

Velindre Cancer Centre Wales Cancer Patient Experience Survey 2021/22

Cancer Centre Report



Contents

1. Executive Summary.....	3
2. Introduction.....	7
3. Methodology.....	8
3.1 Sample Process.....	8
3.2 Questionnaire distribution.....	8
3.3 Assignment of respondents to a Health Board / Velindre.....	8
4. Response rates.....	9
5. Comparisons with previous years.....	12
6. This report, and subsequent publications.....	13
7. Understanding the results.....	15
8. Survey results.....	19
8.1 Before your diagnosis.....	19
8.2 Finding out you had cancer.....	25
8.3 Deciding the best treatment and / or care for you.....	30
8.4 Healthcare professionals.....	35
8.5 Support for people living with cancer.....	48
8.6 Operations.....	52
8.7 Hospital care as an inpatient.....	54
8.8 Outpatients / day case appointments.....	63
8.9 Radiotherapy / chemotherapy.....	65
8.10 Arranging home support.....	67
8.11 Care from your General Practice.....	71
8.12 Your overall NHS care.....	73
Appendix 1.....	78
Appendix 2.....	79
Acknowledgments.....	80

1. Executive Summary

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

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

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

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

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

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

Headline results

The survey results for Velindre Cancer Centre are positive. **92%** of respondents rated their overall care as 7 or more out of 10 (a slight drop from **95%** when the survey was last carried out in 2016), with only **2%** rating their overall care as between 0 and 3 out of 10 (**1%** in 2016). **88%** said they were always treated with dignity and respect while they were in hospital (**89%** in 2016).

Other positive scores in the survey include:

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

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

- **48%** were offered the opportunity to discuss their needs and concerns
- **40%** of respondents said their healthcare team completely discussed with them or gave them information about the impact cancer could have on their day-to-day activities (for example, their work life or education)
- **39%** of respondents said their family or someone else close to them definitely had enough opportunity to talk to a healthcare professional
- **31%** of respondents said that, after leaving hospital, they were definitely given enough care and help from their GP and the GP practice
- **29%** of respondents said they had been offered a written care plan
- **25%** of respondents said that, since their diagnosis, someone had discussed with them whether they would like to take part in cancer research (e.g. clinical trials)

Key Workers, Clinical Nurse Specialists and other health professionals

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

92% of respondents said they were given the name and contact details of their Key Worker. **66%** of these respondents said that it was easy to contact them. **84%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **77%** said their Key Worker provided them with all the information they needed to make informed decisions about their treatment.

In this survey, **91%** of respondents said their care included access to a CNS, (**81%** reported that their CNS was also their Key Worker, **10%** said their CNS was not their Key Worker). **64%** of the respondents who had access said it was easy to contact them. **85%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **76%** said their CNS provided them with all the information they needed to make informed decisions about their treatment.

75% of respondents said that their care included access to another health professional, such as a physiotherapist, dietitian, speech and language therapist, occupational therapist or lymphoedema specialist. **59%** of respondents who had contacted their other health professional said that it was easy to do so. **77%** said that, when they had questions to ask, they got answers they could understand all or most of the time. **73%** said their other healthcare professional provided them with all the information they needed to make informed decisions about their treatment.

Time to first seeing a GP or other doctor

61% of respondents reported that it was less than 3 months from the first time they thought something might be wrong with them until they first saw a GP or other doctor. This is an increase on the 2016 score of **54%**.

Welsh language

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

Within the survey, people living with cancer were asked if they were able to speak in Welsh to staff if they needed to. 239 of respondents who answered this question (**14%**) indicated that they needed to speak to staff in Welsh; of these, **24%** agreed 'Yes, completely' that they were able to do so.

¹ [Key workers for cancer patients \(WHC/2014/001\)](#) (Welsh Government 2014)

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

³ [Cymraeg 2050: A million Welsh speakers \(gov.wales\)](#) (Welsh Government 2017)

Comparisons with 2016

31 questions in the survey are broadly comparable with 2016 (see section 5). Of these 27 scores have worsened and 4 have improved.

The 3 largest improvements were:

- **91.3%** of respondents in 2021/22 reported their care included access to a CNS – **86.2%** in 2016 (**+5.1%**)
- **83.6%** of respondents in 2021/22 reported that before they were told they needed to go to hospital about cancer, they saw their GP (family doctor) 1 or 2 times about the health problem caused by cancer – **80.3%** in 2016 (**+3.3%**)
- **87.9%** of respondents in 2021/22 reported they were always given enough privacy when discussing their condition or treatment – **86.4%** in 2016 (**+1.5%**)

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

- **31.3%** of respondents in 2021/22 reported that after leaving hospital, they were definitely given enough care and help from their GP and the GP practice – **53.6%** in 2016 (**-22.3%**)
- **46.9%** of respondents in 2021/22 reported that they were definitely offered practical advice and support in dealing with the side effects of their treatment at home – **61.4%** in 2016 (**-14.5%**)
- **64.8%** of respondents in 2021/22 reported that since their diagnosis, the different professionals treating and caring for them always worked well together to give the best possible care – **73.7%** in 2016 (**-8.9%**)

2. Introduction

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

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

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

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

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

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

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

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

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

3. Methodology

3.1 Sample Process

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

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

3.2 Questionnaire distribution

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

3.3 Assignment of respondents to a Health Board / Velindre

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

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

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

As the patients in this report are assigned by discharge rather than by residence, it is not appropriate to compare Velindre Cancer Centre's performance to the Health Boards in Wales. In addition, the respondents in Velindre Cancer Centre's report will also be included (duplicated) in the Health Board reports where they are assigned by residence, making comparisons inadvisable.

This report gives an insight into the cancer experience of respondents who were discharged from Velindre Cancer Centre.

4. Response rates

The sample size for Velindre Cancer Centre was **3,109** cancer patients.

Of these **214** were removed as they were ineligible. Ineligible patients were those who had died between the sample being finalised and receiving any of the survey letters (**189**), had moved address (**22**) or had informed the helpline they were ineligible for another reason (**3**).

The eligible sample size was therefore calculated as **2,895** patients. A total of **1,793** questionnaires were returned completed, giving an overall response rate of **61.9%**.

Completed questionnaires were received by post from **1,457** respondents (**81.3%** of responses); and **316** (**17.6%**) chose to complete their questionnaires on-line. **20** respondents called IQVIA's Freephone helpline to give their responses over the telephone.

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

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

Response rates

Post



81.3%

Online



17.6%

Telephone



1.1%

Translation



0%

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

Tumour Group	Number of respondents	Percentage of total respondents
Breast	513	28.6%
Other cancers ⁸	406	22.6%
Prostate	267	14.9%
Colorectal / lower gastrointestinal	153	8.5%
Lung	103	5.7%
Gynaecological	102	5.7%
Head and neck	84	4.7%
Urological (excluding prostate)	61	3.4%
Upper gastrointestinal	46	2.6%
Haematological	22	1.2%
Skin	14	<1%
Brain / central nervous system (CNS)	11	<1%
Sarcoma	11	<1%

Sex of respondents	Number of respondents	Percentage of total respondents
Female	1067	59.5%
Male	726	40.5%

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

Age of respondents	Number of respondents	Percentage of total respondents
16-24	6	<1%
25-34	10	<1%
35-44	70	3.9%
45-54	182	10.2%
55-64	429	23.9%
65-74	617	34.4%
75-84	420	23.4%
85+	59	3.3%

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

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

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

Ethnicity of respondents	Number of respondents	Percentage of total respondents
Asian background	14	<1%
Black / African / Caribbean background	2	<1%
Mixed / multiple ethnic background	13	<1%
Other ethnic group	1	<1%
White background	1669	93.1%
Not available	94	5.2%

Sexual orientation of respondents ¹⁰	Number of respondents	Percentage of total respondents
Heterosexual	1624	90.6%
Bisexual	6	<1%
Gay or lesbian	12	<1%
Other sexuality	6	<1%

⁹ <https://gov.wales/equality-and-diversity-statistics-2017-2019#:~:text=94.8%25%20of%20the%20population%20of,or%20'Other%20ethnic%20group>

¹⁰ *<1% of respondents said that they didn't know or were not sure, 1.7% of respondents said they preferred not to answer this question, and a further 6.2% of all respondents to the survey did not answer the question at all.

5. Comparisons with previous years

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

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

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

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

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

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

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

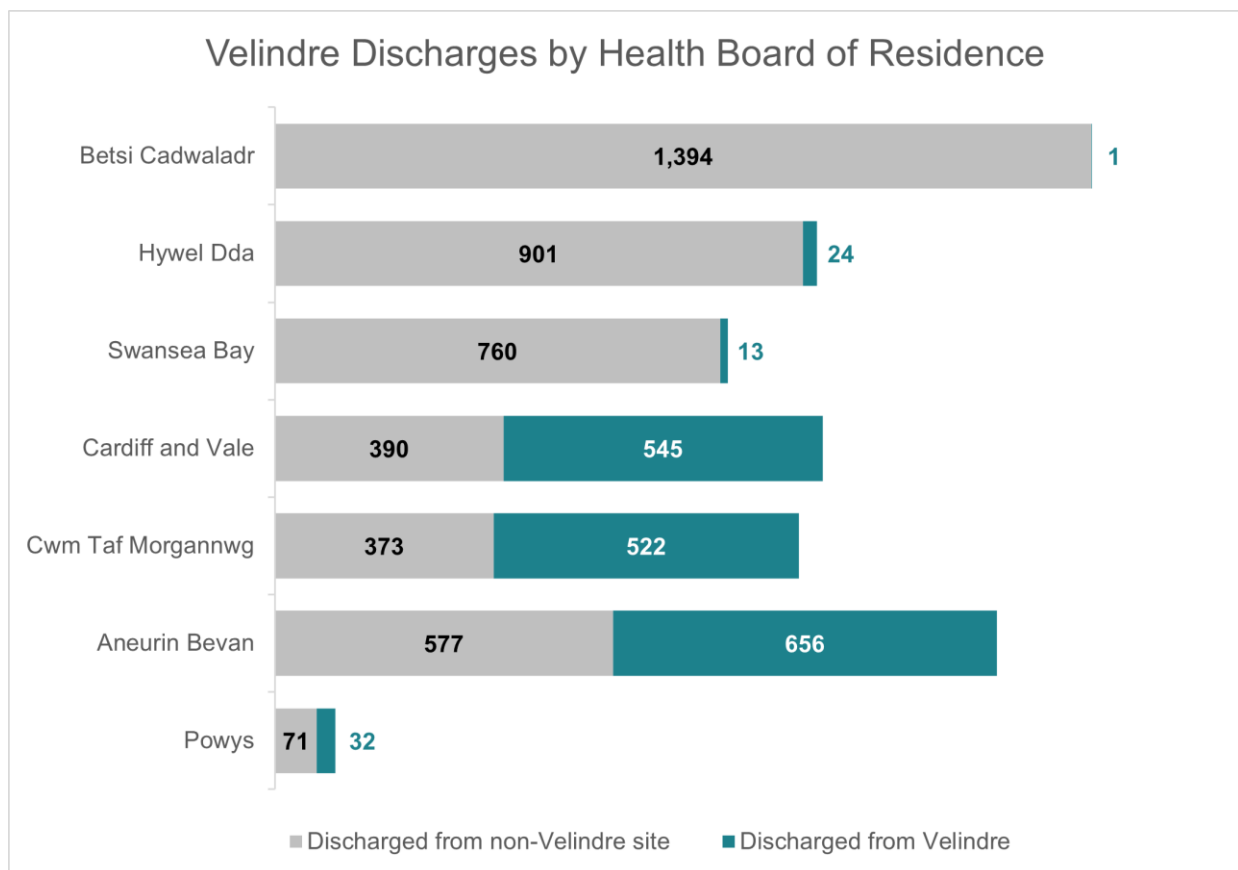
6. This report, and subsequent publications

This report sets out a summary of the results of the survey for Velindre Cancer Centre. Velindre Cancer Centre is part of Velindre University NHS Trust.

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

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

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



Note: When interpreting Velindre Cancer Centre's results, the reported experience will reflect the whole patient pathway which may span multiple Health Boards/Trust.

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

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

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

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

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

7. Understanding the results

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

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

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

Unadjusted raw data. It should be noted that all data used in this report is unadjusted/raw and illustrates exactly how people living with cancer have responded to the survey.

