

Living Well with Cancer in Shropshire

A report into people's experiences of living with and beyond cancer in Shropshire.

Engagement period March – June 2024
Report published 21 October 2024

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If you have an experience to share about the issues raised in the report please do not hesitate to get in touch.

About Healthwatch

Healthwatch Shropshire is your local health and social care champion.

If you use GPs and hospitals, dentists, pharmacies, care homes or other support services in your area, we want to hear about your experiences. We are independent and have the power to make sure NHS leaders and other decision makers listen to local feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice. Last year, the Healthwatch network helped nearly a million people like you to have your say and get the support you need.



We work to make your voice count when it comes to shaping and improving services. We use a variety of methods to find out what people like about services, and what could be improved and we share these views with those with the power to make change happen. Our reports go to:

- the organisations who provide services
- the commissioners who pay for services (e.g. Shropshire, Telford & Wrekin Integrated Care Board, Shropshire Council)
- service regulators (the Care Quality Commission, NHS England)
- our national body Healthwatch England to let them know how local services are working in Shropshire, Telford & Wrekin

We are not experts in health and social care and surveys are just one of the methods we use to put a spotlight on services and ask people to share their views with us.

What would support people to live with and beyond cancer? – Key messages

We also asked people to share with us when things had not gone so well or not gone as they had hoped/expected and their suggestions for improvement.

These can be grouped under the following eight key points, supported by sample quotes:

1. **More personalised support from medical professionals to help patients access information about their condition, treatment and support available (including signposting)**

- 'Listen to individual circumstances.'
- 'Read notes and have some kind of understanding before the appointment. She [carried on] without knowing anything of me as an individual.'
- 'It would be nice to be able to access blood test results remotely via a website or app so I am able to see them on a monthly basis.'

2. **Need for improved communication with patients (including understanding and empathy)**

- 'Talk to the patient, don't assume they won't understand and give them a chance to have someone with them.'
- 'It would be great if you could be contacted as soon as your results come in – I for one would be happy with a phone call whatever the results. Ask us.'
- 'Remind staff that the people they are seeing are human beings and being told you have cancer is devastating.'

3. **Consider the amount, quality and timing of information given to patients after diagnosis**

- 'I would have appreciated being given time for information to sink in then a special session for me to ask questions in regard to my specific condition and the future.'
- 'Lots of leaflets given to read on first appointment. This was overwhelming. So much so that I couldn't read it all until recently. Would have been better

with targeted information face-to-face on simple things, e.g. things I needed post-surgery and possible problems after surgery.'

4. Improved clinical support for patients after diagnosis, treatment / discharge (including increased staffing)

- 'Seeing a doctor more often. Having more physical examinations to reassure you that everything is OK.'
- 'Reinstate funding for the post.'
- 'More support for young women enduring hormonal treatment.'

5. Improved access to additional emotional/wellbeing support and other therapies, including groups/workshops that promote exercise and wellbeing for people living with and beyond cancer (consider terminology, e.g. 'counselling')

- 'It's a very difficult process and such a big psychological change I think they need to intervene earlier with alternatives to medical treatment.'
- 'I really enjoyed the make-up session, you felt so good, we wanted to go out afterwards.'

6. Personalised support and information for families and carers (including at end of life)

- 'Remember the partners are the patients support network.'
- 'Having a link and communicating to immediate family whilst in hospital would be advantageous.'

7. Need for improved communication and joint working between professionals to make sure people are diagnosed early and have access to the right treatment at the right time, and things go smoothly (including improved waiting times and access to parking permits at the hospital)

- 'Chemo should have started sooner and GP should have acted more quickly on health struggles I was having.'
- 'Just do your job in a timely manner... that's all I ask.'
- 'Improve waiting times for GPs to answer calls.'

8. Need for a Shropshire Cancer Network, recognising the importance of community groups and their funding challenges – supported by accurate information and directories for the public and professionals so everyone knows the support is available and how to access it.

- 'If one type of cancer patients needs post-surgery support, then why not everyone?'
- 'Everyone is so focused on what they are doing, there isn't anyone bringing us all together, we don't know what else is out there'.

As we met groups from across Shropshire we heard a huge amount of positive feedback about people running community-led support group, their determination and passion about what they do, for example:

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'There is one person to thank for all of this and that is [], she is a force to be reckoned with but for all the right reasons. We have a lot to thank [her] for'.

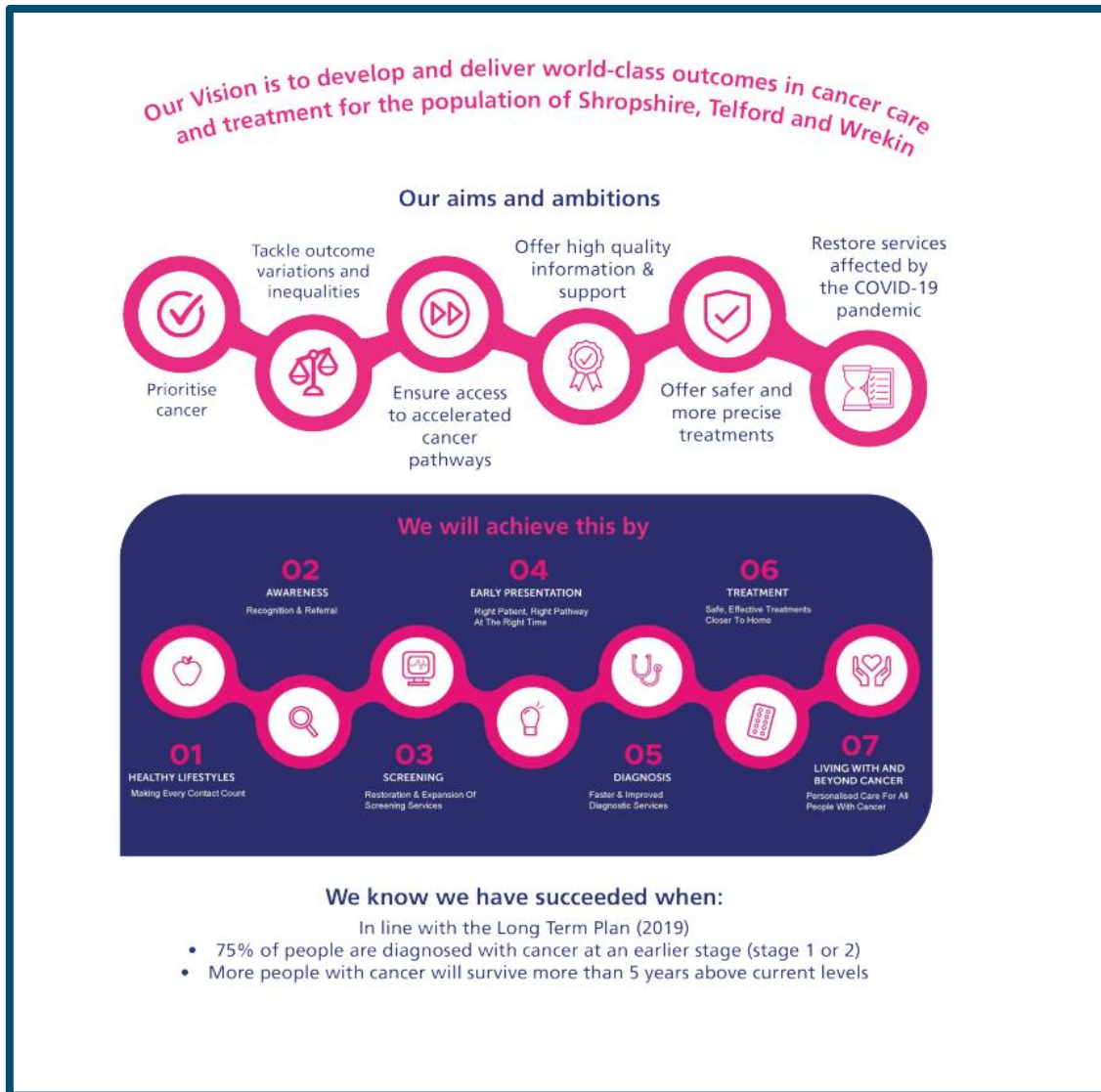
The group is independent of any national charity yet manages to raise thousands of pounds a year for other cancer charities. I'm so proud of the group. Many hours of work by [] and the committee. They were encouraged by our local councillor [] It was her idea to apply. The work continues and the support for people and families who are affected by cancer is now forming a strong network in the South Shropshire area'.

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- **Communicate the findings with the public**

Context

NHS Shropshire, Telford & Wrekin (NHS STW) are working to improve cancer care services for the local population through the implementation of their [Integrated Cancer Strategy 2022 - 2027](#)¹.



In 2024, to help with this aim and to ensure that the patient voice is at the centre of developments Healthwatch Shropshire decided to ask people to share their experiences with us of living with cancer, including the treatment and support they have received within the last two years from hospitals, their GP and community based support from self-help groups and organisations such as Macmillian Cancer support. We asked people to tell us about what has worked well and their suggestions for change or improvement so it could be fed into the ongoing work to implement the strategy and help people to live well with cancer.

