



Scottish Cancer Patient Experience Survey 2018

National Results

Health and Social Care Analysis Division

April 2019



Contents

1. Executive Summary	1
Getting Diagnosed.....	1
Deciding the Best Treatment	1
Operations, Radiotherapy and Chemotherapy	1
Hospital Care.....	2
Support.....	2
Overall Experience	2
2. Introduction and Background	3
Scottish Care Experience Survey Programme	3
Aims of the Survey	3
Survey Methods.....	4
3. Context.....	5
The 2020 Vision.....	5
Recent Changes to Cancer Care Policy	6
4. Demographic & Health Information from Survey Respondents	7
Age and Gender	7
Sexual Orientation.....	8
Ethnicity	8
Work Status	8
Long-term Conditions	8
Deprivation and Rurality	9
Tumour Group	11
5. Getting Diagnosed	12
Summary	12
Initial Contact with Healthcare Professionals.....	12
Diagnostic Tests	13
Finding Out About Your Cancer.....	14
6. Deciding on the Best Treatment	15
Summary	15

Treatment Options.....	15
Side Effects	16
7. Operations, Radiotherapy and Chemotherapy.....	17
Summary	17
Operations.....	17
Radiotherapy & Chemotherapy	18
8. Hospital Care.....	19
Summary	19
Experience in Hospital.....	19
Person-centred Care	20
9. Support	21
Summary	21
Clinical Nurse Specialist.....	21
Support from Health & Social Services.....	22
Information on Additional Support	24
Support from Third Sector Organisations	25
10. Overall Experience.....	27
Summary	27
Travelling to Appointments	27
Coordination of Care	29
Overall Experience	30

1. Executive Summary

Around 5,000 individuals who had received cancer care in Scotland responded to the 2018 Scottish Cancer Patient Experience Survey. The main results are:

Getting Diagnosed

- Over four in five people (83 per cent) thought their **first appointment** with a hospital doctor was **as soon as necessary**.
- People were positive about their **first diagnostic test** – 86 per cent felt they had all the information they needed beforehand, and 76 per cent felt the results were completely explained in a way they could understand.
- Thinking about when they were told they had cancer, respondents were slightly more positive than in 2015 about **being told they could bring a family member or friend** with them and **being given written information that was easy to understand** (76 and 63 per cent respectively).
- Respondents were slightly less positive than in 2015 about **understanding the explanation of what was wrong with them** (73 per cent).
- Most people felt they were **told they had cancer in a sensitive way** (86 per cent) which is consistent with results from 2015.

Deciding the Best Treatment

- Most people (87 per cent) felt their **treatment options** were completely **explained before their treatment started**.
- Around four in five people were positive about being **involved in discussions about the right treatment options** and in **decisions about their care** (80 and 79 per cent respectively).
- People were broadly positive about possible immediate side effects being **explained in a way they could understand** and being **offered practical advice and support** on dealing with them (72 and 66 per cent respectively). They were less positive about **potential future side effects**, with 56 per cent reporting they were definitely told about these.

Operations, Radiotherapy and Chemotherapy

- Respondents who **had an operation** were positive about the **information they were given** – 92 per cent reported they received all the information they needed beforehand, 82 per cent received an explanation of how it had gone that they could understand, and 80 per cent were given clear written information on what they should or should not do afterwards.
- Respondents who had **radiotherapy or chemotherapy** were positive about having **all the information they needed** before treatment (77 and 74 per cent respectively). However, responses to both of these questions were both slightly less positive than in 2015.

Hospital Care

- Respondents were very positive about their experiences of hospital care – 93 per cent were always **called by their preferred name**; 91 per cent were always **given enough privacy** during discussions; and 95 per cent were **told who to contact** if they were worried after they left hospital.
- People were also very positive about their experiences of **person-centred care** whilst in hospital. They were most positive about being listened to and having their condition and treatment discussed with them in a way they could understand, with both statements rated positively by 94 per cent of people.

Support

- Most people were given the name of a Clinical Nurse Specialist (86 per cent). Of those people, 89 per cent found it **easy to contact** them and **got answers they could understand** from them when they had important questions.
- There has been an increase since 2015 in those reporting they definitely **received enough care and support from health or social services** during and after their treatment (60 and 50 per cent respectively).
- Just over half of respondents (55 per cent) felt they had been completely **supported emotionally / psychologically** by healthcare professionals during their cancer treatment.
- Most people received information on the **impact cancer could have** on their day-to-day activities and on **support or self-help groups** (77 and 81 per cent respectively). People were less positive about receiving information on **financial help / benefits** and someone close being given **information to help care for them at home** (60 and 52 per cent respectively).
- During treatment, 54 per cent of people who needed or wanted it received **useful information or support** from the **third sector**. After treatment, this dropped to 46 per cent of people.

Overall Experience

- The vast majority of people (95 per cent) rated their **overall experience** of cancer care positively, supported by 97 per cent reporting they were always treated with **dignity and respect** by healthcare professionals treating them.
- Around seven in ten people (69 per cent) found it **easy to travel to their cancer care appointments** and just over half of respondents (53 per cent) experienced no difficulties with their travel. The most common **difficulties experienced** were length of travel time and cost of travel / parking (experienced by 25 and 18 per cent of people respectively).
- Most people (92 per cent) reported they were **able to bring someone to their appointments** when they wanted to all or most of the time.
- Three in ten people (30 per cent) were given a **care plan** and half of people (51 per cent) were given a **written note of all the treatments** they received.

2. Introduction and Background

The Scottish Cancer Patient Experience Survey (SCPES) is a national postal survey jointly funded by the Scottish Government and Macmillan Cancer Support. It is run in partnership with Information Services Division (ISD), part of NHS National Services Scotland. The survey asks people about their experiences of cancer care, from thinking that something might be wrong with them to the support they received after diagnosis and treatment.

The focus of this report is on the national results of the survey. This is the second iteration of this survey, with the first run in 2015. Comparisons have been made with the 2015 survey results where this is possible.

Results at Regional Cancer Network, NHS Board and Cancer Centre level are available via an online dashboard at: www.gov.scot/CancerSurvey.

Scottish Care Experience Survey Programme

The Scottish Cancer Patient Experience Survey is one of a suite of national surveys which are part of the Scottish Care Experience Survey Programme. The surveys aim to provide local and national information on the quality of health and care services from the perspective of those using them. They allow local health and care providers to compare with other areas of Scotland and to track progress in improving the experiences of people using their services.

Information about the other national care experience surveys is available at www.gov.scot/Topics/Statistics/Browse/Health/careexperience.

The survey programme supports the three quality ambitions of the *2020 Vision*¹ – Safe, Effective, Person-centred – by providing a basis for the measurement of quality as experienced by service users across Scotland. In particular the surveys support the person-centred quality ambition which is focused on ensuring that care is responsive to people’s individual preferences, needs and values. More information about the context for this survey is provided in Chapter 3 of this report.

Aims of the Survey

The survey’s specific objectives were:

For local improvement

- provide Cancer Centres with feedback on the experiences of their patients, relative to previous surveys and other areas in Scotland;
- provide NHS Boards with information on experience in their respective board areas and on variation within and between boards;
- provide Regional Cancer Networks with information on experience in their respective network areas and on variation within and between networks.

¹ www.gov.scot/Topics/Health/Policy/2020-Vision

National results

- providing national results for the survey, identifying variation within and between local areas and if and how the level of positive and negative experiences have changed over time;
- highlight areas of best practice and areas for improvement;
- explore the variations in the experiences of different groups of patients.

Survey Methods

The survey was designed to provide results for each of the five main Cancer Centres, as well as information for use by NHS Boards and Regional Cancer Networks.

Individuals aged 16 or over, who had an inpatient hospital record with a mention of cancer between 1 January and 30 September 2017, **and** a confirmed cancer diagnosis date between 1 July 2016 and 31 March 2017 on the Scottish Cancer Registry were sampled for the survey. A full list of exclusions from the sample is provided in the survey's Technical Report.

In total, 8,090 surveys were sent to eligible respondents and 5,001 were returned completed, giving an **overall response rate of 62 per cent**.

Throughout this report, with the exception of the data in Chapter 4, analysis is presented as weighted percentages. Weighting the results in this way provides results which are more representative of the sample population as a whole. Weighting was introduced as part of the 2018 survey – a paper summarising the reasons for this and the weighting methodology that has been applied is available at www2.gov.scot/Resource/0054/00542173.pdf.

Results from the 2015 survey have been backdated where appropriate to ensure comparability over time. All changes over time that are discussed in the report are statistically significant at the five per cent level.

More information about the survey design, response rates and methodology can be found in the Technical Report available at: <http://www.gov.scot/ISBN/9781787817807>

3. Context

There have been wide reaching programmes of reform to health services in recent years, which are consistent with the wider principles of Public Service Reform². This chapter provides an overview of the key developments.

This survey supports and informs all of these developments, by describing their impact from a user perspective. It is worth noting that this survey includes experiences of cancer care from over a two year period, with some respondents receiving their cancer diagnosis in July 2016. This means that some experiences being reported may have taken place when some of these programmes were at the early stages of implementation.

The 2020 Vision

In 2011, the Scottish Government set out a *2020 Vision*³ for achieving sustainable quality in the delivery of healthcare services across Scotland, in the face of the significant challenges of Scotland's public health record, our changing population and the economic environment. All healthcare policy in Scotland drives the delivery of this Vision, which states:

By 2020 everyone is able to live longer, healthier lives at home or in a homely setting, and that we will have a healthcare system where:

- ❖ We have integrated health and social care;
- ❖ There is a focus on prevention, forward planning and supported self-management;
- ❖ Where hospital treatment is required, and cannot be provided in a community setting, day case treatment will be the norm;
- ❖ Whatever the setting, care will be provided to the highest standards of quality and safety, with the person at the centre of all decisions;
- ❖ There will be a focus on ensuring that people get back into their home or community environment as soon as appropriate, with minimal risk of re-admission.