Scoring

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

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

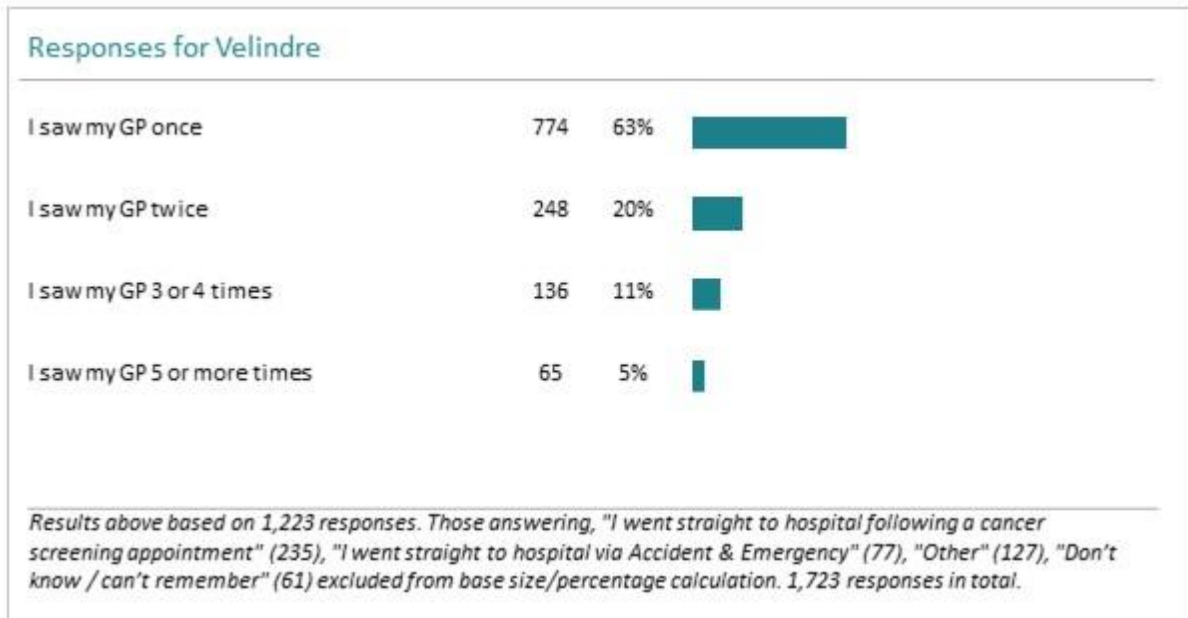
Full details of the scoring methodology are included in the technical document available at <https://wcpes.co.uk/library>

Evaluative patient experience questions

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

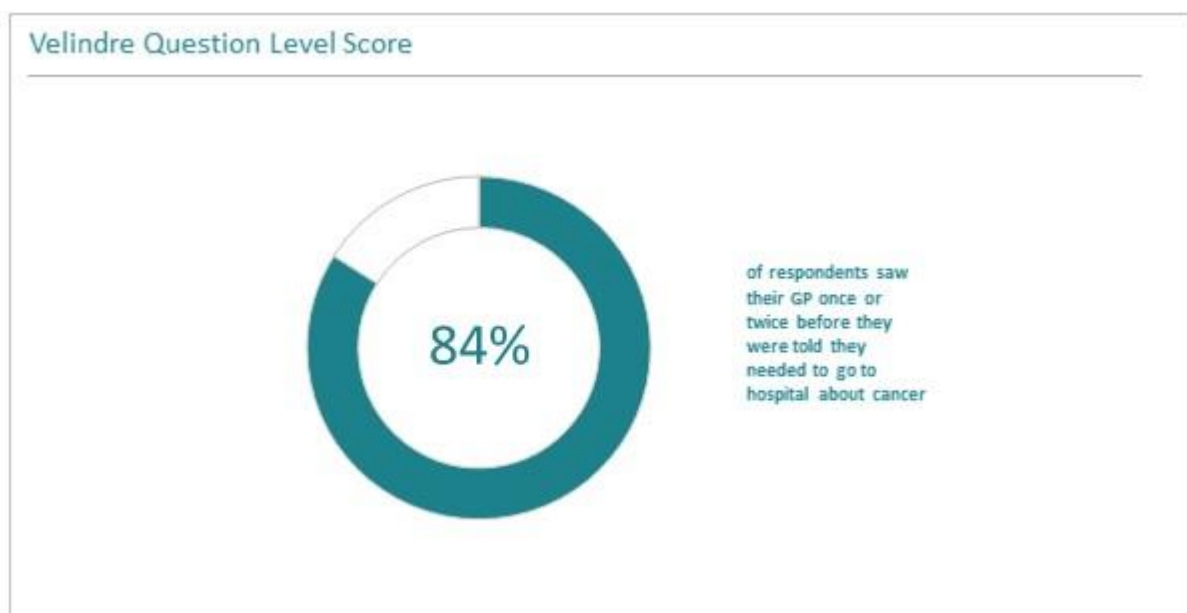
1. **Compositional Chart.** The Compositional Chart shows the range of responses to the question. These charts exclude any non-specific responses such as don't know / can't remember.

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



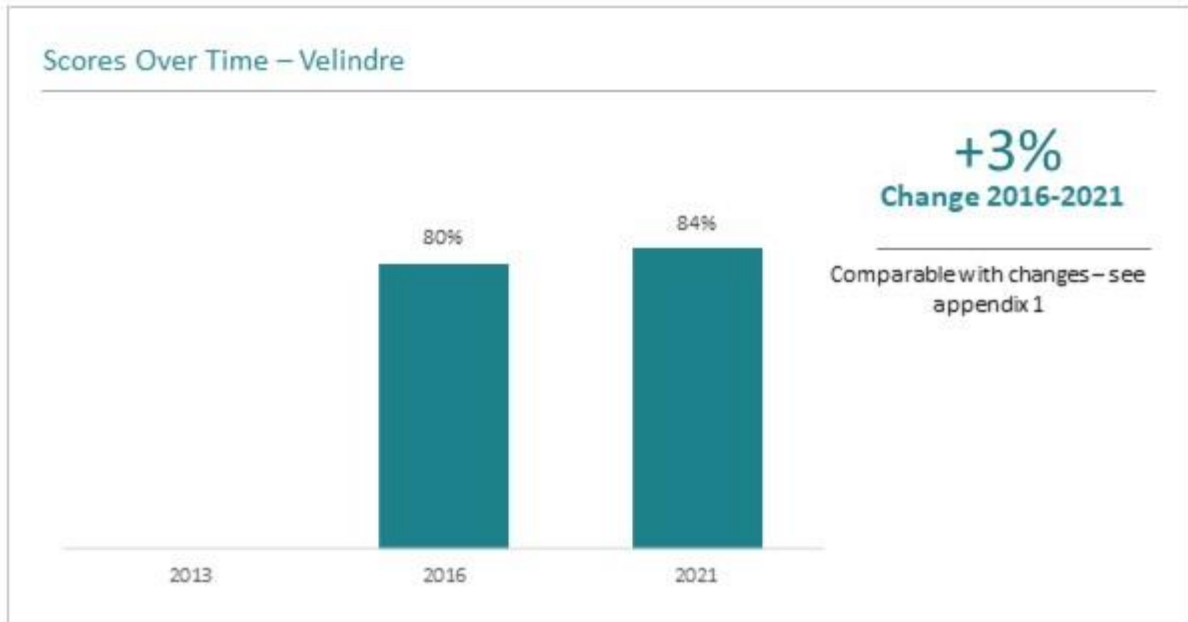
2. **Scored Chart.** These charts illustrate the scored result for each question using unadjusted raw data.

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



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

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

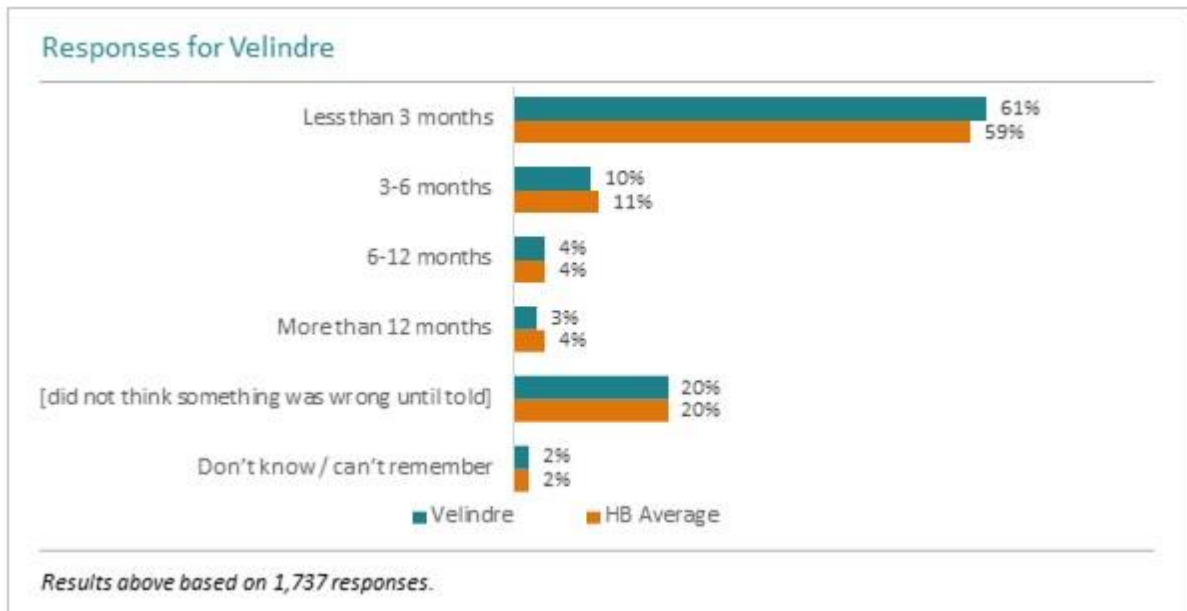


Informational (non-evaluative) questions

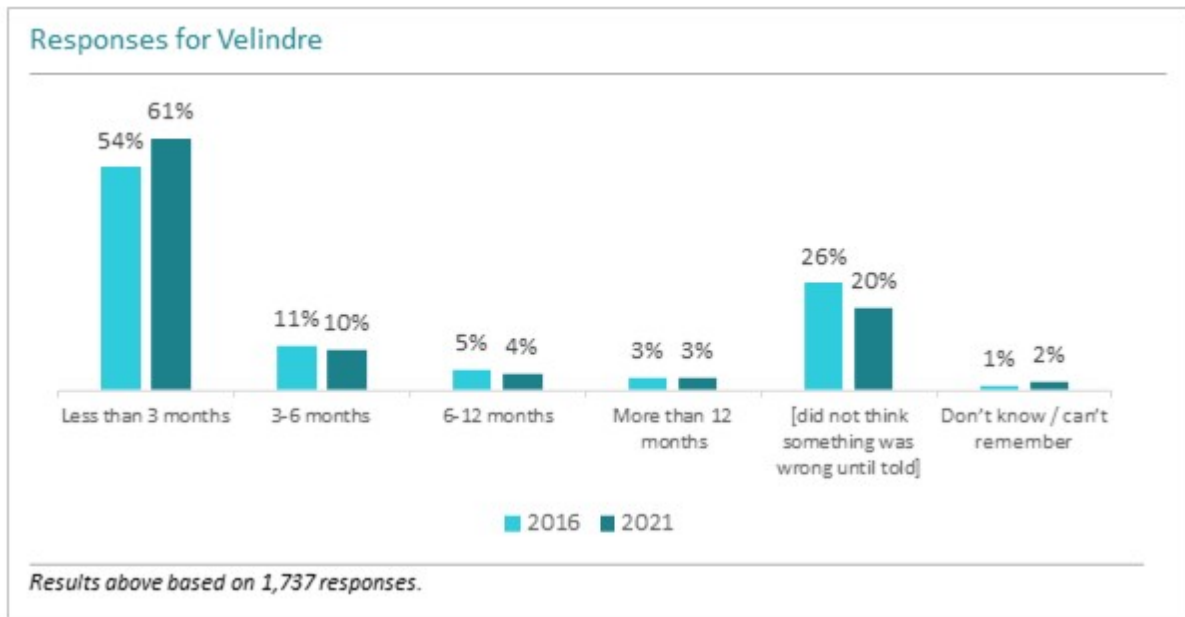
Despite not being assigned a score, 2 of the informational questions (Q02 and Q13) were deemed to contain important data.

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

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



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



Other reporting conventions

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

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

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

Further information

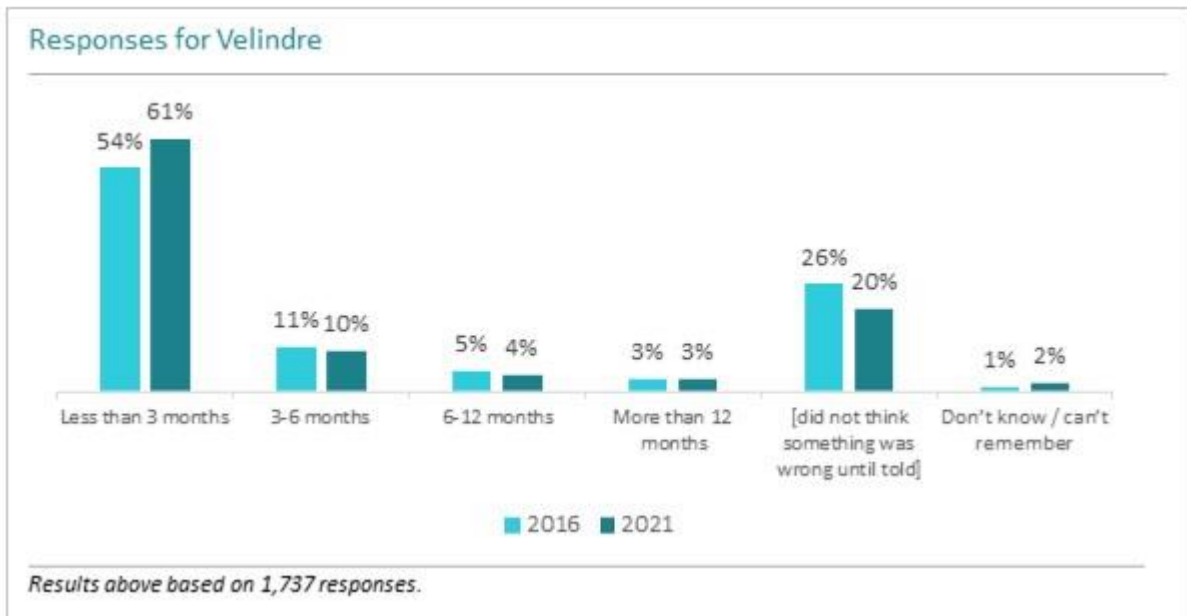
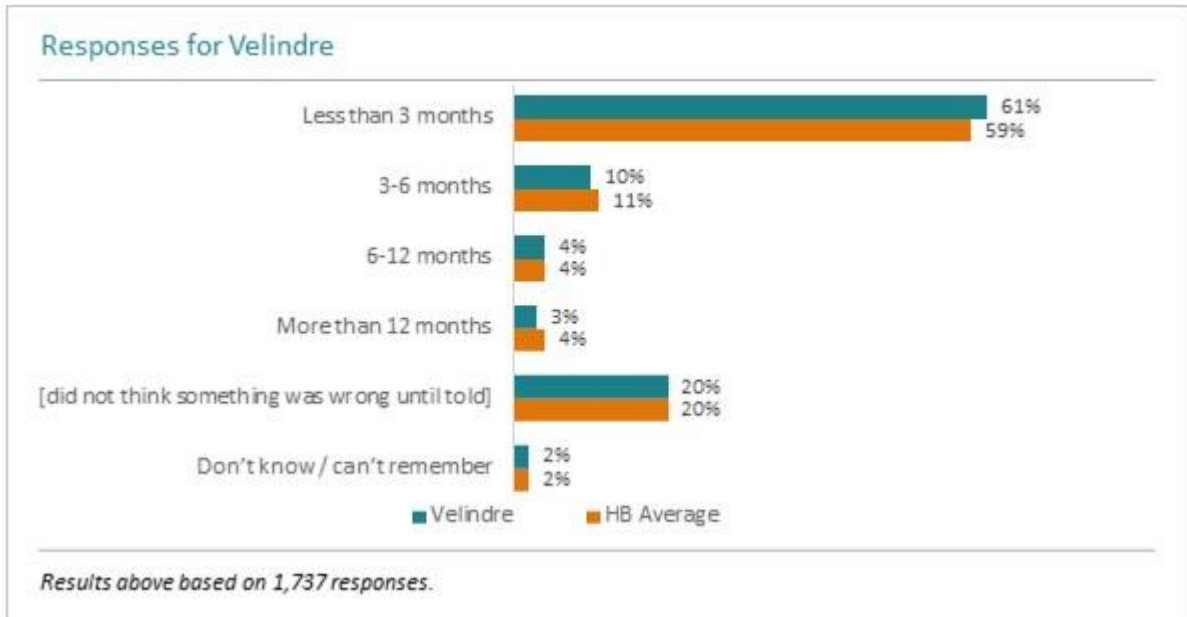
Full details on the scoring is included in the Technical Document for this survey, which is published separately at <https://wcpes.co.uk/library>