¹ <https://www.shropshiretelfordandwrekin.nhs.uk/our-work/cancer-transformation/>

'The Integrated Cancer Strategy for Shropshire, Telford and Wrekin 2022/2027' says:

'Improving cancer outcomes is a system wide responsibility which requires sustained collaborative action to improve prevention, early diagnosis, screening, treatment and living well with cancer' (p.4)

The actions required for the aims and ambitions of the strategy to be achieved by the Shropshire, Telford and Wrekin Integrated Care System² are:

- Promote, encourage and empower people to adopt healthier lifestyles to reduce risks and improve long term outcomes for those diagnosed with cancer.
- Increase earlier diagnosis through increased uptake of screening programmes.
- In collaboration with national campaigns, empower patients to present early with cancer signs and symptoms to promote diagnosis at an earlier stage.
- Ensure prompt access to diagnostic tests and accelerated pathways.
- Providing safe, effective, up-to-date treatments.
- Provide individualised care and support to cancer patients at all parts of the pathway.

p.4

In summary:

- ✓ Support people to have **Healthy Lifestyles**
- ✓ Improve **Awareness and Prevention**
- ✓ Improve **Screening**
- ✓ 'Right patient, right pathway at the right time' to enable **Early presentation**
- ✓ Faster and improved diagnostic services to enable **Early diagnosis**
- ✓ Provide safe and effective **Treatment**

² <https://www.shropshiretelfordandwrekin.ics.nhs.uk/#:~:text=We%20are%20a%20partnership%20of%20NHS%20and%20local>

What we did and who we heard from

In order to hear from as many people as possible we decided to use a range of engagement methods, from February to May 2024, we:

- Created a survey in consultation with the staff from the NHS, including NHS ST&W (e.g. The Senior Cancer Quality Lead) and with The Personalised Care Team in Cancer Services at Shrewsbury and Telford Hospital NHS Trust (SaTH). We promoted it through a press release, our newsletter, website, social media channels and INTune Radio. The survey ran from February to April 2024 and was **completed by 40 people**. (See Appendix 1 p.41 for survey questions)
- Attended Cancer Champions meetings and cancer support groups across Shropshire to promote the survey and **heard 226 people's experiences** (included throughout this report)
- Visited Cancer Charity Shops and displayed information on community notice boards and GP information screens to raise awareness of our project
- Attended events, including the annual Lingen Davies Snowdrop Walk, Prostate Cancer screening event, an awards evening for the volunteer nurse team who facilitate the screening events, the '5K your way' Cancer Support Group and Shrewsbury Park Run to **raise awareness with 115 people**.
- Planned to visit Robert Jones and Agnes Hunt Orthopaedic Hospital to conduct an Enter and View visit involving our [volunteers](#)³. (This visit was not completed at the time of writing this report).
- Met with **nine professionals** working directly with people with lived experience of cancer or responsible for implementing the Cancer Strategy.

We engaged with **390 people across Shropshire**.

For the full list of our engagement activity please see Appendix 2, p.47

³ <https://www.healthwatchshropshire.co.uk/what-can-i-do-volunteer>

What people told us

The survey

40 people completed the survey:

- 29 (73%) women, 10 (25%) men, 1 preferred not to say
- 23 (58%) said they had disability or long-term health condition and 7 (30%) of these were also carers

Feedback from people completing the online survey will appear through the report.

37 people shared their experiences including 3 people responding on behalf of a family member, including two who had recently passed away.

- 24 people (65%) shared a **mixed experience** (both positive and negative)
- Eight people (22%) shared **positive experiences**, for example



'A total professional and exemplary experience which offset all of my personal worries regarding the treatment I received. In fact it was a joy to attend every treatment session because the staff made myself and my fellow patients feel very much at home.' (Now a Cancer Champion)

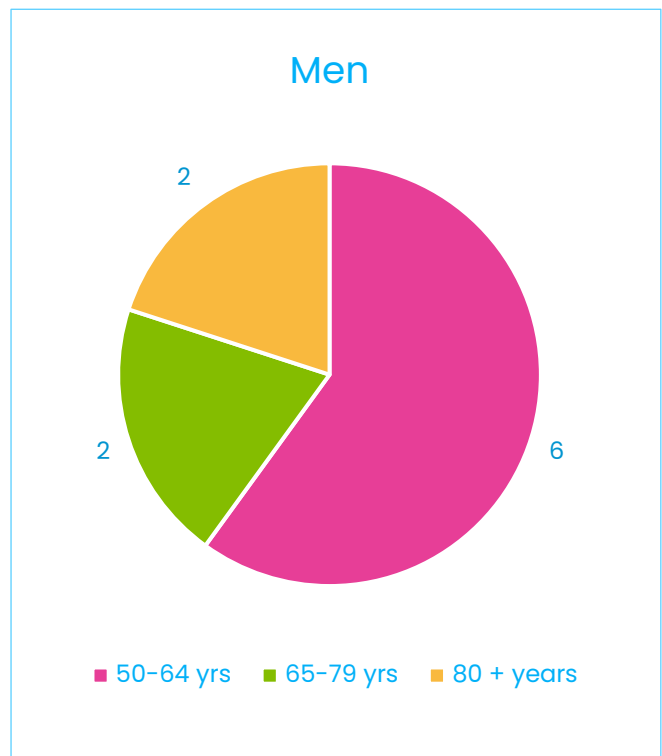
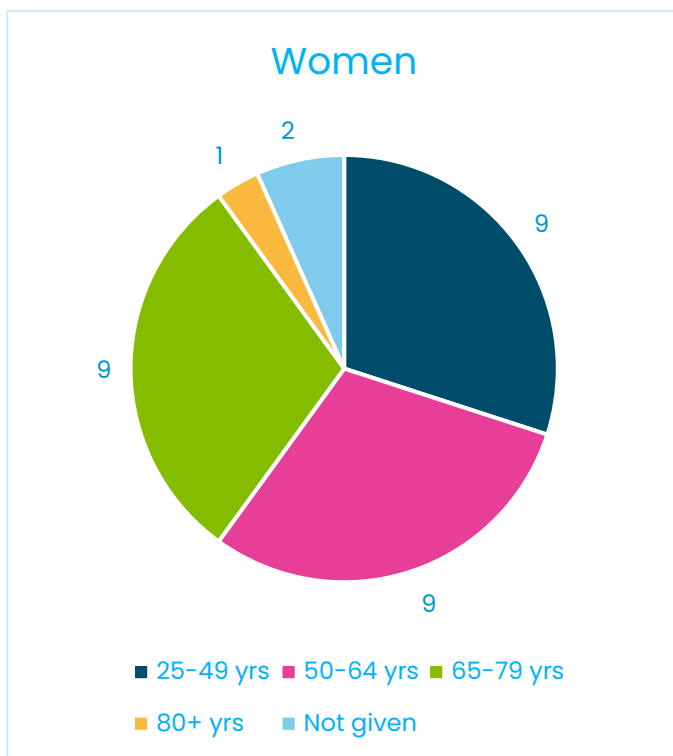
To see all positive comments from people completing the survey, see 'What's working well' p.19.

- Five people (14%) shared only **negative comments**, for example



'Delays, promises broken, waited 7 weeks to see an oncologist after I knew my disease was metastatic. Having to fight for everything. Promised an oncologist spot every 3 months, last time was 5 and half months ago. Meant to have a nurse appointment every month, not had one for 4 months. Multiples PALS complaints. Nothing changes.'

Age of respondents



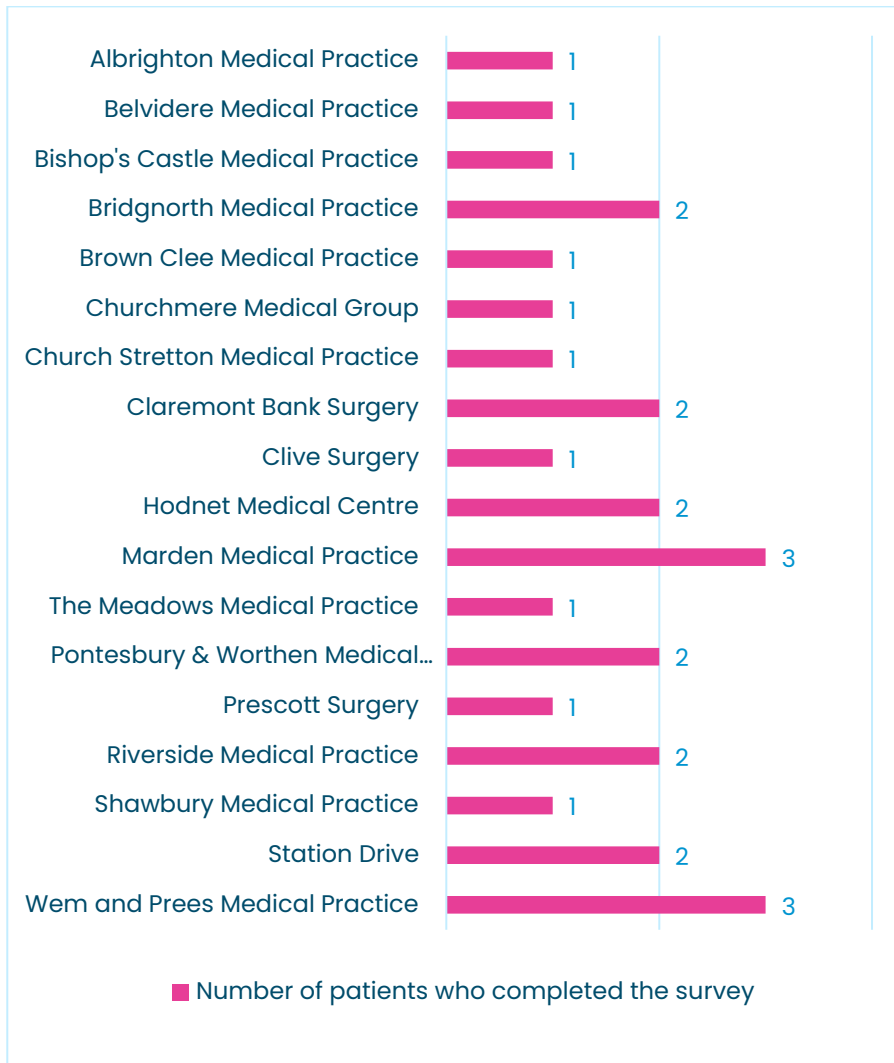
At the time of completing the survey:

- 18 (62%) women were still receiving treatment,
- 6 men (60%) were still receiving treatment
- 2 people were 'unsure' if they were still receiving treatment, one was completing the survey on behalf of a relative.

