healthwatch
Oldham

A review of people's experiences with Health and Care Services whilst living with cancer during COVID-19

August 2021

Contents

Background

Healthwatch Oldham completes a bi-monthly survey called the Healthwatch Oldham 100. This survey is designed to obtain views from local people on a range of subjects. The findings from these surveys can help us to identify trends within service delivery and provide information to guide us on areas to look into further.

In January 2021, we released our Living with Cancer during COVID-19 survey to better understand the experiences people who live with cancer have had during the pandemic. 31 people completed this survey, and we would like to thank everyone for their contributions to this review. We would also like to acknowledge and thank ABCDiagnosis for their support and input in helping us create this survey.

Disclaimer: about our research

Please note that the statements made within this report are subjective accounts by individuals given on the day they submitted the survey and do not represent the views of Healthwatch Oldham.

Healthwatch Oldham research is carried out in line with accredited guidelines set out in Healthwatch England's Research Framework. We aim to identify what matters most to people and use our findings to ensure that people's voices influence and improve the quality of local services.

What we did

We created a survey which was released in January 2021. Due to the COVID-19 pandemic, this survey was completed online but people were invited to complete paper versions of the survey as well as staff offering to complete the survey online over the telephone.

We asked people to tell us about the following areas:

- Has the individual had cancer prior to COVID-19?
- Did their cancer treatment alter in any way due to the COVID-19 pandemic?
- Their opinion on whether any changes to their treatment was limited
- Has the individual been able to access any support groups or information?
- Has the individual's cancer treatment had any impact on whether they can have the COVID-19 vaccine?
- Did the individual have any remote appointments during the COVID-19 pandemic?
- Whether family members and friends were able to be present to support the individual during appointments and treatments

Key Findings

People who completed this survey expressed their understanding of the challenges faced by everyone during the COVID-19 pandemic, especially those working within the health service. However, there has been a few areas for improvement suggested and the following key themes have been identified:

Diagnosis	26% (8 people) stated that they were alone when they received their cancer diagnosis. This resulted in them providing feedback that expressed their feelings of being isolated and upset during this process.
Appointment Changes	Most people had to have their appointments changed during the COVID-19 pandemic from face-to-face to one being delivered remotely. 17 people stated that they could not have anyone attend appointments with them for support.
Treatment Changes	Over half of those who completed the survey had their treatment change during the COVID-19 pandemic. This was mainly from people who stated that their treatment was delayed and/or cancelled. 3 people also stated that they were not informed why their treatment was delayed and/or cancelled.
Access to Support/ Information	39% (12 people) stated that they had not been able to access any support/information to help with side effects to treatment.
COVID-19 vaccination advice	10 people were spoken to about their eligibility for the COVID-19 vaccine. 9 of those 10 people stated that they were advised to take the vaccination.
Remote Appointment Inconsistencies	There was a lack of consistency with regards to the arrangements of remote appointments. There was a variety of responses which stated that appointments were arrange with the patients given a specific time, given a timeslot and/or just given a date without time.

For Consideration

The Healthwatch Oldham 'For Consideration' points are based on the experiences and feedback of people who completed this survey. We are committed to ensuring that the voices of all Oldham residents can reach those who commission, design and deliver local services. The findings from this report will be shared with Oldham Cares Commissioners, Northern Care Alliance NHS Group and Pennine Care NHS Foundation Trust to help shape health and social care services moving forward.

1. Diagnosis

When a patient receives a life-changing diagnosis, communication is key to help ensure the patient understands the information provided, know what the next steps are in their treatment and where they can get further support if required. The COVID-19 pandemic has resulted in changes to face-to-face appointments and meant that a lot of patients have not been able to have someone there to support them during the appointments where they receive their diagnosis.

Whilst restrictions are changing constantly about people being able to have someone attend an appointment with them for support, we would encourage infection risks to be managed but where feasible, allow people attending important appointments to have support from a family member/friend. For online consultations, we would encourage services to make patients aware before the appointment that they can have a family member/friend present.

2. Appointment Changes

The most common change to patients' appointments was having to do them remotely. There was both positive and negative feedback for this. Most patients felt that positives for remote appointments were not having to wait at a location to be seen, not having to worry about parking their car and found the process a lot quicker than having to attend an appointment in person. The negative feedback received stated that patients did have concerns about receiving an accurate diagnosis without being seen in person.

3. Treatment Changes

Patients stated that the main way their treatment was changed during the pandemic, was that it was actually delayed or cancelled entirely. Whilst patients understood that certain procedures couldn't be carried out, there was a concern about important treatments being scaled back or cancelled and how this could affect their long-term health.

There was a small number of patients who stated that they were not informed why their treatment had been delayed/cancelled. We would suggest that clear communication is undertaken with patients to ensure they fully understand the situation, including, why treatment is being changed, what the changes are when things could potentially change and support information if any of these changes cause concerns for the patient.

4. Access to Support/Information

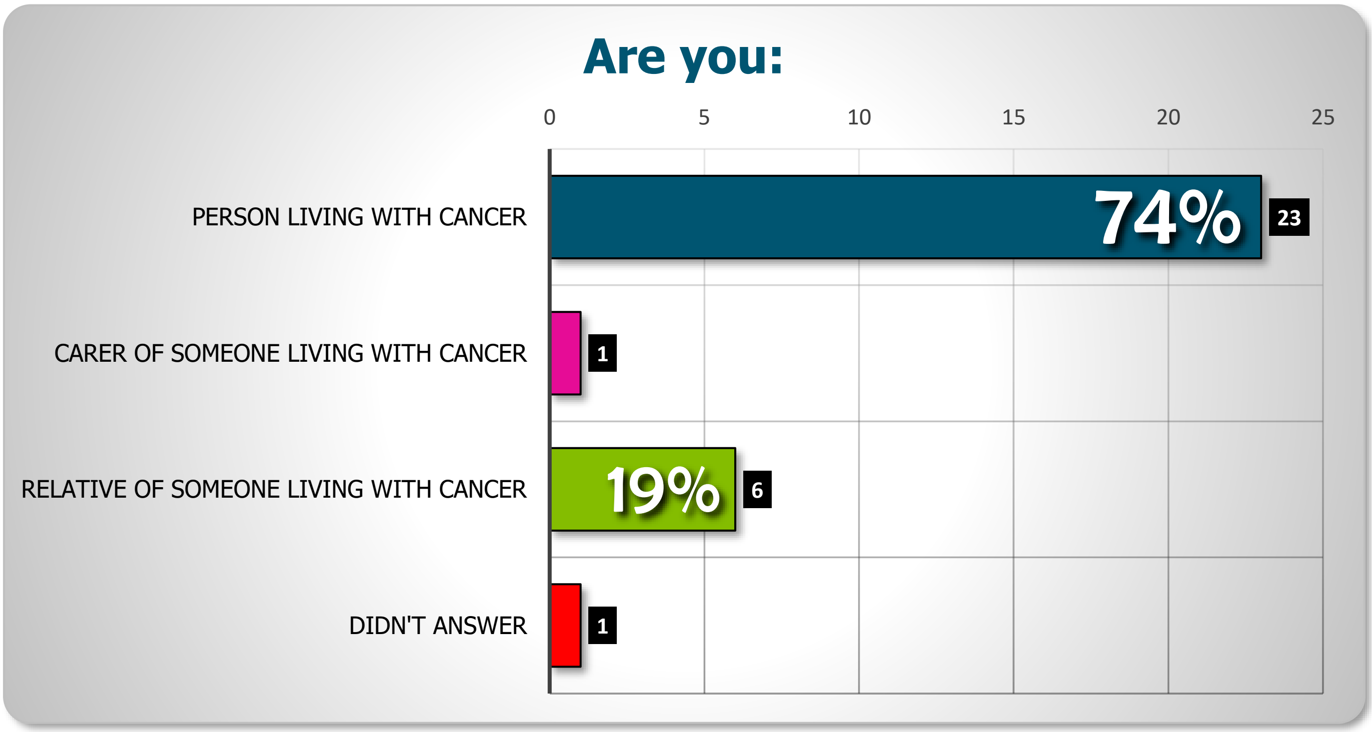
We would suggest that any information for patients to support them is clearly stated and available to access when someone starts a specific treatment. This is because patients stated that they were not provided with any support/information to deal with the side effects of undertaking their treatment.

5. Remote Appointment Inconsistencies

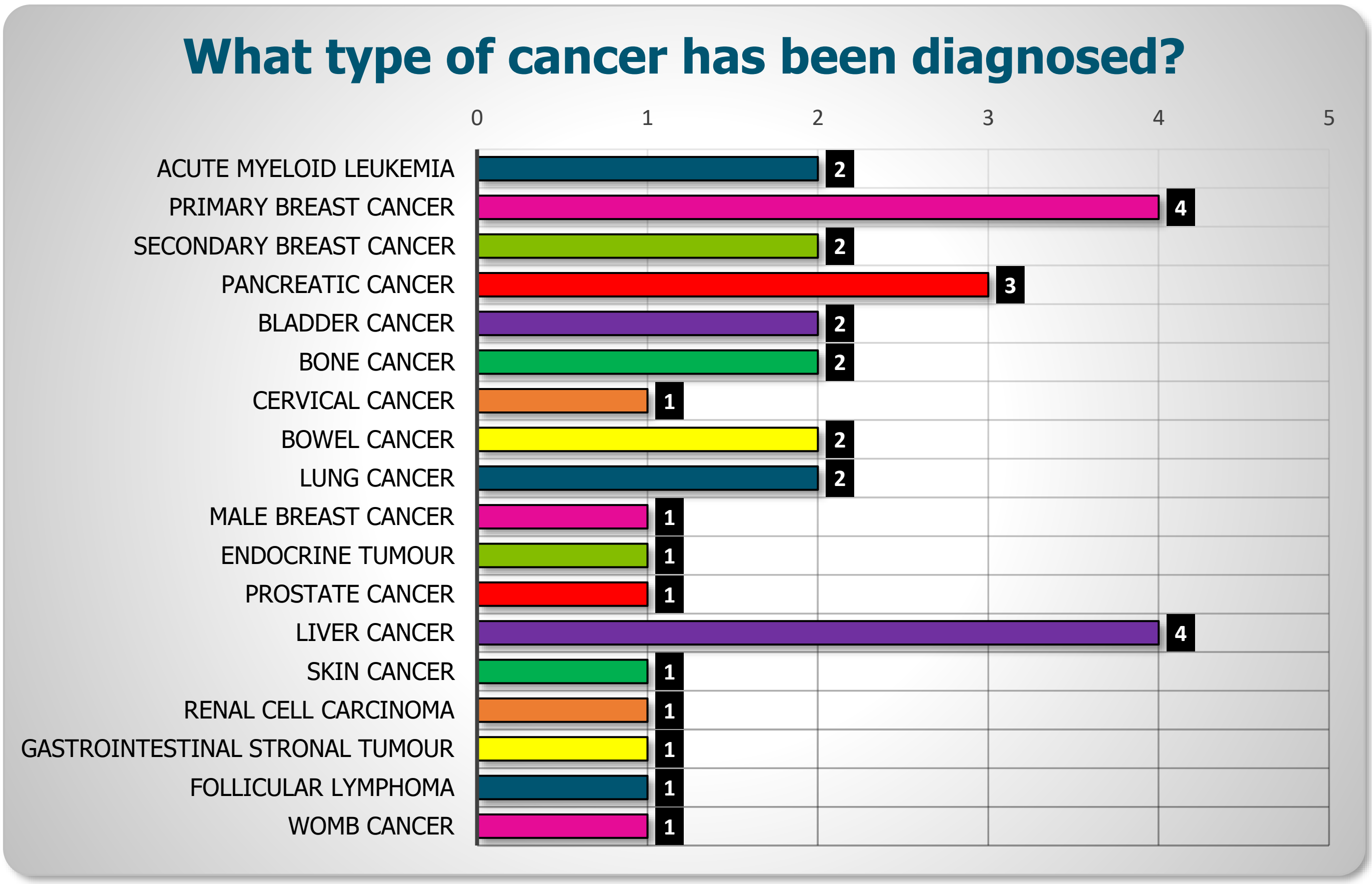
Feedback from patients indicated that there is an inconsistency in the arrangement of remote appointments. Patients reported that some of their remote appointments were arranged with a specific time, some with a time period and some just were provided with a date and no time. We would suggest that a more structured approach to remote appointments is undertaken to provide a consistent service where patients clearly understand when an appointment will take place.

Detailed findings

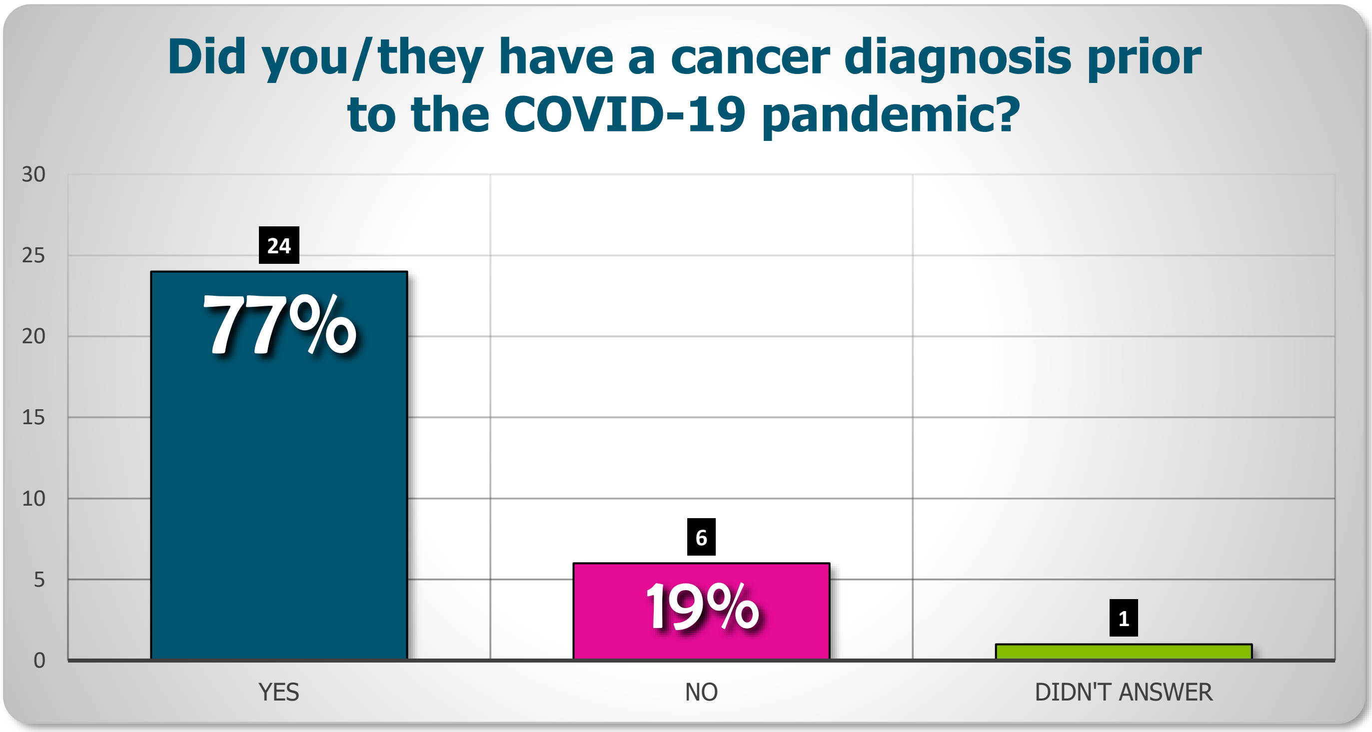
Below are the detailed findings of the 31 completed surveys.