8. Survey results

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

8.1 Before your diagnosis

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



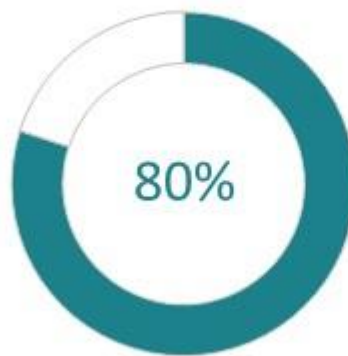
Question 3: "Did you understand the explanation of what was wrong with you?"

Responses for Velindre

Yes, I completely understood it	1,400	80%	
Yes, I understood some of it	290	17%	
No, I did not understand it	58	3%	

Results above based on 1,748 responses. Those answering, "Don't know / can't remember" (10) excluded from base size/percentage calculation. 1,758 responses in total.



Velindre Question Level Score



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

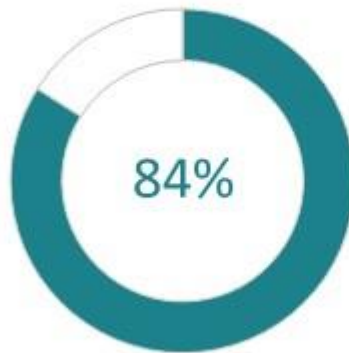
Question 4: "Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?"

Responses for Velindre

I saw my GP once	774	63%	
I saw my GP twice	248	20%	
I saw my GP 3 or 4 times	136	11%	
I saw my GP 5 or more times	65	5%	

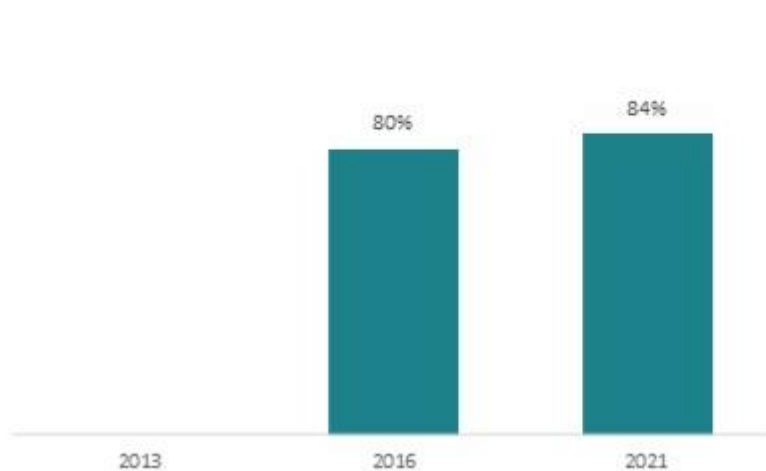
Results above based on 1,223 responses. Those answering, "I went straight to hospital following a cancer screening appointment" (235), "I went straight to hospital via Accident & Emergency" (77), "Other" (127), "Don't know / can't remember" (61) excluded from base size/percentage calculation. 1,723 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



+3%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for Velindre

I was seen as soon as I thought was necessary	1,479	84%	
I should have been seen a bit sooner	180	10%	
I should have been seen a lot sooner	102	6%	

Results above based on 1,761 responses.




Velindre Question Level Score



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

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

Responses for Velindre

Yes	1,230	92%	
No, I would have liked more information	73	5%	
No, I did not need any information	32	2%	

Results above based on 1,335 responses. Those answering, "Don't know / can't remember" (21) excluded from base size/percentage calculation. 1,356 responses in total.

Velindre Question Level Score



of respondents had all the information they needed about their test.

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

Responses for Velindre

Yes, completely	1,052	78%	
Yes, to some extent	271	20%	
No, I did not understand the explanation	9	1%	
No, but I would have liked an explanation	12	1%	

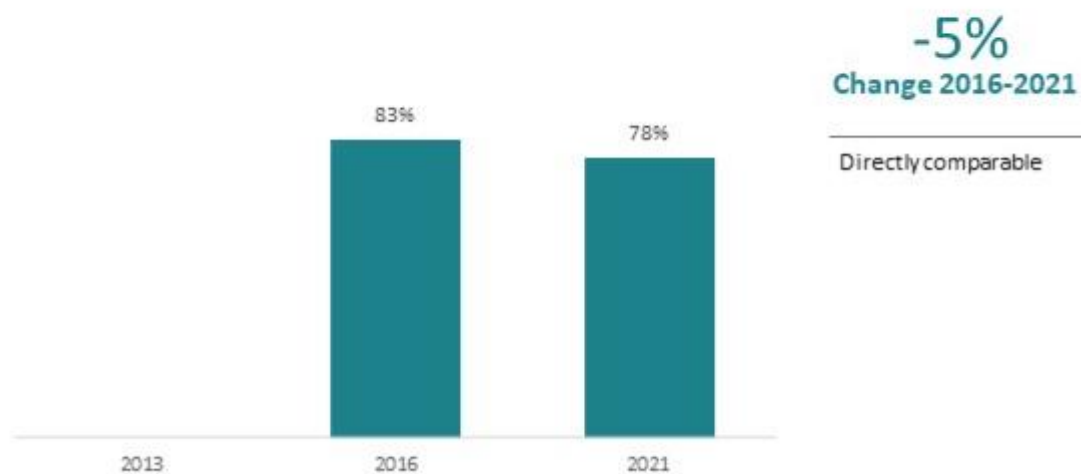
Results above based on 1,344 responses. Those answering, "I did not need an explanation" (6), "Don't know / can't remember" (6) excluded from base size/percentage calculation. 1,356 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



8.2 Finding out you had cancer

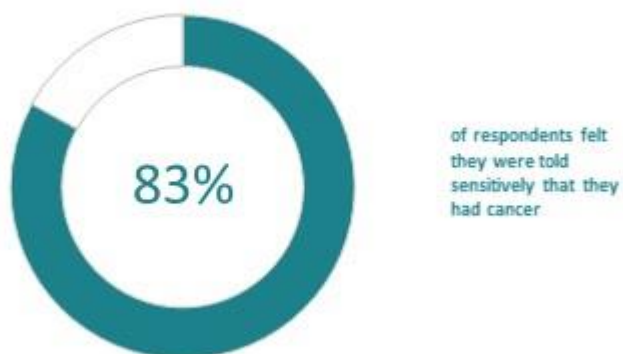
Question 10: "How do you feel about the way you were told you had cancer?"

Responses for Velindre

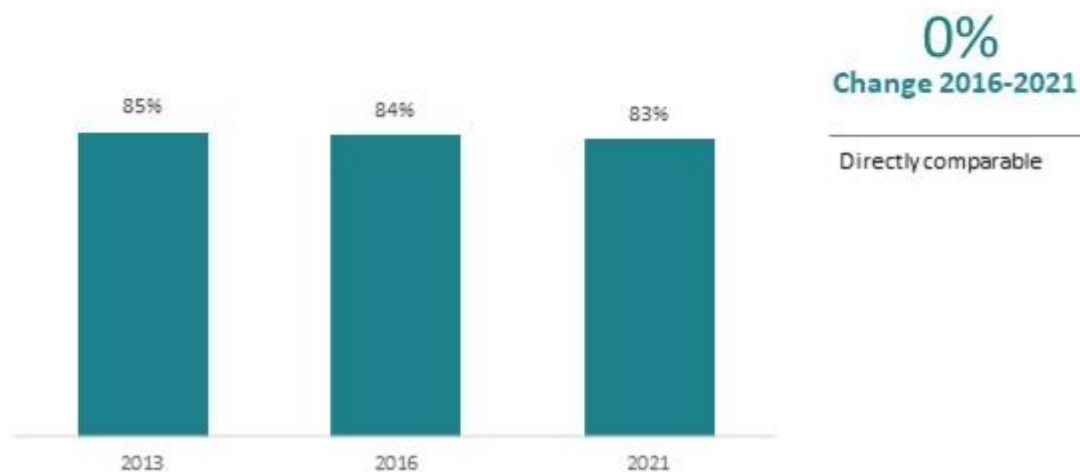
It was done sensitively	1,465	83%	
It should have been done a bit more sensitively	189	11%	
It should have been done a lot more sensitively	106	6%	

Results above based on 1,760 responses.

Velindre Question Level Score



Scores Over Time – Velindre



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

Responses for Velindre

Yes, I completely understood it	1,378	78%	
Yes, I understood some of it	378	21%	
No, I did not understand it	19	1%	

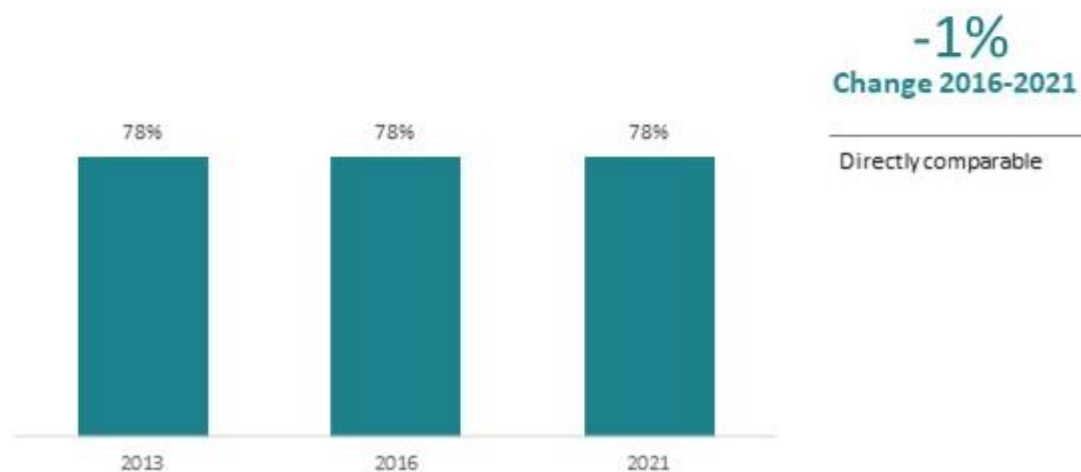
Results above based on 1,775 responses. Those answering, "Don't know / can't remember" (4) excluded from base size/percentage calculation. 1,779 responses in total.

Velindre Question Level Score






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

Scores Over Time – Velindre



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

Responses for Velindre

Yes, and it waseasy to understand	948	63%	
Yes, but it was difficult to understand	122	8%	
[No, not given written info. re. cancer type]	431	29%	

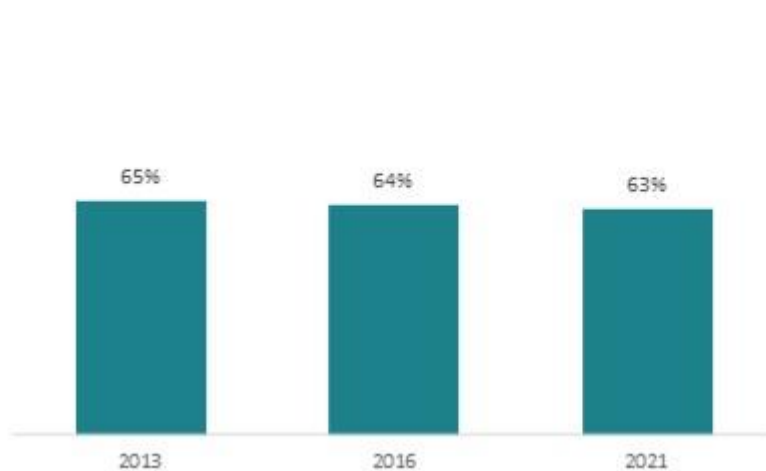
Results above based on 1,501 responses. Those answering, "I did not need written information" (146), "Don't know / can't remember" (112) excluded from base size/percentage calculation. 1,759 responses in total.