We heard from patients from 18 Shropshire GP practices and 12 people registered with a GP outside the Shropshire local authority area. Including one person who had been registered with

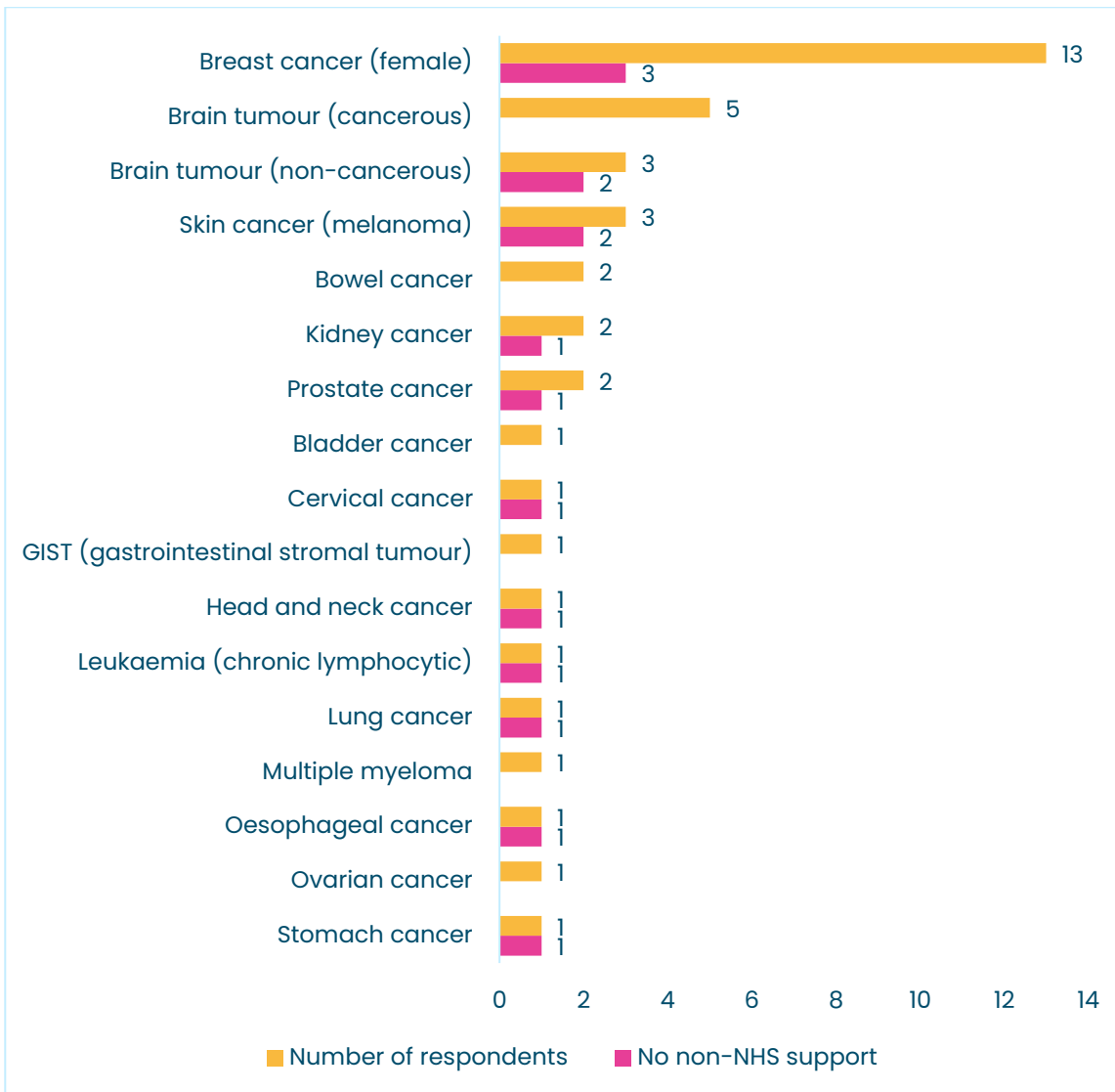
a GP in Herefordshire when diagnosed, three people registered with practices near the Welsh border and eight registered with a practice in Telford & Wrekin.

Shropshire GP Practices people were registered with



Your condition

We asked them to share the type of cancer they had or were receiving treatment for. We also asked people to tell us if they had received no support beyond that provided by the NHS service – 15 people said they hadn't had any additional support.



Where are/have you received your treatment?

32 out of 40 people (80%) had received the majority of their treatment at Royal Shrewsbury Hospital (RSH) including 12 out of 13 people with Breast cancer. Five of these had been treated at both RSH and the Princess Royal in Telford.

One person with Breast cancer had received treatment at the Nuffield in Wolverhampton.

One person with Head and Neck cancer said they had received care from both RSH and the Princess Royal in Telford (PRH). Another person said the majority of their treatment for Head and Neck cancer took place at PRH.

We were concerned that some people might be travelling out of county to receive their treatment rather than getting care close to home. However, it seems that only one person out

of the 40 respondents was travelling from Shrewsbury to the Queen Elizabeth Hospital in Birmingham for their treatment for skin cancer. They told us:

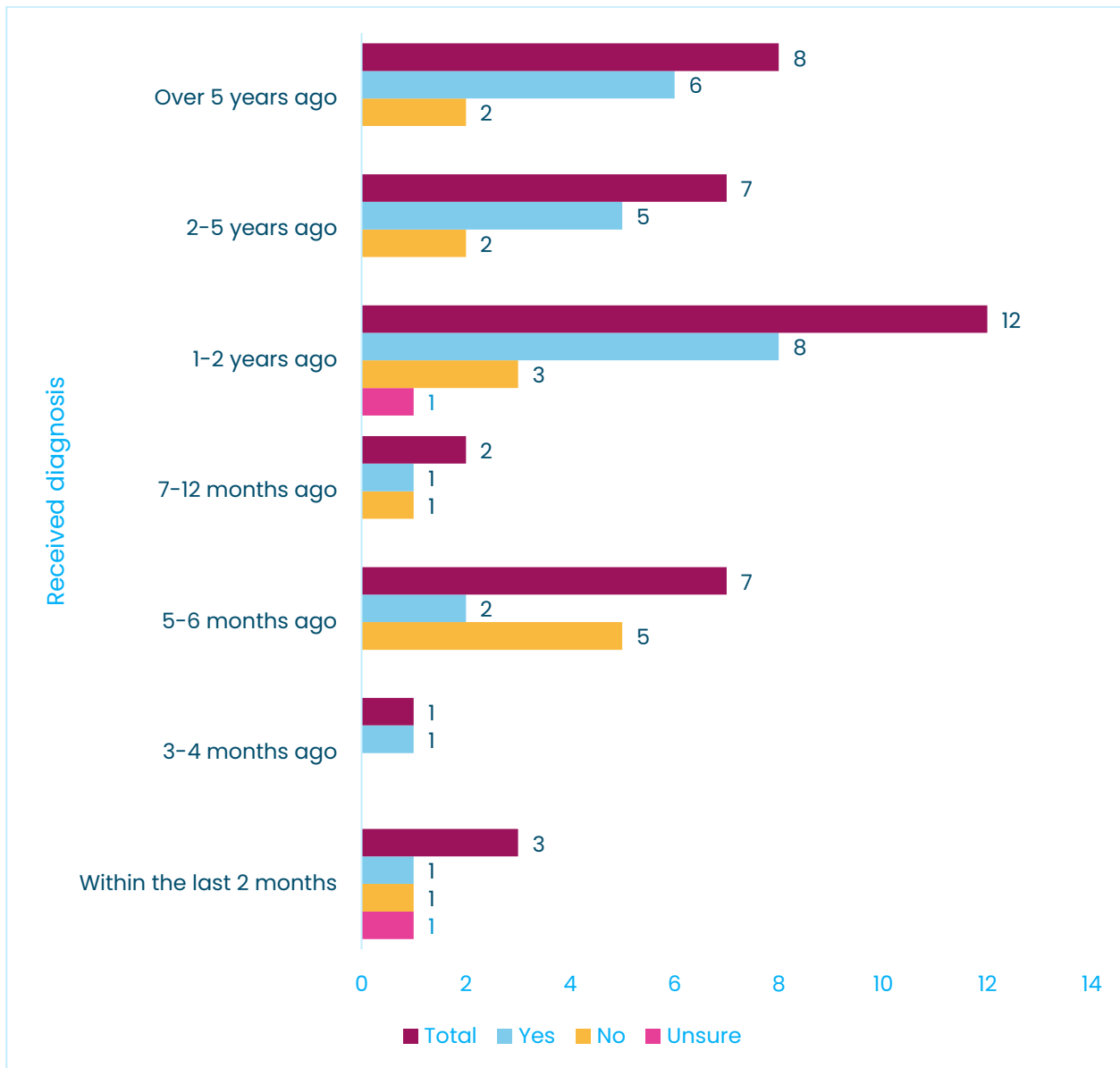


'Waiting for results causes a lot of anxiety and can really impact your health so it would be great if you could be contacted as soon as they come in - I for one would be happy with a telephone call (whatever the results) although I know some people would prefer face to face, but I think it would be good to ask us.'