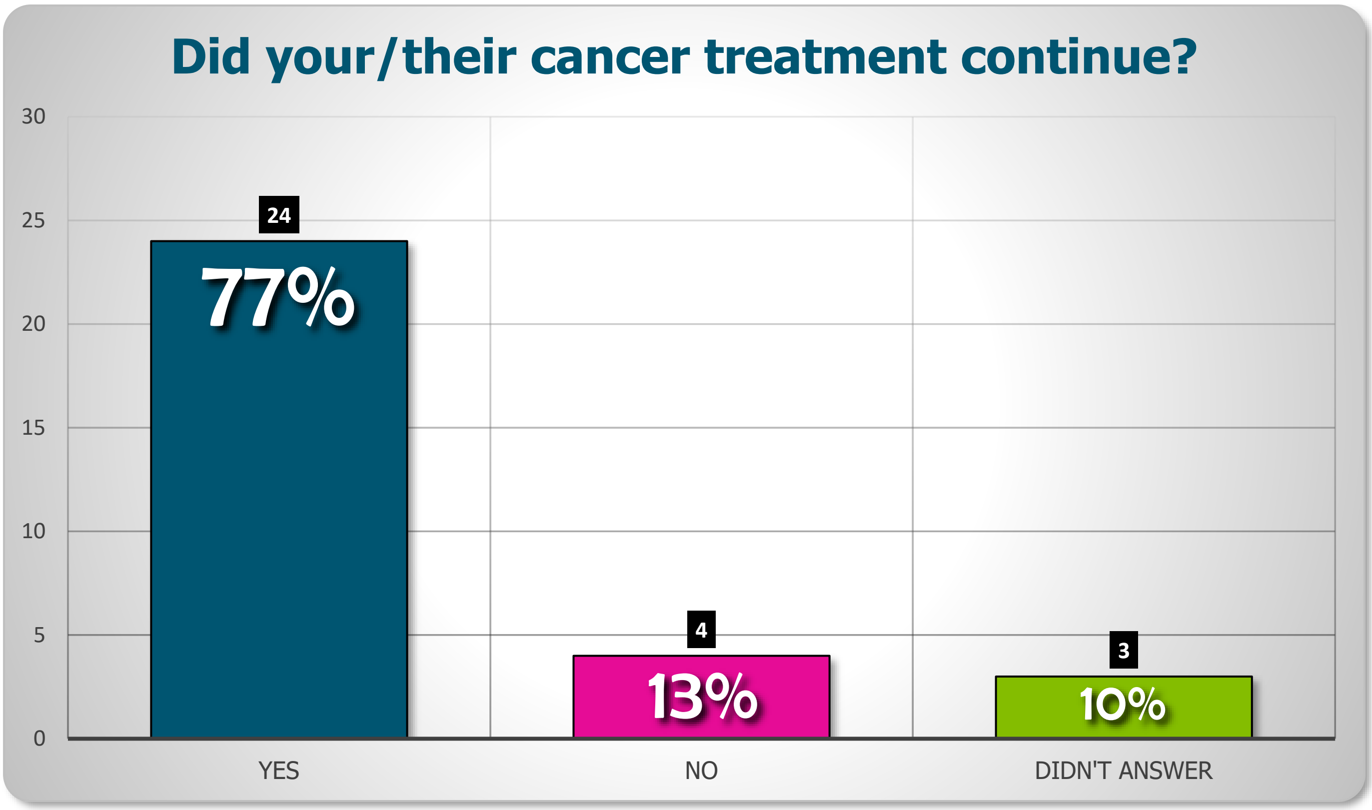
We asked the 31 people who completed the survey whether they had cancer or was a carer or relative of someone living with cancer. 74% (23 people) stated that they are a person living with cancer. 19% (6 people) stated that they are a relative of someone who is living with cancer.



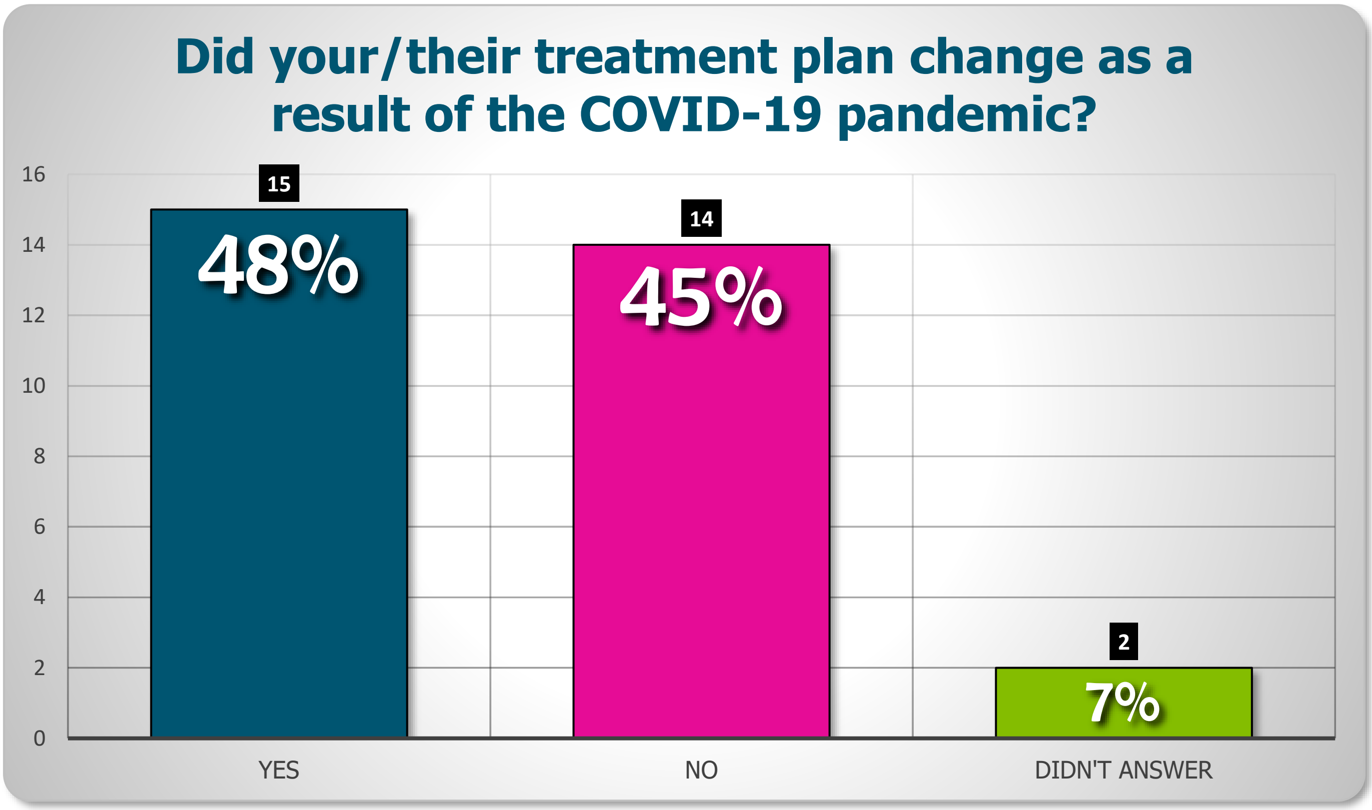
We asked individuals what cancer had been diagnosed. There were various cancers mentioned with the highest being primary breast cancer and liver cancer with 13% (4 people) answers each. There are more answers than individuals as some have stated that they have more than one cancer diagnosis.



We asked whether people had a cancer diagnosis prior to the COVID-19 pandemic. 77% (24 people) stated that their cancer diagnosis was prior to the COVID-19 pandemic compared to 19% (6 people) who stated that their diagnosis was during the COVID-19 pandemic.



We asked whether their cancer treatment continued during the COVID-19 pandemic. 77% (24 people) stated that it did compared to 13% (4 people) who stated that it did not. 10% (3 people) chose not to answer this question.



We asked whether their treatment plan had changed due to the COVID-19 pandemic. 48% (15 people) stated that it did compared to 45% (14 people) who stated that it did not. 7% (2 people) did not answer this question.

What changes were made to your treatment plan due to the COVID-19 pandemic?

We asked individuals what changes were made to their treatment plan due to the COVID-19 pandemic. There were equal responses to individuals having their treatments spread out or stopped altogether, appointments being completed remotely, and surgeries being postponed.

"Denosumab injections spread out, routine scan delayed by several weeks (ended up hospitalised before results came back from cancer progression)".

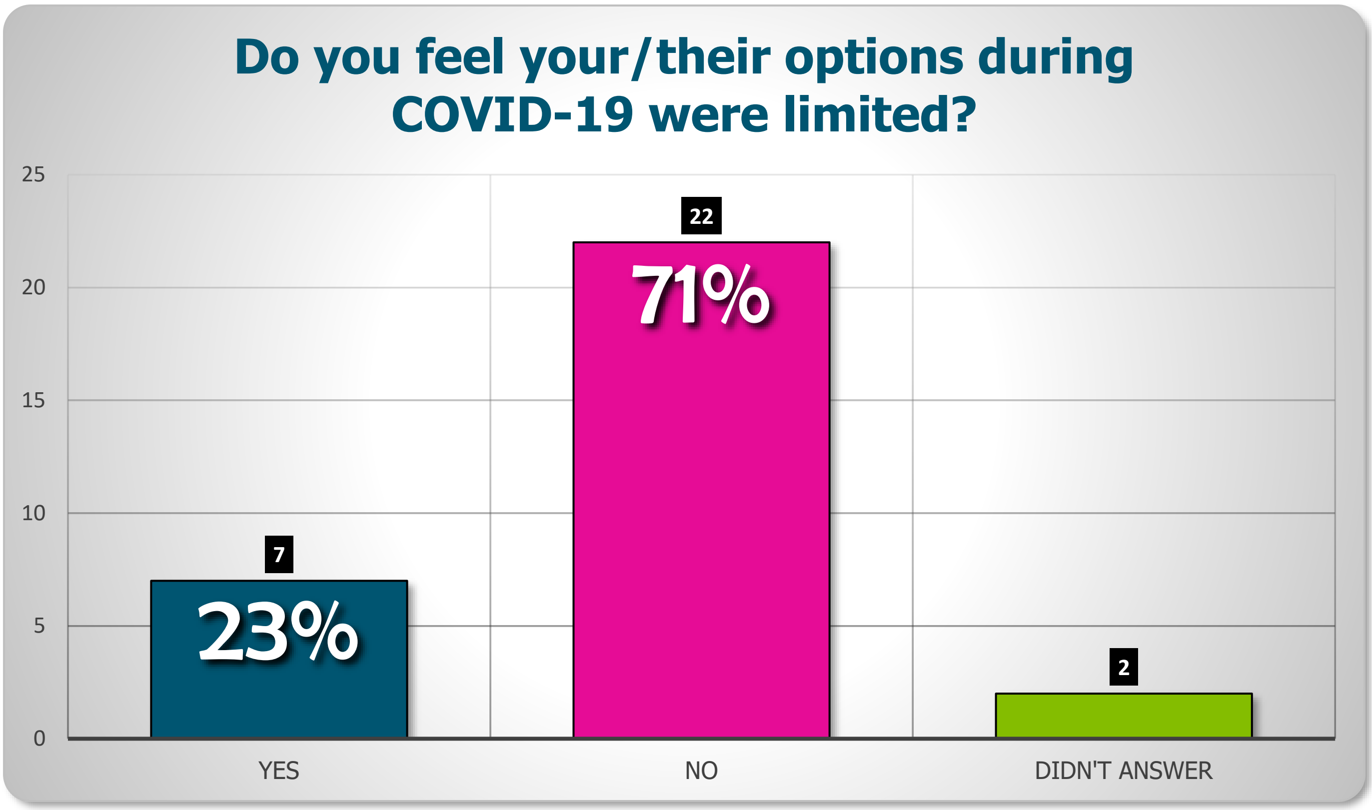
"Several cancelled appointments. Should have had a prosthesis fitted after 2 months have had to wait 11 months".

"Surgical procedure keeps being postponed due to lack of ICU beds filled with Covid patients".