Velindre Question Level Score



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

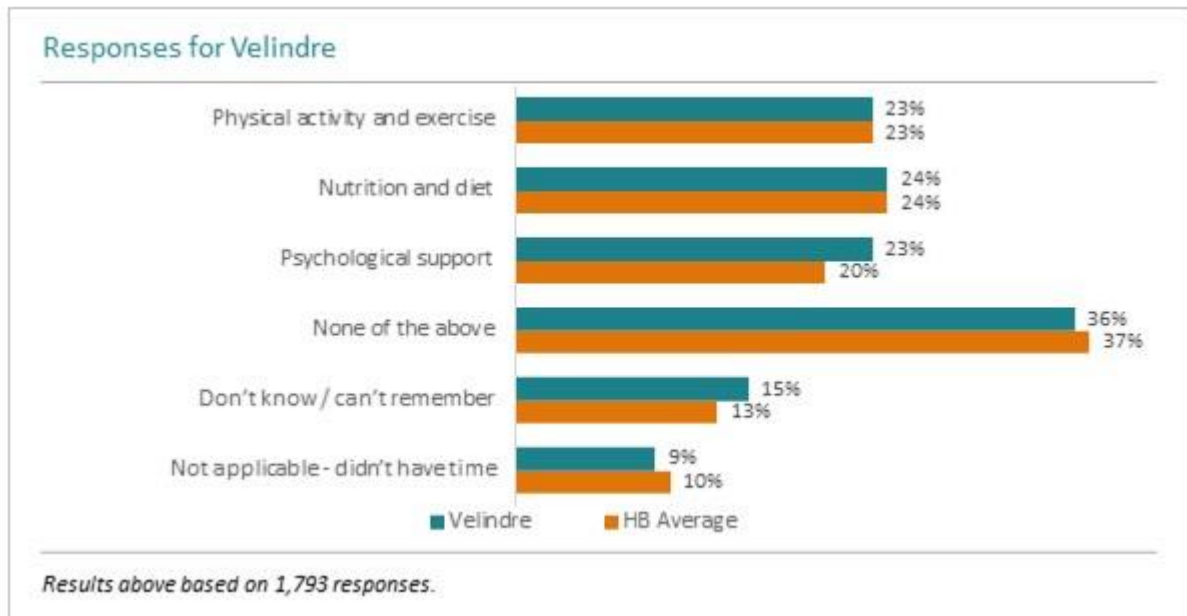
Scores Over Time – Velindre



-1%
Change 2016-2021




Directly comparable

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



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

Responses for Velindre

Yes	1,130	67%	
No	482	29%	
I was told by phone or letter	66	4%	

Results above based on 1,678 responses. Those answering, "Don't know / can't remember" (77) excluded from base size/percentage calculation. 1,755 responses in total.

Velindre Question Level Score



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

8.3 Deciding the best treatment and / or care for you

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

Responses for Velindre

Yes, completely	1,254	81%	
Yes, to some extent	262	17%	
No	35	2%	

Results above based on 1,551 responses. Those answering, "There was only one type of treatment that was suitable for me" (195), "Don't know / can't remember" (13) excluded from base size/percentage calculation. 1,759 responses in total.

Velindre Question Level Score



81% of respondents felt their treatment options were completely discussed with them

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

Responses for Velindre

Yes, definitely	1,347	76%	
Yes, to some extent	360	20%	
No	55	3%	

Results above based on 1,762 responses. Those answering, "Don't know / can't remember" (14) excluded from base size/percentage calculation. 1,776 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes, definitely	1,252	72%	
Yes, to some extent	428	25%	
No, side effects were not explained	61	4%	

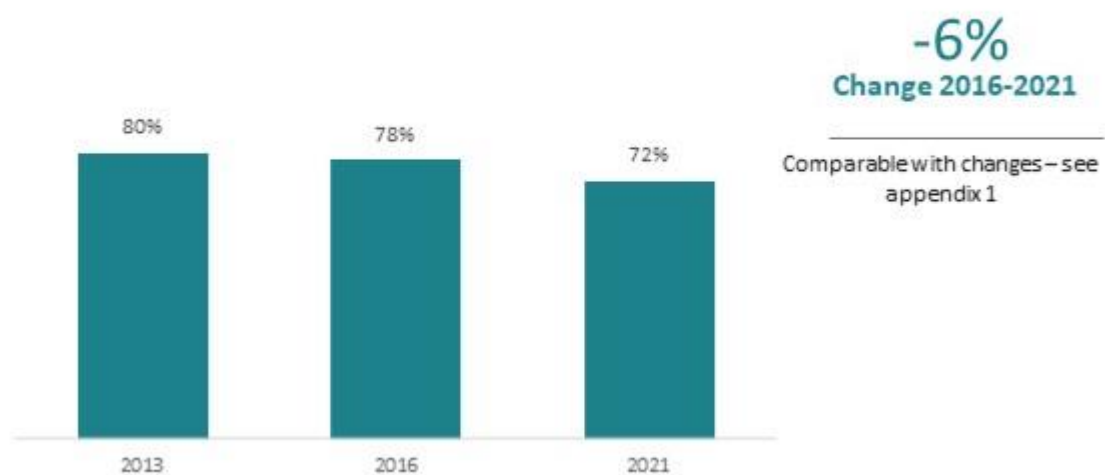
Results above based on 1,741 responses. Those answering, "I did not need an explanation" (22), "Don't know" (7) excluded from base size/percentage calculation. 1,770 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



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

Responses for Velindre

Yes, definitely	1,068	62%	
Yes, to some extent	523	30%	
[No, not offered practical advice/support]	126	7%	

Results above based on 1,717 responses. Those answering, "Don't know / can't remember" (53) excluded from base size/percentage calculation. 1,770 responses in total.

Velindre Question Level Score



of respondents said that they were definitely offered practical advice and support to deal with side effects

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

Responses for Velindre

Yes, definitely	877	53%	
Yes, to some extent	476	29%	
No, future side effects were not explained	303	18%	

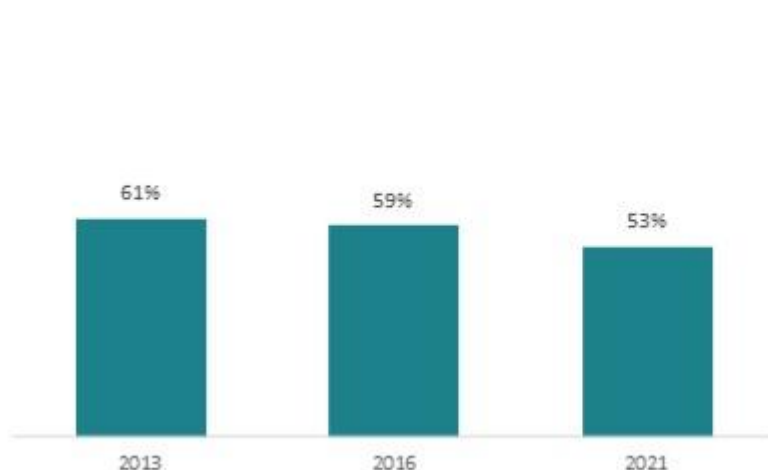
Results above based on 1,656 responses. Those answering, "I did not need an explanation" (36), "Don't know / can't remember" (78) excluded from base size/percentage calculation. 1,770 responses in total.

Velindre Question Level Score



of respondents were definitely told about side effects of treatment that could affect them in the future

Scores Over Time – Velindre

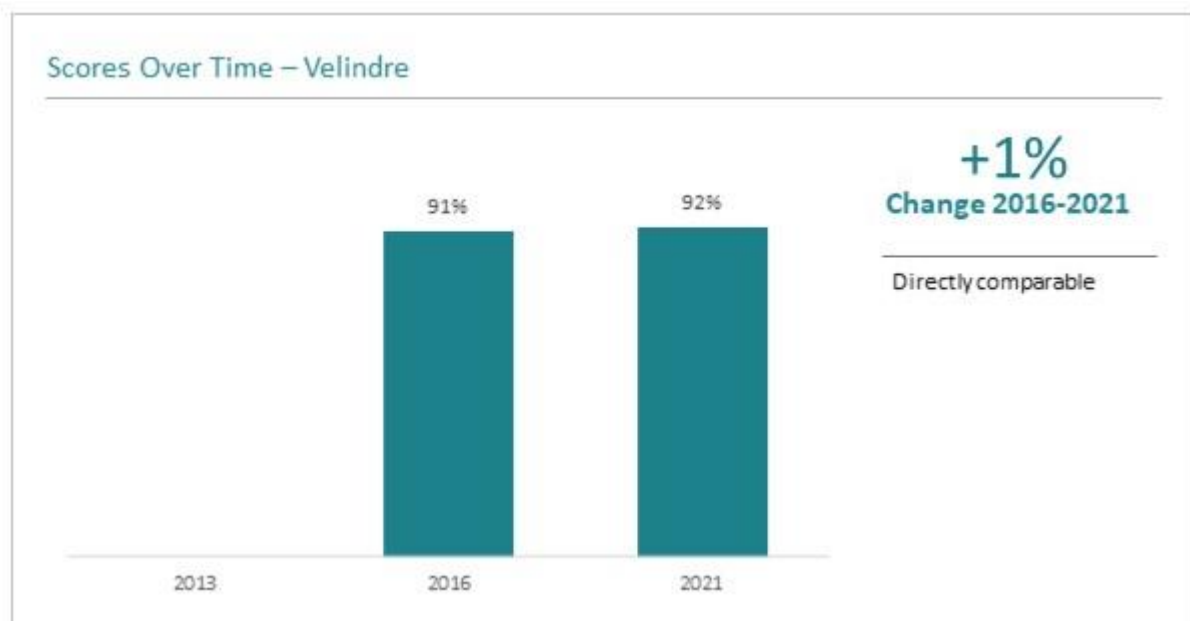
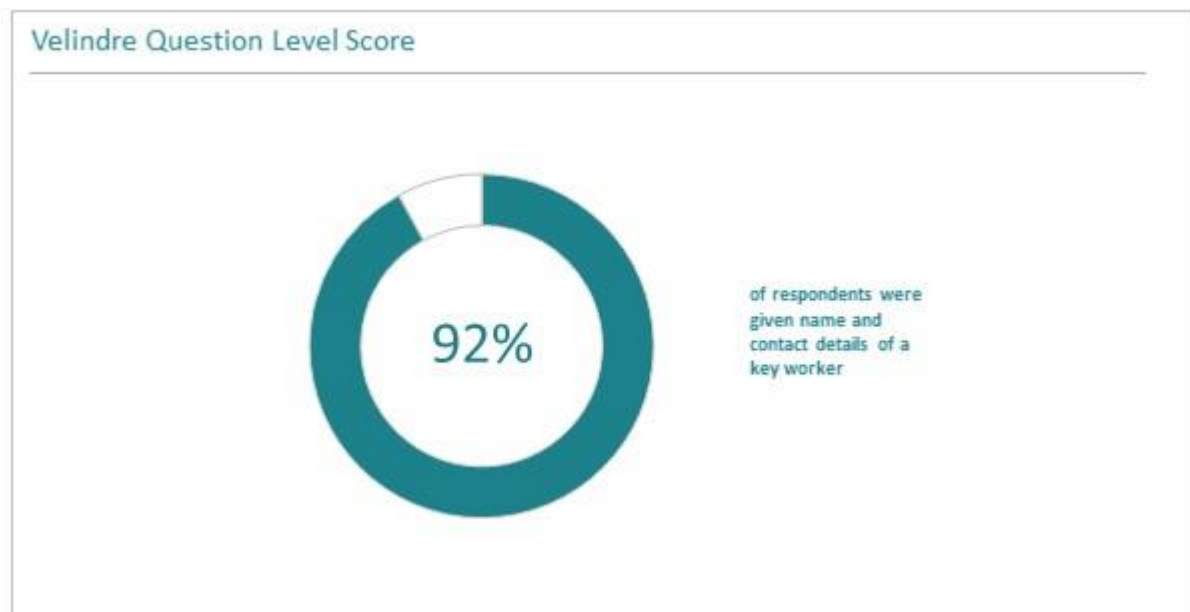
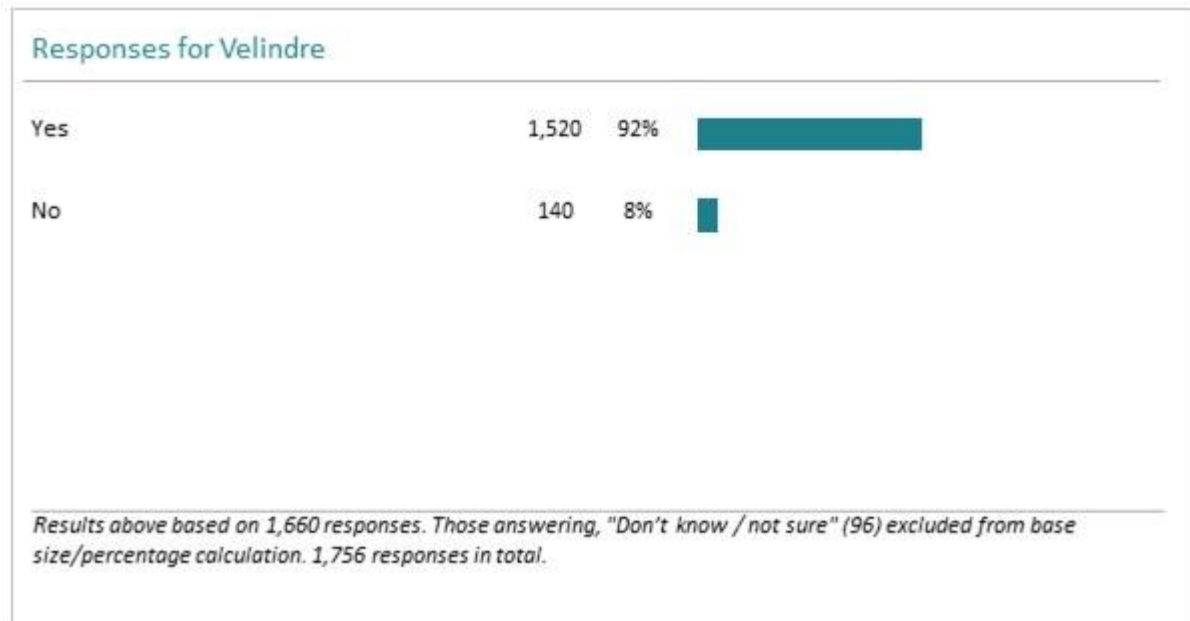