² The approach to reform is guided by a commitment that public services will exhibit three key characteristics: that people can expect their services to be **person-centred, assets based** and **values driven**. For more information see

www.gov.scot/Topics/Government/PublicServiceReform/Christie

³ www.gov.scot/Topics/Health/Policy/2020-Vision

The Vision will be delivered according to three **Quality Ambitions**⁴:

- **Safe:** There will be no avoidable injury or harm to people from healthcare, and an appropriate, clean and safe environment will be provided for the delivery of healthcare services at all times.
- **Person-centred:** Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrates compassion, continuity, clear communication and shared decision-making.
- **Effective:** The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated.

A *National Clinical Strategy for Scotland*⁵, published by the Scottish Government in February 2016, reinforced the importance of these ambitions and called for a new clinical paradigm that incorporated person-centred approaches to care.

Scotland's **Chief Medical Officer** has also articulated her vision for delivering care in this context through her Annual Reports '*Realistic Medicine*'⁶, '*Realising Realistic Medicine*'⁷ and '*Practising Realistic Medicine*'⁸. She said:

“ You should expect the doctor (or other health professional) to explore and understand what matters to you personally and what your goals are, to explain to you the possible treatments or interventions available with a realistic explanation of their potential benefits and risks for you as an individual, and to discuss the option and implications of doing nothing. You should expect to be given enough information and time to make up your mind. You should consider carefully the value to you of anything that is being proposed whether it be a treatment, consultation or diagnostic investigation and be prepared to offer challenge if you feel it appropriate. ”

Recent Changes to Cancer Care Policy

The Scottish Government published *Beating Cancer: Ambition and Action*⁹, a new cancer strategy, in March 2016. It sets out the Scottish Government's ambitions on improving cancer services across Scotland.

The strategy outlines more than 50 actions to be taken forward, with actions to reduce health inequalities and to provide person-centred care being central to its delivery. It also specifically recognises that understanding individual's experiences of cancer care is vital to help make improvements in cancer care services and directly supports the continuation of the SCPES as a vital source of data on this area.

⁴ www.gov.scot/Resource/Doc/311667/0098354.pdf

⁵ www.gov.scot/publications/national-clinical-strategy-scotland/

⁶ www.gov.scot/Resource/0049/00492520.pdf

⁷ www.gov.scot/Publications/2017/02/3336

⁸ www.gov.scot/publications/practising-realistic-medicine/

⁹ <https://www.gov.scot/publications/beating-cancer-ambition-action/>

4. Demographic & Health Information from Survey Respondents

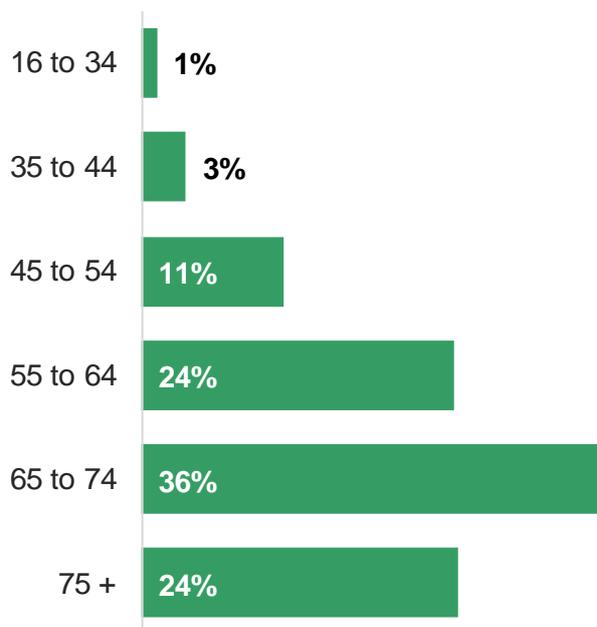
As the survey is a voluntary sample survey, it is important to consider the results in the context of the demographics of respondents. This chapter provides a summary of demographic information, either self-reported through the survey by respondents or linked to from other data sources¹⁰. Unlike the rest of the survey results in this report, this analysis is based on unweighted data.

Age and Gender

Respondents were asked what best described their gender: male, female or other. Males made up 46 per cent of respondents and females 54 per cent.

Respondent age was taken from the individual's CHI record, as advised in the survey's Privacy Notice, and was calculated as their age when the sample was drawn. Three in five respondents (60 per cent) were aged 65 or more (Figure 4.1) and only five per cent of respondents were aged under 45.

Figure 4.1: Age of respondents



Comparing these figures to those for the sample population shows that the age and gender of respondents were broadly consistent with the survey's sample population.

¹⁰ Survey respondents were advised that their responses would be linked to additional demographic information via the survey's Privacy Notice, available at www.gov.scot/CancerSurveyPrivacyNotice

Sexual Orientation

The vast majority of respondents (96 per cent) described themselves as heterosexual or straight. Three per cent described themselves as gay or lesbian, and less than one per cent of respondents described themselves as bisexual or other.

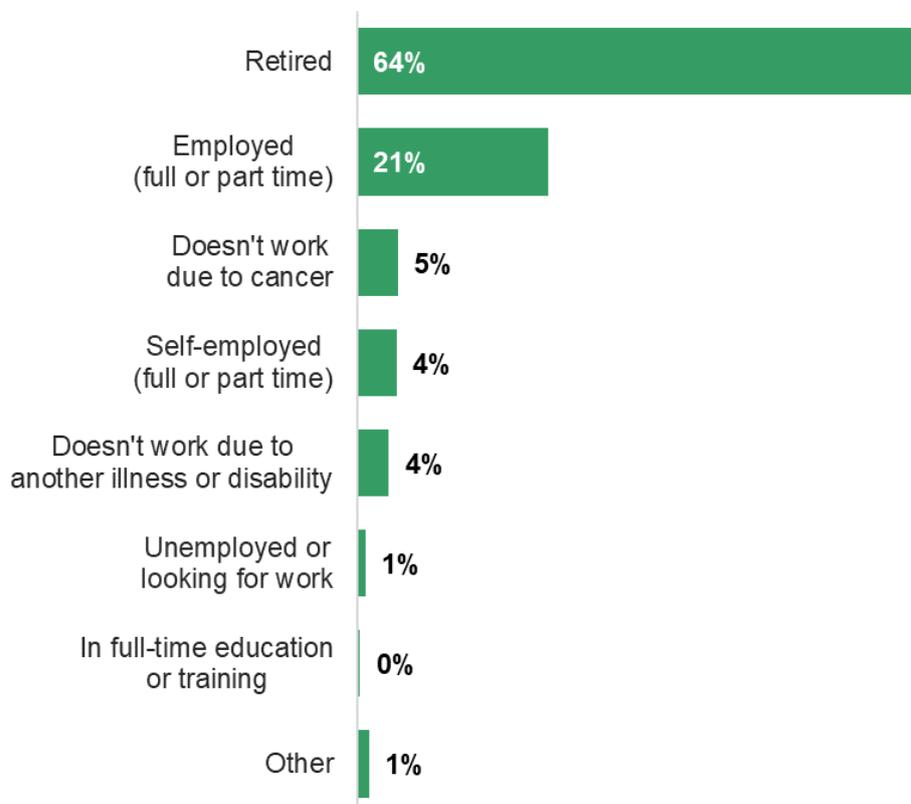
Ethnicity

Almost all respondents (99 per cent) described their ethnic group as white.

Work Status

Almost two in three respondents (64 per cent) were retired and around one in four were in full or part time employment (21 per cent employed; 4 per cent self-employed) (Figure 4.2).

Figure 4.2: Work status of respondents



Long-term Conditions

Just under half of respondents (47 per cent) said that they had one or more long-term health conditions. Of the conditions listed, the most commonly reported were chronic pain lasting at least three months and deafness or a severe hearing impairment, which were both reported by 15 per cent of respondents (Table 1). Just over two in five respondents (22 per cent) reported that they had a long term condition not listed.

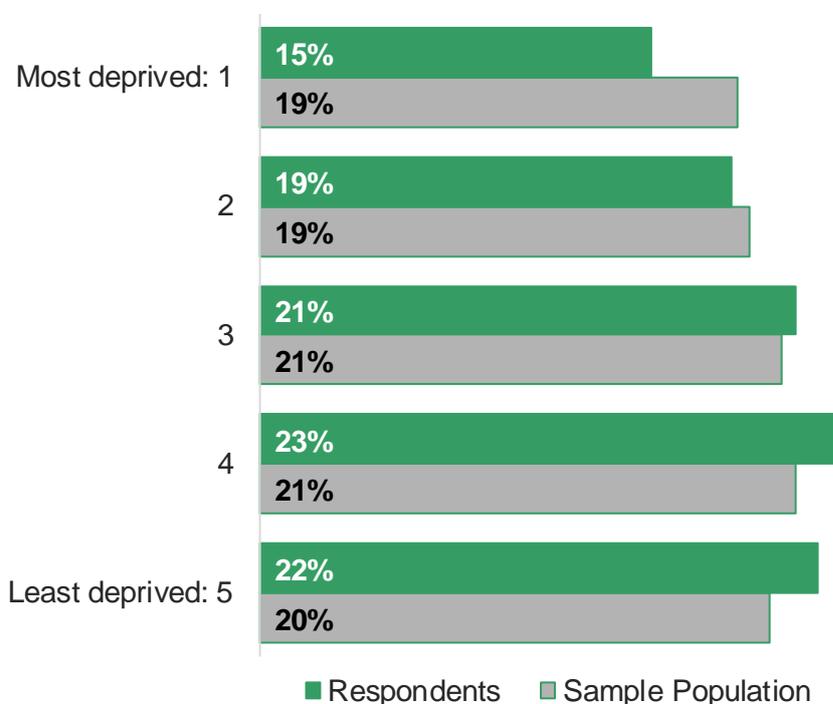
Table 4.1: Long-term health conditions¹¹

	%
Deafness or severe hearing impairment	15
Chronic pain lasting at least 3 months	15
A physical disability	10
A mental health condition	5
Blindness or severe vision impairment	3
A learning disability	0
Another long-term condition	22
None of the above	53

Deprivation and Rurality

Analysis of the Scottish Index of Multiple Deprivation (SIMD)¹² and Urban/Rural Indicator¹³ was based on the datazone of the respondents home address at the time of their cancer treatment. Respondents were broadly representative of the sample population, although the most deprived quintile had a slightly lower proportion of respondents, and the two least deprived quintiles had slightly higher proportions of respondents (Figure 4.3).

