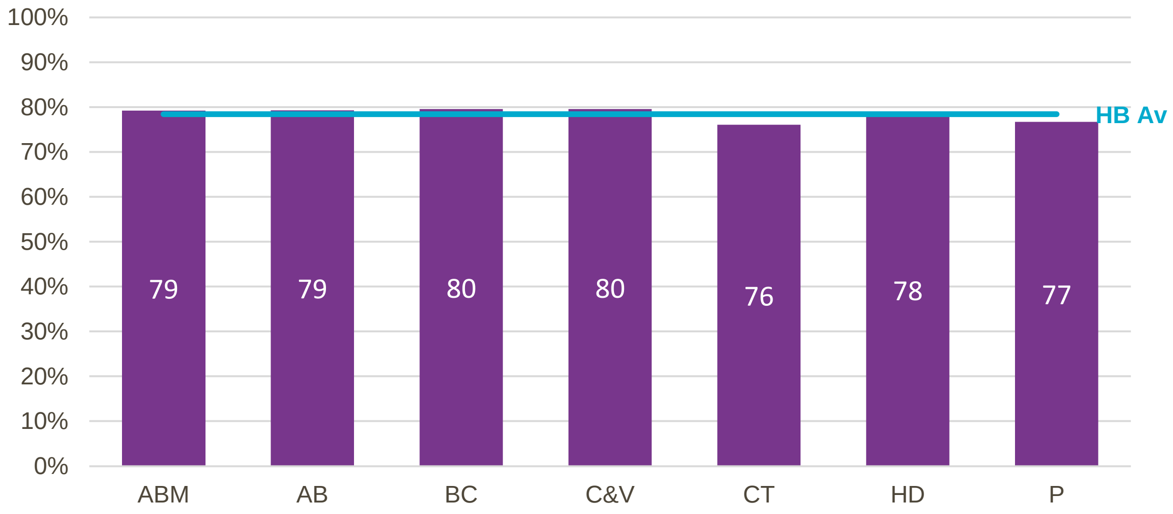
ABM	Abertawe Bro Morgannwg University Health Board
AB	Aneurin Bevan University Health Board
BC	Betsi Cadwaladr University Health Board
C&V	Cardiff & Vale University Health Board
CT	Cwm Taf University Health Board
HD	Hywel Dda University Health Board
P	Powys Teaching Health Board

Health board analysis: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

Q3+: Before diagnosis: patients whose GP took symptoms completely seriously

All respondents

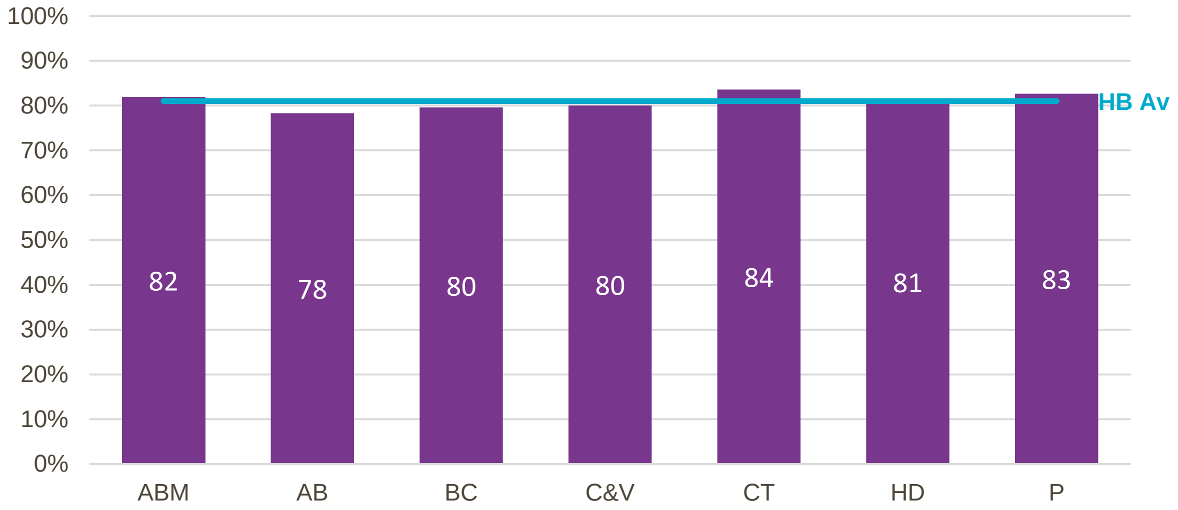


🟪 Health board positive score

— Health board average

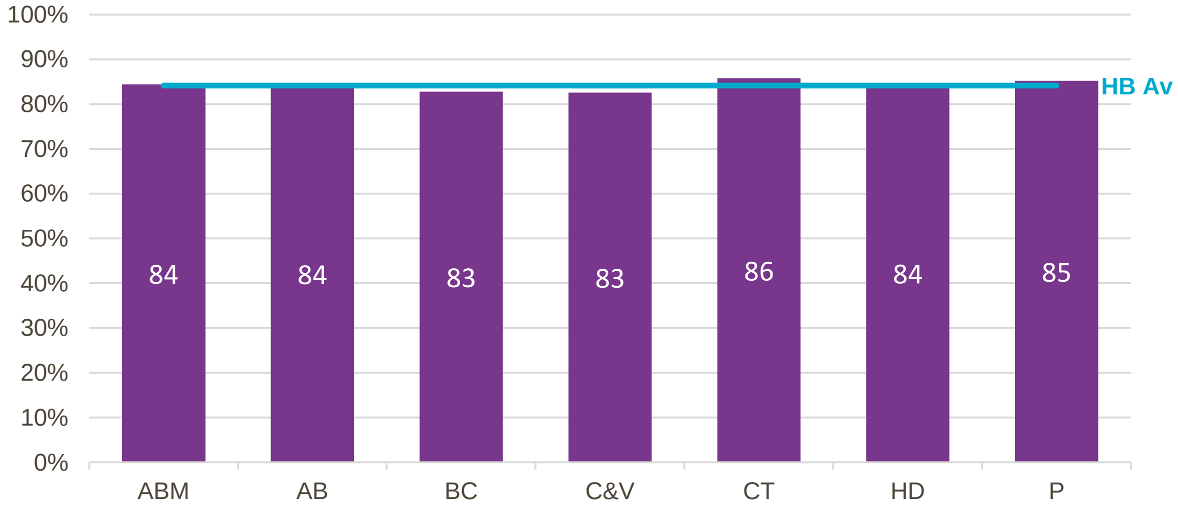
Q4: Before diagnosis: was seen as soon as necessary

All respondents



Q5: Before diagnosis: while waiting for first appointment with hospital doctor, health stayed the same/got better

All respondents

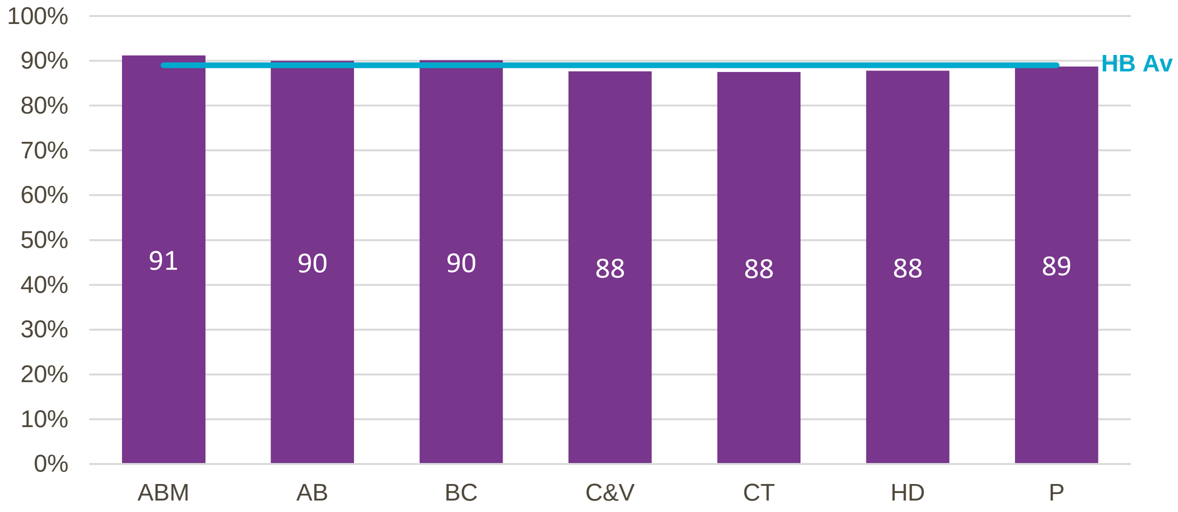


■ Health board positive score

▬ Health board average

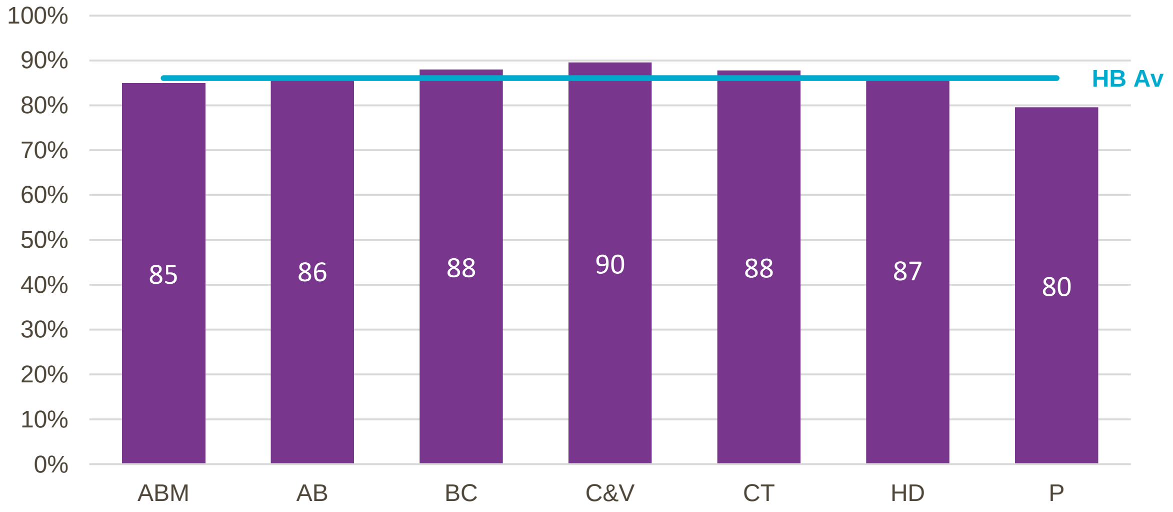
Q8+: Before diagnosis: what would be done during test(s) completely explained

Respondents who had a diagnostic test



Q9+: Before diagnosis: received written information about test(s) that was easy to understand

Respondents who had a diagnostic test

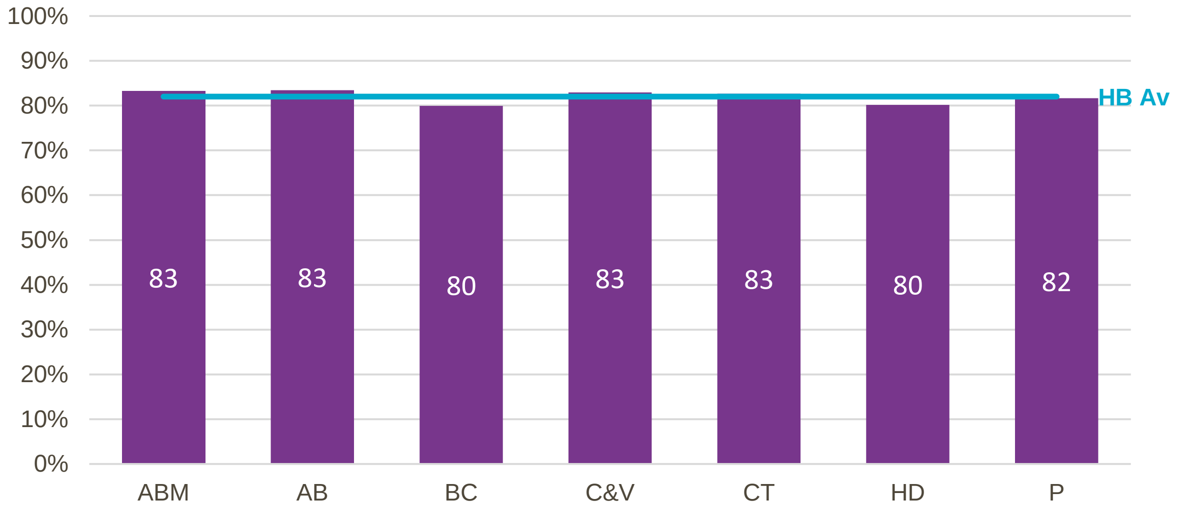


■ Health board positive score

— Health board average

Q10+: Before diagnosis: results of test(s) completely explained

Respondents who had a diagnostic test

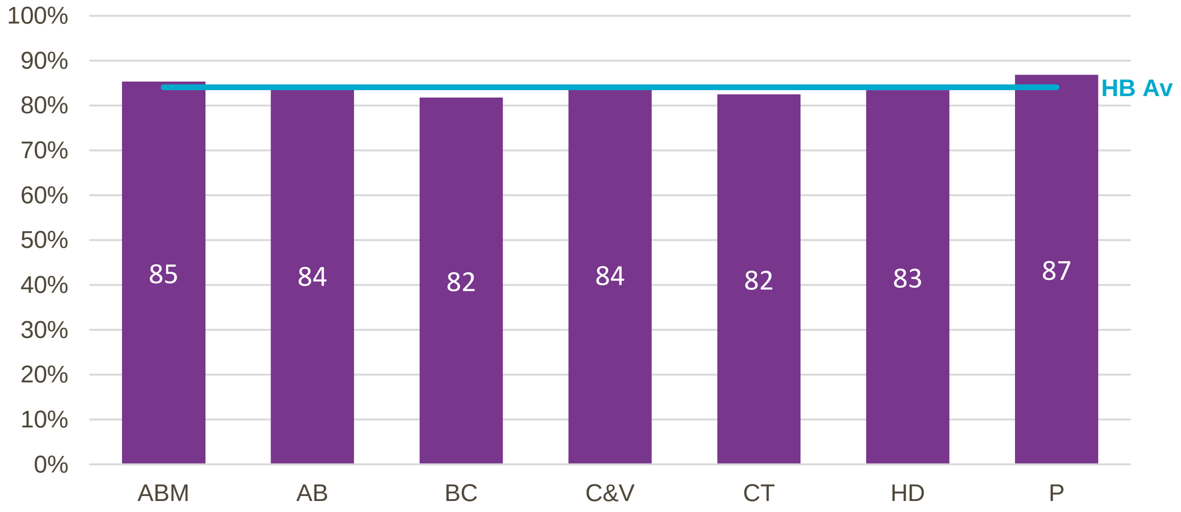


Health board analysis: Finding out you had cancer

These questions are about what happened when patients found out they had cancer.

Q11: Finding out about cancer: was told sensitively

All respondents

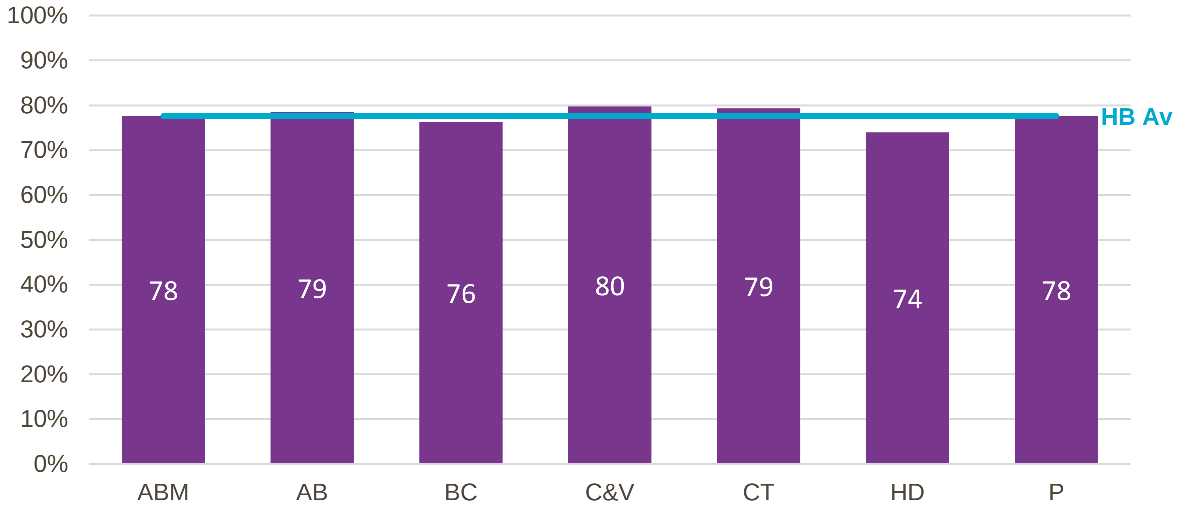


🟪 Health board positive score

— Health board average

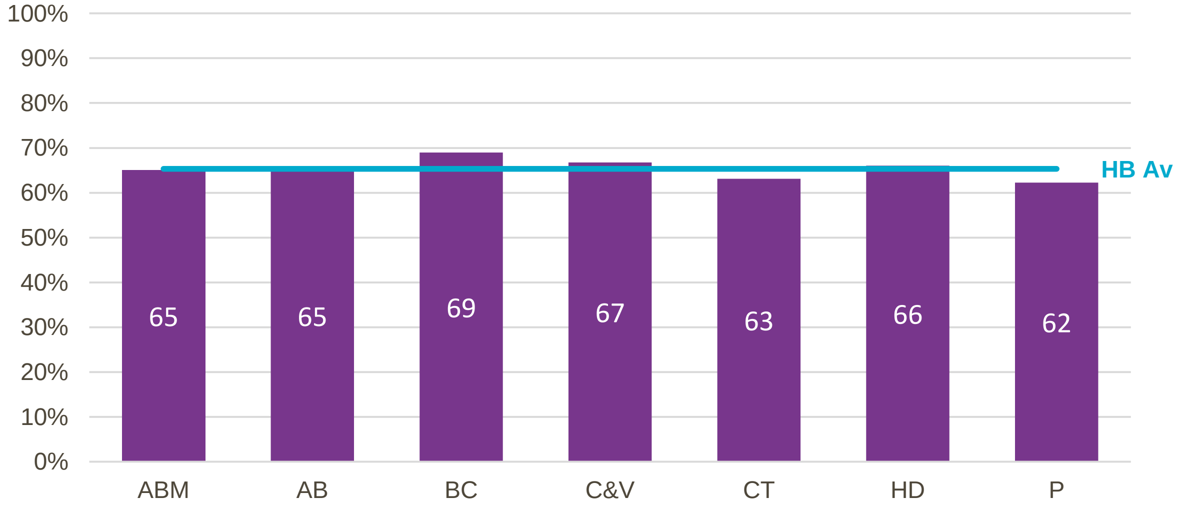
Q12: Finding out about cancer: completely understood explanation of what was wrong

All respondents



Q13+: Finding out about cancer: received written information about type of cancer that was easy to understand

All respondents



■ Health board positive score

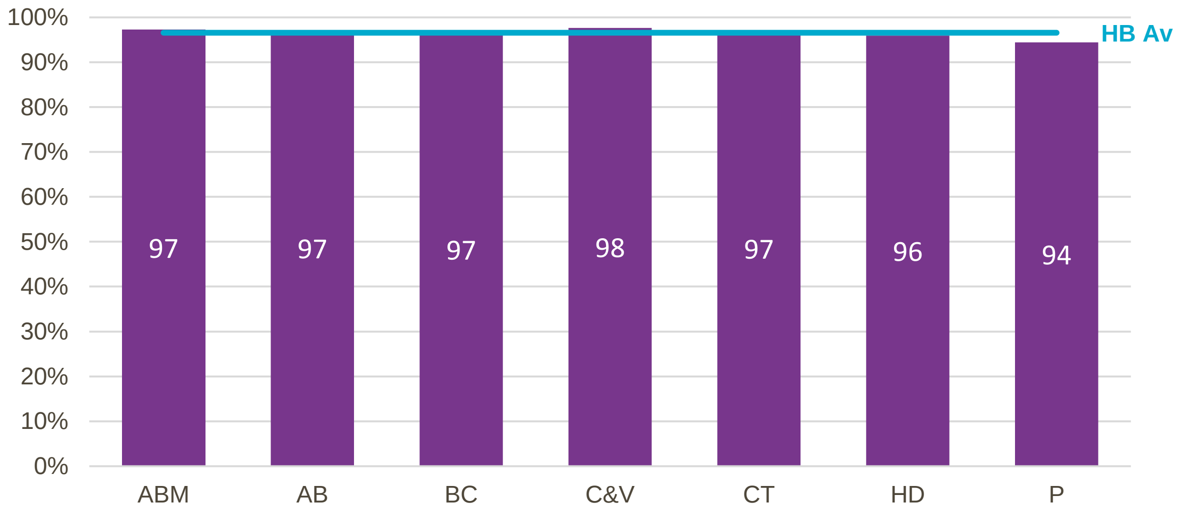
▬ Health board average

Health board analysis: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

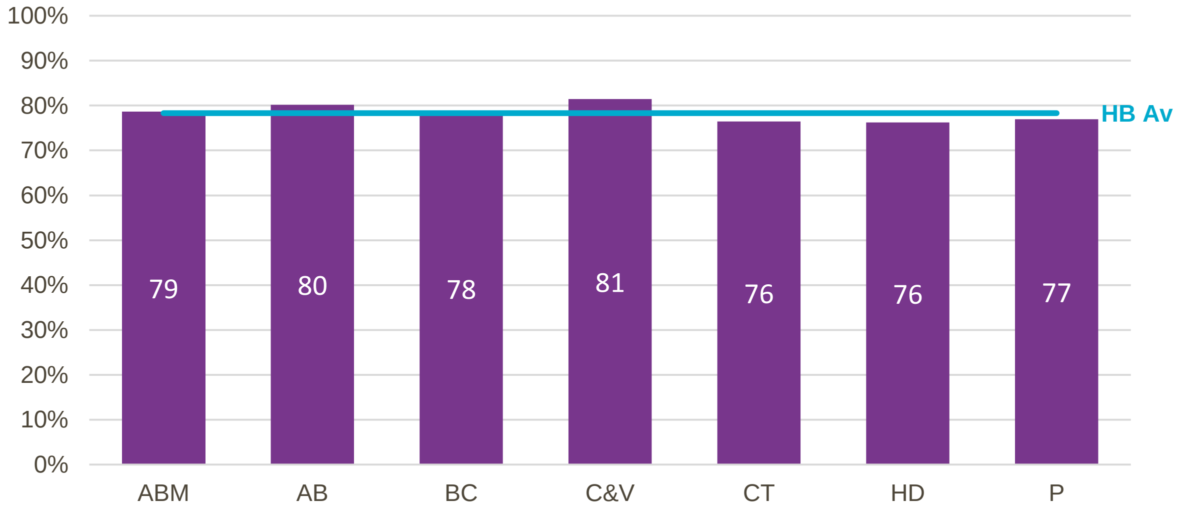
Q14+: Before treatment: options explained

All respondents



Q15: Before treatment: definitely as involved in decision about care and treatment as wanted

All respondents

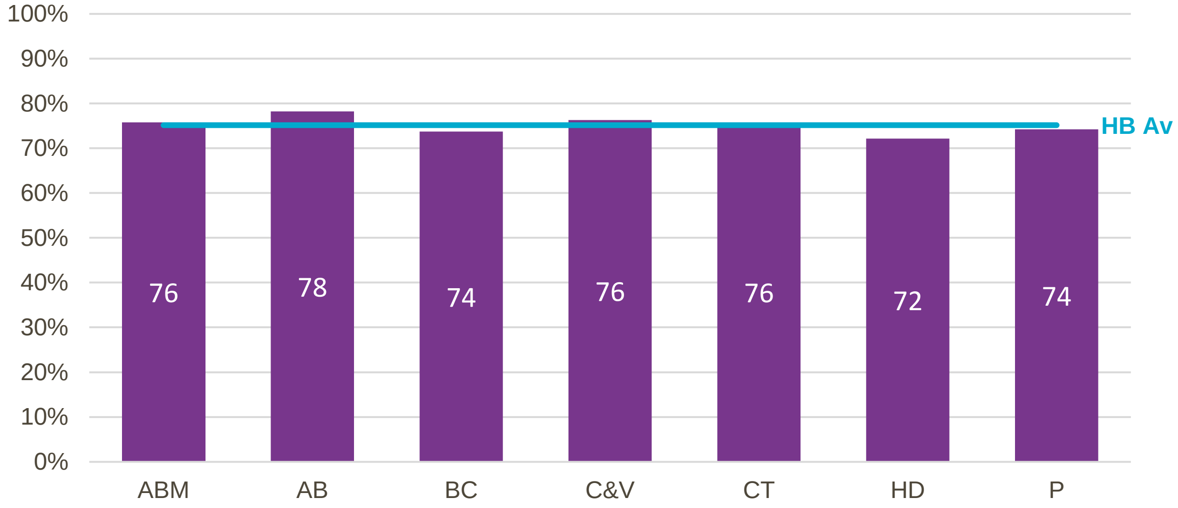


■ Health board positive score

▬ Health board average

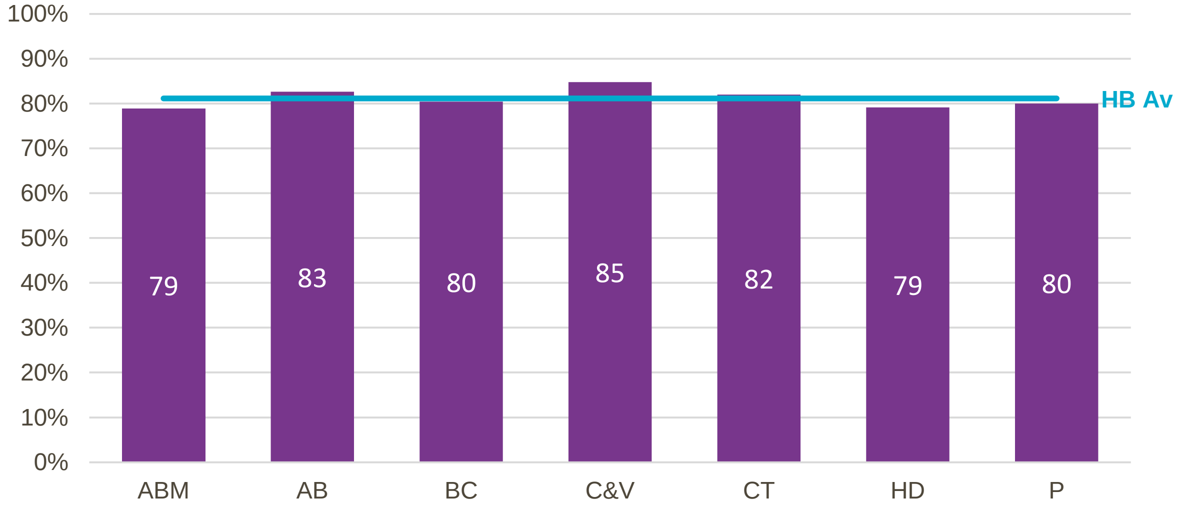
Q16+: Before treatment: side effects definitely explained in an understandable way

All respondents



Q17+: Before treatment: received written information about side effects that was easy to understand

All respondents

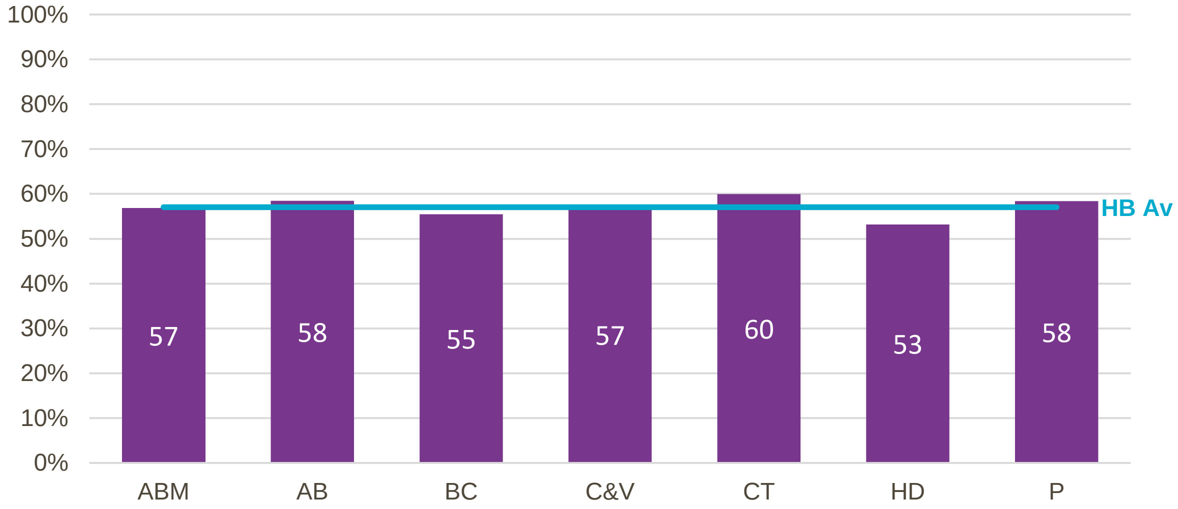


🟪 Health board positive score

— Health board Average

Q18+: Before treatment: definitely told about future side effects

All respondents

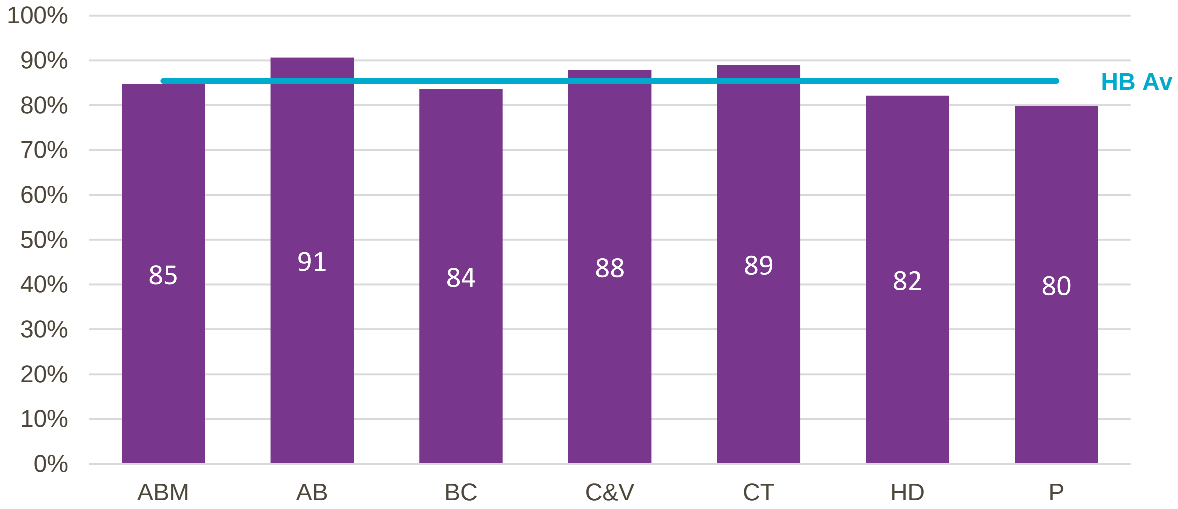


Health board analysis: Key Worker

These questions are about Key Workers.

Q19: Key Worker: given name and contact details

All respondents

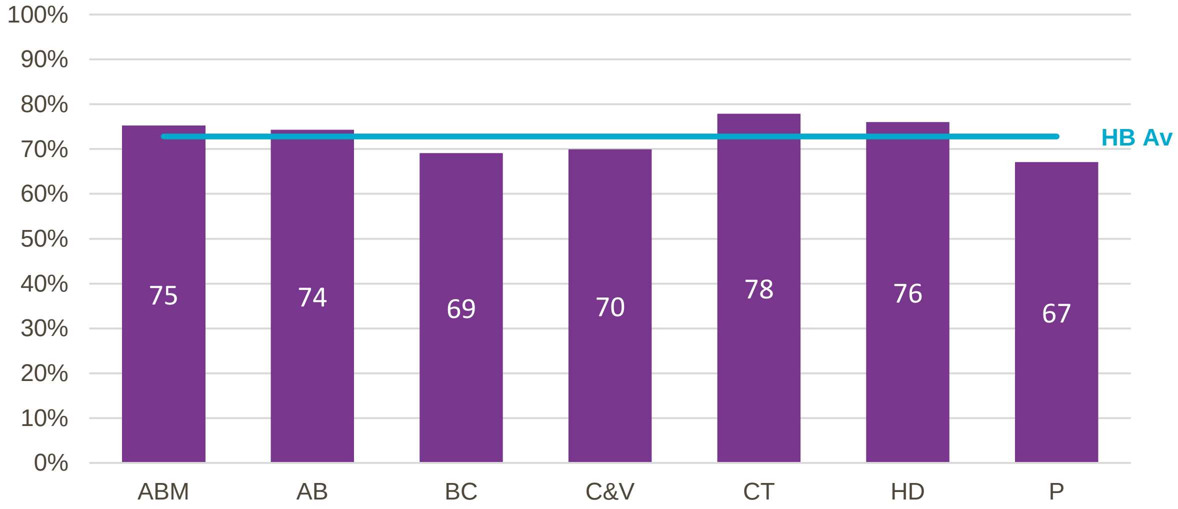


■ Health board positive score

— Health board average

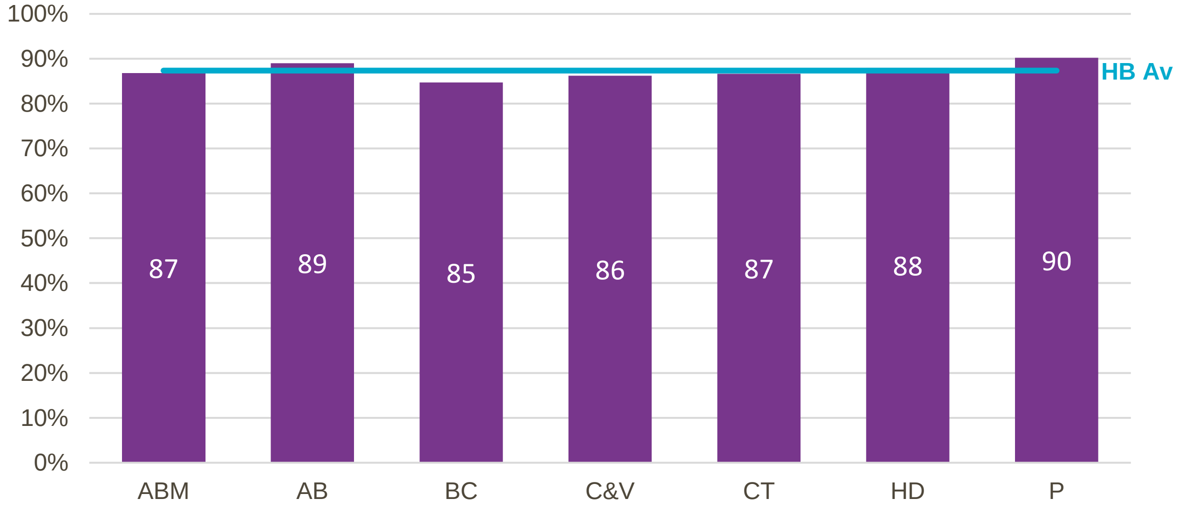
Q20+: Key Worker: easy to contact

Respondents who had the name and contact details of a Key Worker



Q21+: Key Worker: all or most of the time received answers to questions

Respondents who had the name and contact details of a Key Worker



■ Health board positive score

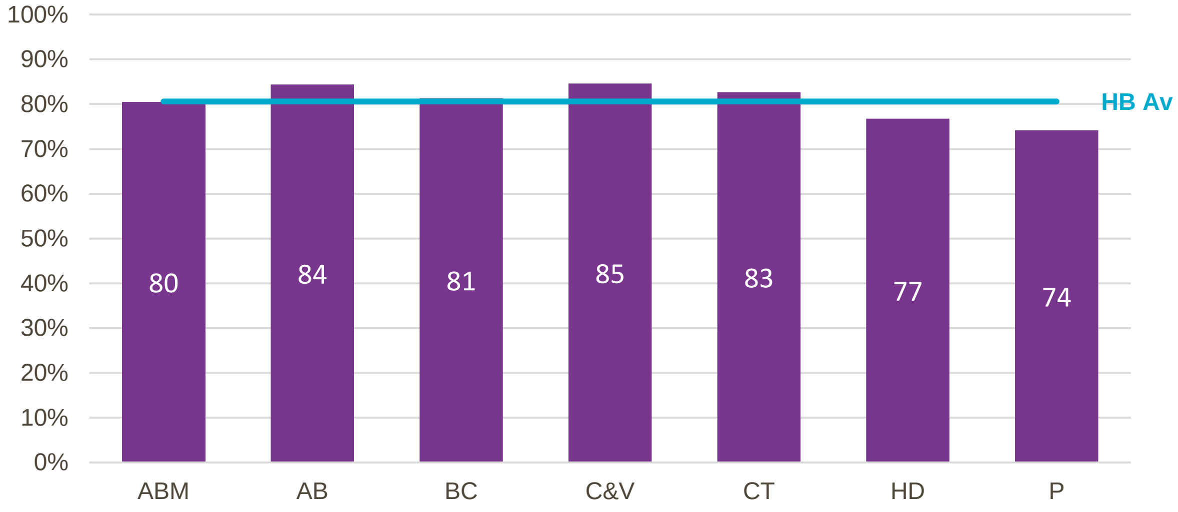
▬ Health board average

Health board analysis: Clinical Nurse Specialist

These questions are about Clinical Nurse Specialists.

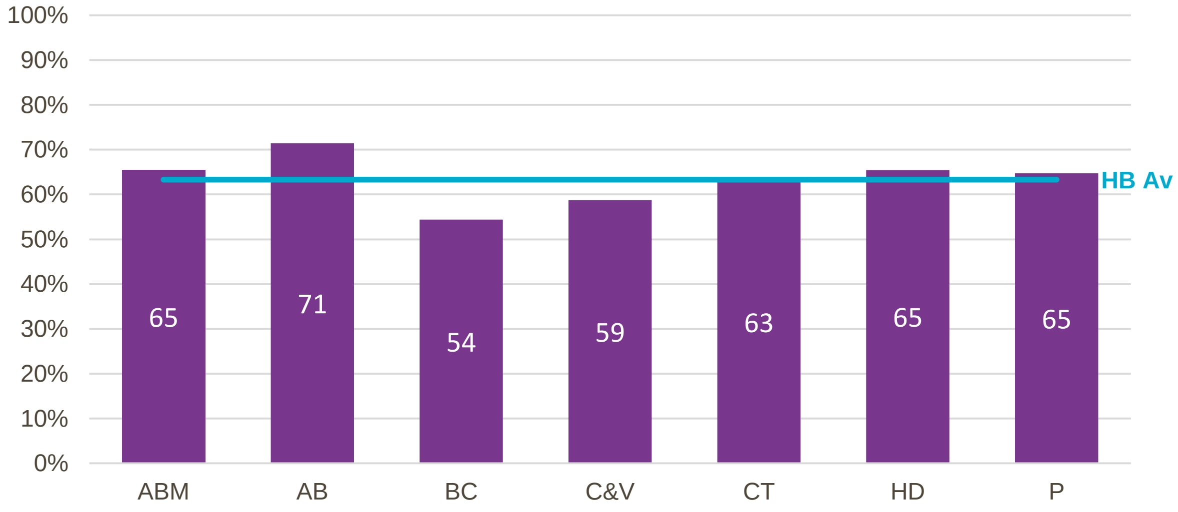
Q22: Clinical Nurse Specialist: access to a CNS

All respondents



Q23+: Clinical Nurse Specialist: easy to contact

Respondents who had the name and contact details of a Clinical Nurse Specialist

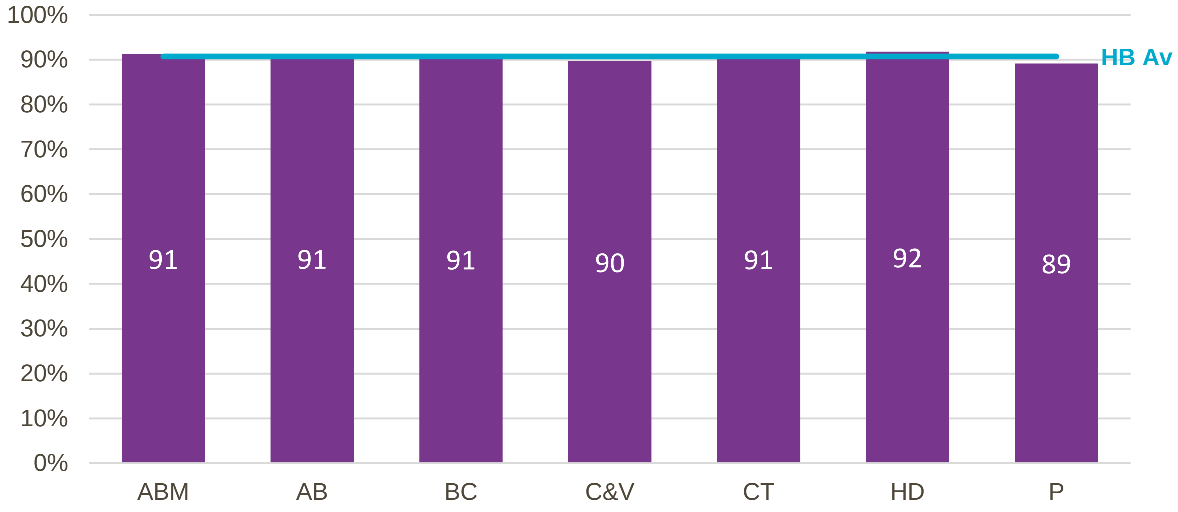


■ Health board positive score

— Health board average

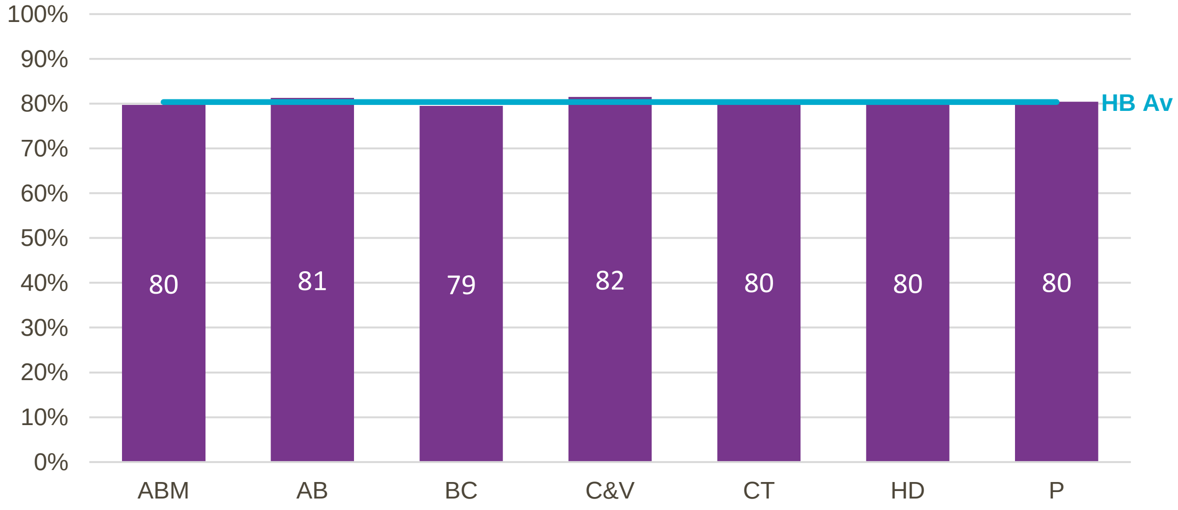
Q24+: Clinical Nurse Specialist: understood answers to questions all or most of the time

Respondents who had the name and contact details of a Clinical Nurse Specialist



Q25: Clinical Nurse Specialist: completely provided information to make informed decisions about treatment and care

Respondents who had the name and contact details of a Clinical Nurse Specialist



🟪 Health board positive score

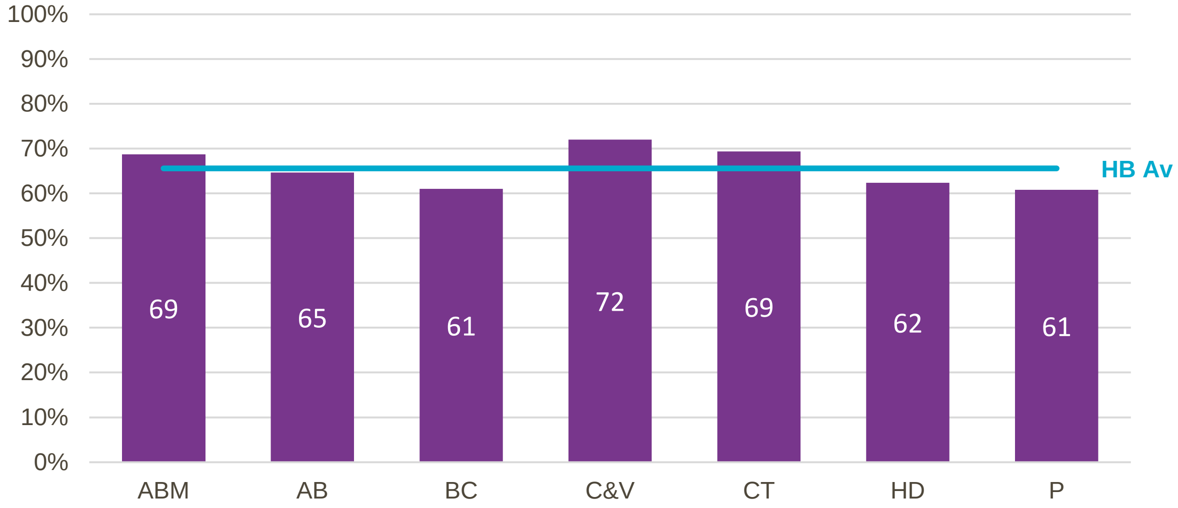
▬ Health board average

Health board analysis: Support for people with cancer

These questions are about support for a patient when their cancer treatment first started.

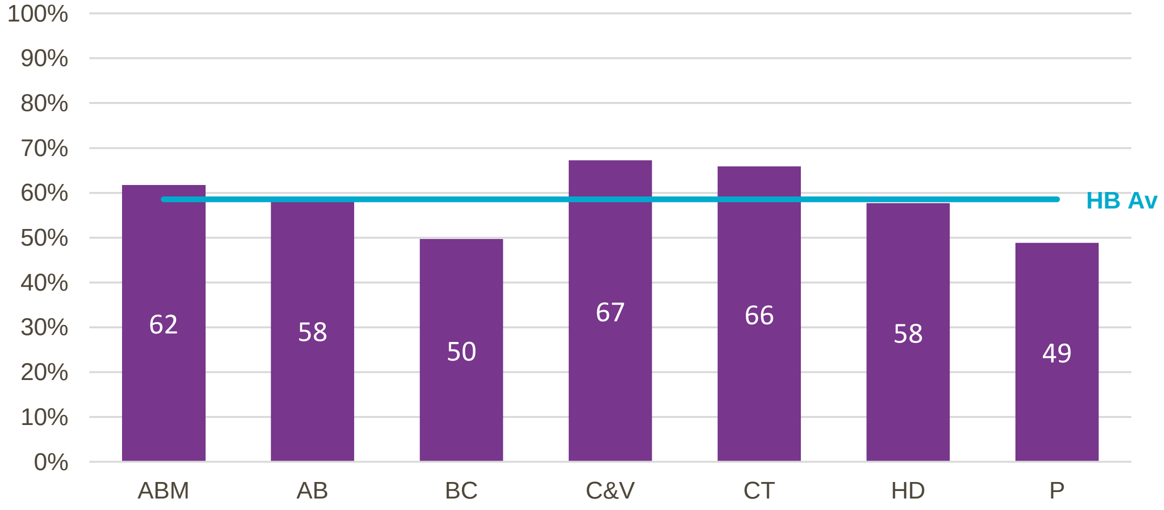
Q26: Support: received the right amount of information about support/self-help groups

All respondents



Q27: Support: told about voluntary and charity support

All respondents

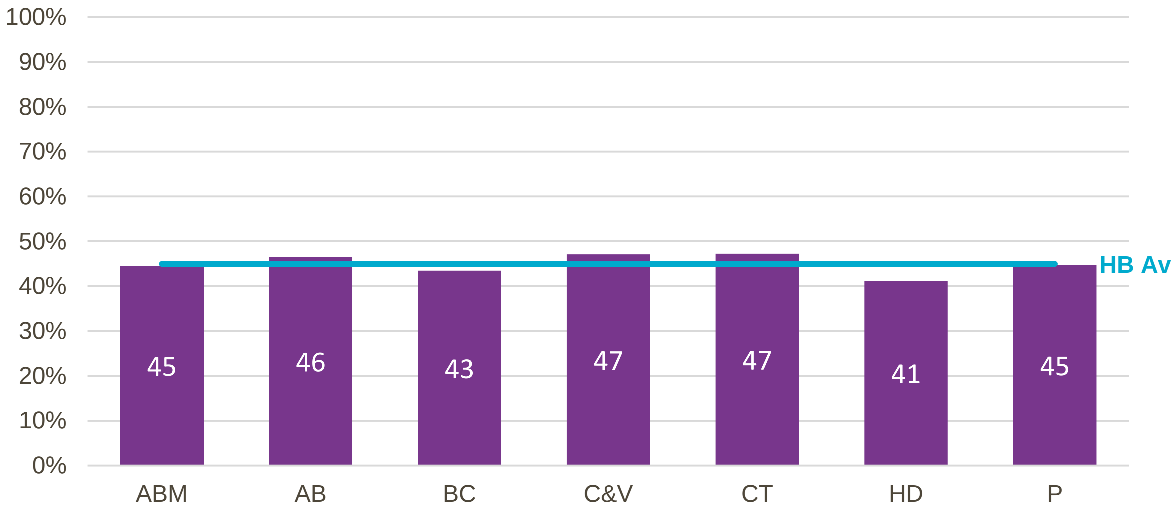


▮ Health board positive score

— Health board average

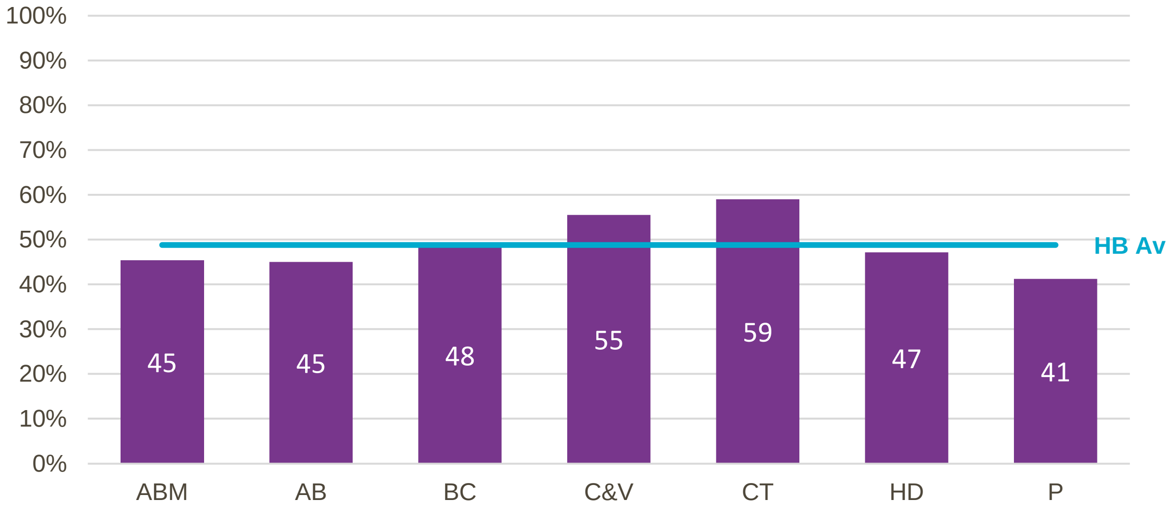
Q28: Support: completely discussed the impact of cancer on day to day activities

All respondents



Q29+: Support: received information about financial help/benefits

All respondents



■ Health board positive score

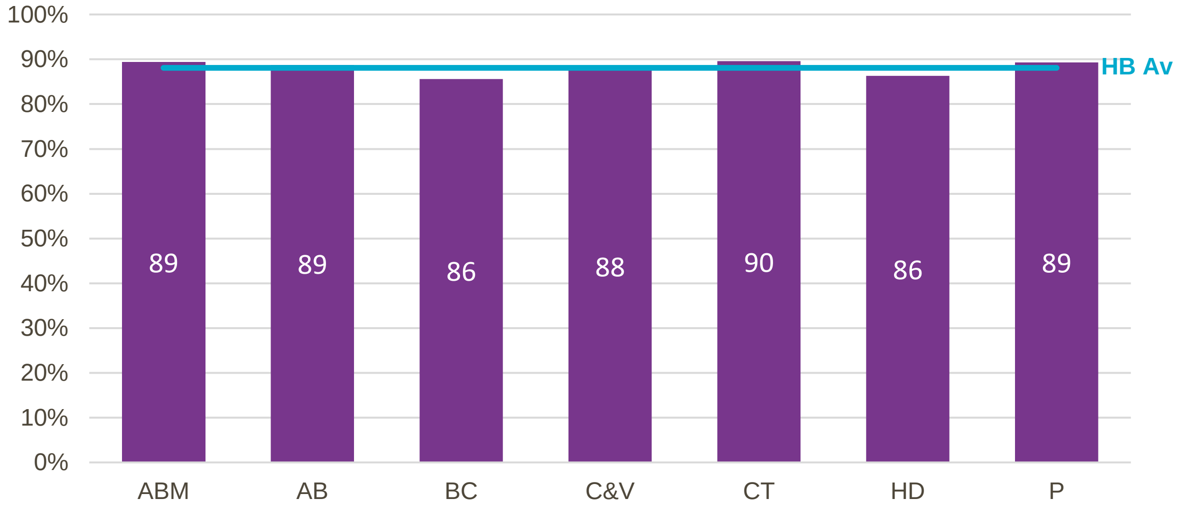
— Health board average

Health board analysis: Operations

These questions are about any operation a patient may have had related to cancer.

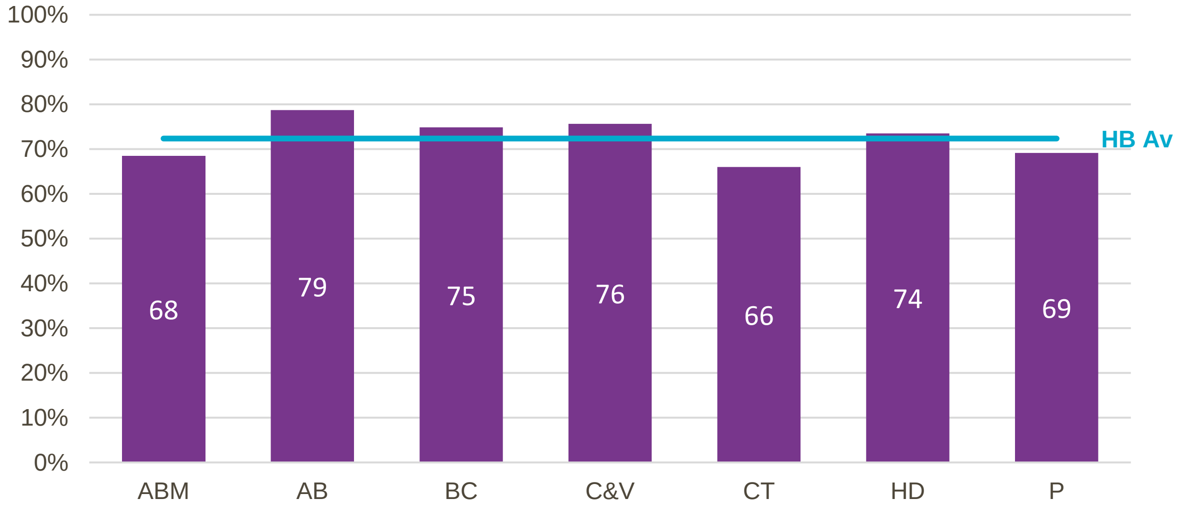
Q32+: Operation: staff completely explained what would be done

Respondents who had an operation for their cancer



Q33+: Operation: received written information that was easy to understand

Respondents who had an operation for their cancer

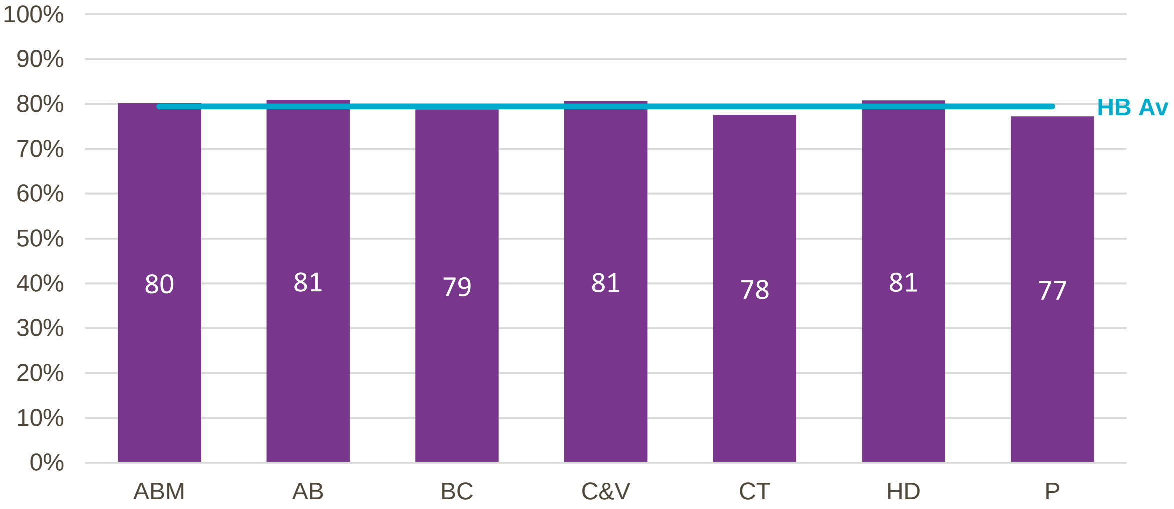


■ Health board positive score

▬ Health board average

Q34+: Operation: staff completely explained how it had gone

Respondents who had an operation for their cancer

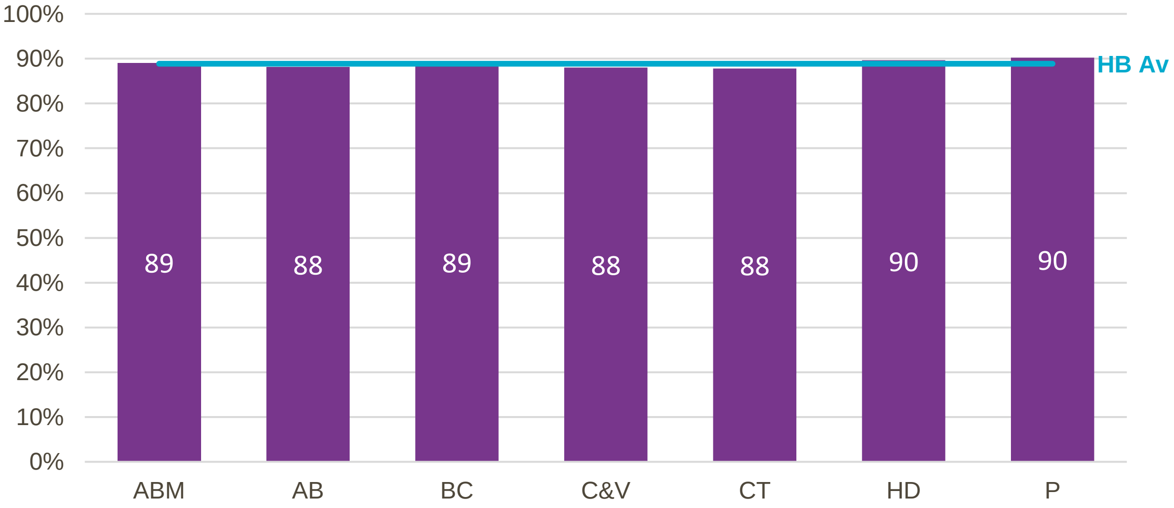


Health board analysis: Hospital care as an inpatient

These questions are about any inpatient stay in hospital related to cancer treatment.