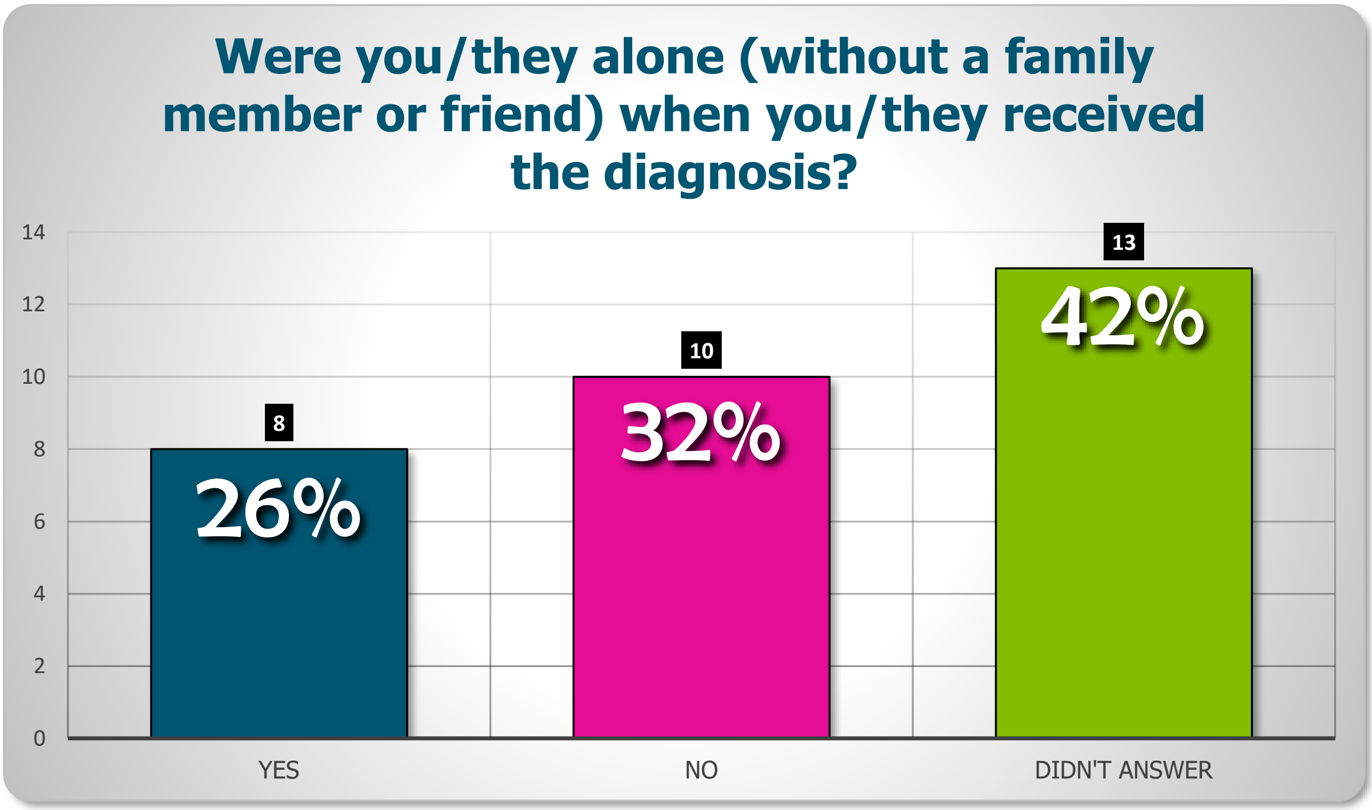
"They were told would not operate due to risk of covid - age and health related so went with daily medication and regular review".

"3 weekly Trastuzumab and Pertuzumab cycles were reduced to 6 weekly from Feb 2021. After arguing I got them to agree to a single 4 weekly cycle followed by a review".

"Initially my radiotherapy was cancelled due to COVID-19 and I was told the surgery was "good enough" however a few weeks later I was given radiotherapy but not 15 doses as previously advised but 5 doses at a stronger dose".



We asked whether they felt there were any limitations on their treatment options due to the COVID-19 pandemic. 71% (22 people) stated that there were no limitations compared to 23% (7 people) who stated that there were.



We asked whether they were alone when they received their diagnosis. 42% (13 people) did not answer this question. 32% (10 people) stated that they were not alone compared to 26% (8 people) who stated that they were alone when they received their diagnosis.

How did this make you/them feel?

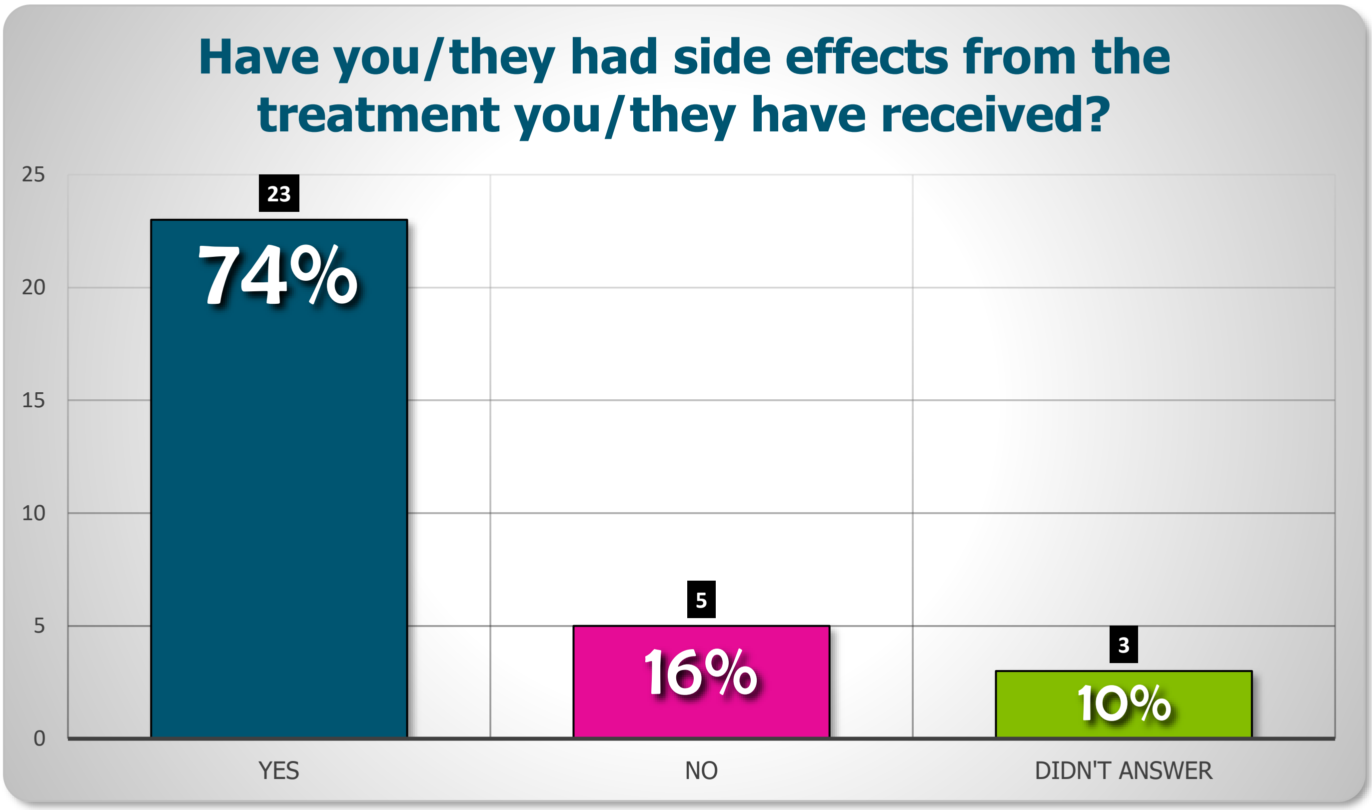
Emotional
Traumatised
Isolated
Upset
Vulnerable
Scared

We asked how people felt when receiving their diagnosis. From those who were given their diagnosis whilst they were alone, they stated they felt isolated. Understandably, most feedback highlighted that people felt upset, scared and emotional.

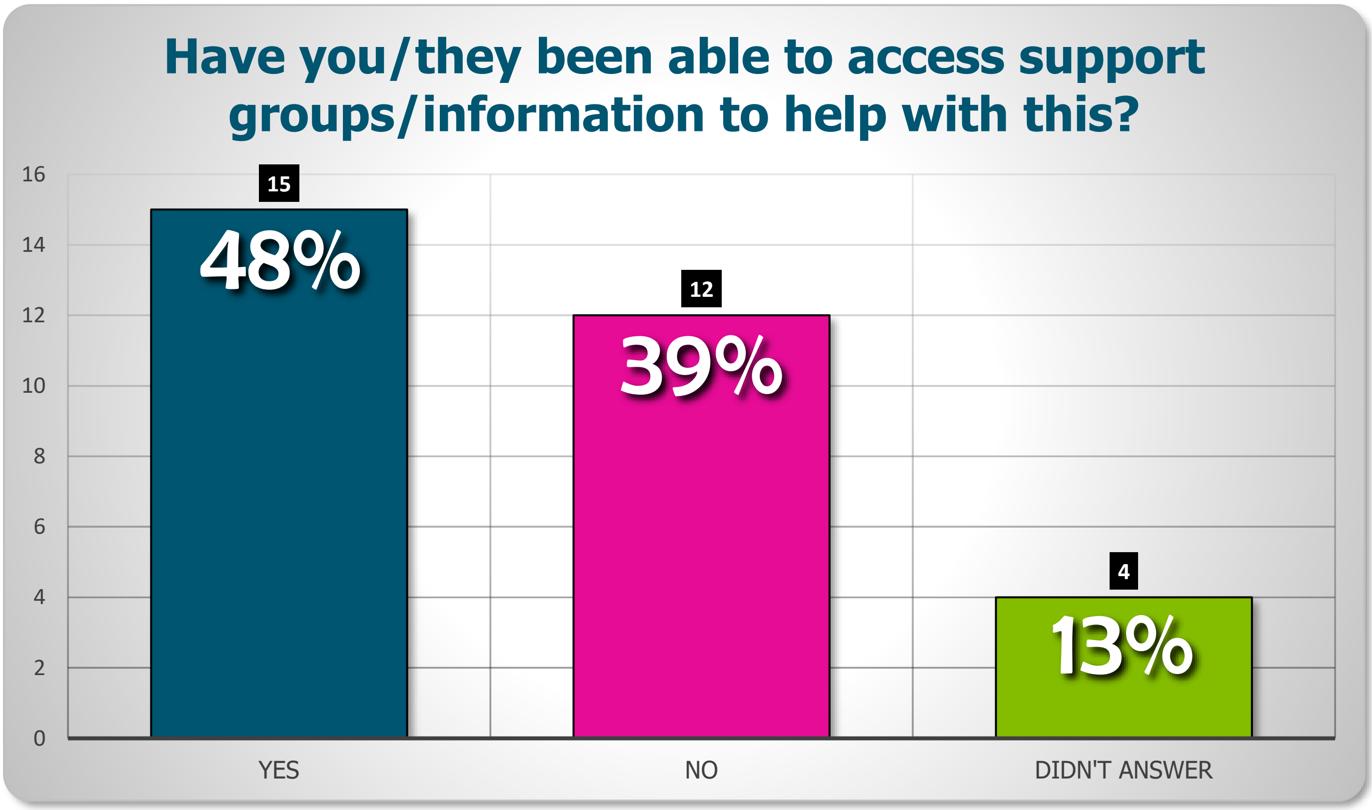
"I was told about progression and change of tumour type on my own - it was hard both emotionally and practically - support and someone to take notes."

"Traumatised, still having flashbacks to the appointment, this could be a normal reaction, but as a relative I wanted to say to them phone up and say you need to take someone but didn't want to raise her anxieties before appointment."

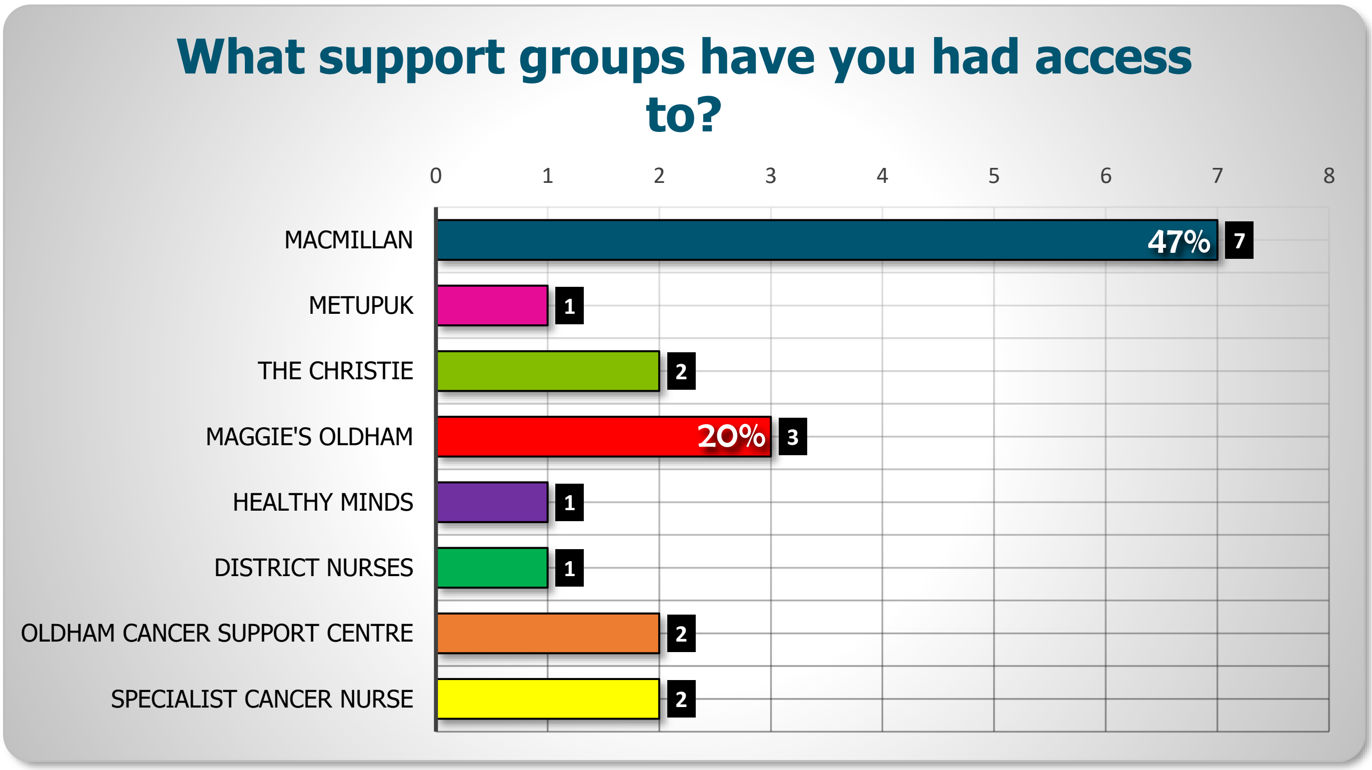
"It was before COVID-19, but I heard it alone. I was obviously upset and couldn't wait to see my wife."