Figure 4.3: SIMD Quintile of respondents against sample population



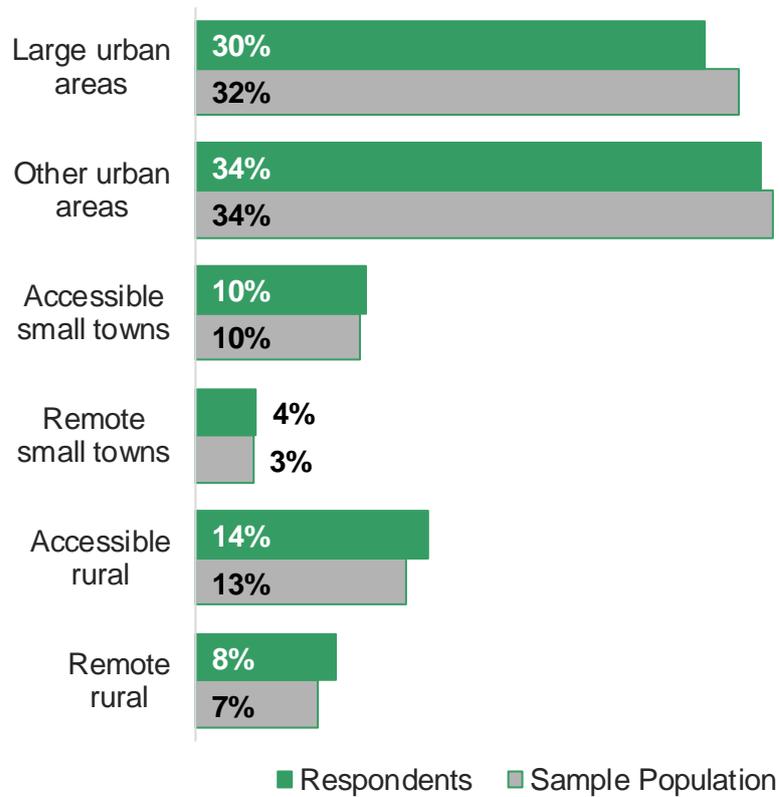
¹¹ Respondents were asked to tick all that applied and so results **cannot** be summed.

¹² www.gov.scot/Topics/Statistics/SIMD

¹³ www.gov.scot/Topics/Statistics/About/Methodology/UrbanRuralClassification

The distribution of respondents by rurality is broadly in line with that for the sample population as a whole (Figure 4.4).

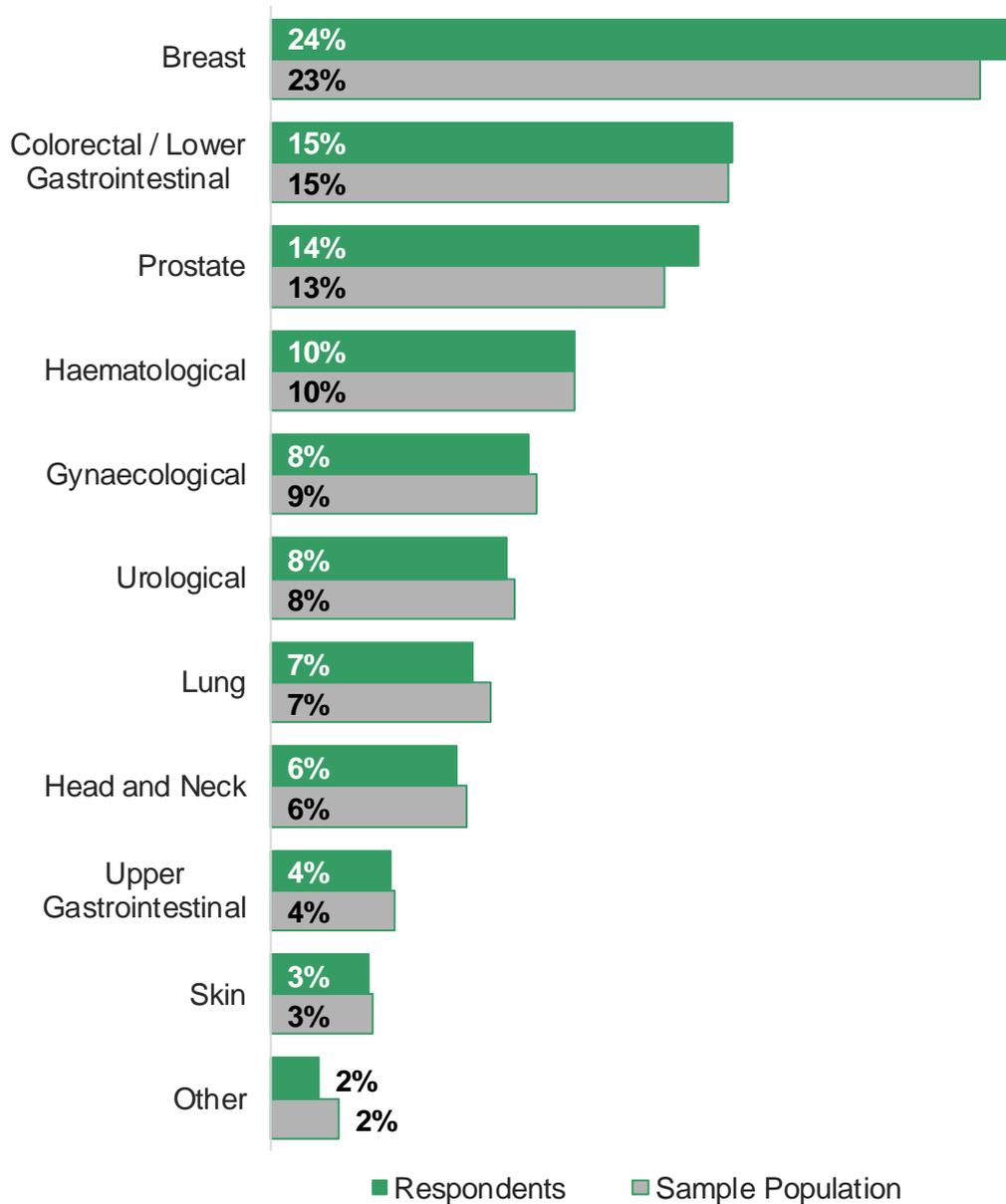
Figure 4.4: Urban-Rural category of respondents against sample population



Tumour Group

Respondent tumour group was taken from the individual's Scottish Cancer Registry record, as advised in the survey's Privacy Notice. Looking at respondents by tumour group, they are in line with those of the sample population (Figure 4.5).

Figure 4.5: Tumour group of respondents against sample population



Note: The 'Other' category includes all tumour groups with less than 50 respondents and respondents for whom a tumour group is not known.

5. Getting Diagnosed

Summary

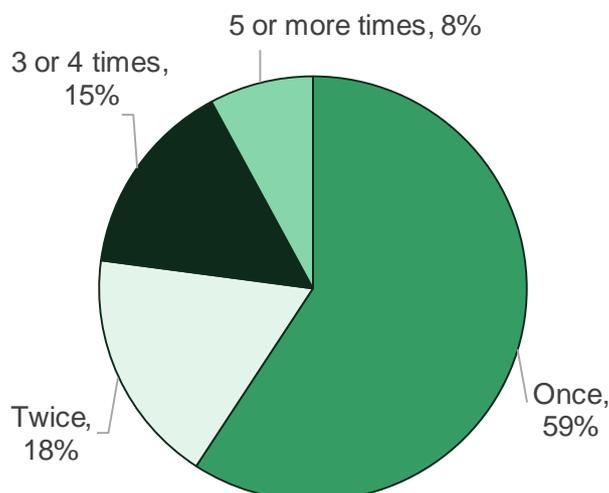
- Over four in five people (83 per cent) thought their **first appointment** with a hospital doctor was **as soon as necessary**.
- People were positive about their **first diagnostic test** – 86 per cent felt they had all the information they needed beforehand, and 76 per cent felt the results were completely explained in a way they could understand.
- Thinking about when they were told they had cancer, respondents were slightly more positive than in 2015 about **being told they could bring a family member or friend** with them and **being given written information that was easy to understand** (76 and 63 per cent respectively).
- Respondents were slightly less positive than in 2015 about **understanding the explanation of what was wrong with them** (73 per cent).
- Most people felt they were **told they had cancer in a sensitive way** (86 per cent) which is consistent with results from 2015.

Initial Contact with Healthcare Professionals

The survey started by asking individuals how many times they saw a healthcare professional at their GP Practice about the health problem caused by cancer before they were told they needed to go to hospital. Early diagnosis is a critical issue in Scotland, and is widely recognised as significant in improving peoples' chances of surviving cancer.

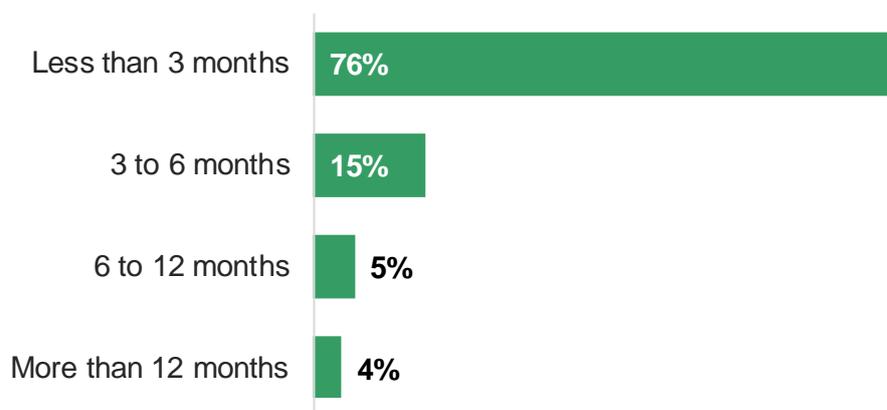
Just under a quarter of people (23 per cent) reported that they did not see anyone at their GP Practice before they went to hospital about their cancer. Of those who did see someone at their GP Practice, just over three in four (77 per cent) only saw a healthcare professional once or twice (Figure 5.1).