Q37: Inpatient: always treated with dignity and respect

Respondents who had an operation or stayed overnight for their cancer care

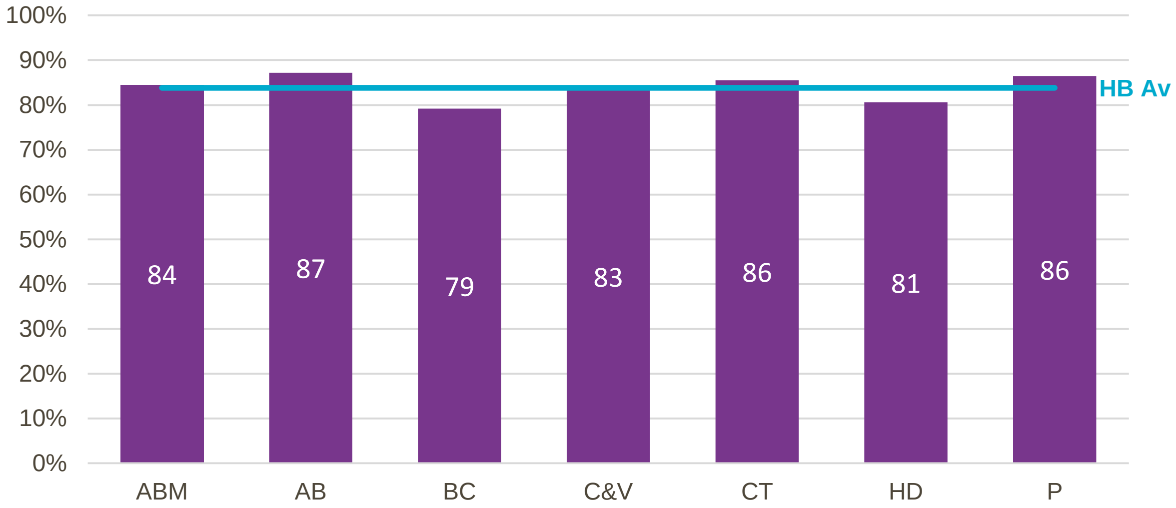


■ Health board positive score

— Health board average

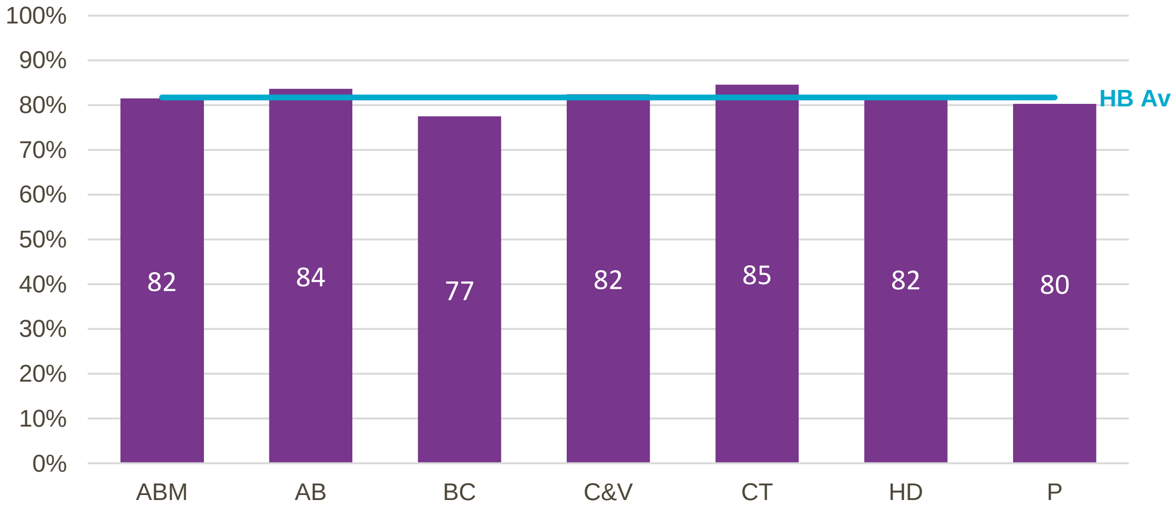
Q38: Inpatient: doctors and nurses did not talk in front of patients as if they were not there

Respondents who had an operation or stayed overnight for their cancer care



Q39: Inpatient: staff never contradicted each other

Respondents who had an operation or stayed overnight for their cancer care

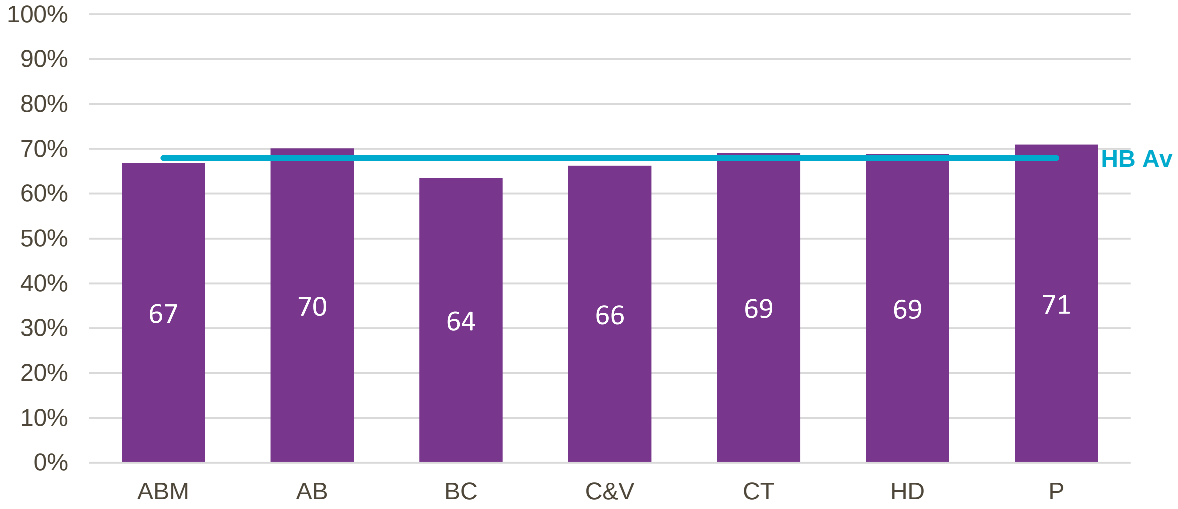


■ Health board positive score

— Health board average

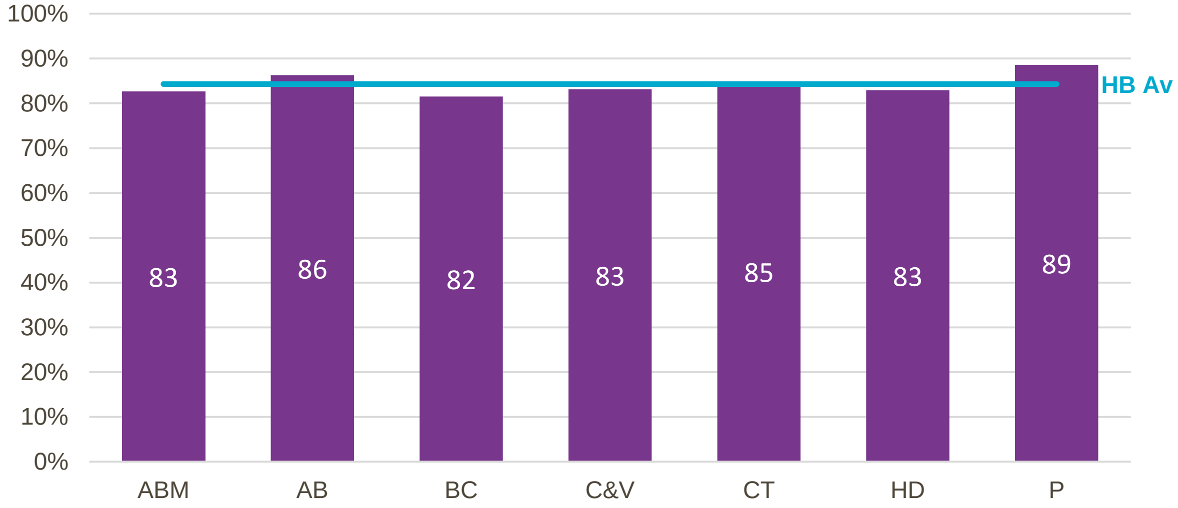
Q40+: Inpatient: able to discuss worries/fears as much as wanted with staff

Respondents who had an operation or stayed overnight for their cancer care



Q41+: Inpatient: understood answers to questions all or most of the time

Respondents who had an operation or stayed overnight for their cancer care

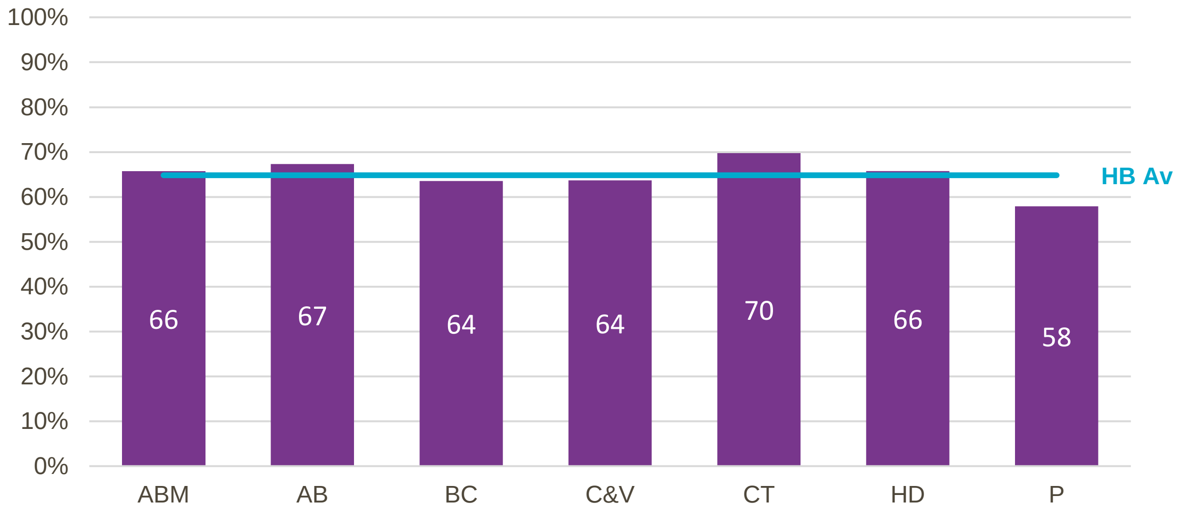


🟪 Health board positive score

— Health board average

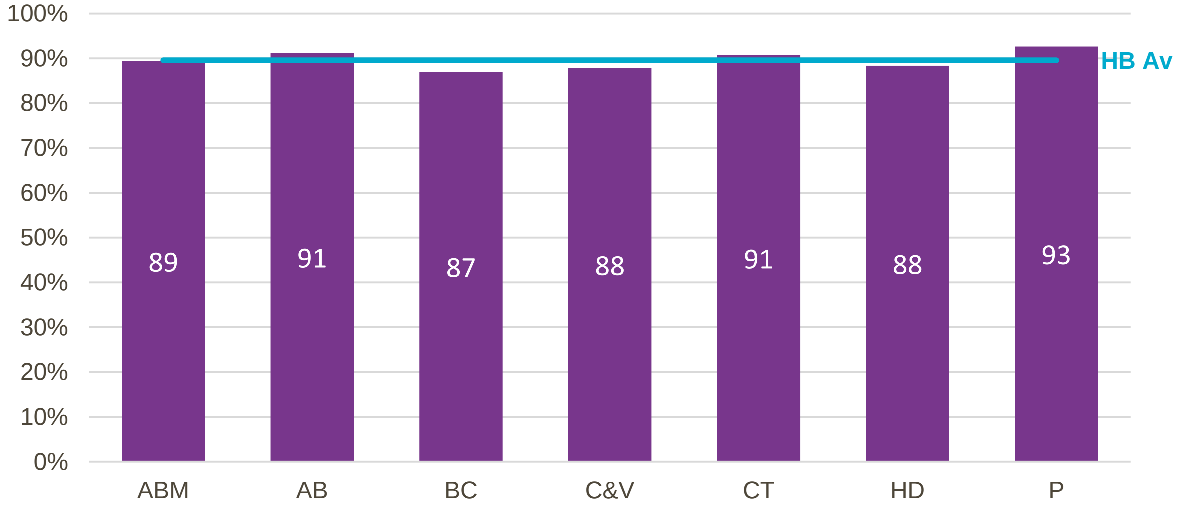
Q42+: Inpatient: family definitely had enough opportunity to talk to a health professional

Respondents who had an operation or stayed overnight for their cancer care



Q43: Inpatient: confidence and trust in all of the doctors

Respondents who had an operation or stayed overnight for their cancer care

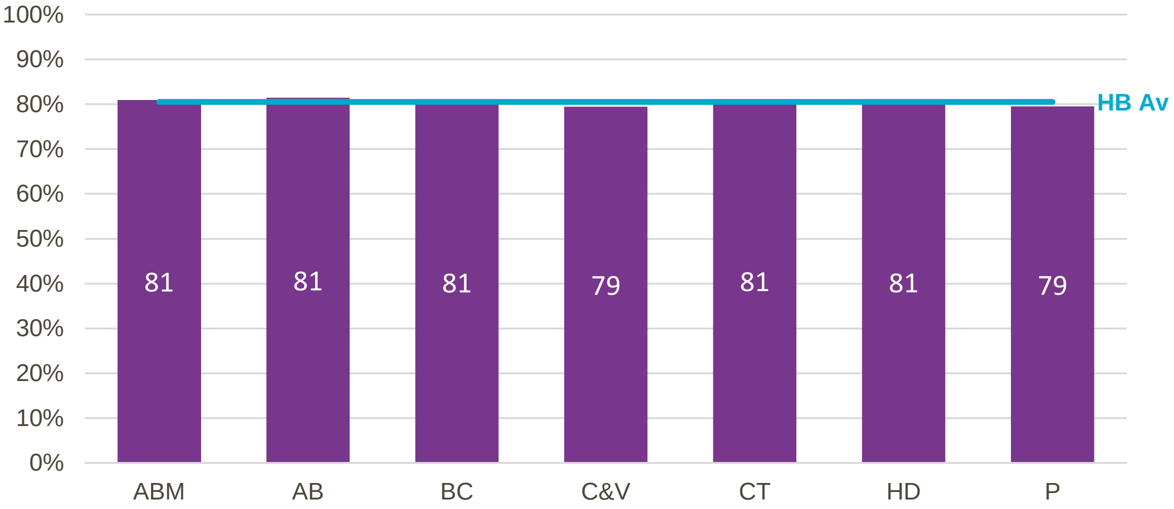


🟪 Health board positive score

— Health board average

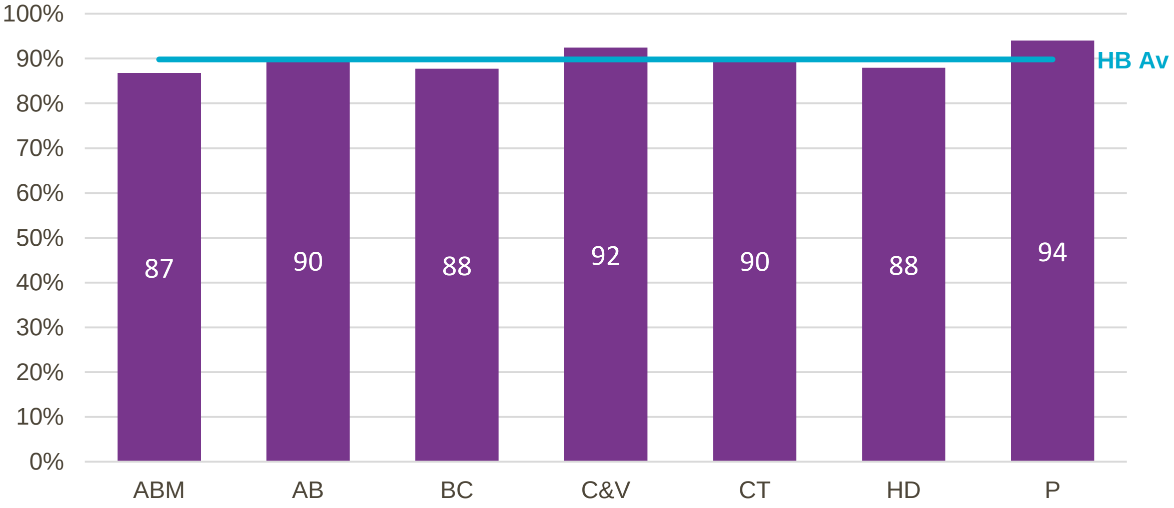
Q44: Inpatient: confidence and trust in all of the nurses

Respondents who had an operation or stayed overnight for their cancer care



Q45+: Inpatient: received help quickly when call button was used

Respondents who had an operation or stayed overnight for their cancer care

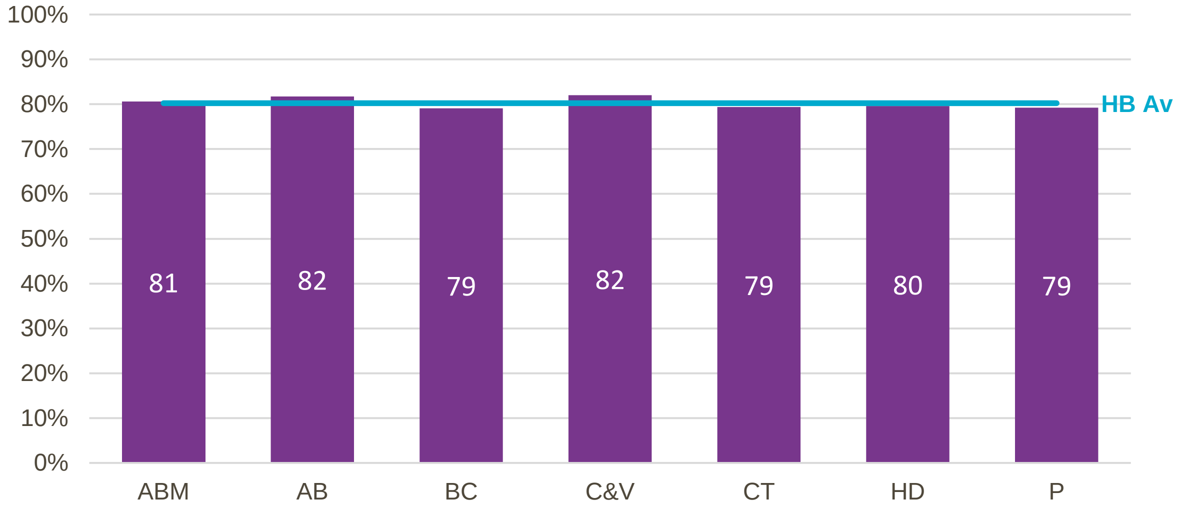


🟪 Health board positive score

▬ Health board average

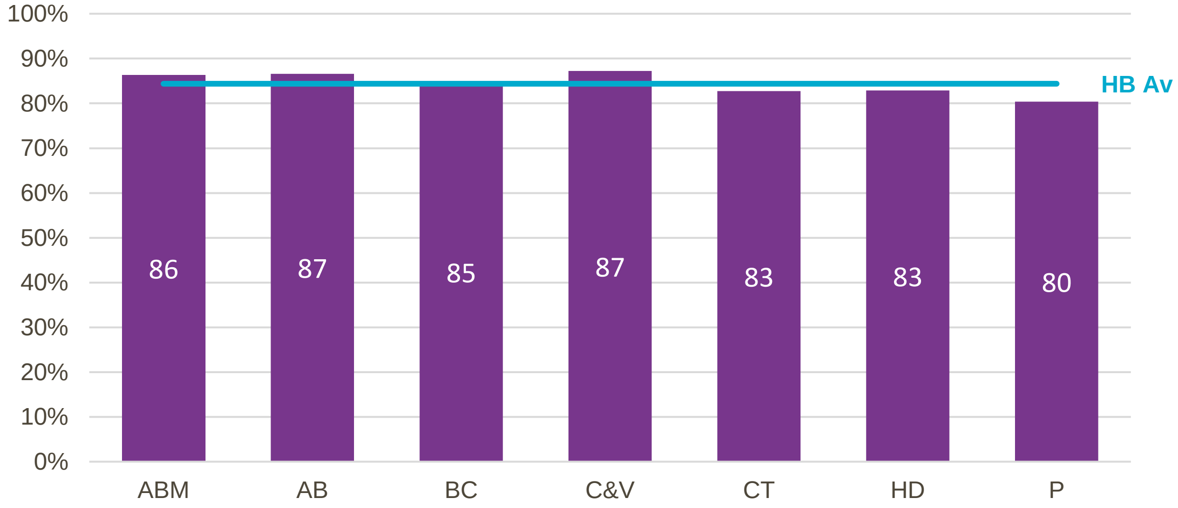
Q46: Inpatient: doctors and nurses always communicated effectively

Respondents who had an operation or stayed overnight for their cancer care



Q47: Inpatient: always enough privacy when discussing condition

Respondents who had an operation or stayed overnight for their cancer care

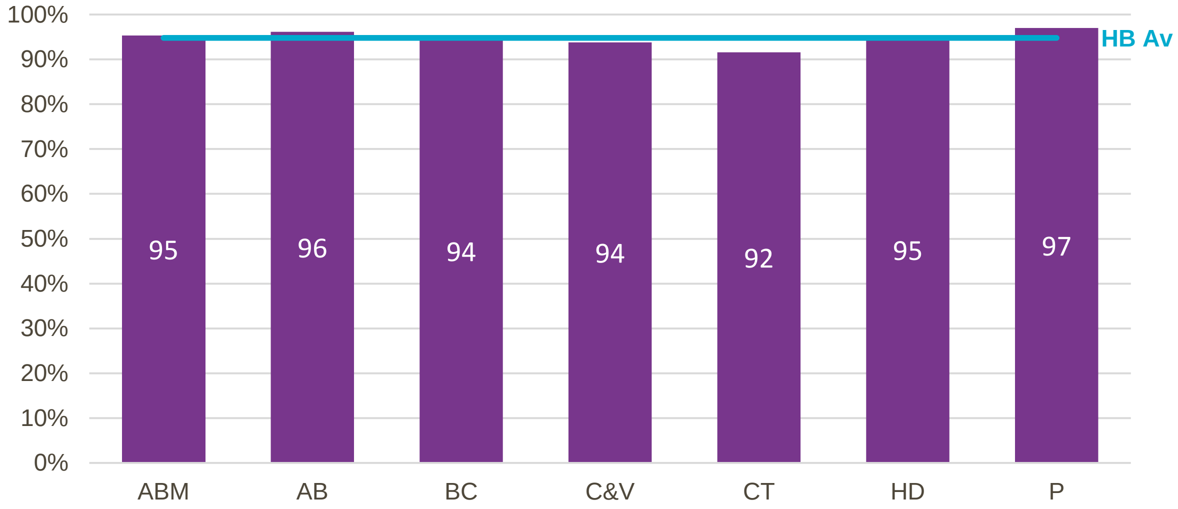


🟪 Health board positive score

— Health board average

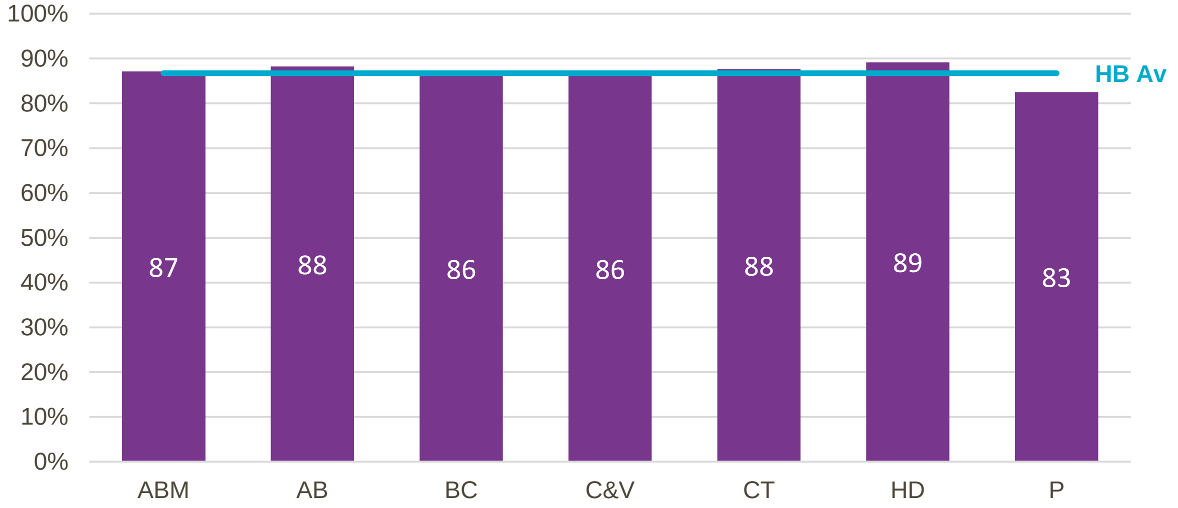
Q48: Inpatient: always enough privacy when examined or treated

Respondents who had an operation or stayed overnight for their cancer care



Q49+: Inpatient: hospital staff did everything they could to control patient’s pain

Respondents who had an operation or stayed overnight for their cancer care

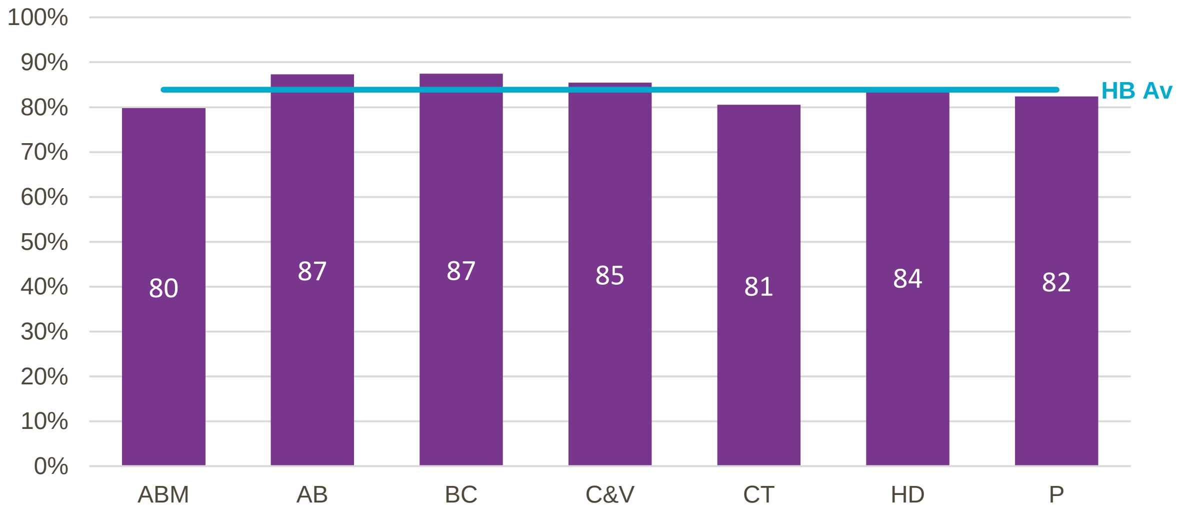


■ Health board positive score

— Health board average

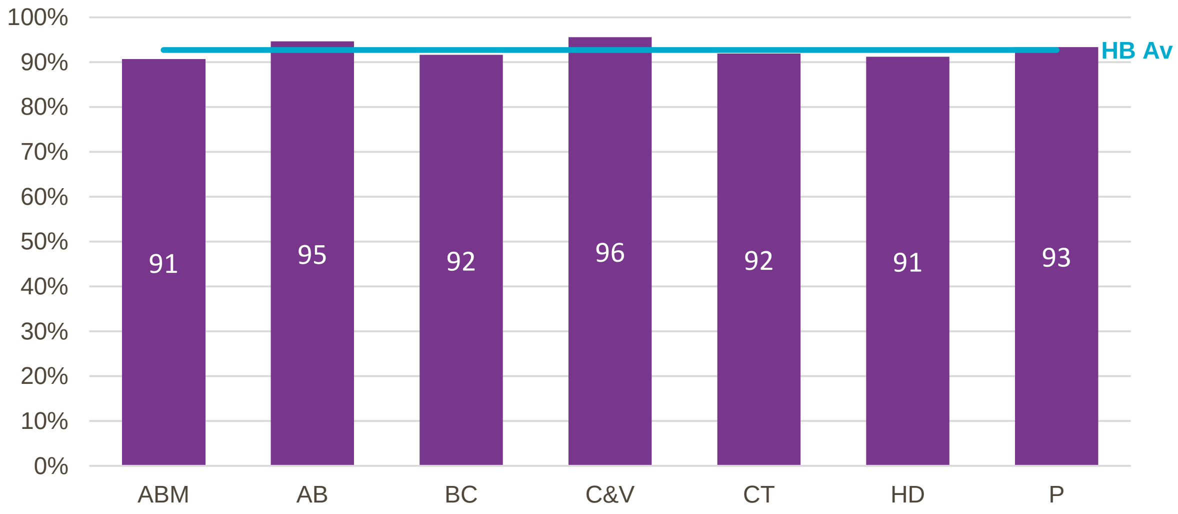
Q50+: Inpatient: clear written information what should or should not do after leaving hospital

Respondents who had an operation or stayed overnight for their cancer care



Q51: Inpatient: told who to contact if worried after leaving hospital

Respondents who had an operation or stayed overnight for their cancer care



■ Health board positive score

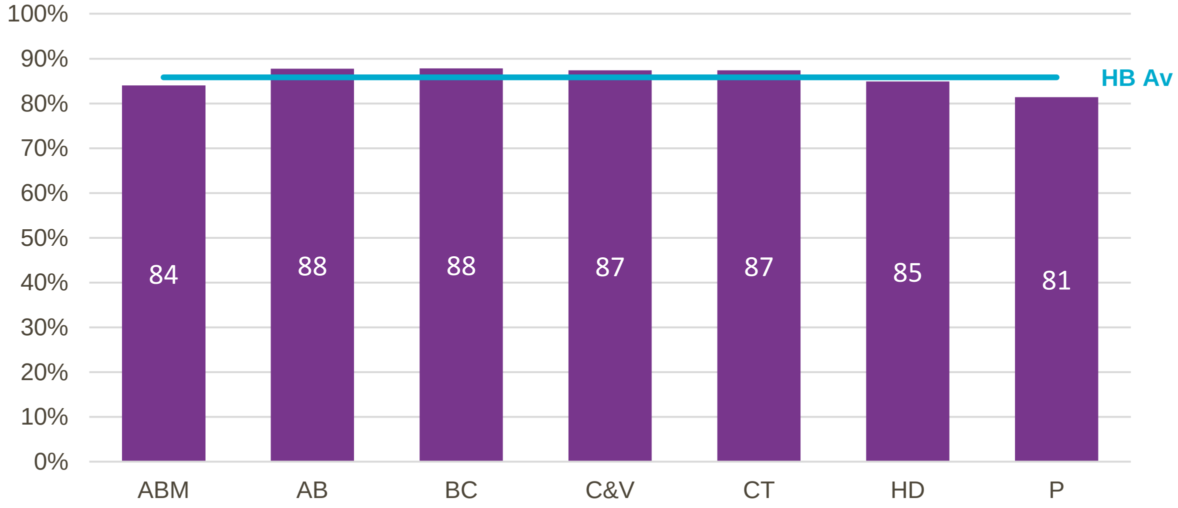
— Health board average

Health board analysis: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

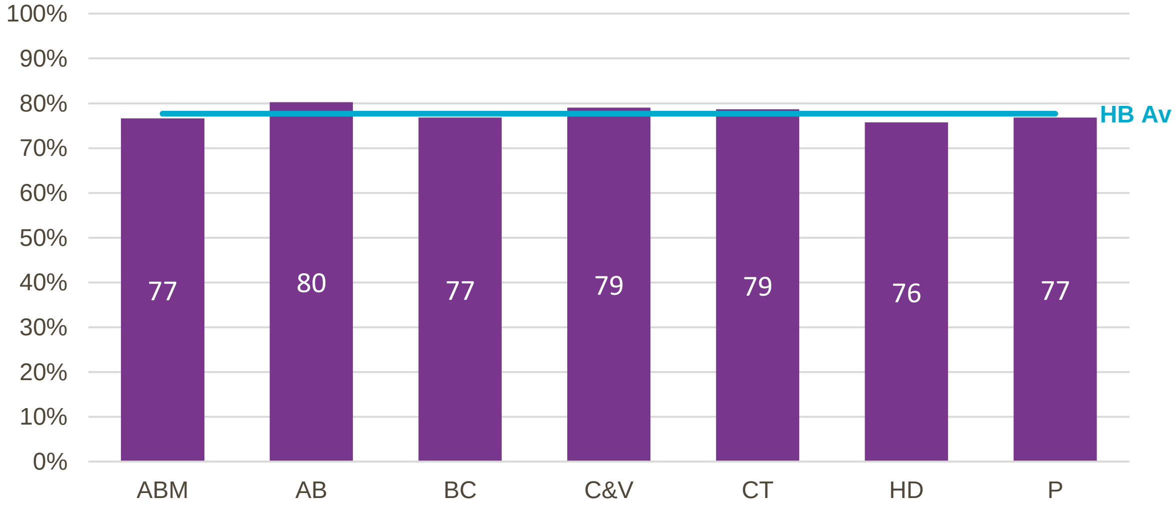
Q54+: Outpatient/Day Case: staff definitely did everything to control pain

Respondents who had an outpatient or day case appointment



Q55+: Outpatient/Day Case: definitely received enough emotional support

Respondents who had an outpatient or day case appointment



■ Health board positive score

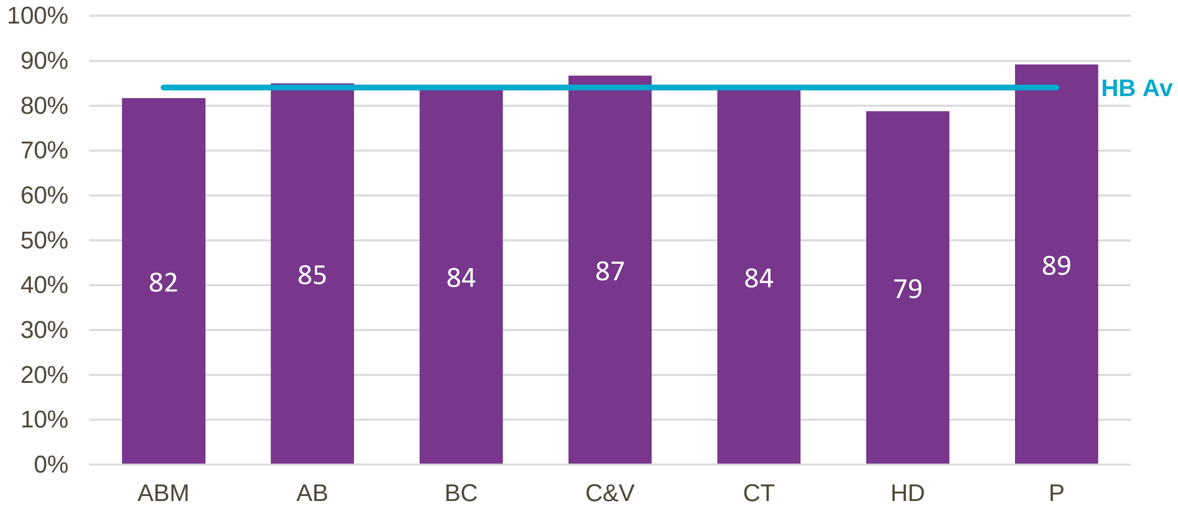
▬ Health board average

Health board analysis: Radiotherapy/chemotherapy

These questions relate to any radiotherapy or chemotherapy patients may have had.

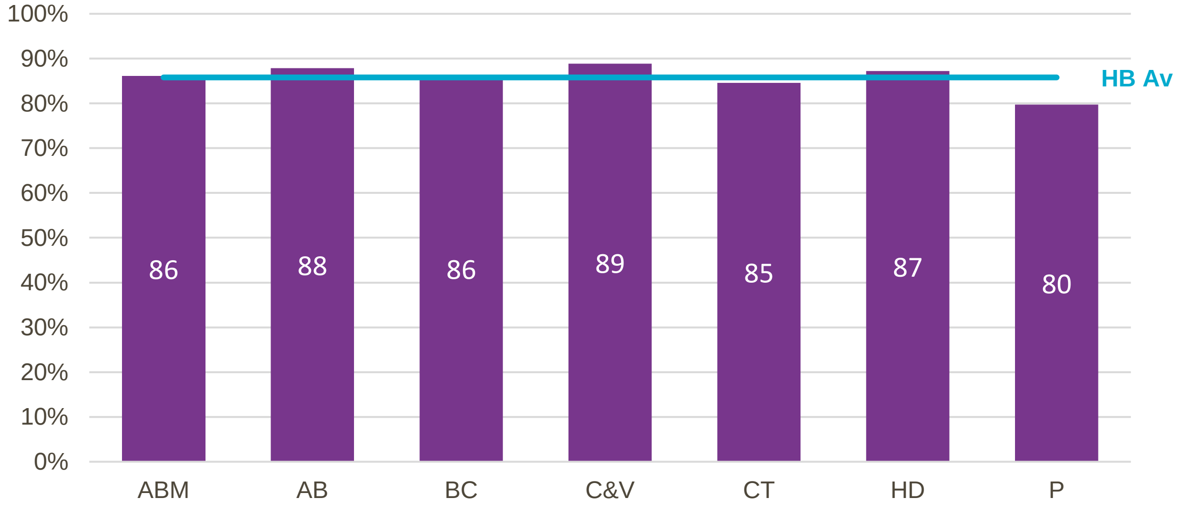
Q58+: Radiotherapy: staff definitely did everything to control side effects from radiotherapy

Respondents who had radiotherapy



Q61+: Chemotherapy: staff definitely did everything to control side effects from chemotherapy

Respondents who had chemotherapy



■ Health board positive score

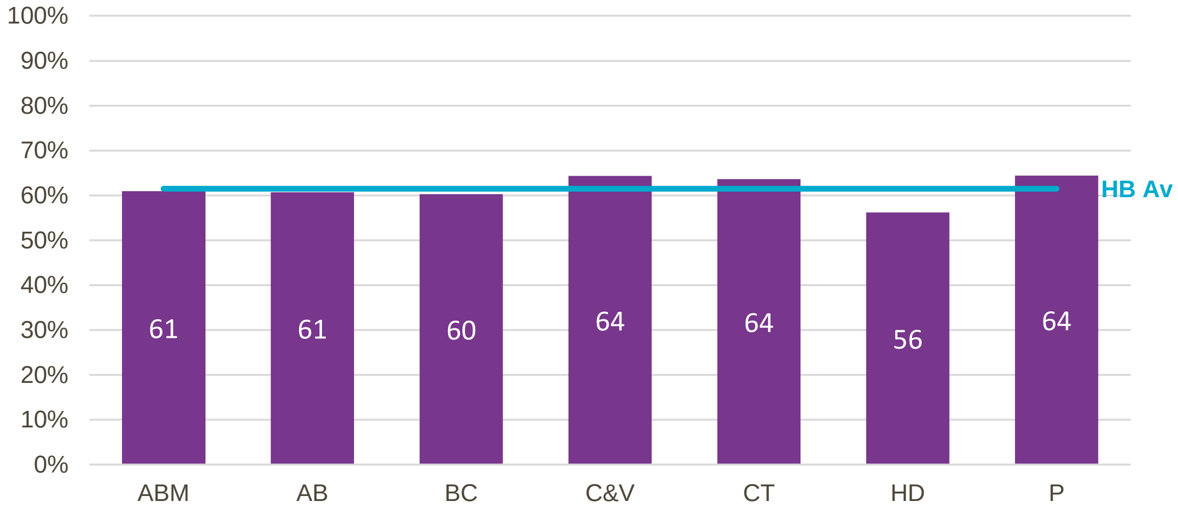
▬ Health board average

Health board analysis: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for their cancer.

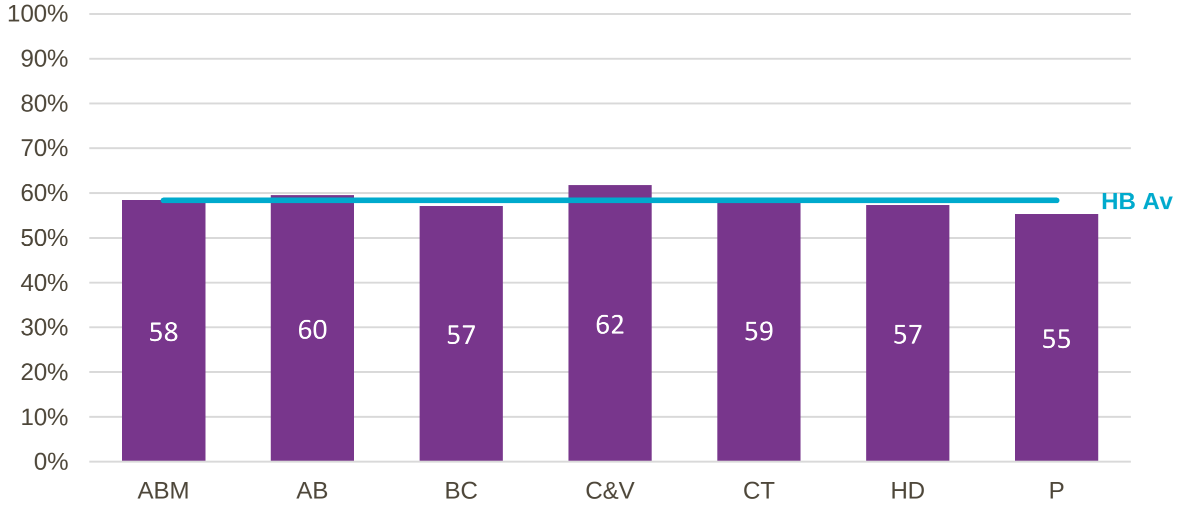
Q62+: Home Support: family definitely given enough information to care at home

All respondents



Q63: Home Support: definitely offered practical advice for side effects

All respondents

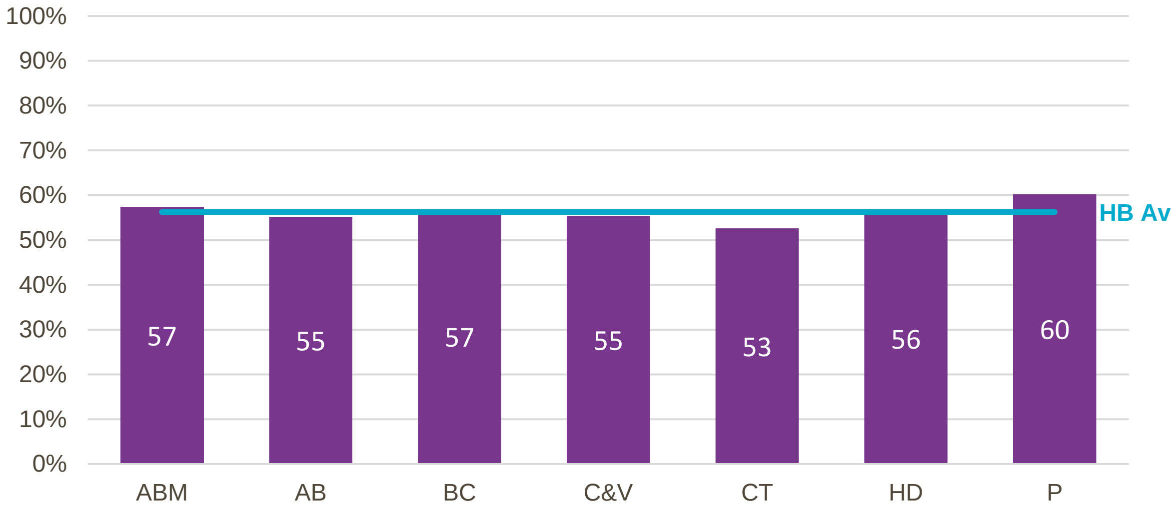


🟪 Health board positive score

▬ Health board average

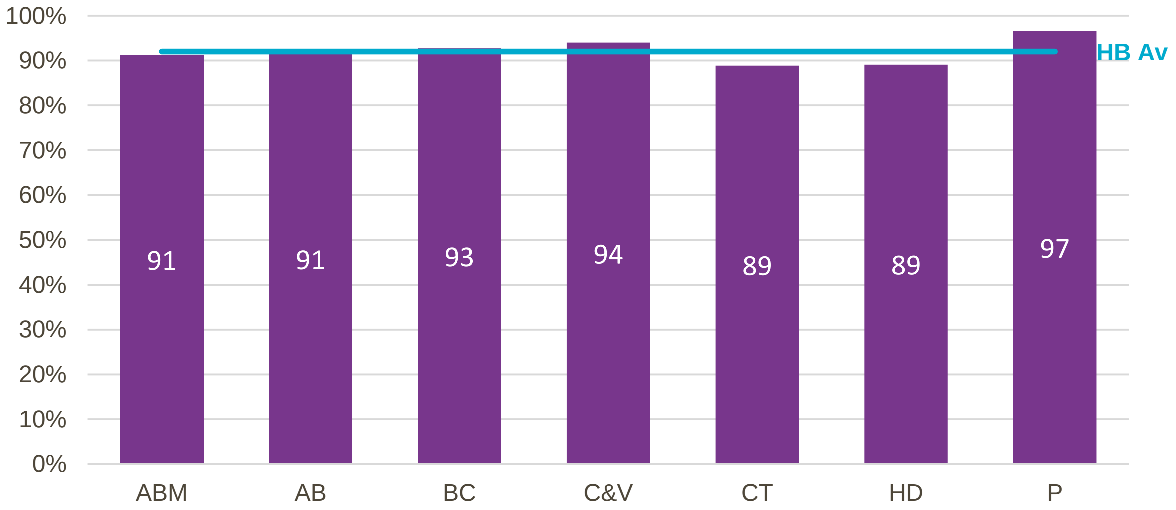
Q64+: Home Support: definitely given enough care and help from GP

All respondents



Q65: Home Support: GP had all the information

All respondents

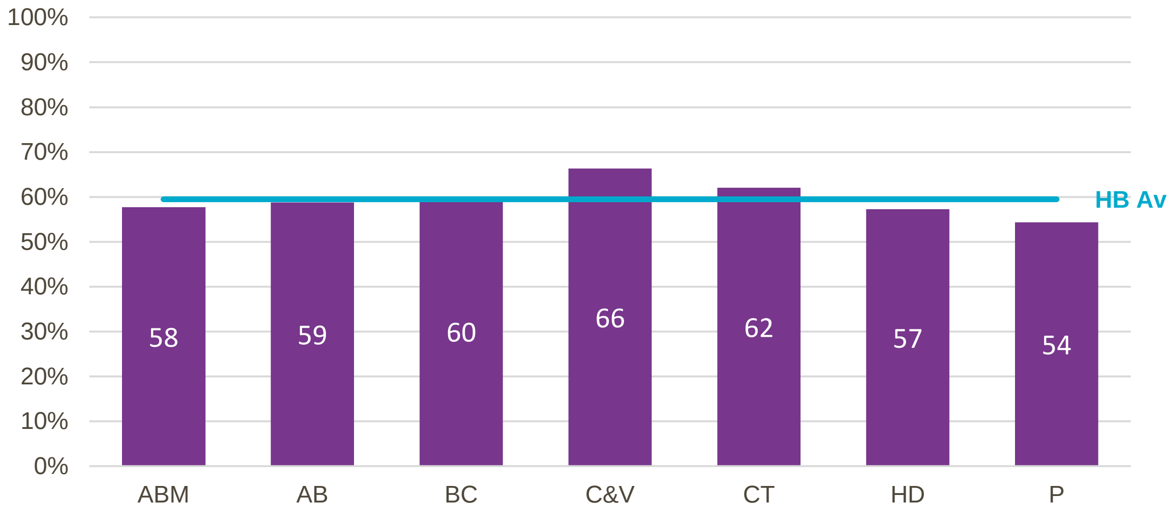


■ Health board positive score

— Health board average

Q66+: Home Support: definitely given enough care and help from health or social services

All respondents

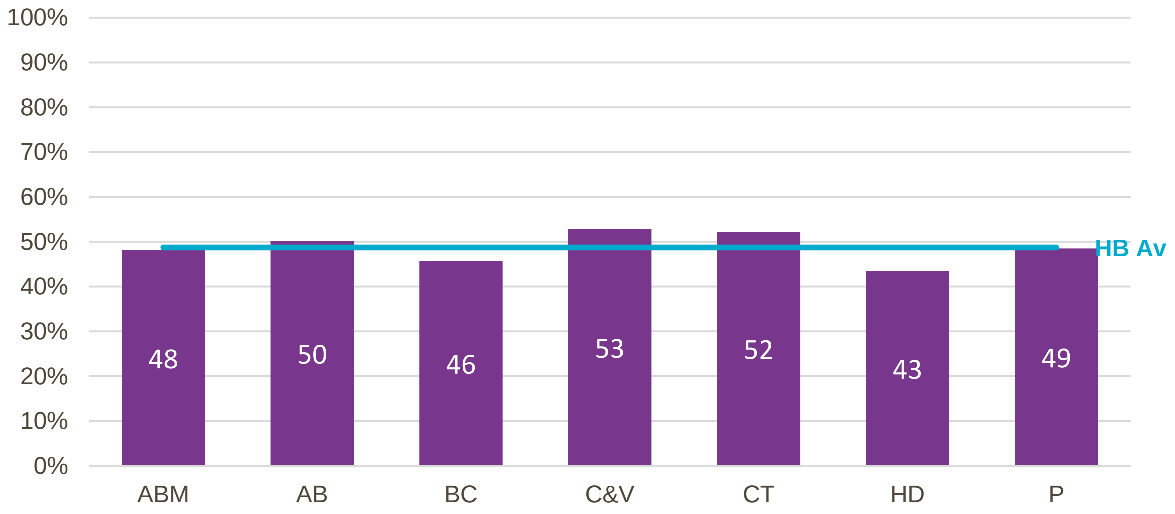


Health board analysis: Your overall NHS care

These questions relate to patients' overall experience of the care they received from the NHS.

