

Where would the people and communities of Swindon like to find Cancer information and support?



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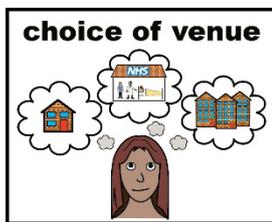
Introduction

The aim of this report

On behalf of Macmillan Cancer Support we have looked at understanding where people would like information and support in Swindon.

We spoke to people across Swindon in different places, there was also an online questionnaire available.

What we've found



Experts to be available to talk to at the doctors and in community spaces. To be easy to get to and available at a range of times/days



Leaflets and information available at GP Surgeries and the Hospital



The leaflets and posters to give information on signs, symptoms, preventative measures, and support during diagnosis



Poster need to have QR codes as well as weblinks and a phone number



Families would like support and information for them



Have the information in easy read and different languages

Images from [Easy on the i - Learning Disability Service \(learningdisabilityservice-leeds.nhs.uk\)](http://learningdisabilityservice-leeds.nhs.uk)

Message from our CEO

I am exceptionally proud of our Healthwatch services tradition of engagement, co-production, and person-centred approach to sensitive areas of work. No where better is this showcased than in this partnership with Macmillan Cancer Support, for who we are grateful of their support and trust in us for the delivery of this piece of engagement. Our Healthwatch staff and volunteers are incredible, I always feel the need to express my gratitude for their time, accomplishments and their passion for delivering high quality work that places people at the heart of delivery.

Cancer, its treatment and its management are a complex and challenging world. The work that is delivered in Swindon to do this is incredible, we should be in no doubt that people work tirelessly to support those affected by cancer. Where we can though, we should look to ensure that pathways and information are clear and accessible for everyone and that we create a system of support and treatment that is as dynamic as it is sustainable.

My heartfelt thank you to those who took part in the project, I am genuinely thankful that you shared your experiences with us. I hope we have done you justice in the work we've delivered.

Kevin Peltonen-Messenger

The Care Forum CEO and Healthwatch Swindon's Chair

Who are Healthwatch?

Healthwatch Swindon are the local independent champion, for people who use health and social care services, we are hosted by The Care Forum, a local charity. We're here to make sure that those running services, put people at the heart of care.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care.

We are here to listen and understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

We focus on ensuring that people's worries and concerns about current services are addressed. We are totally independent and can provide you with impartial and independent signposting advice.

We are part of a network of 150 local Healthwatch across England.

Cancer in Swindon

222,881 people live in Swindon (as defined by the local authority boundary) and 256,677 patients are served by Swindon GP practices.

The town is growing with the population projected to increase by around 5% between 2020 and 2030.

It has more people in middle age than most of England with 45-55 the most common age group.

Cancer was the eighth most common condition seen by Swindon GP Practices in 2020/2021.

Between now and 2040, there is some growth predicted in the 15- 34 year old age groups but the most growing age group will be those aged 60+, with a projected additional 4000 residents over the age of 85 by 2040.

Around 90% of Swindon's population are estimated to be from a white ethnic background, with over 16,000 people from an Asian or Asian British background.

Swindon has always celebrated its diversity and has particularly strong Goan, Nepalese and Polish communities.

Main Cause of Years of Life Lost to Cancer in Swindon

Cancer Type	2010	2019	% Change
Tracheal, bronchus and Lung Cancer	1839	2070	11.2
Colon and rectum Cancer	930	1112	16.4
Breast Cancer	849	928	8.5

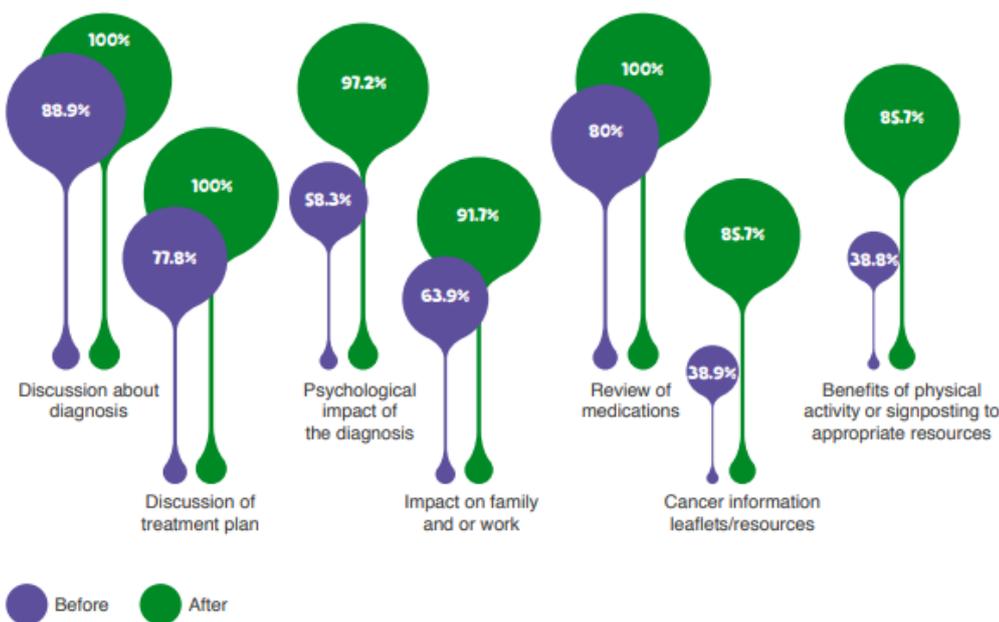
Under 75 Mortality Rate from cancers considered preventable in Swindon during 2020 was 57.1 per 100,000 of population. This is worse in comparison to regional rates.