Other care centres we heard about:

- Health Harmonie (community health care provider) - 1 person with Skin cancer living in Telford.
- Hereford Hospital - 1 person with Cervical cancer living in Hereford at the time.
- Queen Elizabeth Hospital, Birmingham - 1 person with skin cancer from Shrewsbury and 1 person with Multiple myeloma (cancer of the bone marrow) living near Shrewsbury but the majority of their treatment was being provided at RSH.
- Wrexham Hospital - 1 person with lung cancer living near the Welsh border

When did you receive your initial diagnosis and is your treatment ongoing?



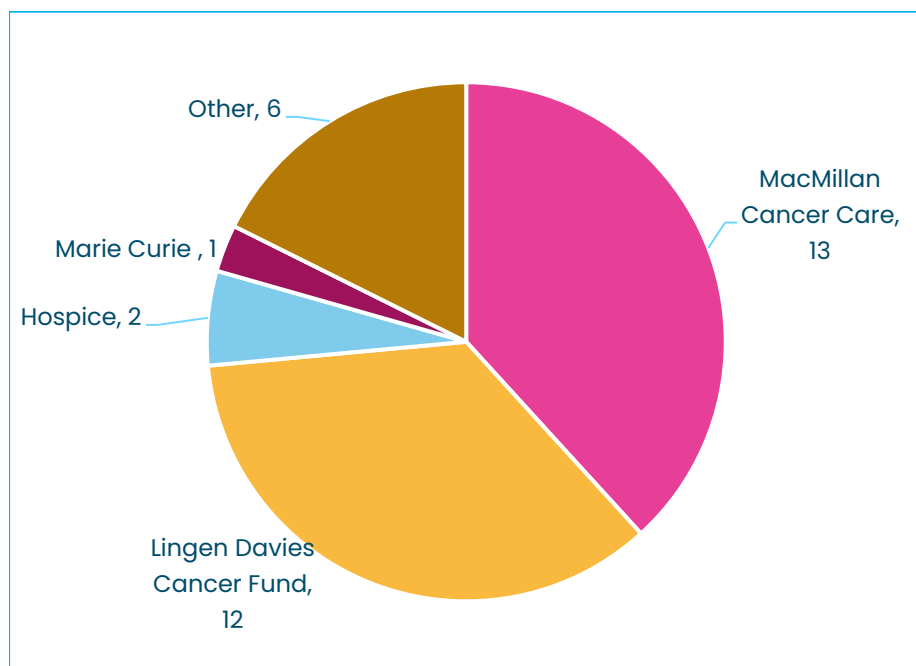
Two people said they were ‘unsure’ if their treatment was ongoing:

- The person diagnosed with breast cancer 1-2 years ago said they had had a mixed experience but overall it was ‘an excellent experience’. However they did say ‘following my surgery no-one ever contacted me re ongoing support’.
- The second person was completing the survey on behalf of an elderly relative with head and neck cancer. They said ‘it’s appalling that [my] relative wasn’t told that a cancerous growth had been removed.’

Which services outside the NHS supported you and/or your family after your diagnosis

Non-NHS support

Twenty five people (63%) had received support from agencies not involved with providing their treatment, including five people who had received support from two agencies. Three of these were still receiving treatment for cancer including two people with Breast Cancer and one person with Multiple Myeloma.



Other:

- The Bennett Centre (Stoke)
- Blood Cancer Uk
- Brain Tumour Support Group
- Cancer Research
- Local Self-Help Group (Telford)
- Sightloss Shropshire

No additional support

Fifteen people (38%) said they had received no other services or support outside of their NHS treatment. Six of these were still receiving treatment for cancer and four of these have had their diagnosis for over a year.

Those who had received no other services or formal support included:

- Three of the 13 women with breast cancer, two diagnosed between 1-2 years ago (one was no longer receiving treatment) and one diagnosed within the last 5-6 months.
- Two of the three people with a non-cancerous Brain tumour (one was no longer receiving treatment)

A patient who has completed their treatment for Prostate cancer said:



'I believe that [my GP] went out of their way to provide me with all of the information that I needed and gave me the opportunity to have my say.'

A patient with a non-cancerous Brain tumour said that during their biopsy at RSH:



'I did not like that my partner had to wait in a different area this was for nearly two hours. Remember the partners are the patients support network.' However they also reported that 'Staff are all very kind and caring.'

One person who was completing the survey on behalf of their mum who had died from Lung cancer in Wrexham Maelor Hospital just a week earlier said:



'[There was a] lack of support. I spent hundreds of hours on the phone. Recently found out [post of] hospice mentor / head of has been stopped.' 'Hospice Director [needs] to make things happen without having to go through multiple agencies ...'

The people we met who were or had received cancer treatment (e.g. support groups, events) and those co-ordinating support groups

What's working well

When speaking to members of the public at support groups or one-to-one outside of the sessions we asked them for their views on what works well and what needs improvement. We also spent time with the group coordinators and asked them the same questions but also what support they need in order to deliver their objectives more successfully.

Many people shared positive feedback about:

- The quality of their care and treatment and response times
 - The treatment environment
 - NHS staff who were proactive and encouraging (including PCN Cancer Coordinators, the Breast Cancer Navigators, The Personalised Care Navigators and Facilitators, the Oncology Nurses, Radiotherapy Team, etc)
-
- 'The actual diagnosis went like clockwork, no issues at all. I can't fault the treatment. From diagnosis to being in the op theatre was no more than 1 month'.
 - 'It's difficult to leave, you feel so supported and well looked after. We are so fortunate in Shropshire to have such a centre, if it wasn't for them, I wouldn't be here'. (Care received at Lingen Davies at RSH)
 - 'The chemo area is nice, you can take anything, phone, laptop, iPad, books. You are provided with sandwiches, tea, coffee and biscuits. I went with her on her first session, and they offered me lunch too. The staff are really friendly and really nice, they constantly check up on you to see if you are okay. I couldn't criticise it at all. It is a very friendly place'.
 - 'It's the sort of thing that makes the whole treatment so pleasurable'. (Care received at Lingen Davies at RSH)
 - 'I had wonderful attention in RSH, I have no complaints and I was in there for 3 weeks'. (Oncology day surgery)
 - 'The nurses wanted you to live as best as you could while you were having your treatment.'

- 'Ward 23 & AMU (Acute Medical Unit), the staff are brilliant. I can't fault the staff on 23 and I only have positive things to say about my time on AMU'.
- 'The support we have got from Oncology has been absolutely fantastic.'
- 'The radiotherapy staff were fantastic.'
- 'The breast navigators are brilliant they are easy to get hold of.'
- 'People can be very quick to judge but not very quick to compliment. I can't complain at all about the treatment I received.'
- 'She enrolled me, she said "You would be perfect for it", so she just did it, "You're going to that" and yes it was lovely and then I was enrolled at the men's shed for the men's group, 'Men Like Us'... a horticultural course. [She] was there [at Men Like Us] so she introduced what was happening, all the programme, she said "You must go to that and that". (About a member of The Personalised Care Team at SaTH)
- 'The parking guys (at SaTH) are fabulous.'

Positive feedback from people completing the online survey:

- [My GP] arranged for me to have a routine blood test and the results showed an elevated PSA. The practice phoned me ... the same day as the results came back and called me in the very same day for an appointment with a GP. We discussed the test, results and a way forward. This resulted in a repeat blood test one month later... The result was in the normal range. I believe that Marden went out of their way to provide me with all of the information that I needed and gave me the opportunity to have my say.
- 'Health Harmonie have been fantastic. They saw me almost straight away, did my surgeries and had my results within a few weeks.'
- 'The procedure was carried out almost instantly.'
- 'It took 3 weeks from my GP referral to having my mammogram and biopsy. Three surgical ops, mastectomy, reconstruction, chemo, radiotherapy all went well.'
- 'At the commencement of my cancer diagnosis in 2011 and again in 2016 when it metastasised I felt helped by the complementary therapies via the Hamar Centre'
- 'Quick appointment and surgery. Staff were very caring.'

- 'Relative lives alone and woke up the next day with massive breathing difficulties. Contacted the GP who called an ambulance. This part of their treatment was brilliant.'
- 'Everything went well. Appointments were always prompt. Staff were fantastic. I was always kept informed.'
- 'I have no complaints. The Radiotherapy Team were amazing and really supportive and my CNS [Clinical Nurse Specialist]. They are really helpful and easily contactable.'
- 'Mostly very positive, efficient and caring. Doctors, sisters, nurses, secretaries and pharmacists have been supportive and friendly.'
- 'I have absolutely no complaints about my experience. Everyone was amazing and thoroughly professional from start to finish.'
- 'I have incurable bowel cancer so I'm having on-going chemo, the treatment I am receiving is incredible.'
- 'It took a couple of months to see a consultant but when I saw him he knew straight away I had kidney cancer. Surgery was organised quickly.'
- 'I have follow up video consultation with The Bennet Centre post surgery. [Doctor] has been such an incredible support to me and my husband.'
- 'I was diagnosed at the start of Covid yet I never missed a single day of treatment thanks to the Radiology Department. The specialist tumour nurse has been very supportive ringing me regularly to check in as I am still having regular scans to keep an eye on my tumour.'
- 'RSH have been fantastic throughout, literally fabulous.'
- 'Treatment has been amazing.'
- 'Second palliative care nurse a lot better and provided family with details on how to request a larger bed.'
- 'I was quickly diagnosed, from GP visit to diagnosis took six weeks.'
- 'Routine mammogram picked up my breast cancer. Supportive medical team through each appointment. Everything was explained well. Radiology and oncology team were supportive and made it less frightening.'
- 'Overall my experience has been excellent. [The team] at the Lingen Davies Centre has been exemplary.'
- 'The nursing staff when I had the operation were excellent. The subsequent care at the oncology department is much better and I feel I am being treated with dignity, care and compassion.'