Q67: Overall: offered the opportunity to discuss needs and concerns to develop care plan

All respondents

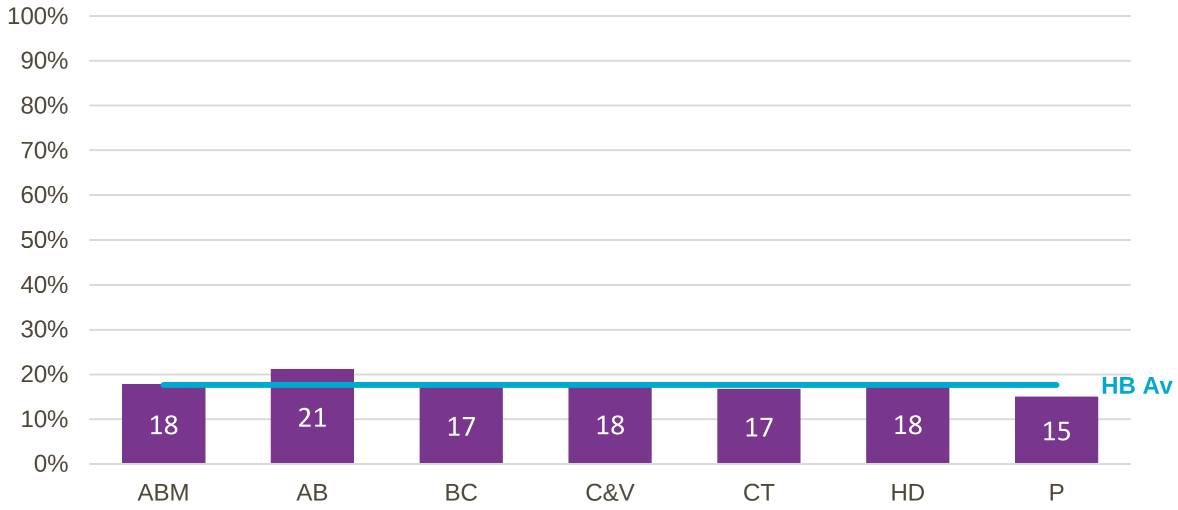


🟪 Health board positive score

— Health board average

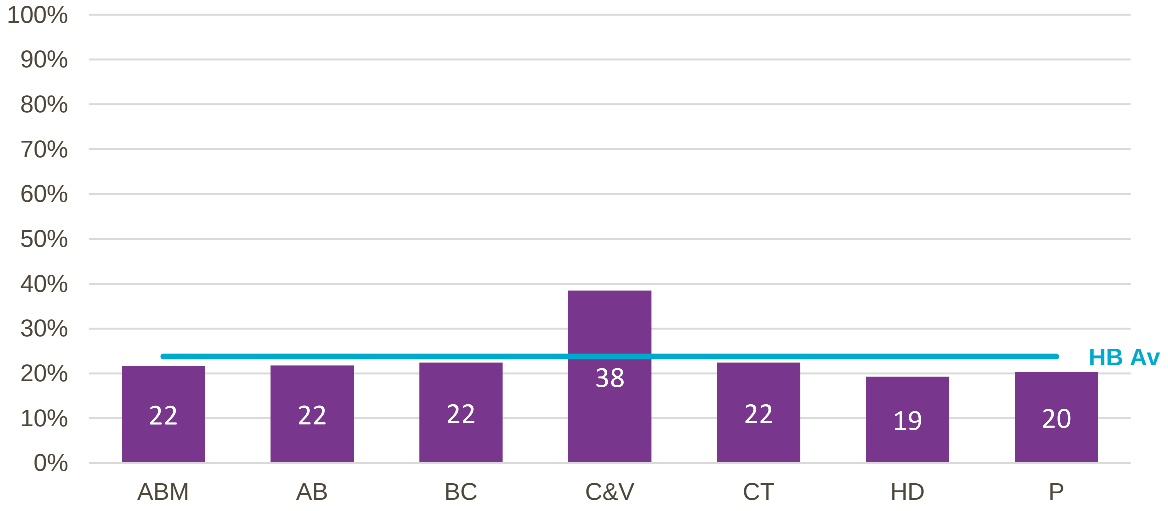
Q68: Overall: offered a written care plan

All respondents



Q69: Overall: discussed taking part in cancer research

All respondents

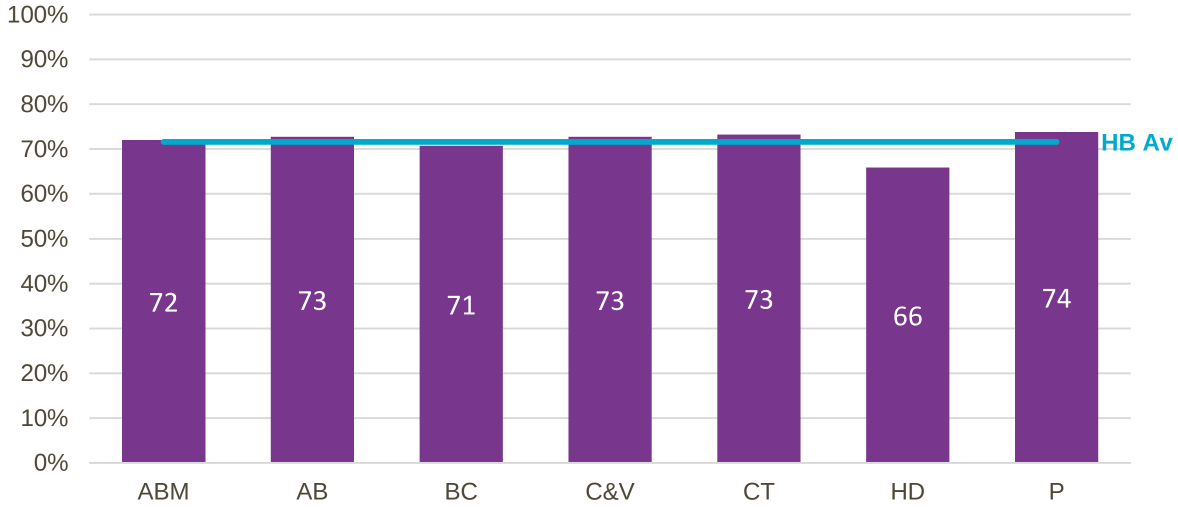


🟪 Health board positive score

— Health board average

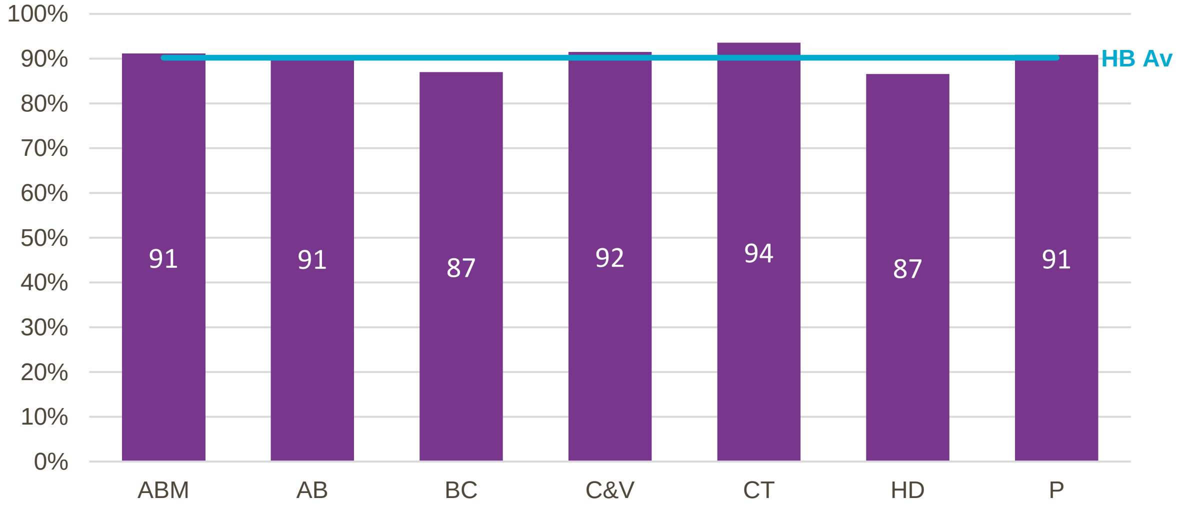
Q70: Overall: health professionals always worked well together

All respondents



Q71: Overall: administration of care rated as good or very good

All respondents

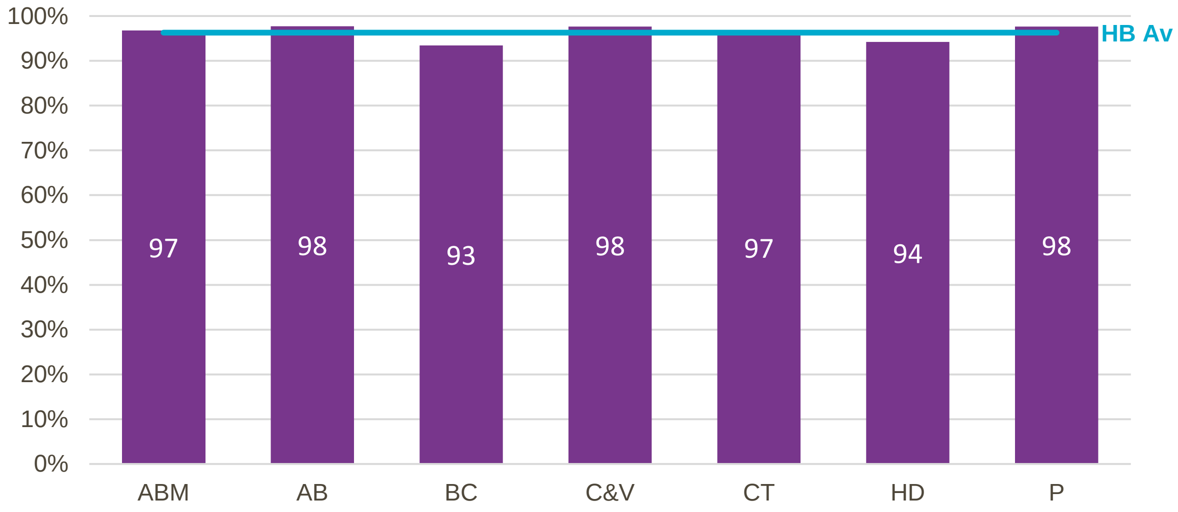


🟪 Health board positive score

— Health board average

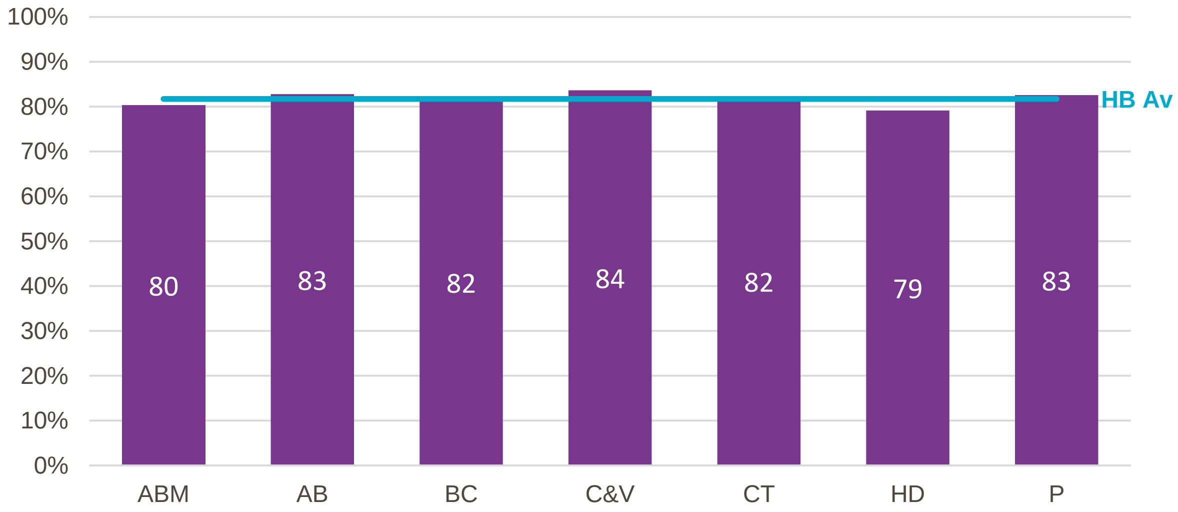
Q72: Overall: information was completely in preferred language

All respondents



Q73: Overall: did not feel treated as "a set of cancer symptoms"

All respondents

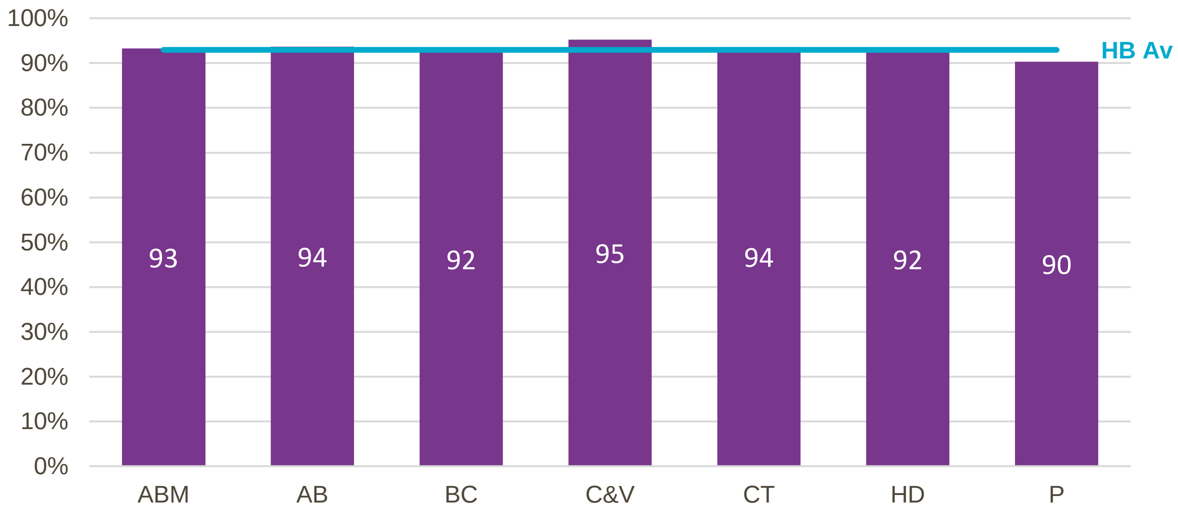


🟪 Health board positive score

▬ Health board average

Q74: Overall: rated experience as 7/10 or more

All respondents



Appendix two: Velindre NHS Trust

As a specialist cancer centre treatment centre, Velindre NHS Trust has no residents. The trust treated many patients that will be assigned to the health boards in the previous section. For these reasons, it is not appropriate to compare Velindre NHS Trust to the health boards in Wales.

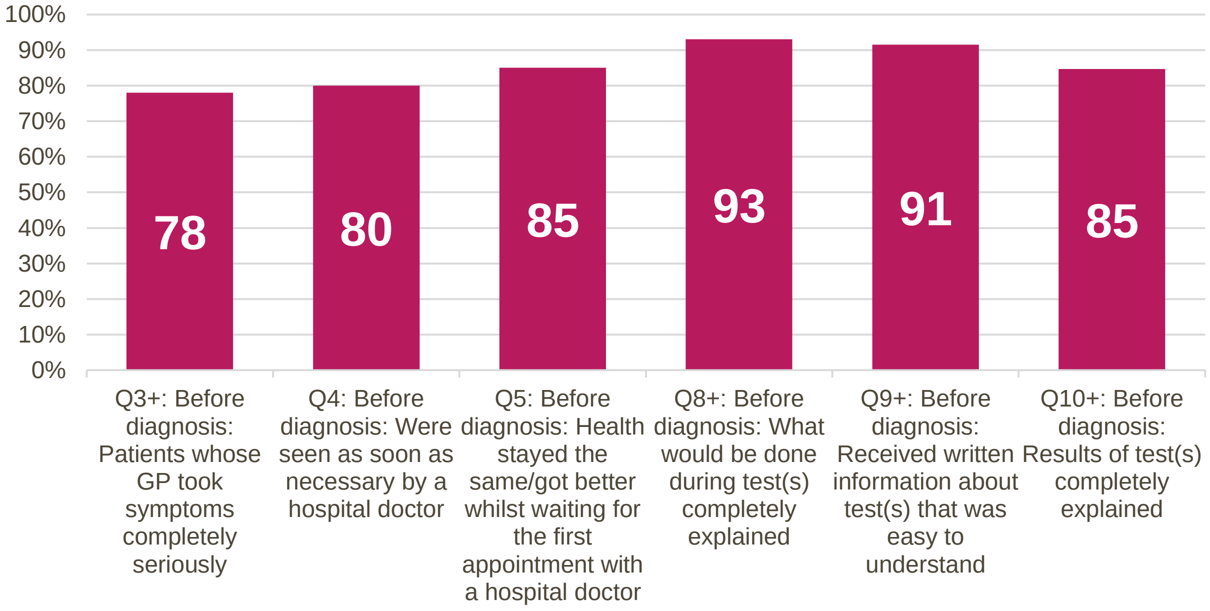
Therefore, unlike the health board comparison data, Velindre NHS Trust's data has not been standardised.

The graphs in this section show the positive score from patients discharged from Velindre NHS Trust for each question in the survey.

Velindre NHS Trust positive score chart: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

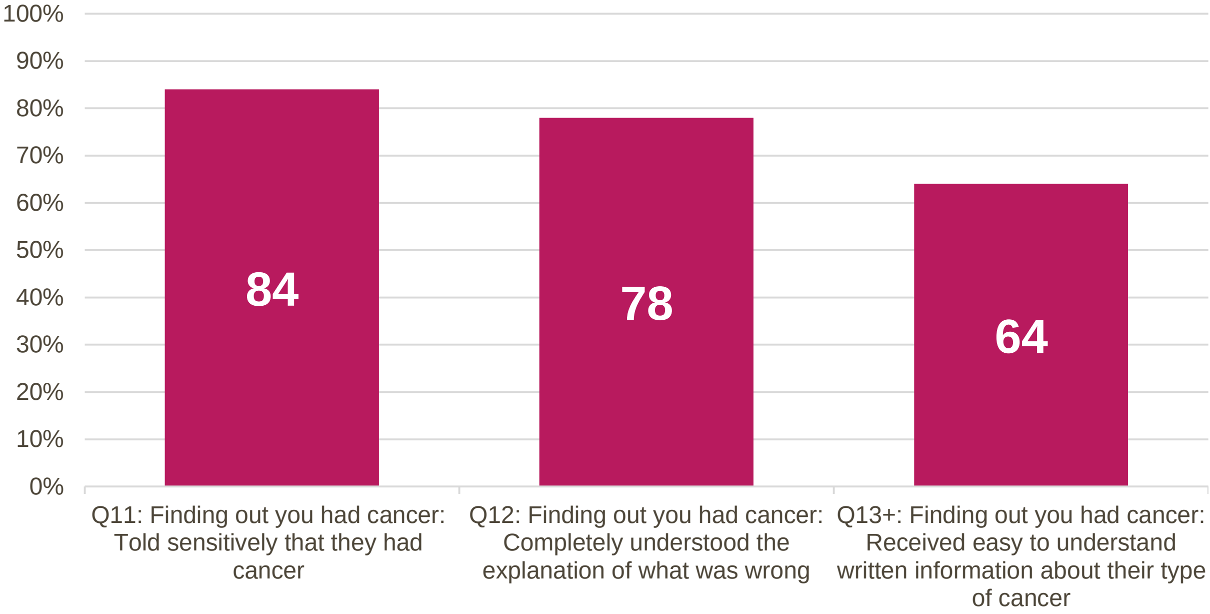
Q3+ – Q5: All respondents
Q8+ – Q10+: Respondents who had a diagnostic test



Velindre NHS Trust positive score chart: Finding out you had cancer

These questions are about what happened when patients found out they had cancer.

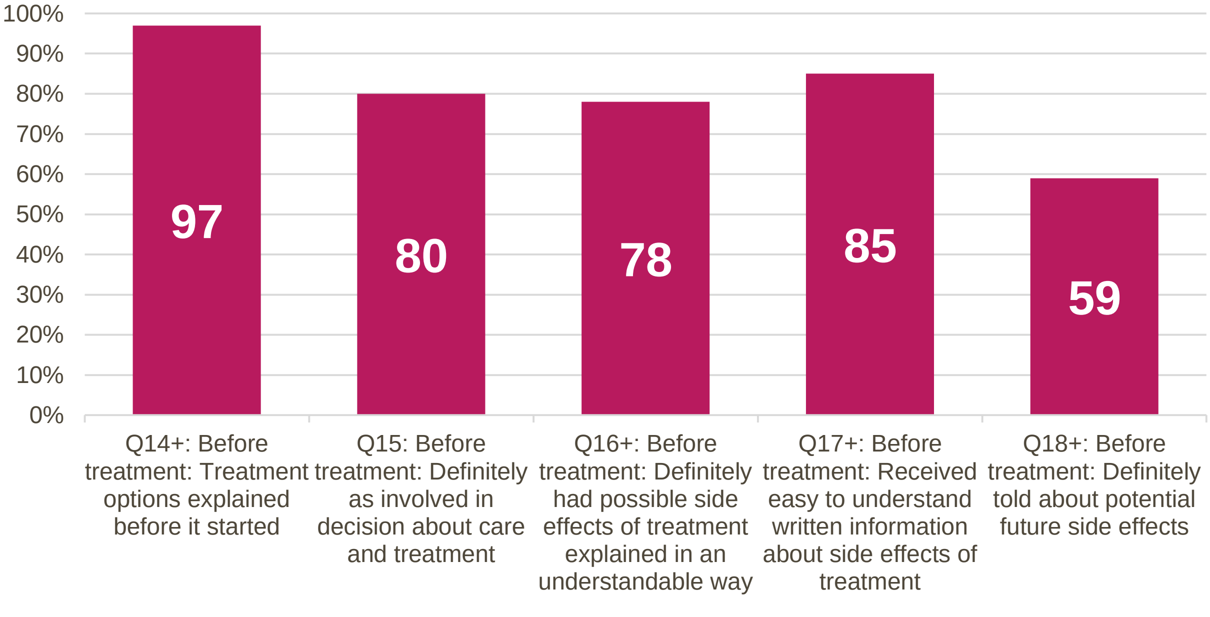
All respondents



Velindre NHS Trust positive score chart: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

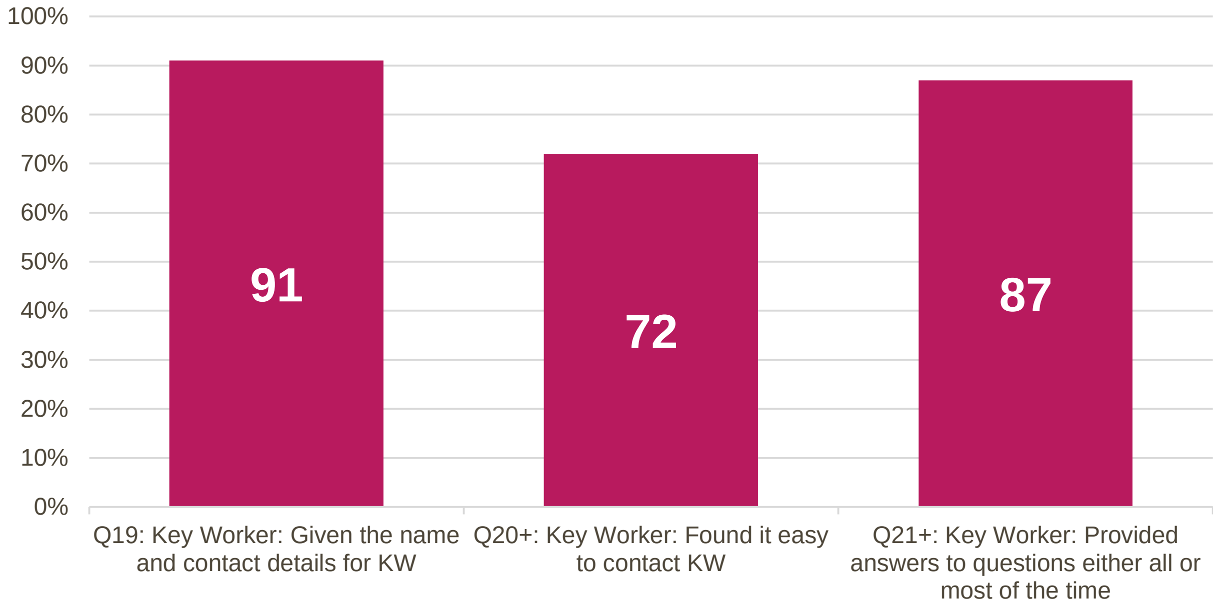
All respondents



Velindre NHS Trust positive score chart: Key Worker

These questions are about Key Workers.

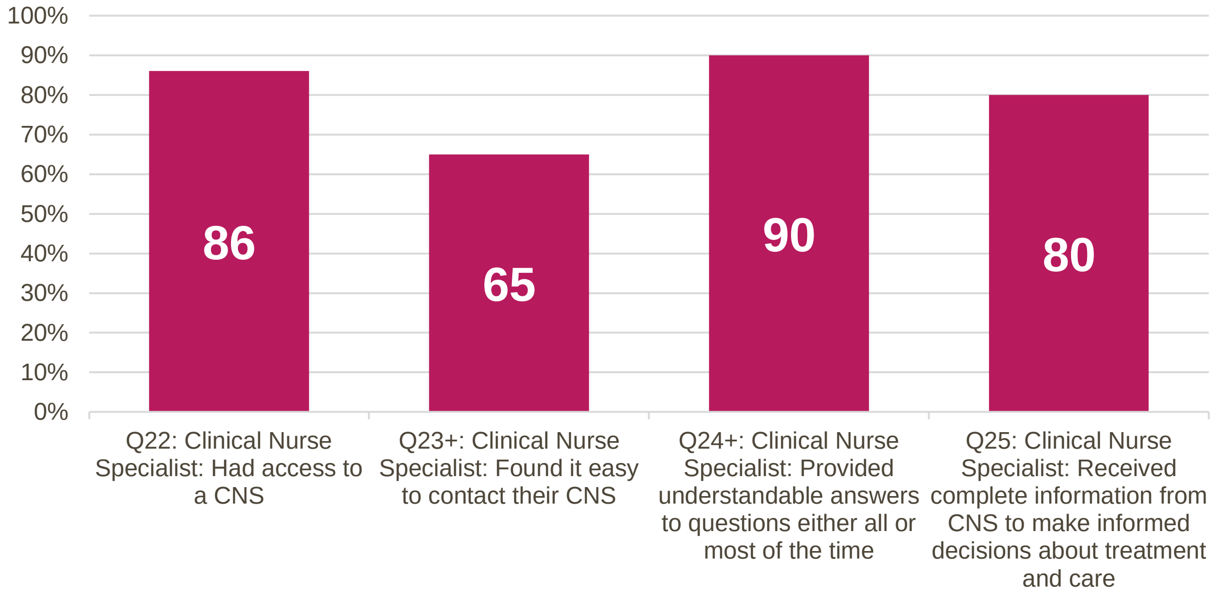
Q19: All respondents
Q20+ – Q21+: Respondents who had the name and contact details of a Key Worker



Velindre NHS Trust positive score chart: Clinical Nurse Specialist

These questions are about Clinical Nurse Specialists.

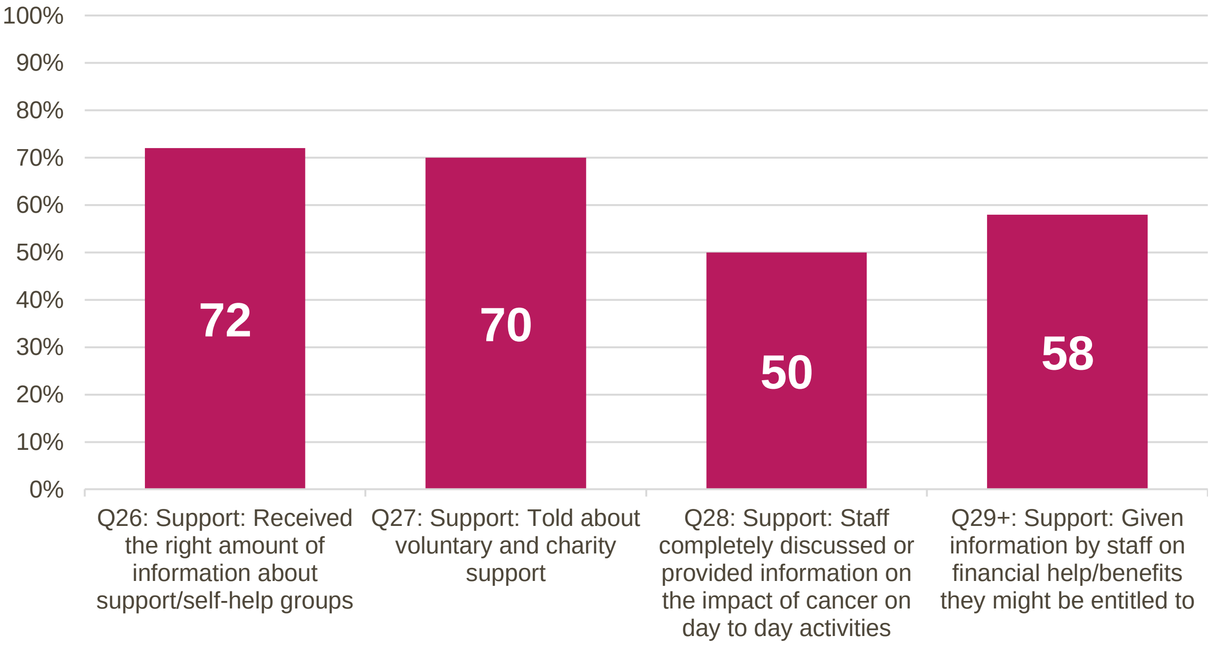
Q22: All respondents
Q23+ – Q25: Respondents who had the name and contact details of a Clinical Nurse Specialist



Velindre NHS Trust positive score chart: Support for people with cancer

These questions are about support for a patient when their cancer treatment first started.

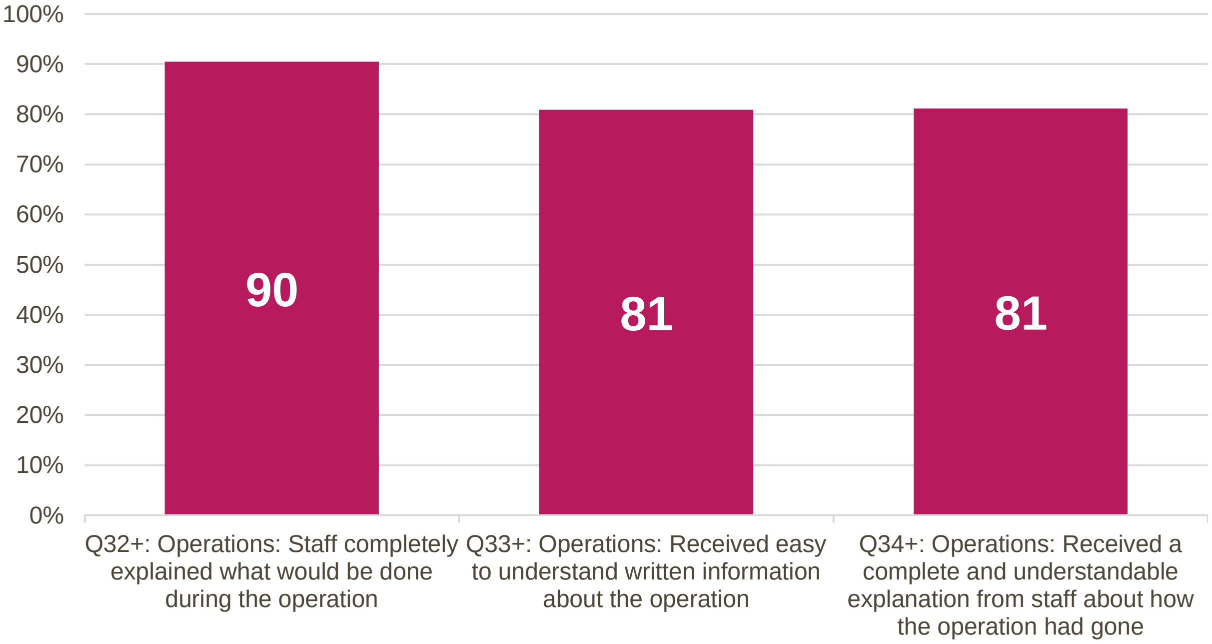
All respondents



Velindre NHS Trust positive score chart: Operations

These questions are about any operation a patient may have had related to their cancer.

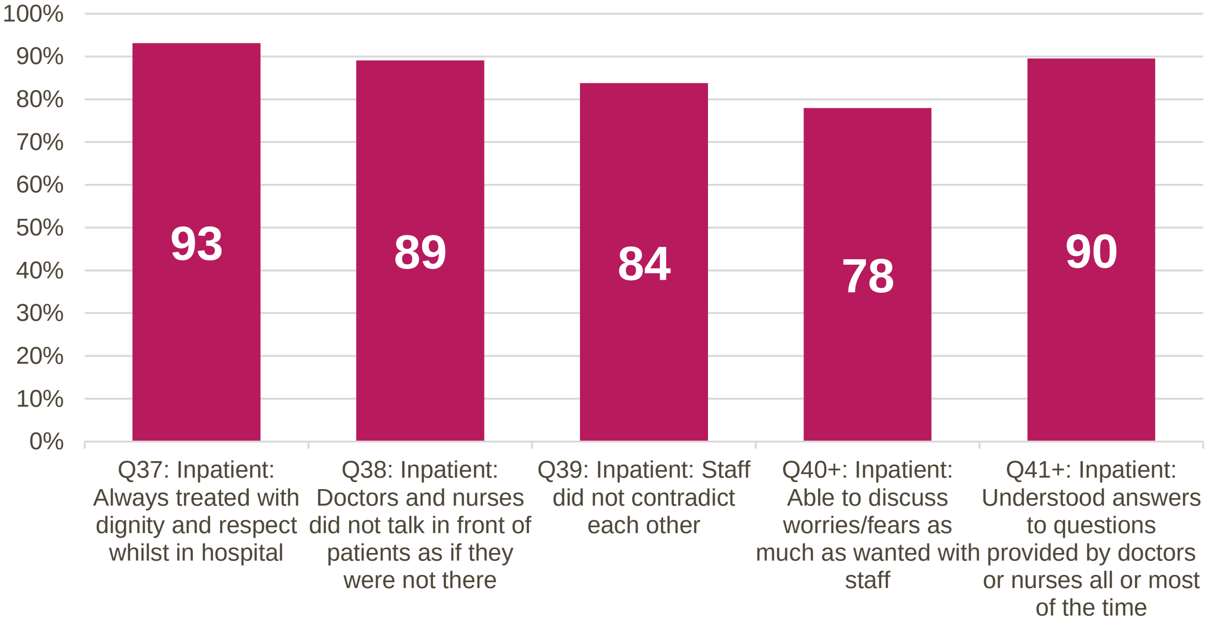
Respondents who had an operation for their cancer

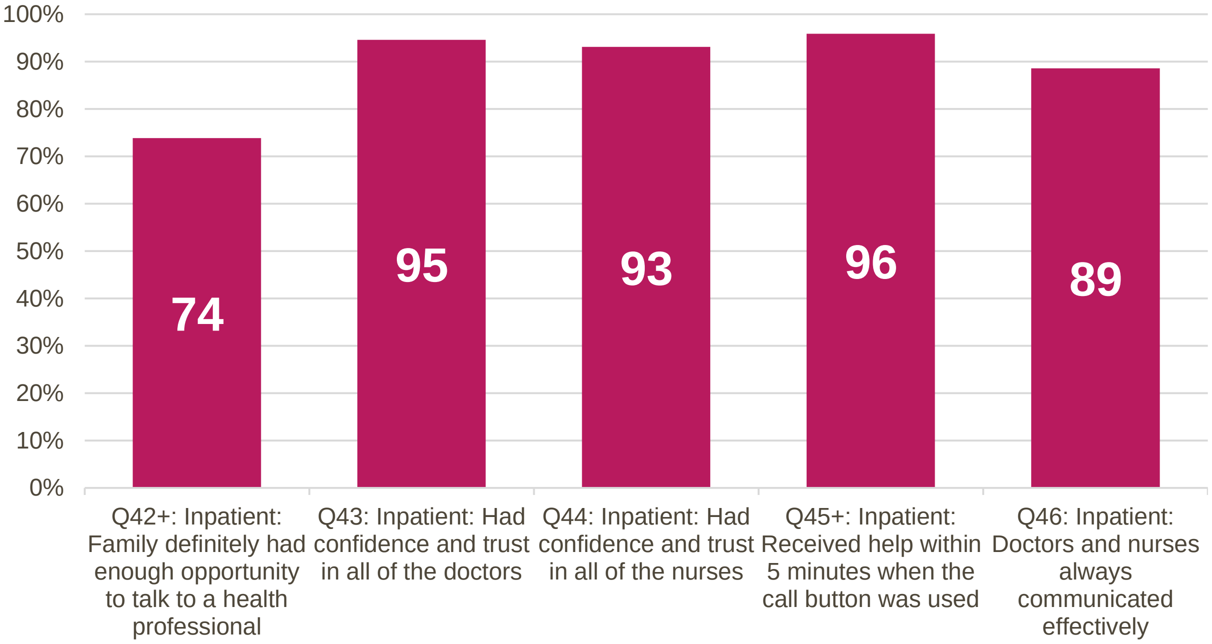


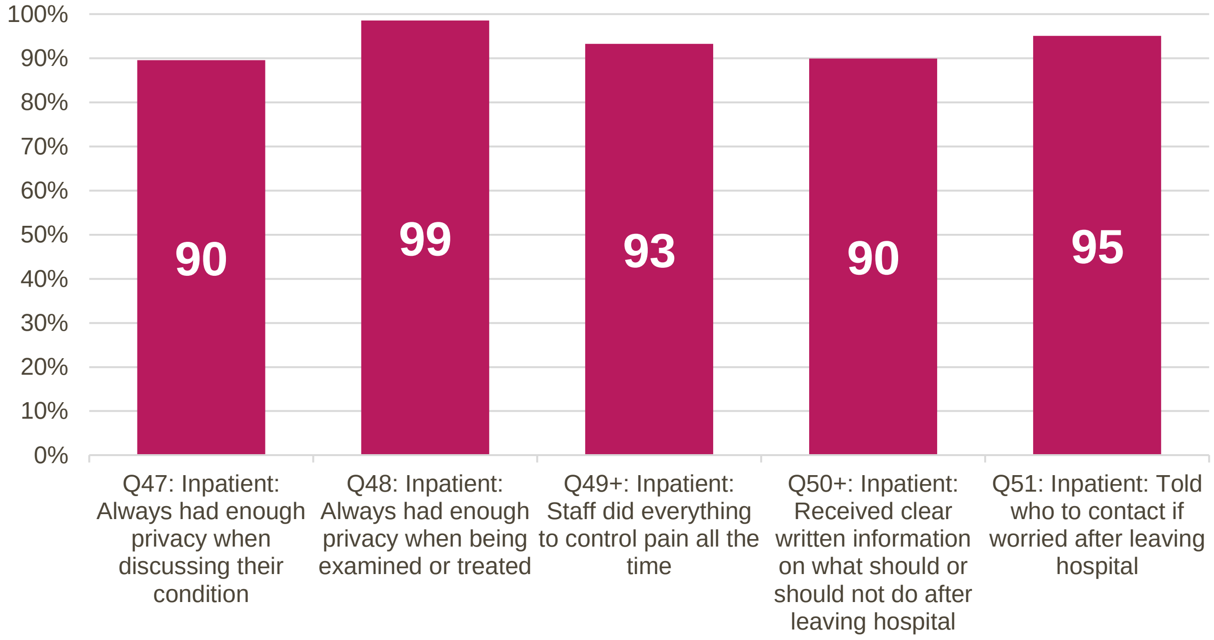
Velindre NHS Trust positive score chart: Hospital care as an inpatient

These questions are about any inpatient stay in hospital related to cancer treatment.

Respondents who had an operation or stayed overnight for their cancer care



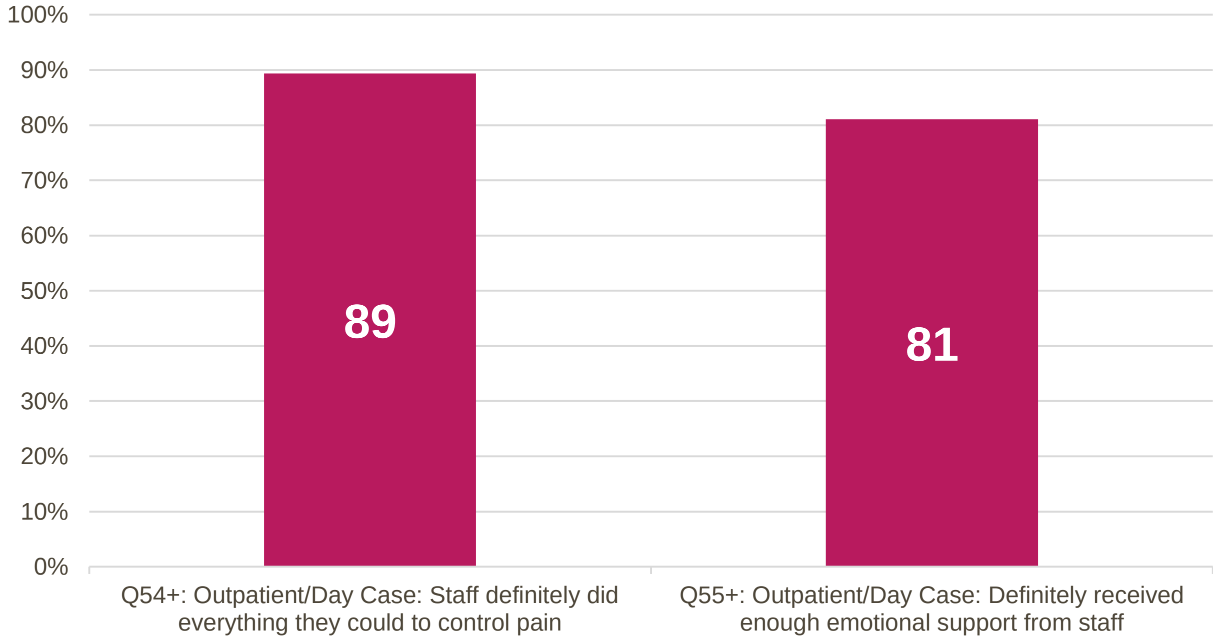




Velindre NHS Trust positive score chart: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

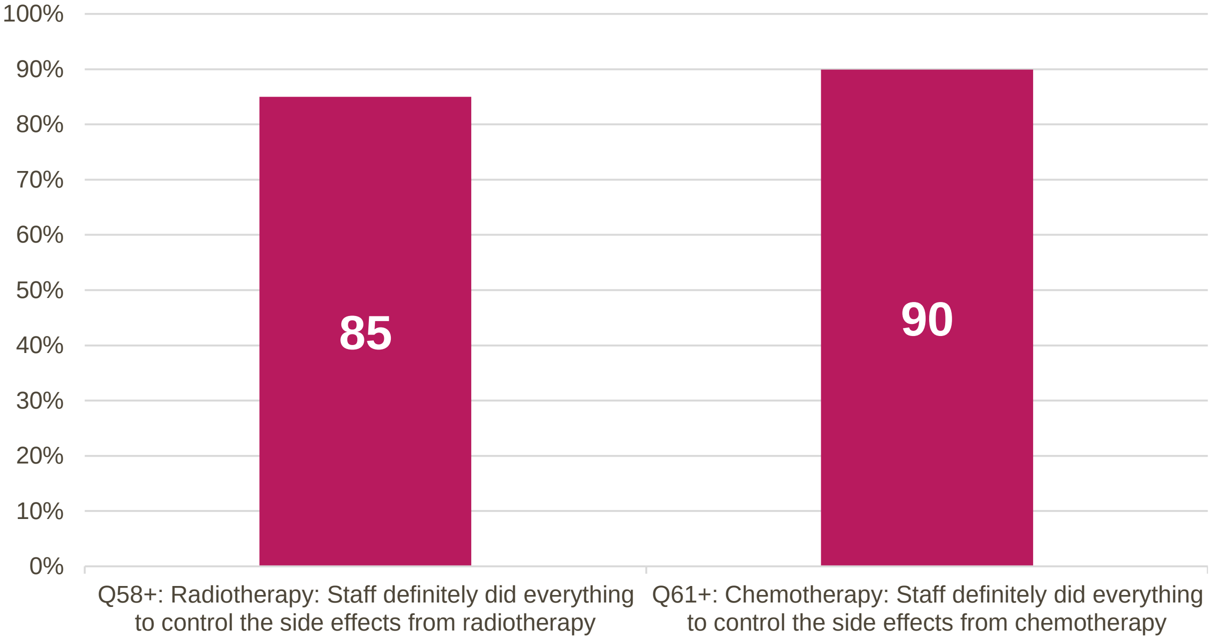
Respondents who had an outpatient or day case appointment



Velindre NHS Trust positive score chart: Radiotherapy/chemotherapy

These questions relate to any radiotherapy or chemotherapy patients may have had.

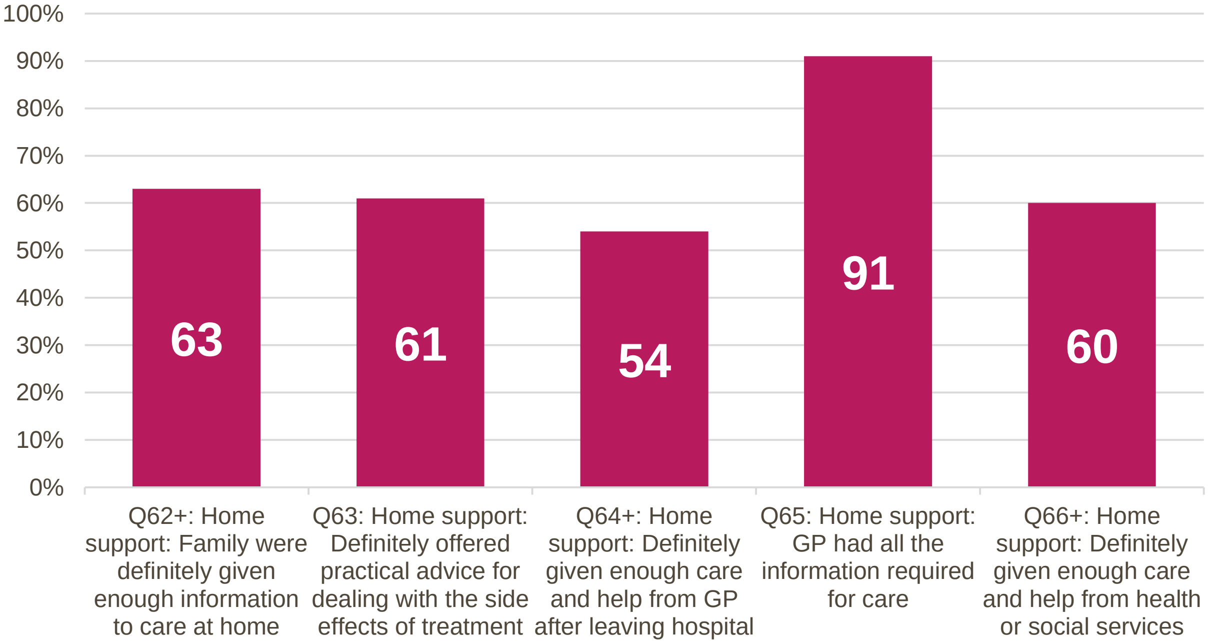
Q58+: Respondents who had radiotherapy
Q61+: Respondents who had chemotherapy



Velindre NHS Trust positive score chart: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for their cancer.

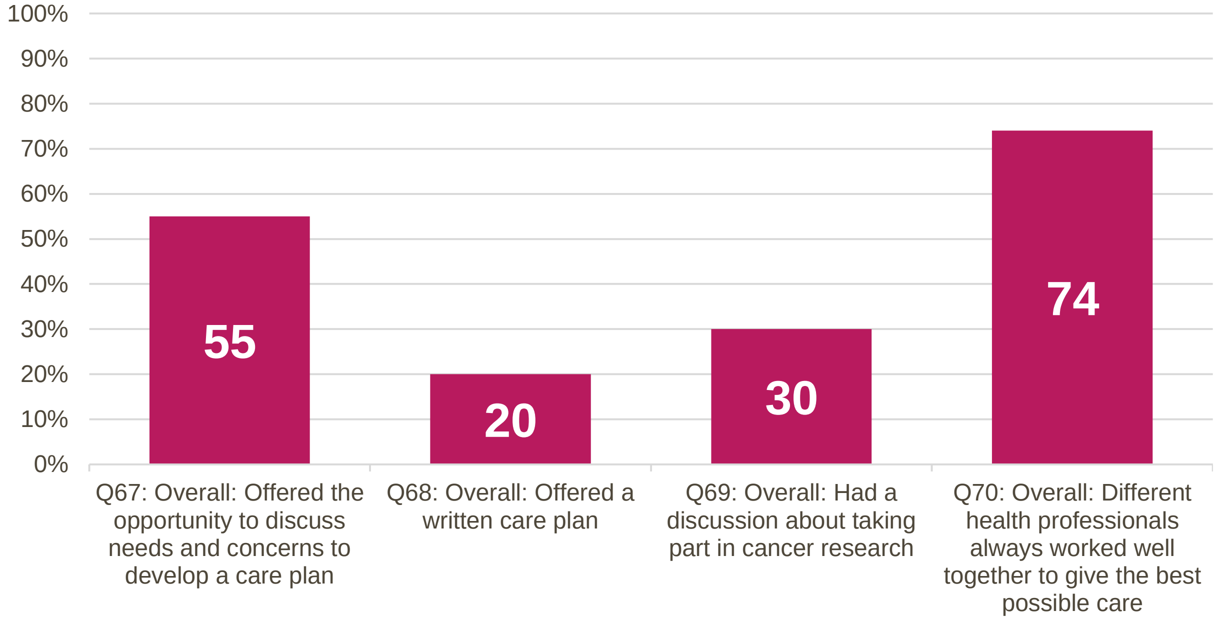
All respondents

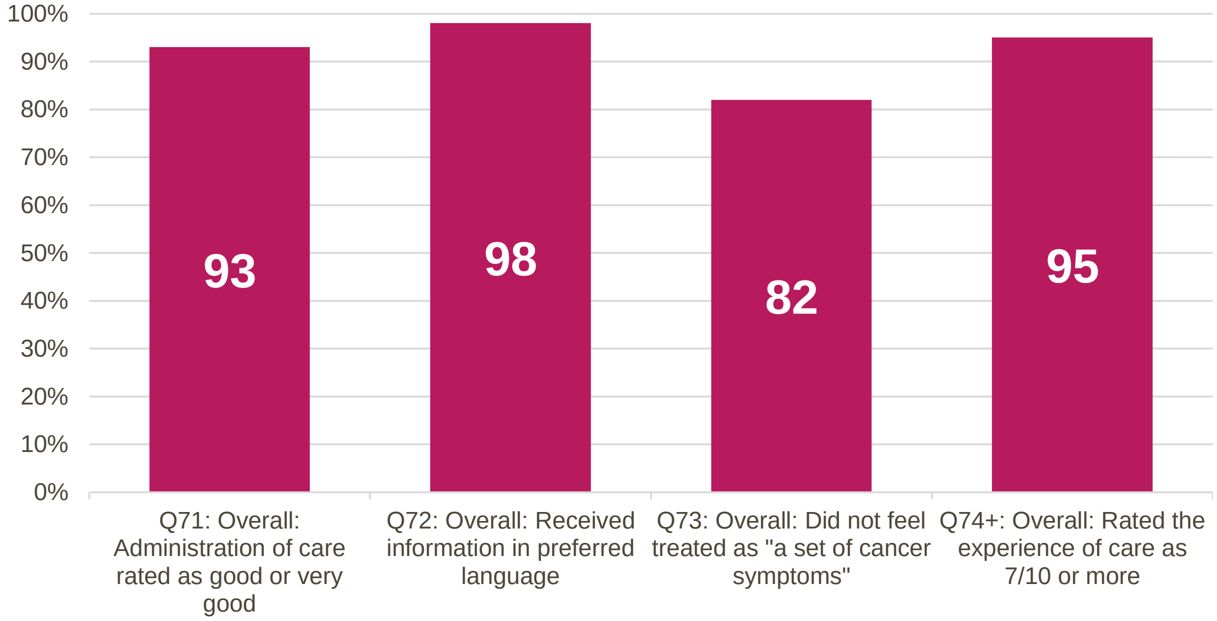


Velindre NHS Trust positive score chart: Your overall NHS care

These questions relate to patients' overall experience of the care they received from the NHS.

All respondents





Appendix three: Effect of Clinical Nurse Specialist (CNS) provision

81% of respondents in Wales reported having the name and contact details of a CNS. These specialist cancer nurses assist patients by providing help and advice on coping with cancer.

The charts below represent the 73 questions where there is a statistically significant difference between the positive scores of respondents who had access to a CNS and those who did not.

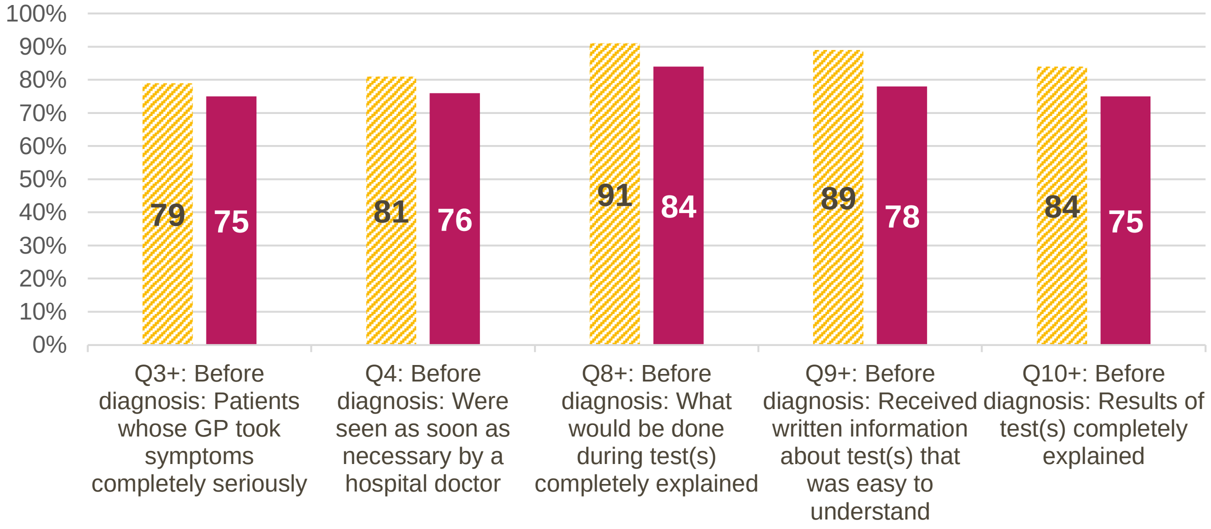
▨ Respondents who had access to CNS

■ Respondents who did not have access to CNS

Effect of CNS provision: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

Q3+ – Q5: All respondents
Q8+ – Q10+: Respondents who had a diagnostic test



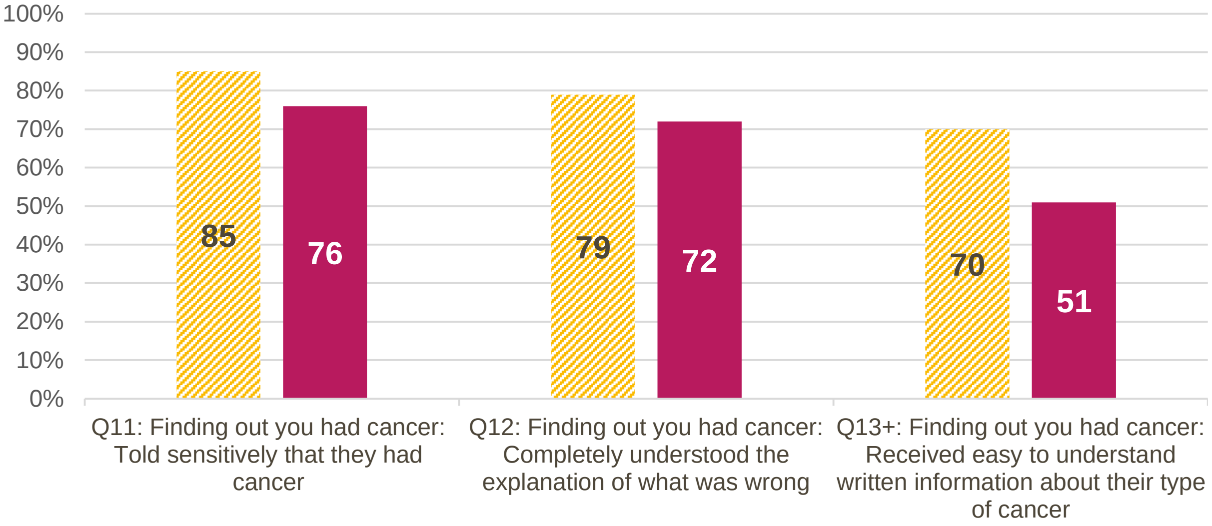
▨ Respondents who had access to CNS

■ Respondents who did not have access to CNS

Effect of CNS provision: Finding out you had cancer

These questions are about what happened when patients found out they had cancer.

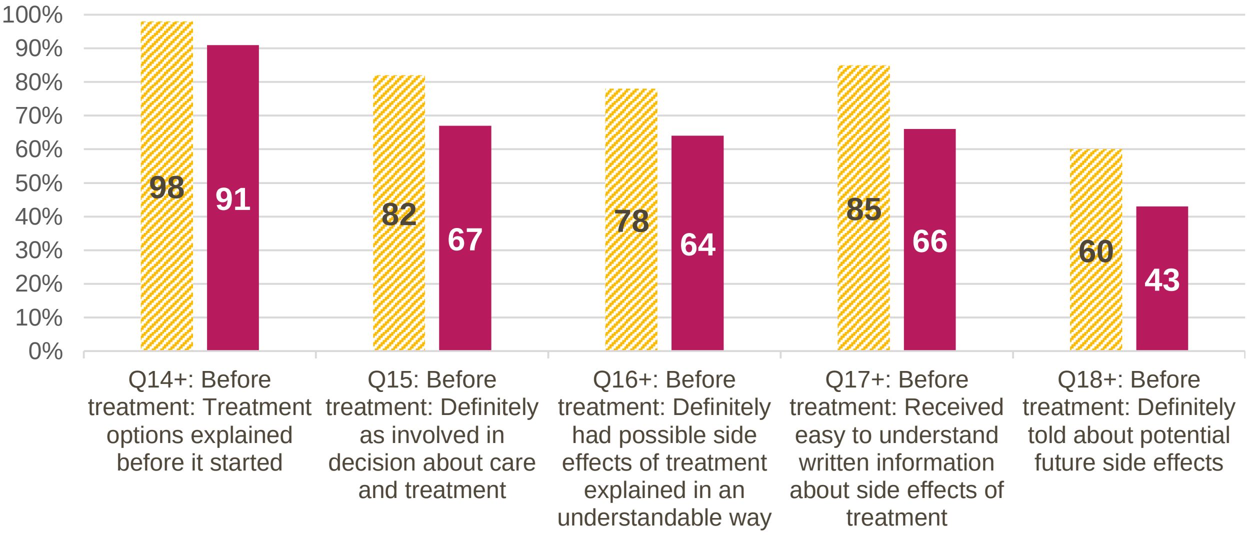
All respondents



Effect of CNS provision: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

All respondents



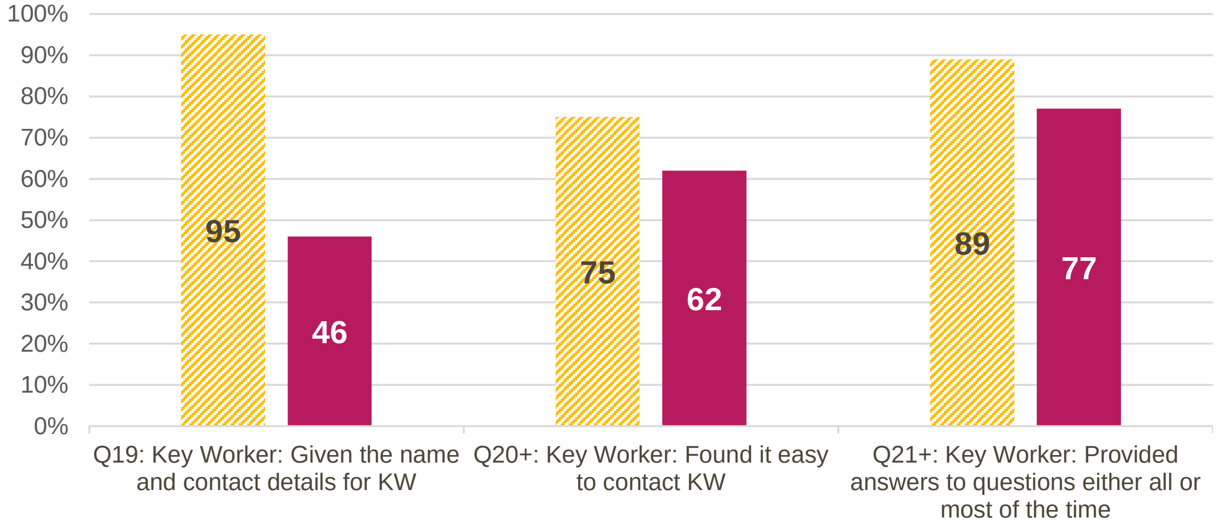
▨ Respondents who had access to CNS

■ Respondents who did not have access to CNS

Effect of CNS provision: Key Worker

These questions are about Key Workers.

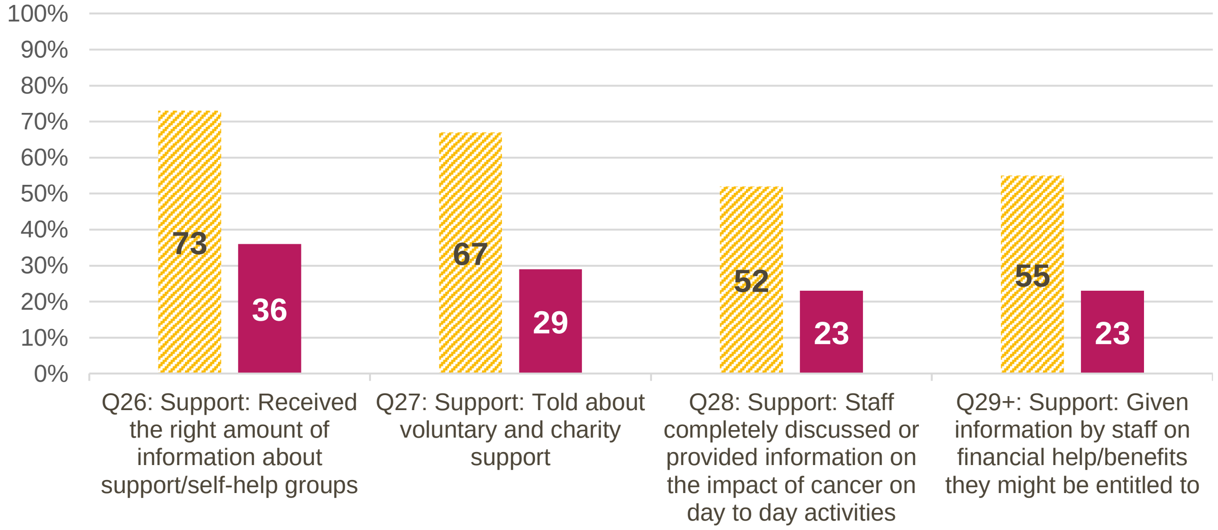
Q19: All respondents
Q20+ – Q21+: Respondents who had the name and contact details of a Key Worker



Effect of CNS provision: Support for people with cancer

These questions are about support for a patient when their cancer treatment was first started.