For further details please refer to the JSNA [PowerPoint Presentation \(swindonjsna.co.uk\)](http://swindonjsna.co.uk)

According to research by Macmillan, produced for the Integrated Care Board of Bath and North East Somerset, Swindon and Wiltshire;

“More than 54% of people who received a cancer diagnosis in 2020 felt they did not receive adequate support from their GP surgery within Swindon and more than half of people surveyed by Macmillan (2020 trust results. 2020) were found to have unmet emotional needs after their diagnosis. Unmet needs after a cancer diagnosis are likely to manifest as additional GP contacts, averaging between 3- 5 additional contacts for

up to 10 years post diagnosis (Khan, Evans and Rose, 2011).” [Cancer Care Review Guidance and Information Toolkit - Bath and North East Somerset, Swindon and Wiltshire ICB](#)



The evaluation showed that clinicians using a cancer care review approach,

were more likely to meet the needs of the patient. This can be demonstrated in the

infographic highlighting the improvement in a patient's well-being from the additional support and information provided.

Why?

Up until recently Swindon has not had a Radiotherapy unit in the town, it officially opened in June 2022 at the Great Western Hospital.

The unit was made possible through the fundraising efforts of Brighter Futures who wanted to ensure cancer patients diagnosed in Swindon could have the best possible care and treatment closer to home. Previously patients had to travel to Oxford and other locations.

This has meant that there has been limited cancer support and services in Swindon to date.

Macmillan Cancer Support asked Healthwatch Swindon (part of The Care Forum) to undertake scoping and engagement work to investigate community venues to identify the key places for provision of Macmillan cancer information and support.

Macmillan wish to:

- Understand where members of the community would like to see more cancer information and support.
- Meet Objective 3 of their strategic plan: Everyone with cancer will have their needs met by high quality services.
- Meet Objective 6 of their strategic plan: We will reflect and represent the communities we serve in everything we do to support everyone living with cancer.
- Consult with people who live, work, visit or have a vested interest in Swindon, and to consider where to serve the community of Swindon by providing more information on cancer.

What we did

Healthwatch Swindon used several different engagement methods to gather people's feedback:

- Online and paper survey
- Spoke to the public at Community cafés and venues mainly in disadvantaged areas.
- Spent the day at a local shopping centre (West Swindon)
- Went into a Secondary school and Sixth Form

- Attended events for specific communities – South Asian, Diabetes, Visually Impaired, women who are disadvantaged, along with people who have Learning Disabilities and/or Autism.
- Hosted a workshop for people with lived experience of cancer to give their views.

Who we spoke to and what we heard

Community cafés and local venues

Over the past two years we have built up strong connections to various community cafés across Swindon in areas experiencing deprivation. We believe in offering everyone the opportunity to have their voice heard.

58 % of community café users stated that they have limited access to the internet. They rely on computers in public spaces or limited data packages on their phones.

With most people stating leaflets or posters as a preferred method to receive cancer information and support.

We asked people at venues across Swindon the locations included community cafés, libraries, and a local shopping centre, for their views on what they felt about cancer support and where they would like to find it; these are some of the responses:

- “Tried asking GP but not much, then tried library”.
- “Tried GP Surgery but they have nothing”.
- “Want them to come and talk to us, had tests but no support was offered it came back clear, but the process was scary. I do not have access to the internet”.
- “Tried online but they are hard to find”.
- “Would like information or a stand at my local community café, so it's less formal and allows me to talk more freely about cancer and my experiences.”
- “Would like information at GPS, women’s centres, female only clinics”.
- “Don't like to look unless I have to, I want to ignore it.”
- “Online or events but not sure would want to talk to people about it when first around.”



- “Information has been readily available in hospitals but not in the community, in places of work or GP surgeries.”
- “Use of jargon is difficult, Explanatory pictures are good”.
- “Information on the surgeons and doctors who deliver the best outcomes”.
- “A recent event at the Railway Village centre was overcrowded and not private enough”.

“No support for LGBTQ+, people feel like they have to hide.”

- “Don’t get married and have a job you love that is the key to a happy and long life”.



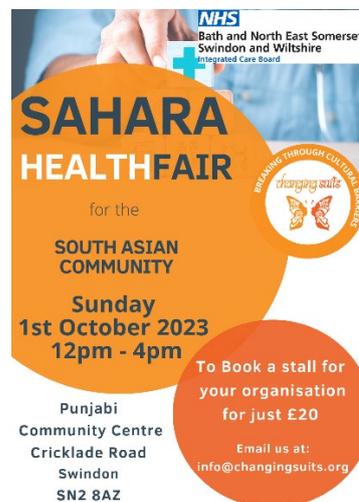
- “My surgery are hopeless at providing support.”
- “More work needed to support our diverse communities”.
- “No point. You’re swamped like everyone. So, I’ll paddle my own canoe until I die. Because until you get cancer and told you’re incurable etc you can’t get it.”
- “Not enough is done since Covid. Many people are diagnosed too late.”

Sahara Health Fair

We attended a Changing Suites event; they are a community-based organisation that aims to break through cultural barriers and get the South Asian community to engage with local support services. We spoke to over 100 people at the event, about what they would like Cancer support to look like in Swindon and by which means they would like it delivered.

Most people we spoke to said they would like to access the information online rather than face to face, we then asked why that was the case.

The response was that they had experienced a lot of accessibility issues with obtaining a face-to-face appointment with their GP so they could not see how cancer support



would be any different. This is due to a lack of availability of appointments and often language barriers when calling to get an appointment.