Figure 5.1: Number of times respondents saw a healthcare professional at their GP Practice before going to hospital



Around three in four people (76 per cent) reported that it was less than three months between them thinking that something might be wrong and first contacting a healthcare professional at their GP Practice (Figure 5.2). Only four per cent waited more than 12 months.

Figure 5.2: Length of wait between thinking something might be wrong and contacting a healthcare professional at GP Practice



When asked how they felt about the length of time they had to wait before their first appointment with a hospital doctor, over four in five people (83 per cent) responded that they were seen as soon as they thought was necessary. Eleven per cent of people felt they should have been seen **a bit** sooner and six per cent of people thought they should have been seen **a lot** sooner. This is consistent with results from the 2015 survey.

Diagnostic Tests

Respondents were asked to think about the **first time** they had a diagnostic test for cancer, such as an endoscopy, biopsy, mammogram or scan. This differs to the 2015 survey, where respondents were asked similar questions about the **last time** they had a diagnostic test and so these questions are not comparable over time.

Diagnostic tests can involve taking in a large amount of complicated information and can be an unsettling time for individuals. It is therefore important to understand the quality of information and explanations provided at this time.

Most people (86 per cent) felt that, knowing what they know now, they had all the information they needed about their test beforehand. Looking in more detail at those who did not feel they had all the information they needed, three per cent would have liked more **written** information; six per cent would have liked more **verbal** information; and four per cent would have like more **written and verbal** information.

Around three in four people (76 per cent) reported that the results of their first diagnostic test were 'completely' explained in a way they could understand. A further one in five (21 per cent) reported the results were explained in a way they could understand 'to some extent'. Only three per cent of people did not understand the explanation they received or did not have one but would have liked it.

Finding Out About Your Cancer

Finding out you have cancer can be daunting. The way that someone is told about their diagnosis and the option to have family or friends there for support are therefore vital aspects of this part of the cancer journey.

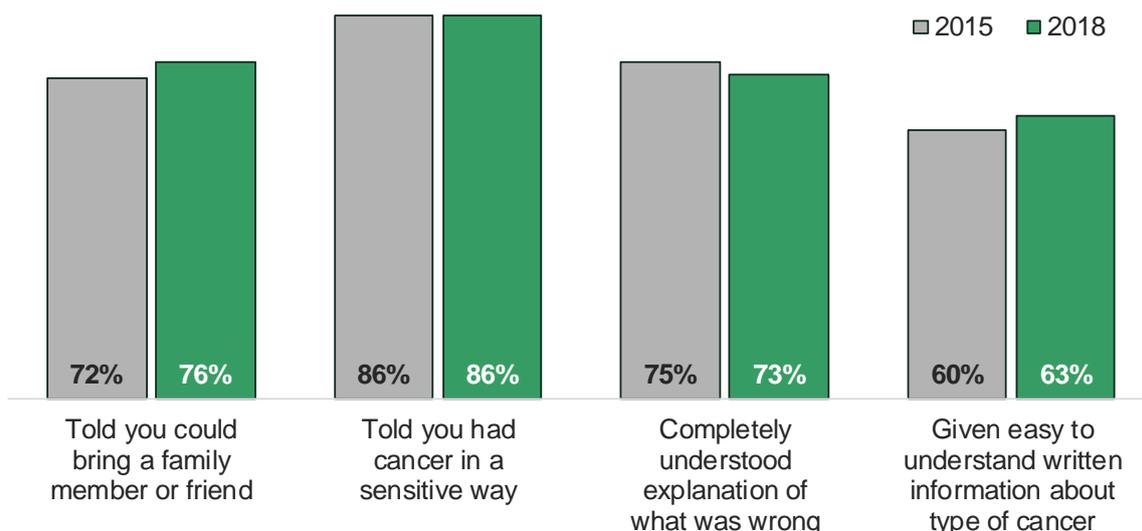
When they were first told that they had cancer, around three in four people (76 per cent) had been told they could bring a family member or friend with them. This is an increase from 72 per cent of people in 2015.

Most people (86 per cent) felt they were told they had cancer in a sensitive way which is consistent with results from the 2015 survey. Nine per cent of people felt the way they were told should have been done **a bit more** sensitively; and five per cent of people felt it should have been done **a lot more** sensitively.

Just under three in four people (73 per cent) reported that they completely understood the explanation of what was wrong with them, a decrease from 75 per cent in 2015. One in four people (25 per cent) said that they understood some of the explanation and only two per cent of people reported that they did not understand it.

The survey asked whether respondents had been given written information about the type of cancer they had when they were told they had cancer. Just over three in five people (63 per cent) reported they had and that the information had been easy to understand. This is an increase from 60 per cent in 2015. A further seven per cent of people responded that they had received written information but it was difficult to understand. Three in ten people (30 per cent) were not given any written information about the type of cancer they had.

Figure 5.3: Changes between 2015 and 2018 on % positive responses to questions on finding out about cancer



6. Deciding on the Best Treatment

Summary

- Most people (87 per cent) felt their **treatment options** were completely **explained before their treatment started**.
- Around four in five people were positive about being **involved in discussions about the right treatment options** and in **decisions about their care** (80 and 79 per cent respectively).
- People were broadly positive about advice on possible immediate side effects, with 72 per cent reporting they were **explained in a way they could understand** and 66 per cent being **offered practical advice and support**.
- Respondents were less positive about **potential future side effects**, with 56 per cent reporting they were definitely told about these.

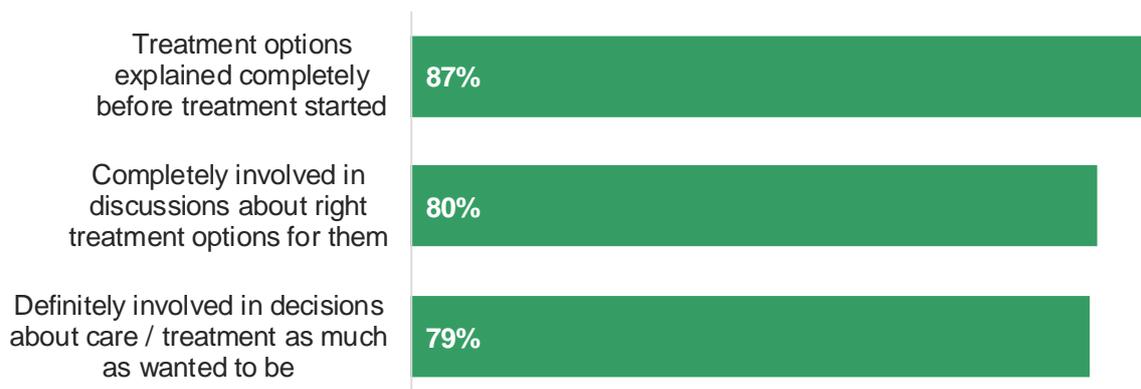
Treatment Options

It is important that individuals feel fully informed to be able to make the decisions about which treatment, if any, they want to undergo. Most people (87 per cent) reported that their **treatment options** were ‘completely’ **explained before their treatment started**. This is consistent with results from 2015. Eleven per cent of people felt that their treatment options were explained ‘to some extent’ and three per cent reported they were not explained.

The survey also asked respondents whether they were involved in discussions with healthcare professionals about the **right treatment options for them**, which may have included the option of not treating their cancer. Four in five people (80 per cent) reported that they were ‘completely’ involved in these discussions. Sixteen per cent felt that they were involved to some extent and four per cent reported that they were not involved but would have liked to discuss this.

Almost four-fifths of people (79 per cent) felt that they were ‘definitely’ involved in **decisions about their care and treatment** as much as they wanted to be which is consistent with 2015 figures. Seventeen per cent were involved to some extent and four per cent reported that they were not but would have like to be more involved.

Figure 6.1: Proportion of positive responses to questions on treatment options



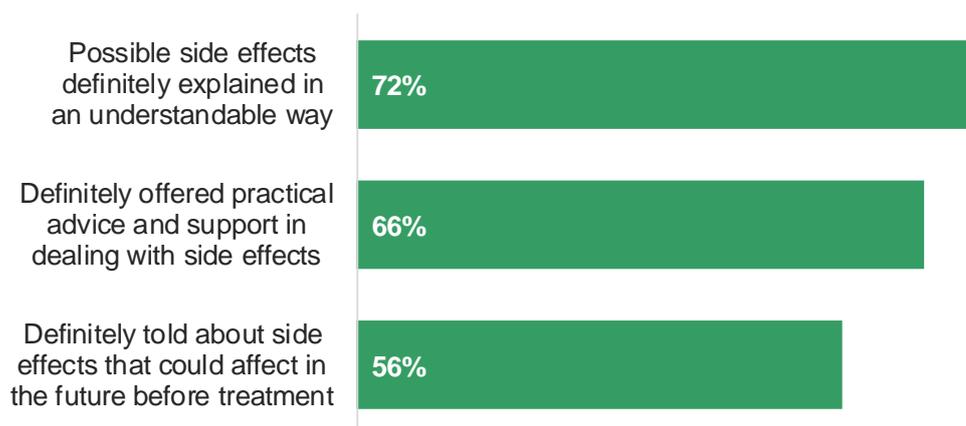
Side Effects

Just over seven in ten people (72 per cent) felt that the possible side effects of their treatment(s) were definitely **explained in a way they could understand**. This is in line with results from 2015. Almost one in four people (23 per cent) reported that they were explained in an understandable way to some extent. Four per cent of people did not receive an explanation but would have liked one.