All respondents



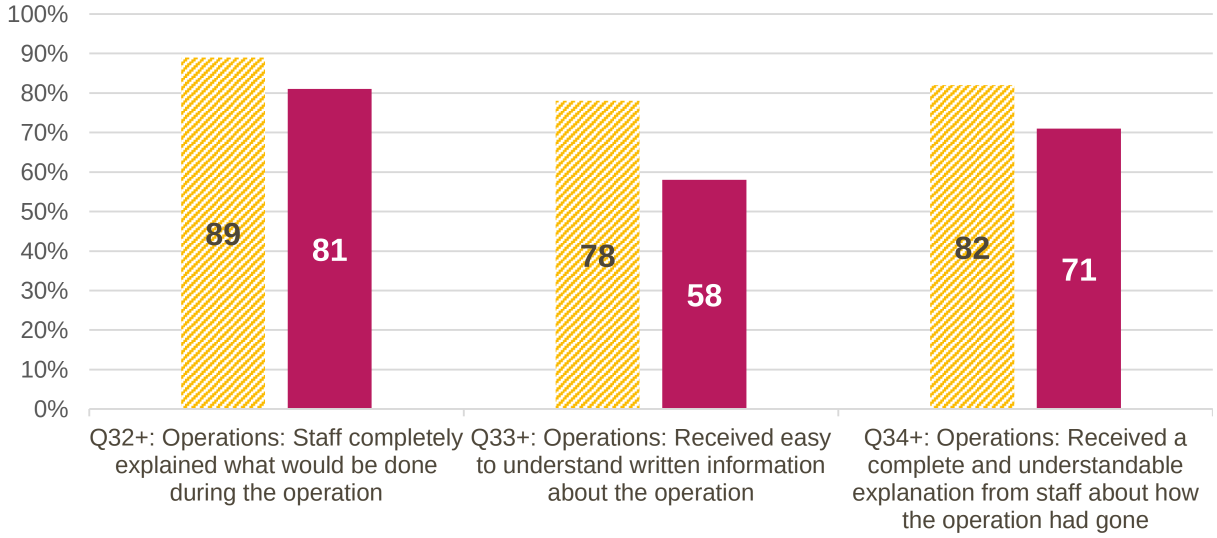
▨ Respondents who had access to CNS

🟥 Respondents who did not have access to CNS

Effect of CNS provision: Operations

These questions are about any operation a patient may have had related to their cancer.

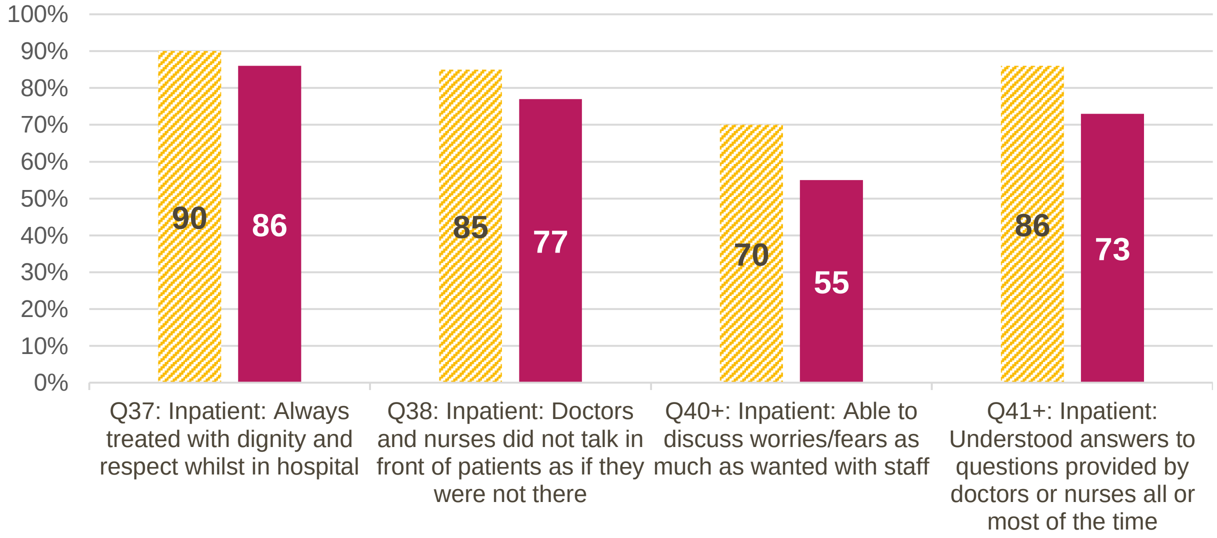
Respondents who had an operation for their cancer



Effect of CNS provision: Hospital care as an inpatient

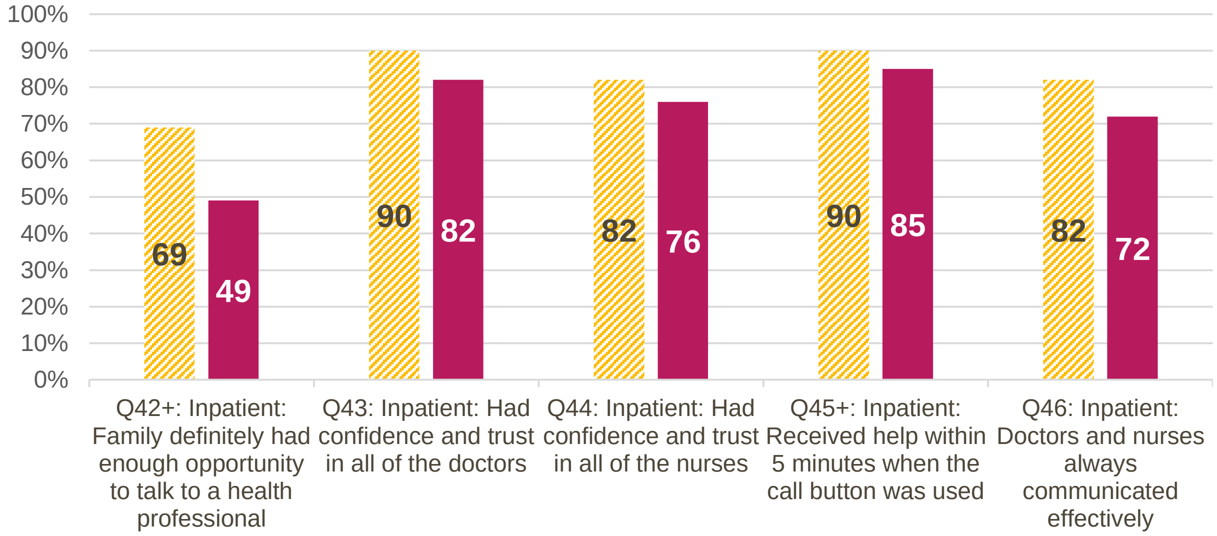
These questions are about any inpatient stay in hospital related to cancer treatment.

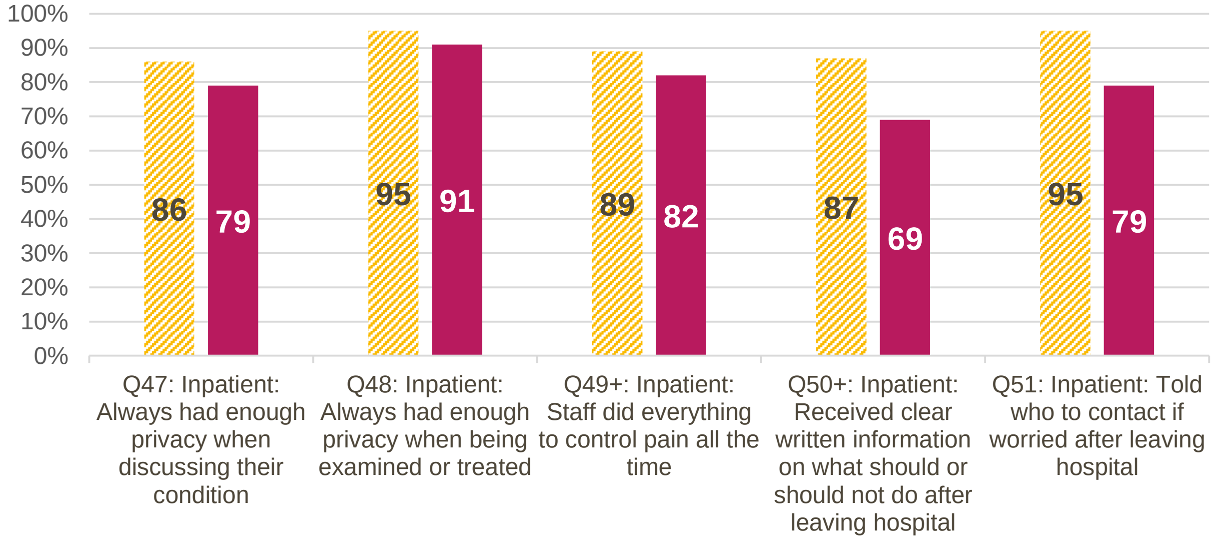
Respondents who had an operation or stayed overnight for their cancer care



▨ Respondents who had access to CNS

🟥 Respondents who did not have access to CNS





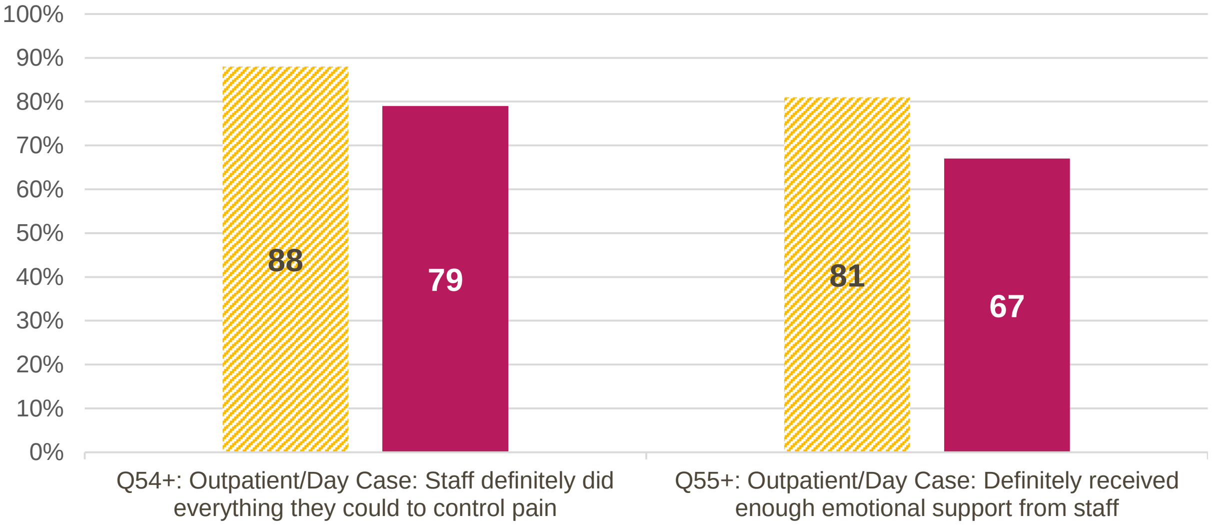
▨ Respondents who had access to CNS

■ Respondents who did not have access to CNS

Effect of CNS provision: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

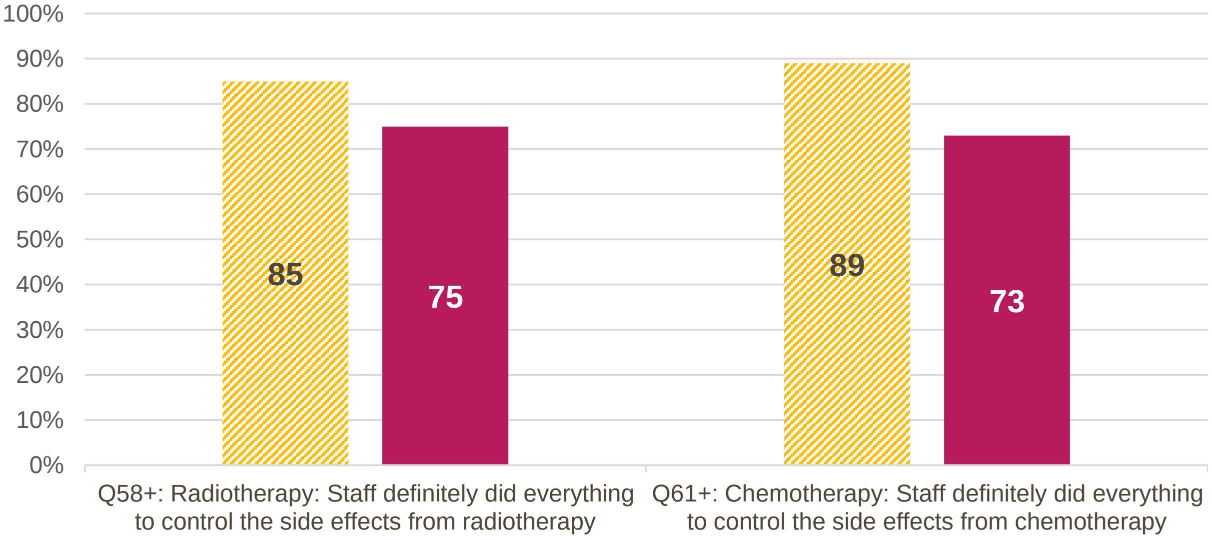
Respondents who had an outpatient or day case appointment



Effect of CNS provision: Radiotherapy/chemotherapy

These questions relate to any radiotherapy or chemotherapy patients may have had.

Q58+: Respondents who had radiotherapy
Q61+: Respondents who had chemotherapy



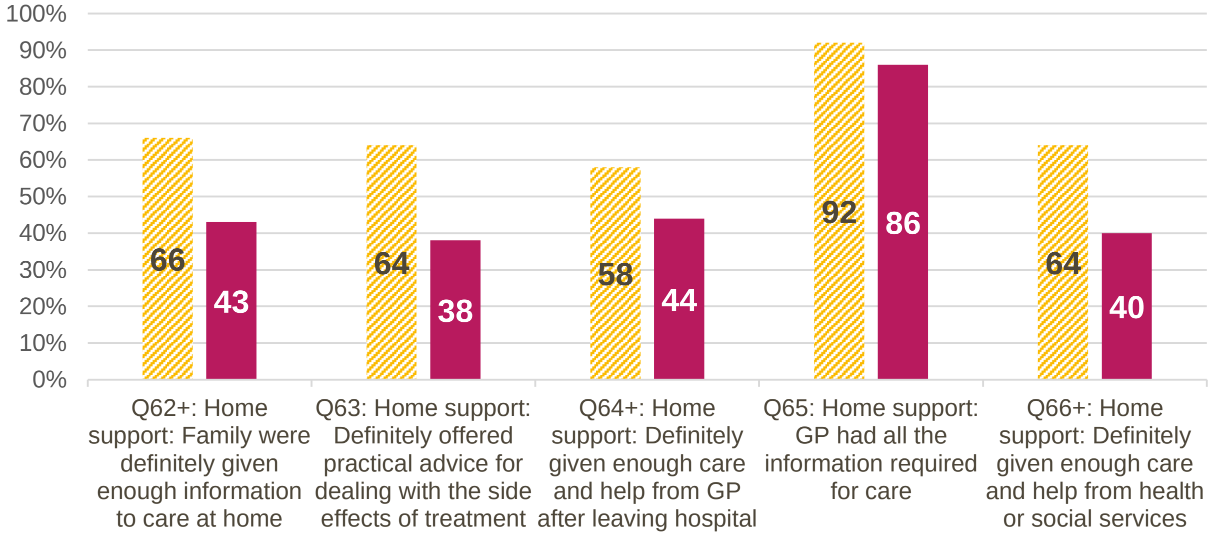
▨ Respondents who had access to CNS

🟥 Respondents who did not have access to CNS

Effect of CNS provision: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for their cancer.

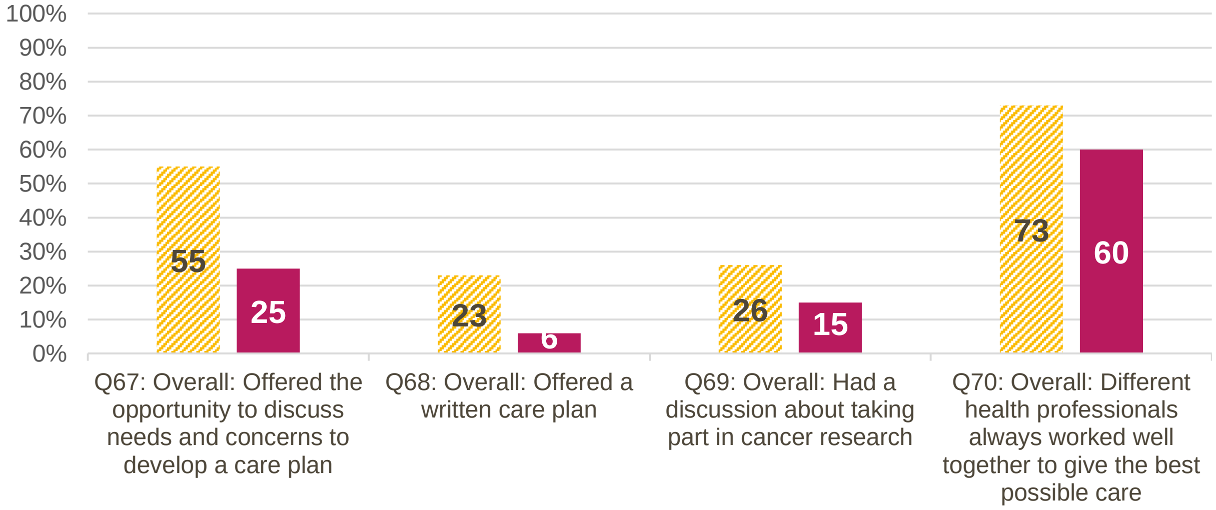
All respondents

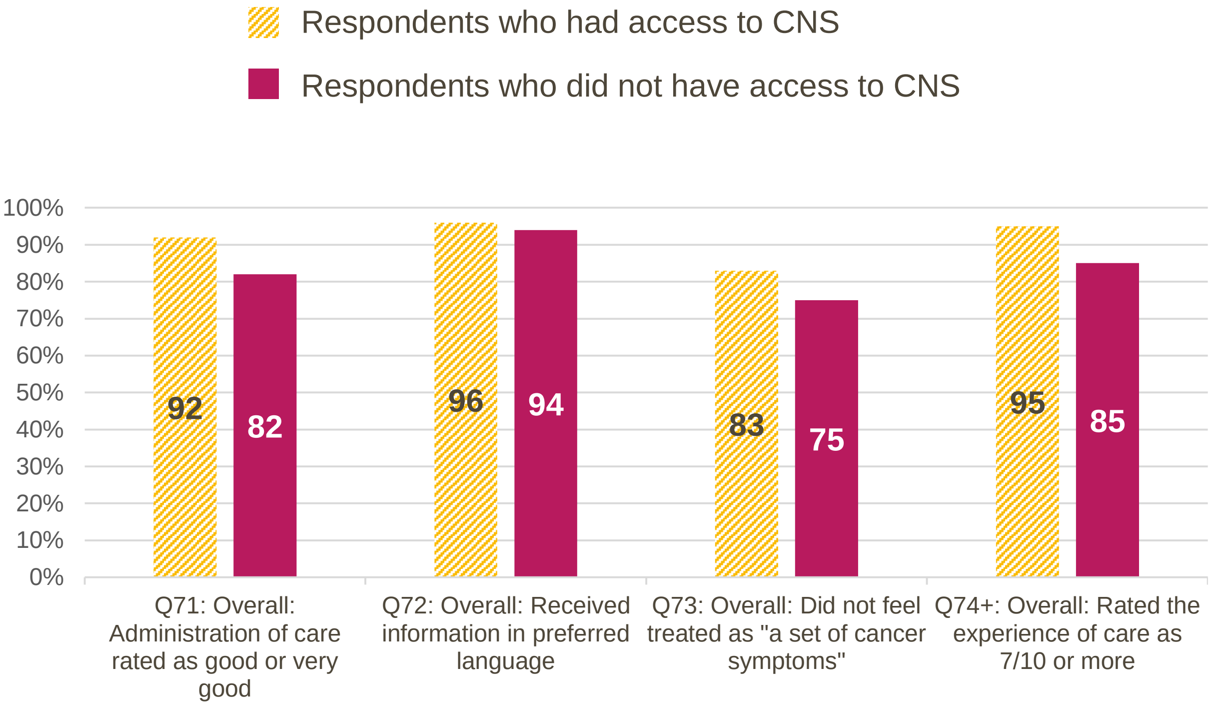


Effect of CNS provision: Your overall NHS care

These questions relate to patients' overall experience of the care they received from the NHS.

All respondents




Respondents who had access to CNS
Respondents who did not have access to CNS
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
92
82
96
94
83
75
95
85
Q71: Overall: Administration of care rated as good or very good
Q72: Overall: Received information in preferred language
Q73: Overall: Did not feel treated as "a set of cancer symptoms"
Q74+: Overall: Rated the experience of care as 7/10 or more

Appendix four: Effect of Key Worker (KW) allocation

86% of respondents in Wales reported having the name and contact details for a KW. These are professionals who co-ordinate patients' care and are a source of advice and information.

The charts below represent the 57 questions where there is a statistically significant difference between the positive scores of patients that had access to a designated Key Worker and those who did not.

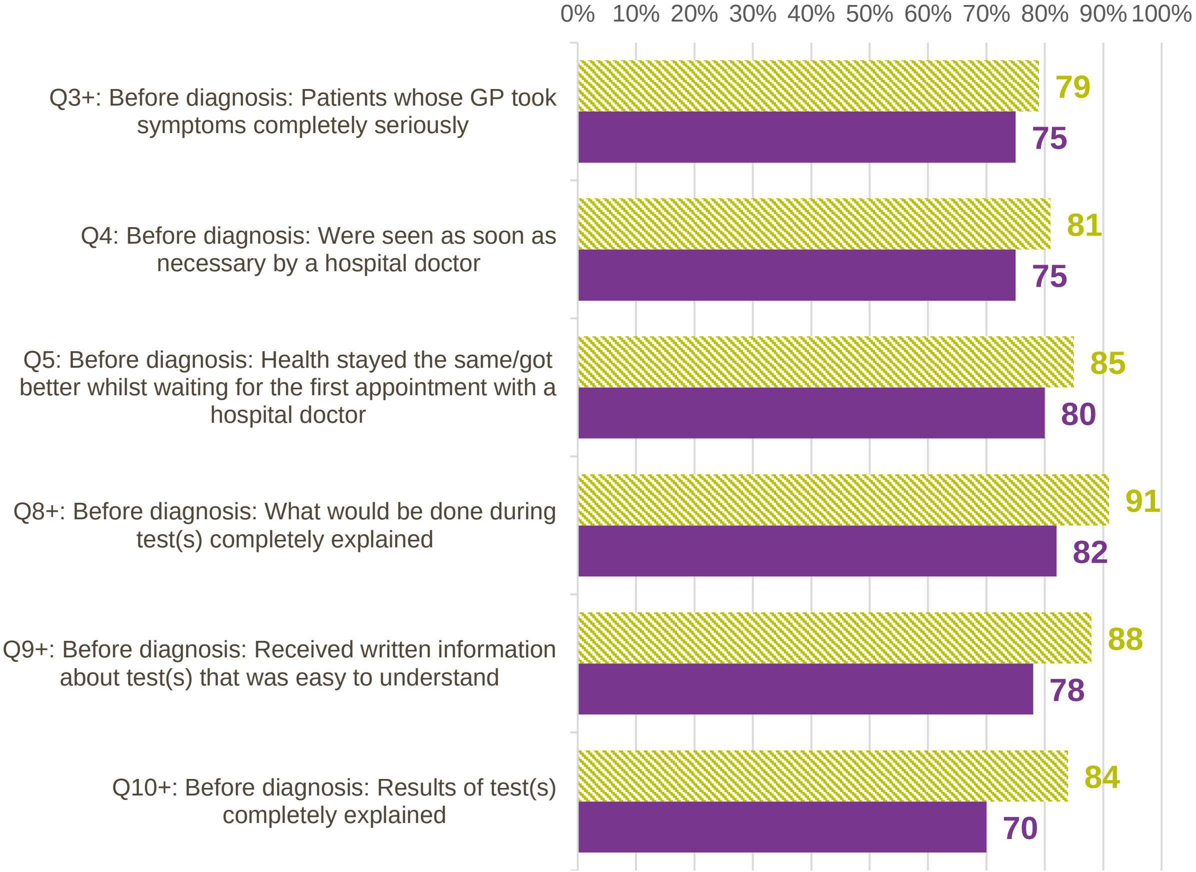
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

Q3+ – Q5: All respondents
Q8+ – Q10+: Respondents who had a diagnostic test



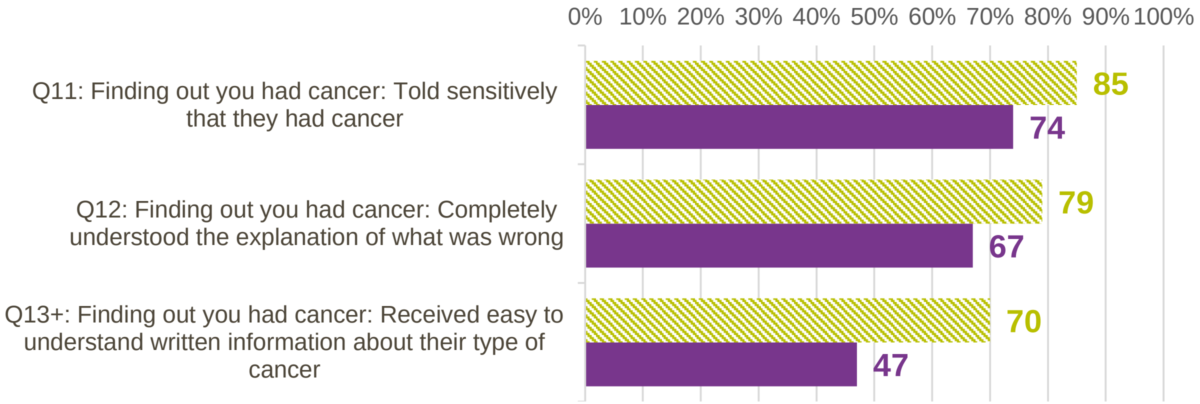
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Finding out you had cancer

These questions are about what happened when patients found out they had cancer.

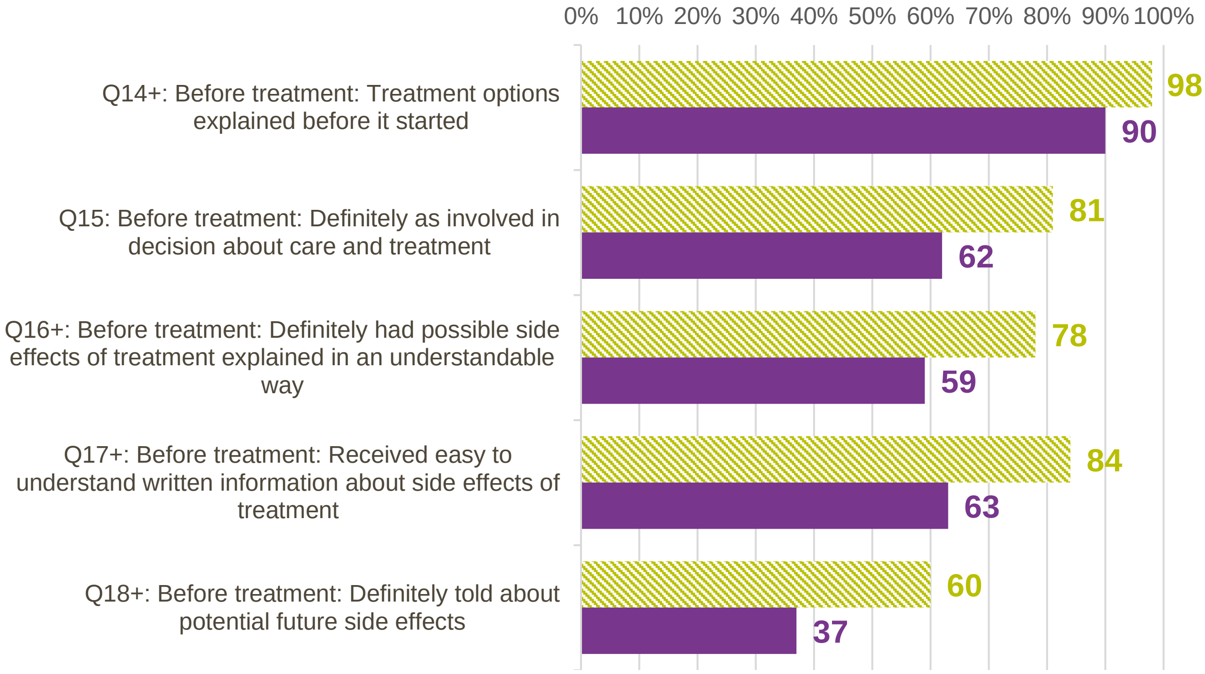
All respondents



Effect of Key Worker allocation: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

All respondents



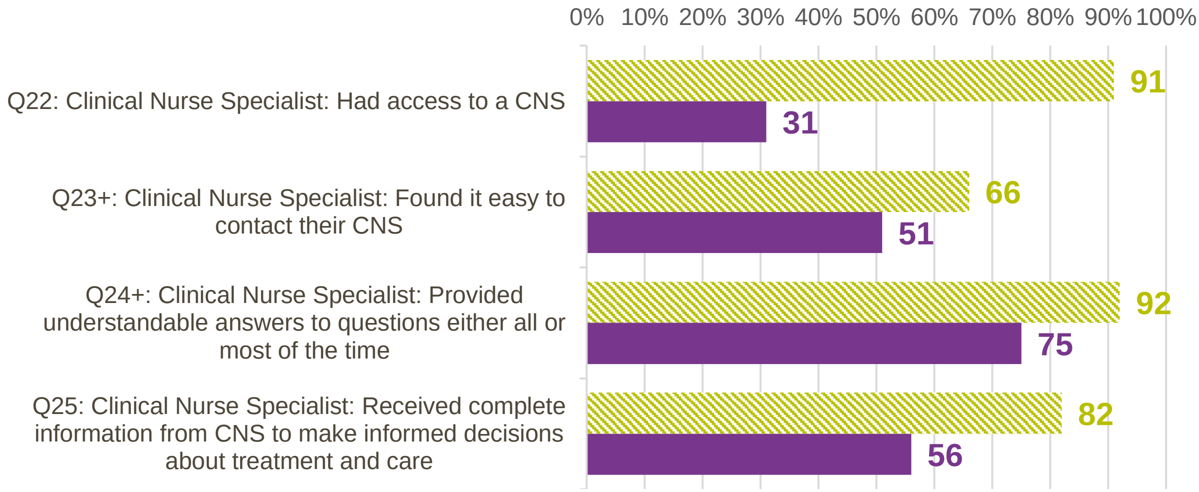
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Clinical Nurse Specialist

These questions are about Clinical Nurse Specialists.

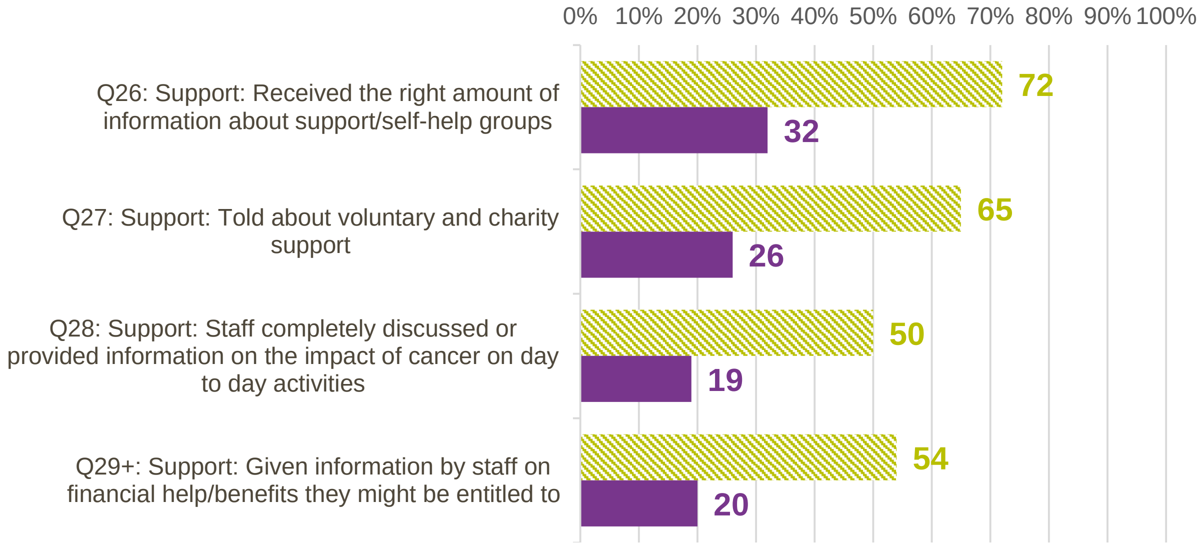
Q22: All respondents
Q23+ – Q25: Respondents who had the name and contact details of a Clinical Nurse Specialist



Effect of Key Worker allocation: Support for people with cancer

These questions are about support for a patient when their cancer treatment first started.

All respondents



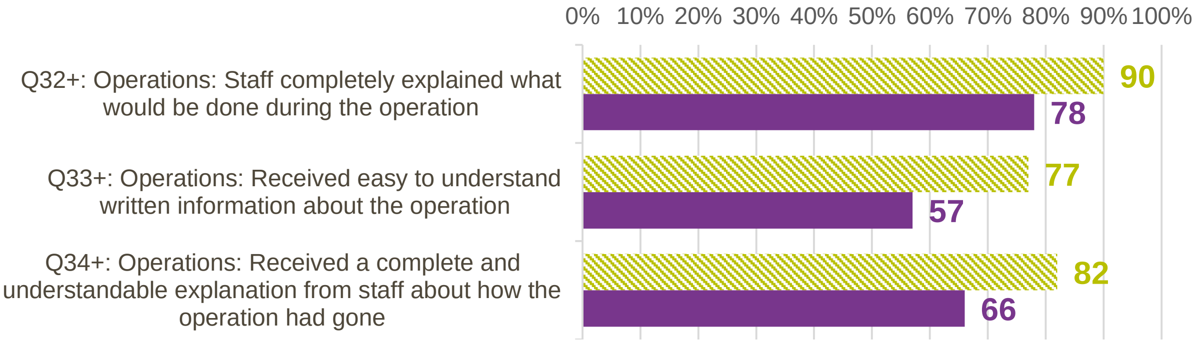
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Operations

These questions are about any operation a patient may have had related to cancer.

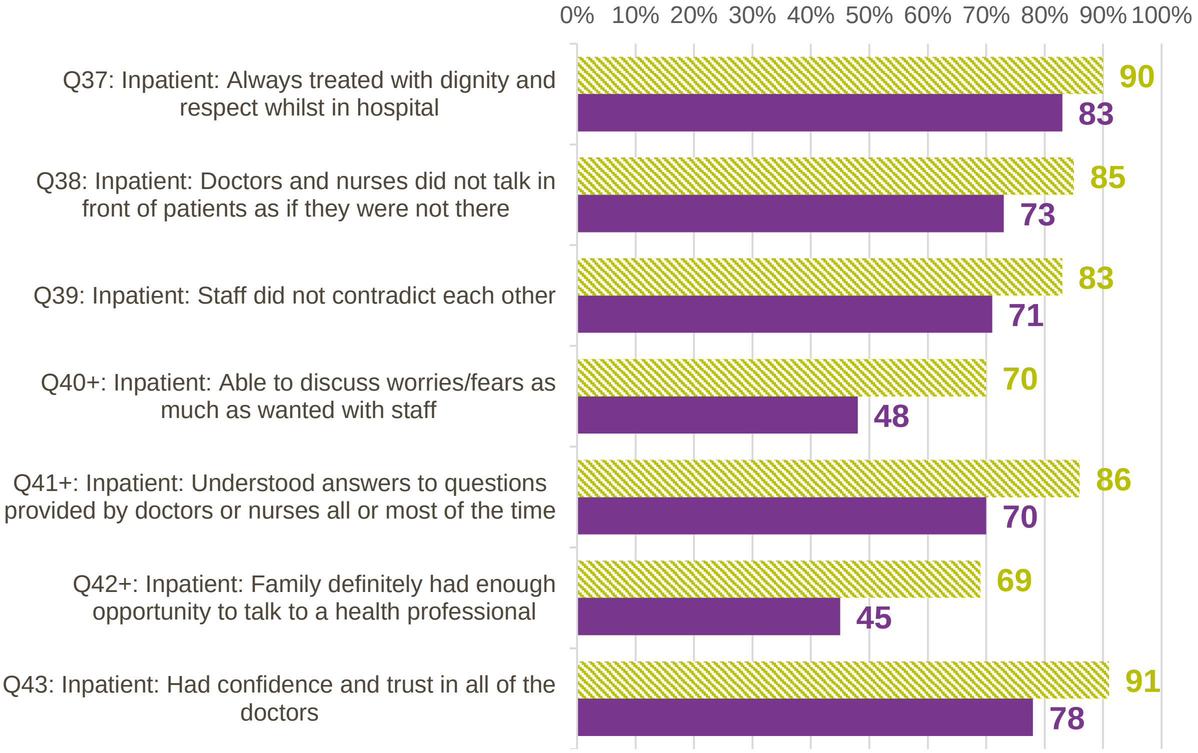
Respondents who had an operation for their cancer

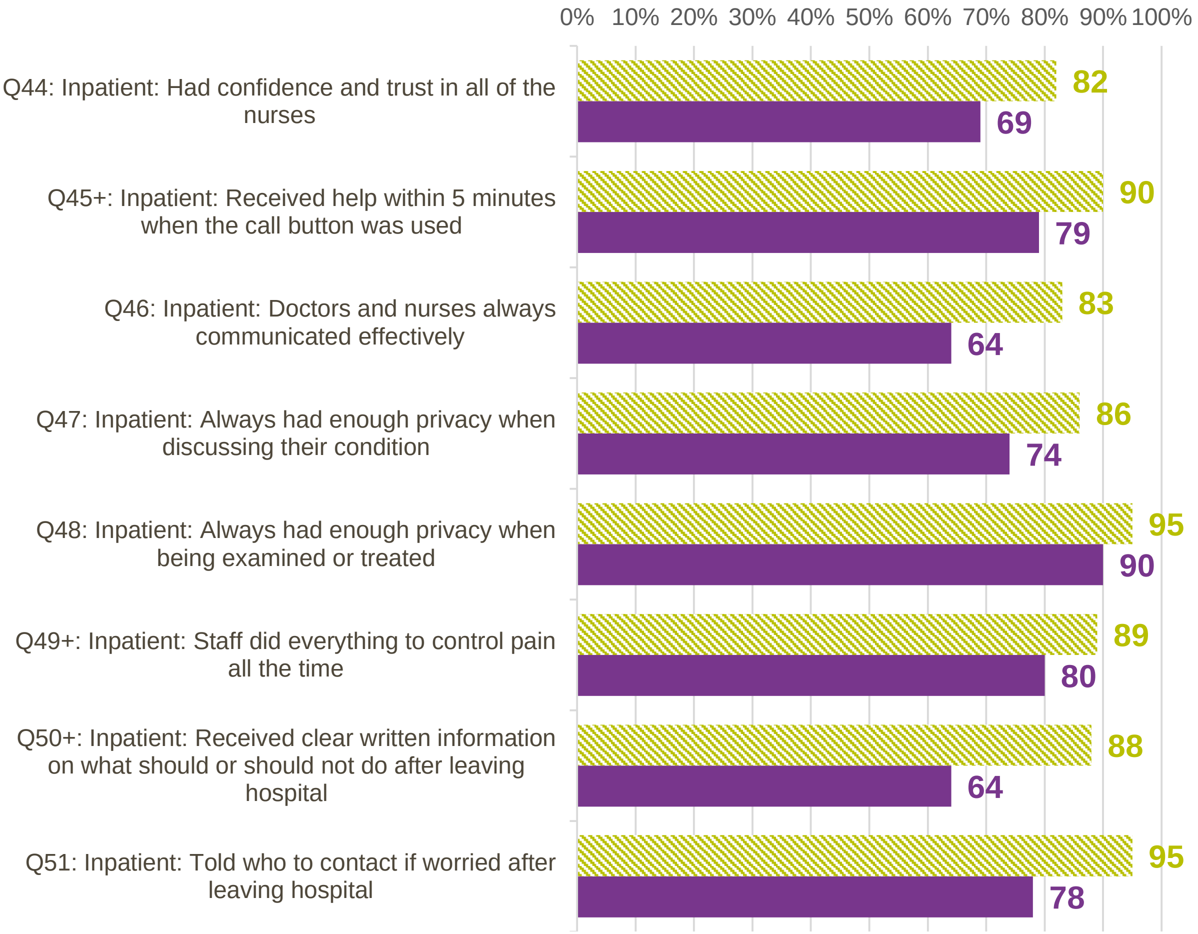


Effect of Key Worker allocation: Hospital care as an inpatient

These questions are about any inpatient stay in hospital related to cancer treatment.

Respondents who had an operation or stayed overnight for their cancer care




▨ Respondents who had access to KW
■ Respondents who did not have access to KW
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Q44: Inpatient: Had confidence and trust in all of the nurses
82
69
Q45+: Inpatient: Received help within 5 minutes when the call button was used
90
79
Q46: Inpatient: Doctors and nurses always communicated effectively
83
64
Q47: Inpatient: Always had enough privacy when discussing their condition
86
74
Q48: Inpatient: Always had enough privacy when being examined or treated
95
90
Q49+: Inpatient: Staff did everything to control pain all the time
89
80
Q50+: Inpatient: Received clear written information on what should or should not do after leaving hospital
88
64
Q51: Inpatient: Told who to contact if worried after leaving hospital
95
78

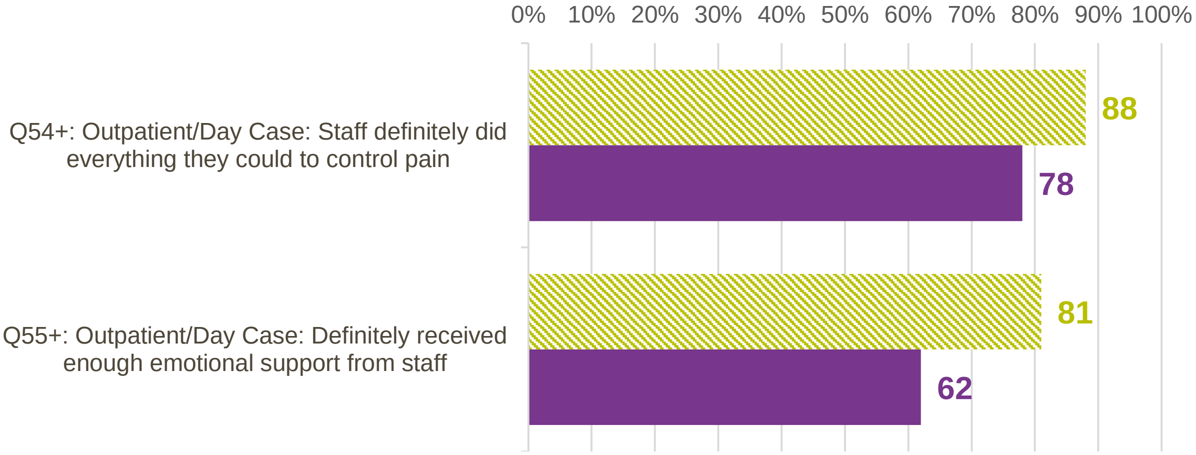
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

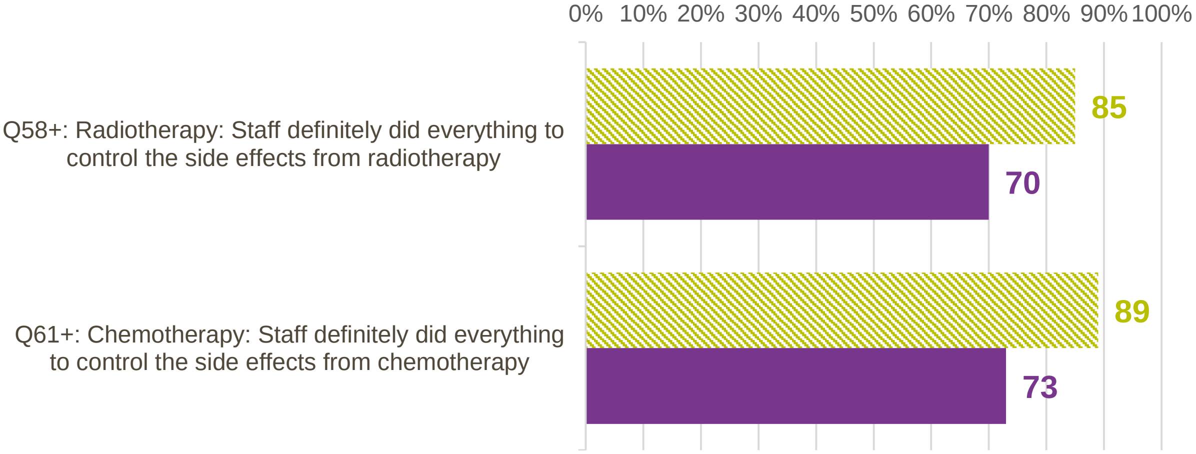
Respondents who had an outpatient or day case appointment



Effect of Key Worker allocation: Radiotherapy/chemotherapy

These questions are about any radiotherapy or chemotherapy patients may have had.

Q58+: Respondents who had radiotherapy
Q61+: Respondents who had chemotherapy



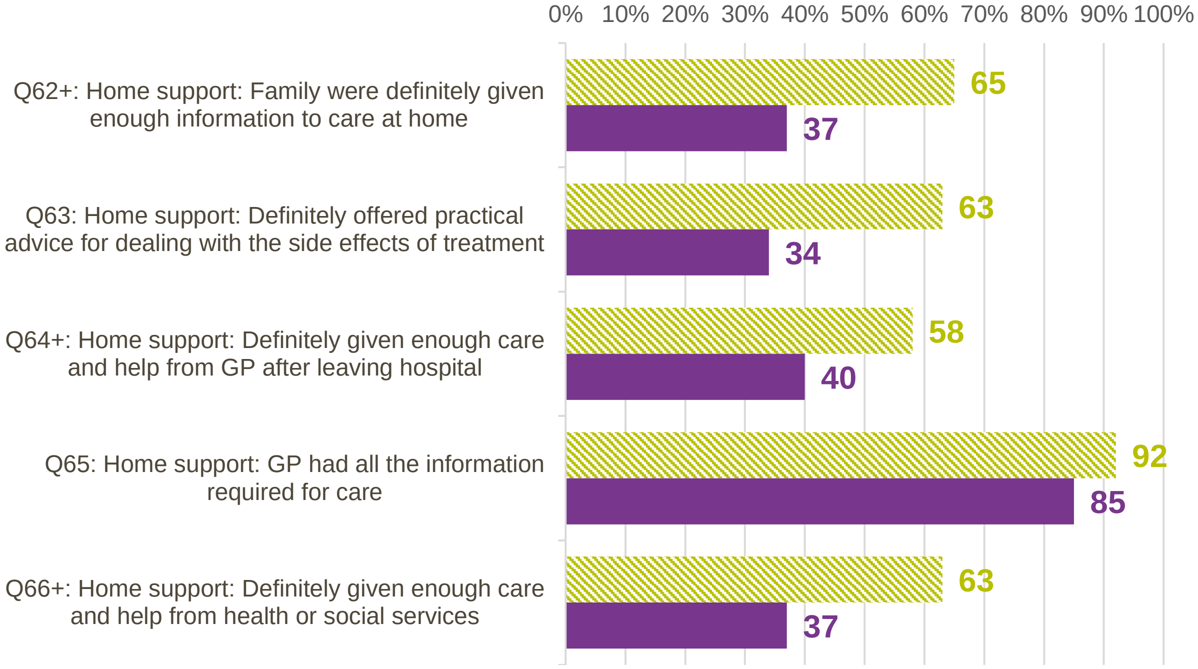
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for their cancer.

All respondents



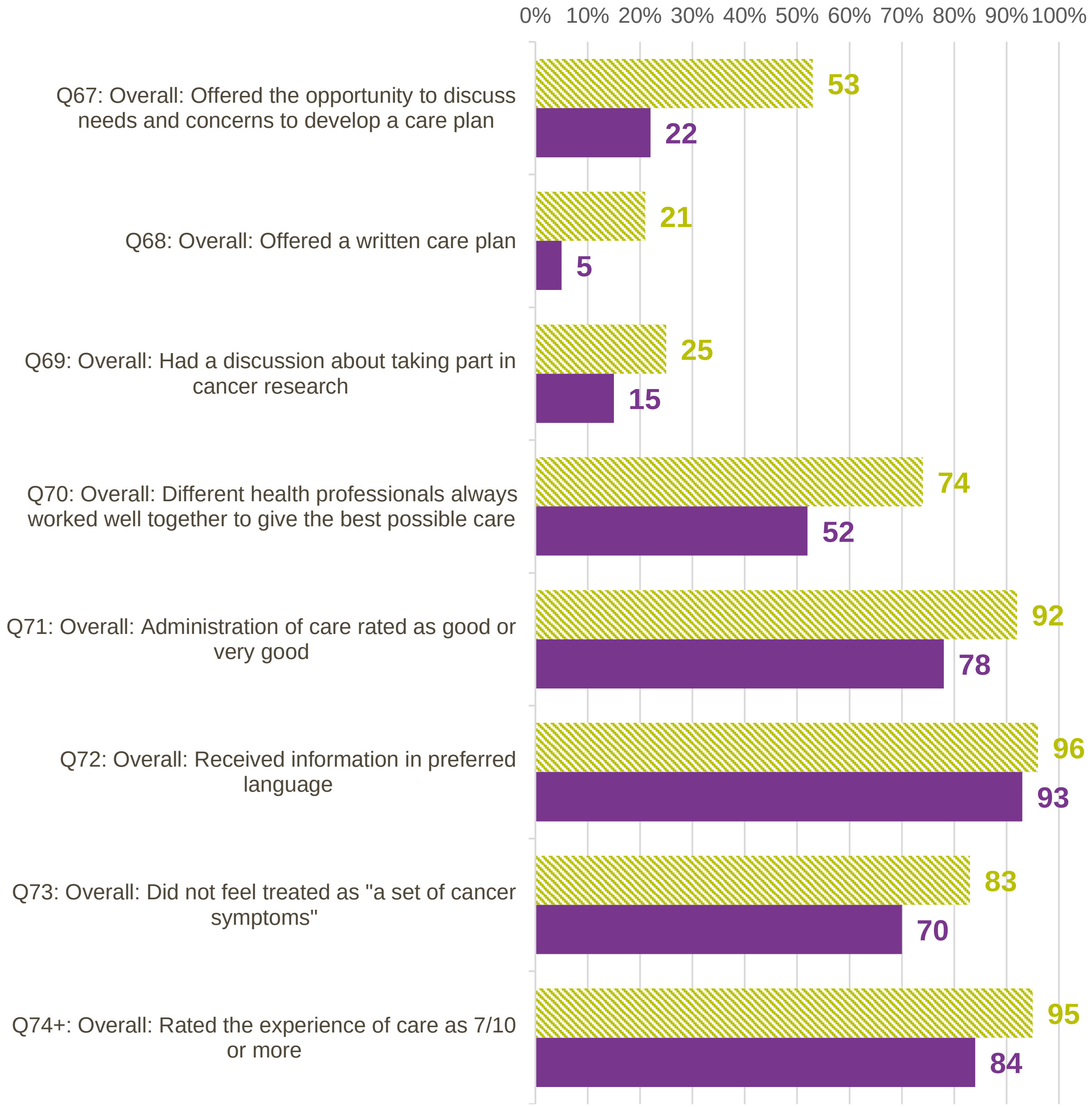
▨ Respondents who had access to KW

■ Respondents who did not have access to KW

Effect of Key Worker allocation: Your overall NHS care

These questions relate to patients’ overall experience of the care they received from the NHS.

All respondents



Appendix five: Establishment of a care plan

48% of respondents in Wales reported having the opportunity to discuss their needs and concerns in order to formulate a care plan and 18% of respondents reported that they were offered a written care plan.

The charts below represent the 57 questions where there is a statistically significant difference between the positive scores of patients who had an established care plan and those who did not.

The following response options were used to break the results down by the establishment of a care plan:

- *Q67 – Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?*
  - 🟥 *Yes* – Respondents who had a care plan
  - ▨ *No* – Respondents who did not have a care plan

- *Q68 – Have you been offered a written care plan?*
  - ▩ *Yes* – Respondent who had a written care plan

🟥 Respondents who had a care plan

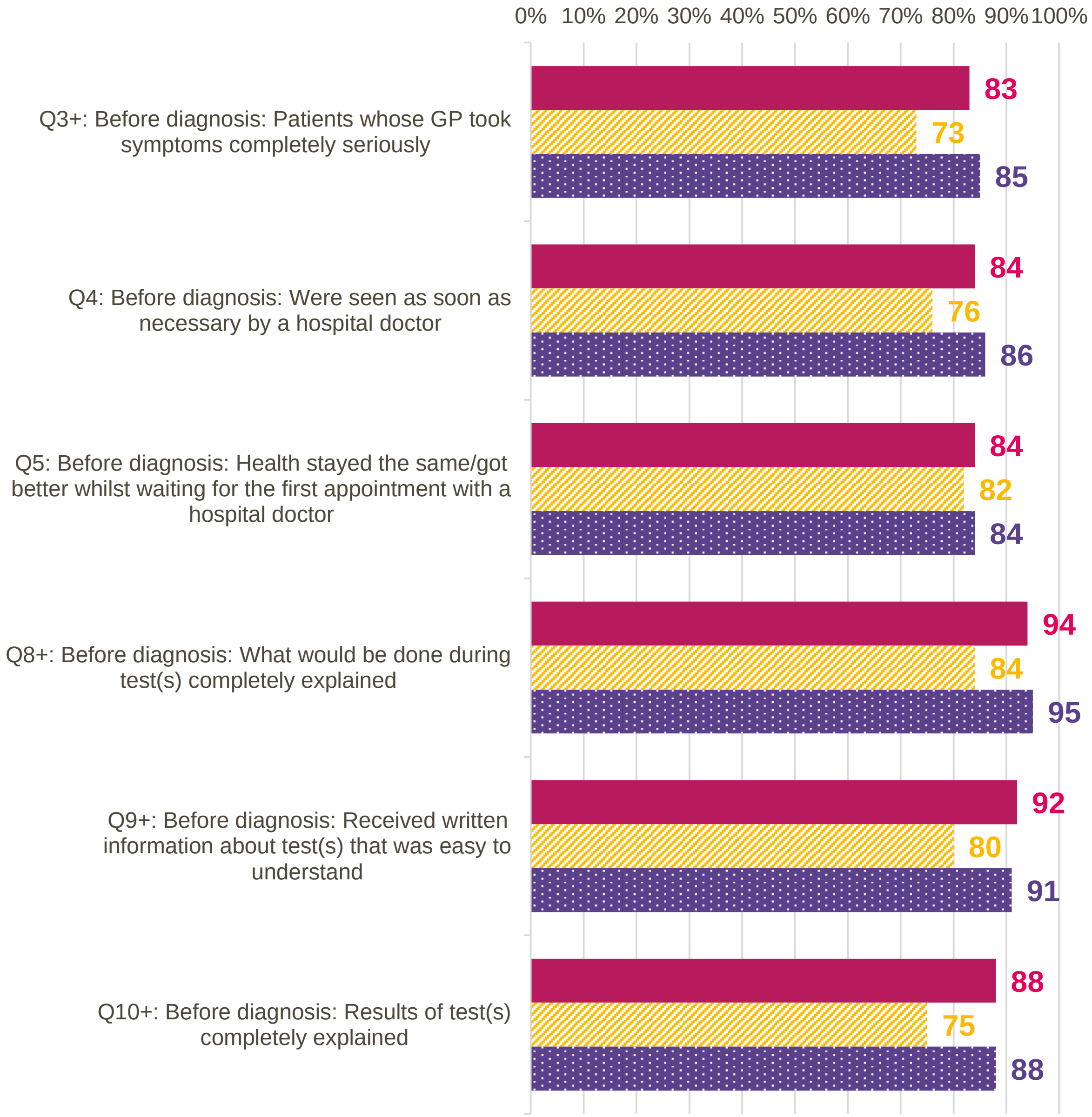
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Before your diagnosis

These questions are about what happened before patients found out they had cancer.

Q3+ – Q5: All respondents
Q8+ – Q10+: Respondents who had a diagnostic test



🟥 Respondents who had a care plan

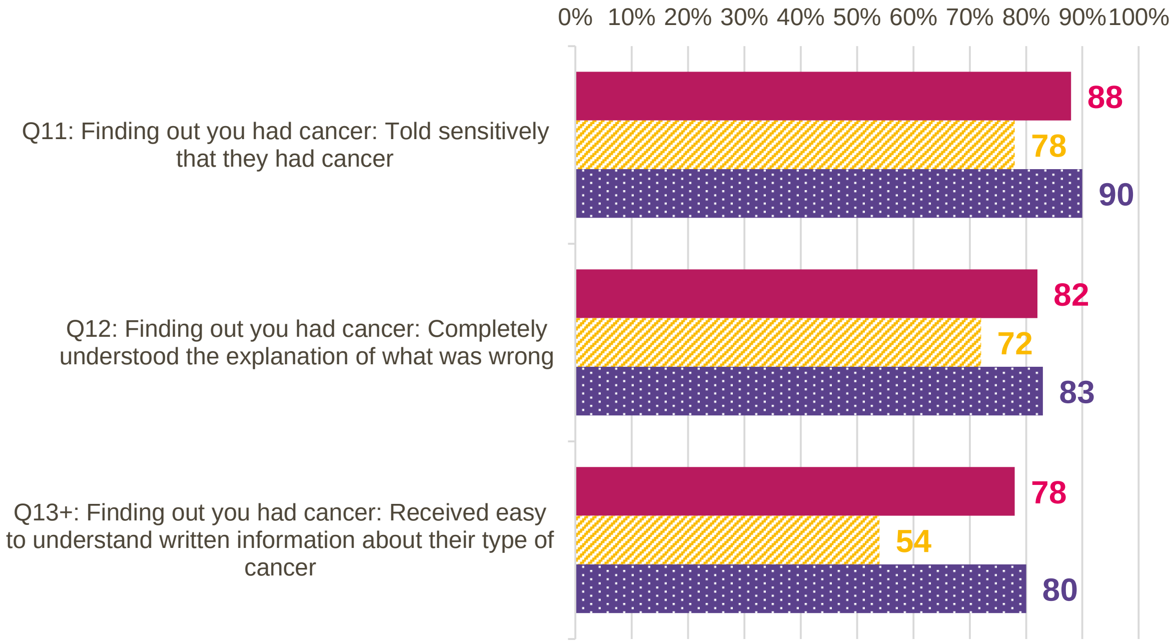
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Finding out you had cancer

These questions are about what happened when patients found out they had cancer.