-6%
Change 2016-2021

Comparable with changes – see appendix 1




8.4 Healthcare professionals

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



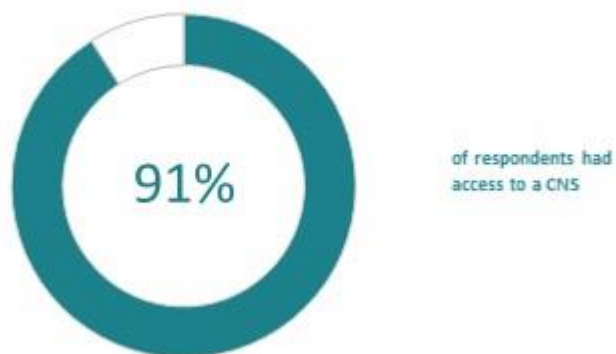
Question 21a: "Did your care include access to... A CNS?"

Responses for Velindre

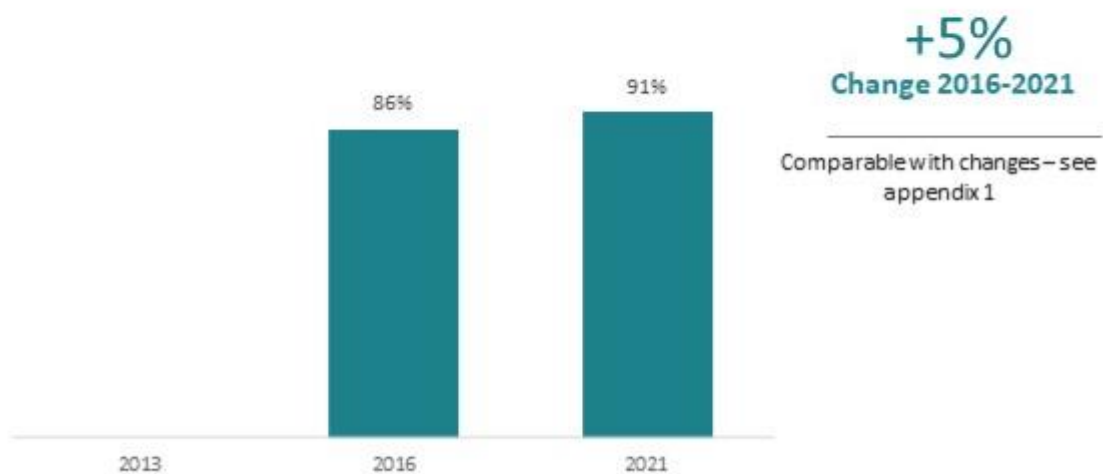
Yes, and this was my Key Worker	1,148	81%	
Yes, but this was not my Key Worker	141	10%	
No, I did not have one as part of my care team	123	9%	

Results above based on 1,412 responses. Those answering, "Don't know / can't remember" (209) excluded from base size/percentage calculation. 1,621 responses in total.

Velindre Question Level Score



Scores Over Time – Velindre



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

Responses for Velindre

Easy	713	66%	
Sometimes easy, sometimes difficult	318	29%	
Difficult	54	5%	

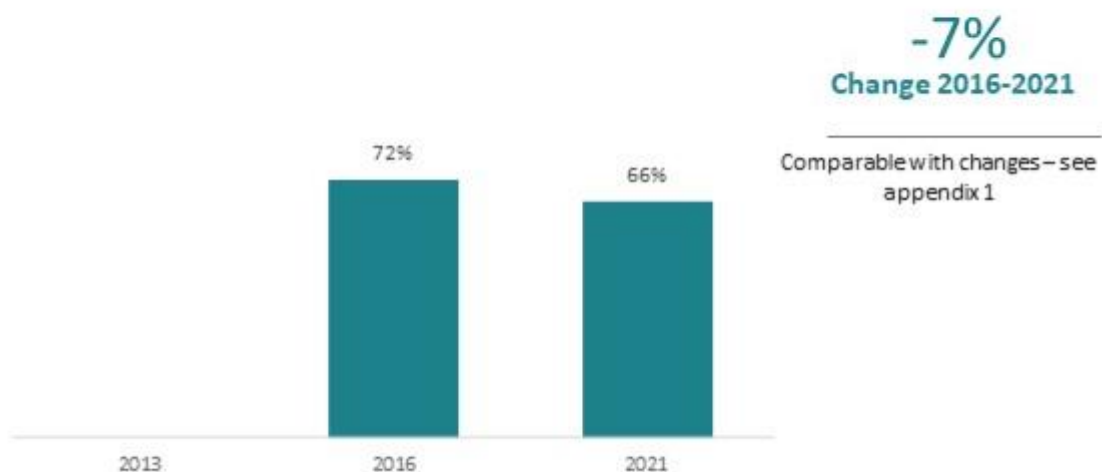
Results above based on 1,085 responses. Those answering, "I have not tried to contact them" (183), "Not applicable" (122) excluded from base size/percentage calculation. 1,390 responses in total.

Velindre Question Level Score



of respondents said it was easy to contact their key worker

Scores Over Time – Velindre



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

Responses for Velindre

Easy	555	64%	
Sometimes easy, sometimes difficult	256	30%	
Difficult	50	6%	

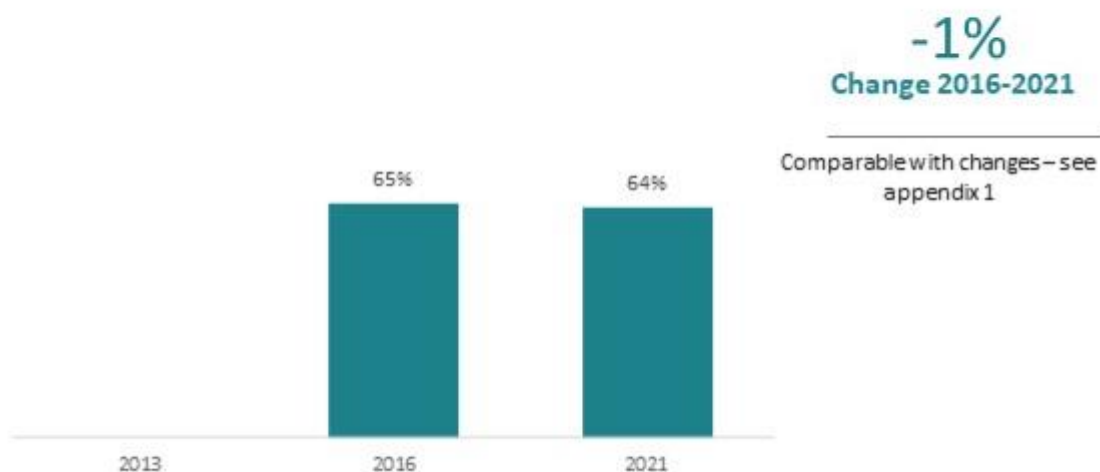
Results above based on 861 responses. Those answering, "I have not tried to contact them" (115), "Not applicable" (124) excluded from base size/percentage calculation. 1,100 responses in total.

Velindre Question Level Score



of respondents said it was easy to contact their CNS

Scores Over Time – Velindre



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

Responses for Velindre

Easy	326	59%	
Sometimes easy, sometimes difficult	180	33%	
Difficult	43	8%	

Results above based on 549 responses. Those answering, "I have not tried to contact them" (128), "Not applicable" (175) excluded from base size/percentage calculation. 852 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

All or most of the time	866	84%	
Some of the time	133	13%	
Rarely or never	34	3%	

Results above based on 1,033 responses. Those answering, "I did not ask any questions" (110), "Not applicable" (151) excluded from base size/percentage calculation. 1,294 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

All or most of the time	772	85%	
Some of the time	109	12%	
Rarely or never	26	3%	

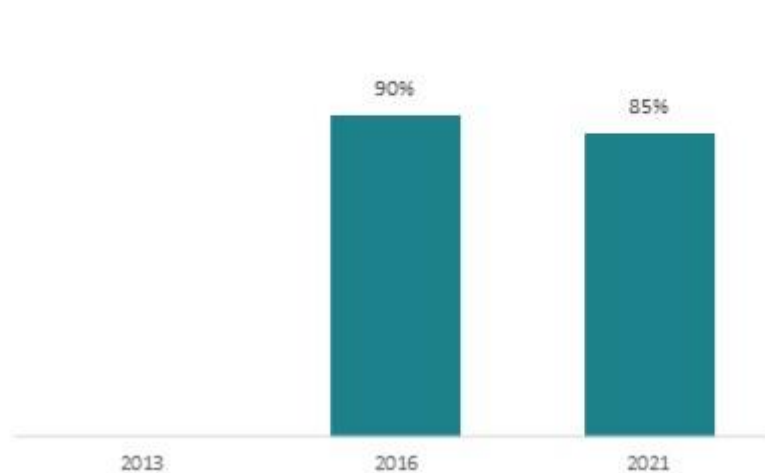
Results above based on 907 responses. Those answering, "I did not ask any questions" (82), "Not applicable" (144) excluded from base size/percentage calculation. 1,133 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-5%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for Velindre

All or most of the time	501	77%	
Some of the time	135	21%	
Rarely or never	17	3%	

Results above based on 653 responses. Those answering, "I did not ask any questions" (62), "Not applicable" (190) excluded from base size/percentage calculation. 905 responses in total.

Velindre Question Level Score



77% of respondents were able to get answers from other health professionals all or most of the time

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

Responses for Velindre

Yes, completely	802	77%	
Yes, to some extent	191	18%	
No	50	5%	

Results above based on 1,043 responses. Those answering, "Don't know / can't remember" (46), "Not applicable" (184) excluded from base size/percentage calculation. 1,273 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes, completely	701	76%	
Yes, to some extent	181	20%	
No	43	5%	

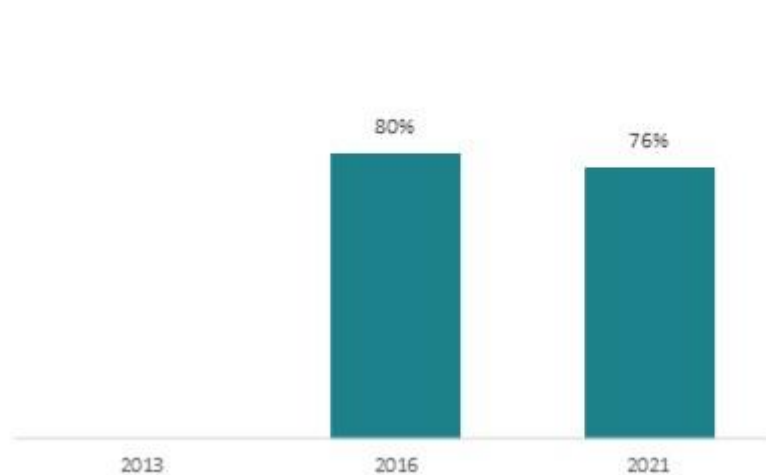
Results above based on 925 responses. Those answering, "Don't know / can't remember" (35), "Not applicable" (164) excluded from base size/percentage calculation. 1,124 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-5%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for Velindre

Yes, completely	483	73%	
Yes, to some extent	139	21%	
No	39	6%	

Results above based on 661 responses. Those answering, "Don't know / can't remember" (38), "Not applicable" (196) excluded from base size/percentage calculation. 895 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes - using a Holistic Needs Assessment	159	14%	■
Yes - using a PROM assessment	56	5%	■
[Yes, asked to complete HNA & PROM]	20	2%	■
[Yes, offered discussion but unsure of format]	309	27%	■
No	600	52%	■

Results above based on 1,144 responses. Those answering, "Don't know / can't remember" (551) excluded from base size/percentage calculation. 1,695 responses in total.

Velindre Question Level Score




of respondents were offered an opportunity to discuss their needs and concerns

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

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

Responses for Velindre

Yes	386	29%	
No	957	71%	

Results above based on 1,343 responses. Those answering, "I do not know / understand what a care plan is" (123), "Don't know / can't remember" (270) excluded from base size/percentage calculation. 1,736 responses in total.

Velindre Question Level Score







of respondents were offered a written care plan

8.5 Support for people living with cancer

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

Responses for Velindre

Not enough	224	14%	
The right amount	1,033	66%	
Too much	23	1%	
I was not given any information	285	18%	

Results above based on 1,565 responses. Those answering, "Don't know / can't remember" (188) excluded from base size/percentage calculation. 1,753 responses in total.