The overwhelming view was that face to face was not feasible, as it was not generally offered to their community. But they would welcome it if it was possible.

Online was a simpler option, due to the issues and inequalities they are facing accessing primary care services at present.

People also felt that by having the information available online they would be able to access it anytime they needed it. The areas they highlighted they would look at are:

- looking up signs and symptoms
- what action to take next for Diagnosis
- where support is available in Swindon.

Most told us that if the information was delivered online, it should be easy for them to navigate and find the appropriate information easily.

It should also be available in several translatable languages allowing the South Asian community to be able to read the information in their own language taking away some anxiety of not understanding the information available.

We spoke to people who had experienced cancer either themselves or with a family member. Most of these people said they had a negative experience and felt the system did not do enough to support them or their loved ones. They said:



• “My husband had throat cancer and wanted to pass away at home but was not able to do so due to resources -the system did not come together to put this in place in time, he did eventually come home but by this time he had lost all of his senses. He would not have known he was at home -which left me really sad.”

- “We had to wait a couple of weeks to get a GP appointment to raise our concerns about her symptoms which turned out to be bowel cancer for my mother “
- “It would be good to have a centralised Cancer centre in Swindon which would offer support from diagnosis to cancer support care which all GPs could refer you to.”
- “Talking to the same people when you are undergoing treatment and receiving information is so important as it takes so much anxiety away as you are able to gain trust in the people in charge of your care “

- “Having translators more readily available is key “
- “Someone taking the time to understand mine and my family's wishes”.
- “We need more events like this one hosted by changing Suits–so would be good if the NHS and Cancer support service could raise more awareness of cancer in our communities by doing more open events allowing us to access information and ask questions if we have concerns”.



- “The system is really hard to navigate for support and we rely heavily on our GP to give us information and access to support groups for cancer to find out GP lack knowledge of the local offer of support”.

- “I went online to find information about cancer for my father on my medical practice website and found nothing which helped “

- “I am suffering from an incurable cancer, and I cannot find any support groups which I can attend to talk to

people who are suffering from the same cancer as me “

- “I have lost faith in the NHS and would look at going back to India for treatment if I need treatment for anything serious”.
- “A centralised pool of cancer information available to Swindon residents would be good “
- “It would be good for McMillian Cancer/NHS cancer services to put together an event like this one (Sahara Fair) on certain cancers “
- “My son is a Doctor, I went to him for all the information and further support, he attended every appointment with me as I do not speak English”.
- “My children are not always available to attend face-to-face appointments or if I need to access information online, I would not be able to do it myself”.
- “The older generation would find it difficult to access information online, many do not use digital equipment and have only mastered having a mobile phone”.



People living with Learning Disabilities (LD) and Autism

Working with DASH, Swindon Advocacy Movement and Swindon Borough Council, we were able to engage with several adults with a learning disability and/or autism through their bespoke groups and drop-in sessions.

- “Not sure where I would go, daughter has LD, and it is hard to get her to understand about cancer and signs of it”

Tea & Chat
A local get together for people with a learning disability

at Swindon Hub cafe
36 The Parade
(Next to Wilko)

Every   

“Come down and make friends”
“Why not come along and try it out”
“Easy to get to – let us know if you need help to get here”

If you have any questions – contact Annie Baker at
07989 387810 abaker2@swindon.gov.uk

*You can bring somebody to support you at the session

- “Daughter has LD and finds all information on cancer scary will not engage with it”.
- “Recently had a smear test, it was uncomfortable, but the nurses were great. I find there is too much information in cancer leaflets and easy read would be better.”
- “I have artificial joints and LD smear is uncomfortable as cannot open legs properly, not listened to”
- “Smear tests and cervical screening are not the same thing, are they?”
- “I do not know how to spot cancer; we need something simple or someone to come and talk to us to show us”

One reoccurring theme was the need for accessible information, not just in easy read but in known safe spaces. Which was also reflected in our questionnaire; whereby when asked ‘what’s most important to you when accessing information’ easily accessible received a response rate of **85.33%**.

People living with Cancer

We invited representatives from cancer support groups in Swindon and people who have experienced cancer to have their say. During which the following viewpoints were shared:



- “I googled it (I’m straight in at stage 4!) Whilst waiting I had NO support, Hospital but also GP’s surgery should be used more for info & support”.
- “I went to the doctors. They were really informative took a few weeks to get an appointment though.”
- “Doctors only had limited info had to ask Macmillan”.
- “Patient on Saturn ward (GWH) for cancer care felt really ignored. Turned down for PIP and lacked support.”
- “Feels like the receptionist picks and chooses when cancer patients get to see the doctor or a nurse, with no regards for the patient’s needs.”
- “Had cancer when young. It has come a long way since cancer treatment has ended, and its due to research.”
- “Patient had a time sensitive cancer required injection booked at GP surgery, but surgery failed to notify patient that the nurse had covid.

Patient had to go private as surgery could not accommodate, costing individual £300."

- "Cancer patient died - no treatment due to COVID and died."
- "Cancer services at GWH are great."
- "John Bristow was fantastic at helping me access support".
- "I had cancer. I no longer have it but live with the consequences of surgery".
- "Skin cancer. I have an artificial aorta valve that is 1000% successful so I live a normal life".
- "I was given an opportunity to join men from SPCSG prostate group from the NHS and find that it very helpful and informative."

"The information from the specialist service was great, wish it was accessed more easily, closer to home + not at the hospital."