We asked whether they had any side effects from their cancer treatment. 74% (23 people) stated that they did have side effects compared to 16% (5 people) who stated that they had not. 10% (3 people) chose not to answer this question.

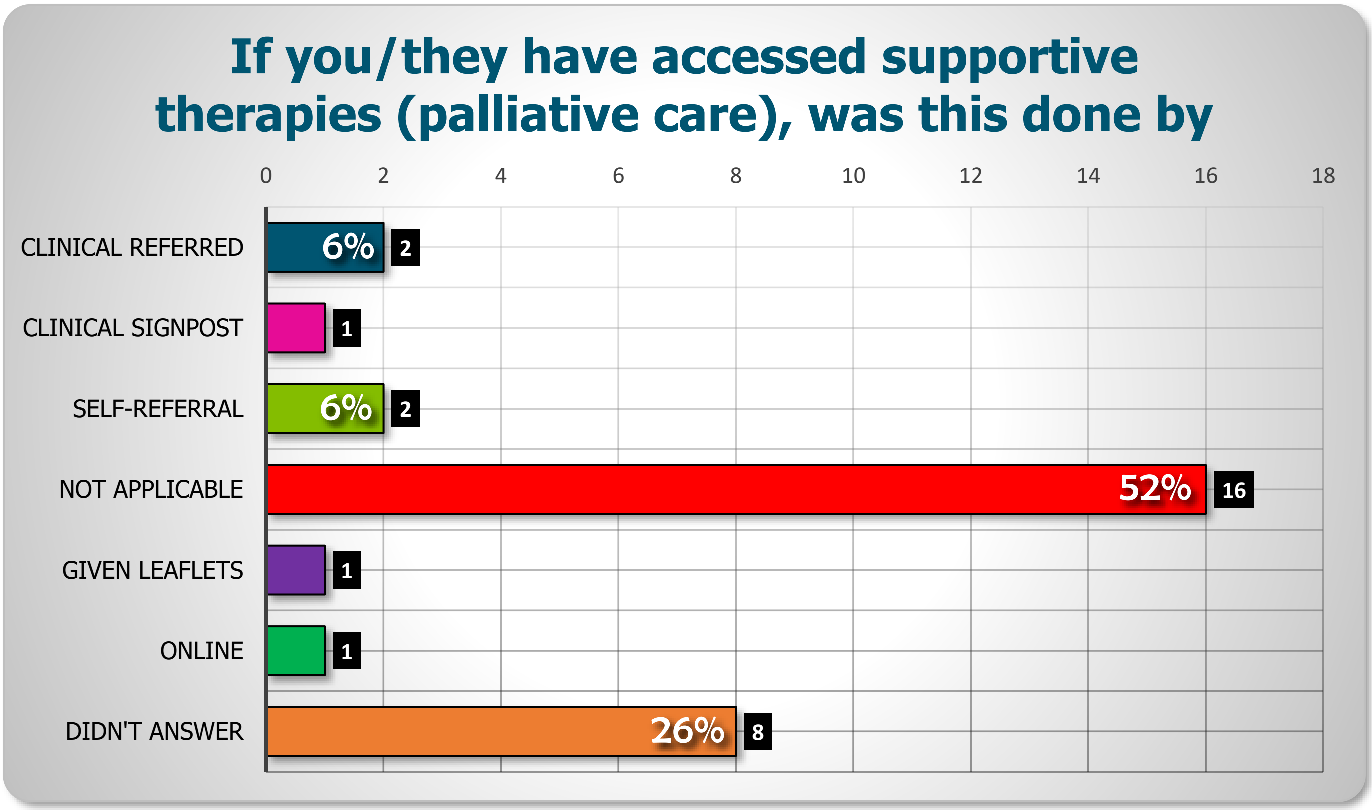


We asked whether they were able to access any support groups/information. 48% (15 people) stated that they had compared to 39% (12 people) who stated that they had not. 14% (4 people) did not answer this question.



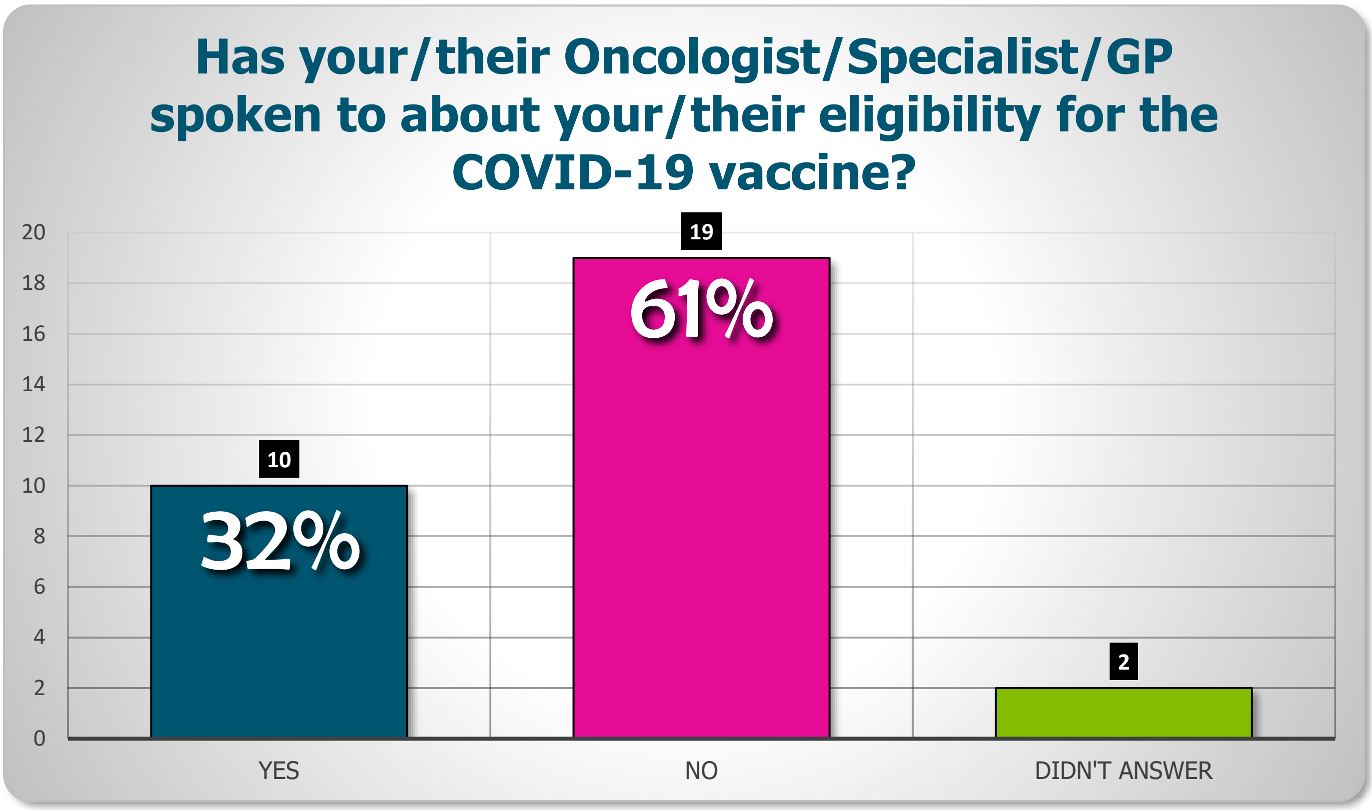
What support groups have you had access to?

We asked the 15 people who stated they had accessed support groups and information, who they got this from. 47% (7 people) stated that they used Macmillan's services. 20% (3 people) stated that they used Maggie's Oldham. There are more answers than individuals for this question as people accessed more than one service.

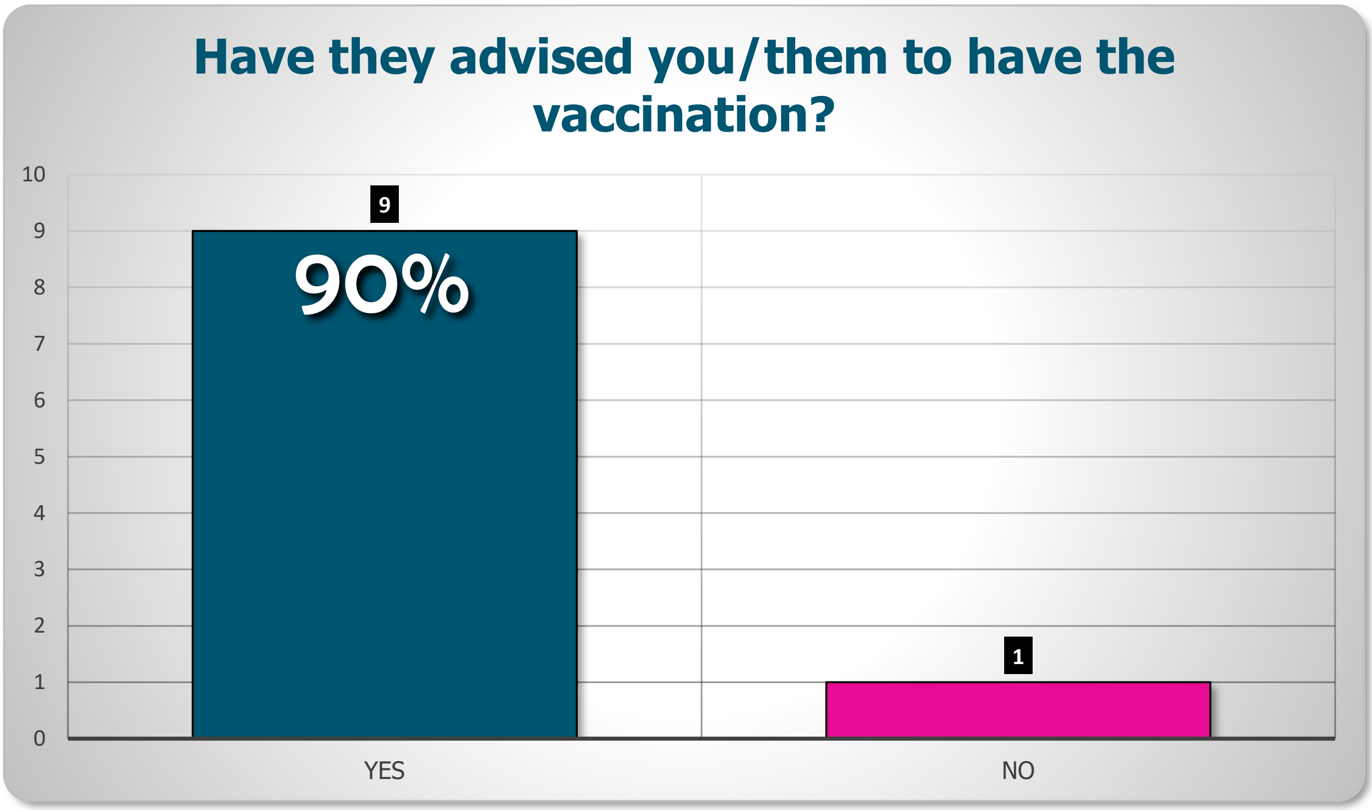


If you/they have accessed supportive therapies (palliative care), was this done by

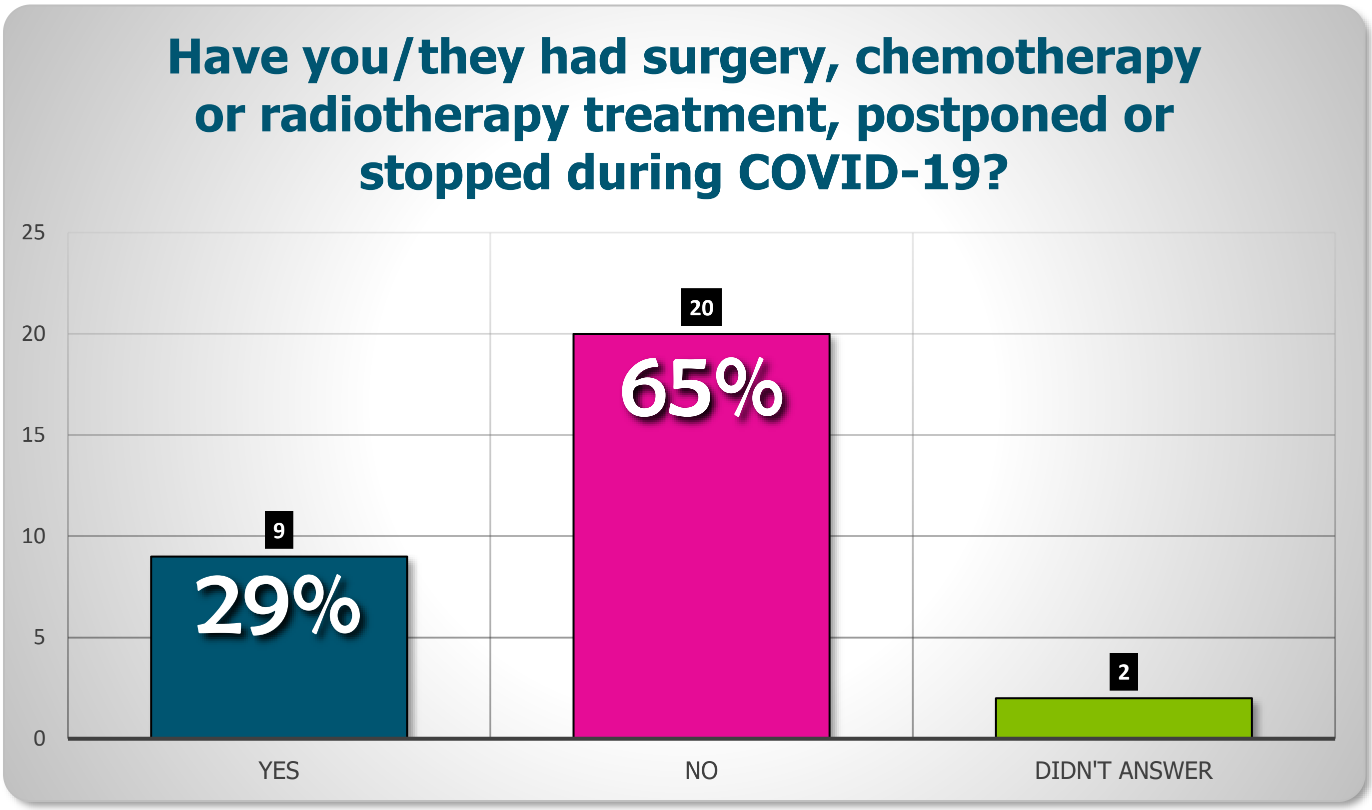
We asked how people had been informed about palliative care. For most this was not applicable, however, the most common way people had accessed this care was via referral both clinical and self-referral with 2 people each.