Velindre Question Level Score



66% of respondents said they were given the right amount of information about support/self help groups

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

Responses for Velindre

Yes	972	64%	
No	544	36%	

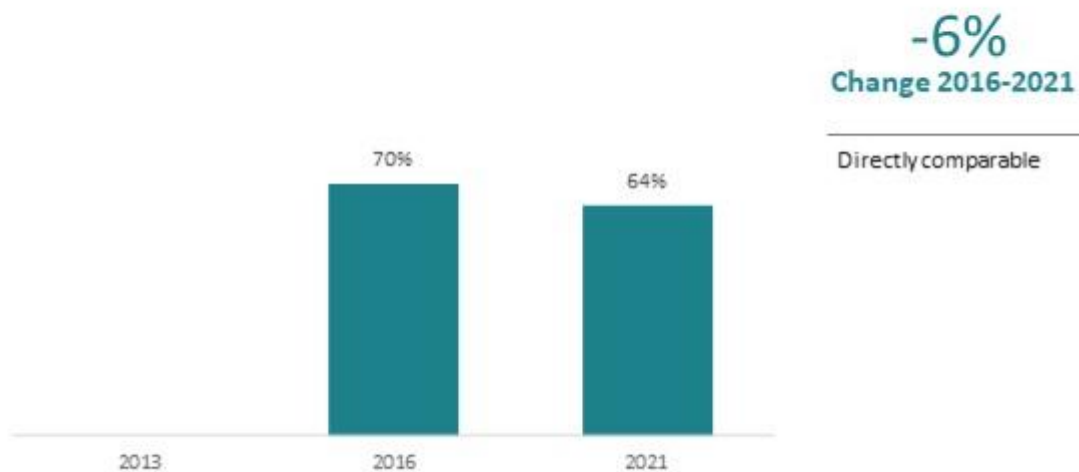
Results above based on 1,516 responses. Those answering, "Don't know / can't remember" (246) excluded from base size/percentage calculation. 1,762 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



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

Responses for Velindre

Yes, completely	642	40%	
Yes, to some extent	580	36%	
No	402	25%	

Results above based on 1,624 responses. Those answering, "Don't know / can't remember" (131) excluded from base size/percentage calculation. 1,755 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes	628	60%	
Yes, but I would have liked more information	122	12%	
No, but I would have liked information	302	29%	

Results above based on 1,052 responses. Those answering, "It was not necessary" (614), "Don't know / can't remember" (86) excluded from base size/percentage calculation. 1,752 responses in total.

Velindre Question Level Score



60% of respondents said they were given enough information on how to get financial support or any benefits they were entitled to

8.6 Operations

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

Responses for Velindre

Yes	352	94%	
No, I would have liked more information	23	6%	

Results above based on 375 responses. Those answering, "Don't know / can't remember" (3) excluded from base size/percentage calculation. 378 responses in total.




Velindre Question Level Score



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

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

Responses for Velindre

Yes, completely	271	74%	
Yes, to some extent	78	21%	
No, but I would have liked an explanation	19	5%	

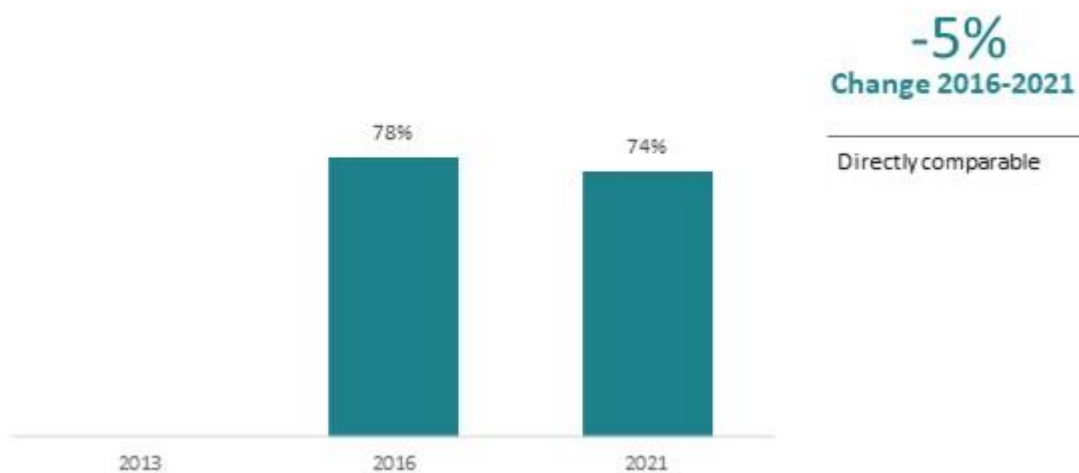
Results above based on 368 responses. Those answering, "I did not need an explanation" (5) excluded from base size/percentage calculation. 373 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



8.7 Hospital care as an inpatient

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

Responses for Velindre

Yes, always	365	88%	
Yes, sometimes	40	10%	
No	8	2%	

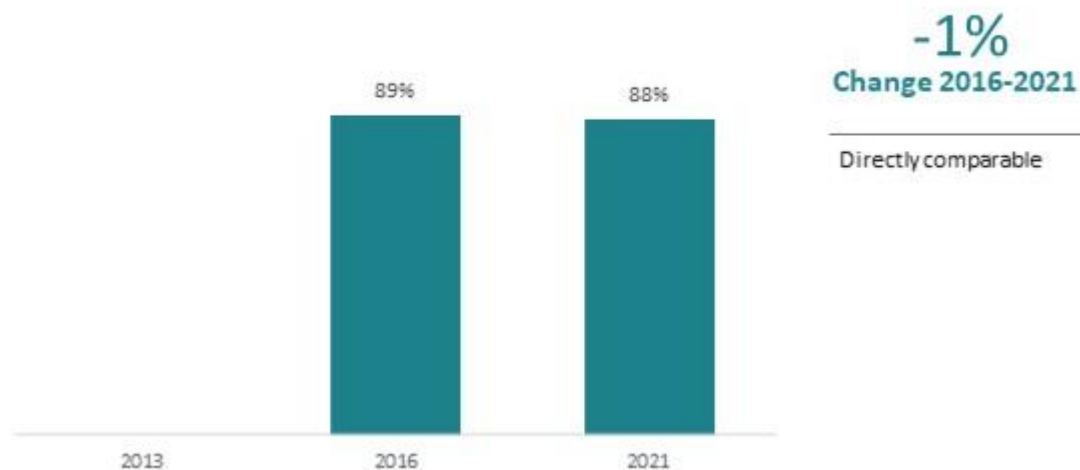
Results above based on 413 responses.

Velindre Question Level Score



of respondents said that they were always treated with dignity and respect in hospital

Scores Over Time – Velindre



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

Responses for Velindre

As much as I wanted	238	63%	
Most of the time	65	17%	
Some of the time	44	12%	
Not at all, but would have liked to	30	8%	

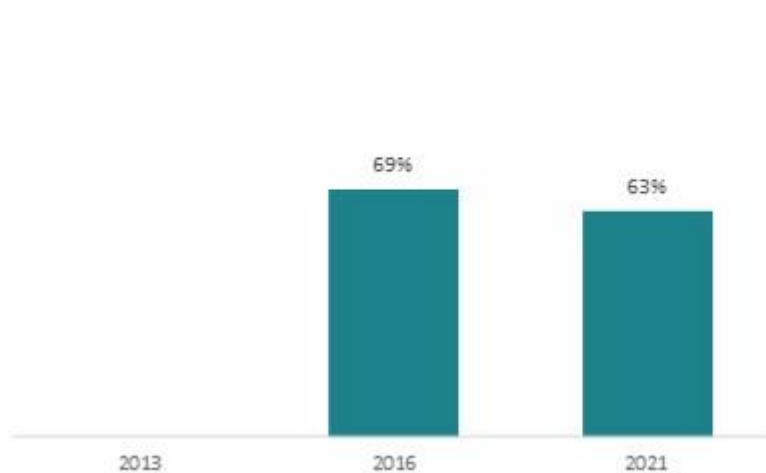
Results above based on 377 responses. Those answering, "I did not have any worries or fears" (33) excluded from base size/percentage calculation. 410 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-6%
Change 2016-2021

Directly comparable

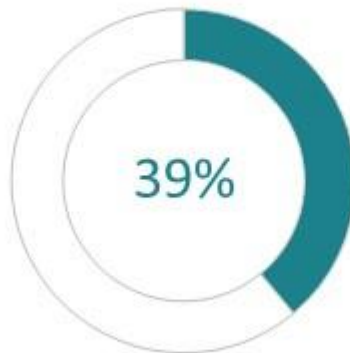
Question 37: "Did your family or someone else close to you have enough opportunity to talk to a healthcare professional?"

Responses for Velindre

Yes, definitely	134	39%	
Yes, to some extent	94	27%	
No	120	34%	

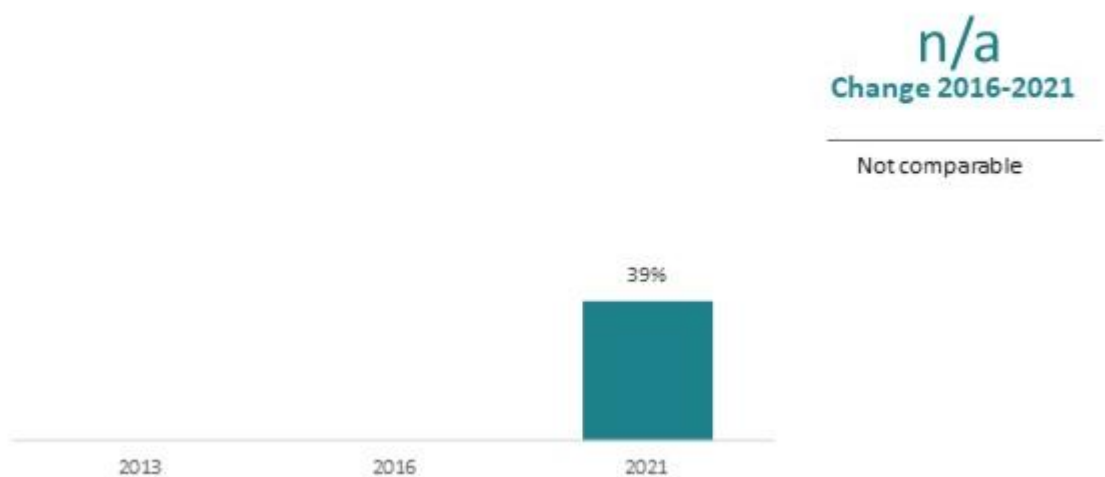
Results above based on 348 responses. Those answering, "No family or friends were involved" (53), "My family did not want to talk to a healthcare professional" (10) excluded from base size/percentage calculation. 411 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



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

Responses for Velindre

Yes, in all of them	341	82%	
Yes, in some of them	71	17%	
No, in none of them	5	1%	

Results above based on 417 responses.

Velindre Question Level Score



82% of respondents had confidence and trust in all of the healthcare professionals involved in their care

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

Responses for Velindre

Yes, always	364	88%	
Yes, sometimes	38	9%	
No	12	3%	

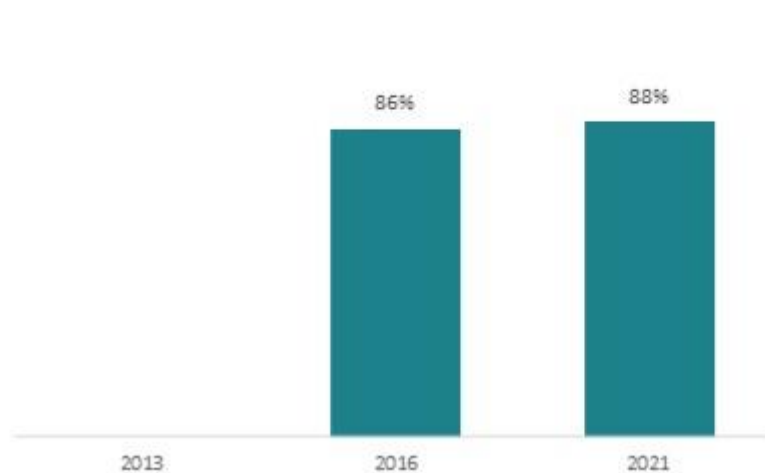
Results above based on 414 responses.

Velindre Question Level Score



of respondents said they were always given enough privacy when discussing their condition or treatment

Scores Over Time – Velindre



+1%
Change 2016-2021

Directly comparable

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

Responses for Velindre

Yes, always	389	93%	
Yes, sometimes	27	6%	
No	2	0%	

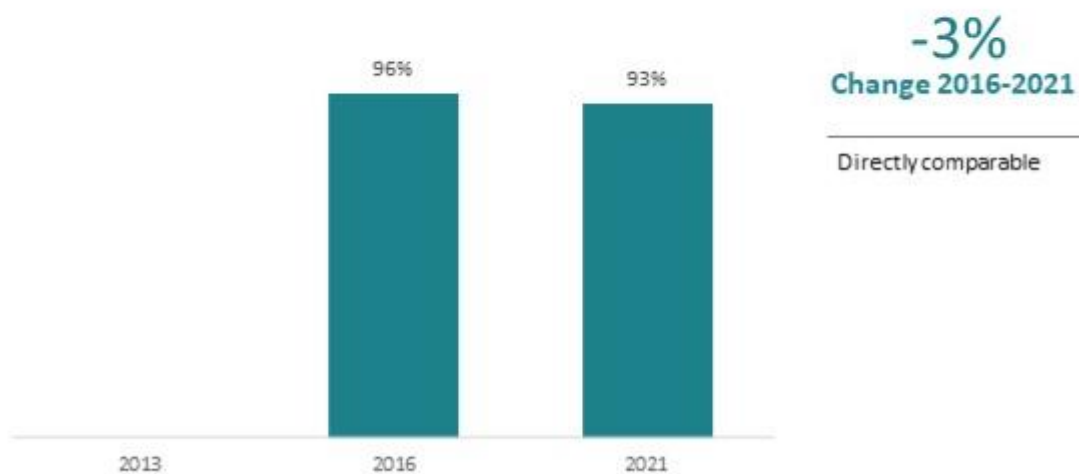
Results above based on 418 responses.