- 'A lot of support primarily with the initial diagnosis, surgery and radiotherapy. Staff were extremely caring at Lingen Davies and the Brewster Care Nurse at Telford was so supportive with helping me to tell my children.'
- 'I was really pleased with the care and treatment that I have received over the last 22 months.'
- 'The care from Shrewsbury and Birmingham was very good.'
- 'Consultants and doctors – Brilliant.'

We heard from one person about their positive experience of working with the Cancer Coordinator at their GP practice/Primary Care Network⁴ and how they helped them to start exercising again and going back to Park Run.



'She rang me and said "would I like an appointment or would like to talk to her about things that she could support with, or she could direct me to be supported with" and she put me on to the iCan⁵. I was not well for a long time, and I didn't feel that I was ever going to sort of recover properly, but she directed me to iCan and it was amazing. Then, 5K Your Way came and I came to the group, the iCan exercise class and then I started coming here. I had done Park Run before this, but I had lost the confidence to come back.'

⁴ GP practices are working together with community, mental health, social care, pharmacy, hospital and voluntary services in their local areas in groups of practices known as primary care networks (PCNs).

⁵ iCan is a cancer rehabilitation programme for those before, during and after cancer – '5k Your Way' went along to a meeting to speak to the people there.

What would support people to live with and beyond cancer? – Key messages

1. More personalised support from medical professionals to access information about their condition and support available (including signposting)

Many of the members of community led cancer support groups told us that they didn't feel supported enough by clinicians and medical professionals, including a lack of information post surgery/treatment (including signs and symptoms and how to look out for secondary cancers), lack of empathy and appropriate guidance.

- 'She's had no information given her on underwear / bras... just said, go and have a look at [M&S] they have got a good range, but in fact there are people that do post-surgery bras and things. She said it's really hard and she finds that embarrassing just walking into [M&S]... It's the smaller things that are the things that caused her the most grief or worry or trauma really. Such as being asked just to strip off in the consulting room and they're all stood there talking when obviously it's a really personal thing'.
- People attending a Stoma support group told us, 'None of us were told about hernias and that is a common thing with everyone here' and there is very little information about having sex when you have a stoma bag, 'There must be a need for it for some people, there's got to be'.
- 'I go once every 3 weeks and have done for the last 4 years for chemo day treatment, it was about 2 years before I knew the dental care rules. The rule for cancer patients for general anaesthetic is that you need to have it when you a week free of treatment before and after, but this isn't shared or common knowledge. There would be things that it would be really helpful to have information on, I could have had an anaesthetic without knowing the rules.'
- 'A list of what to look out for would be helpful'.
- 'If you don't ask you don't get.'

Feedback from people completing the online survey:

- 'The referral process wasn't too easy as the consultant appeared to offer mixed messages and the mechanism of the referral could have been much clearer.'

- Taken in for a biopsy, kept overnight and released the next day. Absolutely no information supplied about the fact it wasn't just a biopsy that had been taken... That extra week of trauma would have been prevented if the simple information of the removal had been shared after the original visit. Appalling for someone so frail.' (Person completing on behalf of elderly relative)
- 'No assigned nurse. No follow-up. Total lack of any follow up or Clinical Nurse Specialist was terrifying.'
- 'I did not engage well with my initial consultant and asked if I could change – he made me extremely uncomfortable and terribly anxious, stating I might have to go to Wolverhampton for treatment "If they would have me".'
- 'The consultant was extremely rude. It was obvious she hadn't read my notes. It was a confusing time and only time I cried. It was implied I was an idiot and didn't know what I was talking about which was not the case. The treatment I received was awful.'

People told us that they only became aware of the group/s they attended through word of mouth and not because they had been signposted by a professional. Many said they had to locate these support systems themselves and had difficulty in doing so.

- 'There are things going on, but people don't know about them.'
- 'I found that I struggled because I kept putting in the search engine about groups that are near to me. It just didn't show up.'
- 'She's lovely but she took some trouble tracking down.'
- 'I didn't learn about this group through the hospital, I had to do my own research.'

The people running groups shared their concerns

- 'I do a lot of work connecting with people, trying to get the message across, the worst thing, it's hard to get the healthcare professionals to be telling patients about us.'

2. Need for Improved communication with patients (including understanding and empathy)

People told us they often didn't get the simple information they need, for example what to bring with them to an appointment.

- 'Having breast cancer is very personal and you would expect staff to be considerate but when she would go for treatment they would ask if she brought a vest top with her, yet they had never asked her to bring one.'
- There is a 'lack of communication, between hospital and patient, wards and hospital services, and between departments.'

We also heard from people about the impact of how professionals spoke to them, the lack of empathy:

- 'The Dr asked her if she had a DNR in place which she responded with no, as she had no intention of dying yet and wants to live as long as possible for her 2 children. She was so distressed after being told she needed a DNR, she felt like there was something she wasn't being told, that she must not have as long as the 3 years remaining that she had previously been told and that things were more serious than she was being made aware of'.
- 'It is what it is' (phrase used to a Breast cancer patient)
- 'Sometimes you can be treated more like a number and not a person with actual fears and feelings'
- 'My nurse was offhand and dismissive'

A relative we spoke to shared their mum's experience of staff ignoring her wishes when being given her diagnosis:



'Staff tried to deliver the diagnosis to the patient but the patient said she didn't want to know without a relative present. The staff returned the next morning and told her the diagnosis even though she did not have a relative present as previously requested. Later that morning a family member called to request what time they should come in to support the patient when being told about her diagnosis, only to be told that the patient had been told already which was against her wishes. It was a lung cancer diagnosis which was possibly terminal.'

Some people told us they felt communication was one sided, for example they had asked for help or information but were left feeling ignored.

- 'I rang and asked a number of questions, and I didn't get any answers, um, I often didn't get a call back.'
- 'Whenever I try to get in touch with my cancer nurse, I feel like I am a burden. I called, emailed and got no reply from the cancer nurse. Nurse doesn't reply or call back when she says she will.'
- 'I am seen in Oncology once every 3 months, but they never let me know how I am getting on. I am still trying to get to see someone to let me know. I have never seen anyone about my results.'
- 'They said they would keep in touch, but I only heard from them once, but it just feels like a tick box exercise.'

We also heard that sometimes professionals assumed the patient knew or understood the information and was comfortable with their diagnosis:

- "Suddenly I've got this piece of paper that's saying I'm attending the Lingen Davies Ward just handed to me, no explanations and now I've got to go and give that to the carpark man". Those are the little things amongst all the massive things that have been going on that have really upset her that she's cried about.'

Some people felt there was a lack of understanding from the NHS about the impact cancer has on their day-to-day lives and families

- 'I am due for an appointment every 3 weeks but whenever I go for treatment and then need to reschedule afterwards there is always concern on if they have got the availability for the next appointment and if they can fit me in. It makes it hard as I try to live outside of my diagnosis, yet I need to keep my availability free as my diagnosis controls my schedule'.

Feedback from people completing the online survey:

- 'The only thing I was disappointed about is that I received my cancer diagnosis via a letter in the post. I opened it whilst sitting next to my three young children not having any idea what it was.'

- 'Reception staff calling out on the desk "Chemo patients to the chemo department" or similar is not good, you feel like cattle, but you take it because you need treatment. Being constantly weighed and height checked but no one explains why. People constantly asking for a date of birth really ages you.'



'Initial diagnosis was very clinical and cold – I felt I was treated like a number and being processed when I had [surgery] there was no communication at all. At the follow-up to get the test result there was no time to discuss options and I felt pushed down the route for the kind of surgery the consultant wanted. When I phoned to ask if a mastectomy was a better option I felt like I was being a nuisance.'

3. Consider the amount, quality and timing of information given to patients after diagnosis

People told us that how information was communicated was important to them.

Some people felt overwhelmed with the 'leaflet pack' that they were given when they received their diagnosis. Very few of them referred to or looked at the resources they had been given because of this and were concerned they had potentially missed information they needed. Some people suggested that this information would be better given in person at a time and pace suitable for each person.

- 'They gave me too many booklets... and I was like, I really can't get this into my head just yet, I need to get my cancer treatment through first before I do that. And I think that is where a lot of these things were missed because they were in the books but people don't read them. I think it would be better is someone told you, "Well you can go to this group and that group".'
- 'You know when you start your treatments, or just before your treatments, it would be good to have somewhere to go... I could have done with someone saying to me "well there's this group you can go to".'

Some people told us there was a lack of communication from clinicians and medical professionals in between diagnosis, treatment, discharge and beyond.

- “I wish they would communicate more after diagnosis; it was 15 weeks until treatment started for me. I was in shock, trying to absorb what was being said. I was given my diagnosis but then had to wait for details of what happens next. Consultants focus on the diagnosis not the treatment.”

Feedback from people completing the online survey:

- ‘I’m someone who wants information so I contacted Kidney Cancer UK who offered counselling and Macmillan who offered practical support. I visited the Hamar Centre at RSH and attended some courses and couldn’t believe the difference in support available to other cancers. I’ve learned a lot since 2018 – mostly by my own efforts.’

4. Improved clinical support for patients after diagnosis, treatment / discharge (including increased staffing)

People told us they felt well supported during admission to hospital but this support varied at different stages of their treatment.

- ‘When I was in hospital, I felt very connected to the people. Seeing the oncology nurses was absolutely brill. When I was on oral chemo I felt more alone’.

Feedback from people completing the online survey:

- “My treatment was good but because it was close to Christmas I came home early, I left before I felt ready. No follow-up care whatsoever.”

Some people told us they had felt abandoned after their diagnosis:

- ‘There is a focus on diagnosis, with the effects of chemo you just have to get on with it’.
- ‘I felt abandoned after confirmation that I had cancer. You should not be made to feel guilty to ask for additional help’.