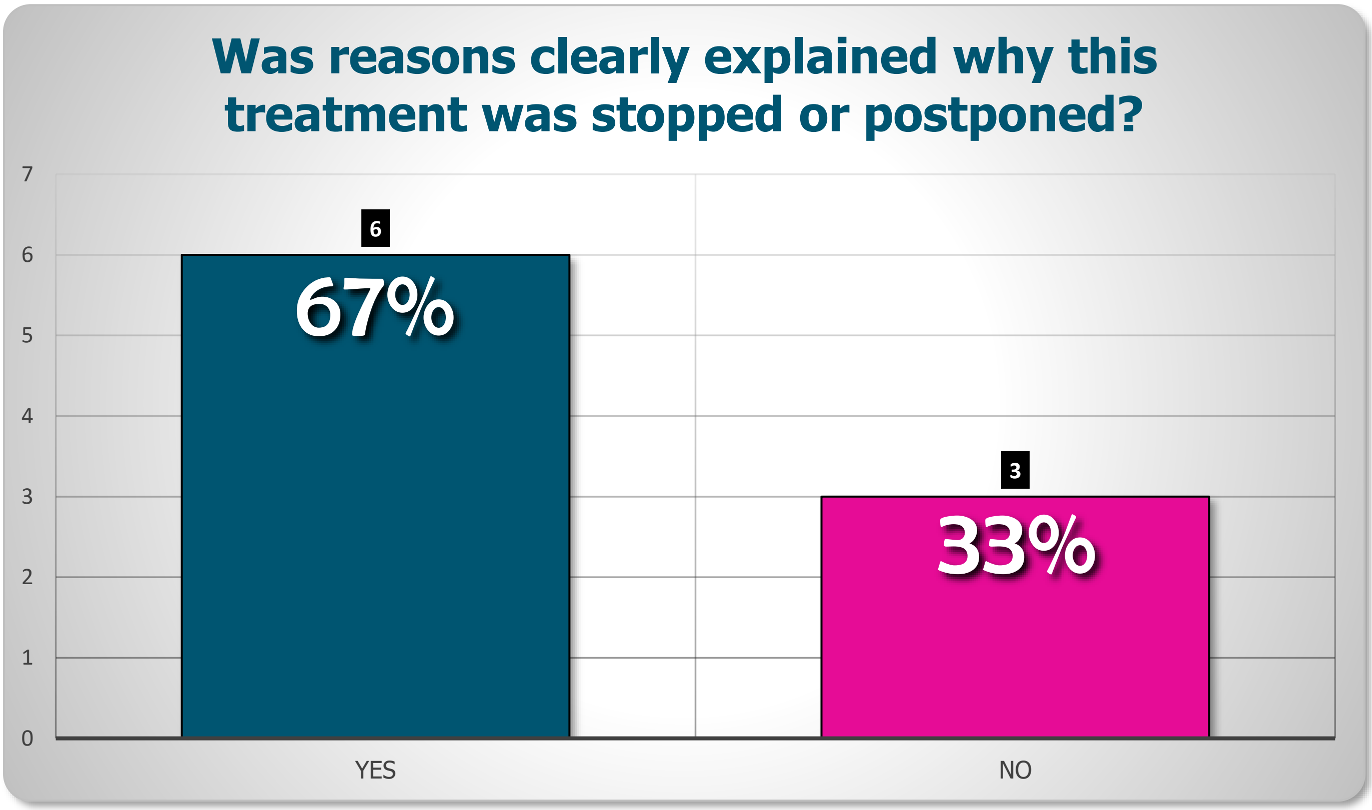
We asked whether the individual had been spoken to about their eligibility of the COVID-19 vaccine. 61% (19 people) stated that they had not compared to 32% (10 people) stated that they had.



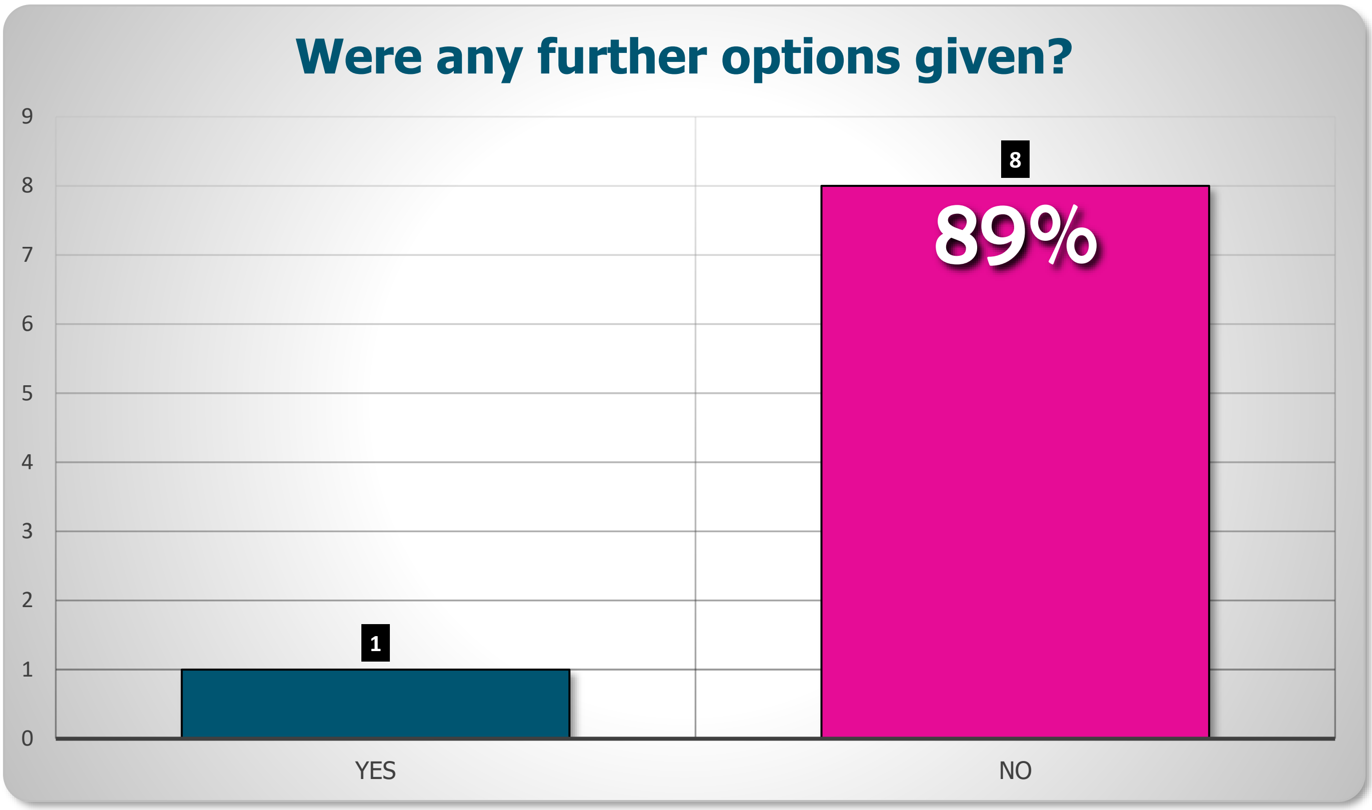
Out of the 10 individuals who were spoken to about the vaccine, we asked whether they were advised to get the vaccination. 90% (9 people) stated that they were advised to get the vaccine compared to 10% (1 person) who was advised not to.



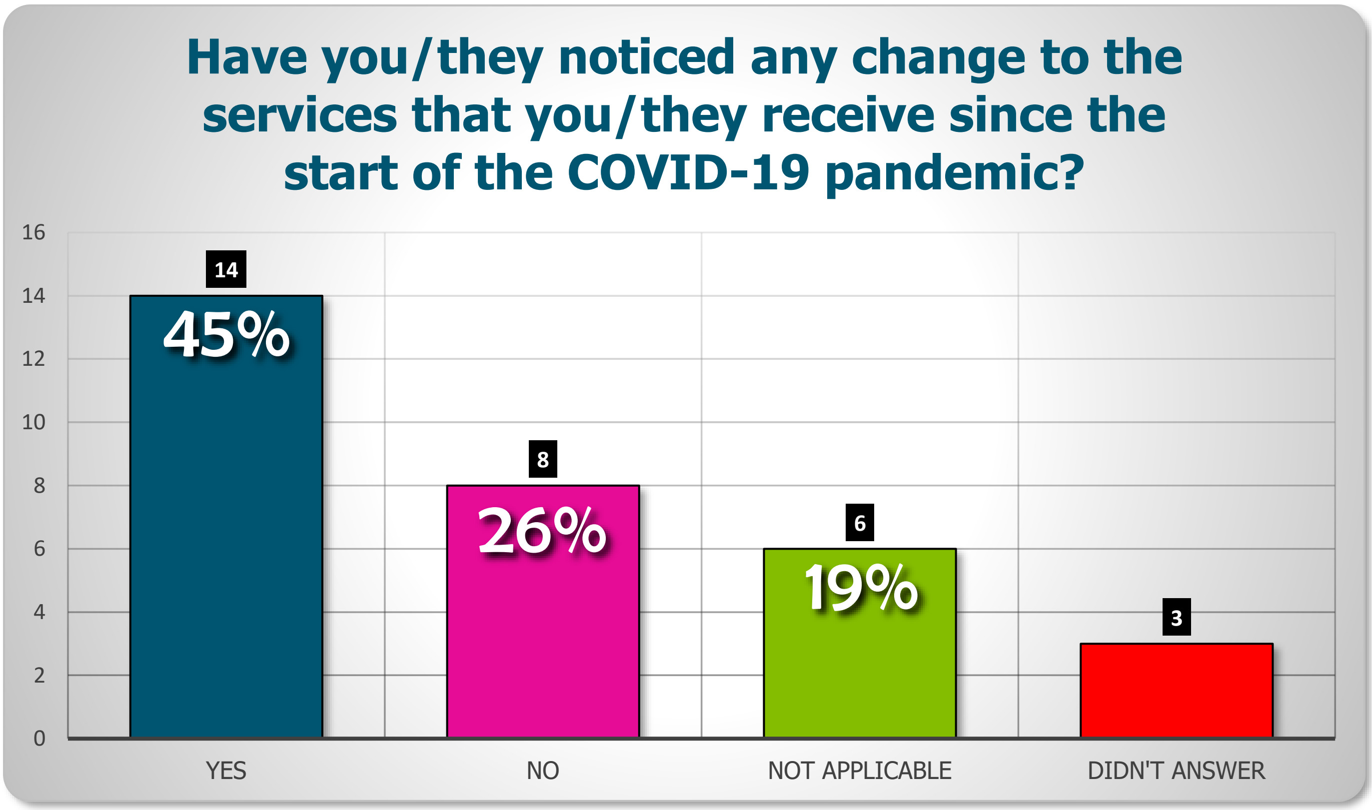
We asked individuals whether they had any surgery, chemotherapy or radiotherapy treatment postponed or stopped during the COVID-19 pandemic. 65% (20 people) stated that they had not compared to 29% (9 people) who said that they had.



We asked the 9 individuals who stated that their treatment was stopped or postponed whether they were clearly told why. 67% (6 people) stated that they were compared to 33% (3 people) who stated that they were not given a clear explanation.



We also asked the 9 individuals whether they were given any other options due to their treatment being stopped. 89% (8 people) stated that they were not and only 11% (1 person) was given further options.



We asked individuals whether they had noticed any positive or negative changes to the services they have accessed when the COVID-19 pandemic started. 45% (14 people) stated that they did notice changes compared to 26% (8 people) who stated that they did not. 19% (6 people) stated that this question was not applicable to them.

Are there any positive changes in service?