- "A one-to-one, visit from Macmillan nurse, helpline, Oxford team were great, end of life help for certain categories could be improved."
- "Had breast cancer great support while being treated but no support after. Phoned and felt like I was ignored".
- "After operation I phoned Macmillan nurses at GWH for advice. They were very helpful and reassuring that my recovery was as it should be".
- "I am not in remission. I had cancer and major surgery 18 years ago. I no longer have cancer, but I live with the consequences of surgery+"
- "Stage 4, with spread No contact with MacMillan. Not rung them. Neither have I been referred. Who does that??"
- "Unable to operate or receive chemo so in limbo with nothing to live for."

"I would have welcomed more information at GWH rather than just picking up a leaflet. Someone available to talk to whilst waiting for chemo etc".

- "I have Neuroendocrine cancer and there was no help in Swindon Any help was for "regular" cancer, and I felt abandoned, and still do, by services in Swindon".
- "There is no support for the person who has cancer".
- "When waiting for diagnosis - no support bar family, friends and MR GOOGLE!! I'm a mix of private and NHS so I fall thru s hole Asking for a GP appointment - waiting weeks - and I'm low maintenance. Sorting myself! As for A&E - I waited 5.5 hrs after a 6 hr wait for Ill. DISGRACE. YES, everybody's time is precious. Mine is limited! I was stuck in a crowded room in pain".
- "Don't be afraid of using the word 'Cancer'".

- “Wording used in letters copied to patients – ‘worrying results’”.
- “Terminology used by medical professionals – Vagueness by use of Mass/tumour/Lesion. Has patient understood diagnosis? Is patient clear it is cancer?”
- “Chemo Nurses as good listeners and provide good communication to patients”.
- “Treat people as individuals/whole person”
- “Hospital staff to ask, ‘what are you struggling with’ rather than ‘how are you?’”
- “Two types of patients: ones that wants to know basics and that is it and ones that want all the facts to deal with their diagnosis. How does medical professional determine what type of patient they are speaking to – Ask them?”

“Give as much information as the patient is requesting”.

- “Cannot take in detailed information at time of diagnosis – in shock but want more information after the initial diagnosis meeting”.
- “To be less of a pawn in the cancer process and more in control of decisions & treatment options”.
- “Advise Patient what they can do to help themselves – empower them”.
- “Acknowledgement of self-care and ownership of things we can do to help own health should be encouraged – not enough at the moment”.
- “Patients not being presented or advised of different/alternative treatment options outside of local NHS. Patients having to research and seek access to treatment themselves. ”
- “Need to mitigate risk and take into account carcinogenic cultural factors as well as medical factors”.
- “Waiting for results after investigations/lack of communication of results/scan results causes anxiety”.

“More direct access to consultants to ask Questions and get answers”.

- “Weekend access to consultants/nurses – lack of availability. The day of the week or time of year you are diagnosed can affect the support you receive.”
- “Consultants don’t have the time to provide the support after a cancer diagnosis – Macmillan bridging this gap.”
- “Direct experience is key for a medical professional to provide the correct support and deliver the correct information.”
- “GP cancer care reviews at 3/12 and 12/12 not happening with the community.”

- “Affects all the family around the individual who has the diagnosis – should be involved”.
- “FU apps and less monitoring/scans as you get further from diagnosis. This creates a feeling of being dropped from the radar and the care of your medical professionals.”
- “Macmillan nurse present at the diagnosis meeting to acknowledge what patient has been told and bridge the gap in information/support.”
- “Trust of medical care/decisions between the patient and consultant is very important”.



Friends and Families of People with Cancer

In the community we spoke to people who have experience of cancer through a friend or family member. The view that came across clearly was that information and support is needed for them. They often felt lost and did not know how to support the person with cancer or themselves during the cancer journey.

- “Bereaved individual needs support as feeling suicidal following the loss of his partner to cancer.”
- “Mother and father diagnosed with cancer. Got support from WHY Counselling Service”.
- “Husband has cancer and family not currently receiving support. They have two small children and only been in the country for 2 months. With no family nearby, the local community is providing the wife support. But not sure how much longer they can keep going.”
- My dad has cancer and I feel like I have not had much support for me.”
- “My parent has cancer and I feel alone”.
- “Daughter has cancer and has been referred to Churchill in Oxford finding it difficult to access and have very little support while there and at home in Swindon”.
- “Support for my sister who has bowel cancer at GWH, has been excellent.”
- “Went to bereavement counselling only man in the room so turned around and walked out. Struggled to battle against turning to alcohol”.
- “Cancer support for me and my sister was brilliant. Couldn’t fault it”.
- “A lot of friends have / had major cancer issues and felt lost”.
- “My sister had cancer and did not know where to start. Once in the system. Was great.”

“Having lost 4 family members, I found it hard to work out which information was credible or just hear say.”

- "Need information for families looked online".
- "Family member has cancer but does know what support was available for me. I assume that family are not supported and now realise there is support available".
- "Lost wife to cancer and needed support, did not know where to turn need signposting".
- "Lost wife to cancer and daughter is screened yearly had a cancer scare and did not feel like she got much support and did it know how to help her".
- "I think it should be pointed out that successful treatment of any cancer depends on early diagnosis. Getting a diagnosis is, however, not always



easy, or straightforward. I've lost friends and relatives to ovarian cancer, colon cancer, pancreatic cancer, and gallbladder cancer and in each case, symptoms were reported to a GP but by the time cancer was diagnosed it was inoperable. Of course, it's important to report any symptoms that may be cancer, but this must be backed up by government investment in research and education and training of GPs."

Visually Impaired People

We attended a conference for visually impaired people organised by Wiltshire Sight. Facing unique challenges in accessing information and support for cancer, they shared a need for a variety of formats to get the right support.