- 'Feel completely abandoned and in horrific pain. No follow up, just "Go to your Dr and get pain killers". Had such bad pain and side effects of the drugs and I had no one to go to so I went back to my GP'.
- 'I felt the support was quite poor really after [diagnosis].'

One person shared that in their case, staff hadn't even guided them out of the clinic, so they felt literally lost:

- 'You are taken through the back door exit after diagnosis. I didn't know where I was or how to get back to my car'.

We heard from some people that they felt there were not enough staff available, including specialists and this meant people felt there was a lack of consistency and/or their wishes and needs were not always met:

- 'The NHS is so overburdened, so there are not enough people to consider you as an individual.'
- 'What they need is a stoma expert, they have stoma nurses, but they aren't experts'.
- 'Second, lack of staff. Lack of Radiographers, scan results take 6+ weeks and because they are often sent abroad for analysis they can be of variable quality. Lack of nursing staff, in CDU (Clinical Decision Unit) this can result in the worry that an appointment may not be available on the date that the routine 3 weekly chemo is due'.
- 'Experiences vary between consultants. I don't feel I have a set oncologist'.
- 'I think the nurses on the Oncology Day unit are much more stretched than they were 4 years ago, it can sometimes mean that you feel unsupported'.
- 'It's bursting at the seams. It is serious because the GP is the gatekeeper to your treatment'.
- 'We had made her a personal preference file / end of life file but none of the staff spoke English or had the time to actually read and consider her preferences before they had to leave again for their next job.'



'We are deeply upset that recent cuts mean the Patient Care Navigator (who supports our Tumour Oncology Clinical Nurse Specialist) has been cut. She was always at the end of the phone/email, ready to feedback our worries/problems to the Clinical Nurse Specialist who has a massive workload. We hope the hospital brings back this position to we don't just end up in A&E looking for help.'

Some people felt that resources/support were taken away when they still needed them.

- 'I was supposed to see the Stoma nurses and I have to say, although they were very nice people, it took them 12 months to sort out the right kind of colostomy bag for me and stuff and it was horrible, and it leaked all the time, so I lost confidence about going out and stuff. So, it was after 12 months, and they discharge you after 12 months because they don't have the resources to keep seeing you. And I think that's not long enough'.
- 'All of a sudden going from getting all of the support and then it stops'.

5. Improved access to additional emotional wellbeing support and other therapies, including access to groups/workshops that promote exercise and wellbeing

Some people told us that the emotional support from their clinical team wasn't enough and they needed additional mental health support. People said that the 'little things' and the 'smaller touches' can make the biggest difference and how important it is for them to be included as part of their care.

- 'I don't think that they give enough thought to the holistic side of things, so it's sort of like you've got breast cancer... But then I don't think she's had any understanding as to how that has affected her mentally and it has affected her mentally, it's quite traumatised her. So, she is left then to ring her doctors. And the doctor says, oh, here's a sick note, do you need sleeping tablets? She has had a referral to speak to a counsellor, but she hasn't taken them up on that yet. But you know, I thought that they interlinked with holistic therapies.'

- 'Yeah, they need to look at it as a whole. You need people to talk to, you need people to just, do things with.'

We also heard that some people found it hard to admit they were struggling and had poor mental health and so accessing counselling can be quite challenging. Some people would have preferred to be referred to counselling rather than told they could access it themselves as this was not something they felt able to do. People also told us that the terminology and phrase 'counselling' can be off-putting and that perhaps more people would seek support if it was promoted differently.

- 'I think she's terrified of this, but it's just like here it is, enrol yourself in it, get yourself started. Rather than having somebody say, oh, you know, you've been referred to oncology and you are having this treatment done, have you thought about taking up counselling?... Because counselling always suggests mental health. And then you think, have I got mental health problems? I keep saying that to her, if you went to somebody that was anonymous to you, you wouldn't have that same feeling, you wouldn't have that same guilt of offloading. She has just been given contact numbers, but she won't make that effort to do any of it'.

Many expressed their disappointment in the change of support being offered since the Covid 19 Pandemic

- 'I think Covid was a great excuse to not bring back / re-start the support groups. We've got this building, which is underutilized greatly, but it has all changed' (referring to the Hamar building at SaTH)

Feedback from people completing the online survey:

- 'I think having a recurrence in February 2023 the support this time has been different. If I want or need any services or support I have to find them myself.'

People we spoke to told us about how exercise groups and workshops impacted their mental health and wellbeing,

- 'It's been amazing to get out, to get air to my head, to meet other people and to know that you're not the only person this is happening to.'
- 'One participant felt confident enough to remove her wig during the workshop'.

Including the 'iCan' Group funded by Lingen Davies, some aspects of which are also available online, the '5K Your Way Group' that does Park Runs, and yoga workshops:

- 'We were offered that chance with iCan and it has been absolutely amazing, we've just met really lovely people.'



'I've gone from nothing in 8 months literally, to coming out of hospital after having this massive operation and coming to iCan and it's done me the world of good, I'm getting my fitness back now... Coming out on a Saturday and seeing all these guys, amazing, absolutely amazing. It really is, seriously.' (5K Your Way)

- 'You do 45 minutes of exercise, that's what we were doing, and stretching and just getting yourself prepared again through exercise.'
- 'It is a fitness group, but you do fill in a questionnaire about what your diagnosis has been, what you need to do to look after yourself really while you are there. If you've got any health stuff at the time, they look after you. They are trained to make sure that you're safe.'
- 'It's given us a lift and we have talked about our experiences which is nice... you don't get that when you talk to people who haven't had cancer. It's quite nice.' (5K Your Way)
- 'It was so helpful, so I have started to recover much better with exercise and stuff.'
- 'Immensely helpful, [it] has been a part of the aftercare that was really good. I really needed them in December.'
- 'The iCan online mindfulness session was a one-off class.'
- 'It was brilliant, it was absolutely brilliant'. (Jenna Blair Cancer specific yoga sessions)

Some people fed back to us that the promotional materials for the iCan group made it look like it was a class for older / more inactive people rather than a support group.

6. Personalised support and information for families and carers (including at end of life)

The groups we visited discussed the lack of support and information for families and carers.

- 'She was a wife of someone who had cancer and there's very little out there, unless it is just generic carers support, but she wouldn't view herself as a carer.'
- 'There was nothing that we could find that was cancer specific that wasn't here [at Severn Hospice] And obviously not everyone is eligible to come here if they are not palliative'.

People told us what support is needed and where the gaps are. For example, one relative who was supporting someone nearing the end of their life said:

- 'I've given up on cancer charities because they have done nothing for us. [The person with cancer] needed sitting with, not funding and benefits. What she needed was the opportunity, when you download your entire life, to relive it through words to allow you to get ready for death. It is the wrong approach from Macmillan. It was an awful ending to a wonderful life. If I can help that one person to have a better experience. It's got to change for others, that's what mum would want.'

We also heard about support offered to parents by Macmillan:

- 'Macmillan have been supporting her and the family. They email us (parents) and ask us if we need anything.'

7. Need for improved communication and joint working between professionals to make sure people are diagnosed early and have access to the right treatment at the right time, and things go smoothly (waiting times)

Some people were concerned that delays in communication and procedures had slowed things down and affected their experience:

- 'I sat in a waiting room for 2 hours to get a sick note'.
- 'She was able to be discharged at 3pm but was told to wait until 8pm for the pharmacist to dispense the medication'.
- 'Waiting for the pharmacy is taking up time and resources

- 'On multiple occasions when admitted to hospital, appointments were scheduled at set times with planned porters to take me, but they didn't turn up.'

Some people were concerned that delays in their diagnosis and treatment might have affected their recovery:



'I reported my concerns to the day nurse in Oncology, she suggested that they didn't give her concern and to get them checked by my GP. I saw my GP, they made referrals for both of my concerns. Both concerns turned out to be cancer. I think if the cancer department had made the referrals to ENT⁶ rather than the GP doing it then communication would have been more efficient. Because the initial referral come from the GP, that is who they report back to, not Oncology. Information seems to get missed in the communication. There seemed to be a lack of communication between the ENT and Oncology department even though they were working on the same area'.

- 'If the consultant had carried out the biopsy last year as planned then the cancer may not have spread to the other lung.'

Feedback from people completing the online survey:

- 'Speed of operation happening and MRI results getting back – could be quicker.'
- 'Had four chemo sessions before seeing a Doctor/Consultant – to then be told the dose was too high and antibiotics were making me ill.'
- 'Time between having my MRI scan and getting the results was not good.'
- 'Continual cancelled appointments with surgeon due to lab results not being back in time.'

⁶ Ear, nose and throat

- 'I am now waiting for another suspicious mole to be removed and it will be about 10 weeks from it being assessed to being removed. It's worrying after only just having a Stage 2 nodular melanoma removed.'
- 'When using the 24-hour oncology helpline the response from the oncology nurse is excellent. They return calls in a timely manner and make a plan for hospital attendance. However on arrival at RSH the plan is changed or abandoned and the oncology pathway is lost. I often wonder if the oncology nurses realise that all their efforts are disregarded by the hospital?'

8. Need for a Shropshire Cancer Network, recognising the importance of community groups and their funding challenges – supported by accurate information and directories for the public and professionals so everyone knows the support available and how to access it.

Community support groups are often responsible for advertising and promoting themselves and not all the people leading these groups have the digital skills or time to do this effectively.

Some of the groups we spoke to did not know what other groups and support is available across Shropshire and so we were able to share the information we had gathered to help them to connect.

The people attending groups told us how important they are, and the bigger associations, and the role they play in providing information. Particularly when the information has been gained through personal experience (a perspective which many professionals don't have).

- 'Joining this and the Urostomy Association has given me far more information than I ever received from the NHS.'

We also heard from people who were finding it hard to find a regular group close to where they live and groups for different people/cancers.