Velindre Question Level Score





of respondents said they were always given enough privacy when being examined or treated

Scores Over Time – Velindre



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

Responses for Velindre

All of the time	319	85%	
Some of the time	54	14%	
Not at all	4	1%	

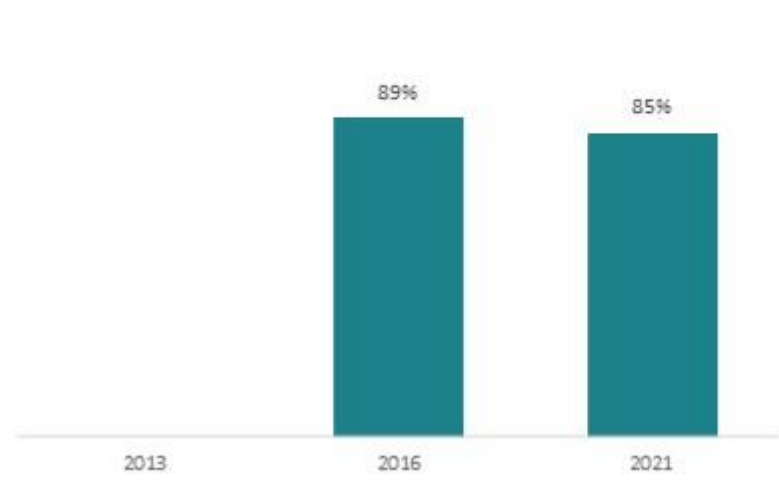
Results above based on 377 responses. Those answering, "I did not have any pain" (36) excluded from base size/percentage calculation. 413 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-4%
Change 2016-2021

Directly comparable

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

Responses for Velindre

Yes	278	78%	
No	77	22%	

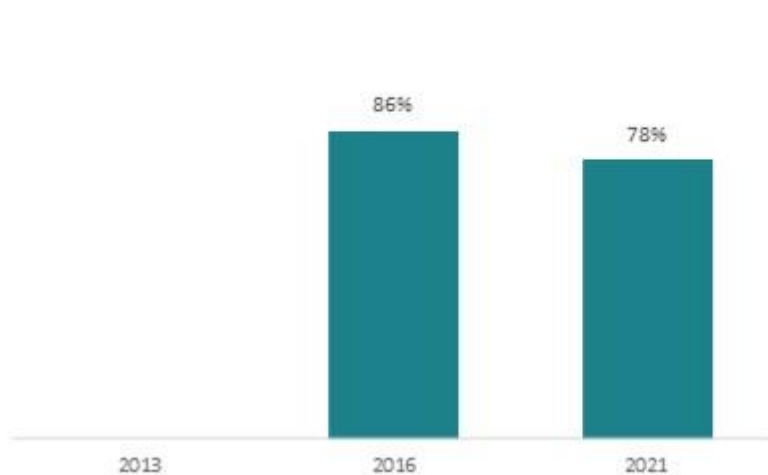
Results above based on 355 responses. Those answering, "I did not need written information" (49), "Don't know / can't remember" (13) excluded from base size/percentage calculation. 417 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-7%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for Velindre



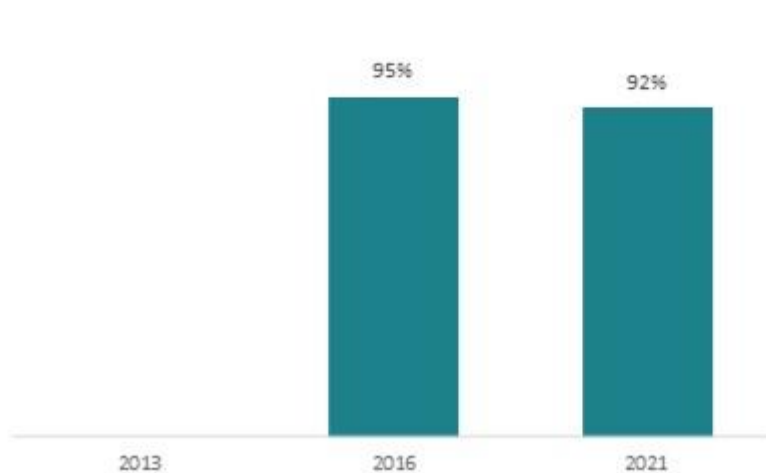
Results above based on 397 responses. Those answering, "Don't know / can't remember" (23) excluded from base size/percentage calculation. 420 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-3%
Change 2016-2021

Directly comparable

8.8 Outpatients / day case appointments

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

Responses for Velindre

Yes, definitely	630	84%	
Yes, to some extent	106	14%	
No, they could have done more	17	2%	

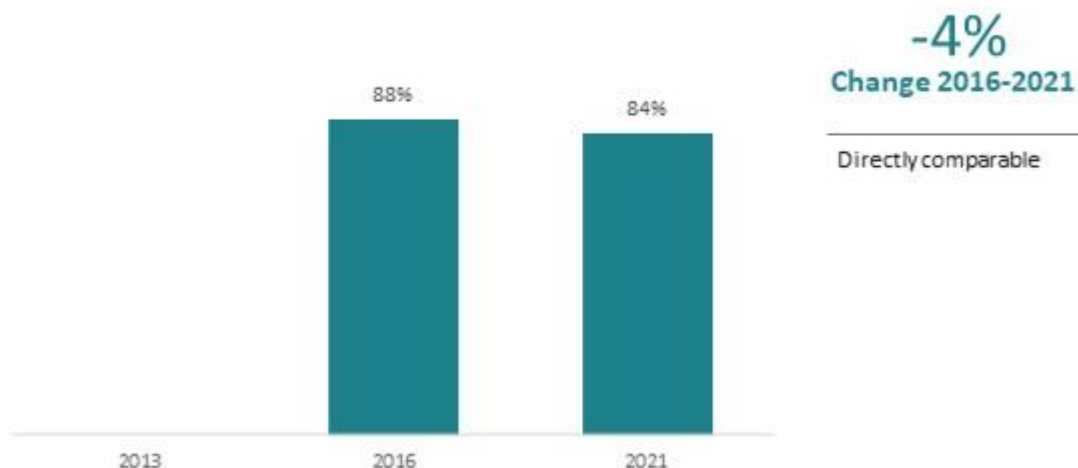
Results above based on 753 responses. Those answering, "I did not have any pain" (741) excluded from base size/percentage calculation. 1,494 responses in total.

Velindre Question Level Score






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

Scores Over Time – Velindre



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

Responses for Velindre

Yes, definitely	794	72%	
Yes, to some extent	244	22%	
No, I would have liked more support	67	6%	

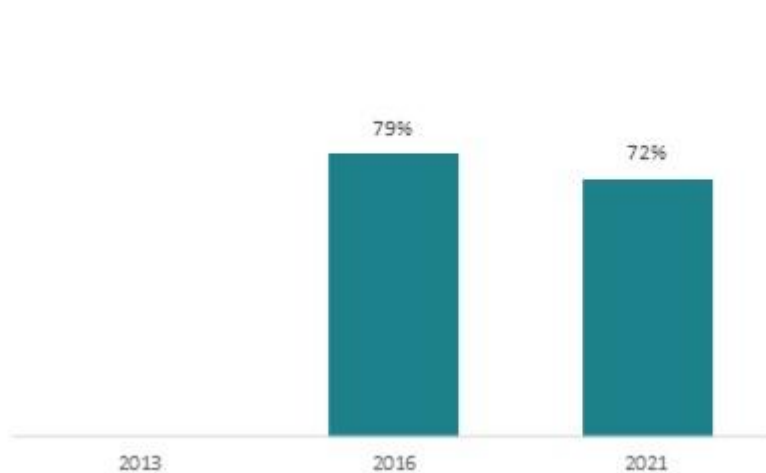
Results above based on 1,105 responses. Those answering, "I did not need emotional support from staff" (392) excluded from base size/percentage calculation. 1,497 responses in total.

Velindre Question Level Score



of respondents said that hospital staff definitely gave them enough emotional support while being treated as an outpatient or day case

Scores Over Time – Velindre



-7%
Change 2016-2021

Directly comparable

8.9 Radiotherapy / chemotherapy

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

Responses for Velindre

Yes, completely	1,071	82%	
Yes, to some extent	210	16%	
No	29	2%	

Results above based on 1,310 responses. Those answering, "I did not need any information" (6) excluded from base size/percentage calculation. 1,316 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes, completely	769	78%	
Yes, to some extent	199	20%	
No	22	2%	

Results above based on 990 responses. Those answering, "I did not need any information" (8) excluded from base size/percentage calculation. 998 responses in total.

Velindre Question Level Score



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

8.10 Arranging home support

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

Responses for Velindre

Yes, definitely	633	44%	
Yes, to some extent	370	26%	
No	425	30%	

Results above based on 1,428 responses. Those answering, "No family or friends were involved" (256), "My family did not want to talk to a healthcare professional" (38) excluded from base size/percentage calculation. 1,722 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes, definitely	633	45%	
Yes, to some extent	395	28%	
No	368	26%	

Results above based on 1,396 responses. Those answering, "Don't know / can't remember" (127), "Not applicable" (221) excluded from base size/percentage calculation. 1,744 responses in total.

Velindre Question Level Score



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

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

Responses for Velindre

Yes, definitely	765	47%	
Yes, to some extent	585	36%	
[No, not offered practical advice/support]	282	17%	

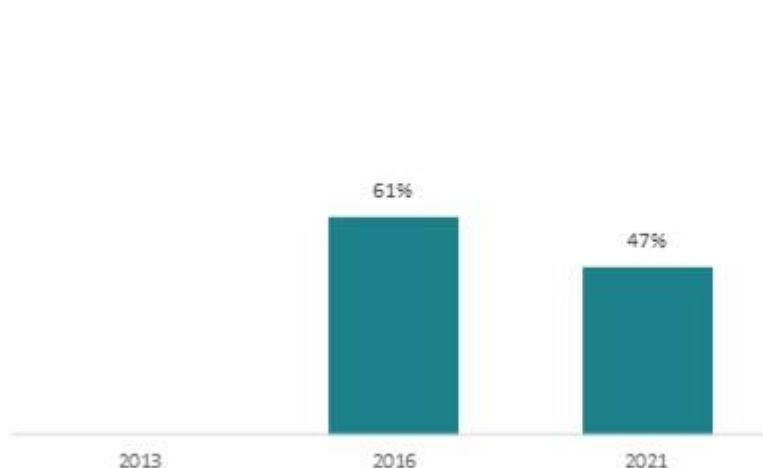
Results above based on 1,632 responses. Those answering, "Don't know / can't remember" (108) excluded from base size/percentage calculation. 1,740 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-15%
Change 2016-2021

Comparable with changes – see appendix 1

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

Responses for Velindre

Yes, definitely	539	52%	
Yes, to some extent	277	27%	
No	229	22%	

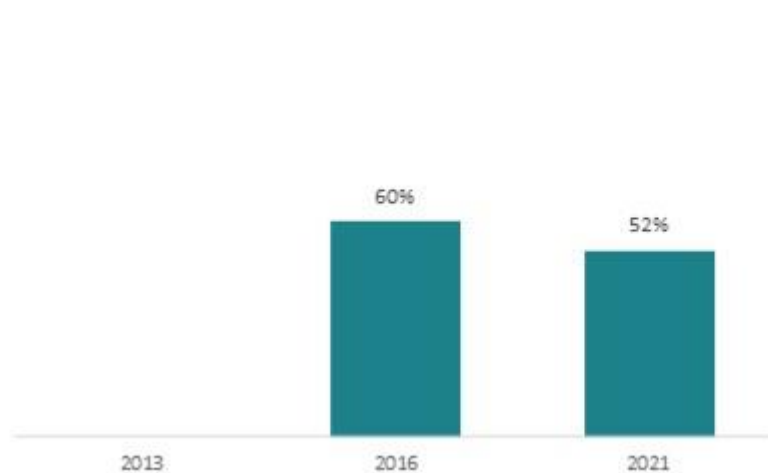
Results above based on 1,045 responses. Those answering, "I did not need help" (666), "Don't know / can't remember" (12) excluded from base size/percentage calculation. 1,723 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-8%
Change 2016-2021

Directly comparable

8.11 Care from your General Practice

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

Responses for Velindre

Yes, definitely	373	31%	
Yes, to some extent	320	27%	
No	498	42%	

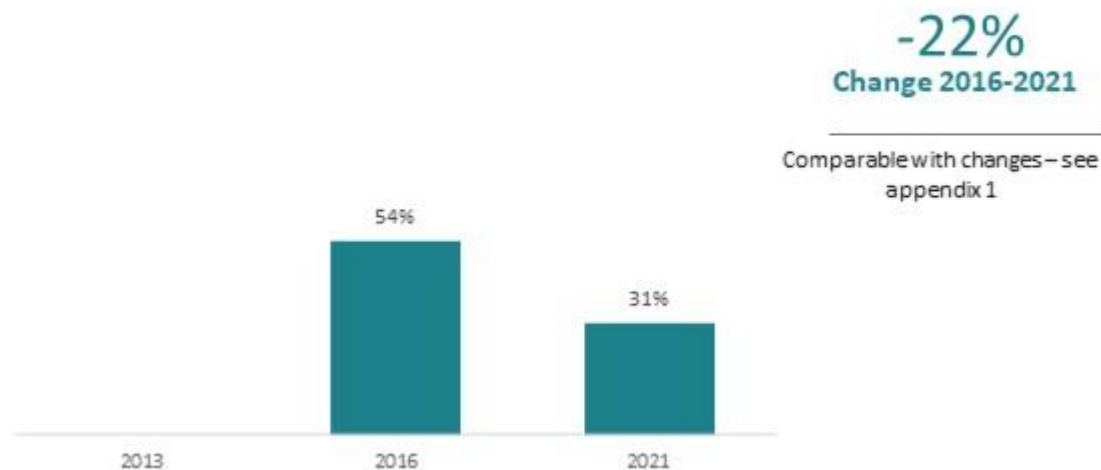
Results above based on 1,191 responses. Those answering, "I did not need help" (527), "Don't know / can't remember" (14) excluded from base size/percentage calculation. 1,732 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



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

Responses for Velindre

Yes	878	86%	
No	142	14%	

Results above based on 1,020 responses. Those answering, "Don't know / can't remember" (718) excluded from base size/percentage calculation. 1,738 responses in total.