Two thirds of people (66 per cent) were **offered practical advice and support** in dealing with the side effects of their treatment(s) which is consistent with results from 2015. Around a quarter (26 per cent) were offered advice to some extent and eight per cent of people were not offered any practical advice or support.

As more people continue to live with cancer, understanding side effects of treatment which may affect them in the future, as well as immediately, becomes increasingly important. Slightly more than half of respondents (56 per cent) were told about any side effects of the treatment that could affect them in the future, rather than straight away, **before** they started their treatment. This was an increase from 54 per cent in 2015. Almost one third of people (31 per cent) reported that they were told to some extent and 13 per cent were not told but would have liked an explanation.

Figure 6.2: Proportion of positive responses to questions on side effects



7. Operations, Radiotherapy and Chemotherapy

Summary

- Respondents who **had an operation** were positive about the **information they were given** – 92 per cent reported they received all the information they needed beforehand, 82 per cent received an explanation of how it had gone that they could understand, and 80 per cent were given clear written information on what they should or should not do afterwards.
- Respondents who had **radiotherapy or chemotherapy** were positive about having **all the information they needed** before treatment (77 and 74 per cent respectively). However, responses to both of these questions were both slightly less positive than in 2015.

Operations

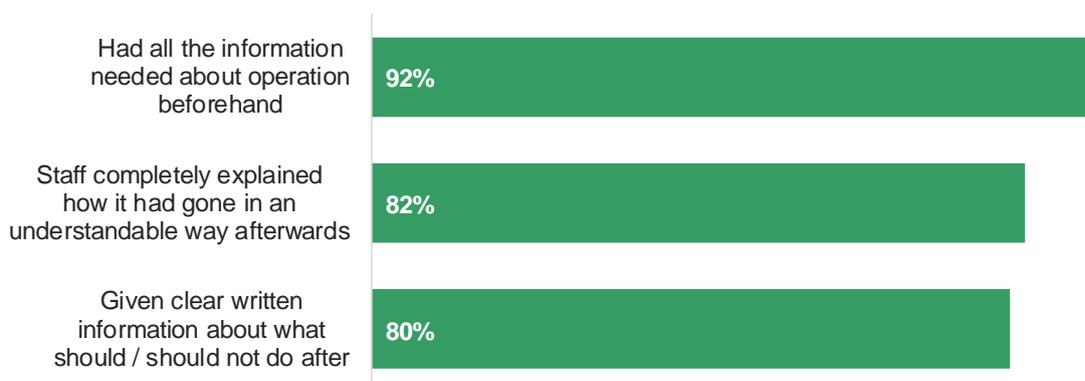
Around three in four people (74 per cent) had an operation for their cancer, such as removal of a tumour or lump. These respondents were then asked to complete a number of questions about the **last** time they had an operation for their cancer.

Most people (92 per cent) responded that, knowing what they know now, they had all the **information they needed about their operation beforehand**. This is consistent with results from 2015. Looking in more detail at the eight per cent who would have liked more information, they were evenly split between wanting more written information, more verbal information and more written and verbal information.

Just over four-fifths of people (82 per cent) felt that a member of staff **explained how the operation had gone** afterward in a way they could completely understand. This is an increase from 80 per cent in 2015. Fifteen per cent felt this was explained in a way they could understand to some extent and three per cent did not receive an explanation but would have liked one.

Four in five people (80 per cent) were given clear written information about what they should or should not do after their operation.

Figure 7.1: Proportion of positive responses to questions on operations



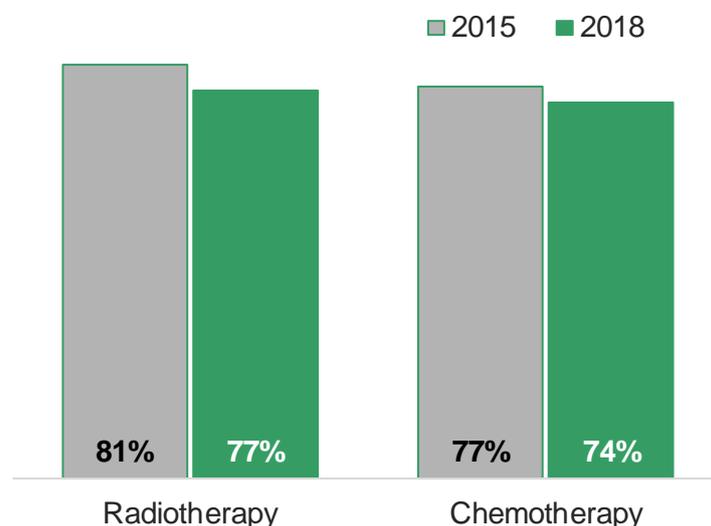
Radiotherapy & Chemotherapy

Going through chemotherapy and / or radiotherapy can be a very difficult experience. To help them prepare, individuals should be offered all the information they need beforehand, such as information on possible side effects that may occur, both during the course of the treatment and in the future. Clarity of communication is crucial given the many types of chemotherapy drugs and types of radiotherapy available, and the rate at which new drugs and techniques emerge.

Just under half of respondents (47 per cent) had received **radiotherapy treatment**. Of these respondents, just over three-quarters (77 per cent) reported that, knowing what they know now, they had all the **information they needed about their radiotherapy treatment beforehand**. This is a decrease from 81 per cent in 2015. Almost one-fifth of people (19 per cent) felt that they had some of the information they needed, and four per cent reported that they did not have all the information they needed beforehand.

Similarly, just under half of respondents (47 per cent) had received **chemotherapy treatment**. Of those who had chemotherapy, around three in four (74 per cent) felt that, knowing what they know now, they had all the **information they needed about their chemotherapy treatment beforehand**. This is a decrease from 77 per cent in 2015. Just over one in five people (22 per cent) had some of the information they needed and four per cent reported that they did not have all the information they needed beforehand.

Figure 7.2: Proportion of respondents receiving treatment type who had all the information they needed about their treatment beforehand



8. Hospital Care

Summary

- Respondents were very positive about their experiences of hospital care – 93 per cent were always **called by their preferred name**, 91 per cent were always **given enough privacy** during discussions, and 95 per cent were **told who to contact** if they were worried after they left hospital.
- People were also very positive about their experiences of **person-centred care** whilst in hospital. They were most positive about being listened to and having their condition and treatment discussed with them in a way they could understand, with both statements rated positively by 94 per cent of people.

Experience in Hospital

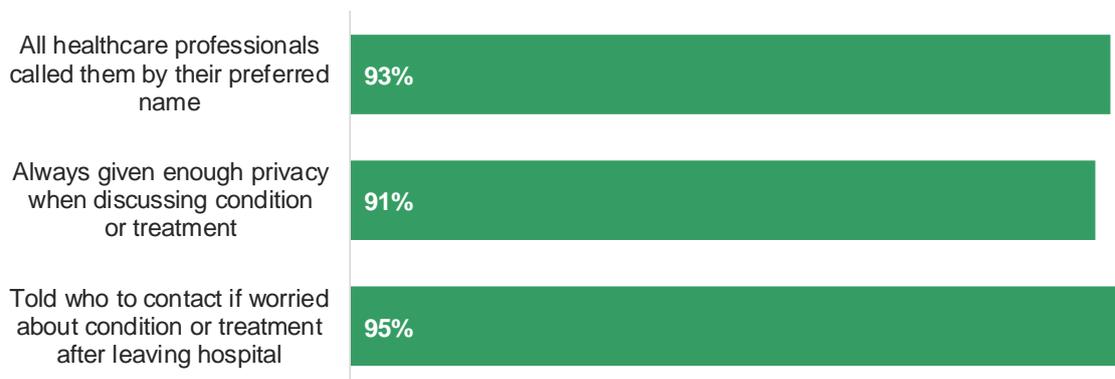
All respondents would have experienced care in hospital as part of their cancer journey and receiving good quality care whilst in hospital can help cancer patients to feel that they are viewed as more than their cancer diagnosis. Respondents were asked about their experience the **last** time that they received hospital treatment for their cancer. This may have been as an inpatient or an outpatient / day case. In the 2015 survey, respondents were asked similar questions but specifically about their inpatient care and so these questions are not comparable to 2015.

Most people (93 per cent) reported that all healthcare professionals caring for them **called them by their preferred name**. Six per cent of people reported that only some healthcare professionals called them by their preferred name, and one per cent said that none of them did.

Around nine in ten people (91 per cent) were always **given enough privacy when discussing their condition or treatment**. Eight per cent were sometimes given enough privacy and one per cent reported that they were not given enough privacy when discussing their condition or treatment.

The vast majority of respondents (95 per cent) were told by a healthcare professional **who to contact if they were worried** about their condition or treatment after they left hospital.