- "Visually impaired woman tried to do the home screening test for bowel cancer but unable to complete as she can't see. Called the helpline number to be told 'oh, we can't help then'. How do people who are visually impaired get screened for bowel cancer?"
- "The letters sent, and any leaflets are too small to read and not accessible. Got a results letter from the hospital and it was too small. Called them and they said it was the standard format, sorry"
- Great Western Hospital is not accessible, the lift buttons are too small cannot work out which one I need, and no help is offered"
- "I am a veteran of Christmas Island experiments and have several types of cancer. The support has been amazing, and Macmillan have been great, but information is not that easy to access. However, have received the right information at the right time"
- I have not been able to get a mammogram as the mobile ward would not look after my guide dog while having a scan. No information was provided about it and no support offered"

The Nelson Trust

Nelson Trust is a local charity supporting 900 women annually experiencing a combination of disadvantages including homelessness, addictions, sexual exploitation, domestic abuse, poverty, ill health, justice involvement, long-term unemployment, and more.

- “Would want support at the Doctors or local support groups”
- “Would like to find support online, women’s centres or GP surgery”
- “Support at pharmacy or local groups”
- “GP based online service or a centre in Swindon”
- “Would first look for information at doctors, call 111, find groups for support, ask family and professionals for help”
- “Would like to find information in local hubs and centres or GP Practices”

Young people

Engaging with young people from both secondary school and sixth form, one key theme emerged that young people would like to be provided with more information and general support during personal experiences of Cancer.

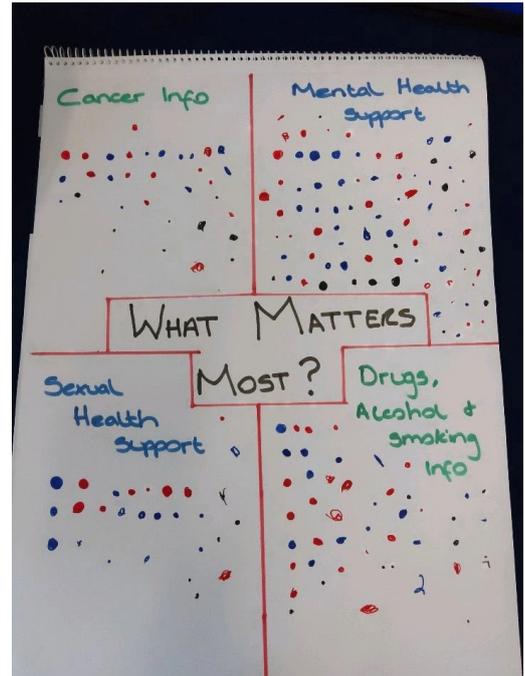
One group of girls aged between 16-19 shared that they had never thought about certain health complaints and didn’t receive much information in schools either.

- “It’s a shame, as we need to know. Especially about things like heart disease, diabetes, and Cancers as it would allow us to take or adopt different lifestyle choices to lead healthier lives which could potentially eliminate certain health complaints like cancers.”
- “Many of my classmate’s smoke (aged 15). If we had more education in schools about the risks associated with Smoking like lung cancer and life expectancy, then maybe we would have fewer school-aged children smoking.”
- “Educating Children from a young age is important as it is more likely to stay embedded into adulthood”.
- “Within Swindon we have a diverse range of cultures whereby it is frowned upon to Smoke or drink heavily – but it still happens within those communities that’s why we need more awareness events and preventative information handed out to us”.
- “My grandmother had cancer, my parents chose not to discuss it with me as they were trying to protect me from what was going to come next, looking back at it now being much older I wish they did “.

Attending an event at The Commonweal School, we ran a poll to find out what sort of information and support matters most. Although Mental Health support was a clear winner with 82 votes, Cancer Information recorded a staggering 35 votes.

With only one young person stating, "there is lots of support for cancer but little for young people to get support for drugs and alcohol support".

- "Need cancer information available in sixth form to make sure we know what to look for when we are older or to look for in our parents".
- "Dad has cancer feel there is little support or signposting for young people who are affected by parents going through it".
- "Need support in Schools on coping with a parent having cancer. I feel that I have had no support and need some."
- "Not had the HPV vaccine as I did not know it was for boys, thought it was only for girls".