- 'People come from Ludlow and Telford as the other groups are a bit ad hoc, men can be a bit intimidated to join, other groups aren't advertised'.

However, we did hear about a new men's cancer support group 'Men Like Us' that was launched by The Personalised Care Team in Cancer Services at The Shrewsbury and Telford Hospital Trust in March 2024 and their exciting plans to expand and get men talking and supporting one another⁷.

⁷ <https://www.sath.nhs.uk/news/trust-cancer-support-group-expands-in-shropshire/>

- 'The most important thing is to get men talking about the issue of cancer. It is just there for listening and chatting.'

There was a call for the groups to work more collaboratively, perhaps through a Shropshire Cancer Network, to promote groups and services:

- 'I think a lot of people don't know we exist'.

Many of the member told us how important the support groups are to them, the value of the navigator/co-ordinator role and ongoing concerns about funding cuts. When hearing that the co-ordinator role might be cut one breast cancer group told us:

- 'We said that if there was anything we could do, that we would do it.'
- 'I think the coordinator role is incredibly important.'

Feedback from people completing the online survey:

- 'I rang Macmillan on several occasions, mainly for financial advice, and they have been amazing.'
- 'The Brain Tumour Support Group has been a very important support network for [me and my husband] over my months of radiotherapy and chemotherapy treatment. They are instrumental in my positivity and attitude towards living with cancer.'
- 'Very good support. The development of a Brain Tumour Support Group at the hospital has been a wonderful addition.'

Please note: During this project we contacted a Brain Tumour Support Group which was held at The Hamar Centre at The Royal Shrewsbury Hospital and arranged to go along to their next session but just before we went we were contacted and informed that, due to funding cuts, the patient navigator post for this department had been stopped and so the support group would cease to exist.

Feedback from people completing the online survey:

- Sadly, just recently we got told that the Brain Tumour Support Group was having to end due to a lack of funding. This is a HUGE decision as it's the only group that supports the Brain Tumour Community and it is only held every 6 weeks but it is supported by the Specialist Nurse. There simply isn't anywhere else to go for the group.'

People we spoke to told us that this sudden ending of support can have a major impact on people's mental health and wellbeing and how important groups and workshops are during and after treatment:

- 'This is a community of people who know what it's like. They have been a rock; they have been absolutely fantastic and should have the recognition they deserve.'
- 'This is a fabulous group to come to. I'm still coming 5 years on.' (Person still attending the group after finishing cancer treatment)
- 'Especially the coffee with everyone after, have a chat. Wednesdays to me are fantastic, really, just gets me going.'
- 'They take part in every aspect, they make their own contributions, there is a lot of laughter. The members are so good, they are so supportive of one another.'

People told us about how important these groups are for getting peer support and finding out what other support is out there:

- 'It's just nice to be around people that have been through the same thing as you. I mean, we don't often sit there talking about cancer, but you know that people have been through the same things, no one really knows until they have been through it themselves, so yeah, that's quite nice.'

People told us about how groups are promoted by friends and family even when their loved one has passed away:

- "'Legacy networking", we get a lot of support through networking and we often hear about support groups by word of mouth from family members who have lost someone to cancer.'

At the start of this project we experienced first-hand the difficulty finding currently active local support groups. How must it feel for someone who has just received a diagnosis and doesn't know where to turn for information and support?

The people we spoke to told us about recurring issues with online service/support directories not being accurate and outdated, incorrect or contradicting information and simply not getting a response.

- 'It's sort of like, you know, today come and this will happen at your visit, but actually it doesn't happen. Or information that contradicts itself, so she's then having to go back and check.'

Other factors that can impact people's experience of living well with cancer

Throughout this project we have also heard from people about other factors that impact their experience, including:

- Equipment
 - Access to car parking and struggling to understand 'the rules' due to conflicting information
 - Transport and length of journeys
 - Financial pressures and lack of information about car parking permits and where they can be used
 - Work pressures as they try to work around their appointments
 - Access to care at end of life
 - Changes to practice that makes peoples experience different to those in other parts of the country.'
- 'Parking is absolutely horrific. If you have to take anybody or visit anyone then you have no chance. I think last time we had to park on the pavement, we had no choice.'
 - 'She said how tiring it was to be driving from Church Stretton, finding parking, receiving treatment and then driving home again'.
 - 'There is a car park pad within the chemo day unit where you put in your cars registration plate for free parking, but you can only do this when you are receiving treatment, it can't be used for meetings with the consultant.'

A lot of people mentioned car parking permits and how useful they are:

- 'It is essential because you don't know how long you are going to be [for your appointment].'

Some people told us that they didn't understand why some permits lasted 3 months and other 12 and there was a lack of consistent support and information from care staff. One person was very concerned that there was no evidence to show the pass was working and so they were worried they would get a parking fine.

- 'There was no evidence on what I was coming in for, I was worried about it not working, there was no way to see if it was working'.

Some of the people we spoke with were unaware of the permit process all together and hadn't received this benefit or any financial assistance.

Feedback from people completing the online survey:

- 'Some lengthy visits to radiotherapy due to machine break downs.'
- 'The chronic lack of parking space remains a disgrace.' (Receiving treatment for 2-5 years)
- 'I am self-employed... so the timescale for the [operation] was important to me to make plans on how I would manage financially. No timescale could be given which added to the stress of the situation.'
- 'Appointments cancelled or times changed several times without notice.'
- 'Excessive wait for me to return home to die. Made to feel a burden. I was only funded for 3 nights care and on one occasion I was unable to provide myself any fluids and was desperately dehydrated by the morning. Carers found me. No funding was sourced for more care.'
- 'I missed being able to ring the bell at the end of [treatment] as at Shrewsbury Hospital the bell has been taken away which is disappointing, especially when you see people on social media elsewhere in the country being able to ring that bell.'

Thank you

We want to thank everyone who has contributed, supported and been involved with this project. Without your feedback we would not be able to let professionals and commissioners know if people in Shropshire are living well with cancer. Sharing your feedback with us has allowed us to understand how the services are being received, what works well and what needs improvement.

Response from NHS Shropshire, Telford & Wrekin

NHS Shropshire, Telford, and Wrekin (NHS STW) would like to thank Healthwatch Shropshire for sharing the results of the Cancer Survey and the 390 people for sharing their experiences of living with and beyond cancer.

We value these insights and fully recognise the importance of understanding individual experiences to help further shape cancer care and support in Shropshire, Telford and Wrekin. The report offers useful feedback on our strengths and the areas that could be improved.

It is encouraging to see positive feedback about the collaborative work across our system, particularly the role of community-led cancer support groups and partnerships with local and national charities. These services play a vital role in supporting patients' mental health and well-being, and it is reassuring to know that they are making a meaningful difference. This highlights the value of our integrated care approach, which we are committed to continue to build upon.

We are pleased to hear from people who report prompt referrals from primary to secondary care, as well as timely procedures. The feedback highlighting the care, compassion, and efficiency shown throughout diagnosis and treatment is positive. Additionally, many people express appreciation for the support provided by system partners and community groups, including fitness programmes, financial advice, cancer-specific information, and opportunities to share their experiences of living with and beyond cancer.

The report also brings to light areas of care which may need strengthening, and we especially note that some people experience issues with communication approaches, delays in receiving test results, and care which was not always personalised to their needs and circumstances. We fully understand that these challenges significantly impact individual and family experiences, and we take these concerns very seriously.

We are committed to continue to work with Healthwatch Shropshire, partners and the public to explore practical solutions to improving key areas highlighted in the report.

In addition, we will ensure that the themes from this report are included in our upcoming Shropshire Telford and Wrekin cancer patient engagement event. This will allow for further discussion and insight into the experiences of individuals and carers to inform the improvement of cancer care, which includes personalised care, and clear, timely communication throughout people’s cancer journey.

Thank you again for sharing these valuable insights. We look forward to ongoing collaboration with Healthwatch Shropshire and other stakeholders to enhance cancer care for our population.

For further information on available cancer support services, please contact the Personalised Care Team using the details below, or download the Living with and Beyond Cancer App, which provides a comprehensive list of services across the county.

Download the Living with and beyond cancer app by clicking below:



[Click here for Android App on Google play](#)



[Click to download on Apple iPhone or iPad](#)



Personalised Care Team

✉ The Shrewsbury and Telford Hospital NHS Trust | C/o Cancer Services | Mytton Oak House | The Royal Shrewsbury Hospital | Mytton Oak Road | Shrewsbury | Shropshire | SY3 8XQ

☎ Office: 01743 492 424

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Response from Lingen Davies Cancer Fund

We welcome the Living Well with Cancer in Shropshire report and recognise a number of its' findings from our own interactions and research in the communities we support. It is great to see that many people are having a positive experience of their clinical treatment, and while this is unfortunately not reported universally, it seems there are examples of really excellent practice amongst professionals. However, we have also received feedback about the loss of the Cancer Navigators and the impact that this has had on some patient groups. We are pleased to see almost all of the respondents were able to access the majority of their care in-county.

We recognise the challenges patients are experiencing in finding out about non-clinical support options for them, both during and after treatment. We would really welcome the chance to work more closely with clinical teams to ensure this information reaches patients at the right time for them. We are currently investing significant funds in wellbeing and support activities, including the iCan scheme, which is referenced in the report. The main challenge we experience is low referrals and getting the message out to patients, as we do not have access to patient data ourselves. If there was a coherent way in which these opportunities were communicated by clinicians, we believe this would really enhance the patient experience. We are also aware of the need to improve information and support service for the family and friends of those living with cancer and are actively looking into this at present.

We can really see the value in a Shropshire Cancer Network and would be keen to take a leading role in this; we are all here to support the same people and if a more joined up approach could be taken, this could help us all have a greater impact on peoples' lives.