Figure 8.1: Proportion of positive responses to questions on hospital care



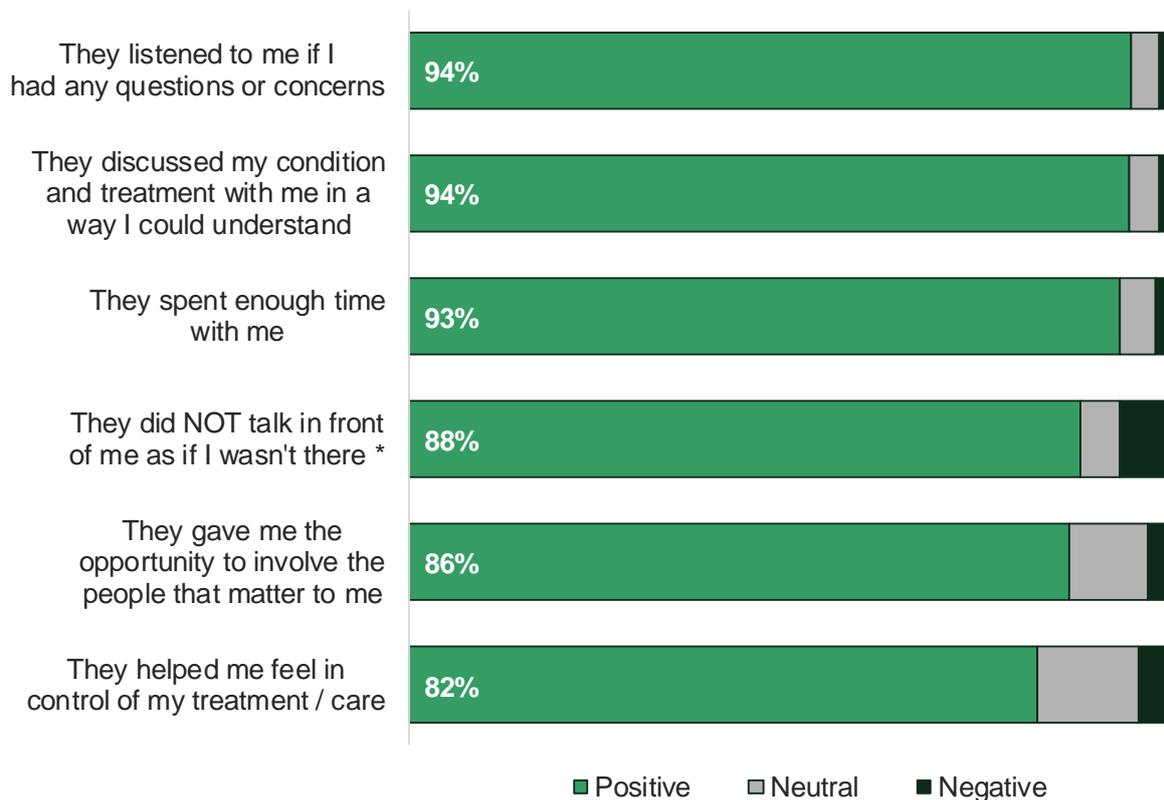
Person-centred Care

The survey asked individuals whether they agreed or disagreed with six statements relating to person-centred behaviours they experienced during their hospital care. As shown in Figure 8.2, respondents were positive about their experience of person-centred care, with all statements rated positively by more than four in five people.

The most positively rated statements were 'They listened to me if I had any questions or concerns' and 'They discussed my condition and treatment with me in a way I could understand', which were both rated positively by 94 per cent of people.

The statements with the lowest positive responses were 'They helped me feel in control of my treatment / care' and 'They gave me the opportunity to involve the people that matter to me', however both these statements were still rated positively by 82 and 86 per cent of respondents respectively. It should also be noted that both these statements had a higher proportion of neutral responses than the other statements.

Figure 8.2: Responses to person-centred statements – Hospital Care



* **Note:** The statement in the survey read as "They talked in front of me as if I wasn't there" and so the per cent positive figure for this statement is the percentage of respondents who disagreed or strongly disagreed with the statement.

9. Support

Summary

- Most people were given the name of a Clinical Nurse Specialist (86 per cent). Of those people, 89 per cent found it **easy to contact** them and **got answers they could understand** from them when they had important questions.
- There has been an increase since 2015 in those reporting they definitely **received enough care and support from health or social services** during and after their treatment (60 and 50 per cent respectively).
- Just over half of respondents (55 per cent) felt they had been completely **supported emotionally / psychologically** by healthcare professionals during their cancer treatment.
- Most people received information on the **impact cancer could have** on their day-to-day activities and on **support or self-help groups** (77 and 81 per cent respectively). People were less positive about receiving information on **financial help / benefits** and someone close being given **information to help care for them at home** (60 and 52 per cent respectively).
- During treatment, 54 per cent of people who needed or wanted it received **useful information or support** from the **third sector**. After treatment, this dropped to 46 per cent of people.

Clinical Nurse Specialist

A Clinical Nurse Specialist (CNS) is a specialist cancer nurse who helps individuals get the right care and gives them help and advice on coping with cancer.

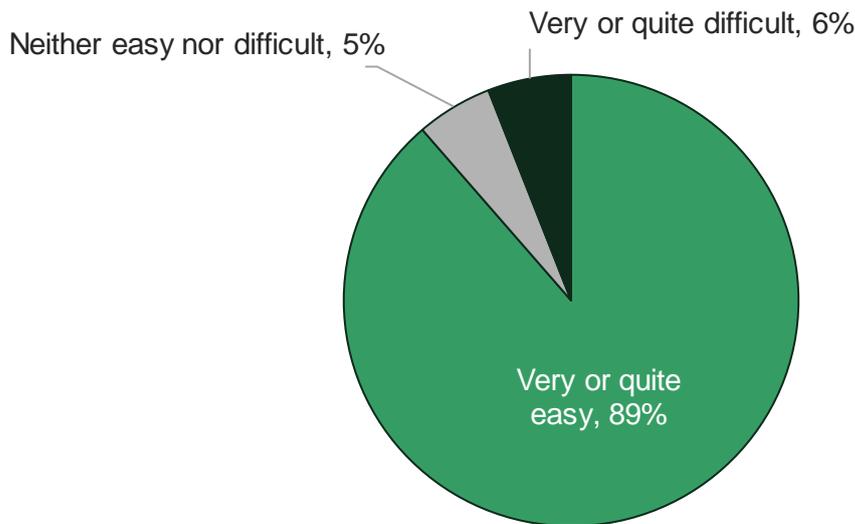
It has previously been demonstrated that access to a CNS can have a significant positive influence on patients' experiences. In particular, additional analysis of the 2015 SCPES results¹⁴ found that those who did not have an easily contactable CNS were significantly more negative for all questions. Further analysis on other Cancer Patient Experience Surveys across the UK¹⁵ has also shown that CNS provision was the most important driver of positive responses.

Most survey respondents (86 per cent) reported that they had been **given the name of a CNS** who would support them through their treatment. Of those who had tried to **contact their CNS**, 89 per cent found it very or quite easy to contact them (Figure 9.1). This is a slight decrease from 90 per cent in 2015. Six per cent of people found it very or quite difficult to contact their named CNS, and the remaining five per cent reported that they had found contacting them neither easy nor difficult.

¹⁴ <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2015-16-exploring-differences-cancer/pages/2/>

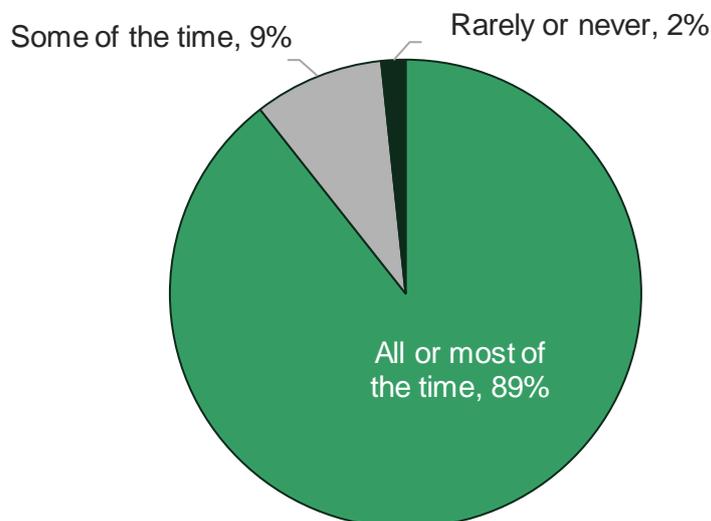
¹⁵ [Northern Ireland Cancer Patient Experience Survey, 2018 All Trusts Report, January 2019.](#) [English National Cancer Patient Experience Survey, National Report 2014, September 2014.](#) [Wales Cancer Patient Experience Survey, National Report 2013, January 2014.](#)

Figure 9.1: Ease with which respondents were able to contact their Clinical Nurse Specialist.



When respondents had important questions to ask their CNS, 89 per cent got answers they could understand all or most of the time (Figure 9.2). This is consistent with results from 2015. Nine per cent got answers they could understand some of the time, and two per cent got answers they could understand rarely or never.

Figure 9.2: Frequency with which respondents understood answers to important questions, provided by their Clinical Nurse Specialist.

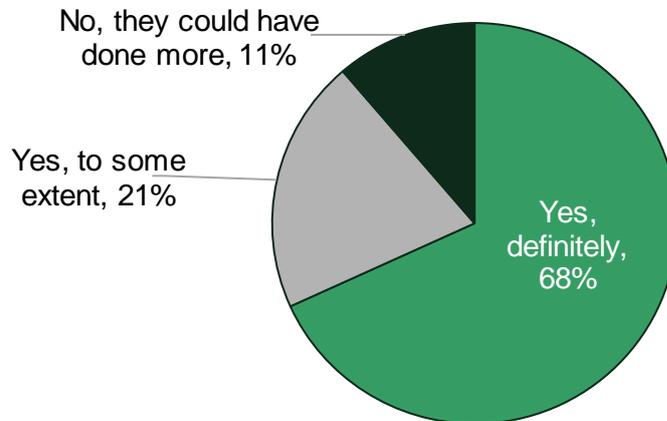


Support from Health & Social Services

During treatment, a cancer patient will often continue to need the support and care of their local GP and nurses. Around two in three people (68 per cent) thought that their GP Practice definitely did everything they could to support them while they were having cancer treatments (Figure 9.3) which is in line with results from 2015. Around one in five people (21 per cent) thought their GP Practice supported them some of

the time, and around one in ten people (11 per cent) felt their GP Practice could have done more to support them.