Quicker
Safer
Less waiting
No parking required
Easier to get scan results

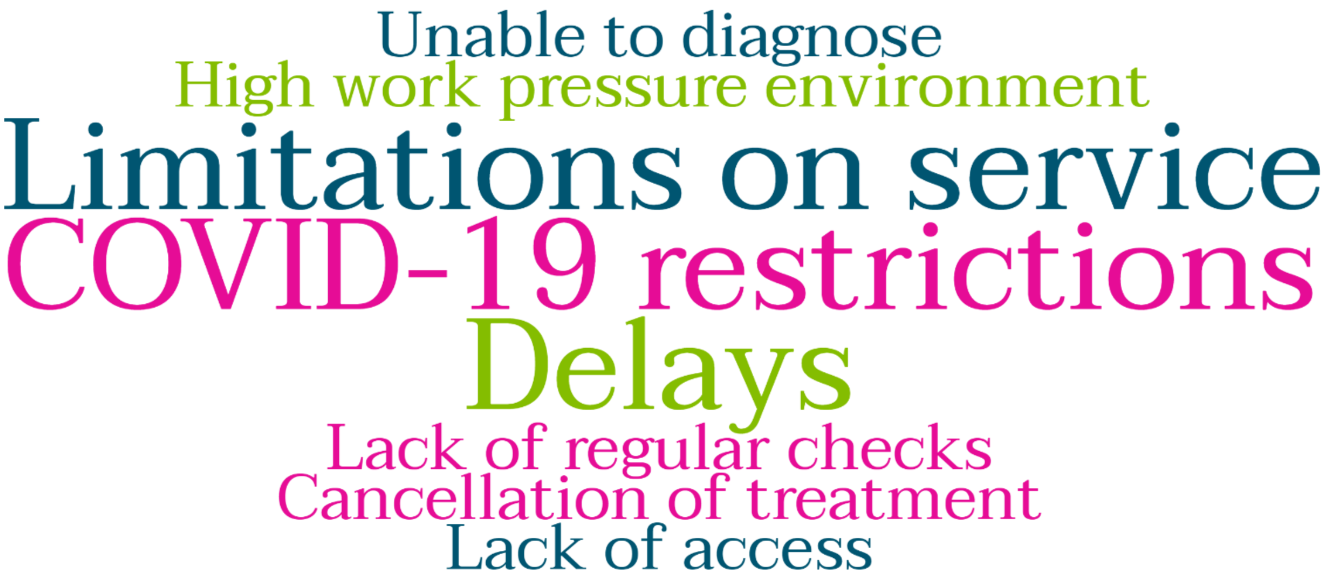
We asked people whether they would like to express any positive changes in service during the COVID-19 pandemic. The most common comments made were about there being less waiting times as appointments are being held remotely and that individuals felt safer in this process during the pandemic.

> *"Like not having to wait for face-to-face appointments for scan results, and better use of digital services - hope this continues with a good mix of face-to-face and digital access. Being able to email etc has made a huge difference in being able to put forward smaller issues in the hope issues will be picked up sooner."*

> *"Telephone consultations are fairly positive when you are phoned by someone you have met. A bit trickier when you don't know them but still better than waiting in a crowded clinic after a long journey and finding somewhere to park. Face to face consultations when necessary have been better as never in a crowded waiting room. Smaller number of people means you feel safe."*

> *"The Christie have been amazing at trying to keep everything ticking over. We have certainly felt my husband's care and treatment has been the best it could be under difficult circumstances."*

Are there any negative changes in service?



We asked people what negative changes there has been during the COVID-19 pandemic. The most common statements made were regarding the restrictions the pandemic has caused and delays (and in some cases cancellations) of treatment.

> *"Delays. Things take more time due to procedures with infection control."*

> *"There's more delays and limitations – e.g. lymphedema service - massages etc not currently available, and everything has COVID-19 delays.*

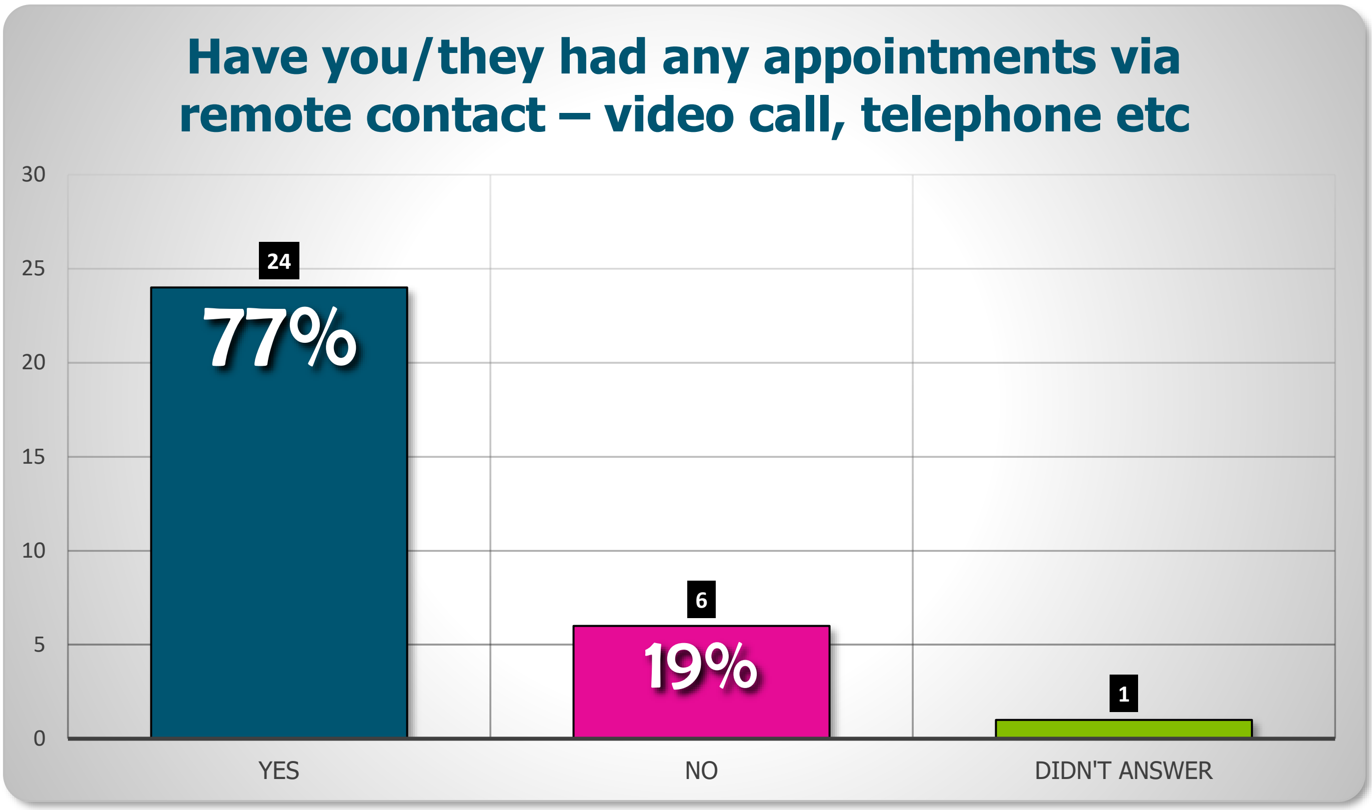
> *"COVID-19 made access to support much harder, seeing a GP is nigh on impossible, and you cannot diagnose during a phone consultation."*

> *"Only offered telephone appointments. Occasional telephone appointments are good, but no face to face appointments for almost a year isn't. Telling me to pause my 3 weekly infusions to 6 weeklies isn't good in any way. I was not presented with any evidence that this is safe. Where is the data collection about existing patients having their treatment pathways changed?*
>
> *If we don't collect data, then we will not be able to hold decision makers accountable for changes made. We desperately need a review of how cancer patients, particularly metastatic cancer patients, have been seen as expendable."*

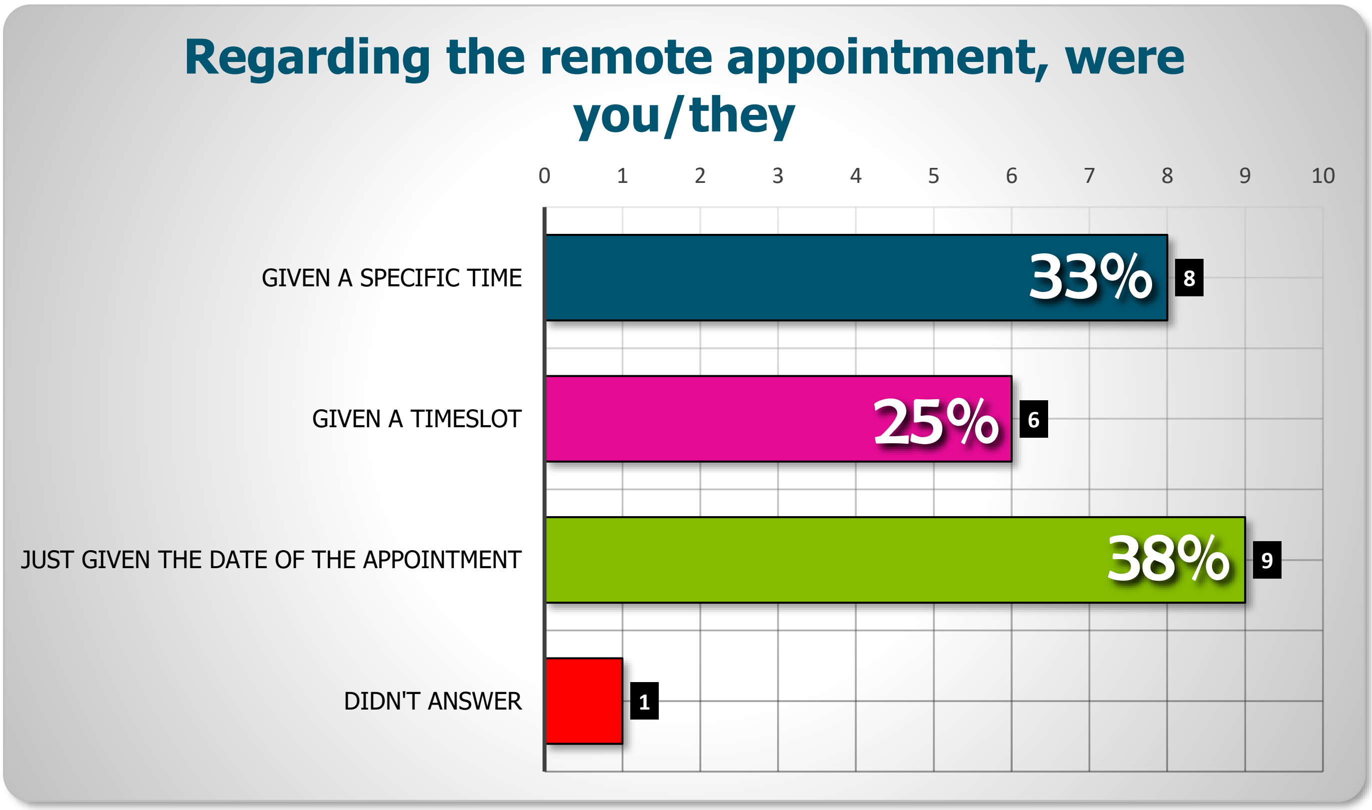
"Appointments were cancelled and constantly re-arranged of course due to COVID-19 which I understand, but I was still dealing with cancer."

"Not able to see a Consultant face to face was understandable but a shame. Regular weight and blood pressure checks were done at each appointment, so they have not been done since February 2019."

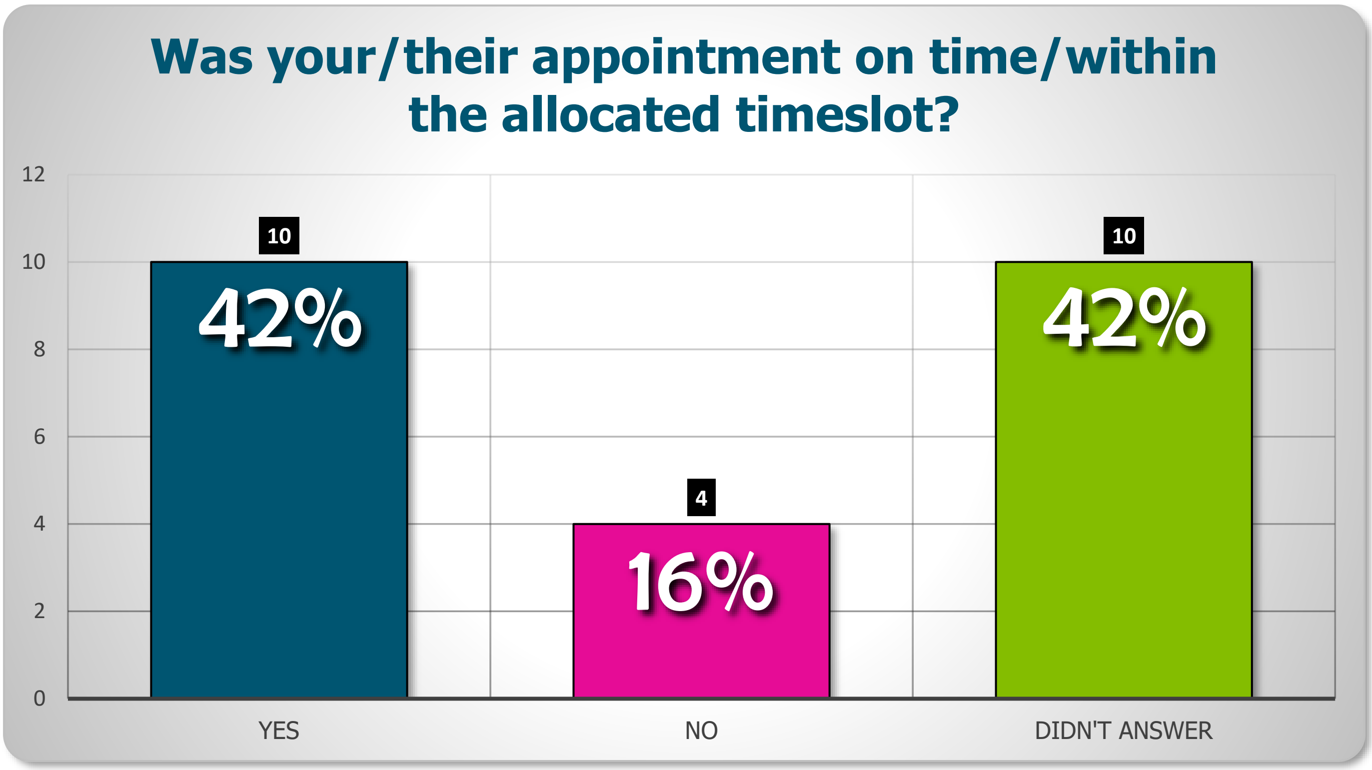
"Very limited face-to-face contact with services."