Key themes

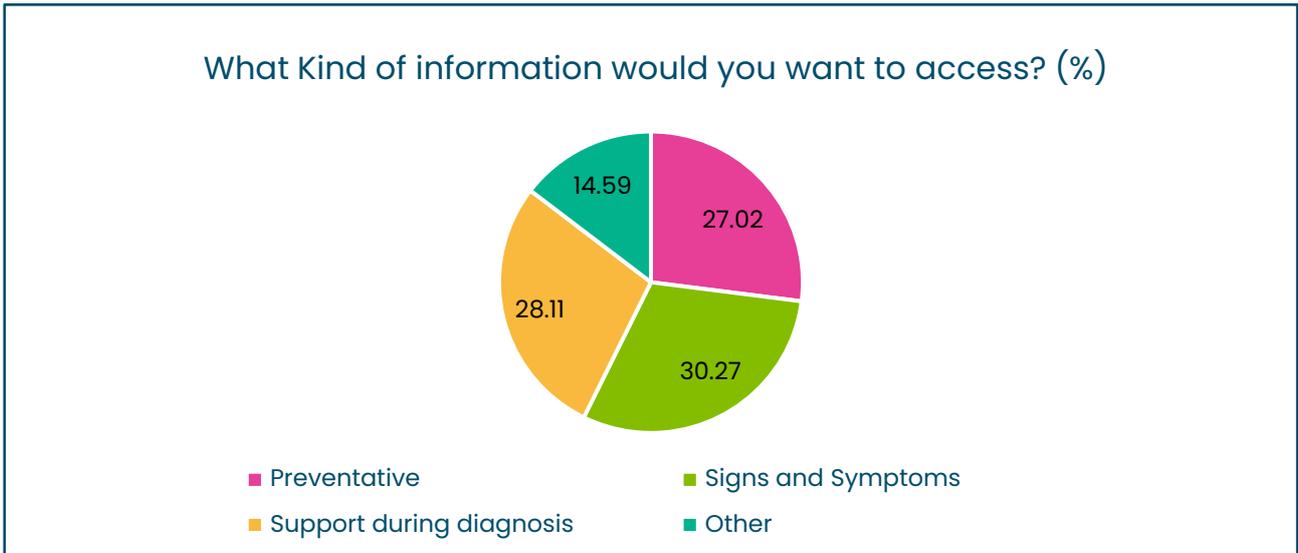
Type of information requested

There was an almost even split in people requesting information about prevention, signs, symptoms, and support during diagnosis.

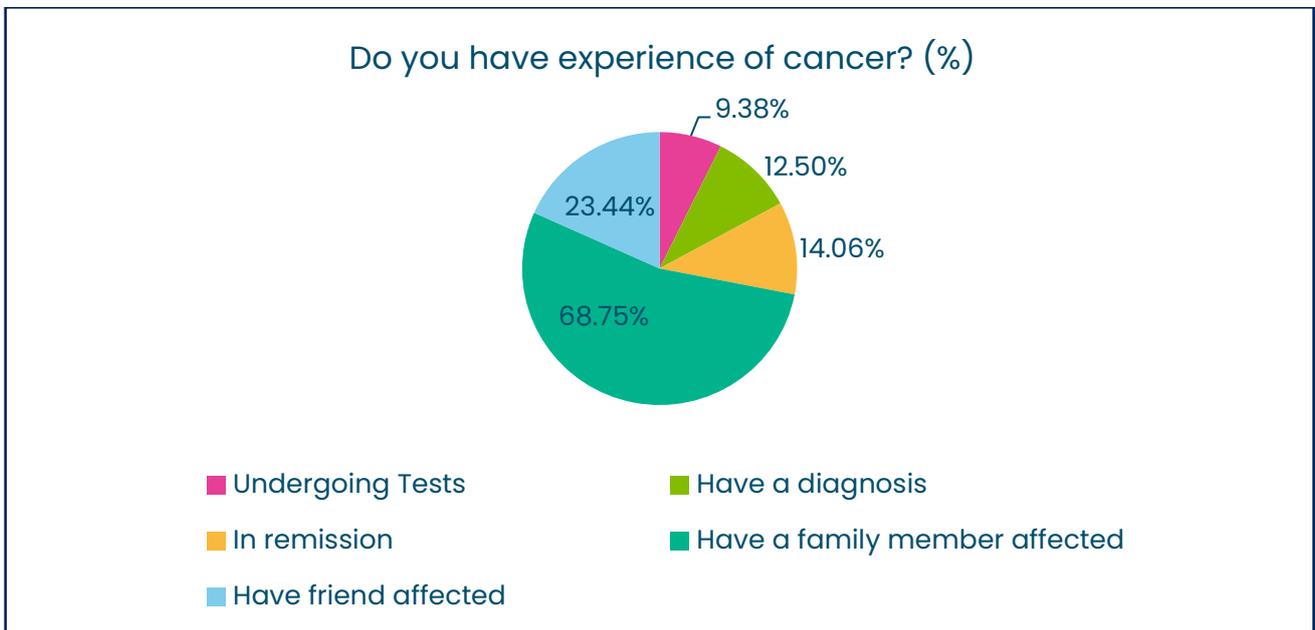
Other comments included wanting information on:

- Relevant local information from GWH
- Information on rarer cancers
- What the availability of appointments are
- Everything, costs of transport to chemo sessions, radiation, family support, benefits available
- Are there any walk-in centres?
- Psychology, talk to professional, mental wellbeing
- General family support
- Post treatment follow ups
- Support for me as a child

In conversation, people told us that they would initially like details on basic support such as where to get information, what support Macmillan can provide and general information about signs and symptoms.