All respondents



🟥 Respondents who had a care plan

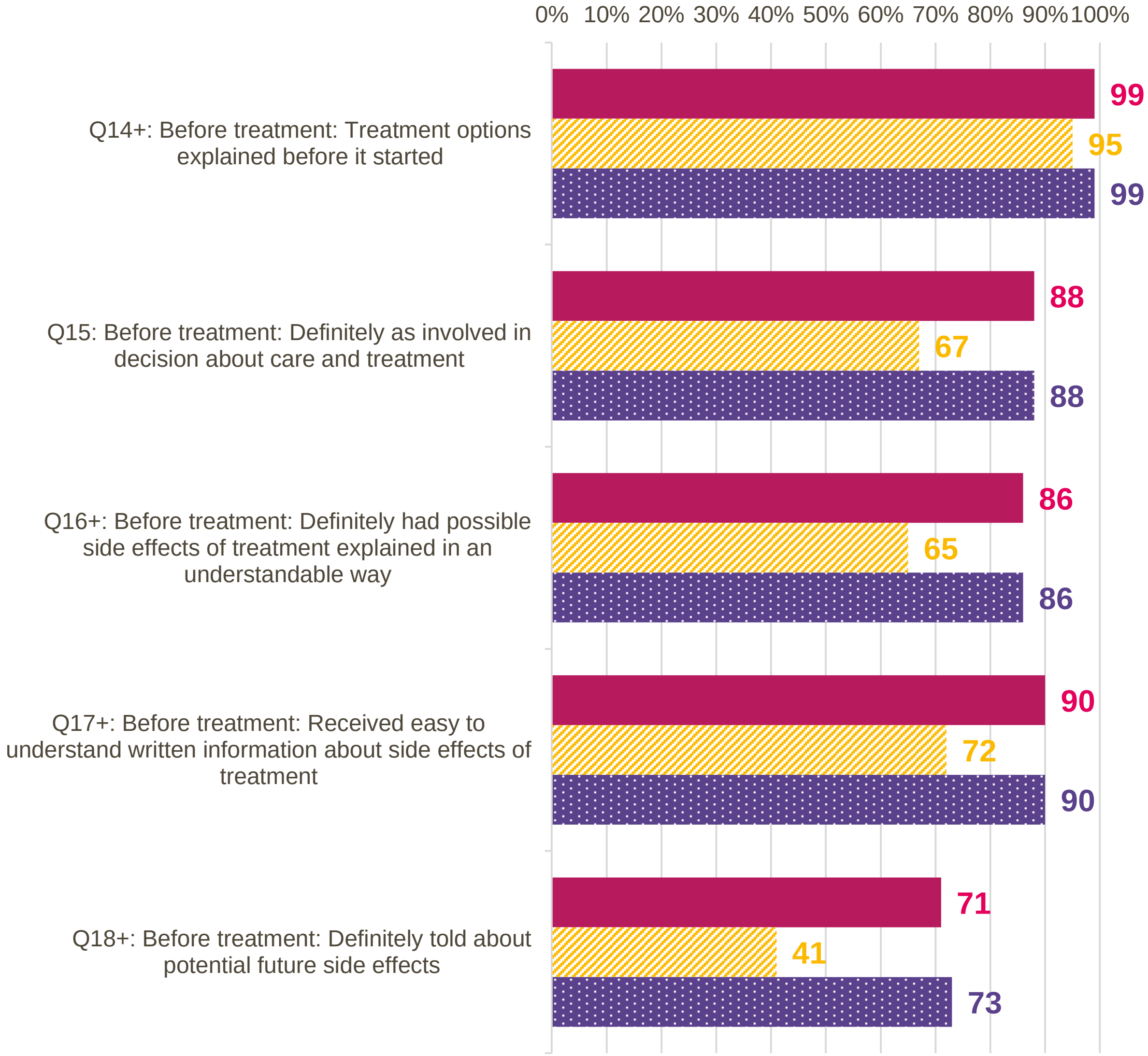
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Deciding the best treatment and/or care for you

These questions are about the decisions made about the best treatment or care.

All respondents



🟥 Respondents who had a care plan

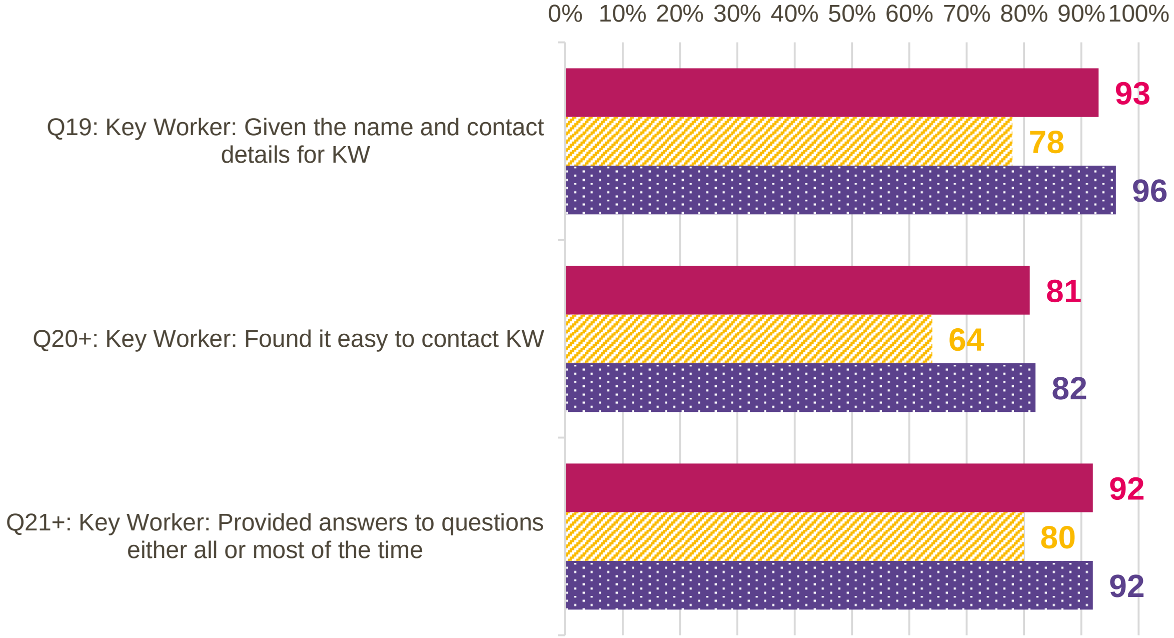
▨ Respondents who did not have a care plan

▦ Respondent who had a written care plan

Establishment of a care plan: Key Worker

These questions are about Key Workers.

Q19: All respondents
Q20+ – Q21+: Respondents who had the name and contact details of a Key Worker



🟥 Respondents who had a care plan

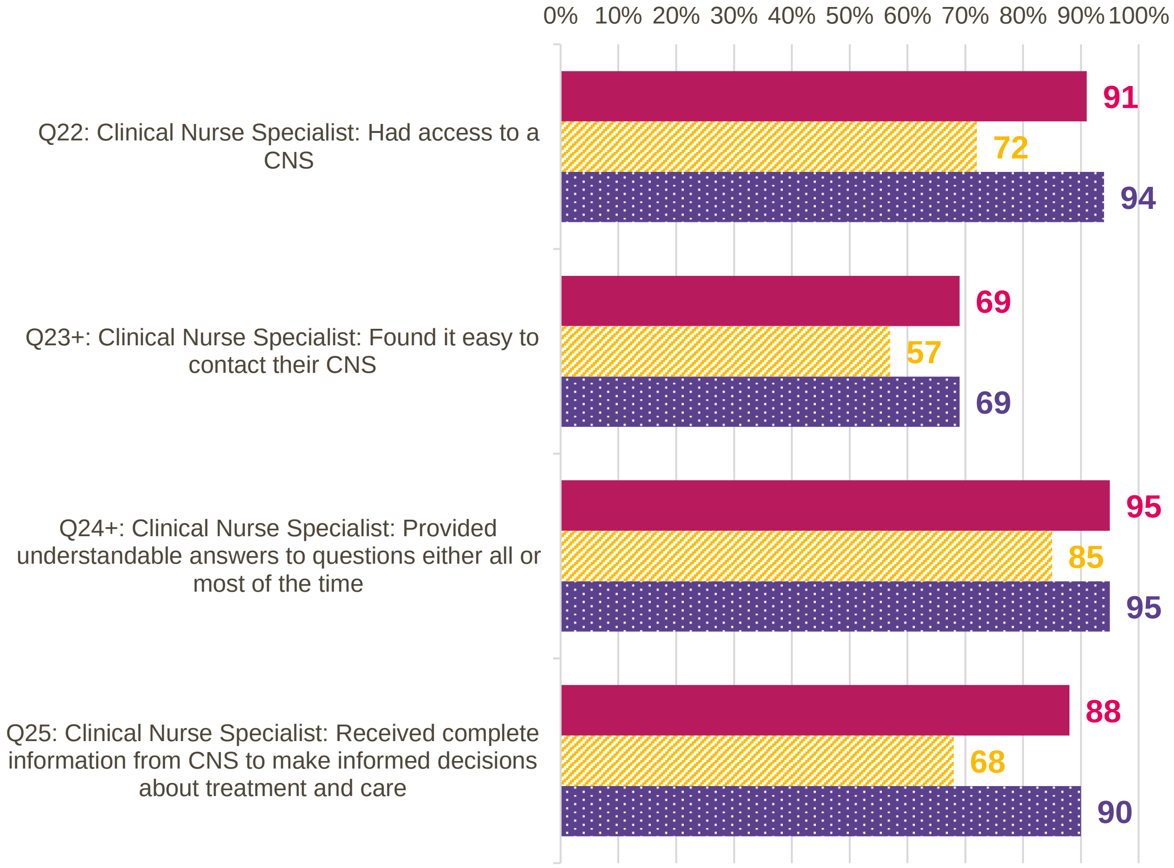
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Clinical Nurse Specialist

These questions are about Clinical Nurse Specialists.

Q22: All respondents
Q23+ – Q25: Respondents who had the name and contact details of a Clinical Nurse Specialist



🟥 Respondents who had a care plan

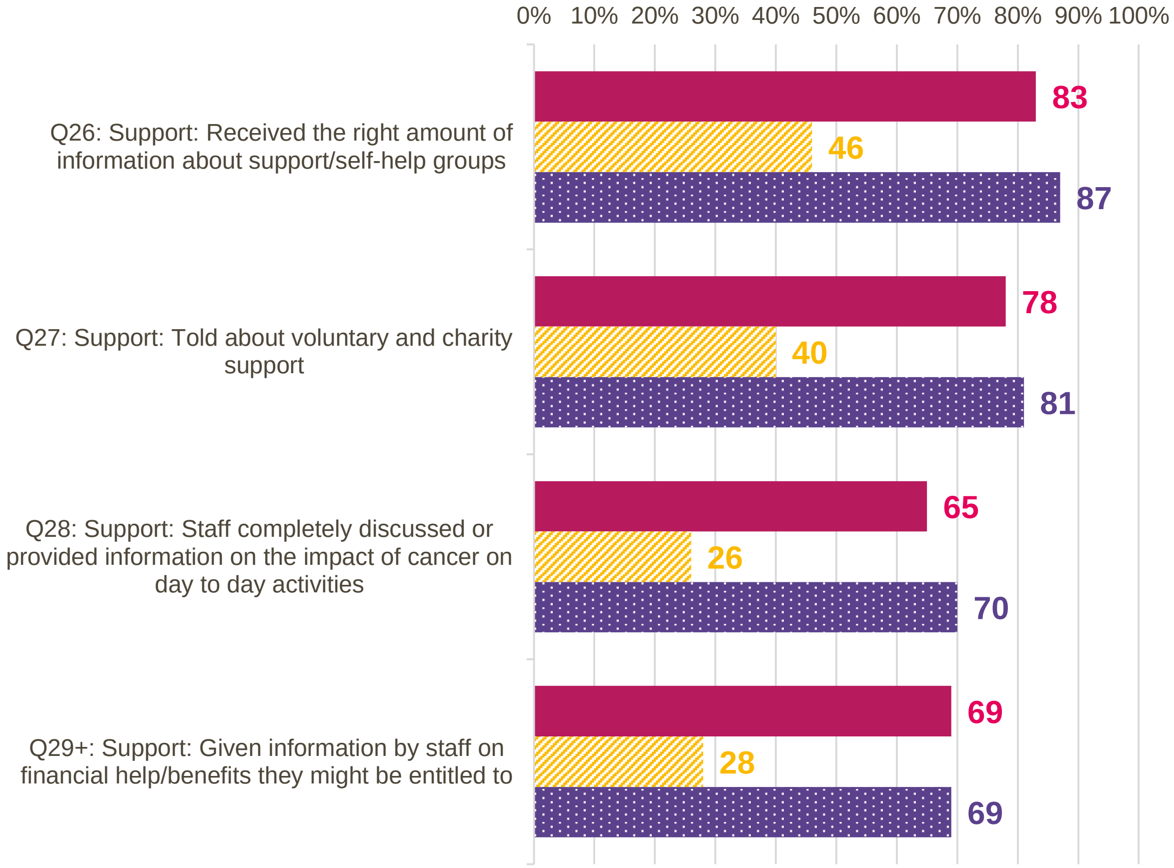
▨ Respondents who did not have a care plan

▒ Respondent who had a written care plan

Establishment of a care plan: Support for people with cancer

These questions are about support for a patient when their cancer treatment first started.

All respondents



🟥 Respondents who had a care plan

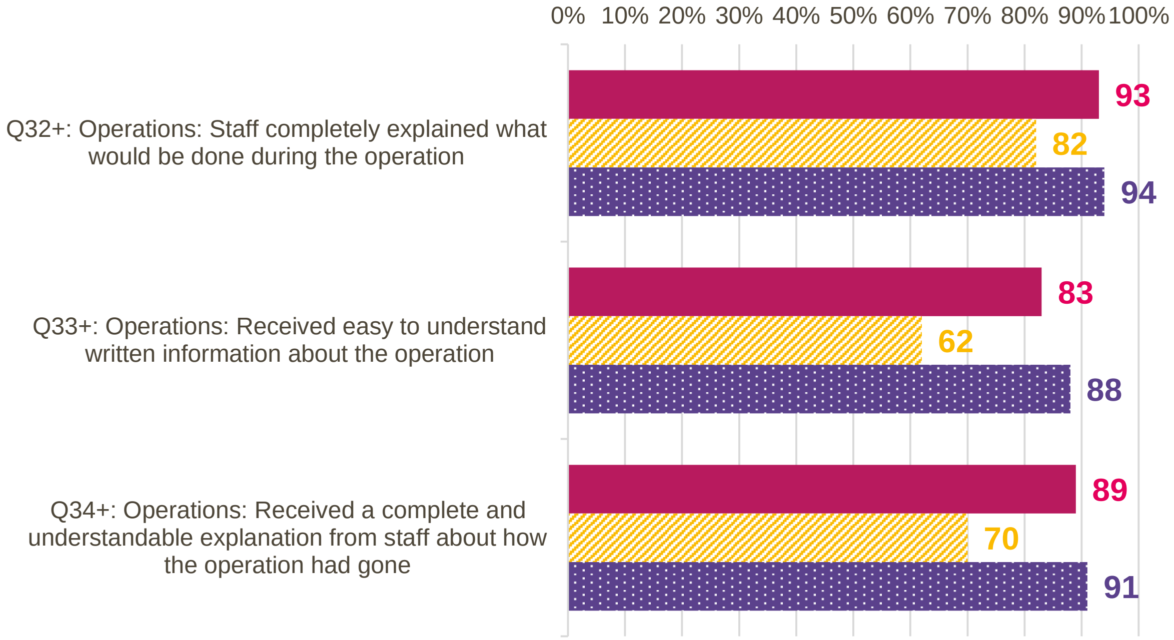
▨ Respondents who did not have a care plan

🟪 Respondent who had a written care plan

Establishment of a care plan: Operations

These questions are about any operation a patient may have had related to their cancer.

Respondents who had an operation for their cancer

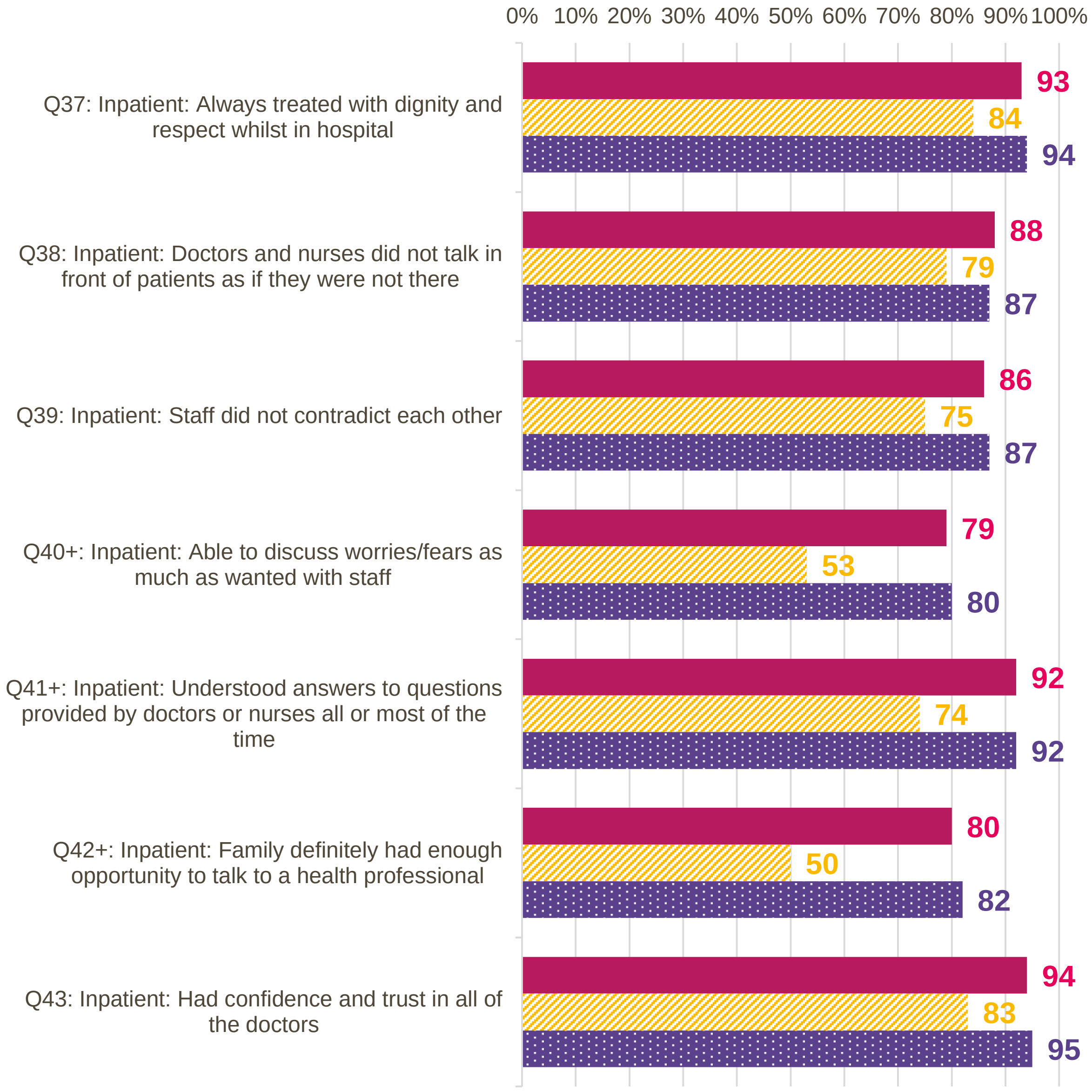


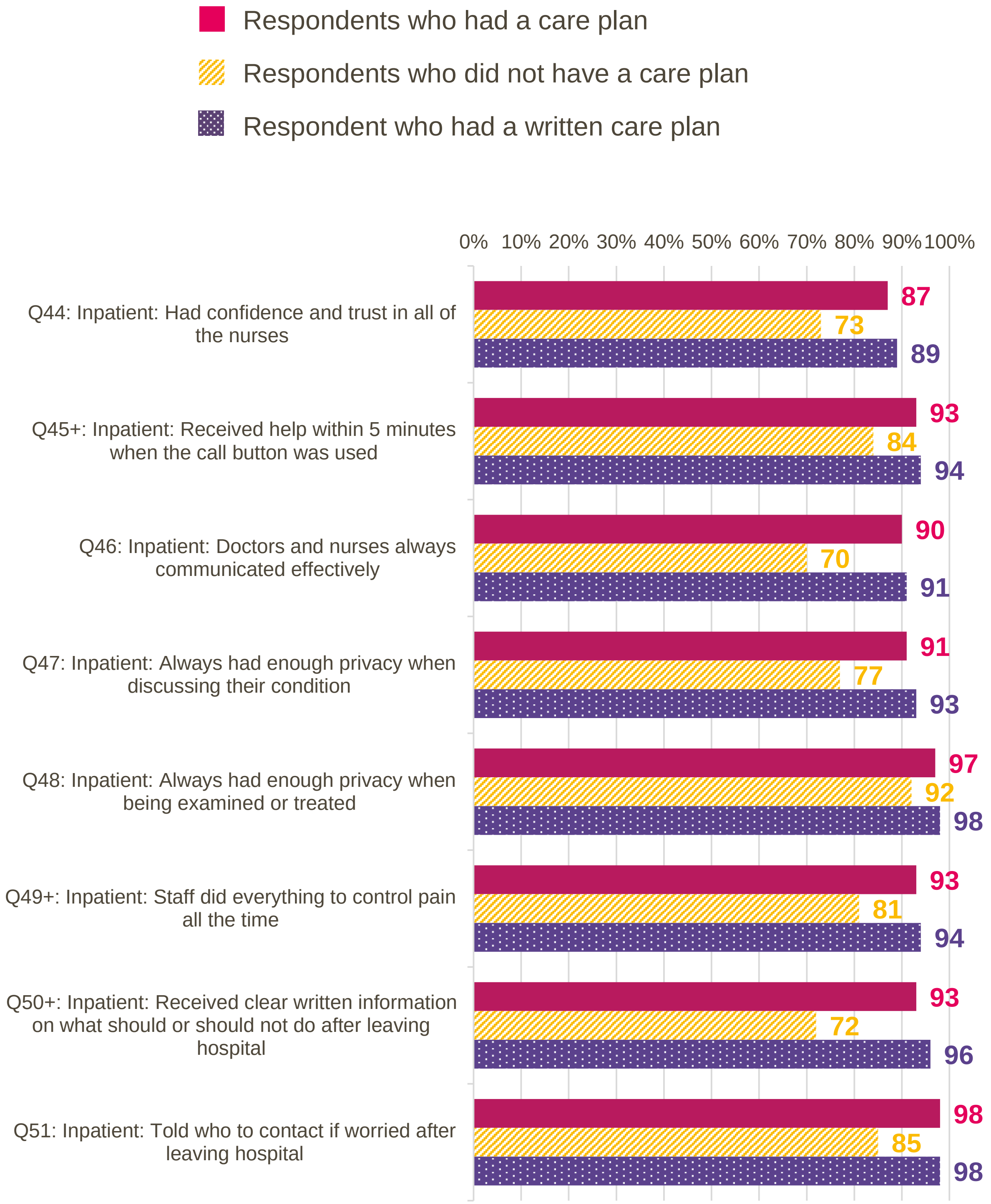
- 🟥 Respondents who had a care plan
- ▨ Respondents who did not have a care plan
- ▦ Respondent who had a written care plan

Establishment of a care plan: Hospital care as an inpatient

These questions are about any inpatient stay in hospital related to cancer treatment.

Respondents who had an operation or stayed overnight for their cancer care




🟥 Respondents who had a care plan
▨ Respondents who did not have a care plan
▩ Respondent who had a written care plan
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Q44: Inpatient: Had confidence and trust in all of the nurses
87
73
89
Q45+: Inpatient: Received help within 5 minutes when the call button was used
93
84
94
Q46: Inpatient: Doctors and nurses always communicated effectively
90
70
91
Q47: Inpatient: Always had enough privacy when discussing their condition
91
77
93
Q48: Inpatient: Always had enough privacy when being examined or treated
97
92
98
Q49+: Inpatient: Staff did everything to control pain all the time
93
81
94
Q50+: Inpatient: Received clear written information on what should or should not do after leaving hospital
93
72
96
Q51: Inpatient: Told who to contact if worried after leaving hospital
98
85
98

🟥 Respondents who had a care plan

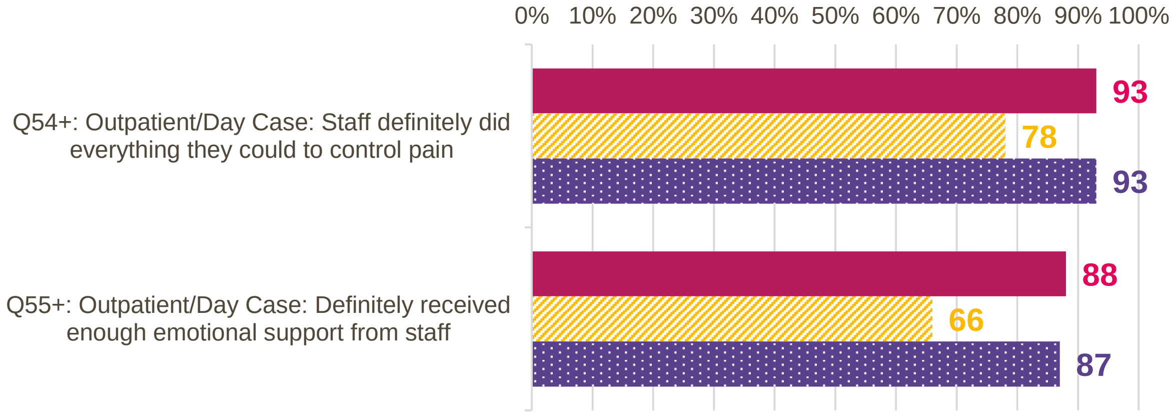
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Outpatients/day case appointments

These questions are about any outpatient or day case appointments related to cancer treatment.

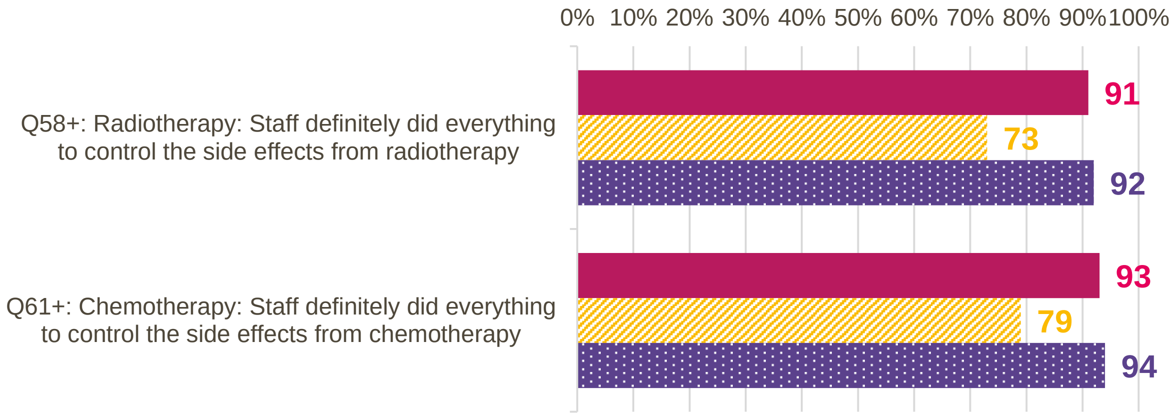
Respondents who had an outpatient or day case appointment



Establishment of a care plan: Radiotherapy/chemotherapy

These questions relate to any radiotherapy or chemotherapy patients may have had.

Q58+: Respondents who had radiotherapy
Q61+: Respondents who had chemotherapy



🟥 Respondents who had a care plan

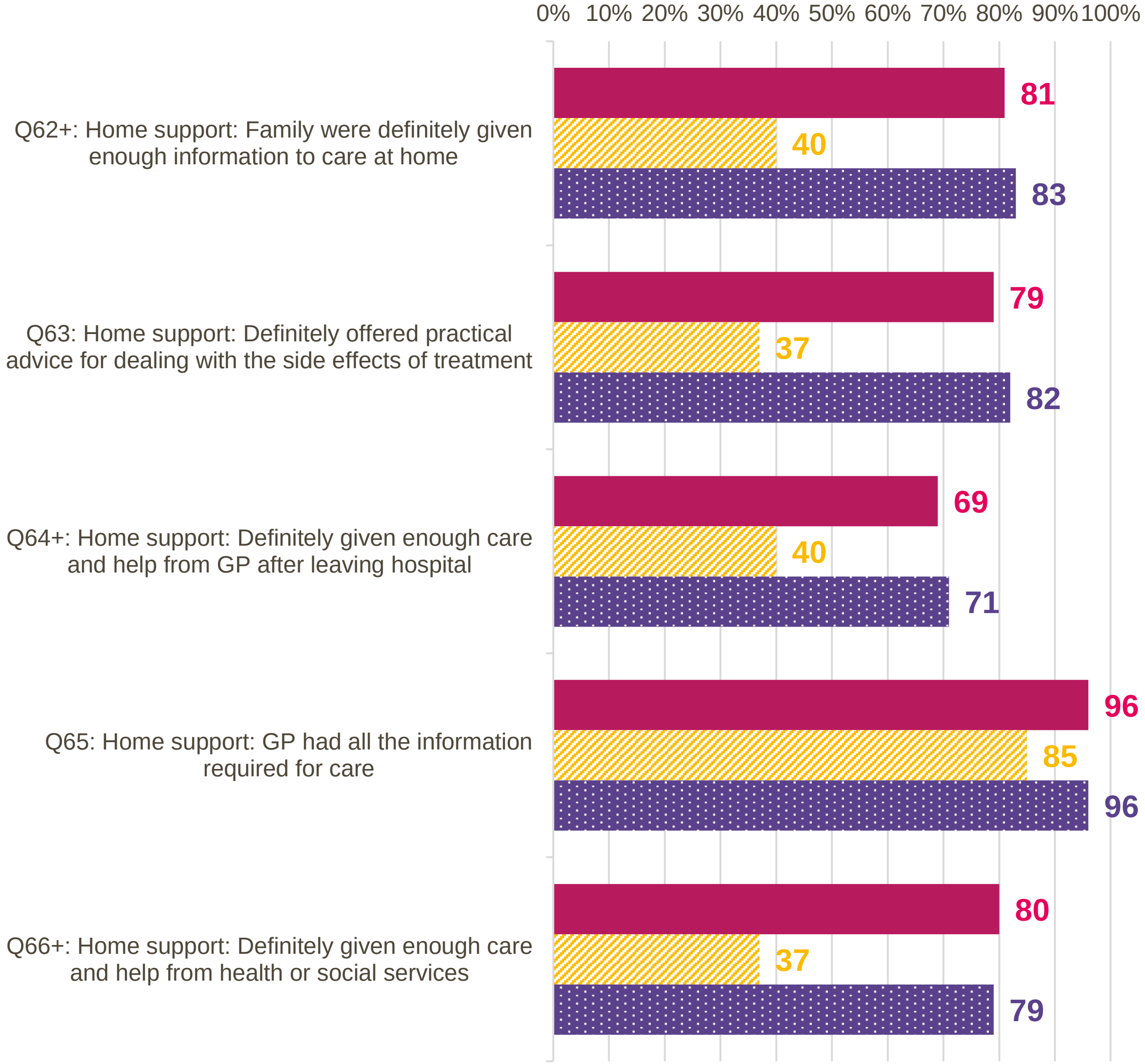
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Arranging home support

These questions are about home support being arranged for when a patient returned home from hospital following care for cancer.

All respondents



🟥 Respondents who had a care plan

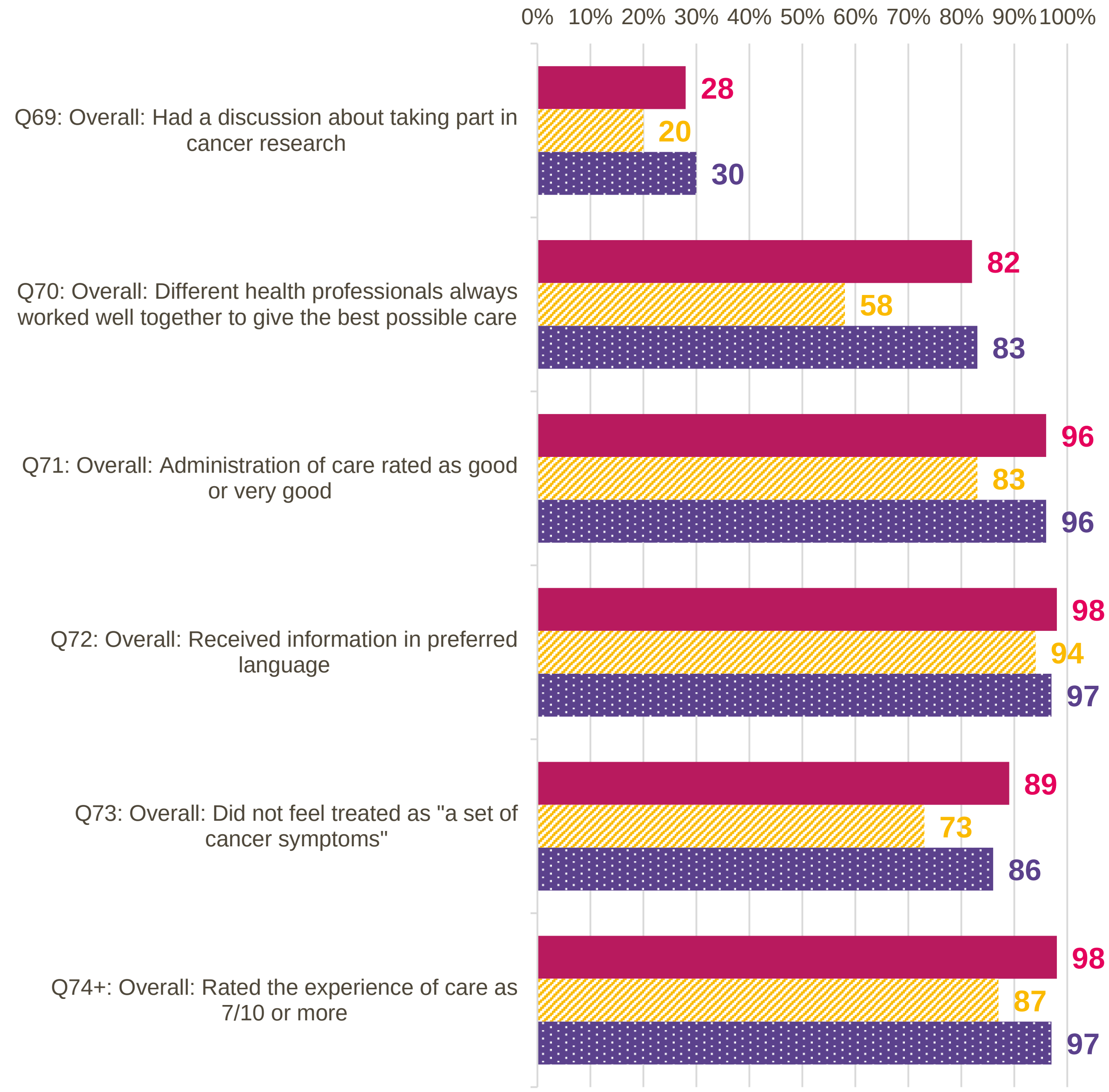
▨ Respondents who did not have a care plan

▩ Respondent who had a written care plan

Establishment of a care plan: Your overall NHS care

These questions relate to patients’ overall experience of the care they received from the NHS.

All respondents



Appendix six: Ranked positive scores

This section ranks all questions in accordance with how highly patients; throughout Wales, rated their experience.

The All Wales score is unadjusted data and includes responses from everyone across Wales.

Question	All Wales
Q14+: Before treatment: Treatment options explained before it started	97
Q72: Overall: Received information in preferred language	96
Q48: Inpatient: Always had enough privacy when being examined or treated	95
Q74+: Overall: Rated the experience of care as 7/10 or more	93
Q51: Inpatient: Told who to contact if worried after leaving hospital	92
Q24+: Clinical nurse specialist: Provided understandable answers to questions either all or most of the time	91
Q65: Home support: GP had all the information required for care	91
Q8+: Before diagnosis: What would be done during test(s) completely explained	90
Q71: Overall: Administration of care rated as good or very good	90
Q37: Inpatient: Always treated with dignity and respect whilst in hospital	89
Q43: Inpatient: Had confidence and trust in all of the doctors	89
Q45+: Inpatient: Received help within 5 minutes when the call button was used	89
Q32+: Operations: Staff completely explained what would be done during the operation	88
Q9+: Before diagnosis: Received written information about test(s) that was easy to understand	87
Q21+: Key Worker: Provided answers to questions either all or most of the time	87
Q49+: Inpatient: Staff did everything to control pain all the time	87
Q61+: Chemotherapy: Staff definitely did everything to control the side effects from chemotherapy	87
Q19: Key Worker: Given the name and contact details for KW	86
Q54+: Outpatient/Day Case: Staff definitely did everything they could to control pain	86

Question	**All Wales**
Q47: Inpatient: Always had enough privacy when discussing their condition	85
Q5: Before diagnosis: Health stayed the same/got better whilst waiting for the first appointment with a hospital doctor	84
Q11: Finding out you had cancer: Told sensitively that they had cancer	84
Q50+: Inpatient: Received clear written information what should or should not do after leaving hospital	84
Q38: Inpatient: Doctors and nurses did not talk in front of patients as if they were not there	83
Q41+: Inpatient: Understood answers to questions provided by doctors or nurses all or most of the time	83
Q58+: Radiotherapy: Staff definitely did everything to control the side effects from radiotherapy	83
Q10+: Before diagnosis: Results of test(s) completely explained	82
Q39: Inpatient: Staff did not contradict each other	82
Q4: Before diagnosis: Were seen as soon as necessary by a hospital doctor	81
Q17+: Before treatment: Received easy to understand written information about side effects of treatment	81
Q22: Clinical nurse specialist: Had access to a CNS	81
Q44: Inpatient: Had confidence and trust in all of the nurses	81
Q73: Overall: Did not feel treated as "a set of cancer symptoms"	81
Q25: Clinical nurse specialist: Received complete information from CNS to make informed decisions about treatment and care	80
Q34+: Operations: Received a complete and understandable explanation from staff about how the operation had gone	80
Q46: Inpatient: Doctors and nurses always communicated effectively	80
Q3+: Before diagnosis: Patients whose GP took symptoms completely seriously	79
Q15: Before treatment: Definitely as involved in decision about care and treatment	78
Q55+: Outpatient/Day Case: Definitely received enough emotional support from staff	78
Q12: Finding out you had cancer: Completely understood the explanation of what was wrong	77

Question	**All Wales**
Q16+: Before treatment: Definitely had possible side effects of treatment explained in an understandable way	75
Q20+: Key Worker: Found it easy to contact KW	74
Q33+: Operations: Received easy to understand written information about the operation	74
Q70: Overall: Different health professionals always worked well together to give the best possible care	71
Q40+: Inpatient: Able to discuss worries/fears as much as wanted with staff	67
Q13+: Finding out you had cancer: Received easy to understand written information about their type of cancer	66
Q42+: Inpatient: Family definitely had enough opportunity to talk to a health professional	66
Q26: Support: Received the right amount of information about support/self-help groups	65
Q23+: Clinical nurse specialist: Found it easy to contact their CNS	64
Q62+: Home support: Family were definitely given enough information to care at home	61
Q63: Home support: Definitely offered practical advice for dealing with the side effects of treatment	59
Q66+: Home support: Definitely given enough care and help from health or social services	59
Q27: Support: Told about voluntary and charity support	58
Q18+: Before treatment: Definitely told about potential future side effects	56
Q64+: Home support: Definitely given enough care and help from GP after leaving hospital	56
Q29+: Support: Given information by staff on financial help/benefits they might be entitled to	48
Q67: Overall: Offered the opportunity to discuss needs and concerns to develop a care plan	48
Q28: Support: Staff completely discussed or provided information on the impact of cancer on day to day activities	45
Q69: Overall: Had a discussion about taking part in cancer research	23
Q68: Overall: Offered a written care plan	18

Appendix seven: Methodological approach

Methodological approach for the theming of respondent comments

Free text comments were collated in an Excel database. A three tier thematic framework was developed and applied to all comments. This thematic framework was then applied to all comments, with 10% of comments being cross-checked by a second reviewer.

1. Developing thematic framework

Tier 1: Tier one themes were applied to all comments such that each comment was assigned a theme of

- “positive”
- “negative”
- “neutral”
- “suggestion”

Tier 2: An initial tier two thematic framework was designed based on

- Stage of the patient pathway through care (e.g. screening, before diagnosis, finding out about cancer, before arrival, admission to hospital)
- Staff groups (e.g. doctors, nurses, Key Worker)
- Elements of treatment (chemotherapy, radiotherapy)
- Aspects of the institution (e.g. hospital and ward environment, cleanliness, food)

One researcher applied the framework all the free text comments, expanding the tier two themes as necessary to accommodate all comments.

Tier 3: Tier three themes were added below each tier two theme to allow more fine-grained analysis. So, for example, under the tier two codes for the different professional groups (doctors, nurses, Key Workers, CNS, other hospital staff) sat the following tier three themes:

- Attitude and empathy
- Availability
- Communication
- Skill/knowledge/professionalism

Two researchers separately examined a subset of 50 responses to each of the three open-ended questions. Where this process identified that adjustments to the framework were needed, these were noted, and the wider team then discussed them until agreement was reached and themes were changed or added. The framework continued to be developed to accommodate additional themes and subthemes as they emerged during the analytic process.

2. Applying thematic framework

Once the three-tier framework was established, it was applied to all comments received. All comments were assigned at least one theme, and each could be allocated with multiple themes. 10% of comments were checked by a second researcher and where discrepancies arose, they were reviewed. If a researcher had any doubts as to which themes to assign a comment it was also flagged for review by the wider team.

Appendix eight: Frequency tables

This section shows a breakdown of responses for each question, across all survey data. It shows how many patients responded to each question and how the positive score was calculated. The response categories that have been combined to calculate the positive score are indicated with an asterisk.

	All Wales
Base	6538
Q1. 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?	
Less than 3 months	3568 54.6%
3-6 months	715 10.9%
6-12 months	309 4.7%
More than 12 months	237 3.6%
I did not think something was wrong with me until I was told	1611 24.6%
Don’t know / can’t remember	98 1.5%

Please note that this data is unadjusted.

	All Wales
Base	6440
Q1. 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?	
Less than 3 months	3568 55.4%
3-6 months	715 11.1%
6-12 months	309 4.8%
More than 12 months	237 3.7%
I did not think something was wrong with me until I was told	1611 25.0%

Please note that this data is unadjusted.

	All Wales
Base	6436
Q2. 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?	
I saw my GP once	2673 41.5%
I saw my GP twice	1114 17.3%
I saw my GP 3 or 4 times	701 10.9%
I saw my GP 5 or more times	346 5.4%
I went straight to hospital following a cancer screening appointment	1086 16.9%
I went straight to hospital via Accident & Emergency	268 4.2%
Don't know / can't remember	248 3.9%

Please note that this data is unadjusted.

	All Wales
Base	6188
Q2. 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?	
I saw my GP once	2673 43.2%
I saw my GP twice	1114 18.0%
I saw my GP 3 or 4 times	701 11.3%
I saw my GP 5 or more times	346 5.6%
I went straight to hospital following a cancer screening appointment	1086 17.6%
I went straight to hospital via Accident & Emergency	268 4.3%

Please note that this data is unadjusted.

	All Wales
Base	6594
Q3. When you first told your GP or hospital doctor about your symptoms, do you feel they took your symptoms seriously?	
Yes, completely	4352 66.0%
Yes, to some extent	659 10.0%
No	514 7.8%
I did not have any symptoms	1033 15.7%
Don't know / can't remember	36 0.5%

	All Wales
Base	5525
Q3+. When you first told your GP or hospital doctor about your symptoms, do you feel they took your symptoms seriously?	
* Yes, completely	4352 78.8%
Yes, to some extent	659 11.9%
No	514 9.3%

Please note that this data is unadjusted.

	All Wales
Base	6557
Q4. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	
* I was seen as soon as I thought was necessary	5290 80.7%
I should have been seen a bit sooner	727 11.1%
I should have been seen a lot sooner	540 8.2%

	All Wales
Base	6569
Q5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?	
My health got worse	1048 16.0%
* My health got better	43 0.7%
* My health stayed about the same	5478 83.4%

Please note that this data is unadjusted.

	All Wales
Base	6432
Q6. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?	
Yes	5504 85.6%
No	928 14.4%

	All Wales
Base	5421
Q7. Did the test(s) take place at the hospital named on the letter that came with this survey?	
Yes	3692 68.1%
No, at another NHS hospital in Wales	1546 28.5%
No, at a private hospital/centre in Wales	80 1.5%
No, somewhere outside Wales	49 0.9%
Don't know / can't remember	54 1.0%

Please note that this data is unadjusted.

	All Wales
Base	5620
Q8. Beforehand, did a member of staff explain what would be done during the test(s) to you?	
Yes, completely	4919 87.5%
Yes, to some extent	523 9.3%
No, but I would have liked an explanation	49 0.9%
I did not need an explanation	101 1.8%
Don't know / can't remember	28 0.5%

	All Wales
Base	5491
Q8+. Beforehand, did a member of staff explain what would be done during the test(s) to you?	
* Yes, completely	4919 89.6%
Yes, to some extent	523 9.5%
No, but I would have liked an explanation	49 0.9%

Please note that this data is unadjusted.

	All Wales
Base	5613
Q9. Beforehand, were you given written information about your test(s)?	
Yes, and it was easy to understand	3587 63.9%
Yes, but it was difficult to understand	143 2.5%
No, I would have liked written information about the test(s)	405 7.2%
I did not need written information	1119 19.9%
Don’t know / can’t remember	359 6.4%

	All Wales
Base	4135
Q9+. Beforehand, were you given written information about your test(s)?	
* Yes, and it was easy to understand	3587 86.7%
Yes, but it was difficult to understand	143 3.5%
No, I would have liked written information about the test(s)	405 9.8%

Please note that this data is unadjusted.

	All Wales
Base	5638
Q10. Were the results of the test(s) explained in a way you could understand?	
Yes, completely	4557 80.8%
Yes, to some extent	914 16.2%
No, I did not understand the explanation	29 0.5%
No, but I would have liked an explanation	59 1.0%
I did not need an explanation	42 0.7%
Don't know / can't remember	37 0.7%

	All Wales
Base	5559
Q10+. Were the results of the test(s) explained in a way you could understand?	
* Yes, completely	4557 82.0%
Yes, to some extent	914 16.4%
No, I did not understand the explanation	29 0.5%
No, but I would have liked an explanation	59 1.1%

Please note that this data is unadjusted.

	All Wales
Base	6640
Q11. How do you feel about the way you were told you had cancer?	
* It was done sensitively	5553 83.6%
It should have been done a bit more sensitively	712 10.7%
It should have been done a lot more sensitively	375 5.6%

	All Wales
Base	6674
Q12. Did you understand the explanation of what was wrong with you?	
Yes, I completely understood it	5134 76.9%
Yes, I understood some of it	1399 21.0%
No, I did not understand it	116 1.7%
Can't remember	25 0.4%

Please note that this data is unadjusted.

	All Wales
Base	6649
Q12+. Did you understand the explanation of what was wrong with you?	
* Yes, I completely understood it	5134 77.2%
Yes, I understood some of it	1399 21.0%
No, I did not understand it	116 1.7%

	All Wales
Base	6591
Q13. When you were told you had cancer, were you given written information about the type of cancer you had?	
Yes, and it was easy to understand	3600 54.6%
Yes, but it was difficult to understand	350 5.3%
No, I was not given written information about the type of cancer I had	1494 22.7%
I did not need written information	786 11.9%
Don’t know / can’t remember	361 5.5%

Please note that this data is unadjusted.

	All Wales
Base	5444
Q13+. When you were told you had cancer, were you given written information about the type of cancer you had?	
* Yes, and it was easy to understand	3600 66.1%
Yes, but it was difficult to understand	350 6.4%
No, I was not given written information about the type of cancer I had	1494 27.4%

	All Wales
Base	6591
Q14. Before your cancer treatment started, were your treatment options explained to you?	
Yes	4924 74.7%
No, but I would have liked a choice	158 2.4%
There was only one type of treatment that was suitable for me	1416 21.5%
Not sure / can't remember	93 1.4%

Please note that this data is unadjusted.

	All Wales
Base	5082
Q14+. Before your cancer treatment started, were your treatment options explained to you?	
* Yes	4924 96.9%
No, but I would have liked a choice	158 3.1%

	All Wales
Base	6632
Q15. Were you involved as much as you wanted to be in decisions about your care and treatment?	
Yes, definitely	5152 77.7%
Yes, to some extent	1218 18.4%
No, but I would like to have been more involved	201 3.0%
Not sure / can't remember	61 0.9%

Please note that this data is unadjusted.

	All Wales
Base	6571
Q15+. Were you involved as much as you wanted to be in decisions about your care and treatment?	
* Yes, definitely	5152 78.4%
Yes, to some extent	1218 18.5%
No, but I would like to have been more involved	201 3.1%

	All Wales
Base	6616
Q16. Were the possible side effects of treatment(s) explained in a way you could understand?	
Yes, definitely	4761 72.0%
Yes, to some extent	1331 20.1%
No, side effects were not explained	233 3.5%
I did not need an explanation	221 3.3%
Not sure / can't remember	70 1.1%

Please note that this data is unadjusted.

	All Wales
Base	6325
Q16+. Were the possible side effects of treatment(s) explained in a way you could understand?	
* Yes, definitely	4761 75.3%
Yes, to some extent	1331 21.0%
No, side effects were not explained	233 3.7%

	All Wales
Base	6503
Q17. Before you started your treatment, were you given written information about the side effects of your treatment(s)?	
Yes, and it was easy to understand	4503 69.2%
Yes, but it was difficult to understand	327 5.0%
No, I was not given any written information about side effects	723 11.1%
I did not need written information	656 10.1%
Don’t know / can’t remember	294 4.5%

Please note that this data is unadjusted.

	All Wales
Base	5553
Q17+. Before you started your treatment, were you given written information about the side effects of your treatment(s)?	
* Yes, and it was easy to understand	4503 81.1%
Yes, but it was difficult to understand	327 5.9%
No, I was not given any written information about side effects	723 13.0%

	All Wales
Base	6497
Q18. 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?	
Yes, definitely	3256 50.1%
Yes, to some extent	1529 23.5%
No, future side effects were not explained	983 15.1%
I did not need an explanation	417 6.4%
Not sure / can't remember	312 4.8%

Please note that this data is unadjusted.

	All Wales
Base	5768
Q18+. 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?	
* Yes, definitely	3256 56.4%
Yes, to some extent	1529 26.5%
No, future side effects were not explained	983 17.0%

	All Wales
Base	6521
Q19. Were you given the name and contact details of your Key Worker?	
Yes	5296 81.2%
No	871 13.4%
Don't know / not sure	354 5.4%

Please note that this data is unadjusted.

	All Wales
Base	6167
Q19. Were you given the name and contact details of your Key Worker?	
* Yes	5296 85.9%
No	871 14.1%

	All Wales
Base	5289
Q20. How easy is it for you to contact your Key Worker?	
Easy	3437 65.0%
Sometimes easy , sometimes difficult	1084 20.5%
Difficult	148 2.8%
I have not tried to contact her/him	620 11.7%

Please note that this data is unadjusted.

	All Wales
Base	4669
Q20+. How easy is it for you to contact your Key Worker?	
* Easy	3437 73.6%
Sometimes easy , sometimes difficult	1084 23.2%
Difficult	148 3.2%

	All Wales
Base	5200
Q21. When you have important questions to ask, how often does your Key Worker help you get answers to your questions?	
All or most of the time	3709 71.3%
Some of the time	438 8.4%
Rarely or never	115 2.2%
I do not ask any questions	938 18.0%

Please note that this data is unadjusted.

	All Wales
Base	4262
Q21+. When you have important questions to ask, how often does your Key Worker help you get answers to your questions?	
* All or most of the time	3709 87.0%
Some of the time	438 10.3%
Rarely or never	115 2.7%

	All Wales
Base	6423
Q22. Did your care include access to a Clinical Nurse Specialist?	
Yes, and this was my Key Worker	3858 60.1%
Yes, but this was not my Key Worker	715 11.1%
No, I did not have a Clinical Nurse Specialist as part of my care team	1047 16.3%
Don’t know / not sure	803 12.5%

Please note that this data is unadjusted.

	All Wales
Base	5620
Q22+. Did your care include access to a Clinical Nurse Specialist?	
* Yes, and this was my Key Worker	3858 68.6%
* Yes, but this was not my Key Worker	715 12.7%
No, I did not have a Clinical Nurse Specialist as part of my care team	1047 18.6%

	All Wales
Base	780
Q23. How easy is it for you to contact your Clinical Nurse Specialist?	
Easy	399 51.2%
Sometimes easy, sometimes difficult	192 24.6%
Difficult	38 4.9%
I have not tried to contact her/him	151 19.4%

Please note that this data is unadjusted.

	All Wales
Base	629
Q23+. How easy is it for you to contact your Clinical Nurse Specialist?	
* Easy	399 63.4%
Sometimes easy, sometimes difficult	192 30.5%
Difficult	38 6.0%

	All Wales
Base	4642
Q24. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	
All or most of the time	3695 79.6%
Some of the time	322 6.9%
Rarely or never	51 1.1%
I do not ask any questions	574 12.4%

Please note that this data is unadjusted.

	All Wales
Base	4068
Q24+. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	
* All or most of the time	3695 90.8%
Some of the time	322 7.9%
Rarely or never	51 1.3%

	All Wales
Base	4588
Q25. Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?	
Yes, completely	3577 78.0%
Yes, to some extent	705 15.4%
No	181 3.9%
Don’t know / can’t remember	125 2.7%

Please note that this data is unadjusted.

	All Wales
Base	4463
Q25+. Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?	
* Yes, completely	3577 80.1%
Yes, to some extent	705 15.8%
No	181 4.1%

	All Wales
Base	6465
Q26. How much information about support or self-help groups did hospital staff give you?	
Not enough	701 10.8%
The right amount	3860 59.7%
Too much	81 1.3%
I was not given any information	1266 19.6%
Don’t know / can’t remember	557 8.6%

Please note that this data is unadjusted.

	All Wales
Base	5908
Q26+. How much information about support or self-help groups did hospital staff give you?	
Not enough	701 11.9%
* The right amount	3860 65.3%
Too much	81 1.4%
I was not given any information	1266 21.4%

	All Wales
Base	6454
Q27. During your care, were you told about voluntary or charity support?	
Yes	3305 51.2%
No	2368 36.7%
Don’t know / can’t remember	781 12.1%

Please note that this data is unadjusted.

	All Wales
Base	5673
Q27+. During your care, were you told about voluntary or charity support?	
* Yes	3305 58.3%
No	2368 41.7%

	All Wales
Base	6458
Q28. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	
Yes, completely	2722 42.1%
Yes, to some extent	1861 28.8%
No	1511 23.4%
Don't know / can't remember	364 5.6%

Please note that this data is unadjusted.

	All Wales
Base	6094
Q28+. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	
* Yes, completely	2722 44.7%
Yes, to some extent	1861 30.5%
No	1511 24.8%

	All Wales
Base	6482
Q29. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	
Yes	1761 27.2%
Yes, but I would have liked more information	375 5.8%
No, but I would have liked information	1504 23.2%
It was not necessary	2633 40.6%
Don't know / can't remember	209 3.2%

Please note that this data is unadjusted.

	All Wales
Base	3640
Q29+. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	
* Yes	1761 48.4%
Yes, but I would have liked more information	375 10.3%
No, but I would have liked information	1504 41.3%

	All Wales
Base	6559
Q30. During the last 12 months, have you had an operation for your cancer (such as removal of a tumour or lump)?	
Yes	3476 53.0%
No	3083 47.0%

Please note that this data is unadjusted.

	All Wales
Base	3401
Q31. Did the operation take place at the hospital named on the letter that came with this survey?	
Yes	2240 65.9%
No, at another NHS hospital in Wales	1023 30.1%
No, at a private hospital/centre in Wales	26 0.8%
No, somewhere outside Wales	82 2.4%
Dont know / can't remember	30 0.9%

	All Wales
Base	3517
Q32. Before you had your operation, did a member of staff explain what would be done during the operation?	
Yes, completely	3041 86.5%
Yes, to some extent	383 10.9%
No, but I would have liked an explanation	36 1.0%
I did not need an explanation	45 1.3%
Don't know / can't remember	12 0.3%

Please note that this data is unadjusted.

	All Wales
Base	3460
Q32+. Before you had your operation, did a member of staff explain what would be done during the operation?	
* Yes, completely	3041 87.9%
Yes, to some extent	383 11.1%
No, but I would have liked an explanation	36 1.0%

	All Wales
Base	3490
Q33. Beforehand, were you given written information about your operation?	
Yes, and it was easy to understand	2071 59.3%
Yes, but it was difficult to understand	116 3.3%
No, I was not given written information about my operation	615 17.6%
I did not need written information	465 13.3%
Don't know / can't remember	223 6.4%

Please note that this data is unadjusted.

	All Wales
Base	2802
Q33+. Beforehand, were you given written information about your operation?	
* Yes, and it was easy to understand	2071 73.9%
Yes, but it was difficult to understand	116 4.1%
No, I was not given written information about my operation	615 21.9%

	All Wales
Base	3514
Q34. After the operation, did a member of staff explain how it had gone in a way you could understand?	
Yes, completely	2760 78.5%
Yes, to some extent	563 16.0%
No, but I would have liked an explanation	128 3.6%
I did not need an explanation	63 1.8%

Please note that this data is unadjusted.

	All Wales
Base	3451
Q34+. After the operation, did a member of staff explain how it had gone in a way you could understand?	
* Yes, completely	2760 80.0%
Yes, to some extent	563 16.3%
No, but I would have liked an explanation	128 3.7%

	All Wales
Base	6473
Q35. During the last 12 months, have you had an operation or stayed overnight for cancer care?	
Yes	3665 56.6%
No	2808 43.4%

Please note that this data is unadjusted.

	All Wales
Base	3632
Q36. Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?	
Yes	2479 68.3%
No, at another NHS hospital in Wales	1018 28.0%
No, at a private hospital/centre in Wales	18 0.5%
No, somewhere outside Wales	84 2.3%
Dont know / can't remember	33 0.9%

	All Wales
Base	3753
Q37. Overall, while you were in hospital, were you treated with dignity and respect?	
* Yes, always	3336 88.9%
Yes, sometimes	356 9.5%
No	61 1.6%

Please note that this data is unadjusted.

	All Wales
Base	3752
Q38. Did doctors and nurses talk in front of you as if you weren’t there?	
Yes, often	126 3.4%
Yes, sometimes	498 13.3%
* No	3128 83.4%

	All Wales
Base	3738
Q39. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?	
Often	84 2.2%
Sometimes	416 11.1%
Only once	189 5.1%
* Never	3049 81.6%

Please note that this data is unadjusted.