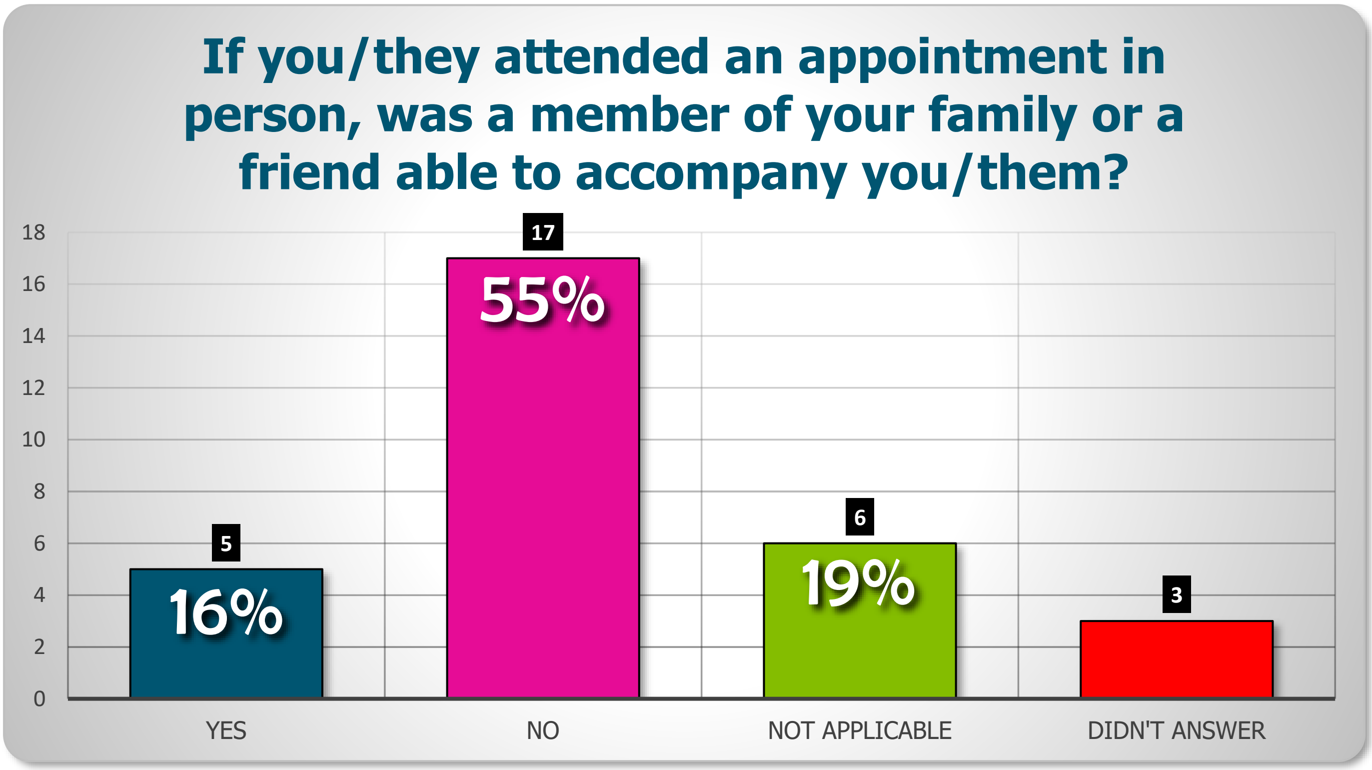
We asked whether the individual had any remote appointments during this period. 77% (24 people) stated that they had compared to 19% (6 people) who had not.



We asked individuals how their remote appointment was structured. 38% (9 people) stated that they were only given a date for their remote appointment. 33% (8 people) stated that their appointment included a specific time to meet and 25% (6 people) stated that they were provided with a timeslot of when they could be contacted.



We asked individuals whether their remote appointment was on time. 42% (10 people) stated that it was compared to 16% (4 people) who stated that it was not. 42% (10 people) chose not to answer this question.



We asked individuals if they had an appointment in-person, was they able to have a family member or friend accompany them. 55% (17 people) stated that they were not able to bring anyone with them compared to 16% (5 people) who stated that they could. 19% (6 people) stated that this question was not applicable to them.

Is there anything else you would like to comment on?

Cast aside
Delays in treatment
Isolated
Inconsistent delivery
Thankful
Unable to retain information from challenging diagnosis
Outstanding service
Poor communication

We asked people whether there was anything else they would like to comment/share with us. Most comments made suggested a concern over inconsistent delivery of services.

"My mum has struggled with symptoms since the start of lockdown 2020. After several courses of antibiotics, she was finally referred to a specialist and this again was a long wait until her GP got on the case. She attended alone for a cystoscopy and was told there and then it was a tumour and she would be referred urgently to the hospital. She waited weeks again until the GP contacted the hospital to see what was going on. They then phoned her a day later and said she would have a surgery appointment within 2 weeks. After 2 weeks of silence, again the appointments centre said it was a 4-week referral and then changed their mind and said yes, it actually was 2 weeks and so we are waiting again. I sincerely hope the care she gets from now on is entirely different to the lack of it so far!"

"On some occasions, I was given a time and on others just a date. Once the consultant rang earlier than the appointment and another time, I think I was last! One time they phoned as I was on my way back from the blood test they had sent me for so I pulled in and had my consultation at the roadside in the car."

"We haven't been able to believe the speed of tests & appointments being booked and the level of contact from various health professionals. An appointment was arranged over the phone for the following day & a letter sent the same day by taxi to confirm the details! Absolutely outstanding service."

"I found it very difficult to remember everything said at appointment, and as I was alone couldn't double check with my partner."

"COVID-19, not only isolated the population, it turned the light off and shut the door for those going through cancer treatment. In phase one, we were cast aside, in this phase that has also reappeared, with cancellations and postponements."

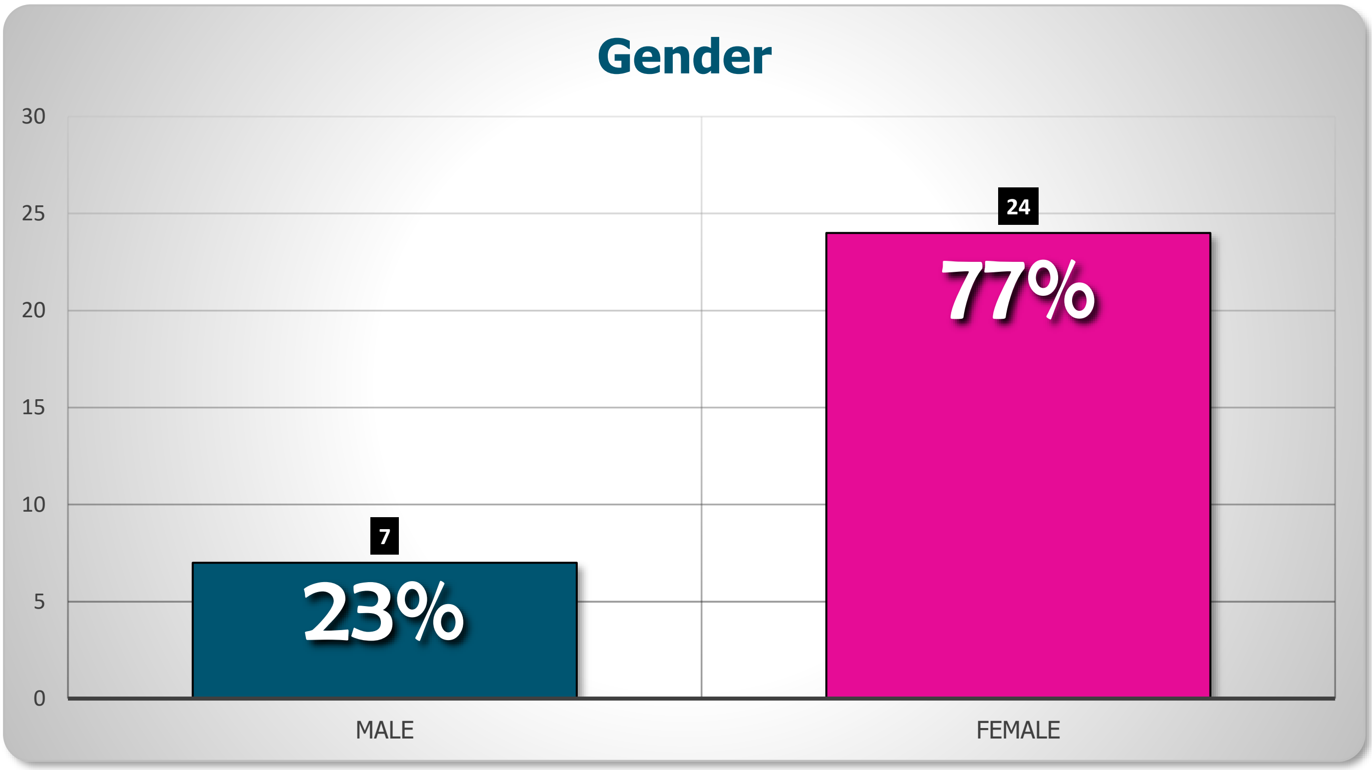
"The time slots for telephone appointments are a joke. I never get called before 11.30, even though sometimes I'm given a 9.30. It's because they want to see the face-to-face patients first, I get that. So just offer telephone appointment patients a time after 11.30, it's not hard."

"We believe that my husband was very fortunate to be under the care of The Christie and have started his treatment at the end of January/start of February 2019. We're not sure what position he would be in now if his diagnosis was later given the backlogs and cancelled treatments etc."

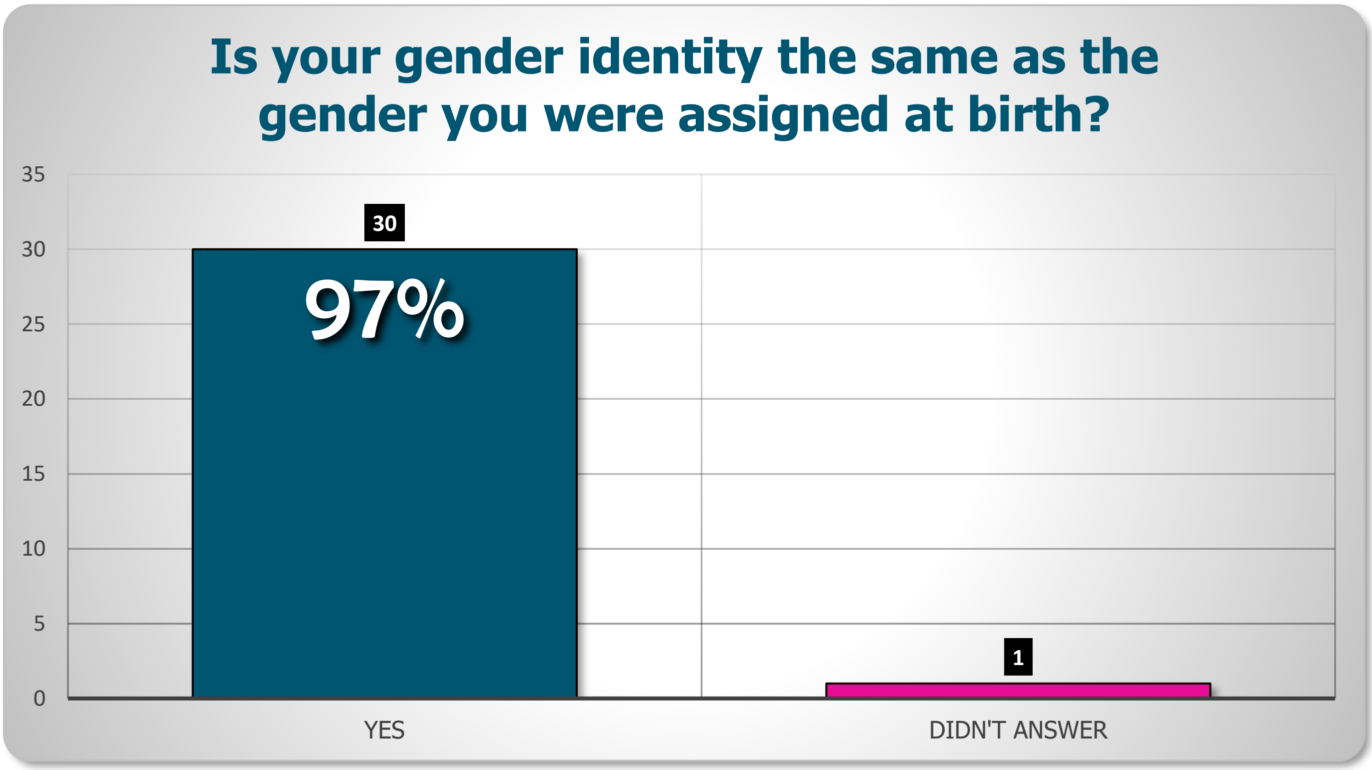
"I am still waiting for a follow up appointment at the breast clinic. The last time I had an appointment, it was March 2020. The remote appointment was with The Christie."