Note. More information about the Lingen Davies Cancer Fund and their current projects can be found here, [Our Cancer Appeals | Lingen Davies Cancer Fund Shropshire](#)

Appendix

Appendix 1: Survey questions

Section 1. Your condition

1. Your condition

- Anal cancer
- Bile duct cancer
- Bladder cancer
- Bone cancer
- Bowel cancer
- Brain tumour (cancerous)
- Brain tumour (non-cancerous)
- Breast cancer (female)
- Breast cancer (male)
- Carcinoid tumours
- Cervical cancer
- Endometrial cancer
- Ewing sarcoma
- Eye cancer
- Gallbladder cancer
- Head and neck cancer
- Hodgkin lymphoma
- Kaposi's sarcoma
- Kidney cancer
- Laryngeal cancer
- Leukaemia (Acute lymphoblastic leukaemia)
- Leukaemia (Acute myeloid leukaemia)
- Leukaemia (Chronic lymphocytic leukaemia)
- Leukaemia (Chronic myeloid leukaemia)
- Leukaemia (Hairy cell leukaemia)
- Liver cancer
- Lung cancer
- Mesothelioma
- Mouth cancer
- Multiple myeloma
- Nasal and sinus cancer
- Nasopharyngeal cancer
- Neuroendocrine tumours
- Non-Hodgkin lymphoma
- Oesophageal cancer
- Ovarian cancer
- Pancreatic cancer
- Penile cancer
- Prostate cancer
- Rectal cancer
- Retinoblastoma
- Skin cancer (melanoma)
- Skin cancer (non-melanoma)
- Soft tissue sarcoma
- Stomach cancer
- Testicular cancer
- Thyroid cancer
- Vaginal cancer
- Vulval cancer
- Womb cancer
- Other (please specify):

2. When did you receive your initial diagnosis?

- | | |
|---|--|
| <ul style="list-style-type: none"> • Within the last 2 months • 3 – 4 months ago • 5 – 6 months ago • 7 – 12 months ago | <ul style="list-style-type: none"> • 1 – 2 years ago • 2 – 5 years ago • over 5 years ago |
|---|--|

3. Is your medical treatment ongoing?

- Yes
- No
- Unsure

Section 2. Your care and support

We would like to understand which organisations are, or have been, supporting you to live with or after cancer.

4. Please tell us which GP practice you are registered with:

- | | |
|---|---|
| <ul style="list-style-type: none"> • Albrighton Medical Practice • Alveley Medical Practice • The Beeches Medical Practice • Belvidere Medical Practice • Bishop's Castle Medical Practice • Bridgnorth Medical Practice • Broseley Medical Centre • Brown Clee Medical Practice • Cambrian Medical Centre • The Caxton Surgery • Churchmere Medical Group • Church Stretton Medical Practice • Claremont Bank Surgery • Cleobury Mortimer Medical Centre • Clive Surgery • Craven Arms Medical Practice • Drayton Medical Practice • Highley Medical Centre • Hodnet Medical Centre • Knockin Medical Centre | <ul style="list-style-type: none"> • Marden Medical Practice • Marysville Medical Practice • The Meadows Medical Practice • Much Wenlock & Cressage Medical Practice • Mytton Oak Medical Practice • Plas Ffynnon Medical Centre • Pontesbury and Worthen Medical Practice • Portcullis Surgery • Prescott Surgery • Radbrook Green Surgery • Riverside Medical Practice • Severn Fields Medical Practice • Shawbury Medical Practice • Shifnal & Priorslee Medical Practice • South Hermitage Surgery • Station Drive Surgery • Wem & Prees Medical Practice • Westbury Medical Centre • I am not registered with a GP • Other (please specify): |
|---|---|

5. In which hospital is the majority of your treatment taking place or did it take place if completed?

- | | |
|---|---|
| <ul style="list-style-type: none">• Royal Shrewsbury Hospital• Princess Royal Hospital, Telford• Robert Jones & Agnes Hunt Hospital, Oswestry | <ul style="list-style-type: none">• The Christie, Manchester• New Cross Hospital, Wolverhampton• The Queen Elizabeth Hospital, Birmingham• Other (please specify): |
|---|---|

6. Which hospital is leading the treatment or led it if completed?

(If your treatment was organised by a different hospital to where it took place please let us know)

Options as above

7. Please tell us which organisations outside of the NHS have provided you or your family with care and support

- Macmillian Cancer Care
- Lingen Davies Cancer Fund
- Marie Curie
- None
- Other (please specify):

8. Please describe your experience, what went well and what didn't go so well?

9. Do you have any suggestions on how your care and support could be improved?

Section 3. About you

Please tell us a bit more about you (or the patient if you are filling this out on behalf of somebody else)

By answering the following questions, you can help us understand how some people may experience things in different ways. However, if you'd prefer not to answer, you can select "prefer not to say".

Please note that your data is always stored and used in line with data protection law.

10. Your Postcode:

(Your postcode will only be used to help us get a better picture of where comments come from and will not be published or attached to any comments we share with service providers, commissioners or regulatory bodies.)

11. Please tell us which age category you fall into:

- | | |
|--|---|
| <ul style="list-style-type: none"> • Under 18 • 18 to 24 years • 25 to 49 years • 50 to 64 years | <ul style="list-style-type: none"> • 65 to 79 years • 80+ years • Prefer not to say • Not known |
|--|---|

12. Ethnic origin

- Arab
- Asian / Asian British: Bangladeshi
- Asian / Asian British: Chinese
- Asian / Asian British: Indian
- Asian / Asian British: Pakistani
- Asian / Asian British: Any other Asian / Asian British background
- Black / Black British: African
- Black / Black British: Caribbean
- Black / Black British: Any other Black / Black British background
- Mixed / Multiple ethnic groups: Asian and White
- Mixed / Multiple ethnic groups: Black African and White
- Mixed / Multiple ethnic groups: Black Caribbean and White
- Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic groups background
- White: British / English / Northern Irish / Scottish / Welsh
- White: Irish
- White: Gypsy, Traveller or Irish Traveller
- White: Roma
- White: Any other White background
- Any other ethnic group
- Not Known
- Prefer not to say

13. Gender

- Woman
- Man
- Non-binary
- Prefer not to say
- Not known
- Prefer to self-describe:

14. Please tell us which sexual orientation you identify with

- | | |
|---|--|
| <ul style="list-style-type: none"> • Asexual • Bisexual • Gay man • Heterosexual/straight | <ul style="list-style-type: none"> • Lesbian/Gay woman • Pansexual • Prefer not to say • Prefer to self-describe |
|---|--|

15. Do you consider yourself to be a carer?

(Who is a carer? Someone of any age who provides unpaid care for another person (of any age) who may be ill, frail, with disabilities, have poor mental health or drugs and alcohol problems, meaning they're unable to manage without this care and support.)

- Yes
- No
- Prefer not to say

16. Do you have a disability or long-term health condition?

- Yes
- No
- Prefer not to say

17. Do you have any of the following disabilities or long-term health conditions?

- | | |
|---|---|
| <ul style="list-style-type: none"> • A physical or mobility impairment • Deaf or hearing impaired • Blind or sight impairment • Learning disability • Autism • Mental health condition • Asthma, COPD or respiratory condition • Cancer | <ul style="list-style-type: none"> • Cardiovascular condition • Chronic kidney disease • Dementia • Epilepsy • Diabetes • High blood pressure • Prefer not to say • Other (please specify): |
|---|---|

4. Further contact

18. Case studies and focus groups

Would you be happy for us to contact you if we would like to use your story as a case study in our material or invite you to be a member of a focus group to look into the issues further?

(We won't do either of these without speaking to you first about what it involves and you can withdraw consent at any time.)

- Yes, I am happy to be contacted to discuss whether my story could be a case study or to invite me to attend a focus group.

- No, I don't want to be contacted by to discuss whether my story could be a case study or to invite me to attend a focus group

19. Sign-up to our mailing list

Sign-up to our mailing list to stay up to date with what people are telling us about health and social care, our advice and information, and our latest reports, including the report based on the feedback from this survey.

(You can unsubscribe from our mailing list at any time.)

- Yes, sign me up.
- No, don't sign me up

20. If you have answered yes to either question above, please leave your contact details here.

(These will not be shared outside Healthwatch Shropshire unless we have your explicit consent or in exceptional circumstances such as for safeguarding purposes, as described in our Privacy Policy.)

Name

Email address

Appendix 2: Engagement Activity

Engagement method	Number of service users	Number of professionals
Online survey	40	
Attending events <ul style="list-style-type: none"> • 5K Your Way Cancer Support Group • Lingen Davies Snowdrop Walk • Prostate Cancer Screening Event • Cancer Screening Awards Evening • Ludlow Cancer Support Group Kings Award Celebration 	<p>20</p> <p>5</p> <p>10</p> <p>30</p> <p>50</p>	
Attending groups (including speaking to people 1:1) <ul style="list-style-type: none"> • ‘Bosom Buddies’ Support Group • Bridgnorth Cancer Support Groups • ‘Bums on Tums’ Stoma Support Group • Cancer Champions Monthly Catch-Up • Church Stretton Cancer Support Group • Ludlow Cancer Support Group • Severn Hospice • SaTH Head & Neck Cancer Support Group • SaTH Bowel Cancer Support Group • SaTH Breast Cancer Support Group 	<p>12</p> <p>25</p> <p>30</p> <p>56</p> <p>4</p> <p>26</p> <p>22</p> <p>8</p> <p>13</p> <p>14</p>	
Attending workshops: <ul style="list-style-type: none"> • ‘I can’ Rehabilitation Workshop • ‘Look good, feel good’ Cosmetic Workshop 	<p>8</p> <p>8</p>	
Attending professionals meetings and 1:1s		9
Total	381	9



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