Velindre Question Level Score



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

8.12 Your overall NHS care

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

Responses for Velindre

Yes	413	25%	
No	1,251	75%	

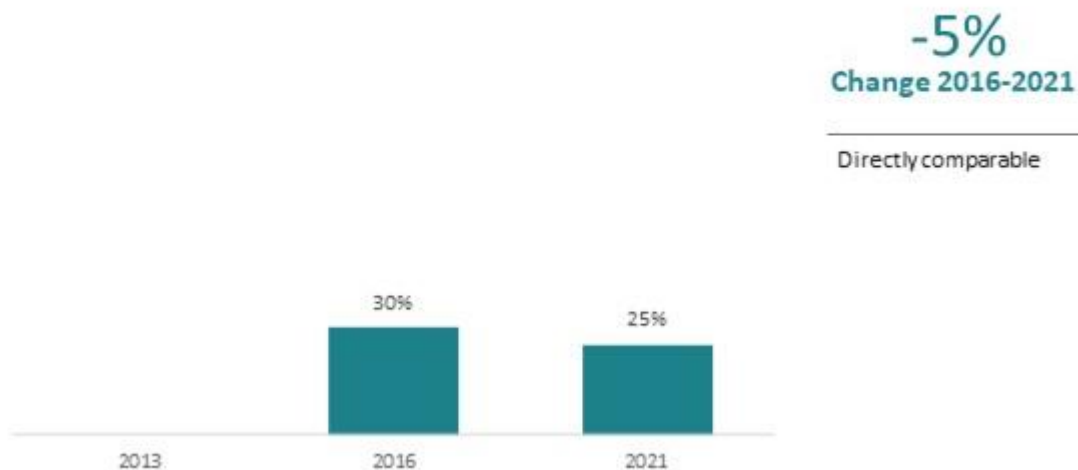
Results above based on 1,664 responses. Those answering, "Don't know / can't remember" (103) excluded from base size/percentage calculation. 1,767 responses in total.

Velindre Question Level Score







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

Scores Over Time – Velindre



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

Responses for Velindre

Yes, always	1,106	65%	
Yes, most of the time	393	23%	
Yes, some of the time	167	10%	
No, never	42	2%	

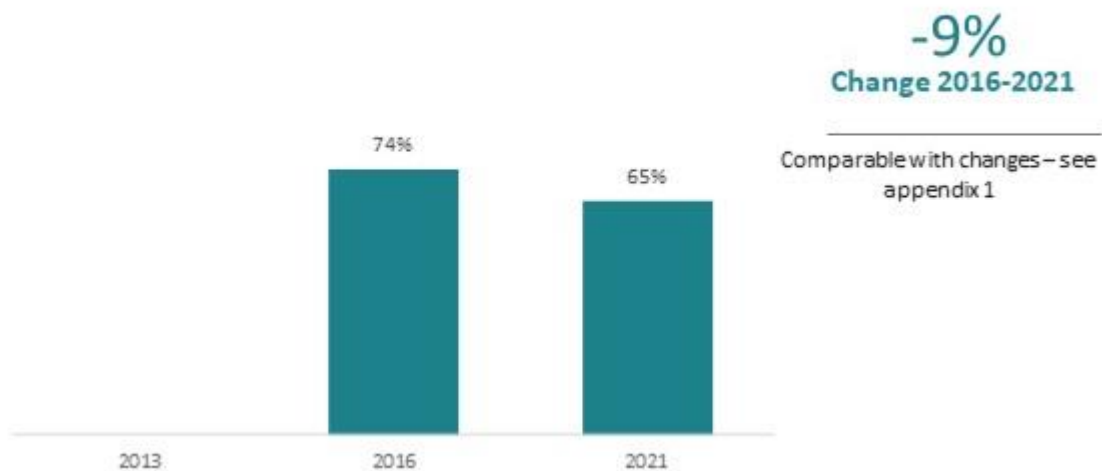
Results above based on 1,708 responses. Those answering, "Don't know / can't remember" (52) excluded from base size/percentage calculation. 1,760 responses in total.

Velindre Question Level Score








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

Scores Over Time – Velindre



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

Responses for Velindre

Very good	1,086	62%	
Good	475	27%	
Neither good nor bad	140	8%	
Quite bad	39	2%	
Very bad	12	1%	

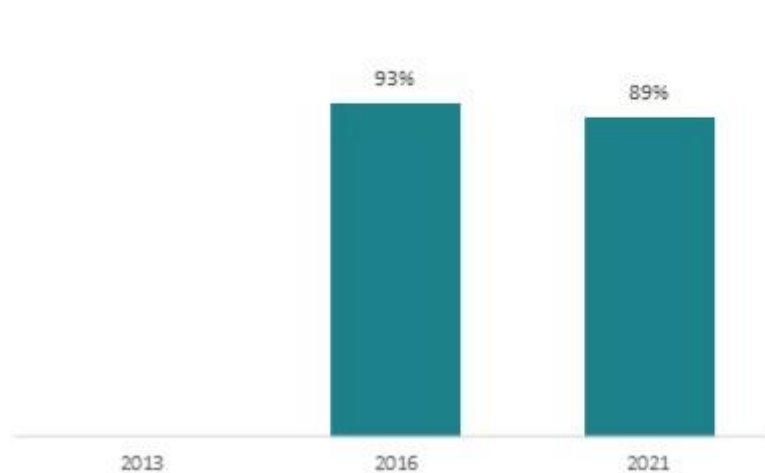
Results above based on 1,752 responses. Those answering, "Don't know / can't remember" (15) excluded from base size/percentage calculation. 1,767 responses in total.

Velindre Question Level Score



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

Scores Over Time – Velindre



-4%
Change 2016-2021

Directly comparable

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

Responses for Velindre

Yes, completely	57	24%	
Yes, to some extent	29	12%	
No	153	64%	

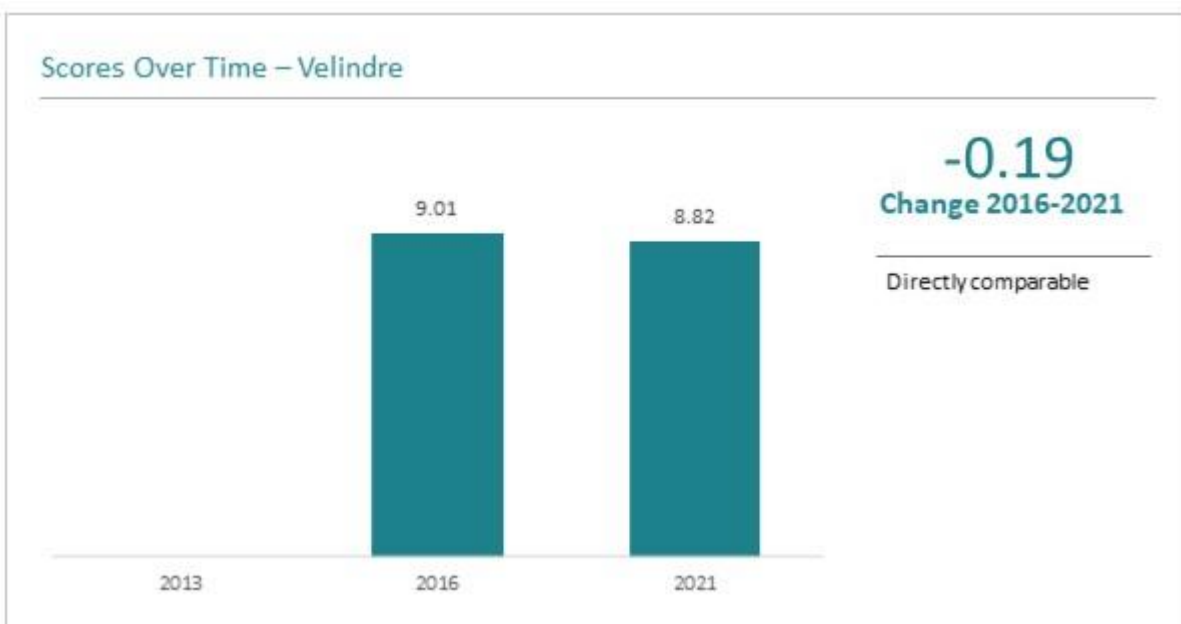
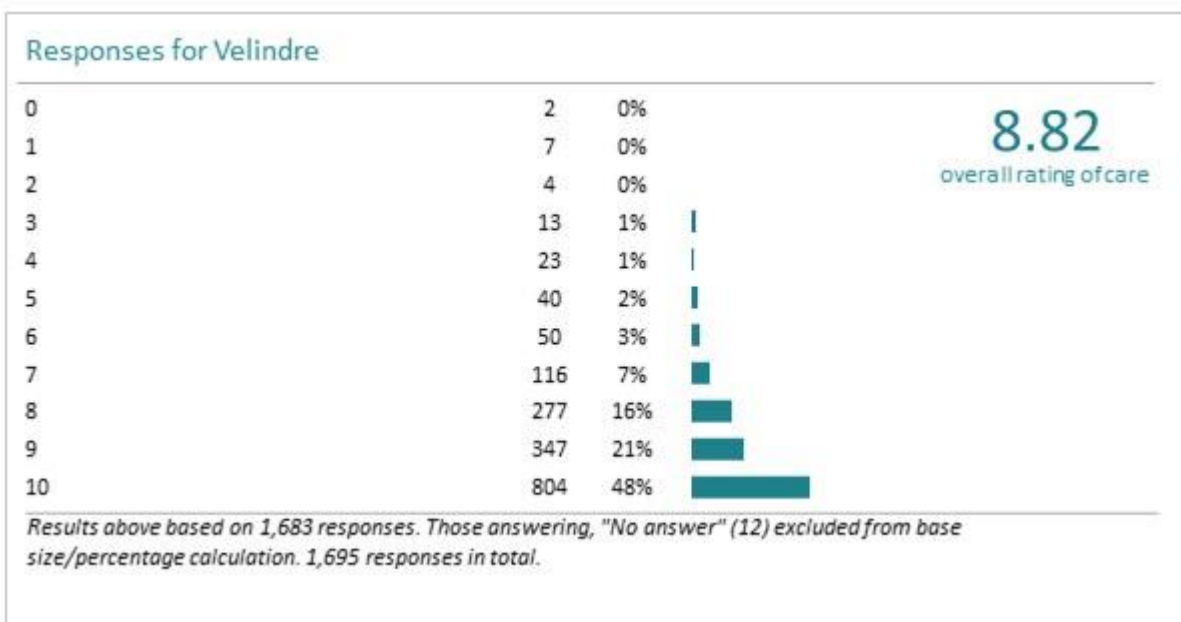
Results above based on 239 responses. Those answering, "Don't know / can't remember" (30), "Not applicable to me" (1477) excluded from base size/percentage calculation. 1,746 responses in total.

Velindre Question Level Score



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

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



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

Appendix 1

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

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

Appendix 2

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

Secondary

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

Any other

- C00 Malignant neoplasm of lip
- C05 Malignant neoplasm of palate
- C11 Malignant neoplasm of oropharynx
- C12 Malignant neoplasm of pyriform sinus
- C13 Malignant neoplasm of hypopharynx
- C14 Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx
- C24 Malignant neoplasm of other and unspecified parts of biliary tract
- C26 Malignant neoplasm of other and ill-defined digestive organs
- C30 Malignant neoplasm of nasal cavity and middle ear
- C31 Malignant neoplasm of accessory sinuses
- C37 Malignant neoplasm of thymus
- C38 Malignant neoplasm of heart, mediastinum and pleura
- C39 Malignant neoplasm of other and ill-defined sites in the respiratory system and intrathoracic organs

- C47 Malignant neoplasm of peripheral nerves and autonomic nervous system
- C57 Malignant neoplasm of other and unspecified female genital organs
- C58 Malignant neoplasm of placenta
- C63 Malignant neoplasm of other and unspecified male genital organs
- C68 Malignant neoplasm of other and unspecified urinary organs
- C69 Malignant neoplasm of eye and adnexa
- C70 Malignant neoplasm of meninges
- C72 Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system
- C74 Malignant neoplasm of adrenal gland
- C75 Malignant neoplasm of other endocrine glands and related structures
- C76 Malignant neoplasm of other and ill-defined sites
- C80 Malignant neoplasm, without specification of site
- C86 Other specified types of T/NK-cell lymphoma
- C88 Malignant immunoproliferative diseases
- C96 Other and unspecified malignant neoplasms of lymphoid, haematopoietic and related tissue
- C97 Malignant neoplasms of independent (primary) multiple sites

Acknowledgments

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

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