	All Wales
Base	3743
Q40. Were you able to discuss any worries or fears with staff during your hospital visit?	
As much as I wanted	2158 57.7%
Most of the time	520 13.9%
Some of the time	375 10.0%
Not at all, but would have liked to	153 4.1%
I did not have any worries or fears	537 14.3%

	All Wales
Base	3206
Q40+. Were you able to discuss any worries or fears with staff during your hospital visit?	
* As much as I wanted	2158 67.3%
Most of the time	520 16.2%
Some of the time	375 11.7%
Not at all, but would have liked to	153 4.8%

Please note that this data is unadjusted.

	All Wales
Base	3749
Q41. When you had important questions to ask a doctor or nurse, how often did you get answers that you could understand?	
All or most of the time	2779 74.1%
Some of the time	499 13.3%
Rarely or never	47 1.3%
I did not ask any questions	424 11.3%

	All Wales
Base	3325
Q41+. When you had important questions to ask a doctor or nurse, how often did you get answers that you could understand?	
* All or most of the time	2779 83.6%
Some of the time	499 15.0%
Rarely or never	47 1.4%

Please note that this data is unadjusted.

	All Wales
Base	3736
Q42. Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?	
Yes, definitely	2239 59.9%
Yes, to some extent	845 22.6%
No	322 8.6%
No family or friends were involved	330 8.8%

	All Wales
Base	3406
Q42+. Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?	
* Yes, definitely	2239 65.7%
Yes, to some extent	845 24.8%
No	322 9.5%

Please note that this data is unadjusted.

	All Wales
Base	3770
Q43. Did you have confidence and trust in the doctors treating you?	
* Yes, in all of them	3360 89.1%
Yes, in some of them	398 10.6%
No, in none of them	12 0.3%

	All Wales
Base	3766
Q44. Did you have confidence and trust in the ward nurses treating you?	
* Yes, in all of them	3038 80.7%
Yes, in some of them	679 18.0%
No, in none of them	49 1.3%

Please note that this data is unadjusted.

	All Wales
Base	3716
Q45. How many minutes after you used the call button did it usually take before you got the help you needed?	
0 minutes / right away	473 12.7%
1-2 minutes	889 23.9%
3-5 minutes	490 13.2%
More than 5 minutes	215 5.8%
I never got help when I used the call button	20 0.5%
I never used the call button	1629 43.8%

	All Wales
Base	2087
Q45+. How many minutes after you used the call button did it usually take before you got the help you needed?	
* 0 minutes / right away	473 22.7%
* 1-2 minutes	889 42.6%
* 3-5 minutes	490 23.5%
More than 5 minutes	215 10.3%
I never got help when I used the call button	20 1.0%

Please note that this data is unadjusted.

	All Wales
Base	3751
Q46. Do you think doctors and nurses communicated effectively with you during your hospital stay?	
* Yes, always	3013 80.3%
Yes, sometimes	656 17.5%
No	82 2.2%

	All Wales
Base	3749
Q47. Were you given enough privacy when discussing your condition or treatment?	
* Yes, always	3193 85.2%
Yes, sometimes	404 10.8%
No	152 4.1%

Please note that this data is unadjusted.

	All Wales
Base	3761
Q48. Were you given enough privacy when being examined or treated?	
* Yes, always	3564 94.8%
Yes, sometimes	162 4.3%
No	35 0.9%

	All Wales
Base	3754
Q49. Do you think the hospital staff did everything they could to help control your pain?	
All of the time	2833 75.5%
Some of the time	365 9.7%
Not at all	40 1.1%
I did not have any pain	516 13.7%

Please note that this data is unadjusted.

	All Wales
Base	3238
Q49+. Do you think the hospital staff did everything they could to help control your pain?	
* All of the time	2833 87.5%
Some of the time	365 11.3%
Not at all	40 1.2%

	All Wales
Base	3757
Q50. Were you given clear written information about what you should or should not do after leaving hospital?	
Yes	2732 72.7%
No	508 13.5%
I did not need written information	380 10.1%
Can't remember	137 3.6%

Please note that this data is unadjusted.

	All Wales
Base	3240
Q50+. Were you given clear written information about what you should or should not do after leaving hospital?	
* Yes	2732 84.3%
No	508 15.7%

	All Wales
Base	3762
Q51. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	
Yes	3340 88.8%
No	275 7.3%
Don't know / can't remember	147 3.9%

Please note that this data is unadjusted.

	All Wales
Base	3615
Q51+. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	
* Yes	3340 92.4%
No	275 7.6%

	All Wales
Base	6517
Q52. In the last 12 months, have you had an outpatients or day case appointment for your cancer?	
Yes	6075 93.2%
No	442 6.8%

Please note that this data is unadjusted.

	All Wales
Base	**5943**
Q53. The last time you attended hospital as a day case or outpatient, was this at the hospital named on the letter that came with this survey?	
Yes	**4444 74.8%**
No, at another NHS hospital in Wales	**1369 23.0%**
No, at a private hospital/centre in Wales	**8 0.1%**
No, somewhere outside Wales	**68 1.1%**
Dont know / can't remember	**54 0.9%**

	All Wales
Base	**6052**
Q54. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?	
Yes, definitely	**2662 44.0%**
Yes, to some extent	**350 5.8%**
No, they could have done more	**80 1.3%**
I did not have any pain	**2960 48.9%**

Please note that this data is unadjusted.

	All Wales
Base	3092
Q54+. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?	
* Yes, definitely	2662 86.1%
Yes, to some extent	350 11.3%
No, they could have done more	80 2.6%

	All Wales
Base	6053
Q55. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?	
Yes, definitely	3456 57.1%
Yes, to some extent	772 12.8%
No, I would have liked more support	210 3.5%
I did not need emotional support from staff	1615 26.7%

Please note that this data is unadjusted.

	All Wales
Base	4438
Q55+. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?	
* Yes, definitely	3456 77.9%
Yes, to some extent	772 17.4%
No, I would have liked more support	210 4.7%

	All Wales
Base	6498
Q56. Have you had radiotherapy treatment?	
Yes	3301 50.8%
No	3197 49.2%

Please note that this data is unadjusted.

	All Wales
Base	**3281**
Q57. Thinking of the last time you had radiotherapy treatment, was this at:	
Glan Clwyd Hospital	**641** **19.5%**
Singleton Hospital	**795** **24.2%**
Velindre Cancer Centre	**1762** **53.7%**
A private hospital/centre in Wales	**3** **0.1%**
Somewhere outside Wales	**79** **2.4%**
Dont know / can't remember	**1** **0.0%**

	All Wales
Base	**3206**
Q58. Did hospital staff do everything possible to control the side effects of radiotherapy?	
Yes, definitely	**2305** **71.9%**
Yes, to some extent	**376** **11.7%**
No, they could have done more	**84** **2.6%**
I have not had any side effects from radiotherapy	**441** **13.8%**

Please note that this data is unadjusted.

	All Wales
Base	2765
Q58+. Did hospital staff do everything possible to control the side effects of radiotherapy?	
* Yes, definitely	2305 83.4%
Yes, to some extent	376 13.6%
No, they could have done more	84 3.0%

	All Wales
Base	6463
Q59. Have you had chemotherapy treatment?	
Yes	3493 54.0%
No	2970 46.0%

Please note that this data is unadjusted.

	All Wales
Base	3425
Q60. Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?	
Yes	2726 79.6%
No, at another NHS hospital in Wales	630 18.4%
No, at a private hospital/centre in Wales	15 0.4%
No, somewhere outside Wales	28 0.8%
Dont know / can't remember	26 0.8%

	All Wales
Base	3525
Q61. Did hospital staff do everything possible to control the side effects of chemotherapy?	
Yes, definitely	2892 82.0%
Yes, to some extent	361 10.2%
No, they could have done more	81 2.3%
I have not had any side effects from chemotherapy	191 5.4%

Please note that this data is unadjusted.

	All Wales
Base	3334
Q61+. Did hospital staff do everything possible to control the side effects of chemotherapy?	
* Yes, definitely	2892 86.7%
Yes, to some extent	361 10.8%
No, they could have done more	81 2.4%

	All Wales
Base	6354
Q62. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	
Yes, definitely	3342 52.6%
Yes, to some extent	1093 17.2%
No	1065 16.8%
No family or friends were involved	854 13.4%

Please note that this data is unadjusted.

	All Wales
Base	5500
Q62+. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	
* Yes, definitely	3342 60.8%
Yes, to some extent	1093 19.9%
No	1065 19.4%

	All Wales
Base	6368
Q63. 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)?	
Yes, definitely	3514 55.2%
Yes, to some extent	1608 25.3%
No, I was not offered any practical advice or support	872 13.7%
Not sure / can’t remember	374 5.9%

Please note that this data is unadjusted.

	All Wales
Base	5994
Q63+. 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)?	
* Yes, definitely	3514 58.6%
Yes, to some extent	1608 26.8%
No, I was not offered any practical advice or support	872 14.5%

	All Wales
Base	6459
Q64. After leaving hospital, were you given enough care and help from your GP and the GP surgery?	
Yes, definitely	2617 40.5%
Yes, to some extent	1216 18.8%
No	877 13.6%
I did not need help	1696 26.3%
Don’t know / can’t remember	53 0.8%

Please note that this data is unadjusted.

	All Wales
Base	4710
Q64+. After leaving hospital, were you given enough care and help from your GP and the GP surgery?	
* Yes, definitely	2617 55.6%
Yes, to some extent	1216 25.8%
No	877 18.6%

	All Wales
Base	6473
Q65. As far as you know, did your GP have all the information they needed about your care after leaving hospital?	
Yes	4238 65.5%
No	403 6.2%
Don’t know / can’t remember	1832 28.3%

Please note that this data is unadjusted.

	All Wales
Base	4641
Q65+. As far as you know, did your GP have all the information they needed about your care after leaving hospital?	
* Yes	4238 91.3%
No	403 8.7%

	All Wales
Base	6439
Q66. After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?	
Yes, definitely	2227 34.6%
Yes, to some extent	726 11.3%
No	793 12.3%
I did not need help	2649 41.1%
Don’t know / can’t remember	44 0.7%

Please note that this data is unadjusted.

	All Wales
Base	3746
Q66+. After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?	
* Yes, definitely	2227 59.5%
Yes, to some extent	726 19.4%
No	793 21.2%

	All Wales
Base	6309
Q67. Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?	
Yes	2635 41.8%
No	2839 45.0%
Don’t know / can’t remember	835 13.2%

Please note that this data is unadjusted.

	All Wales
Base	5474
Q67+. Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?	
* Yes	2635 48.1%
No	2839 51.9%

	All Wales
Base	6322
Q68. Have you been offered a written care plan?	
Yes	1003 15.9%
No	4512 71.4%
Don’t know / can’t remember	807 12.8%

	All Wales
Base	5515
Q68+. Have you been offered a written care plan?	
* Yes	1003 18.2%
No	4512 81.8%

Please note that this data is unadjusted.

	All Wales
Base	6489
Q69. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?	
Yes	1441 22.2%
No	4788 73.8%
Don't know / can't remember	260 4.0%

	All Wales
Base	6229
Q69+. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?	
* Yes	1441 23.1%
No	4788 76.9%

Please note that this data is unadjusted.

	All Wales
Base	6447
Q70. Since your diagnosis, have the different professionals treating and caring for you worked well together to give you the best possible care?	
Yes, always	4342 67.3%
Yes, most of the time	1201 18.6%
Yes, some of the time	411 6.4%
No, never	173 2.7%
Don’t know	320 5.0%

	All Wales
Base	6127
Q70+. Since your diagnosis, have the different professionals treating and caring for you worked well together to give you the best possible care?	
* Yes, always	4342 70.9%
Yes, most of the time	1201 19.6%
Yes, some of the time	411 6.7%
No, never	173 2.8%

Please note that this data is unadjusted.

	All Wales
Base	6502
Q71. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?	
Very good	4173 64.2%
Good	1602 24.6%
Neither good nor bad	421 6.5%
Quite bad	175 2.7%
Very bad	72 1.1%
Don’t know / can’t remember	59 0.9%

Please note that this data is unadjusted.

	All Wales
Base	6443
Q71+. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?	
* Very good	4173 64.8%
* Good	1602 24.9%
Neither good nor bad	421 6.5%
Quite bad	175 2.7%
Very bad	72 1.1%

	All Wales
Base	6495
Q72. During your care, did you receive the information you needed in your preferred language?	
Yes, completely	6213 95.7%
Yes, to some extent	177 2.7%
No	83 1.3%
Don’t know / can’t remember	22 0.3%

Please note that this data is unadjusted.

	All Wales
Base	6473
Q72+. During your care, did you receive the information you needed in your preferred language?	
* Yes, completely	6213 96.0%
Yes, to some extent	177 2.7%
No	83 1.3%

	All Wales
Base	6427
Q73. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?	
Yes, often	311 4.8%
Yes, sometimes	880 13.7%
* No	5236 81.5%

Please note that this data is unadjusted.

	All Wales
Base	6351
Q74. Overall how would you rate your care?	
0 - I had a very poor experience	14 0.2%
1	23 0.4%
2	21 0.3%
3	28 0.4%
4	50 0.8%
5	124 2.0%
6	174 2.7%
7	382 6.0%
8	1166 18.4%
9	1511 23.8%
10 - I had a very good experience	2858 45.0%

Please note that this data is unadjusted.

	All Wales
Base	6351
Q74+. Overall how would you rate your care?	
0 - I had a very poor experience	14 0.2%
1	23 0.4%
2	21 0.3%
3	28 0.4%
4	50 0.8%
5	124 2.0%
6	174 2.7%
* 7	382 6.0%
* 8	1166 18.4%
* 9	1511 23.8%
* 10 - I had a very good experience	2858 45.0%

Please note that this data is unadjusted.

	All Wales
Base	**6479**
Q75. How long is it since you were first treated for this cancer?	
Less than 1 year	**2754 42.5%**
1 to 5 years	**3176 49.0%**
More than 5 years	**528 8.1%**
Don’t know / can’t remember	**21 0.3%**

	All Wales
Base	**6477**
Q76. Is this the first time you have been treated for cancer?	
Yes, this is the first time I have been treated for cancer	**5185 80.1%**
No, I have been treated for the same type of cancer before but it has now come back	**645 10.0%**
No, I have been treated for a different type of cancer before	**619 9.6%**
Don't know	**28 0.4%**

Please note that this data is unadjusted.

	All Wales
Base	652
Q77. When your cancer came back did it:	
Come back only in the same place as before	327 50.2%
Spread to somewhere else in the body	325 49.8%

	All Wales
Base	6017
Q78. How has your cancer responded to treatment?	
My cancer has responded fully to treatment (I have no signs or symptoms of cancer)	3373 56.1%
My cancer has been treated but is still present	1374 22.8%
My cancer has not been treated at all	103 1.7%
My cancer has come back after it was originally treated	196 3.3%
My original cancer responded but I now have a new cancer	221 3.7%
I am not certain what is happening with my cancer	750 12.5%

Please note that this data is unadjusted.

	All Wales
Base	6370
Q79. What year were you born? (Converted to age band)	
Under 20	5 0.1%
20-29	19 0.3%
30-39	97 1.5%
40-49	305 4.8%
50-59	1010 15.9%
60-69	1969 30.9%
70-79	2108 33.1%
80-89	791 12.4%
90+	66 1.0%

Please note that this data is unadjusted.

	All Wales
Base	6482
Q80. Are you male or female	
Male	3116 48.1%
Female	3363 51.9%
Transgender	1 0.0%
Prefer not to say	2 0.0%

	All Wales
Base	6299
Q81. Which of the following best describes how you think of yourself?	
Heterosexual / straight (opposite sex)	6077 96.5%
Bisexual (both sexes)	14 0.2%
Gay or lesbian (same sex)	33 0.5%
Other	37 0.6%
Prefer not to answer	138 2.2%

Please note that this data is unadjusted.

	All Wales
Base	6474
Q82. What is your main employment status?	
Full time employment	887 13.7%
Part time employment	488 7.5%
Homemaker	158 2.4%
Student (in education)	6 0.1%
Retired	4358 67.3%
Unemployed - and seeking work	26 0.4%
Unemployed - unable to work for health reasons	407 6.3%
Other	144 2.2%

Please note that this data is unadjusted.

	All Wales
Base	6207
Q83. Do you have any of the following longstanding conditions?	
Deafness or severe hearing impairment	881 14.2%
Blindness or partially sighted	179 2.9%
A long-standing physical condition	1185 19.1%
A learning disability	47 0.8%
A mental health condition	224 3.6%
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	932 15.0%
No, I do not have a longstanding condition	3710 59.8%

	All Wales
Base	6450
Q84. Could we send you a survey in the future to ask about your health and healthcare?	
Yes, and I understand that this does NOT mean that I would have to take part in the future survey	5305 82.2%
No, I would prefer you not to contact me again	1145 17.8%

Please note that this data is unadjusted.

	All Wales
Base	6519
Q85. To which of these ethnic groups would you say you belong?	
White - English/ Welsh/ Scottish/ Northern Irish/ British	6388 98.0%
White - Irish	28 0.4%
White - Gypsy or Irish Traveller	1 0.0%
Any other White background	52 0.8%
Mixed / Multiple Ethnic groups - White & Black Caribbean	1 0.0%
Mixed / Multiple Ethnic groups - White & Black African	4 0.1%
Mixed / Multiple Ethnic groups - White and Asian	2 0.0%
Any other Mixed/ Multiple Ethnic background	2 0.0%
Asian / Asian British - Indian	10 0.2%
Asian/ Asian British - Pakistani	2 0.0%
Asian/ Asian British - Bangladeshi	2 0.0%
Asian/ Asian British - Chinese	8 0.1%
Any other Asian background	5 0.1%
Black / African / Caribbean/ Black British - African	3 0.0%
Black / African/ Caribbean / Black British - Caribbean	4 0.1%
Any other Black / African / Caribbean background	3 0.0%

Please note that this data is unadjusted.

	All Wales
Base	6519
Other Ethnic Group - Arab	2 0.0%
Any other ethnic group	2 0.0%

Please note that this data is unadjusted.