Demographics

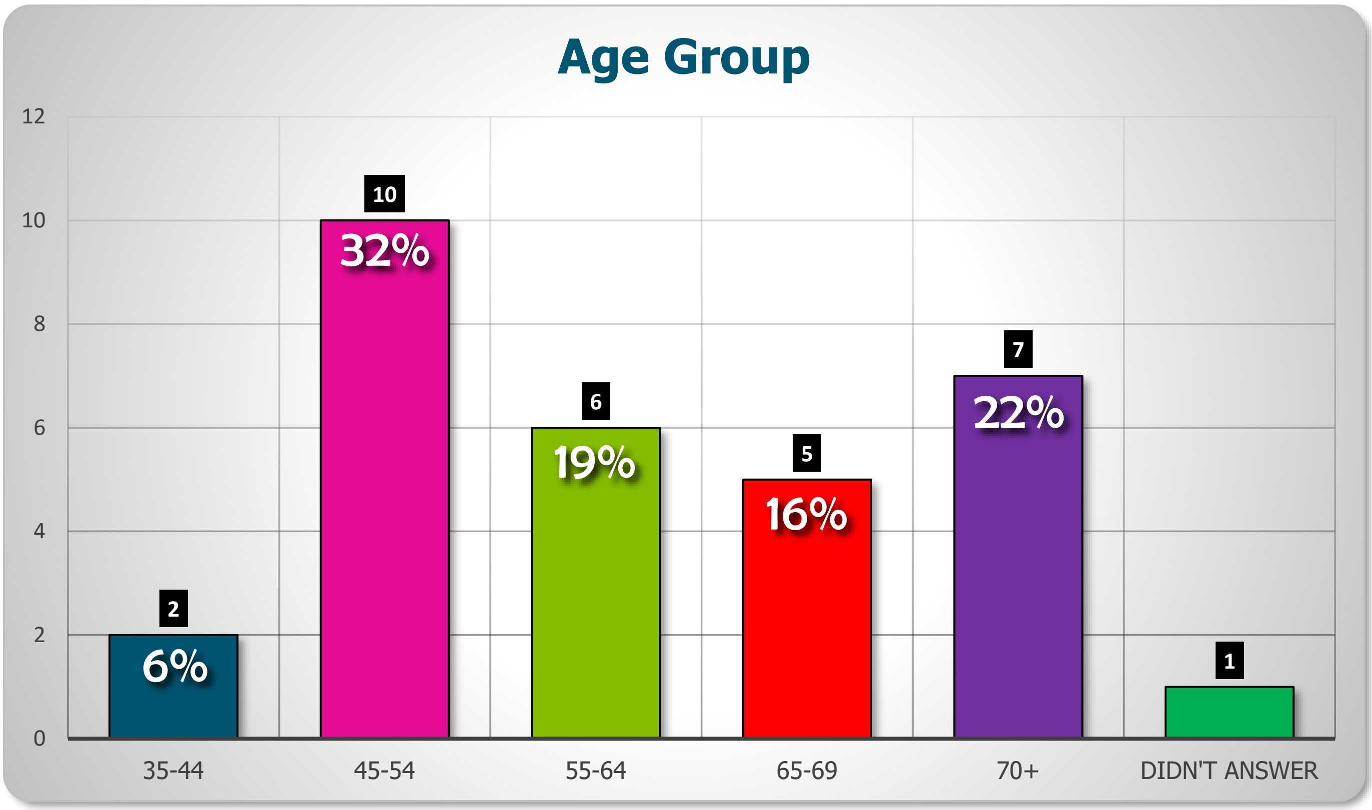
The following information looks at the individual's demographic responses.



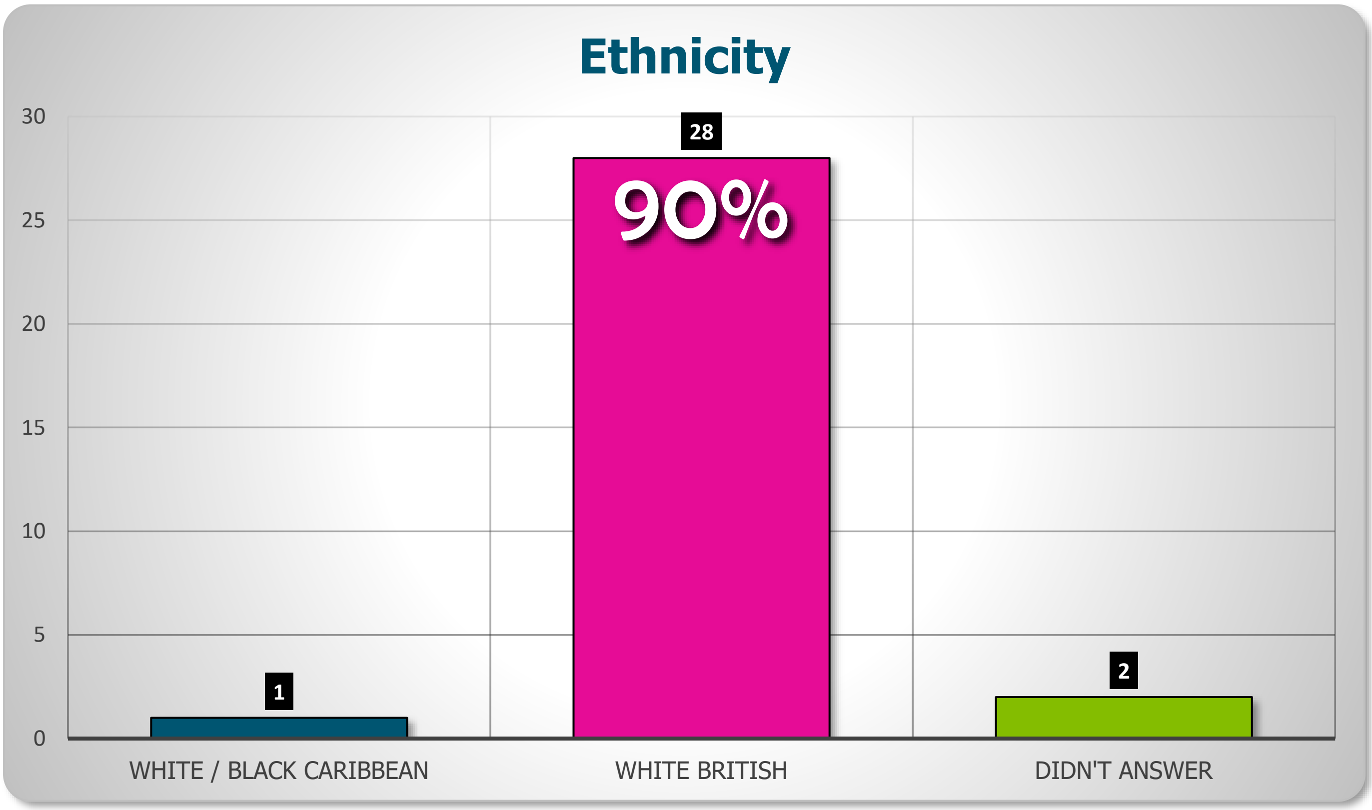
We asked individuals what gender they identify as. 77% (24 people) stated they are female compared to 23% (7 people) who stated they are male.



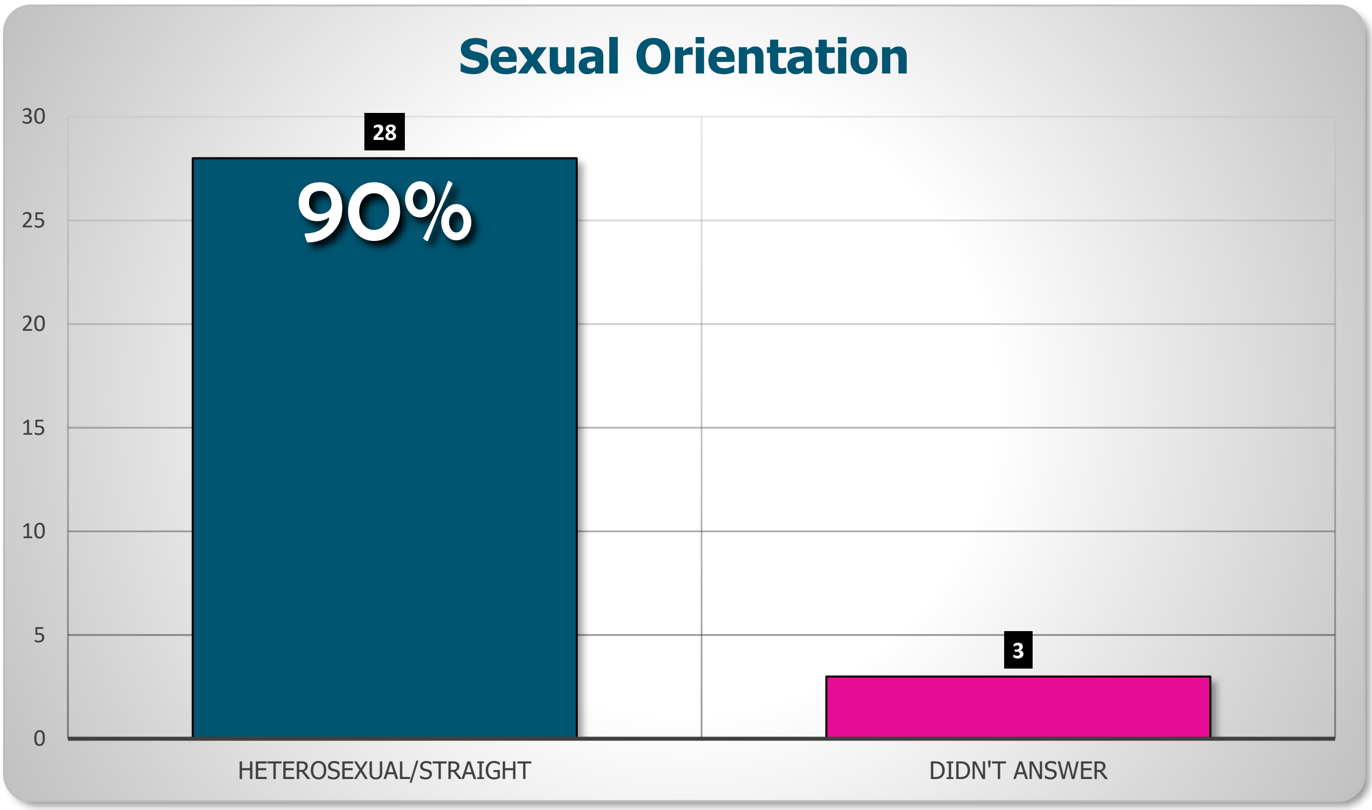
We asked individuals whether their gender is the same as it was at birth. 97% (30 people) stated that it is and 3% (1 person) chose not to answer this question.



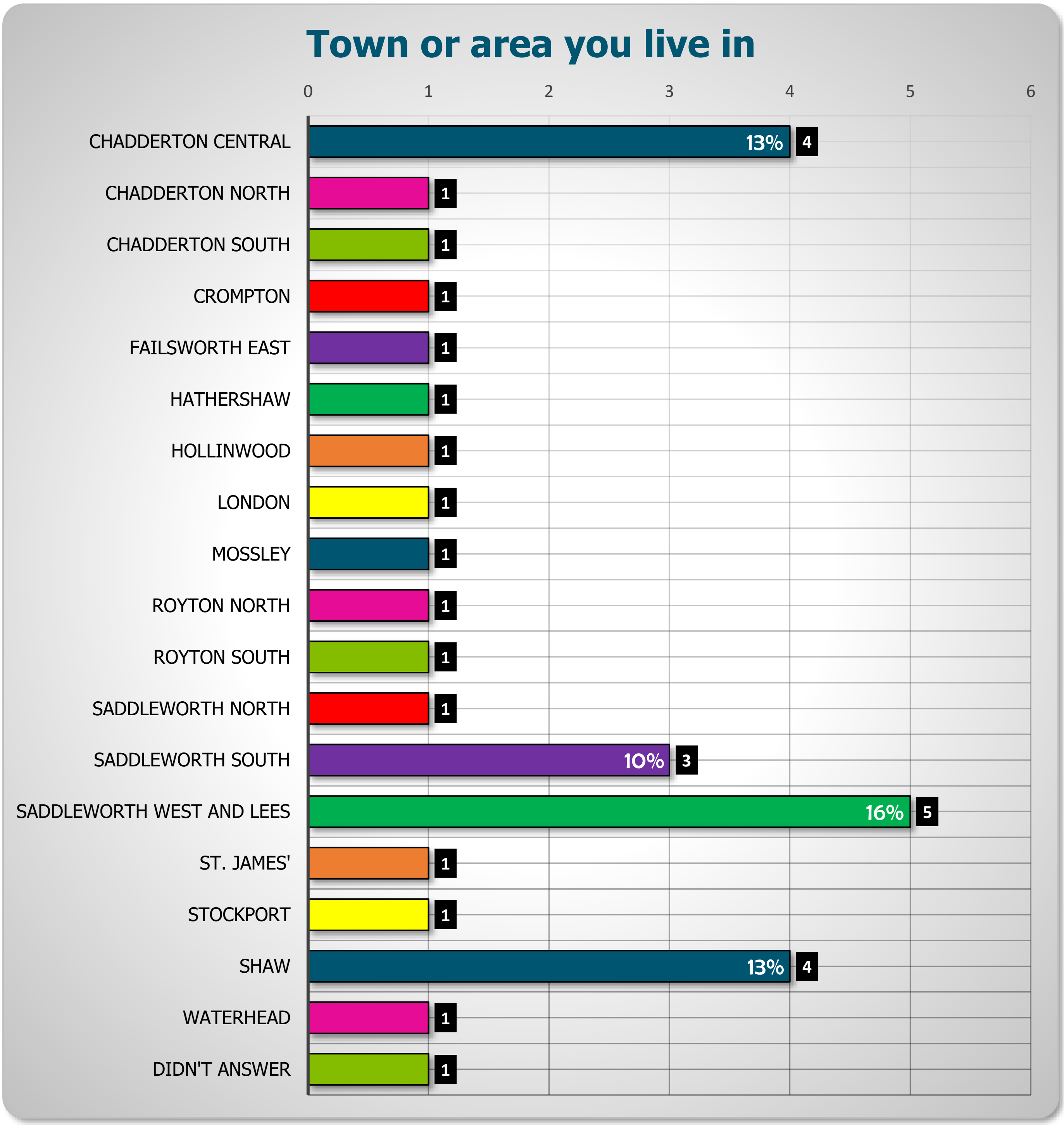
We asked individuals to select their age group. 32% (10 people) stated they were between 45-54 years of age with the next highest response being 22% (7 people) who stated they were 70+ years of age.



We asked individuals what their ethnicity is. 90% (28 people) stated they were white British. 2 chose not to answer this question and 1 person stated they are white/black Caribbean.



We asked individuals to select their sexual orientation. 90% (28 people) stated they are heterosexual/straight. 10% (3 people) chose not to answer this question.



We asked individuals where they live. Most areas of the Oldham Borough were represented within this survey. 16% (5 people) stated that they lived in the Saddleworth West and Lees area with the next highest being 13% (4 people) for both Shaw and Chadderton Central areas.