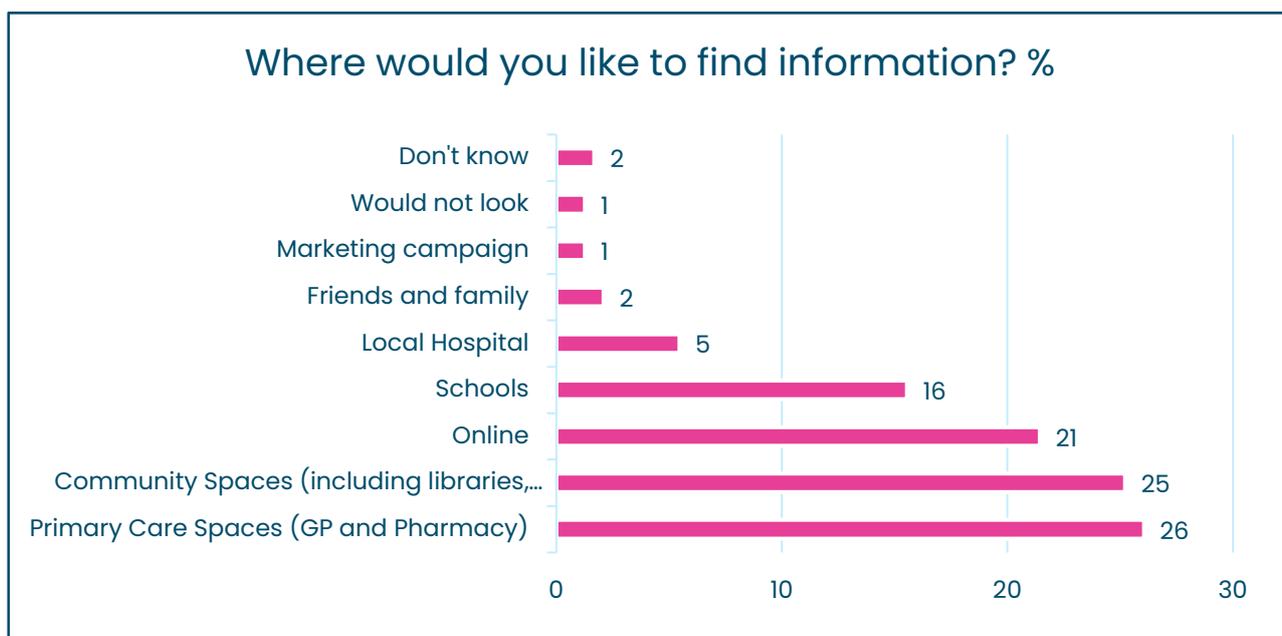
A key area that emerged in needing information, was for the families and friends of people with cancer. This came up regularly in the conversations we had and was also reflected in our questionnaire. They felt like they didn't know where to go to understand how to support their loved one or how to get support for themselves.



Where people would want to find the information

There was again an almost even split with people wanting information in Primary Care Spaces like GP Surgeries and Pharmacies, along with community spaces - these cover community buildings including Community Fridges, cafés, and libraries.

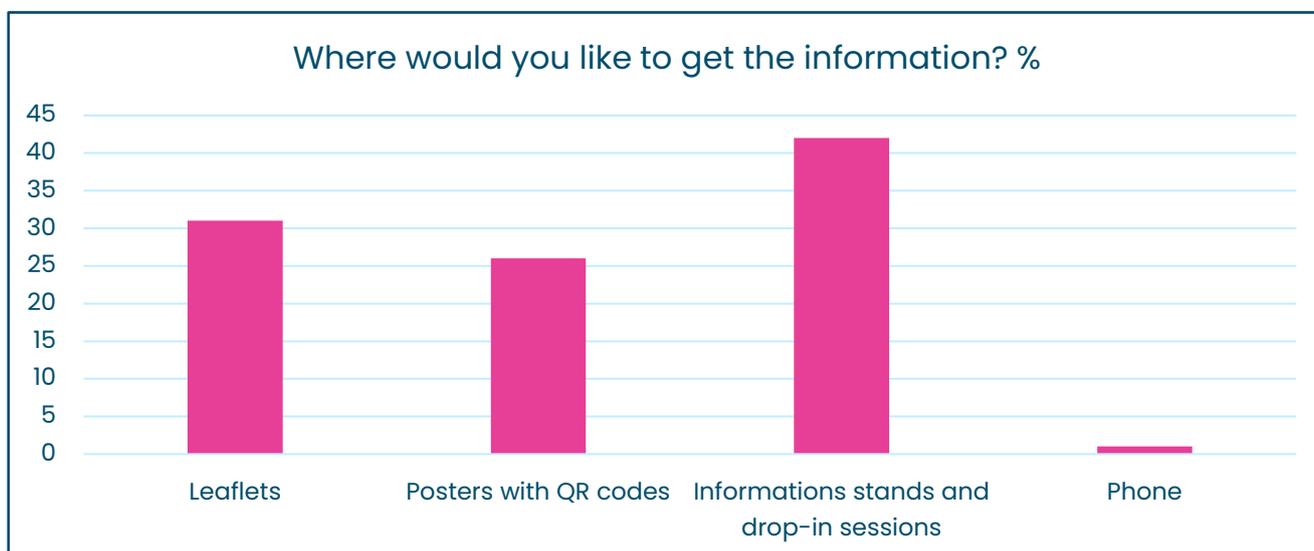
Most respondents wanted to find the information in more than one place and suggested that it would be best in three spaces: in the Community, in Primary Care and a backup of online for more in-depth information.



How people would like to receive the information

31% of respondents indicated they would prefer to use leaflets to get information, 26% indicated they would prefer posters with QR codes in community and Primary Care spaces.