Appendix nine: Tumour group frequency tables

This section shows a breakdown of responses for each question by tumour group. It shows how many patients responded to each question and how the positive score was calculated. The response categories that have been combined to calculate the positive score are indicated with an asterisk.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1515	795	345	595	227	308	931	58	138	236	657	696
Q1. 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?													
Less than 3 months	17 45.9%	803 53.0%	400 50.3%	221 64.1%	338 56.8%	143 63.0%	165 53.6%	406 43.6%	34 58.6%	83 60.1%	150 63.6%	411 62.6%	397 57.0%
3-6 months	3 8.1%	87 5.7%	113 14.2%	45 13.0%	64 10.8%	46 20.3%	28 9.1%	111 11.9%	8 13.8%	18 13.0%	20 8.5%	71 10.8%	101 14.5%
6-12 months	1 2.7%	51 3.4%	40 5.0%	17 4.9%	26 4.4%	15 6.6%	16 5.2%	58 6.2%	4 6.9%	8 5.8%	16 6.8%	25 3.8%	32 4.6%
More than 12 months	- -	30 2.0%	32 4.0%	13 3.8%	26 4.4%	7 3.1%	5 1.6%	45 4.8%	7 12.1%	8 5.8%	9 3.8%	23 3.5%	32 4.6%
I did not think something was wrong with me until I was told	16 43.2%	537 35.4%	192 24.2%	45 13.0%	134 22.5%	14 6.2%	90 29.2%	291 31.3%	4 6.9%	19 13.8%	41 17.4%	112 17.0%	116 16.7%
Don’t know / can’t remember	- -	7 0.5%	18 2.3%	4 1.2%	7 1.2%	2 0.9%	4 1.3%	20 2.1%	1 1.7%	2 1.4%	- -	15 2.3%	18 2.6%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1508	777	341	588	225	304	911	57	136	236	642	678
Q1. 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?													
Less than 3 months	17 45.9%	803 53.2%	400 51.5%	221 64.8%	338 57.5%	143 63.6%	165 54.3%	406 44.6%	34 59.6%	83 61.0%	150 63.6%	411 64.0%	397 58.6%
3-6 months	3 8.1%	87 5.8%	113 14.5%	45 13.2%	64 10.9%	46 20.4%	28 9.2%	111 12.2%	8 14.0%	18 13.2%	20 8.5%	71 11.1%	101 14.9%
6-12 months	1 2.7%	51 3.4%	40 5.1%	17 5.0%	26 4.4%	15 6.7%	16 5.3%	58 6.4%	4 7.0%	8 5.9%	16 6.8%	25 3.9%	32 4.7%
More than 12 months	- -	30 2.0%	32 4.1%	13 3.8%	26 4.4%	7 3.1%	5 1.6%	45 4.9%	7 12.3%	8 5.9%	9 3.8%	23 3.6%	32 4.7%
I did not think something was wrong with me until I was told	16 43.2%	537 35.6%	192 24.7%	45 13.2%	134 22.8%	14 6.2%	90 29.6%	291 31.9%	4 7.0%	19 14.0%	41 17.4%	112 17.4%	116 17.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1475	789	337	588	228	296	927	58	140	232	647	683
Q2. 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?													
I saw my GP once	11 30.6%	680 46.1%	278 35.2%	149 44.2%	187 31.8%	100 43.9%	77 26.0%	393 42.4%	23 39.7%	98 70.0%	95 40.9%	292 45.1%	290 42.5%
I saw my GP twice	5 13.9%	93 6.3%	139 17.6%	66 19.6%	124 21.1%	56 24.6%	73 24.7%	229 24.7%	8 13.8%	17 12.1%	44 19.0%	132 20.4%	128 18.7%
I saw my GP 3 or 4 times	1 2.8%	31 2.1%	101 12.8%	45 13.4%	108 18.4%	35 15.4%	44 14.9%	120 12.9%	9 15.5%	14 10.0%	32 13.8%	68 10.5%	93 13.6%
I saw my GP 5 or more times	2 5.6%	12 0.8%	46 5.8%	22 6.5%	71 12.1%	12 5.3%	28 9.5%	45 4.9%	8 13.8%	3 2.1%	21 9.1%	29 4.5%	47 6.9%
I went straight to hospital following a cancer screening appointment	1 2.8%	627 42.5%	145 18.4%	29 8.6%	37 6.3%	14 6.1%	36 12.2%	61 6.6%	3 5.2%	4 2.9%	14 6.0%	50 7.7%	65 9.5%
I went straight to hospital via Accident & Emergency	13 36.1%	10 0.7%	54 6.8%	19 5.6%	36 6.1%	2 0.9%	23 7.8%	28 3.0%	6 10.3%	- -	18 7.8%	35 5.4%	24 3.5%
Don't know / can't remember	3 8.3%	22 1.5%	26 3.3%	7 2.1%	25 4.3%	9 3.9%	15 5.1%	51 5.5%	1 1.7%	4 2.9%	8 3.4%	41 6.3%	36 5.3%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	33	1453	763	330	563	219	281	876	57	136	224	606	647
Q2. 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?													
I saw my GP once	11 33.3%	680 46.8%	278 36.4%	149 45.2%	187 33.2%	100 45.7%	77 27.4%	393 44.9%	23 40.4%	98 72.1%	95 42.4%	292 48.2%	290 44.8%
I saw my GP twice	5 15.2%	93 6.4%	139 18.2%	66 20.0%	124 22.0%	56 25.6%	73 26.0%	229 26.1%	8 14.0%	17 12.5%	44 19.6%	132 21.8%	128 19.8%
I saw my GP 3 or 4 times	1 3.0%	31 2.1%	101 13.2%	45 13.6%	108 19.2%	35 16.0%	44 15.7%	120 13.7%	9 15.8%	14 10.3%	32 14.3%	68 11.2%	93 14.4%
I saw my GP 5 or more times	2 6.1%	12 0.8%	46 6.0%	22 6.7%	71 12.6%	12 5.5%	28 10.0%	45 5.1%	8 14.0%	3 2.2%	21 9.4%	29 4.8%	47 7.3%
I went straight to hospital following a cancer screening appointment	1 3.0%	627 43.2%	145 19.0%	29 8.8%	37 6.6%	14 6.4%	36 12.8%	61 7.0%	3 5.3%	4 2.9%	14 6.3%	50 8.3%	65 10.0%
I went straight to hospital via Accident & Emergency	13 39.4%	10 0.7%	54 7.1%	19 5.8%	36 6.4%	2 0.9%	23 8.2%	28 3.2%	6 10.5%	- -	18 8.0%	35 5.8%	24 3.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1508	807	344	601	229	308	946	60	139	240	669	706
Q3. When you first told your GP or hospital doctor about your symptoms, do you feel they took your symptoms seriously?													
Yes, completely	20 54.1%	921 61.1%	522 64.7%	248 72.1%	359 59.7%	160 69.9%	191 62.0%	658 69.6%	32 53.3%	111 79.9%	163 67.9%	502 75.0%	465 65.9%
Yes, to some extent	4 10.8%	81 5.4%	81 10.0%	42 12.2%	90 15.0%	29 12.7%	34 11.0%	92 9.7%	10 16.7%	10 7.2%	21 8.8%	71 10.6%	94 13.3%
No	5 13.5%	50 3.3%	71 8.8%	22 6.4%	74 12.3%	32 14.0%	34 11.0%	38 4.0%	15 25.0%	9 6.5%	35 14.6%	43 6.4%	86 12.2%
I did not have any symptoms	8 21.6%	454 30.1%	126 15.6%	31 9.0%	75 12.5%	7 3.1%	48 15.6%	153 16.2%	3 5.0%	8 5.8%	21 8.8%	46 6.9%	53 7.5%
Don't know / can't remember	- -	2 0.1%	7 0.9%	1 0.3%	3 0.5%	1 0.4%	1 0.3%	5 0.5%	- -	1 0.7%	- -	7 1.0%	8 1.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	29	1052	674	312	523	221	259	788	57	130	219	616	645
Q3+. When you first told your GP or hospital doctor about your symptoms, do you feel they took your symptoms seriously?													
* Yes, completely	20 69.0%	921 87.5%	522 77.4%	248 79.5%	359 68.6%	160 72.4%	191 73.7%	658 83.5%	32 56.1%	111 85.4%	163 74.4%	502 81.5%	465 72.1%
Yes, to some extent	4 13.8%	81 7.7%	81 12.0%	42 13.5%	90 17.2%	29 13.1%	34 13.1%	92 11.7%	10 17.5%	10 7.7%	21 9.6%	71 11.5%	94 14.6%
No	5 17.2%	50 4.8%	71 10.5%	22 7.1%	74 14.1%	32 14.5%	34 13.1%	38 4.8%	15 26.3%	9 6.9%	35 16.0%	43 7.0%	86 13.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1502	799	339	599	226	308	946	57	139	240	664	703
Q4. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?													
* I was seen as soon as I thought was necessary	24 68.6%	1246 83.0%	627 78.5%	281 82.9%	473 79.0%	178 78.8%	270 87.7%	785 83.0%	39 68.4%	114 82.0%	177 73.8%	551 83.0%	525 74.7%
I should have been seen a bit sooner	4 11.4%	167 11.1%	93 11.6%	31 9.1%	58 9.7%	24 10.6%	22 7.1%	124 13.1%	8 14.0%	14 10.1%	23 9.6%	68 10.2%	91 12.9%
I should have been seen a lot sooner	7 20.0%	89 5.9%	79 9.9%	27 8.0%	68 11.4%	24 10.6%	16 5.2%	37 3.9%	10 17.5%	11 7.9%	40 16.7%	45 6.8%	87 12.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1508	799	340	594	225	310	948	59	141	240	667	702
Q5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?													
My health got worse	11 30.6%	88 5.8%	163 20.4%	70 20.6%	175 29.5%	47 20.9%	56 18.1%	66 7.0%	20 33.9%	6 4.3%	71 29.6%	104 15.6%	171 24.4%
* My health got better	1 2.8%	4 0.3%	7 0.9%	1 0.3%	5 0.8%	1 0.4%	4 1.3%	7 0.7%	1 1.7%	2 1.4%	3 1.3%	6 0.9%	1 0.1%
* My health stayed about the same	24 66.7%	1416 93.9%	629 78.7%	269 79.1%	414 69.7%	177 78.7%	250 80.6%	875 92.3%	38 64.4%	133 94.3%	166 69.2%	557 83.5%	530 75.5%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1476	797	331	577	223	307	914	59	136	234	647	695
Q6. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?													
Yes	33 91.7%	1314 89.0%	721 90.5%	261 78.9%	413 71.6%	199 89.2%	281 91.5%	715 78.2%	52 88.1%	101 74.3%	217 92.7%	594 91.8%	603 86.8%
No	3 8.3%	162 11.0%	76 9.5%	70 21.1%	164 28.4%	24 10.8%	26 8.5%	199 21.8%	7 11.9%	35 25.7%	17 7.3%	53 8.2%	92 13.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	30	1290	704	268	412	197	270	709	50	101	203	593	594
Q7. Did the test(s) take place at the hospital named on the letter that came with this survey?													
Yes	20 66.7%	772 59.8%	518 73.6%	192 71.6%	318 77.2%	127 64.5%	165 61.1%	480 67.7%	32 64.0%	72 71.3%	127 62.6%	484 81.6%	385 64.8%
No, at another NHS hospital in Wales	9 30.0%	452 35.0%	173 24.6%	71 26.5%	81 19.7%	65 33.0%	97 35.9%	213 30.0%	16 32.0%	26 25.7%	67 33.0%	96 16.2%	180 30.3%
No, at a private hospital/centre in Wales	- -	46 3.6%	6 0.9%	4 1.5%	- -	1 0.5%	- -	6 0.8%	- -	- -	3 1.5%	4 0.7%	10 1.7%
No, somewhere outside Wales	1 3.3%	7 0.5%	6 0.9%	- -	7 1.7%	1 0.5%	4 1.5%	5 0.7%	2 4.0%	1 1.0%	4 2.0%	2 0.3%	9 1.5%
Don't know / can't remember	- -	13 1.0%	1 0.1%	1 0.4%	6 1.5%	3 1.5%	4 1.5%	5 0.7%	- -	2 2.0%	2 1.0%	7 1.2%	10 1.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1351	731	271	425	197	285	737	52	104	218	609	608
Q8. Beforehand, did a member of staff explain what would be done during the test(s) to you?													
Yes, completely	26 81.3%	1193 88.3%	641 87.7%	229 84.5%	368 86.6%	170 86.3%	259 90.9%	673 91.3%	44 84.6%	88 84.6%	190 87.2%	529 86.9%	509 83.7%
Yes, to some extent	1 3.1%	108 8.0%	68 9.3%	35 12.9%	41 9.6%	21 10.7%	20 7.0%	52 7.1%	5 9.6%	14 13.5%	22 10.1%	67 11.0%	69 11.3%
No, but I would have liked an explanation	- -	10 0.7%	5 0.7%	2 0.7%	5 1.2%	3 1.5%	2 0.7%	5 0.7%	1 1.9%	1 1.0%	1 0.5%	6 1.0%	8 1.3%
I did not need an explanation	2 6.3%	32 2.4%	11 1.5%	3 1.1%	11 2.6%	1 0.5%	3 1.1%	5 0.7%	2 3.8%	1 1.0%	5 2.3%	7 1.1%	18 3.0%
Don't know / can't remember	3 9.4%	8 0.6%	6 0.8%	2 0.7%	- -	2 1.0%	1 0.4%	2 0.3%	- -	- -	- -	- -	4 0.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1311	714	266	414	194	281	730	50	103	213	602	586
Q8+. Beforehand, did a member of staff explain what would be done during the test(s) to you?													
* Yes, completely	26 96.3%	1193 91.0%	641 89.8%	229 86.1%	368 88.9%	170 87.6%	259 92.2%	673 92.2%	44 88.0%	88 85.4%	190 89.2%	529 87.9%	509 86.9%
Yes, to some extent	1 3.7%	108 8.2%	68 9.5%	35 13.2%	41 9.9%	21 10.8%	20 7.1%	52 7.1%	5 10.0%	14 13.6%	22 10.3%	67 11.1%	69 11.8%
No, but I would have liked an explanation	- -	10 0.8%	5 0.7%	2 0.8%	5 1.2%	3 1.5%	2 0.7%	5 0.7%	1 2.0%	1 1.0%	1 0.5%	6 1.0%	8 1.4%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	31	1344	728	268	426	196	286	733	53	105	219	615	609
Q9. Beforehand, were you given written information about your test(s)?													
Yes, and it was easy to understand	18 58.1%	756 56.3%	532 73.1%	165 61.6%	218 51.2%	118 60.2%	195 68.2%	566 77.2%	24 45.3%	60 57.1%	152 69.4%	425 69.1%	358 58.8%
Yes, but it was difficult to understand	- -	20 1.5%	23 3.2%	9 3.4%	9 2.1%	4 2.0%	11 3.8%	19 2.6%	1 1.9%	2 1.9%	3 1.4%	23 3.7%	19 3.1%
No, I would have liked written information about the test(s)	4 12.9%	102 7.6%	33 4.5%	23 8.6%	44 10.3%	19 9.7%	16 5.6%	40 5.5%	7 13.2%	4 3.8%	11 5.0%	50 8.1%	52 8.5%
I did not need written information	7 22.6%	369 27.5%	107 14.7%	47 17.5%	121 28.4%	40 20.4%	45 15.7%	73 10.0%	18 34.0%	31 29.5%	38 17.4%	82 13.3%	141 23.2%
Don't know / can't remember	2 6.5%	97 7.2%	33 4.5%	24 9.0%	34 8.0%	15 7.7%	19 6.6%	35 4.8%	3 5.7%	8 7.6%	15 6.8%	35 5.7%	39 6.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	22	878	588	197	271	141	222	625	32	66	166	498	429
Q9+. Beforehand, were you given written information about your test(s)?													
* Yes, and it was easy to understand	18 81.8%	756 86.1%	532 90.5%	165 83.8%	218 80.4%	118 83.7%	195 87.8%	566 90.6%	24 75.0%	60 90.9%	152 91.6%	425 85.3%	358 83.4%
Yes, but it was difficult to understand	- -	20 2.3%	23 3.9%	9 4.6%	9 3.3%	4 2.8%	11 5.0%	19 3.0%	1 3.1%	2 3.0%	3 1.8%	23 4.6%	19 4.4%
No, I would have liked written information about the test(s)	4 18.2%	102 11.6%	33 5.6%	23 11.7%	44 16.2%	19 13.5%	16 7.2%	40 6.4%	7 21.9%	4 6.1%	11 6.6%	50 10.0%	52 12.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1351	731	271	426	198	285	744	53	105	219	610	613
Q10. Were the results of the test(s) explained in a way you could understand?													
Yes, completely	22 68.8%	1142 84.5%	611 83.6%	216 79.7%	322 75.6%	160 80.8%	232 81.4%	608 81.7%	39 73.6%	85 81.0%	174 79.5%	488 80.0%	458 74.7%
Yes, to some extent	8 25.0%	178 13.2%	100 13.7%	49 18.1%	81 19.0%	30 15.2%	50 17.5%	124 16.7%	10 18.9%	15 14.3%	40 18.3%	100 16.4%	129 21.0%
No, I did not understand the explanation	- -	3 0.2%	3 0.4%	4 1.5%	4 0.9%	1 0.5%	- -	2 0.3%	2 3.8%	1 1.0%	1 0.5%	3 0.5%	5 0.8%
No, but I would have liked an explanation	- -	7 0.5%	6 0.8%	- -	9 2.1%	4 2.0%	1 0.4%	9 1.2%	2 3.8%	1 1.0%	2 0.9%	9 1.5%	9 1.5%
I did not need an explanation	1 3.1%	7 0.5%	4 0.5%	2 0.7%	7 1.6%	3 1.5%	2 0.7%	- -	- -	3 2.9%	2 0.9%	6 1.0%	5 0.8%
Don't know / can't remember	1 3.1%	14 1.0%	7 1.0%	- -	3 0.7%	- -	- -	1 0.1%	- -	- -	- -	4 0.7%	7 1.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	30	1330	720	269	416	195	283	743	53	102	217	600	601
Q10+. Were the results of the test(s) explained in a way you could understand?													
* Yes, completely	22 73.3%	1142 85.9%	611 84.9%	216 80.3%	322 77.4%	160 82.1%	232 82.0%	608 81.8%	39 73.6%	85 83.3%	174 80.2%	488 81.3%	458 76.2%
Yes, to some extent	8 26.7%	178 13.4%	100 13.9%	49 18.2%	81 19.5%	30 15.4%	50 17.7%	124 16.7%	10 18.9%	15 14.7%	40 18.4%	100 16.7%	129 21.5%
No, I did not understand the explanation	- -	3 0.2%	3 0.4%	4 1.5%	4 1.0%	1 0.5%	- -	2 0.3%	2 3.8%	1 1.0%	1 0.5%	3 0.5%	5 0.8%
No, but I would have liked an explanation	- -	7 0.5%	6 0.8%	- -	9 2.2%	4 2.1%	1 0.4%	9 1.2%	2 3.8%	1 1.0%	2 0.9%	9 1.5%	9 1.5%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1540	811	346	605	228	314	948	58	140	240	661	713
Q11. How do you feel about the way you were told you had cancer?													
* It was done sensitively	27 75.0%	1360 88.3%	684 84.3%	277 80.1%	477 78.8%	200 87.7%	267 85.0%	798 84.2%	45 77.6%	127 90.7%	179 74.6%	536 81.1%	576 80.8%
It should have been done a bit more sensitively	7 19.4%	133 8.6%	86 10.6%	43 12.4%	78 12.9%	18 7.9%	35 11.1%	102 10.8%	8 13.8%	9 6.4%	32 13.3%	82 12.4%	79 11.1%
It should have been done a lot more sensitively	2 5.6%	47 3.1%	41 5.1%	26 7.5%	50 8.3%	10 4.4%	12 3.8%	48 5.1%	5 8.6%	4 2.9%	29 12.1%	43 6.5%	58 8.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1542	816	347	608	228	316	953	59	140	241	670	717
Q12. Did you understand the explanation of what was wrong with you?													
Yes, I completely understood it	25 67.6%	1263 81.9%	653 80.0%	256 73.8%	339 55.8%	180 78.9%	245 77.5%	768 80.6%	44 74.6%	106 75.7%	186 77.2%	545 81.3%	524 73.1%
Yes, I understood some of it	10 27.0%	259 16.8%	150 18.4%	83 23.9%	235 38.7%	40 17.5%	68 21.5%	174 18.3%	10 16.9%	30 21.4%	46 19.1%	116 17.3%	178 24.8%
No, I did not understand it	1 2.7%	16 1.0%	6 0.7%	7 2.0%	33 5.4%	8 3.5%	2 0.6%	8 0.8%	4 6.8%	4 2.9%	8 3.3%	7 1.0%	12 1.7%
Can't remember	1 2.7%	4 0.3%	7 0.9%	1 0.3%	1 0.2%	- -	1 0.3%	3 0.3%	1 1.7%	- -	1 0.4%	2 0.3%	3 0.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1538	809	346	607	228	315	950	58	140	240	668	714
Q12+. Did you understand the explanation of what was wrong with you?													
* Yes, I completely understood it	25 69.4%	1263 82.1%	653 80.7%	256 74.0%	339 55.8%	180 78.9%	245 77.8%	768 80.8%	44 75.9%	106 75.7%	186 77.5%	545 81.6%	524 73.4%
Yes, I understood some of it	10 27.8%	259 16.8%	150 18.5%	83 24.0%	235 38.7%	40 17.5%	68 21.6%	174 18.3%	10 17.2%	30 21.4%	46 19.2%	116 17.4%	178 24.9%
No, I did not understand it	1 2.8%	16 1.0%	6 0.7%	7 2.0%	33 5.4%	8 3.5%	2 0.6%	8 0.8%	4 6.9%	4 2.9%	8 3.3%	7 1.0%	12 1.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1525	809	341	601	226	310	945	59	140	238	658	704
Q13. When you were told you had cancer, were you given written information about the type of cancer you had?													
Yes, and it was easy to understand	14 40.0%	882 57.8%	393 48.6%	167 49.0%	361 60.1%	108 47.8%	150 48.4%	657 69.5%	18 30.5%	83 59.3%	121 50.8%	355 54.0%	291 41.3%
Yes, but it was difficult to understand	3 8.6%	74 4.9%	29 3.6%	24 7.0%	66 11.0%	7 3.1%	17 5.5%	53 5.6%	2 3.4%	7 5.0%	12 5.0%	22 3.3%	34 4.8%
No, I was not given written information about the type of cancer I had	10 28.6%	317 20.8%	217 26.8%	101 29.6%	102 17.0%	60 26.5%	82 26.5%	111 11.7%	23 39.0%	21 15.0%	67 28.2%	153 23.3%	230 32.7%
I did not need written information	5 14.3%	158 10.4%	116 14.3%	39 11.4%	47 7.8%	39 17.3%	45 14.5%	91 9.6%	12 20.3%	26 18.6%	26 10.9%	82 12.5%	100 14.2%
Don’t know / can’t remember	3 8.6%	94 6.2%	54 6.7%	10 2.9%	25 4.2%	12 5.3%	16 5.2%	33 3.5%	4 6.8%	3 2.1%	12 5.0%	46 7.0%	49 7.0%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1273	639	292	529	175	249	821	43	111	200	530	555
Q13+. When you were told you had cancer, were you given written information about the type of cancer you had?													
* Yes, and it was easy to understand	14 51.9%	882 69.3%	393 61.5%	167 57.2%	361 68.2%	108 61.7%	150 60.2%	657 80.0%	18 41.9%	83 74.8%	121 60.5%	355 67.0%	291 52.4%
Yes, but it was difficult to understand	3 11.1%	74 5.8%	29 4.5%	24 8.2%	66 12.5%	7 4.0%	17 6.8%	53 6.5%	2 4.7%	7 6.3%	12 6.0%	22 4.2%	34 6.1%
No, I was not given written information about the type of cancer I had	10 37.0%	317 24.9%	217 34.0%	101 34.6%	102 19.3%	60 34.3%	82 32.9%	111 13.5%	23 53.5%	21 18.9%	67 33.5%	153 28.9%	230 41.4%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1526	801	342	601	226	311	941	58	137	238	659	714
Q14. Before your cancer treatment started, were your treatment options explained to you?													
Yes	28 75.7%	1186 77.7%	586 73.2%	221 64.6%	434 72.2%	174 77.0%	235 75.6%	795 84.5%	29 50.0%	86 62.8%	176 73.9%	457 69.3%	517 72.4%
No, but I would have liked a choice	- -	35 2.3%	22 2.7%	5 1.5%	9 1.5%	2 0.9%	9 2.9%	22 2.3%	4 6.9%	1 0.7%	8 3.4%	21 3.2%	20 2.8%
There was only one type of treatment that was suitable for me	8 21.6%	289 18.9%	180 22.5%	108 31.6%	150 25.0%	47 20.8%	65 20.9%	111 11.8%	23 39.7%	50 36.5%	52 21.8%	174 26.4%	159 22.3%
Not sure / can't remember	1 2.7%	16 1.0%	13 1.6%	8 2.3%	8 1.3%	3 1.3%	2 0.6%	13 1.4%	2 3.4%	- -	2 0.8%	7 1.1%	18 2.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	28	1221	608	226	443	176	244	817	33	87	184	478	537
Q14+. Before your cancer treatment started, were your treatment options explained to you?													
* Yes	28 100.0%	1186 97.1%	586 96.4%	221 97.8%	434 98.0%	174 98.9%	235 96.3%	795 97.3%	29 87.9%	86 98.9%	176 95.7%	457 95.6%	517 96.3%
No, but I would have liked a choice	- -	35 2.9%	22 3.6%	5 2.2%	9 2.0%	2 1.1%	9 3.7%	22 2.7%	4 12.1%	1 1.1%	8 4.3%	21 4.4%	20 3.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1537	802	344	606	228	316	944	59	138	238	666	718
Q15. Were you involved as much as you wanted to be in decisions about your care and treatment?													
Yes, definitely	28 77.8%	1225 79.7%	629 78.4%	273 79.4%	444 73.3%	175 76.8%	249 78.8%	752 79.7%	41 69.5%	106 76.8%	185 77.7%	509 76.4%	536 74.7%
Yes, to some extent	8 22.2%	267 17.4%	138 17.2%	63 18.3%	135 22.3%	43 18.9%	55 17.4%	159 16.8%	12 20.3%	25 18.1%	47 19.7%	123 18.5%	143 19.9%
No, but I would like to have been more involved	- -	40 2.6%	29 3.6%	5 1.5%	21 3.5%	9 3.9%	10 3.2%	26 2.8%	6 10.2%	3 2.2%	4 1.7%	20 3.0%	28 3.9%
Not sure / can't remember	- -	5 0.3%	6 0.7%	3 0.9%	6 1.0%	1 0.4%	2 0.6%	7 0.7%	- -	4 2.9%	2 0.8%	14 2.1%	11 1.5%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1532	796	341	600	227	314	937	59	134	236	652	707
Q15+. Were you involved as much as you wanted to be in decisions about your care and treatment?													
* Yes, definitely	28 77.8%	1225 80.0%	629 79.0%	273 80.1%	444 74.0%	175 77.1%	249 79.3%	752 80.3%	41 69.5%	106 79.1%	185 78.4%	509 78.1%	536 75.8%
Yes, to some extent	8 22.2%	267 17.4%	138 17.3%	63 18.5%	135 22.5%	43 18.9%	55 17.5%	159 17.0%	12 20.3%	25 18.7%	47 19.9%	123 18.9%	143 20.2%
No, but I would like to have been more involved	- -	40 2.6%	29 3.6%	5 1.5%	21 3.5%	9 4.0%	10 3.2%	26 2.8%	6 10.2%	3 2.2%	4 1.7%	20 3.1%	28 4.0%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1535	802	342	607	227	312	942	56	138	240	662	716
Q16. Were the possible side effects of treatment(s) explained in a way you could understand?													
Yes, definitely	32 86.5%	1141 74.3%	601 74.9%	256 74.9%	409 67.4%	168 74.0%	226 72.4%	700 74.3%	35 62.5%	78 56.5%	178 74.2%	435 65.7%	502 70.1%
Yes, to some extent	4 10.8%	317 20.7%	146 18.2%	50 14.6%	153 25.2%	47 20.7%	69 22.1%	186 19.7%	10 17.9%	21 15.2%	44 18.3%	132 19.9%	152 21.2%
No, side effects were not explained	1 2.7%	39 2.5%	21 2.6%	14 4.1%	24 4.0%	7 3.1%	8 2.6%	25 2.7%	5 8.9%	7 5.1%	9 3.8%	39 5.9%	34 4.7%
I did not need an explanation	- -	31 2.0%	28 3.5%	15 4.4%	14 2.3%	5 2.2%	7 2.2%	22 2.3%	6 10.7%	29 21.0%	5 2.1%	39 5.9%	20 2.8%
Not sure / can't remember	- -	7 0.5%	6 0.7%	7 2.0%	7 1.2%	- -	2 0.6%	9 1.0%	- -	3 2.2%	4 1.7%	17 2.6%	8 1.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1497	768	320	586	222	303	911	50	106	231	606	688
Q16+. Were the possible side effects of treatment(s) explained in a way you could understand?													
* Yes, definitely	32 86.5%	1141 76.2%	601 78.3%	256 80.0%	409 69.8%	168 75.7%	226 74.6%	700 76.8%	35 70.0%	78 73.6%	178 77.1%	435 71.8%	502 73.0%
Yes, to some extent	4 10.8%	317 21.2%	146 19.0%	50 15.6%	153 26.1%	47 21.2%	69 22.8%	186 20.4%	10 20.0%	21 19.8%	44 19.0%	132 21.8%	152 22.1%
No, side effects were not explained	1 2.7%	39 2.6%	21 2.7%	14 4.4%	24 4.1%	7 3.2%	8 2.6%	25 2.7%	5 10.0%	7 6.6%	9 3.9%	39 6.4%	34 4.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1505	783	334	599	226	308	927	56	137	232	650	710
Q17. Before you started your treatment, were you given written information about the side effects of your treatment(s)?													
Yes, and it was easy to understand	27 75.0%	1160 77.1%	545 69.6%	231 69.2%	378 63.1%	143 63.3%	206 66.9%	703 75.8%	29 51.8%	56 40.9%	173 74.6%	390 60.0%	462 65.1%
Yes, but it was difficult to understand	6 16.7%	62 4.1%	30 3.8%	15 4.5%	56 9.3%	7 3.1%	22 7.1%	51 5.5%	3 5.4%	1 0.7%	5 2.2%	28 4.3%	41 5.8%
No, I was not given any written information about side effects	2 5.6%	133 8.8%	90 11.5%	40 12.0%	71 11.9%	33 14.6%	32 10.4%	73 7.9%	11 19.6%	21 15.3%	20 8.6%	104 16.0%	93 13.1%
I did not need written information	1 2.8%	97 6.4%	81 10.3%	34 10.2%	62 10.4%	30 13.3%	36 11.7%	66 7.1%	13 23.2%	55 40.1%	22 9.5%	90 13.8%	69 9.7%
Don’t know / can’t remember	- -	53 3.5%	37 4.7%	14 4.2%	32 5.3%	13 5.8%	12 3.9%	34 3.7%	- -	4 2.9%	12 5.2%	38 5.8%	45 6.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1355	665	286	505	183	260	827	43	78	198	522	596
Q17+. Before you started your treatment, were you given written information about the side effects of your treatment(s)?													
* Yes, and it was easy to understand	27 77.1%	1160 85.6%	545 82.0%	231 80.8%	378 74.9%	143 78.1%	206 79.2%	703 85.0%	29 67.4%	56 71.8%	173 87.4%	390 74.7%	462 77.5%
Yes, but it was difficult to understand	6 17.1%	62 4.6%	30 4.5%	15 5.2%	56 11.1%	7 3.8%	22 8.5%	51 6.2%	3 7.0%	1 1.3%	5 2.5%	28 5.4%	41 6.9%
No, I was not given any written information about side effects	2 5.7%	133 9.8%	90 13.5%	40 14.0%	71 14.1%	33 18.0%	32 12.3%	73 8.8%	11 25.6%	21 26.9%	20 10.1%	104 19.9%	93 15.6%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1511	786	334	598	223	308	923	57	135	235	644	707
Q18. 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?													
Yes, definitely	23 63.9%	800 52.9%	400 50.9%	170 50.9%	243 40.6%	117 52.5%	152 49.4%	566 61.3%	23 40.4%	50 37.0%	120 51.1%	268 41.6%	324 45.8%
Yes, to some extent	7 19.4%	374 24.8%	181 23.0%	79 23.7%	178 29.8%	62 27.8%	69 22.4%	217 23.5%	12 21.1%	18 13.3%	54 23.0%	116 18.0%	162 22.9%
No, future side effects were not explained	4 11.1%	205 13.6%	116 14.8%	46 13.8%	118 19.7%	25 11.2%	56 18.2%	74 8.0%	9 15.8%	15 11.1%	39 16.6%	132 20.5%	144 20.4%
I did not need an explanation	1 2.8%	64 4.2%	52 6.6%	23 6.9%	28 4.7%	11 4.9%	20 6.5%	36 3.9%	9 15.8%	45 33.3%	12 5.1%	81 12.6%	35 5.0%
Not sure / can't remember	1 2.8%	68 4.5%	37 4.7%	16 4.8%	31 5.2%	8 3.6%	11 3.6%	30 3.3%	4 7.0%	7 5.2%	10 4.3%	47 7.3%	42 5.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1379	697	295	539	204	277	857	44	83	213	516	630
Q18+. 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?													
* Yes, definitely	23 67.6%	800 58.0%	400 57.4%	170 57.6%	243 45.1%	117 57.4%	152 54.9%	566 66.0%	23 52.3%	50 60.2%	120 56.3%	268 51.9%	324 51.4%
Yes, to some extent	7 20.6%	374 27.1%	181 26.0%	79 26.8%	178 33.0%	62 30.4%	69 24.9%	217 25.3%	12 27.3%	18 21.7%	54 25.4%	116 22.5%	162 25.7%
No, future side effects were not explained	4 11.8%	205 14.9%	116 16.6%	46 15.6%	118 21.9%	25 12.3%	56 20.2%	74 8.6%	9 20.5%	15 18.1%	39 18.3%	132 25.6%	144 22.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1521	804	333	595	227	312	928	58	136	234	638	698
Q19. Were you given the name and contact details of your Key Worker?													
Yes	27 73.0%	1379 90.7%	672 83.6%	283 85.0%	431 72.4%	201 88.5%	277 88.8%	751 80.9%	42 72.4%	91 66.9%	209 89.3%	380 59.6%	553 79.2%
No	5 13.5%	93 6.1%	95 11.8%	34 10.2%	121 20.3%	18 7.9%	20 6.4%	129 13.9%	12 20.7%	31 22.8%	19 8.1%	185 29.0%	109 15.6%
Don't know / not sure	5 13.5%	49 3.2%	37 4.6%	16 4.8%	43 7.2%	8 3.5%	15 4.8%	48 5.2%	4 6.9%	14 10.3%	6 2.6%	73 11.4%	36 5.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1472	767	317	552	219	297	880	54	122	228	565	662
Q19. Were you given the name and contact details of your Key Worker?													
* Yes	27 84.4%	1379 93.7%	672 87.6%	283 89.3%	431 78.1%	201 91.8%	277 93.3%	751 85.3%	42 77.8%	91 74.6%	209 91.7%	380 67.3%	553 83.5%
No	5 15.6%	93 6.3%	95 12.4%	34 10.7%	121 21.9%	18 8.2%	20 6.7%	129 14.7%	12 22.2%	31 25.4%	19 8.3%	185 32.7%	109 16.5%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1374	667	286	429	198	277	751	42	91	205	380	562
Q20. How easy is it for you to contact your Key Worker?													
Easy	14 51.9%	938 68.3%	433 64.9%	188 65.7%	314 73.2%	128 64.6%	192 69.3%	430 57.3%	28 66.7%	52 57.1%	152 74.1%	214 56.3%	354 63.0%
Sometimes easy , sometimes difficult	10 37.0%	282 20.5%	139 20.8%	43 15.0%	71 16.6%	50 25.3%	51 18.4%	152 20.2%	10 23.8%	13 14.3%	36 17.6%	86 22.6%	141 25.1%
Difficult	1 3.7%	30 2.2%	16 2.4%	10 3.5%	6 1.4%	7 3.5%	8 2.9%	23 3.1%	- -	6 6.6%	8 3.9%	17 4.5%	16 2.8%
I have not tried to contact her/him	2 7.4%	124 9.0%	79 11.8%	45 15.7%	38 8.9%	13 6.6%	26 9.4%	146 19.4%	4 9.5%	20 22.0%	9 4.4%	63 16.6%	51 9.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	25	1250	588	241	391	185	251	605	38	71	196	317	511
Q20+. How easy is it for you to contact your Key Worker?													
* Easy	14 56.0%	938 75.0%	433 73.6%	188 78.0%	314 80.3%	128 69.2%	192 76.5%	430 71.1%	28 73.7%	52 73.2%	152 77.6%	214 67.5%	354 69.3%
Sometimes easy , sometimes difficult	10 40.0%	282 22.6%	139 23.6%	43 17.8%	71 18.2%	50 27.0%	51 20.3%	152 25.1%	10 26.3%	13 18.3%	36 18.4%	86 27.1%	141 27.6%
Difficult	1 4.0%	30 2.4%	16 2.7%	10 4.1%	6 1.5%	7 3.8%	8 3.2%	23 3.8%	- -	6 8.5%	8 4.1%	17 5.4%	16 3.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	26	1364	658	271	425	199	271	736	41	86	203	371	549
Q21. When you have important questions to ask, how often does your Key Worker help you get answers to your questions?													
All or most of the time	16 61.5%	1012 74.2%	461 70.1%	180 66.4%	327 76.9%	157 78.9%	197 72.7%	481 65.4%	28 68.3%	49 57.0%	164 80.8%	226 60.9%	411 74.9%
Some of the time	5 19.2%	121 8.9%	51 7.8%	21 7.7%	47 11.1%	18 9.0%	17 6.3%	47 6.4%	4 9.8%	5 5.8%	20 9.9%	28 7.5%	54 9.8%
Rarely or never	2 7.7%	22 1.6%	17 2.6%	10 3.7%	8 1.9%	5 2.5%	3 1.1%	14 1.9%	2 4.9%	3 3.5%	4 2.0%	14 3.8%	11 2.0%
I do not ask any questions	3 11.5%	209 15.3%	129 19.6%	60 22.1%	43 10.1%	19 9.5%	54 19.9%	194 26.4%	7 17.1%	29 33.7%	15 7.4%	103 27.8%	73 13.3%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	23	1155	529	211	382	180	217	542	34	57	188	268	476
Q21+. When you have important questions to ask, how often does your Key Worker help you get answers to your questions?													
* All or most of the time	16 69.6%	1012 87.6%	461 87.1%	180 85.3%	327 85.6%	157 87.2%	197 90.8%	481 88.7%	28 82.4%	49 86.0%	164 87.2%	226 84.3%	411 86.3%
Some of the time	5 21.7%	121 10.5%	51 9.6%	21 10.0%	47 12.3%	18 10.0%	17 7.8%	47 8.7%	4 11.8%	5 8.8%	20 10.6%	28 10.4%	54 11.3%
Rarely or never	2 8.7%	22 1.9%	17 3.2%	10 4.7%	8 2.1%	5 2.8%	3 1.4%	14 2.6%	2 5.9%	3 5.3%	4 2.1%	14 5.2%	11 2.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1499	791	324	592	225	303	911	57	135	232	633	685
Q22. Did your care include access to a Clinical Nurse Specialist?													
Yes, and this was my Key Worker	22 61.1%	1059 70.6%	475 60.1%	198 61.1%	313 52.9%	141 62.7%	217 71.6%	528 58.0%	31 54.4%	59 43.7%	166 71.6%	250 39.5%	399 58.2%
Yes, but this was not my Key Worker	2 5.6%	191 12.7%	111 14.0%	37 11.4%	73 12.3%	24 10.7%	20 6.6%	92 10.1%	6 10.5%	14 10.4%	19 8.2%	43 6.8%	83 12.1%
No, I did not have a Clinical Nurse Specialist as part of my care team	4 11.1%	91 6.1%	112 14.2%	49 15.1%	129 21.8%	27 12.0%	36 11.9%	164 18.0%	15 26.3%	40 29.6%	28 12.1%	224 35.4%	128 18.7%
Don't know / not sure	8 22.2%	158 10.5%	93 11.8%	40 12.3%	77 13.0%	33 14.7%	30 9.9%	127 13.9%	5 8.8%	22 16.3%	19 8.2%	116 18.3%	75 10.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	28	1341	698	284	515	192	273	784	52	113	213	517	610
Q22+. Did your care include access to a Clinical Nurse Specialist?													
* Yes, and this was my Key Worker	22 78.6%	1059 79.0%	475 68.1%	198 69.7%	313 60.8%	141 73.4%	217 79.5%	528 67.3%	31 59.6%	59 52.2%	166 77.9%	250 48.4%	399 65.4%
* Yes, but this was not my Key Worker	2 7.1%	191 14.2%	111 15.9%	37 13.0%	73 14.2%	24 12.5%	20 7.3%	92 11.7%	6 11.5%	14 12.4%	19 8.9%	43 8.3%	83 13.6%
No, I did not have a Clinical Nurse Specialist as part of my care team	4 14.3%	91 6.8%	112 16.0%	49 17.3%	129 25.0%	27 14.1%	36 13.2%	164 20.9%	15 28.8%	40 35.4%	28 13.1%	224 43.3%	128 21.0%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	2	198	116	44	79	25	27	101	8	14	21	48	97
Q23. How easy is it for you to contact your Clinical Nurse Specialist?													
Easy	* *	97 49.0%	59 50.9%	23 52.3%	53 67.1%	10 40.0%	12 44.4%	48 47.5%	* *	* *	10 47.6%	19 39.6%	56 57.7%
Sometimes easy, sometimes difficult	* *	54 27.3%	27 23.3%	9 20.5%	17 21.5%	11 44.0%	8 29.6%	17 16.8%	* *	* *	6 28.6%	13 27.1%	26 26.8%
Difficult	* *	13 6.6%	5 4.3%	2 4.5%	1 1.3%	1 4.0%	2 7.4%	4 4.0%	* *	* *	2 9.5%	- -	5 5.2%
I have not tried to contact her/him	* *	34 17.2%	25 21.6%	10 22.7%	8 10.1%	3 12.0%	5 18.5%	32 31.7%	* *	* *	3 14.3%	16 33.3%	10 10.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	2	164	91	34	71	22	22	69	7	10	18	32	87
Q23+. How easy is it for you to contact your Clinical Nurse Specialist?													
* Easy	* *	97 59.1%	59 64.8%	23 67.6%	53 74.6%	10 45.5%	12 54.5%	48 69.6%	* *	* *	* *	19 59.4%	56 64.4%
Sometimes easy, sometimes difficult	* *	54 32.9%	27 29.7%	9 26.5%	17 23.9%	11 50.0%	8 36.4%	17 24.6%	* *	* *	* *	13 40.6%	26 29.9%
Difficult	* *	13 7.9%	5 5.5%	2 5.9%	1 1.4%	1 4.5%	2 9.1%	4 5.8%	* *	* *	* *	- -	5 5.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	23	1264	594	243	391	165	243	625	38	74	187	302	493
Q24. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?													
All or most of the time	16 69.6%	1037 82.0%	482 81.1%	190 78.2%	323 82.6%	134 81.2%	195 80.2%	465 74.4%	28 73.7%	48 64.9%	157 84.0%	227 75.2%	393 79.7%
Some of the time	4 17.4%	79 6.3%	40 6.7%	16 6.6%	38 9.7%	12 7.3%	17 7.0%	31 5.0%	5 13.2%	5 6.8%	12 6.4%	20 6.6%	43 8.7%
Rarely or never	- -	12 0.9%	3 0.5%	4 1.6%	5 1.3%	3 1.8%	2 0.8%	7 1.1%	1 2.6%	1 1.4%	1 0.5%	4 1.3%	8 1.6%
I do not ask any questions	3 13.0%	136 10.8%	69 11.6%	33 13.6%	25 6.4%	16 9.7%	29 11.9%	122 19.5%	4 10.5%	20 27.0%	17 9.1%	51 16.9%	49 9.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	20	1128	525	210	366	149	214	503	34	54	170	251	444
Q24+. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?													
* All or most of the time	16 80.0%	1037 91.9%	482 91.8%	190 90.5%	323 88.3%	134 89.9%	195 91.1%	465 92.4%	28 82.4%	48 88.9%	157 92.4%	227 90.4%	393 88.5%
Some of the time	4 20.0%	79 7.0%	40 7.6%	16 7.6%	38 10.4%	12 8.1%	17 7.9%	31 6.2%	5 14.7%	5 9.3%	12 7.1%	20 8.0%	43 9.7%
Rarely or never	- -	12 1.1%	3 0.6%	4 1.9%	5 1.4%	3 2.0%	2 0.9%	7 1.4%	1 2.9%	1 1.9%	1 0.6%	4 1.6%	8 1.8%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	23	1250	587	238	387	164	241	618	37	75	186	296	486
Q25. Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?													
Yes, completely	19 82.6%	1018 81.4%	457 77.9%	193 81.1%	300 77.5%	129 78.7%	184 76.3%	478 77.3%	25 67.6%	56 74.7%	142 76.3%	233 78.7%	343 70.6%
Yes, to some extent	2 8.7%	168 13.4%	88 15.0%	33 13.9%	67 17.3%	22 13.4%	43 17.8%	84 13.6%	9 24.3%	6 8.0%	33 17.7%	44 14.9%	106 21.8%
No	1 4.3%	39 3.1%	26 4.4%	8 3.4%	13 3.4%	6 3.7%	7 2.9%	27 4.4%	3 8.1%	10 13.3%	6 3.2%	14 4.7%	21 4.3%
Don’t know / can’t remember	1 4.3%	25 2.0%	16 2.7%	4 1.7%	7 1.8%	7 4.3%	7 2.9%	29 4.7%	- -	3 4.0%	5 2.7%	5 1.7%	16 3.3%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	22	1225	571	234	380	157	234	589	37	72	181	291	470
Q25+. Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?													
* Yes, completely	19 86.4%	1018 83.1%	457 80.0%	193 82.5%	300 78.9%	129 82.2%	184 78.6%	478 81.2%	25 67.6%	56 77.8%	142 78.5%	233 80.1%	343 73.0%
Yes, to some extent	2 9.1%	168 13.7%	88 15.4%	33 14.1%	67 17.6%	22 14.0%	43 18.4%	84 14.3%	9 24.3%	6 8.3%	33 18.2%	44 15.1%	106 22.6%
No	1 4.5%	39 3.2%	26 4.6%	8 3.4%	13 3.4%	6 3.8%	7 3.0%	27 4.6%	3 8.1%	10 13.9%	6 3.3%	14 4.8%	21 4.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1507	790	328	598	223	309	917	56	133	233	627	708
Q26. How much information about support or self-help groups did hospital staff give you?													
Not enough	6 16.7%	143 9.5%	96 12.2%	34 10.4%	84 14.0%	20 9.0%	43 13.9%	67 7.3%	5 8.9%	14 10.5%	27 11.6%	50 8.0%	112 15.8%
The right amount	25 69.4%	1051 69.7%	464 58.7%	207 63.1%	317 53.0%	152 68.2%	182 58.9%	597 65.1%	31 55.4%	58 43.6%	144 61.8%	236 37.6%	396 55.9%
Too much	- -	38 2.5%	9 1.1%	2 0.6%	1 0.2%	4 1.8%	4 1.3%	11 1.2%	- -	- -	2 0.9%	4 0.6%	6 0.8%
I was not given any information	5 13.9%	159 10.6%	140 17.7%	60 18.3%	141 23.6%	36 16.1%	52 16.8%	162 17.7%	17 30.4%	44 33.1%	41 17.6%	260 41.5%	149 21.0%
Don’t know / can’t remember	- -	116 7.7%	81 10.3%	25 7.6%	55 9.2%	11 4.9%	28 9.1%	80 8.7%	3 5.4%	17 12.8%	19 8.2%	77 12.3%	45 6.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1391	709	303	543	212	281	837	53	116	214	550	663
Q26+. How much information about support or self-help groups did hospital staff give you?													
Not enough	6 16.7%	143 10.3%	96 13.5%	34 11.2%	84 15.5%	20 9.4%	43 15.3%	67 8.0%	5 9.4%	14 12.1%	27 12.6%	50 9.1%	112 16.9%
*** The right amount**	25 69.4%	1051 75.6%	464 65.4%	207 68.3%	317 58.4%	152 71.7%	182 64.8%	597 71.3%	31 58.5%	58 50.0%	144 67.3%	236 42.9%	396 59.7%
Too much	- -	38 2.7%	9 1.3%	2 0.7%	1 0.2%	4 1.9%	4 1.4%	11 1.3%	- -	- -	2 0.9%	4 0.7%	6 0.9%
I was not given any information	5 13.9%	159 11.4%	140 19.7%	60 19.8%	141 26.0%	36 17.0%	52 18.5%	162 19.4%	17 32.1%	44 37.9%	41 19.2%	260 47.3%	149 22.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1501	785	331	598	224	306	915	57	129	230	630	711
Q27. During your care, were you told about voluntary or charity support?													
Yes	23 62.2%	909 60.6%	403 51.3%	181 54.7%	284 47.5%	138 61.6%	195 63.7%	445 48.6%	26 45.6%	38 29.5%	140 60.9%	149 23.7%	374 52.6%
No	12 32.4%	404 26.9%	275 35.0%	110 33.2%	254 42.5%	65 29.0%	73 23.9%	349 38.1%	24 42.1%	67 51.9%	65 28.3%	403 64.0%	267 37.6%
Don’t know / can’t remember	2 5.4%	188 12.5%	107 13.6%	40 12.1%	60 10.0%	21 9.4%	38 12.4%	121 13.2%	7 12.3%	24 18.6%	25 10.9%	78 12.4%	70 9.8%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1313	678	291	538	203	268	794	50	105	205	552	641
Q27+. During your care, were you told about voluntary or charity support?													
*** Yes**	23 65.7%	909 69.2%	403 59.4%	181 62.2%	284 52.8%	138 68.0%	195 72.8%	445 56.0%	26 52.0%	38 36.2%	140 68.3%	149 27.0%	374 58.3%
No	12 34.3%	404 30.8%	275 40.6%	110 37.8%	254 47.2%	65 32.0%	73 27.2%	349 44.0%	24 48.0%	67 63.8%	65 31.7%	403 73.0%	267 41.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1508	783	329	598	221	312	917	55	133	233	622	710
Q28. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?													
Yes, completely	18 48.6%	735 48.7%	319 40.7%	132 40.1%	246 41.1%	115 52.0%	134 42.9%	406 44.3%	23 41.8%	54 40.6%	111 47.6%	178 28.6%	251 35.4%
Yes, to some extent	15 40.5%	443 29.4%	241 30.8%	86 26.1%	199 33.3%	54 24.4%	98 31.4%	269 29.3%	14 25.5%	30 22.6%	65 27.9%	132 21.2%	215 30.3%
No	4 10.8%	257 17.0%	174 22.2%	84 25.5%	127 21.2%	43 19.5%	63 20.2%	195 21.3%	15 27.3%	43 32.3%	49 21.0%	255 41.0%	202 28.5%
Don't know / can't remember	- -	73 4.8%	49 6.3%	27 8.2%	26 4.3%	9 4.1%	17 5.4%	47 5.1%	3 5.5%	6 4.5%	8 3.4%	57 9.2%	42 5.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1435	734	302	572	212	295	870	52	127	225	565	668
Q28+. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?													
* Yes, completely	18 48.6%	735 51.2%	319 43.5%	132 43.7%	246 43.0%	115 54.2%	134 45.4%	406 46.7%	23 44.2%	54 42.5%	111 49.3%	178 31.5%	251 37.6%
Yes, to some extent	15 40.5%	443 30.9%	241 32.8%	86 28.5%	199 34.8%	54 25.5%	98 33.2%	269 30.9%	14 26.9%	30 23.6%	65 28.9%	132 23.4%	215 32.2%
No	4 10.8%	257 17.9%	174 23.7%	84 27.8%	127 22.2%	43 20.3%	63 21.4%	195 22.4%	15 28.8%	43 33.9%	49 21.8%	255 45.1%	202 30.2%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1511	782	337	596	221	315	917	58	135	234	630	709
Q29. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?													
Yes	15 40.5%	445 29.5%	234 29.9%	118 35.0%	136 22.8%	93 42.1%	144 45.7%	153 16.7%	18 31.0%	12 8.9%	87 37.2%	70 11.1%	236 33.3%
Yes, but I would have liked more information	7 18.9%	103 6.8%	40 5.1%	16 4.7%	38 6.4%	22 10.0%	25 7.9%	30 3.3%	6 10.3%	4 3.0%	7 3.0%	16 2.5%	61 8.6%
No, but I would have liked information	10 27.0%	294 19.5%	189 24.2%	69 20.5%	177 29.7%	39 17.6%	58 18.4%	202 22.0%	15 25.9%	24 17.8%	62 26.5%	182 28.9%	183 25.8%
It was not necessary	5 13.5%	625 41.4%	293 37.5%	120 35.6%	217 36.4%	65 29.4%	77 24.4%	496 54.1%	19 32.8%	93 68.9%	73 31.2%	339 53.8%	211 29.8%
Don't know / can't remember	- -	44 2.9%	26 3.3%	14 4.2%	28 4.7%	2 0.9%	11 3.5%	36 3.9%	- -	2 1.5%	5 2.1%	23 3.7%	18 2.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	842	463	203	351	154	227	385	39	40	156	268	480
Q29+. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?													
* Yes	15 46.9%	445 52.9%	234 50.5%	118 58.1%	136 38.7%	93 60.4%	144 63.4%	153 39.7%	18 46.2%	12 30.0%	87 55.8%	70 26.1%	236 49.2%
Yes, but I would have liked more information	7 21.9%	103 12.2%	40 8.6%	16 7.9%	38 10.8%	22 14.3%	25 11.0%	30 7.8%	6 15.4%	4 10.0%	7 4.5%	16 6.0%	61 12.7%
No, but I would have liked information	10 31.3%	294 34.9%	189 40.8%	69 34.0%	177 50.4%	39 25.3%	58 25.6%	202 52.5%	15 38.5%	24 60.0%	62 39.7%	182 67.9%	183 38.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1514	802	332	602	226	311	929	60	138	241	658	710
Q30. During the last 12 months, have you had an operation for your cancer (such as removal of a tumour or lump)?													
Yes	25 69.4%	1096 72.4%	554 69.1%	233 70.2%	88 14.6%	126 55.8%	107 34.4%	200 21.5%	45 75.0%	112 81.2%	106 44.0%	521 79.2%	263 37.0%
No	11 30.6%	418 27.6%	248 30.9%	99 29.8%	514 85.4%	100 44.2%	204 65.6%	729 78.5%	15 25.0%	26 18.8%	135 56.0%	137 20.8%	447 63.0%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	25	1071	546	234	84	122	101	199	45	110	100	503	261
Q31. Did the operation take place at the hospital named on the letter that came with this survey?													
Yes	11 44.0%	650 60.7%	409 74.9%	135 57.7%	60 71.4%	91 74.6%	43 42.6%	132 66.3%	23 51.1%	89 80.9%	49 49.0%	410 81.5%	138 52.9%
No, at another NHS hospital in Wales	12 48.0%	385 35.9%	118 21.6%	99 42.3%	23 27.4%	27 22.1%	41 40.6%	52 26.1%	15 33.3%	15 13.6%	42 42.0%	88 17.5%	106 40.6%
No, at a private hospital/centre in Wales	- -	18 1.7%	3 0.5%	- -	- -	- -	- -	- -	- -	1 0.9%	- -	3 0.6%	1 0.4%
No, somewhere outside Wales	2 8.0%	11 1.0%	10 1.8%	- -	- -	1 0.8%	15 14.9%	13 6.5%	6 13.3%	3 2.7%	7 7.0%	1 0.2%	13 5.0%
Dont know / can't remember	- -	7 0.7%	6 1.1%	- -	1 1.2%	3 2.5%	2 2.0%	2 1.0%	1 2.2%	2 1.8%	2 2.0%	1 0.2%	3 1.1%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	25	1108	563	240	85	128	108	202	45	113	105	526	269
Q32. Before you had your operation, did a member of staff explain what would be done during the operation?													
Yes, completely	19 76.0%	976 88.1%	469 83.3%	205 85.4%	70 82.4%	112 87.5%	94 87.0%	179 88.6%	37 82.2%	99 87.6%	93 88.6%	461 87.6%	227 84.4%
Yes, to some extent	3 12.0%	102 9.2%	77 13.7%	30 12.5%	15 17.6%	11 8.6%	12 11.1%	20 9.9%	7 15.6%	13 11.5%	10 9.5%	49 9.3%	34 12.6%
No, but I would have liked an explanation	- -	11 1.0%	8 1.4%	2 0.8%	- -	2 1.6%	2 1.9%	2 1.0%	1 2.2%	1 0.9%	- -	3 0.6%	4 1.5%
I did not need an explanation	2 8.0%	16 1.4%	6 1.1%	3 1.3%	- -	3 2.3%	- -	- -	- -	- -	2 1.9%	10 1.9%	3 1.1%
Don't know / can't remember	1 4.0%	3 0.3%	3 0.5%	- -	- -	- -	- -	1 0.5%	- -	- -	- -	3 0.6%	1 0.4%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	22	1089	554	237	85	125	108	201	45	113	103	513	265
Q32+. Before you had your operation, did a member of staff explain what would be done during the operation?													
* Yes, completely	19 86.4%	976 89.6%	469 84.7%	205 86.5%	70 82.4%	112 89.6%	94 87.0%	179 89.1%	37 82.2%	99 87.6%	93 90.3%	461 89.9%	227 85.7%
Yes, to some extent	3 13.6%	102 9.4%	77 13.9%	30 12.7%	15 17.6%	11 8.8%	12 11.1%	20 10.0%	7 15.6%	13 11.5%	10 9.7%	49 9.6%	34 12.8%
No, but I would have liked an explanation	- -	11 1.0%	8 1.4%	2 0.8%	- -	2 1.6%	2 1.9%	2 1.0%	1 2.2%	1 0.9%	- -	3 0.6%	4 1.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	24	1095	559	240	87	127	108	205	45	113	102	519	266
Q33. Beforehand, were you given written information about your operation?													
Yes, and it was easy to understand	12 50.0%	695 63.5%	316 56.5%	145 60.4%	43 49.4%	63 49.6%	50 46.3%	158 77.1%	13 28.9%	55 48.7%	59 57.8%	333 64.2%	129 48.5%
Yes, but it was difficult to understand	3 12.5%	24 2.2%	19 3.4%	10 4.2%	3 3.4%	7 5.5%	4 3.7%	3 1.5%	3 6.7%	4 3.5%	5 4.9%	23 4.4%	8 3.0%
No, I was not given written information about my operation	6 25.0%	175 16.0%	122 21.8%	48 20.0%	18 20.7%	29 22.8%	25 23.1%	19 9.3%	12 26.7%	17 15.0%	17 16.7%	68 13.1%	59 22.2%
I did not need written information	3 12.5%	122 11.1%	65 11.6%	27 11.3%	16 18.4%	20 15.7%	17 15.7%	16 7.8%	13 28.9%	30 26.5%	20 19.6%	63 12.1%	53 19.9%
Don't know / can't remember	- -	79 7.2%	37 6.6%	10 4.2%	7 8.0%	8 6.3%	12 11.1%	9 4.4%	4 8.9%	7 6.2%	1 1.0%	32 6.2%	17 6.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	21	894	457	203	64	99	79	180	28	76	81	424	196
Q33+. Beforehand, were you given written information about your operation?													
* Yes, and it was easy to understand	12 57.1%	695 77.7%	316 69.1%	145 71.4%	43 67.2%	63 63.6%	50 63.3%	158 87.8%	13 46.4%	55 72.4%	59 72.8%	333 78.5%	129 65.8%
Yes, but it was difficult to understand	3 14.3%	24 2.7%	19 4.2%	10 4.9%	3 4.7%	7 7.1%	4 5.1%	3 1.7%	3 10.7%	4 5.3%	5 6.2%	23 5.4%	8 4.1%
No, I was not given written information about my operation	6 28.6%	175 19.6%	122 26.7%	48 23.6%	18 28.1%	29 29.3%	25 31.6%	19 10.6%	12 42.9%	17 22.4%	17 21.0%	68 16.0%	59 30.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	25	1109	560	240	85	128	107	203	45	113	105	526	268
Q34. After the operation, did a member of staff explain how it had gone in a way you could understand?													
Yes, completely	19 76.0%	891 80.3%	436 77.9%	193 80.4%	59 69.4%	105 82.0%	87 81.3%	164 80.8%	30 66.7%	94 83.2%	88 83.8%	390 74.1%	204 76.1%
Yes, to some extent	5 20.0%	159 14.3%	98 17.5%	39 16.3%	19 22.4%	18 14.1%	16 15.0%	34 16.7%	13 28.9%	9 8.0%	16 15.2%	91 17.3%	46 17.2%
No, but I would have liked an explanation	- -	35 3.2%	23 4.1%	5 2.1%	6 7.1%	2 1.6%	3 2.8%	4 2.0%	1 2.2%	5 4.4%	- -	31 5.9%	13 4.9%
I did not need an explanation	1 4.0%	24 2.2%	3 0.5%	3 1.3%	1 1.2%	3 2.3%	1 0.9%	1 0.5%	1 2.2%	5 4.4%	1 1.0%	14 2.7%	5 1.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	24	1085	557	237	84	125	106	202	44	108	104	512	263
Q34+. After the operation, did a member of staff explain how it had gone in a way you could understand?													
* Yes, completely	19 79.2%	891 82.1%	436 78.3%	193 81.4%	59 70.2%	105 84.0%	87 82.1%	164 81.2%	30 68.2%	94 87.0%	88 84.6%	390 76.2%	204 77.6%
Yes, to some extent	5 20.8%	159 14.7%	98 17.6%	39 16.5%	19 22.6%	18 14.4%	16 15.1%	34 16.8%	13 29.5%	9 8.3%	16 15.4%	91 17.8%	46 17.5%
No, but I would have liked an explanation	- -	35 3.2%	23 4.1%	5 2.1%	6 7.1%	2 1.6%	3 2.8%	4 2.0%	1 2.3%	5 4.6%	- -	31 6.1%	13 4.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1504	800	333	586	227	301	911	58	141	235	650	691
Q35. During the last 12 months, have you had an operation or stayed overnight for cancer care?													
Yes	27 75.0%	1005 66.8%	550 68.8%	239 71.8%	240 41.0%	171 75.3%	148 49.2%	243 26.7%	43 74.1%	53 37.6%	149 63.4%	459 70.6%	338 48.9%
No	9 25.0%	499 33.2%	250 31.3%	94 28.2%	346 59.0%	56 24.7%	153 50.8%	668 73.3%	15 25.9%	88 62.4%	86 36.6%	191 29.4%	353 51.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	26	997	544	241	234	171	143	241	43	52	146	457	337
Q36. Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?													
Yes	10 38.5%	621 62.3%	422 77.6%	156 64.7%	181 77.4%	134 78.4%	74 51.7%	162 67.2%	26 60.5%	42 80.8%	83 56.8%	360 78.8%	208 61.7%
No, at another NHS hospital in Wales	13 50.0%	346 34.7%	106 19.5%	81 33.6%	45 19.2%	33 19.3%	57 39.9%	62 25.7%	15 34.9%	7 13.5%	49 33.6%	95 20.8%	109 32.3%
No, at a private hospital/centre in Wales	- -	14 1.4%	3 0.6%	- -	- -	- -	- -	1 0.4%	- -	- -	- -	- -	- -
No, somewhere outside Wales	3 11.5%	9 0.9%	9 1.7%	3 1.2%	4 1.7%	1 0.6%	11 7.7%	15 6.2%	1 2.3%	2 3.8%	10 6.8%	1 0.2%	15 4.5%
Dont know / can't remember	- -	7 0.7%	4 0.7%	1 0.4%	4 1.7%	3 1.8%	1 0.7%	1 0.4%	1 2.3%	1 1.9%	4 2.7%	1 0.2%	5 1.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1028	558	248	246	173	153	251	44	53	151	474	347
Q37. Overall, while you were in hospital, were you treated with dignity and respect?													
* Yes, always	25 92.6%	955 92.9%	478 85.7%	213 85.9%	219 89.0%	150 86.7%	133 86.9%	230 91.6%	37 84.1%	50 94.3%	139 92.1%	416 87.8%	291 83.9%
Yes, sometimes	2 7.4%	64 6.2%	69 12.4%	31 12.5%	24 9.8%	18 10.4%	17 11.1%	16 6.4%	5 11.4%	2 3.8%	11 7.3%	51 10.8%	46 13.3%
No	- -	9 0.9%	11 2.0%	4 1.6%	3 1.2%	5 2.9%	3 2.0%	5 2.0%	2 4.5%	1 1.9%	1 0.7%	7 1.5%	10 2.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1022	561	248	248	172	154	252	44	53	152	472	347
Q38. Did doctors and nurses talk in front of you as if you weren't there?													
Yes, often	- -	21 2.1%	21 3.7%	7 2.8%	10 4.0%	6 3.5%	10 6.5%	5 2.0%	3 6.8%	1 1.9%	4 2.6%	24 5.1%	14 4.0%
Yes, sometimes	7 25.9%	68 6.7%	99 17.6%	27 10.9%	44 17.7%	20 11.6%	30 19.5%	29 11.5%	9 20.5%	8 15.1%	20 13.2%	73 15.5%	64 18.4%
* No	20 74.1%	933 91.3%	441 78.6%	214 86.3%	194 78.2%	146 84.9%	114 74.0%	218 86.5%	32 72.7%	44 83.0%	128 84.2%	375 79.4%	269 77.5%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1025	558	245	243	172	154	252	43	53	152	469	345
Q39. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?													
Often	- -	24 2.3%	15 2.7%	3 1.2%	3 1.2%	3 1.7%	6 3.9%	3 1.2%	4 9.3%	- -	3 2.0%	9 1.9%	11 3.2%
Sometimes	5 18.5%	62 6.0%	65 11.6%	28 11.4%	41 16.9%	23 13.4%	20 13.0%	20 7.9%	9 20.9%	6 11.3%	29 19.1%	48 10.2%	60 17.4%
Only once	2 7.4%	60 5.9%	34 6.1%	13 5.3%	7 2.9%	12 7.0%	8 5.2%	8 3.2%	1 2.3%	2 3.8%	3 2.0%	22 4.7%	17 4.9%
* Never	20 74.1%	879 85.8%	444 79.6%	201 82.0%	192 79.0%	134 77.9%	120 77.9%	221 87.7%	29 67.4%	45 84.9%	117 77.0%	390 83.2%	257 74.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1024	559	247	247	171	155	251	42	54	151	469	346
Q40. Were you able to discuss any worries or fears with staff during your hospital visit?													
As much as I wanted	18 66.7%	620 60.5%	320 57.2%	148 59.9%	151 61.1%	105 61.4%	80 51.6%	173 68.9%	20 47.6%	27 50.0%	87 57.6%	234 49.9%	175 50.6%
Most of the time	3 11.1%	128 12.5%	88 15.7%	35 14.2%	38 15.4%	19 11.1%	23 14.8%	24 9.6%	6 14.3%	4 7.4%	28 18.5%	60 12.8%	64 18.5%
Some of the time	3 11.1%	83 8.1%	60 10.7%	25 10.1%	30 12.1%	12 7.0%	17 11.0%	18 7.2%	7 16.7%	4 7.4%	13 8.6%	56 11.9%	47 13.6%
Not at all, but would have liked to	1 3.7%	34 3.3%	24 4.3%	8 3.2%	9 3.6%	11 6.4%	9 5.8%	6 2.4%	3 7.1%	3 5.6%	3 2.0%	17 3.6%	25 7.2%
I did not have any worries or fears	2 7.4%	159 15.5%	67 12.0%	31 12.6%	19 7.7%	24 14.0%	26 16.8%	30 12.0%	6 14.3%	16 29.6%	20 13.2%	102 21.7%	35 10.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	25	865	492	216	228	147	129	221	36	38	131	367	311
Q40+. Were you able to discuss any worries or fears with staff during your hospital visit?													
* As much as I wanted	18 72.0%	620 71.7%	320 65.0%	148 68.5%	151 66.2%	105 71.4%	80 62.0%	173 78.3%	20 55.6%	27 71.1%	87 66.4%	234 63.8%	175 56.3%
Most of the time	3 12.0%	128 14.8%	88 17.9%	35 16.2%	38 16.7%	19 12.9%	23 17.8%	24 10.9%	6 16.7%	4 10.5%	28 21.4%	60 16.3%	64 20.6%
Some of the time	3 12.0%	83 9.6%	60 12.2%	25 11.6%	30 13.2%	12 8.2%	17 13.2%	18 8.1%	7 19.4%	4 10.5%	13 9.9%	56 15.3%	47 15.1%
Not at all, but would have liked to	1 4.0%	34 3.9%	24 4.9%	8 3.7%	9 3.9%	11 7.5%	9 7.0%	6 2.7%	3 8.3%	3 7.9%	3 2.3%	17 4.6%	25 8.0%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1024	559	246	245	171	155	252	45	54	151	473	347
Q41. When you had important questions to ask a doctor or nurse, how often did you get answers that you could understand?													
All or most of the time	19 70.4%	808 78.9%	424 75.8%	173 70.3%	183 74.7%	132 77.2%	99 63.9%	203 80.6%	27 60.0%	36 66.7%	116 76.8%	306 64.7%	253 72.9%
Some of the time	5 18.5%	90 8.8%	77 13.8%	39 15.9%	38 15.5%	20 11.7%	28 18.1%	30 11.9%	9 20.0%	5 9.3%	18 11.9%	78 16.5%	62 17.9%
Rarely or never	- -	12 1.2%	8 1.4%	2 0.8%	3 1.2%	3 1.8%	2 1.3%	1 0.4%	2 4.4%	- -	2 1.3%	8 1.7%	4 1.2%
I did not ask any questions	3 11.1%	114 11.1%	50 8.9%	32 13.0%	21 8.6%	16 9.4%	26 16.8%	18 7.1%	7 15.6%	13 24.1%	15 9.9%	81 17.1%	28 8.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	24	910	509	214	224	155	129	234	38	41	136	392	319
Q41+. When you had important questions to ask a doctor or nurse, how often did you get answers that you could understand?													
*** All or most of the time**	19 79.2%	808 88.8%	424 83.3%	173 80.8%	183 81.7%	132 85.2%	99 76.7%	203 86.8%	27 71.1%	36 87.8%	116 85.3%	306 78.1%	253 79.3%
Some of the time	5 20.8%	90 9.9%	77 15.1%	39 18.2%	38 17.0%	20 12.9%	28 21.7%	30 12.8%	9 23.7%	5 12.2%	18 13.2%	78 19.9%	62 19.4%
Rarely or never	- -	12 1.3%	8 1.6%	2 0.9%	3 1.3%	3 1.9%	2 1.6%	1 0.4%	2 5.3%	- -	2 1.5%	8 2.0%	4 1.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1020	561	245	248	172	154	248	45	54	152	464	346
Q42. Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?													
Yes, definitely	22 81.5%	629 61.7%	335 59.7%	140 57.1%	158 63.7%	112 65.1%	90 58.4%	157 63.3%	30 66.7%	31 57.4%	106 69.7%	226 48.7%	203 58.7%
Yes, to some extent	5 18.5%	207 20.3%	148 26.4%	59 24.1%	55 22.2%	43 25.0%	38 24.7%	44 17.7%	9 20.0%	11 20.4%	32 21.1%	106 22.8%	88 25.4%
No	- -	80 7.8%	40 7.1%	26 10.6%	17 6.9%	12 7.0%	13 8.4%	22 8.9%	4 8.9%	1 1.9%	7 4.6%	64 13.8%	36 10.4%
No family or friends were involved	- -	104 10.2%	38 6.8%	20 8.2%	18 7.3%	5 2.9%	13 8.4%	25 10.1%	2 4.4%	11 20.4%	7 4.6%	68 14.7%	19 5.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	916	523	225	230	167	141	223	43	43	145	396	327
Q42+. Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?													
*** Yes, definitely**	22 81.5%	629 68.7%	335 64.1%	140 62.2%	158 68.7%	112 67.1%	90 63.8%	157 70.4%	30 69.8%	31 72.1%	106 73.1%	226 57.1%	203 62.1%
Yes, to some extent	5 18.5%	207 22.6%	148 28.3%	59 26.2%	55 23.9%	43 25.7%	38 27.0%	44 19.7%	9 20.9%	11 25.6%	32 22.1%	106 26.8%	88 26.9%
No	- -	80 8.7%	40 7.6%	26 11.6%	17 7.4%	12 7.2%	13 9.2%	22 9.9%	4 9.3%	1 2.3%	7 4.8%	64 16.2%	36 11.0%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1031	561	248	249	173	155	253	45	54	151	476	347
Q43. Did you have confidence and trust in the doctors treating you?													
* Yes, in all of them	23 85.2%	945 91.7%	497 88.6%	222 89.5%	223 89.6%	156 90.2%	133 85.8%	232 91.7%	37 82.2%	51 94.4%	134 88.7%	422 88.7%	285 82.1%
Yes, in some of them	4 14.8%	83 8.1%	63 11.2%	25 10.1%	26 10.4%	17 9.8%	22 14.2%	20 7.9%	7 15.6%	3 5.6%	17 11.3%	50 10.5%	61 17.6%
No, in none of them	- -	3 0.3%	1 0.2%	1 0.4%	- -	- -	- -	1 0.4%	1 2.2%	- -	- -	4 0.8%	1 0.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1031	562	247	249	173	155	251	43	53	151	475	349
Q44. Did you have confidence and trust in the ward nurses treating you?													
* Yes, in all of them	23 85.2%	881 85.5%	435 77.4%	184 74.5%	196 78.7%	139 80.3%	125 80.6%	222 88.4%	32 74.4%	49 92.5%	120 79.5%	375 78.9%	257 73.6%
Yes, in some of them	3 11.1%	139 13.5%	121 21.5%	55 22.3%	51 20.5%	32 18.5%	26 16.8%	28 11.2%	10 23.3%	3 5.7%	30 19.9%	96 20.2%	85 24.4%
No, in none of them	1 3.7%	11 1.1%	6 1.1%	8 3.2%	2 0.8%	2 1.2%	4 2.6%	1 0.4%	1 2.3%	1 1.9%	1 0.7%	4 0.8%	7 2.0%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1023	556	244	240	171	154	246	44	50	149	468	344
Q45. How many minutes after you used the call button did it usually take before you got the help you needed?													
0 minutes / right away	1 3.7%	146 14.3%	68 12.2%	33 13.5%	30 12.5%	22 12.9%	25 16.2%	37 15.0%	9 20.5%	1 2.0%	18 12.1%	45 9.6%	38 11.0%
1-2 minutes	9 33.3%	178 17.4%	180 32.4%	67 27.5%	76 31.7%	40 23.4%	38 24.7%	51 20.7%	13 29.5%	5 10.0%	58 38.9%	82 17.5%	92 26.7%
3-5 minutes	2 7.4%	77 7.5%	109 19.6%	30 12.3%	46 19.2%	31 18.1%	21 13.6%	16 6.5%	9 20.5%	3 6.0%	25 16.8%	61 13.0%	60 17.4%
More than 5 minutes	1 3.7%	24 2.3%	50 9.0%	20 8.2%	17 7.1%	16 9.4%	8 5.2%	10 4.1%	4 9.1%	- -	6 4.0%	28 6.0%	31 9.0%
I never got help when I used the call button	- -	6 0.6%	4 0.7%	3 1.2%	2 0.8%	- -	- -	- -	- -	- -	- -	3 0.6%	2 0.6%
I never used the call button	14 51.9%	592 57.9%	145 26.1%	91 37.3%	69 28.8%	62 36.3%	62 40.3%	132 53.7%	9 20.5%	41 82.0%	42 28.2%	249 53.2%	121 35.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	13	431	411	153	171	109	92	114	35	9	107	219	223
Q45+. How many minutes after you used the call button did it usually take before you got the help you needed?													
* 0 minutes / right away	* *	146 33.9%	68 16.5%	33 21.6%	30 17.5%	22 20.2%	25 27.2%	37 32.5%	9 25.7%	* *	18 16.8%	45 20.5%	38 17.0%
* 1-2 minutes	* *	178 41.3%	180 43.8%	67 43.8%	76 44.4%	40 36.7%	38 41.3%	51 44.7%	13 37.1%	* *	58 54.2%	82 37.4%	92 41.3%
* 3-5 minutes	* *	77 17.9%	109 26.5%	30 19.6%	46 26.9%	31 28.4%	21 22.8%	16 14.0%	9 25.7%	* *	25 23.4%	61 27.9%	60 26.9%
More than 5 minutes	* *	24 5.6%	50 12.2%	20 13.1%	17 9.9%	16 14.7%	8 8.7%	10 8.8%	4 11.4%	* *	6 5.6%	28 12.8%	31 13.9%
I never got help when I used the call button	* *	6 1.4%	4 1.0%	3 2.0%	2 1.2%	- -	- -	- -	- -	* *	- -	3 1.4%	2 0.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1028	559	248	246	173	155	250	45	52	152	470	346
Q46. Do you think doctors and nurses communicated effectively with you during your hospital stay?													
* Yes, always	22 81.5%	879 85.5%	448 80.1%	194 78.2%	196 79.7%	133 76.9%	119 76.8%	212 84.8%	35 77.8%	46 88.5%	121 79.6%	349 74.3%	259 74.9%
Yes, sometimes	5 18.5%	133 12.9%	101 18.1%	49 19.8%	43 17.5%	35 20.2%	30 19.4%	33 13.2%	8 17.8%	4 7.7%	29 19.1%	110 23.4%	76 22.0%
No	- -	16 1.6%	10 1.8%	5 2.0%	7 2.8%	5 2.9%	6 3.9%	5 2.0%	2 4.4%	2 3.8%	2 1.3%	11 2.3%	11 3.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1025	562	247	244	173	153	254	44	53	151	470	346
Q47. Were you given enough privacy when discussing your condition or treatment?													
* Yes, always	20 74.1%	914 89.2%	468 83.3%	203 82.2%	203 83.2%	146 84.4%	125 81.7%	228 89.8%	37 84.1%	46 86.8%	132 87.4%	399 84.9%	272 78.6%
Yes, sometimes	4 14.8%	80 7.8%	72 12.8%	31 12.6%	33 13.5%	21 12.1%	18 11.8%	16 6.3%	5 11.4%	6 11.3%	14 9.3%	55 11.7%	49 14.2%
No	3 11.1%	31 3.0%	22 3.9%	13 5.3%	8 3.3%	6 3.5%	10 6.5%	10 3.9%	2 4.5%	1 1.9%	5 3.3%	16 3.4%	25 7.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1028	562	248	247	173	154	256	44	53	152	471	346
Q48. Were you given enough privacy when being examined or treated?													
* Yes, always	26 96.3%	990 96.3%	532 94.7%	235 94.8%	234 94.7%	159 91.9%	143 92.9%	241 94.1%	41 93.2%	50 94.3%	148 97.4%	448 95.1%	317 91.6%
Yes, sometimes	1 3.7%	32 3.1%	26 4.6%	8 3.2%	11 4.5%	11 6.4%	9 5.8%	12 4.7%	3 6.8%	3 5.7%	4 2.6%	20 4.2%	22 6.4%
No	- -	6 0.6%	4 0.7%	5 2.0%	2 0.8%	3 1.7%	2 1.3%	3 1.2%	- -	- -	- -	3 0.6%	7 2.0%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1028	559	246	247	173	155	254	45	53	150	471	346
Q49. Do you think the hospital staff did everything they could to help control your pain?													
All of the time	16 59.3%	795 77.3%	455 81.4%	183 74.4%	174 70.4%	130 75.1%	111 71.6%	203 79.9%	34 75.6%	38 71.7%	121 80.7%	307 65.2%	266 76.9%
Some of the time	4 14.8%	50 4.9%	64 11.4%	38 15.4%	27 10.9%	20 11.6%	22 14.2%	16 6.3%	6 13.3%	2 3.8%	13 8.7%	58 12.3%	45 13.0%
Not at all	- -	6 0.6%	5 0.9%	4 1.6%	3 1.2%	3 1.7%	1 0.6%	1 0.4%	1 2.2%	1 1.9%	2 1.3%	9 1.9%	4 1.2%
I did not have any pain	7 25.9%	177 17.2%	35 6.3%	21 8.5%	43 17.4%	20 11.6%	21 13.5%	34 13.4%	4 8.9%	12 22.6%	14 9.3%	97 20.6%	31 9.0%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	20	851	524	225	204	153	134	220	41	41	136	374	315
Q49+. Do you think the hospital staff did everything they could to help control your pain?													
* All of the time	16 80.0%	795 93.4%	455 86.8%	183 81.3%	174 85.3%	130 85.0%	111 82.8%	203 92.3%	34 82.9%	38 92.7%	121 89.0%	307 82.1%	266 84.4%
Some of the time	4 20.0%	50 5.9%	64 12.2%	38 16.9%	27 13.2%	20 13.1%	22 16.4%	16 7.3%	6 14.6%	2 4.9%	13 9.6%	58 15.5%	45 14.3%
Not at all	- -	6 0.7%	5 1.0%	4 1.8%	3 1.5%	3 2.0%	1 0.7%	1 0.5%	1 2.4%	1 2.4%	2 1.5%	9 2.4%	4 1.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1028	562	248	246	173	155	253	45	53	152	469	346
Q50. Were you given clear written information about what you should or should not do after leaving hospital?													
Yes	21 77.8%	832 80.9%	398 70.8%	181 73.0%	156 63.4%	133 76.9%	98 63.2%	203 80.2%	25 55.6%	38 71.7%	102 67.1%	321 68.4%	224 64.7%
No	4 14.8%	87 8.5%	87 15.5%	38 15.3%	42 17.1%	20 11.6%	24 15.5%	24 9.5%	8 17.8%	2 3.8%	27 17.8%	78 16.6%	67 19.4%
I did not need written information	1 3.7%	74 7.2%	49 8.7%	22 8.9%	41 16.7%	16 9.2%	22 14.2%	23 9.1%	9 20.0%	12 22.6%	18 11.8%	54 11.5%	39 11.3%
Can't remember	1 3.7%	35 3.4%	28 5.0%	7 2.8%	7 2.8%	4 2.3%	11 7.1%	3 1.2%	3 6.7%	1 1.9%	5 3.3%	16 3.4%	16 4.6%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	25	919	485	219	198	153	122	227	33	40	129	399	291
Q50+. Were you given clear written information about what you should or should not do after leaving hospital?													
* Yes	21 84.0%	832 90.5%	398 82.1%	181 82.6%	156 78.8%	133 86.9%	98 80.3%	203 89.4%	25 75.8%	38 95.0%	102 79.1%	321 80.5%	224 77.0%
No	4 16.0%	87 9.5%	87 17.9%	38 17.4%	42 21.2%	20 13.1%	24 19.7%	24 10.6%	8 24.2%	2 5.0%	27 20.9%	78 19.5%	67 23.0%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1033	560	247	246	173	155	255	44	53	152	470	347
Q51. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?													
Yes	26 96.3%	965 93.4%	503 89.8%	207 83.8%	223 90.7%	158 91.3%	138 89.0%	234 91.8%	38 86.4%	47 88.7%	131 86.2%	382 81.3%	288 83.0%
No	1 3.7%	36 3.5%	39 7.0%	28 11.3%	12 4.9%	7 4.0%	10 6.5%	16 6.3%	5 11.4%	2 3.8%	16 10.5%	59 12.6%	44 12.7%
Don't know / can't remember	- -	32 3.1%	18 3.2%	12 4.9%	11 4.5%	8 4.6%	7 4.5%	5 2.0%	1 2.3%	4 7.5%	5 3.3%	29 6.2%	15 4.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1001	542	235	235	165	148	250	43	49	147	441	332
Q51+. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?													
* Yes	26 96.3%	965 96.4%	503 92.8%	207 88.1%	223 94.9%	158 95.8%	138 93.2%	234 93.6%	38 88.4%	47 95.9%	131 89.1%	382 86.6%	288 86.7%
No	1 3.7%	36 3.6%	39 7.2%	28 11.9%	12 5.1%	7 4.2%	10 6.8%	16 6.4%	5 11.6%	2 4.1%	16 10.9%	59 13.4%	44 13.3%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1497	798	336	601	225	305	931	60	137	236	653	702
Q52. In the last 12 months, have you had an outpatients or day case appointment for your cancer?													
Yes	34 94.4%	1349 90.1%	725 90.9%	315 93.8%	580 96.5%	215 95.6%	288 94.4%	868 93.2%	58 96.7%	134 97.8%	227 96.2%	611 93.6%	671 95.6%
No	2 5.6%	148 9.9%	73 9.1%	21 6.3%	21 3.5%	10 4.4%	17 5.6%	63 6.8%	2 3.3%	3 2.2%	9 3.8%	42 6.4%	31 4.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	33	1312	715	314	562	211	280	846	55	131	224	597	663
Q53. The last time you attended hospital as a day case or outpatient, was this at the hospital named on the letter that came with this survey?													
Yes	26 78.8%	901 68.7%	554 77.5%	226 72.0%	474 84.3%	141 66.8%	186 66.4%	663 78.4%	34 61.8%	96 73.3%	153 68.3%	492 82.4%	498 75.1%
No, at another NHS hospital in Wales	6 18.2%	382 29.1%	150 21.0%	80 25.5%	76 13.5%	66 31.3%	86 30.7%	162 19.1%	18 32.7%	33 25.2%	59 26.3%	99 16.6%	152 22.9%
No, at a private hospital/centre in Wales	- -	4 0.3%	- -	1 0.3%	- -	- -	- -	- -	1 1.8%	- -	- -	2 0.3%	- -
No, somewhere outside Wales	1 3.0%	13 1.0%	6 0.8%	5 1.6%	6 1.1%	1 0.5%	5 1.8%	12 1.4%	1 1.8%	- -	9 4.0%	1 0.2%	8 1.2%
Dont know / can't remember	- -	12 0.9%	5 0.7%	2 0.6%	6 1.1%	3 1.4%	3 1.1%	9 1.1%	1 1.8%	2 1.5%	3 1.3%	3 0.5%	5 0.8%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1348	727	317	568	214	292	855	57	133	225	608	674
Q54. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?													
Yes, definitely	12 35.3%	599 44.4%	330 45.4%	139 43.8%	269 47.4%	124 57.9%	140 47.9%	306 35.8%	21 36.8%	46 34.6%	109 48.4%	226 37.2%	341 50.6%
Yes, to some extent	5 14.7%	77 5.7%	43 5.9%	20 6.3%	23 4.0%	8 3.7%	26 8.9%	31 3.6%	7 12.3%	8 6.0%	10 4.4%	42 6.9%	50 7.4%
No, they could have done more	- -	13 1.0%	8 1.1%	5 1.6%	5 0.9%	4 1.9%	6 2.1%	11 1.3%	- -	- -	5 2.2%	12 2.0%	11 1.6%
I did not have any pain	17 50.0%	659 48.9%	346 47.6%	153 48.3%	271 47.7%	78 36.4%	120 41.1%	507 59.3%	29 50.9%	79 59.4%	101 44.9%	328 53.9%	272 40.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	17	689	381	164	297	136	172	348	28	54	124	280	402
Q54+. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?													
* Yes, definitely	* *	599 86.9%	330 86.6%	139 84.8%	269 90.6%	124 91.2%	140 81.4%	306 87.9%	21 75.0%	46 85.2%	109 87.9%	226 80.7%	341 84.8%
Yes, to some extent	* *	77 11.2%	43 11.3%	20 12.2%	23 7.7%	8 5.9%	26 15.1%	31 8.9%	7 25.0%	8 14.8%	10 8.1%	42 15.0%	50 12.4%
No, they could have done more	* *	13 1.9%	8 2.1%	5 3.0%	5 1.7%	4 2.9%	6 3.5%	11 3.2%	- -	- -	5 4.0%	12 4.3%	11 2.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	33	1350	721	316	575	212	290	852	58	134	227	610	675
Q55. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?													
Yes, definitely	19 57.6%	862 63.9%	416 57.7%	194 61.4%	327 56.9%	132 62.3%	181 62.4%	419 49.2%	29 50.0%	62 46.3%	136 59.9%	290 47.5%	389 57.6%
Yes, to some extent	8 24.2%	179 13.3%	92 12.8%	35 11.1%	80 13.9%	25 11.8%	45 15.5%	83 9.7%	9 15.5%	10 7.5%	33 14.5%	76 12.5%	97 14.4%
No, I would have liked more support	- -	47 3.5%	23 3.2%	15 4.7%	19 3.3%	7 3.3%	11 3.8%	18 2.1%	4 6.9%	3 2.2%	5 2.2%	28 4.6%	30 4.4%
I did not need emotional support from staff	6 18.2%	262 19.4%	190 26.4%	72 22.8%	149 25.9%	48 22.6%	53 18.3%	332 39.0%	16 27.6%	59 44.0%	53 23.3%	216 35.4%	159 23.6%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	27	1088	531	244	426	164	237	520	42	75	174	394	516
Q55+. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?													
* Yes, definitely	19 70.4%	862 79.2%	416 78.3%	194 79.5%	327 76.8%	132 80.5%	181 76.4%	419 80.6%	29 69.0%	62 82.7%	136 78.2%	290 73.6%	389 75.4%
Yes, to some extent	8 29.6%	179 16.5%	92 17.3%	35 14.3%	80 18.8%	25 15.2%	45 19.0%	83 16.0%	9 21.4%	10 13.3%	33 19.0%	76 19.3%	97 18.8%
No, I would have liked more support	- -	47 4.3%	23 4.3%	15 6.1%	19 4.5%	7 4.3%	11 4.6%	18 3.5%	4 9.5%	3 4.0%	5 2.9%	28 7.1%	30 5.8%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1513	791	341	585	221	303	933	59	141	237	642	696
Q56. Have you had radiotherapy treatment?													
Yes	34 94.4%	1165 77.0%	250 31.6%	139 40.8%	161 27.5%	179 81.0%	185 61.1%	532 57.0%	25 42.4%	11 7.8%	107 45.1%	100 15.6%	413 59.3%
No	2 5.6%	348 23.0%	541 68.4%	202 59.2%	424 72.5%	42 19.0%	118 38.9%	401 43.0%	34 57.6%	130 92.2%	130 54.9%	542 84.4%	283 40.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	33	1164	245	132	159	182	184	531	26	10	104	97	414
Q57. Thinking of the last time you had radiotherapy treatment, was this at:													
Glan Clwyd Hospital	3 9.1%	269 23.1%	78 31.8%	13 9.8%	47 29.6%	39 21.4%	35 19.0%	54 10.2%	4 15.4%	* *	21 20.2%	25 25.8%	51 12.3%
Singleton Hospital	5 15.2%	276 23.7%	54 22.0%	21 15.9%	51 32.1%	51 28.0%	52 28.3%	93 17.5%	10 38.5%	* *	41 39.4%	26 26.8%	110 26.6%
Velindre Cancer Centre	23 69.7%	590 50.7%	108 44.1%	82 62.1%	57 35.8%	91 50.0%	92 50.0%	382 71.9%	10 38.5%	* *	41 39.4%	44 45.4%	239 57.7%
A private hospital/centre in Wales	- -	1 0.1%	1 0.4%	- -	- -	- -	- -	- -	- -	* *	- -	- -	1 0.2%
Somewhere outside Wales	2 6.1%	28 2.4%	4 1.6%	15 11.4%	4 2.5%	1 0.5%	5 2.7%	2 0.4%	2 7.7%	* *	1 1.0%	2 2.1%	13 3.1%
Dont know / can't remember	- -	- -	- -	1 0.8%	- -	- -	- -	- -	- -	* *	- -	- -	- -