Figure 9.3: GP Practice did everything they could to support individual during cancer treatment



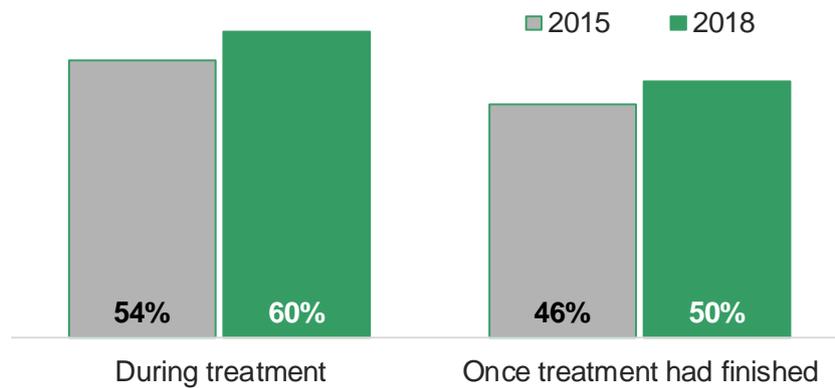
Many people will need to access health and social care services, such as district nurses, home carers or physiotherapists, both during and after cancer treatment. Feeling adequately supported and cared for by these services is vital for a positive care experience.

The survey asked respondents whether they had been given enough **care and support from health or social services**. There was a high proportion of people who reported that they did not need help from health or social services either during or after their treatment (49 and 51 per cent respectively). These people were **excluded** from analysis for these questions.

Three in five people (60 per cent) felt they were definitely given enough care and support from health or social services **during their cancer treatment**. This is an increase from 54 per cent in 2015. Almost one in four (24 per cent) were given care and support to some extent, and the remaining 17 per cent reported that they were not given enough care and support from health or social services.

One in two people (50 per cent) were definitely given enough care and support once their **cancer treatment had finished** – an increase from 46 per cent in 2015. Twenty-eight per cent received care and support to some extent, and 22 per cent felt they were not given enough care and support following their cancer treatment.

Figure 9.4: Proportion definitely being given enough care and support from health or social services during and after treatment, over time



Over half of respondents (55 per cent) felt they had been completely **supported emotionally / psychologically** by healthcare professionals during their cancer treatment. Around three in ten people (31 per cent) felt supported to some extent and 13 per cent reported that they had not felt support emotionally / psychologically by healthcare professionals.

Information on Additional Support

Cancer and its treatments can affect every aspect of an individual’s life, bringing problems from debt to depression, and can last beyond the end of treatment. Support is often available but people may not always be aware of it, and so ensuring individuals receive information on this support is of clear importance.

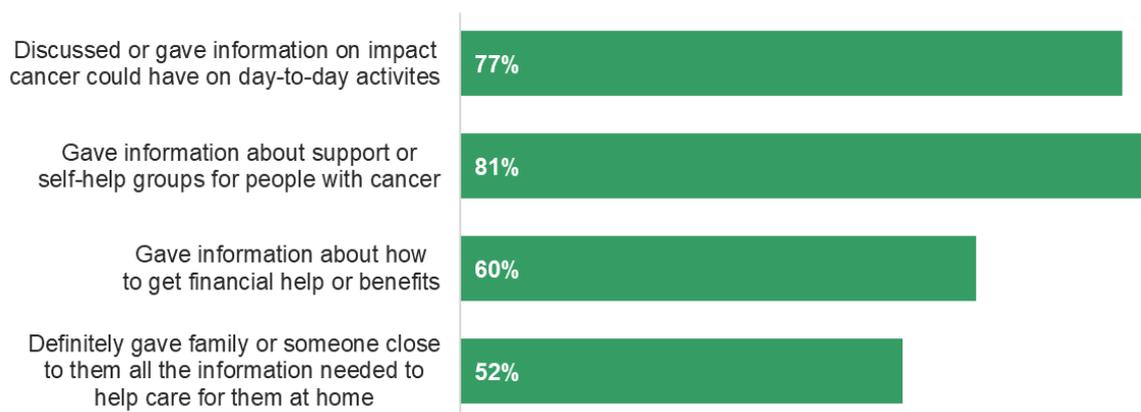
The survey asked respondents whether healthcare professionals had given them information on the impact of cancer on day-to-day activities; support or self-help groups; and financial help or benefits. In 2015, similar questions were asked but specifically about hospital staff, rather than healthcare professionals in general, and so these results are not directly comparable. Respondents who reported that they had not required this type of information were **excluded** from analysis.

Over three in four people (77 per cent) reported that healthcare professionals had discussed with them or given them information about the **impact cancer could have on their day-to-day activities**.

Around four in five people (81 per cent) were given information about **support or self-help groups** for people with cancer.

Three in five people (60 per cent) were given information about how to get **financial help or any benefits** they might have been entitled to.

Figure 9.5: Proportion of positive responses to questions on additional support information provided by healthcare professionals



Both during and after treatment, most people will require help and support at home from family and friends. It is therefore important that an individual's family and friends are provided with adequate information on how to care for them.

Just over half of respondents (52 per cent) reported that healthcare professionals definitely gave their family or someone close to them all the information they needed to help care for them at home. This is a five percentage point decrease from 57 per cent in 2015. Around a quarter (24 per cent) felt that their family or someone close was given information to some extent. The remaining quarter (24 per cent) felt that their family or someone close to them was not given the information they needed to help care for them at home.

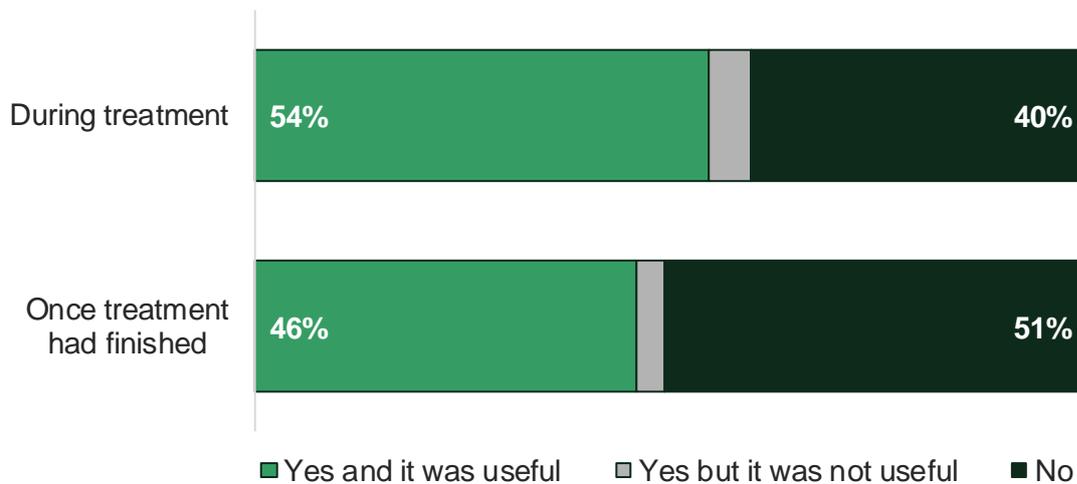
Support from Third Sector Organisations

Respondents were asked whether they had been **given information or support from third sector organisations**, such as charities or voluntary / community groups. There was a high proportion of people who reported that they did not need help from third sector organisations either during or after their treatment (43 and 51 per cent respectively). These people were **excluded** from analysis for these questions.

Just over half of people (54 per cent) who needed help from the third sector were given information / support which they found useful **during their cancer treatment**. Forty per cent of people did not receive any information / support from the third sector and five per cent did receive information / support but did not find it useful.

Once their **cancer treatment had finished**, 46 per cent of those who needed help from the third sector were given information / support and found it useful. Four per cent of people received information / support but did not find it useful and 51 per cent were not given any information / support from the third sector.

Figure 9.6: Received information / support from third sector



When asked whether they felt they had been **supported emotionally and psychologically** by third sector organisations during their cancer treatment, just over half of respondents (53 per cent) reported that they had not needed or wanted this type of support. Of those who did, 35 per cent felt supported completely by third sector organisations; 26 per cent felt supported to some extent; and 39 per cent did not feel they had been supported in this way.

10. Overall Experience

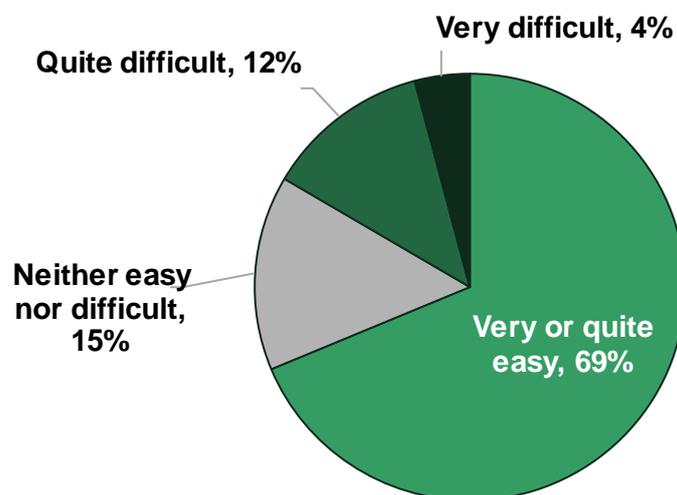
Summary

- The vast majority of people (95 per cent) rated their **overall experience** of cancer care positively, supported by 97 per cent reporting they were always treated with **dignity and respect** by healthcare professionals treating them.
- Around seven in ten people (69 per cent) found it **easy to travel to their cancer care appointments** and just over half of respondents (53 per cent) experienced no difficulties with their travel. The most common **difficulties experienced** were length of travel time and cost of travel / parking (experienced by 25 and 18 per cent of people respectively).
- Most people (92 per cent) reported they were **able to bring someone to their appointments** when they wanted to all or most of the time.
- Three in ten people (30 per cent) were given a **care plan** and half of people (51 per cent) were given a **written note of all the treatments** they received.

Travelling to Appointments

The survey asked respondents a number of questions relating to **travelling to appointments** related to their cancer care. Around seven in ten people (69 per cent) found it, overall, very or quite easy to travel to appointments (Figure 10.1). Fifteen per cent thought it was neither easy nor difficult and 17 per cent reported that they found it quite or very difficult to travel to their cancer care appointments overall.