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	31	1135	243	123	156	180	176	531	23	10	102	96	400
Q58. Did hospital staff do everything possible to control the side effects of radiotherapy?													
Yes, definitely	21 67.7%	826 72.8%	192 79.0%	94 76.4%	107 68.6%	147 81.7%	123 69.9%	356 67.0%	17 73.9%	* *	75 73.5%	63 65.6%	278 69.5%
Yes, to some extent	5 16.1%	138 12.2%	16 6.6%	10 8.1%	15 9.6%	19 10.6%	21 11.9%	60 11.3%	5 21.7%	* *	14 13.7%	13 13.5%	58 14.5%
No, they could have done more	- -	28 2.5%	7 2.9%	1 0.8%	3 1.9%	6 3.3%	8 4.5%	9 1.7%	- -	* *	4 3.9%	2 2.1%	16 4.0%
I have not had any side effects from radiotherapy	5 16.1%	143 12.6%	28 11.5%	18 14.6%	31 19.9%	8 4.4%	24 13.6%	106 20.0%	1 4.3%	* *	9 8.8%	18 18.8%	48 12.0%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	26	992	215	105	125	172	152	425	22	8	93	78	352
Q58+. Did hospital staff do everything possible to control the side effects of radiotherapy?													
* Yes, definitely	21 80.8%	826 83.3%	192 89.3%	94 89.5%	107 85.6%	147 85.5%	123 80.9%	356 83.8%	17 77.3%	* *	75 80.6%	63 80.8%	278 79.0%
Yes, to some extent	5 19.2%	138 13.9%	16 7.4%	10 9.5%	15 12.0%	19 11.0%	21 13.8%	60 14.1%	5 22.7%	* *	14 15.1%	13 16.7%	58 16.5%
No, they could have done more	- -	28 2.8%	7 3.3%	1 1.0%	3 2.4%	6 3.5%	8 5.3%	9 2.1%	- -	* *	4 4.3%	2 2.6%	16 4.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1504	791	338	586	220	312	926	58	136	234	627	695
Q59. Have you had chemotherapy treatment?													
Yes	32 88.9%	768 51.1%	539 68.1%	184 54.4%	534 91.1%	110 50.0%	209 67.0%	179 19.3%	20 34.5%	11 8.1%	184 78.6%	254 40.5%	469 67.5%
No	4 11.1%	736 48.9%	252 31.9%	154 45.6%	52 8.9%	110 50.0%	103 33.0%	747 80.7%	38 65.5%	125 91.9%	50 21.4%	373 59.5%	226 32.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	28	748	519	185	518	108	204	185	20	11	183	257	459
Q60. Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?													
Yes	23 82.1%	569 76.1%	409 78.8%	149 80.5%	433 83.6%	92 85.2%	153 75.0%	153 82.7%	16 80.0%	* *	133 72.7%	224 87.2%	364 79.3%
No, at another NHS hospital in Wales	5 17.9%	160 21.4%	101 19.5%	34 18.4%	74 14.3%	14 13.0%	50 24.5%	30 16.2%	3 15.0%	* *	42 23.0%	30 11.7%	85 18.5%
No, at a private hospital/centre in Wales	- -	8 1.1%	4 0.8%	1 0.5%	1 0.2%	- -	- -	- -	- -	* *	- -	- -	1 0.2%
No, somewhere outside Wales	- -	7 0.9%	2 0.4%	1 0.5%	6 1.2%	1 0.9%	- -	- -	1 5.0%	* *	5 2.7%	1 0.4%	3 0.7%
Dont know / can't remember	- -	4 0.5%	3 0.6%	- -	4 0.8%	1 0.9%	1 0.5%	2 1.1%	- -	* *	3 1.6%	2 0.8%	6 1.3%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	31	771	545	187	539	109	207	184	21	12	188	258	473
Q61. Did hospital staff do everything possible to control the side effects of chemotherapy?													
Yes, definitely	21 67.7%	662 85.9%	462 84.8%	166 88.8%	459 85.2%	90 82.6%	166 80.2%	142 77.2%	17 81.0%	* *	158 84.0%	150 58.1%	391 82.7%
Yes, to some extent	8 25.8%	81 10.5%	48 8.8%	16 8.6%	42 7.8%	9 8.3%	23 11.1%	26 14.1%	4 19.0%	* *	14 7.4%	32 12.4%	57 12.1%
No, they could have done more	- -	16 2.1%	8 1.5%	- -	13 2.4%	4 3.7%	8 3.9%	5 2.7%	- -	* *	4 2.1%	10 3.9%	13 2.7%
I have not had any side effects from chemotherapy	2 6.5%	12 1.6%	27 5.0%	5 2.7%	25 4.6%	6 5.5%	10 4.8%	11 6.0%	- -	* *	12 6.4%	66 25.6%	12 2.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	29	759	518	182	514	103	197	173	21	9	176	192	461
Q61+. Did hospital staff do everything possible to control the side effects of chemotherapy?													
* Yes, definitely	21 72.4%	662 87.2%	462 89.2%	166 91.2%	459 89.3%	90 87.4%	166 84.3%	142 82.1%	17 81.0%	* *	158 89.8%	150 78.1%	391 84.8%
Yes, to some extent	8 27.6%	81 10.7%	48 9.3%	16 8.8%	42 8.2%	9 8.7%	23 11.7%	26 15.0%	4 19.0%	* *	14 8.0%	32 16.7%	57 12.4%
No, they could have done more	- -	16 2.1%	8 1.5%	- -	13 2.5%	4 3.9%	8 4.1%	5 2.9%	- -	* *	4 2.3%	10 5.2%	13 2.8%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1491	785	336	580	222	299	875	58	129	238	616	689
Q62. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?													
Yes, definitely	21 58.3%	787 52.8%	460 58.6%	187 55.7%	325 56.0%	149 67.1%	159 53.2%	408 46.6%	31 53.4%	64 49.6%	134 56.3%	262 42.5%	355 51.5%
Yes, to some extent	6 16.7%	239 16.0%	145 18.5%	60 17.9%	117 20.2%	32 14.4%	60 20.1%	120 13.7%	12 20.7%	20 15.5%	55 23.1%	93 15.1%	134 19.4%
No	7 19.4%	267 17.9%	113 14.4%	58 17.3%	74 12.8%	25 11.3%	47 15.7%	166 19.0%	11 19.0%	15 11.6%	33 13.9%	116 18.8%	133 19.3%
No family or friends were involved	2 5.6%	198 13.3%	67 8.5%	31 9.2%	64 11.0%	16 7.2%	33 11.0%	181 20.7%	4 6.9%	30 23.3%	16 6.7%	145 23.5%	67 9.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1293	718	305	516	206	266	694	54	99	222	471	622
Q62+. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?													
* Yes, definitely	21 61.8%	787 60.9%	460 64.1%	187 61.3%	325 63.0%	149 72.3%	159 59.8%	408 58.8%	31 57.4%	64 64.6%	134 60.4%	262 55.6%	355 57.1%
Yes, to some extent	6 17.6%	239 18.5%	145 20.2%	60 19.7%	117 22.7%	32 15.5%	60 22.6%	120 17.3%	12 22.2%	20 20.2%	55 24.8%	93 19.7%	134 21.5%
No	7 20.6%	267 20.6%	113 15.7%	58 19.0%	74 14.3%	25 12.1%	47 17.7%	166 23.9%	11 20.4%	15 15.2%	33 14.9%	116 24.6%	133 21.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1506	780	332	589	226	304	874	54	127	238	613	689
Q63. 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)?													
Yes, definitely	21 58.3%	918 61.0%	462 59.2%	186 56.0%	311 52.8%	158 69.9%	158 52.0%	466 53.3%	29 53.7%	61 48.0%	145 60.9%	256 41.8%	343 49.8%
Yes, to some extent	12 33.3%	376 25.0%	192 24.6%	93 28.0%	158 26.8%	46 20.4%	83 27.3%	209 23.9%	11 20.4%	30 23.6%	70 29.4%	119 19.4%	209 30.3%
No, I was not offered any practical advice or support	3 8.3%	155 10.3%	91 11.7%	41 12.3%	78 13.2%	15 6.6%	43 14.1%	132 15.1%	12 22.2%	23 18.1%	19 8.0%	151 24.6%	109 15.8%
Not sure / can’t remember	- -	57 3.8%	35 4.5%	12 3.6%	42 7.1%	7 3.1%	20 6.6%	67 7.7%	2 3.7%	13 10.2%	4 1.7%	87 14.2%	28 4.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1449	745	320	547	219	284	807	52	114	234	526	661
Q63+. 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)?													
* Yes, definitely	21 58.3%	918 63.4%	462 62.0%	186 58.1%	311 56.9%	158 72.1%	158 55.6%	466 57.7%	29 55.8%	61 53.5%	145 62.0%	256 48.7%	343 51.9%
Yes, to some extent	12 33.3%	376 25.9%	192 25.8%	93 29.1%	158 28.9%	46 21.0%	83 29.2%	209 25.9%	11 21.2%	30 26.3%	70 29.9%	119 22.6%	209 31.6%
No, I was not offered any practical advice or support	3 8.3%	155 10.7%	91 12.2%	41 12.8%	78 14.3%	15 6.8%	43 15.1%	132 16.4%	12 23.1%	23 20.2%	19 8.1%	151 28.7%	109 16.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1513	793	343	594	225	307	882	59	134	239	638	696
Q64. After leaving hospital, were you given enough care and help from your GP and the GP surgery?													
Yes, definitely	12 33.3%	612 40.4%	350 44.1%	149 43.4%	243 40.9%	95 42.2%	147 47.9%	324 36.7%	21 35.6%	62 46.3%	101 42.3%	226 35.4%	275 39.5%
Yes, to some extent	15 41.7%	282 18.6%	145 18.3%	60 17.5%	109 18.4%	51 22.7%	59 19.2%	142 16.1%	14 23.7%	18 13.4%	53 22.2%	109 17.1%	159 22.8%
No	5 13.9%	196 13.0%	109 13.7%	44 12.8%	92 15.5%	38 16.9%	38 12.4%	88 10.0%	13 22.0%	11 8.2%	42 17.6%	80 12.5%	121 17.4%
I did not need help	3 8.3%	415 27.4%	180 22.7%	89 25.9%	143 24.1%	40 17.8%	60 19.5%	321 36.4%	11 18.6%	41 30.6%	41 17.2%	217 34.0%	135 19.4%
Don’t know / can’t remember	1 2.8%	8 0.5%	9 1.1%	1 0.3%	7 1.2%	1 0.4%	3 1.0%	7 0.8%	- -	2 1.5%	2 0.8%	6 0.9%	6 0.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1090	604	253	444	184	244	554	48	91	196	415	555
Q64+. After leaving hospital, were you given enough care and help from your GP and the GP surgery?													
* Yes, definitely	12 37.5%	612 56.1%	350 57.9%	149 58.9%	243 54.7%	95 51.6%	147 60.2%	324 58.5%	21 43.8%	62 68.1%	101 51.5%	226 54.5%	275 49.5%
Yes, to some extent	15 46.9%	282 25.9%	145 24.0%	60 23.7%	109 24.5%	51 27.7%	59 24.2%	142 25.6%	14 29.2%	18 19.8%	53 27.0%	109 26.3%	159 28.6%
No	5 15.6%	196 18.0%	109 18.0%	44 17.4%	92 20.7%	38 20.7%	38 15.6%	88 15.9%	13 27.1%	11 12.1%	42 21.4%	80 19.3%	121 21.8%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1512	796	342	599	225	309	882	59	136	238	644	695
Q65. As far as you know, did your GP have all the information they needed about your care after leaving hospital?													
Yes	25 69.4%	1022 67.6%	532 66.8%	226 66.1%	380 63.4%	144 64.0%	208 67.3%	557 63.2%	38 64.4%	90 66.2%	160 67.2%	411 63.8%	445 64.0%
No	3 8.3%	71 4.7%	43 5.4%	24 7.0%	43 7.2%	17 7.6%	24 7.8%	49 5.6%	5 8.5%	7 5.1%	22 9.2%	43 6.7%	52 7.5%
Don't know / can't remember	8 22.2%	419 27.7%	221 27.8%	92 26.9%	176 29.4%	64 28.4%	77 24.9%	276 31.3%	16 27.1%	39 28.7%	56 23.5%	190 29.5%	198 28.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	28	1093	575	250	423	161	232	606	43	97	182	454	497
Q65+. As far as you know, did your GP have all the information they needed about your care after leaving hospital?													
* Yes	25 89.3%	1022 93.5%	532 92.5%	226 90.4%	380 89.8%	144 89.4%	208 89.7%	557 91.9%	38 88.4%	90 92.8%	160 87.9%	411 90.5%	445 89.5%
No	3 10.7%	71 6.5%	43 7.5%	24 9.6%	43 10.2%	17 10.6%	24 10.3%	49 8.1%	5 11.6%	7 7.2%	22 12.1%	43 9.5%	52 10.5%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	36	1512	795	345	594	226	302	875	57	136	237	635	689
Q66. After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?													
Yes, definitely	7 19.4%	569 37.6%	429 54.0%	109 31.6%	156 26.3%	92 40.7%	102 33.8%	194 22.2%	23 40.4%	35 25.7%	107 45.1%	124 19.5%	280 40.6%
Yes, to some extent	6 16.7%	170 11.2%	96 12.1%	40 11.6%	70 11.8%	35 15.5%	26 8.6%	52 5.9%	13 22.8%	8 5.9%	41 17.3%	49 7.7%	120 17.4%
No	4 11.1%	164 10.8%	84 10.6%	49 14.2%	87 14.6%	21 9.3%	61 20.2%	99 11.3%	8 14.0%	10 7.4%	27 11.4%	86 13.5%	93 13.5%
I did not need help	19 52.8%	600 39.7%	181 22.8%	147 42.6%	278 46.8%	76 33.6%	111 36.8%	525 60.0%	13 22.8%	82 60.3%	60 25.3%	371 58.4%	186 27.0%
Don't know / can't remember	- -	9 0.6%	5 0.6%	- -	3 0.5%	2 0.9%	2 0.7%	5 0.6%	- -	1 0.7%	2 0.8%	5 0.8%	10 1.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	17	903	609	198	313	148	189	345	44	53	175	259	493
Q66+. After leaving hospital, were you given enough care and help from health or social services (for example, district nurses, home helps or physiotherapists)?													
* Yes, definitely	* *	569 63.0%	429 70.4%	109 55.1%	156 49.8%	92 62.2%	102 54.0%	194 56.2%	23 52.3%	35 66.0%	107 61.1%	124 47.9%	280 56.8%
Yes, to some extent	* *	170 18.8%	96 15.8%	40 20.2%	70 22.4%	35 23.6%	26 13.8%	52 15.1%	13 29.5%	8 15.1%	41 23.4%	49 18.9%	120 24.3%
No	* *	164 18.2%	84 13.8%	49 24.7%	87 27.8%	21 14.2%	61 32.3%	99 28.7%	8 18.2%	10 18.9%	27 15.4%	86 33.2%	93 18.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1476	777	325	585	225	300	872	58	125	236	609	686
Q67. Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?													
Yes	16 45.7%	678 45.9%	334 43.0%	140 43.1%	220 37.6%	136 60.4%	128 42.7%	355 40.7%	21 36.2%	40 32.0%	113 47.9%	177 29.1%	277 40.4%
No	16 45.7%	595 40.3%	326 42.0%	149 45.8%	287 49.1%	60 26.7%	142 47.3%	395 45.3%	31 53.4%	67 53.6%	101 42.8%	348 57.1%	322 46.9%
Don't know / can't remember	3 8.6%	203 13.8%	117 15.1%	36 11.1%	78 13.3%	29 12.9%	30 10.0%	122 14.0%	6 10.3%	18 14.4%	22 9.3%	84 13.8%	87 12.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1273	660	289	507	196	270	750	52	107	214	525	599
Q67+. Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?													
* Yes	16 50.0%	678 53.3%	334 50.6%	140 48.4%	220 43.4%	136 69.4%	128 47.4%	355 47.3%	21 40.4%	40 37.4%	113 52.8%	177 33.7%	277 46.2%
No	16 50.0%	595 46.7%	326 49.4%	149 51.6%	287 56.6%	60 30.6%	142 52.6%	395 52.7%	31 59.6%	67 62.6%	101 47.2%	348 66.3%	322 53.8%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1475	779	329	583	225	300	883	58	125	232	614	685
Q68. Have you been offered a written care plan?													
Yes	4 11.8%	293 19.9%	129 16.6%	47 14.3%	82 14.1%	63 28.0%	52 17.3%	109 12.3%	9 15.5%	9 7.2%	32 13.8%	68 11.1%	106 15.5%
No	28 82.4%	950 64.4%	555 71.2%	242 73.6%	441 75.6%	122 54.2%	212 70.7%	675 76.4%	41 70.7%	104 83.2%	175 75.4%	479 78.0%	488 71.2%
Don't know / can't remember	2 5.9%	232 15.7%	95 12.2%	40 12.2%	60 10.3%	40 17.8%	36 12.0%	99 11.2%	8 13.8%	12 9.6%	25 10.8%	67 10.9%	91 13.3%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1243	684	289	523	185	264	784	50	113	207	547	594
Q68+. Have you been offered a written care plan?													
* Yes	4 12.5%	293 23.6%	129 18.9%	47 16.3%	82 15.7%	63 34.1%	52 19.7%	109 13.9%	9 18.0%	9 8.0%	32 15.5%	68 12.4%	106 17.8%
No	28 87.5%	950 76.4%	555 81.1%	242 83.7%	441 84.3%	122 65.9%	212 80.3%	675 86.1%	41 82.0%	104 92.0%	175 84.5%	479 87.6%	488 82.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1504	788	339	590	224	305	925	60	137	238	646	699
Q69. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?													
Yes	8 23.5%	292 19.4%	180 22.8%	85 25.1%	189 32.0%	50 22.3%	92 30.2%	225 24.3%	9 15.0%	9 6.6%	46 19.3%	54 8.4%	202 28.9%
No	25 73.5%	1155 76.8%	582 73.9%	236 69.6%	370 62.7%	164 73.2%	198 64.9%	671 72.5%	49 81.7%	124 90.5%	187 78.6%	563 87.2%	464 66.4%
Don’t know / can’t remember	1 2.9%	57 3.8%	26 3.3%	18 5.3%	31 5.3%	10 4.5%	15 4.9%	29 3.1%	2 3.3%	4 2.9%	5 2.1%	29 4.5%	33 4.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	33	1447	762	321	559	214	290	896	58	133	233	617	666
Q69+. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research (e.g. clinical trials)?													
* Yes	8 24.2%	292 20.2%	180 23.6%	85 26.5%	189 33.8%	50 23.4%	92 31.7%	225 25.1%	9 15.5%	9 6.8%	46 19.7%	54 8.8%	202 30.3%
No	25 75.8%	1155 79.8%	582 76.4%	236 73.5%	370 66.2%	164 76.6%	198 68.3%	671 74.9%	49 84.5%	124 93.2%	187 80.3%	563 91.2%	464 69.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1498	788	337	590	223	308	913	59	134	237	631	695
Q70. Since your diagnosis, have the different professionals treating and caring for you worked well together to give you the best possible care?													
Yes, always	20 58.8%	1010 67.4%	531 67.4%	223 66.2%	428 72.5%	159 71.3%	209 67.9%	642 70.3%	31 52.5%	94 70.1%	152 64.1%	397 62.9%	446 64.2%
Yes, most of the time	8 23.5%	297 19.8%	151 19.2%	74 22.0%	96 16.3%	43 19.3%	52 16.9%	147 16.1%	15 25.4%	18 13.4%	48 20.3%	98 15.5%	154 22.2%
Yes, some of the time	2 5.9%	87 5.8%	51 6.5%	16 4.7%	32 5.4%	13 5.8%	27 8.8%	51 5.6%	3 5.1%	9 6.7%	19 8.0%	47 7.4%	54 7.8%
No, never	3 8.8%	34 2.3%	21 2.7%	9 2.7%	16 2.7%	3 1.3%	7 2.3%	20 2.2%	5 8.5%	6 4.5%	8 3.4%	27 4.3%	14 2.0%
Don't know	1 2.9%	70 4.7%	34 4.3%	15 4.5%	18 3.1%	5 2.2%	13 4.2%	53 5.8%	5 8.5%	7 5.2%	10 4.2%	62 9.8%	27 3.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	33	1428	754	322	572	218	295	860	54	127	227	569	668
Q70+. Since your diagnosis, have the different professionals treating and caring for you worked well together to give you the best possible care?													
* Yes, always	20 60.6%	1010 70.7%	531 70.4%	223 69.3%	428 74.8%	159 72.9%	209 70.8%	642 74.7%	31 57.4%	94 74.0%	152 67.0%	397 69.8%	446 66.8%
Yes, most of the time	8 24.2%	297 20.8%	151 20.0%	74 23.0%	96 16.8%	43 19.7%	52 17.6%	147 17.1%	15 27.8%	18 14.2%	48 21.1%	98 17.2%	154 23.1%
Yes, some of the time	2 6.1%	87 6.1%	51 6.8%	16 5.0%	32 5.6%	13 6.0%	27 9.2%	51 5.9%	3 5.6%	9 7.1%	19 8.4%	47 8.3%	54 8.1%
No, never	3 9.1%	34 2.4%	21 2.8%	9 2.8%	16 2.8%	3 1.4%	7 2.4%	20 2.3%	5 9.3%	6 4.7%	8 3.5%	27 4.7%	14 2.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1507	794	344	591	223	308	921	60	134	238	648	700
Q71. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?													
Very good	20 58.8%	1053 69.9%	490 61.7%	216 62.8%	387 65.5%	155 69.5%	196 63.6%	605 65.7%	28 46.7%	89 66.4%	145 60.9%	357 55.1%	432 61.7%
Good	8 23.5%	336 22.3%	208 26.2%	94 27.3%	150 25.4%	45 20.2%	76 24.7%	208 22.6%	21 35.0%	29 21.6%	59 24.8%	188 29.0%	180 25.7%
Neither good nor bad	2 5.9%	70 4.6%	57 7.2%	15 4.4%	33 5.6%	11 4.9%	21 6.8%	65 7.1%	4 6.7%	8 6.0%	22 9.2%	54 8.3%	59 8.4%
Quite bad	2 5.9%	26 1.7%	20 2.5%	11 3.2%	15 2.5%	3 1.3%	9 2.9%	25 2.7%	3 5.0%	5 3.7%	8 3.4%	30 4.6%	18 2.6%
Very bad	- -	15 1.0%	6 0.8%	5 1.5%	2 0.3%	6 2.7%	3 1.0%	12 1.3%	2 3.3%	2 1.5%	3 1.3%	10 1.5%	6 0.9%
Don't know / can't remember	2 5.9%	7 0.5%	13 1.6%	3 0.9%	4 0.7%	3 1.3%	3 1.0%	6 0.7%	2 3.3%	1 0.7%	1 0.4%	9 1.4%	5 0.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1500	781	341	587	220	305	915	58	133	237	639	695
Q71+. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?													
* Very good	20 62.5%	1053 70.2%	490 62.7%	216 63.3%	387 65.9%	155 70.5%	196 64.3%	605 66.1%	28 48.3%	89 66.9%	145 61.2%	357 55.9%	432 62.2%
* Good	8 25.0%	336 22.4%	208 26.6%	94 27.6%	150 25.6%	45 20.5%	76 24.9%	208 22.7%	21 36.2%	29 21.8%	59 24.9%	188 29.4%	180 25.9%
Neither good nor bad	2 6.3%	70 4.7%	57 7.3%	15 4.4%	33 5.6%	11 5.0%	21 6.9%	65 7.1%	4 6.9%	8 6.0%	22 9.3%	54 8.5%	59 8.5%
Quite bad	2 6.3%	26 1.7%	20 2.6%	11 3.2%	15 2.6%	3 1.4%	9 3.0%	25 2.7%	3 5.2%	5 3.8%	8 3.4%	30 4.7%	18 2.6%
Very bad	- -	15 1.0%	6 0.8%	5 1.5%	2 0.3%	6 2.7%	3 1.0%	12 1.3%	2 3.4%	2 1.5%	3 1.3%	10 1.6%	6 0.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1514	796	342	589	222	306	916	59	136	236	650	695
Q72. During your care, did you receive the information you needed in your preferred language?													
Yes, completely	33 97.1%	1448 95.6%	762 95.7%	321 93.9%	562 95.4%	217 97.7%	290 94.8%	876 95.6%	54 91.5%	133 97.8%	229 97.0%	619 95.2%	669 96.3%
Yes, to some extent	1 2.9%	41 2.7%	23 2.9%	12 3.5%	16 2.7%	4 1.8%	10 3.3%	25 2.7%	4 6.8%	3 2.2%	7 3.0%	13 2.0%	18 2.6%
No	- -	21 1.4%	8 1.0%	8 2.3%	10 1.7%	- -	5 1.6%	12 1.3%	1 1.7%	- -	- -	13 2.0%	5 0.7%
Don't know / can't remember	- -	4 0.3%	3 0.4%	1 0.3%	1 0.2%	1 0.5%	1 0.3%	3 0.3%	- -	- -	- -	5 0.8%	3 0.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1510	793	341	588	221	305	913	59	136	236	645	692
Q72+. During your care, did you receive the information you needed in your preferred language?													
* Yes, completely	33 97.1%	1448 95.9%	762 96.1%	321 94.1%	562 95.6%	217 98.2%	290 95.1%	876 95.9%	54 91.5%	133 97.8%	229 97.0%	619 96.0%	669 96.7%
Yes, to some extent	1 2.9%	41 2.7%	23 2.9%	12 3.5%	16 2.7%	4 1.8%	10 3.3%	25 2.7%	4 6.8%	3 2.2%	7 3.0%	13 2.0%	18 2.6%
No	- -	21 1.4%	8 1.0%	8 2.3%	10 1.7%	- -	5 1.6%	12 1.3%	1 1.7%	- -	- -	13 2.0%	5 0.7%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1494	787	340	588	223	303	911	58	136	232	631	690
Q73. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?													
Yes, often	- -	58 3.9%	39 5.0%	14 4.1%	36 6.1%	7 3.1%	13 4.3%	49 5.4%	4 6.9%	2 1.5%	9 3.9%	30 4.8%	50 7.2%
Yes, sometimes	6 17.6%	215 14.4%	103 13.1%	50 14.7%	66 11.2%	25 11.2%	59 19.5%	98 10.8%	9 15.5%	10 7.4%	41 17.7%	82 13.0%	116 16.8%
* No	28 82.4%	1221 81.7%	645 82.0%	276 81.2%	486 82.7%	191 85.7%	231 76.2%	764 83.9%	45 77.6%	124 91.2%	182 78.4%	519 82.3%	524 75.9%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1484	769	334	581	219	297	897	58	133	229	639	679
Q74. Overall how would you rate your care?													
0 - I had a very poor experience	- -	- -	3 0.4%	1 0.3%	1 0.2%	- -	1 0.3%	4 0.4%	1 1.7%	- -	- -	1 0.2%	2 0.3%
1	- -	2 0.1%	1 0.1%	2 0.6%	2 0.3%	1 0.5%	- -	4 0.4%	2 3.4%	1 0.8%	- -	4 0.6%	4 0.6%
2	- -	4 0.3%	3 0.4%	- -	1 0.2%	1 0.5%	4 1.3%	2 0.2%	2 3.4%	- -	1 0.4%	1 0.2%	2 0.3%
3	- -	3 0.2%	5 0.7%	- -	3 0.5%	1 0.5%	- -	7 0.8%	2 3.4%	- -	- -	4 0.6%	3 0.4%
4	2 6.3%	6 0.4%	7 0.9%	1 0.3%	2 0.3%	5 2.3%	3 1.0%	4 0.4%	1 1.7%	1 0.8%	4 1.7%	8 1.3%	6 0.9%
5	1 3.1%	27 1.8%	13 1.7%	8 2.4%	11 1.9%	2 0.9%	3 1.0%	10 1.1%	- -	4 3.0%	7 3.1%	21 3.3%	17 2.5%
6	1 3.1%	33 2.2%	26 3.4%	4 1.2%	14 2.4%	2 0.9%	11 3.7%	16 1.8%	2 3.4%	2 1.5%	10 4.4%	26 4.1%	27 4.0%
7	2 6.3%	77 5.2%	53 6.9%	27 8.1%	36 6.2%	20 9.1%	22 7.4%	41 4.6%	4 6.9%	7 5.3%	13 5.7%	40 6.3%	40 5.9%
8	8 25.0%	246 16.6%	141 18.3%	56 16.8%	107 18.4%	27 12.3%	55 18.5%	161 17.9%	12 20.7%	20 15.0%	46 20.1%	143 22.4%	144 21.2%
9	7 21.9%	356 24.0%	200 26.0%	69 20.7%	152 26.2%	56 25.6%	56 18.9%	233 26.0%	11 19.0%	30 22.6%	52 22.7%	129 20.2%	160 23.6%
10 - I had a very good experience	11 34.4%	730 49.2%	317 41.2%	166 49.7%	252 43.4%	104 47.5%	142 47.8%	415 46.3%	21 36.2%	68 51.1%	96 41.9%	262 41.0%	274 40.4%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1484	769	334	581	219	297	897	58	133	229	639	679
Q74+. Overall how would you rate your care?													
0 - I had a very poor experience	- -	- -	3 0.4%	1 0.3%	1 0.2%	- -	1 0.3%	4 0.4%	1 1.7%	- -	- -	1 0.2%	2 0.3%
1	- -	2 0.1%	1 0.1%	2 0.6%	2 0.3%	1 0.5%	- -	4 0.4%	2 3.4%	1 0.8%	- -	4 0.6%	4 0.6%
2	- -	4 0.3%	3 0.4%	- -	1 0.2%	1 0.5%	4 1.3%	2 0.2%	2 3.4%	- -	1 0.4%	1 0.2%	2 0.3%
3	- -	3 0.2%	5 0.7%	- -	3 0.5%	1 0.5%	- -	7 0.8%	2 3.4%	- -	- -	4 0.6%	3 0.4%
4	2 6.3%	6 0.4%	7 0.9%	1 0.3%	2 0.3%	5 2.3%	3 1.0%	4 0.4%	1 1.7%	1 0.8%	4 1.7%	8 1.3%	6 0.9%
5	1 3.1%	27 1.8%	13 1.7%	8 2.4%	11 1.9%	2 0.9%	3 1.0%	10 1.1%	- -	4 3.0%	7 3.1%	21 3.3%	17 2.5%
6	1 3.1%	33 2.2%	26 3.4%	4 1.2%	14 2.4%	2 0.9%	11 3.7%	16 1.8%	2 3.4%	2 1.5%	10 4.4%	26 4.1%	27 4.0%
* 7	2 6.3%	77 5.2%	53 6.9%	27 8.1%	36 6.2%	20 9.1%	22 7.4%	41 4.6%	4 6.9%	7 5.3%	13 5.7%	40 6.3%	40 5.9%
* 8	8 25.0%	246 16.6%	141 18.3%	56 16.8%	107 18.4%	27 12.3%	55 18.5%	161 17.9%	12 20.7%	20 15.0%	46 20.1%	143 22.4%	144 21.2%
* 9	7 21.9%	356 24.0%	200 26.0%	69 20.7%	152 26.2%	56 25.6%	56 18.9%	233 26.0%	11 19.0%	30 22.6%	52 22.7%	129 20.2%	160 23.6%
* 10 - I had a very good experience	11 34.4%	730 49.2%	317 41.2%	166 49.7%	252 43.4%	104 47.5%	142 47.8%	415 46.3%	21 36.2%	68 51.1%	96 41.9%	262 41.0%	274 40.4%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecologi-cal	Haematologi-cal	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1508	789	337	594	224	309	915	59	135	236	649	689
Q75. How long is it since you were first treated for this cancer?													
Less than 1 year	18 51.4%	689 45.7%	390 49.4%	168 49.9%	159 26.8%	121 54.0%	164 53.1%	421 46.0%	30 50.8%	74 54.8%	122 51.7%	221 34.1%	177 25.7%
1 to 5 years	14 40.0%	773 51.3%	384 48.7%	159 47.2%	336 56.6%	93 41.5%	140 45.3%	406 44.4%	28 47.5%	57 42.2%	110 46.6%	324 49.9%	352 51.1%
More than 5 years	2 5.7%	46 3.1%	12 1.5%	10 3.0%	97 16.3%	8 3.6%	5 1.6%	83 9.1%	1 1.7%	2 1.5%	4 1.7%	99 15.3%	159 23.1%
Don't know / can't remember	1 2.9%	- -	3 0.4%	- -	2 0.3%	2 0.9%	- -	5 0.5%	- -	2 1.5%	- -	5 0.8%	1 0.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1512	797	336	593	224	307	910	60	138	239	638	688
Q76. Is this the first time you have been treated for cancer?													
Yes, this is the first time I have been treated for cancer	31 88.6%	1278 84.5%	685 85.9%	279 83.0%	455 76.7%	186 83.0%	254 82.7%	822 90.3%	42 70.0%	110 79.7%	204 85.4%	460 72.1%	379 55.1%
No, I have been treated for the same type of cancer before but it has now come back	3 8.6%	114 7.5%	34 4.3%	26 7.7%	85 14.3%	14 6.3%	18 5.9%	28 3.1%	10 16.7%	13 9.4%	9 3.8%	100 15.7%	191 27.8%
No, I have been treated for a different type of cancer before	1 2.9%	116 7.7%	78 9.8%	31 9.2%	50 8.4%	24 10.7%	35 11.4%	57 6.3%	8 13.3%	14 10.1%	25 10.5%	70 11.0%	110 16.0%
Don't know	- -	4 0.3%	- -	- -	3 0.5%	- -	- -	3 0.3%	- -	1 0.7%	1 0.4%	8 1.3%	8 1.2%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	3	110	37	26	81	15	15	32	9	12	9	104	199
Q77. When your cancer came back did it:													
Come back only in the same place as before	* *	62 56.4%	20 54.1%	13 50.0%	55 67.9%	* *	* *	18 56.3%	* *	* *	* *	91 87.5%	30 15.1%
Spread to somewhere else in the body	* *	48 43.6%	17 45.9%	13 50.0%	26 32.1%	* *	* *	14 43.8%	* *	* *	* *	13 12.5%	169 84.9%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	30	1419	736	320	552	212	276	831	52	129	223	590	647
Q78. How has your cancer responded to treatment?													
My cancer has responded fully to treatment (I have no signs or symptoms of cancer)	3 10.0%	1128 79.5%	461 62.6%	232 72.5%	221 40.0%	165 77.8%	86 31.2%	327 39.4%	28 53.8%	103 79.8%	108 48.4%	301 51.0%	210 32.5%
My cancer has been treated but is still present	13 43.3%	80 5.6%	120 16.3%	50 15.6%	231 41.8%	13 6.1%	133 48.2%	261 31.4%	6 11.5%	6 4.7%	70 31.4%	112 19.0%	279 43.1%
My cancer has not been treated at all	- -	5 0.4%	10 1.4%	- -	6 1.1%	- -	4 1.4%	64 7.7%	1 1.9%	1 0.8%	4 1.8%	5 0.8%	3 0.5%
My cancer has come back after it was originally treated	- -	19 1.3%	7 1.0%	15 4.7%	26 4.7%	4 1.9%	4 1.4%	9 1.1%	8 15.4%	4 3.1%	7 3.1%	57 9.7%	36 5.6%
My original cancer responded but I now have a new cancer	1 3.3%	27 1.9%	41 5.6%	3 0.9%	13 2.4%	5 2.4%	12 4.3%	18 2.2%	2 3.8%	1 0.8%	14 6.3%	21 3.6%	63 9.7%
I am not certain what is happening with my cancer	13 43.3%	160 11.3%	97 13.2%	20 6.3%	55 10.0%	25 11.8%	37 13.4%	152 18.3%	7 13.5%	14 10.9%	20 9.0%	94 15.9%	56 8.7%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1490	769	331	581	219	302	909	59	136	233	635	672
Q79. What year were you born? (Converted to age band)													
Under 20	- -	- -	- -	- -	2 0.3%	- -	- -	- -	3 5.1%	- -	- -	- -	- -
20-29	3 8.8%	5 0.3%	- -	2 0.6%	3 0.5%	2 0.9%	- -	- -	1 1.7%	- -	- -	2 0.3%	1 0.1%
30-39	8 23.5%	40 2.7%	3 0.4%	10 3.0%	8 1.4%	5 2.3%	2 0.7%	- -	4 6.8%	- -	1 0.4%	12 1.9%	4 0.6%
40-49	3 8.8%	150 10.1%	22 2.9%	15 4.5%	27 4.6%	9 4.1%	4 1.3%	3 0.3%	2 3.4%	15 11.0%	4 1.7%	15 2.4%	36 5.4%
50-59	6 17.6%	398 26.7%	104 13.5%	62 18.7%	85 14.6%	51 23.3%	34 11.3%	70 7.7%	8 13.6%	23 16.9%	30 12.9%	46 7.2%	93 13.8%
60-69	8 23.5%	455 30.5%	228 29.6%	120 36.3%	166 28.6%	82 37.4%	111 36.8%	293 32.2%	16 27.1%	30 22.1%	73 31.3%	154 24.3%	233 34.7%
70-79	6 17.6%	328 22.0%	270 35.1%	96 29.0%	216 37.2%	58 26.5%	118 39.1%	416 45.8%	14 23.7%	39 28.7%	101 43.3%	241 38.0%	205 30.5%
80-89	- -	108 7.2%	131 17.0%	25 7.6%	69 11.9%	10 4.6%	31 10.3%	124 13.6%	11 18.6%	28 20.6%	23 9.9%	142 22.4%	89 13.2%
90+	- -	6 0.4%	11 1.4%	1 0.3%	5 0.9%	2 0.9%	2 0.7%	3 0.3%	- -	1 0.7%	1 0.4%	23 3.6%	11 1.6%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1509	785	337	591	223	309	919	59	139	238	650	689
Q80. Are you male or female													
Male	20 58.8%	11 0.7%	487 62.0%	- -	332 56.2%	155 69.5%	154 49.8%	916 99.7%	24 40.7%	72 51.8%	157 66.0%	497 76.5%	291 42.2%
Female	14 41.2%	1498 99.3%	297 37.8%	337 100.0%	259 43.8%	67 30.0%	155 50.2%	2 0.2%	35 59.3%	67 48.2%	81 34.0%	153 23.5%	398 57.8%
Transgender	- -	- -	- -	- -	- -	- -	- -	1 0.1%	- -	- -	- -	- -	- -
Prefer not to say	- -	- -	1 0.1%	- -	- -	1 0.4%	- -	- -	- -	- -	- -	- -	- -

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	34	1461	768	327	571	221	292	905	56	136	231	629	668
Q81. Which of the following best describes how you think of yourself?													
Heterosexual / straight (opposite sex)	32 94.1%	1421 97.3%	745 97.0%	310 94.8%	548 96.0%	207 93.7%	284 97.3%	872 96.4%	54 96.4%	134 98.5%	226 97.8%	607 96.5%	637 95.4%
Bisexual (both sexes)	- -	5 0.3%	- -	2 0.6%	1 0.2%	- -	1 0.3%	2 0.2%	- -	- -	- -	2 0.3%	1 0.1%
Gay or lesbian (same sex)	- -	4 0.3%	5 0.7%	1 0.3%	4 0.7%	4 1.8%	2 0.7%	5 0.6%	- -	- -	1 0.4%	1 0.2%	6 0.9%
Other	- -	7 0.5%	4 0.5%	7 2.1%	3 0.5%	3 1.4%	2 0.7%	5 0.6%	- -	1 0.7%	1 0.4%	1 0.2%	3 0.4%
Prefer not to answer	2 5.9%	24 1.6%	14 1.8%	7 2.1%	15 2.6%	7 3.2%	3 1.0%	21 2.3%	2 3.6%	1 0.7%	3 1.3%	18 2.9%	21 3.1%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1494	786	338	590	224	307	927	59	138	236	651	689
Q82. What is your main employment status?													
Full time employment	12 34.3%	277 18.5%	102 13.0%	54 16.0%	73 12.4%	51 22.8%	17 5.5%	106 11.4%	9 15.3%	32 23.2%	22 9.3%	58 8.9%	74 10.7%
Part time employment	4 11.4%	217 14.5%	37 4.7%	34 10.1%	28 4.7%	20 8.9%	13 4.2%	43 4.6%	6 10.2%	9 6.5%	8 3.4%	35 5.4%	34 4.9%
Homemaker	- -	78 5.2%	8 1.0%	15 4.4%	13 2.2%	4 1.8%	9 2.9%	- -	1 1.7%	2 1.4%	5 2.1%	8 1.2%	15 2.2%
Student (in education)	- -	1 0.1%	- -	- -	2 0.3%	- -	- -	- -	2 3.4%	- -	- -	1 0.2%	- -
Retired	13 37.1%	781 52.3%	574 73.0%	206 60.9%	414 70.2%	114 50.9%	235 76.5%	727 78.4%	35 59.3%	90 65.2%	181 76.7%	508 78.0%	480 69.7%
Unemployed - and seeking work	1 2.9%	11 0.7%	2 0.3%	- -	1 0.2%	3 1.3%	- -	4 0.4%	- -	- -	- -	2 0.3%	2 0.3%
Unemployed - unable to work for health reasons	4 11.4%	86 5.8%	54 6.9%	23 6.8%	40 6.8%	23 10.3%	27 8.8%	27 2.9%	4 6.8%	4 2.9%	16 6.8%	25 3.8%	74 10.7%
Other	1 2.9%	43 2.9%	9 1.1%	6 1.8%	19 3.2%	9 4.0%	6 2.0%	20 2.2%	2 3.4%	1 0.7%	4 1.7%	14 2.2%	10 1.5%

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	32	1441	761	320	561	216	285	895	56	129	227	624	660
Q83. Do you have any of the following longstanding conditions?													
Deafness or severe hearing impairment	2 6.3%	100 6.9%	125 16.4%	24 7.5%	85 15.2%	38 17.6%	60 21.1%	138 15.4%	7 12.5%	15 11.6%	39 17.2%	150 24.0%	98 14.8%
Blindness or partially sighted	1 3.1%	19 1.3%	24 3.2%	5 1.6%	20 3.6%	3 1.4%	10 3.5%	31 3.5%	4 7.1%	5 3.9%	9 4.0%	25 4.0%	23 3.5%
A long-standing physical condition	1 3.1%	231 16.0%	136 17.9%	75 23.4%	120 21.4%	43 19.9%	65 22.8%	161 18.0%	13 23.2%	29 22.5%	50 22.0%	119 19.1%	142 21.5%
A learning disability	2 6.3%	8 0.6%	7 0.9%	5 1.6%	7 1.2%	1 0.5%	3 1.1%	3 0.3%	- -	1 0.8%	- -	7 1.1%	3 0.5%
A mental health condition	1 3.1%	64 4.4%	28 3.7%	13 4.1%	15 2.7%	12 5.6%	13 4.6%	19 2.1%	4 7.1%	7 5.4%	1 0.4%	25 4.0%	22 3.3%
A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy	4 12.5%	158 11.0%	138 18.1%	35 10.9%	90 16.0%	29 13.4%	58 20.4%	136 15.2%	3 5.4%	19 14.7%	39 17.2%	127 20.4%	96 14.5%
No, I do not have a longstanding condition	23 71.9%	990 68.7%	436 57.3%	199 62.2%	319 56.9%	127 58.8%	140 49.1%	558 62.3%	37 66.1%	76 58.9%	123 54.2%	314 50.3%	368 55.8%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	35	1491	786	333	591	223	308	920	60	138	235	640	690
Q84. Could we send you a survey in the future to ask about your health and healthcare?													
Yes, and I understand that this does NOT mean that I would have to take part in the future survey	25 71.4%	1269 85.1%	655 83.3%	274 82.3%	486 82.2%	188 84.3%	235 76.3%	787 85.5%	49 81.7%	113 81.9%	184 78.3%	485 75.8%	555 80.4%
No, I would prefer you not to contact me again	10 28.6%	222 14.9%	131 16.7%	59 17.7%	105 17.8%	35 15.7%	73 23.7%	133 14.5%	11 18.3%	25 18.1%	51 21.7%	155 24.2%	135 19.6%

Please note that this data is unadjusted.

	Brain / CNS	Breast	Colorectal / Lower GI	Gynaecological	Haematological	Head and Neck	Lung	Prostate	Sarcoma	Skin	Upper GI	Urological	Other
Base	37	1508	798	333	593	221	310	936	60	142	235	653	693
Q85. To which of these ethnic groups would you say you belong?													
White - English/ Welsh/ Scottish/ Northern Irish/ British	35 94.6%	1476 97.9%	790 99.0%	326 97.9%	579 97.6%	213 96.4%	302 97.4%	919 98.2%	58 96.7%	142 100.0%	234 99.6%	636 97.4%	678 97.8%
White - Irish	- -	1 0.1%	1 0.1%	1 0.3%	6 1.0%	2 0.9%	3 1.0%	9 1.0%	- -	- -	- -	4 0.6%	1 0.1%
White - Gypsy or Irish Traveller	- -	- -	- -	- -	- -	- -	- -	1 0.1%	- -	- -	- -	- -	- -
Any other White background	1 2.7%	12 0.8%	5 0.6%	5 1.5%	5 0.8%	3 1.4%	3 1.0%	2 0.2%	2 3.3%	- -	- -	7 1.1%	7 1.0%
Mixed / Multiple Ethnic groups - White & Black Caribbean	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	1 0.1%
Mixed / Multiple Ethnic groups - White & Black African	- -	- -	- -	- -	1 0.2%	- -	- -	1 0.1%	- -	- -	- -	1 0.2%	1 0.1%
Mixed / Multiple Ethnic groups - White and Asian	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	2 0.3%	- -
Any other Mixed/ Multiple Ethnic background	- -	- -	- -	- -	- -	1 0.5%	- -	- -	- -	- -	1 0.4%	- -	- -
Asian / Asian British - Indian	1 2.7%	6 0.4%	1 0.1%	- -	- -	- -	- -	2 0.2%	- -	- -	- -	- -	- -
Asian/ Asian British - Pakistani	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	2 0.3%
Asian/ Asian British - Bangladeshi	- -	1 0.1%	- -	- -	1 0.2%	- -	- -	- -	- -	- -	- -	- -	- -
Asian/ Asian British - Chinese	- -	3 0.2%	- -	1 0.3%	- -	- -	- -	- -	- -	- -	- -	2 0.3%	2 0.3%
Any other Asian background	- -	3 0.2%	- -	- -	- -	1 0.5%	- -	- -	- -	- -	- -	1 0.2%	- -
Black / African / Caribbean/ Black British - African	- -	- -	- -	- -	- -	- -	1 0.3%	2 0.2%	- -	- -	- -	- -	- -
Black / African/ Caribbean / Black British - Caribbean	- -	2 0.1%	- -	- -	- -	1 0.5%	1 0.3%	- -	- -	- -	- -	- -	- -
Any other Black / African / Caribbean background	- -	2 0.1%	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -	1 0.1%
Other Ethnic Group - Arab	- -	1 0.1%	- -	- -	1 0.2%	- -	- -	- -	- -	- -	- -	- -	- -
Any other ethnic group	- -	1 0.1%	1 0.1%	- -	- -	- -	- -	- -	- -	- -	- -	- -	- -

Please note that this data is unadjusted.

WE ARE MACMILLAN. CANCER SUPPORT
NI YW MACMILLAN. CYMORTH CANSER
GIG CYMRU NHS WALES

Cancer Patient Experience Survey

This survey is about your experiences of cancer care received in Wales. **Your answers will be entirely confidential**. **Taking part is voluntary.** This questionnaire has been printed in **both English and Welsh. Please complete it in your language of choice.**

Instructions

Please answer all questions, unless the instructions ask you to skip a question. For each question, please place a tick in the box next to the answer that most closely matches your own experience. For example, if your answer is yes, write in a tick as below:

☑ Yes
☐ No

Don't worry if you make a mistake. Simply cross it out and tick the correct answer. Please **do not** write your name or address anywhere on the questionnaire.

If you would prefer, you can fill in this survey **online** in English or Welsh at **www.experiencesurvey.org.uk**.

To do this you will need to enter this ID:

If you have any queries about the questionnaire, please call the FREEPHONE **helpline** number on **0808 801 0678**

Open: 24/7

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate collective statistics about the care and treatment people receive. The results will be used to measure and improve the quality of healthcare services. It will not be shared with the people who look after you and will in no way affect your current or future treatment or care.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to the Welsh Government to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service and other NHS databases can be held and used by an organisation contracted to the Welsh Government to analyse the data
- Your responses to the survey can be held and used by the NHS Welsh Cancer Intelligence and Surveillance Unit and securely linked to information about you held in other databases to help improve services

Your personal information will be handled securely and anonymised after analysis and before any publication. Your personal information will not be released by the Welsh Government or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest. You can withdraw the information you give the NHS in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

Thank you for your time.

BEFORE YOUR DIAGNOSIS

These questions are about what happened before you found out you had cancer.

1. 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**?

1 ☐ Less than 3 months
2 ☐ 3-6 months
3 ☐ 6-12 months
4 ☐ More than 12 months
5 ☐ I did not think something was wrong with me until I was told
6 ☐ Don't know / can't remember

2. 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?

1 ☐ I saw my GP **once**
2 ☐ I saw my GP **twice**
3 ☐ I saw my GP **3 or 4** times
4 ☐ I saw my GP **5 or more** times
5 ☐ I went straight to hospital following a cancer screening appointment
6 ☐ I went straight to hospital via Accident & Emergency
7 ☐ Don't know / can't remember

3. When you first told your GP or hospital doctor about your symptoms, do you feel they took your symptoms seriously?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not have any symptoms
5 ☐ Don't know / can't remember

4. How do you feel about the length of time you had to wait before your **first appointment with a hospital doctor**?

1 ☐ I was seen as soon as I thought was necessary
2 ☐ I should have been seen a bit sooner
3 ☐ I should have been seen a lot sooner

5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?

1 ☐ My health got worse
2 ☐ My health got better
3 ☐ My health stayed about the same

6. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?

1 ☐ Yes ➔ **Go to Q7**
2 ☐ No ➔ **Go to Q11**

Thinking about the LAST time you had a diagnostic test for your cancer…

7. Did the test(s) take place at the hospital named on the letter that came with this survey?

1 ☐ Yes
2 ☐ No, at another NHS hospital in Wales
3 ☐ No, at a private hospital/centre in Wales
4 ☐ No, somewhere outside Wales
5 ☐ Don't know / can't remember

8. Beforehand, did a member of staff explain what would be done during the test(s) to you?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No, but I would have liked an explanation
4 ☐ I did not need an explanation
5 ☐ Don't know / can't remember

9. Beforehand, were you given **written** information about your test(s)?

1 ☐ Yes, and it was **easy** to understand
2 ☐ Yes, but it was **difficult** to understand
3 ☐ No, I would have liked written information about the test(s)
4 ☐ I did not need written information
5 ☐ Don’t know / can’t remember

10. Were the **results** of the test(s) explained in a way you could understand?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No, I did not understand the explanation
4 ☐ No, but I would have liked an explanation
5 ☐ I did not need an explanation
6 ☐ Don’t know / can’t remember

FINDING OUT YOU HAD CANCER

11. How do you feel about the way you were told you had cancer?

1 ☐ It was done sensitively
2 ☐ It should have been done **a bit** more sensitively
3 ☐ It should have been done **a lot** more sensitively

12. Did you understand the explanation of what was wrong with you?

1 ☐ Yes, I completely understood it
2 ☐ Yes, I understood some of it
3 ☐ No, I did not understand it
4 ☐ Can’t remember

13. When you were told you had cancer, were you given **written** information about the type of cancer you had?

1 ☐ Yes, and it was **easy** to understand
2 ☐ Yes, but it was **difficult** to understand
3 ☐ No, I was not given written information about the type of cancer I had
4 ☐ I did not need written information
5 ☐ Don’t know / can’t remember

DECIDING THE BEST TREATMENT AND/OR CARE FOR YOU

14. Before your cancer treatment started, were your treatment options explained to you?

1 ☐ Yes
2 ☐ No, but I would have liked a choice
3 ☐ There was only one type of treatment that was suitable for me
4 ☐ Not sure / can’t remember

15. Were you involved as much as you wanted to be in decisions about your care and treatment?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, but I would like to have been more involved
4 ☐ Not sure / can’t remember

16. Were the possible side effects of treatment(s) explained in a way you could understand?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, side effects were not explained
4 ☐ I did not need an explanation
5 ☐ Not sure / can’t remember

17. Before you started your treatment, were you given **written** information about the side effects of your treatment(s)?

1 ☐ Yes, and it was **easy** to understand
2 ☐ Yes, but it was **difficult** to understand
3 ☐ No, I was not given any written information about side effects
4 ☐ I did not need written information
5 ☐ Don't know / can't remember

18. 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?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, future side effects were not explained
4 ☐ I did not need an explanation
5 ☐ Not sure / can't remember

KEY WORKER

The next few questions are about Key Workers.

Key Worker is the title given to a health professional who you can contact for advice and information and who will coordinate your care. This person may change depending on where you are in your cancer care and treatment. They could be your Clinical Nurse Specialist or another health care professional.

19. Were you given the name and contact details of your Key Worker?

1 ☐ Yes ➔ **Go to Q20**
2 ☐ No ➔ **Go to Q22**
3 ☐ Don't know / not sure ➔ **Go to Q22**

20. How easy is it for you to contact your Key Worker?

1 ☐ Easy
2 ☐ Sometimes easy, sometimes difficult
3 ☐ Difficult
4 ☐ I have not tried to contact her/him

21. When you have important questions to ask, how often does your Key Worker help you get answers to your questions?

1 ☐ All or most of the time
2 ☐ Some of the time
3 ☐ Rarely or never
4 ☐ I do not ask any questions

CLINICAL NURSE SPECIALIST

The next few questions are about Clinical Nurse Specialists.

A Clinical Nurse Specialist is a specialist cancer nurse who makes sure you get the right care and gives you help and advice on coping with cancer.

22. Did your care include access to a Clinical Nurse Specialist?

1 ☐ Yes, and this was my Key Worker ➔ **Go to Q24**
2 ☐ Yes, but this was not my Key Worker ➔ **Go to Q23**
3 ☐ No, I did not have a Clinical Nurse Specialist as part of my care team ➔ **Go to Q26**
4 ☐ Don't know / not sure ➔ **Go to Q26**

23. How easy is it for you to contact your Clinical Nurse Specialist?

1 ☐ Easy
2 ☐ Sometimes easy, sometimes difficult
3 ☐ Difficult
4 ☐ I have not tried to contact her/him

24. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

1 ☐ All or most of the time
2 ☐ Some of the time
3 ☐ Rarely or never
4 ☐ I do not ask any questions

25. Did your Clinical Nurse Specialist provide you with the information you needed to make informed decisions about your treatment and care?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don't know / can't remember

SUPPORT FOR PEOPLE WITH CANCER

Thinking about when your cancer treatment first started …

26. How much information about support or self-help groups did hospital staff give you?

1 ☐ Not enough
2 ☐ The right amount
3 ☐ Too much
4 ☐ I was not given any information
5 ☐ Don't know / can't remember

27. During your care, were you told about voluntary or charity support?

1 ☐ Yes
2 ☐ No
3 ☐ Don't know / can't remember

28. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don't know / can't remember

29. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?

1 ☐ Yes
2 ☐ Yes, but I would have liked more information
3 ☐ No, but I would have liked information
4 ☐ It was not necessary
5 ☐ Don't know / can't remember

OPERATIONS

30. During the last 12 months, have you **had an operation for your cancer** (such as removal of a tumour or lump)?

1 ☐ Yes ➔ **Go to Q31**
2 ☐ No ➔ **Go to Q35**

Thinking about the LAST time you went into hospital for an operation for your cancer…

31. Did the operation take place at the hospital named on the letter that came with this survey?

1 ☐ Yes
2 ☐ No, at another NHS hospital in Wales
3 ☐ No, at a private hospital/centre in Wales
4 ☐ No, somewhere outside Wales
5 ☐ Don't know / can't remember

Please remember you are thinking about the LAST time you went into hospital for an operation for your cancer…

32. Before you had your operation, did a member of staff explain what would be done during the operation?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No, but I would have liked an explanation
4 ☐ I did not need an explanation
5 ☐ Don’t know / can’t remember

33. Beforehand, were you given **written** information about your operation?

1 ☐ Yes, and it was **easy** to understand
2 ☐ Yes, but it was **difficult** to understand
3 ☐ No, I was not given written information about my operation
4 ☐ I did not need written information
5 ☐ Don’t know / can’t remember

34. After the operation, did a member of staff explain how it had gone in a way you could understand?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No, but I would have liked an explanation
4 ☐ I did not need an explanation

HOSPITAL CARE AS AN INPATIENT

35. During the last 12 months, have you had an operation or stayed overnight **for cancer care**?

1 ☐ Yes ➔ **Go to Q36**
2 ☐ No ➔ **Go to Q52**

Thinking about the LAST time you had an operation or stayed overnight for cancer care…

36. Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?

1 ☐ Yes
2 ☐ No, at another NHS hospital in Wales
3 ☐ No, at a private hospital/centre in Wales
4 ☐ No, somewhere outside Wales
5 ☐ Don’t know / can’t remember

37. Overall, while you were in hospital, were you treated with dignity and respect?

1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

38. Did **doctors and nurses** talk in front of you as if you weren’t there?

1 ☐ Yes, often
2 ☐ Yes, sometimes
3 ☐ No

39. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?

1 ☐ Often
2 ☐ Sometimes
3 ☐ Only once
4 ☐ Never

40. Were you able to discuss any worries or fears with staff during your hospital visit?

1 ☐ As much as I wanted
2 ☐ Most of the time
3 ☐ Some of the time
4 ☐ Not at all, but would have liked to
5 ☐ I did not have any worries or fears

Please remember you are thinking about the LAST time you had an operation or stayed overnight for cancer care…

41. When you had important questions to ask a doctor or nurse, how often did you get answers that you could understand?

1 ☐ All or most of the time
2 ☐ Some of the time
3 ☐ Rarely or never
4 ☐ I did not ask any questions

42. Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ No family or friends were involved

43. Did you have confidence and trust in the **doctors** treating you?

1 ☐ Yes, in all of them
2 ☐ Yes, in some of them
3 ☐ No, in none of them

44. Did you have confidence and trust in the **ward nurses** treating you?

1 ☐ Yes, in all of them
2 ☐ Yes, in some of them
3 ☐ No, in none of them

45. How many minutes after you used the call button did it usually take before you got the help you needed?

1 ☐ 0 minutes / right away
2 ☐ 1-2 minutes
3 ☐ 3-5 minutes
4 ☐ More than 5 minutes
5 ☐ I never got help when I used the call button
6 ☐ I never used the call button

46. Do you think doctors and nurses communicated effectively with you during your hospital stay?

1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

47. Were you given enough privacy when discussing your condition or treatment?

1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

48. Were you given enough privacy when being examined or treated?

1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

49. Do you think the hospital staff did everything they could to help control your pain?

1 ☐ All of the time
2 ☐ Some of the time
3 ☐ Not at all
4 ☐ I did not have any pain

50. Were you given clear written information about what you should or should not do after leaving hospital?

1 ☐ Yes
2 ☐ No
3 ☐ I did not need written information
4 ☐ Can’t remember

51. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

OUTPATIENTS / DAY CASE APPOINTMENTS

52. In the last 12 months, have you had an outpatients or day case appointment for your cancer?

1 ☐ Yes ➔ **Go to Q53**
2 ☐ No ➔ **Go to Q56**

Thinking about the LAST time you attended hospital as an outpatient or day case for cancer care …

53. The last time you attended hospital as a day case or outpatient, was this at the hospital named on the letter that came with this survey?

1 ☐ Yes
2 ☐ No, at another NHS hospital in Wales
3 ☐ No, at a private hospital/centre in Wales
4 ☐ No, somewhere outside Wales
5 ☐ Don’t know / can’t remember

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

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, they could have done more
4 ☐ I did not have any pain

55. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, I would have liked more support
4 ☐ I did not need emotional support from staff

RADIOTHERAPY / CHEMOTHERAPY

56. Have you had radiotherapy treatment?

1 ☐ Yes ➔ **Go to Q57**
2 ☐ No ➔ **Go to Q59**

57. Thinking of the **last** time you had radiotherapy treatment, was this at:

1 ☐ Glan Clwyd Hospital
2 ☐ Singleton Hospital
3 ☐ Velindre Cancer Centre
4 ☐ A private hospital/centre in Wales
5 ☐ Somewhere outside Wales
6 ☐ Don’t know / can’t remember

Thinking about the LAST time you had radiotherapy treatment…

58. Did hospital staff do everything possible to control the side effects of radiotherapy?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, they could have done more
4 ☐ I have not had any side effects from radiotherapy

59. Have you had chemotherapy treatment?

1 ☐ Yes ➔ **Go to Q60**
2 ☐ No ➔ **Go to Q62**

Thinking about the LAST time you had chemotherapy treatment…

60. Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?

1 ☐ Yes
2 ☐ No, at another NHS hospital in Wales
3 ☐ No, at a private hospital/centre in Wales
4 ☐ No, somewhere outside Wales
5 ☐ Don’t know / can’t remember

Please remember you are thinking about the LAST time you had chemotherapy treatment…

61. Did hospital staff do everything possible to control the side effects of chemotherapy?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, they could have done more
4 ☐ I have not had any side effects from chemotherapy

ARRANGING HOME SUPPORT

Thinking about the LAST time you left the hospital named on the covering letter following care for your cancer…

62. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ No family or friends were involved

63. 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)?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, I was not offered any practical advice or support
4 ☐ Not sure / can’t remember

64. After leaving hospital, were you given enough care and help from your GP and the GP surgery?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help
5 ☐ Don’t know / can’t remember

65. As far as you know, did your GP have all the information they needed about your care after leaving hospital?

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

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

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I did not need help
5 ☐ Don’t know / can’t remember

YOUR OVERALL NHS CARE

67. Were you offered the opportunity to discuss your needs and concerns in order to put together a care plan?

(This is a discussion to find out as much as possible about your concerns and/or needs, be they physical, emotional, mental, spiritual, social or environmental to put together a care plan to give you the help you need.)

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

68. Have you been offered a written care plan?

(A written care plan is a document that sets out your needs and goals for caring for you and your cancer. It is an agreement or plan between you and your health professional to help meet those goals.)

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

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

1 ☐ Yes
2 ☐ No
3 ☐ Don’t know / can’t remember

70. Since your diagnosis, have the different professionals treating and caring for you worked well together to give you the best possible care?

1 ☐ Yes, always
2 ☐ Yes, most of the time
3 ☐ Yes, some of the time
4 ☐ No, never
5 ☐ Don’t know

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

1 ☐ Very good
2 ☐ Good
3 ☐ Neither good nor bad
4 ☐ Quite bad
5 ☐ Very bad
6 ☐ Don’t know / can’t remember

72. During your care, did you receive the information you needed in your preferred language?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ Don’t know / can’t remember

73. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?

1 ☐ Yes, often
2 ☐ Yes, sometimes
3 ☐ No

74. Overall how would you rate your care? (**Please circle a number**)

I had a very poor experience										I had a very good experience
0	1	2	3	4	5	6	7	8	9	10

YOUR CONDITION

We would like to understand a little more about your cancer and how you are now. Please answer these questions about the cancer that was treated at the hospital named on the covering letter.

75. How long is it since you were first treated for this cancer?

1 ☐ Less than 1 year
2 ☐ 1 to 5 years
3 ☐ More than 5 years
4 ☐ Don’t know / can’t remember

76. Is this the first time you have been treated for cancer?

1 ☐ Yes, this is the first time I have been treated for cancer ➔ **Go to Q78**
2 ☐ No, I have been treated for the same type of cancer before but it has now come back ➔ **Go to Q77**
3 ☐ No, I have been treated for a different type of cancer before ➔ **Go to Q78**
4 ☐ Don't know ➔ **Go to Q78**

77. When your cancer came back did it:

1 ☐ Come back only in the same place as before
2 ☐ Spread to somewhere else in the body

78. How has your cancer responded to treatment?

1 ☐ My cancer has responded fully to treatment (I have no signs or symptoms of cancer)
2 ☐ My cancer has been treated but is still present
3 ☐ My cancer has not been treated at all
4 ☐ My cancer has come back after it was originally treated
5 ☐ My original cancer responded but I now have a new cancer
6 ☐ I am not certain what is happening with my cancer

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's not your own.

79. What year were you born?

(Please write in) e.g. | 1 | 9 | 4 | 4 |

80. Are you male or female?

1 ☐ Male
2 ☐ Female
3 ☐ Transgender
4 ☐ Prefer not to say

81. Which of the following best describes how you think of yourself? **(Tick one box only)**

1 ☐ Heterosexual / straight (opposite sex)
2 ☐ Bisexual (both sexes)
3 ☐ Gay or lesbian (same sex)
4 ☐ Other
5 ☐ Prefer not to answer

82. What is your **main** employment status?

(*If on maternity or sick leave answer in relation to your **usual** employment status.)*

1 ☐ Full time employment
2 ☐ Part time employment
3 ☐ Homemaker
4 ☐ Student (in education)
5 ☐ Retired
6 ☐ Unemployed – and seeking work
7 ☐ Unemployed – unable to work for health reasons
8 ☐ Other

83. Do you have any of the following long-standing conditions? **(Tick all that apply)**

1 ☐ Deafness or severe hearing impairment
2 ☐ Blindness or partially sighted
3 ☐ A long-standing physical condition
4 ☐ A learning disability
5 ☐ A mental health condition
6 ☐ A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy
7 ☐ No, I do not have a longstanding condition

84. Could we send you a survey in the future to ask about your health and healthcare?

1 ☐ Yes, and I understand that this does **NOT** mean that I would have to take part in the future survey
2 ☐ No, I would prefer you not to contact me again

85. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ Welsh / English / Scottish / Northern Irish / British

2 ☐ Irish

3 ☐ Gypsy or Irish Traveller

4 ☐ Any other White background (Please write in box)

b. MIXED / MULTIPLE ETHNIC GROUPS

5 ☐ White and Black Caribbean

6 ☐ White and Black African

7 ☐ White and Asian

8 ☐ Any other Mixed / Multiple ethnic background (Please write in box)

c. ASIAN OR ASIAN BRITISH

9 ☐ Indian

10 ☐ Pakistani

11 ☐ Bangladeshi

12 ☐ Chinese

13 ☐ Any other Asian background (Please write in box)

d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

14 ☐ Caribbean

15 ☐ African

16 ☐ Any other Black / African / Caribbean background (Please write in box)

e. OTHER ETHNIC GROUP

17 ☐ Arab

18 ☐ Any other ethnic group (Please write in box)

OTHER COMMENTS

If there is anything else you would like to tell us about your experiences as a cancer patient in Wales, please do so here.

Please note that the comments you provide in the box below will be looked at in full by the Welsh Government, Macmillan, Local Health boards and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback.

Was there anything particularly good about your care?

Was there anything that could be improved?

Any other comments?

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