Figure 10.1: Ease of travelling to cancer care appointments overall



Respondents were then asked to select which **difficulties they had experienced when travelling to appointments** from a list, they could select as many options as applied. Just over half of people (53 per cent) reported that they had not experienced any difficulties when travelling to their appointments relating to their cancer care.

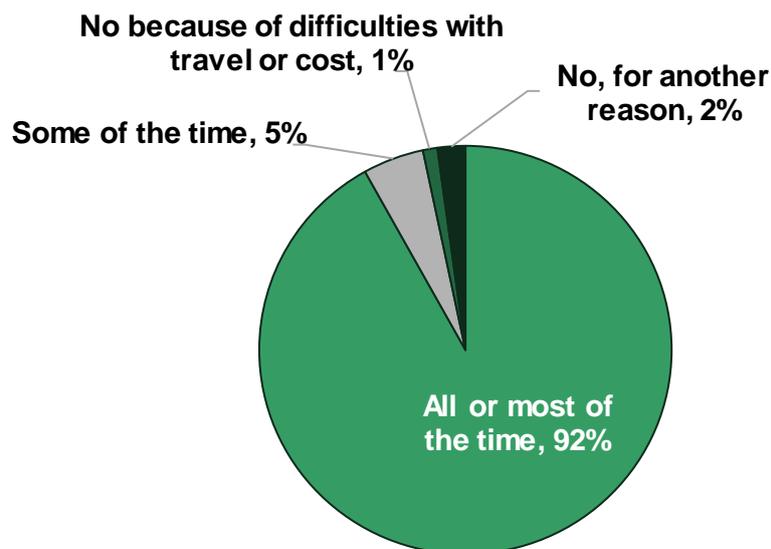
As shown in Table 2, the most common difficulties experienced were length of travel time and cost of travel or parking, which were experienced by 25 and 18 per cent of respondents respectively. Difficulties relating to lack of information and cost of accommodation were least common, with them only being experiences by one and two per cent of people respectively.

Table 10.1: Difficulties experienced when travelling to cancer care appointments¹⁶

	%
Length of travel time	25
Cost of travel or parking	18
Frequency of travel	12
Access to suitable transport	6
Too unwell to travel	5
Cost of accommodation	2
Lack of information	1
Another difficulty	5
No difficulties experienced	53

The survey then asked whether respondents had been able to **bring a family member, friend or someone else** to their appointments **to support them** when they wanted to. The majority of people (92 per cent) reported that they were able to bring someone when they wanted to all or most of the time (Figure 10.2). Five per cent of people were able to bring someone some of the time; one per cent could not bring someone with them when they wanted because of difficulties with travel or cost; and two per cent could not bring someone for another reason.

Figure 10.2: Able to bring someone for support when they wanted to



¹⁶ Respondents were asked to tick all that applied and so results **cannot** be summed.

Coordination of Care

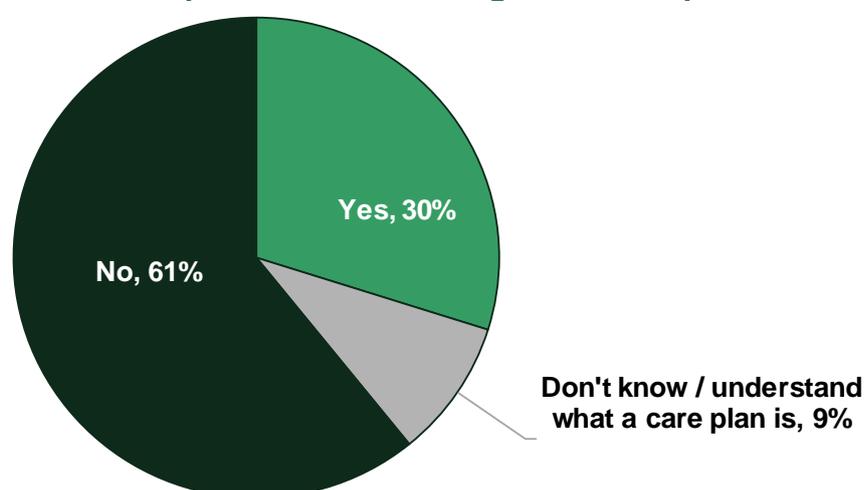
A **care plan** is an agreed plan between an individual and their health or social care professionals which sets out the individual's needs and goals for caring for his or her cancer. This document is received after diagnosis and may include what treatment has been planned for them and the emotional, practical and financial support they will receive.

Additional analysis of the 2015 SCPEs results¹⁷ demonstrated the positive influence the presence of a care plan can have on an individual's experiences of cancer care. Those who did not have a care plan were significantly more negative for 45 out of 47 questions from the 2015 survey analysed.

Three in ten people (30 per cent) reported that they had been given a care plan (Figure 10.3). Around three in five people (61 per cent) had not been given one and around one in ten people (9 per cent) responded that they did not know or understand what a care plan was.

In 2015, 22 per cent of respondents had been given a care plan, with 12 per cent reporting that they did not know or understand what a care plan is. As part of the questionnaire review carried out ahead of the 2018 survey, the explanation of a care plan provided to respondents was expanded to provide examples of the kind of content it might include. It is therefore not possible to directly compare the results as it is not known whether the increase from 2015 is a real increase in those receiving a care plan; an increase in respondents understanding what a care plan is; or both.

Figure 10.3: Whether respondents had been given a care plan



As shown in Figure 10.4, half of respondents (51 per cent) reported that they had been given a **written note** of all **of the treatments they had received** to treat their cancer. Fourteen per cent had received a written note for some of their treatments and 36 per cent had not been given a written note of their treatments.

¹⁷ www.gov.scot/publications/scottish-cancer-patient-experience-survey-2015-16-exploring-differences-cancer/pages/2/

The survey asked respondents to rate the **overall communication around how long appointments relating to their cancer care would take**. Eighty-five per cent rated the overall communication as very good or good. Twelve per cent rated it as neither good nor bad and three per cent of people rated it as quite bad or very bad.

Respondents were also asked to rate the **overall administration of their care**, for example getting letters at the right time, doctors having the right notes / test results, etc. Just over nine in ten people (91 per cent) rated this as very good or good, an increase from 90 per cent in 2015. Five per cent of people rated it as neither good nor bad and four per cent of people rated it as quite bad or very bad.

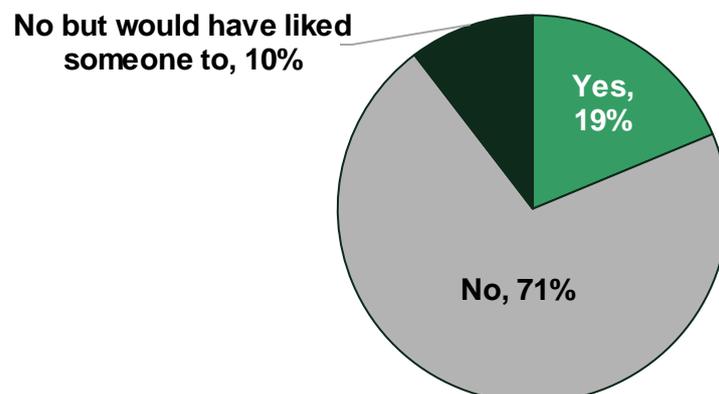
Almost all respondents (97 per cent) reported that they had, overall, been **treated with dignity and respect** by the healthcare professionals treating them for cancer always or most of the time. Two per cent reported that they were treated with dignity and respect sometimes and less than 0.5 per cent of respondents responded that they were not treated with dignity and respect.

Figure 10.5: Proportion responding positively to overall experience questions



Around one in five people (19 per cent) reported that, since their diagnosis, someone had discussed whether they would like to **take part in cancer research** (Figure 10.7). Around seven in ten people (71 per cent) responded that no one had discussed this with them and one in ten people (10 per cent) responded that no one had discussed this with them but they would have liked someone to.

Figure 10.7: Discussion with someone about whether they would like to take part in cancer research



An Official Statistics Publication for Scotland

Official and National Statistics are produced to high professional standards set out in the Code of Practice for Official Statistics. Both undergo regular quality assurance reviews to ensure that they meet customer needs and are produced free from any political interference.

Correspondence and Enquiries

For enquiries about this publication please contact:

The Care Experience Survey Team,
Health and Social Care Analysis

Telephone: 0131 244 3201

e-mail: patientexperience@gov.scot

For general enquiries about Scottish Government statistics please contact:

Office of the Chief Statistician

Telephone: 0131 244 0442,

e-mail: statistics.enquiries@gov.scot

How to Access Background or Source Data

The data collected for this statistical publication are available in more detail through www.gov.scot/CancerSurvey.

Complaints and Suggestions

If you are not satisfied with our service or have any comments or suggestions, please write to the Chief Statistician, GR, St Andrew's House, Edinburgh, EH1 3DG, Telephone: (0131) 244 0302, e-mail: statistics.enquiries@gov.scot.

If you would like to be consulted about statistical collections or receive notification of publications, please register your interest at www.gov.scot/scotstat. Details of forthcoming publications can be found at www.gov.scot/statistics.

Crown Copyright

You may use or re-use this information (not including logos) free of charge in any format or medium, under the terms of the Open Government Licence. See: www.nationalarchives.gov.uk/doc/open-government-licence/.



Scottish Government
Riaghaltas na h-Alba
gov.scot

© Crown copyright 2019



This publication is licensed under the terms of the Open Government Licence v3.0 except where otherwise stated. To view this licence, visit nationalarchives.gov.uk/doc/open-government-licence/version/3 or write to the Information Policy Team, The National Archives, Kew, London TW9 4DU, or email: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This publication is available at www.gov.scot

Any enquiries regarding this publication should be sent to us at
The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78781-781-4 (web only)

Published by The Scottish Government, April 2019

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDA577310 (04/19)