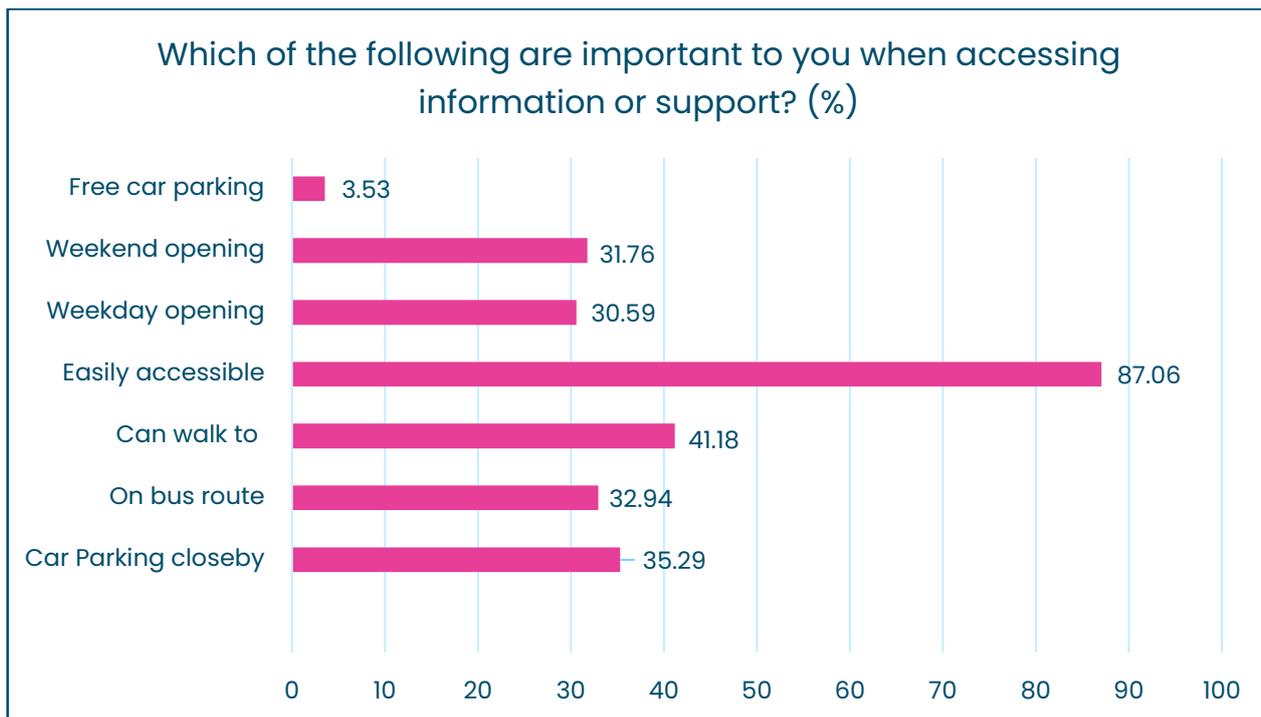
42% of respondents stated they would prefer information stands and drop-in sessions in community spaces, 1% suggested on the phone would be preferable.



What is important when accessing the support?

Most people who responded wanted the information to be easily accessible to them, in their community spaces. They wanted it to be somewhere they could walk to and that was open in the week. This is reflective of the people we spoke to, who were attending community spaces and are mainly from disadvantaged areas.

There was also a range of people who wanted support available in the evening and weekends. With people expressing the view that being on a bus route or having car parking nearby would be useful.



One size does not fit all

A message which came across very strongly when talking to the South Asian community is they all had very different needs and different levels of education and did not fit into the same box. This ultimately meant that every individual we spoke to at the Sahara event had different opinions of what cancer support should look like in Swindon based on their own individual needs and experiences.

Service providers should not make assumptions based on a person's ethnicity or disability as to what level of support they need and how this should be delivered until they have established a person's needs.

Health and social care services should have a strong focus on delivering a person-centred approach alongside delivering the local offer of support to our local communities.

Information needs to be available in Easy Read and accessible for people with Learning Disabilities and Autism

Whilst attending Swindon Advocacy Movement's project boost for people with Learning Disabilities and Autism, they expressed a wish to see more information in easy read. Too often the information is online when it would be better if it could be provided in a drop-in style session. These could be in small groups whereby questions can be asked, and they can bring their support workers along if they wish. Also allowing 1:1 time should they feel it necessary.

Next steps and recommendations

Moving forward our recommendations will be shared with Macmillan and highlighted to our local authority, NHS Integrated Care Board and Healthwatch England.

In response to this piece of work, we have already been invited to the Cancer unit at GWH to observe from a patient's perspective and make recommendations for improvement.

Our research has highlighted the need to continue face to face engagements to avoid members of the public being digitally excluded and unable to share their thoughts on how services should be provided.

We have identified several key areas to focus on and support the implementation of Macmillan services in Swindon.

Recommendations

Our key findings have demonstrated a need for:

- Physical presence within primary care and multiple community spaces. Ensuring they are easily accessible and available at a range of times/days.
- GP surgeries are perceived to provide healthcare resources as well as accessing a variety of different clinicians. Therefore, a range of materials providing information should be made available.
- A range of leaflets and posters, providing information on signs, symptoms, preventative measures, and support during diagnosis.
- Posters should include QR codes as well as weblinks and phone number, to maximise accessibility and prevent digital exclusion.
- Support should not be limited to those with a cancer diagnosis, but also their family and friends.
- Information should also be made available in easy read format and a variety of languages to compliment Swindon's diverse range of cultures.

Individuals in England, affected by multiple disadvantages are more likely to get long-term health conditions 10-15 years earlier than those from more advantaged areas.

In England, there is a 19-year gap in healthy life expectancy (whether we experience health conditions or diseases that impact how long we live in good health) between the most and least affluent areas of the country, with people in the most deprived neighbourhoods, certain ethnic minority and inclusion health groups getting multiple long-term health conditions 10 to 15 years earlier than the least deprived communities, spending more years in ill health and dying sooner. (Health disparities and health inequalities: applying All Our Health - GOV.UK (www.gov.uk))

Eight localities within Swindon, also known as local super output areas (LSOA), have been identified as being within the top 10% of most deprived areas nationally.

In Swindon's health and wellbeing strategy 2017-2022 ([Swindon's health and wellbeing strategy 2017-2022.pdf](#)), it states 'access to health and social care should be equitable'. Our recommendations have been made to support what the communities of Swindon have asked for but also to help reduce health disparities across the town.

Next Steps

- This report will be shared widely across the NHS and local council network and Healthwatch England.
- We will share the report on our social media channels and webpage
- We will review this report and use it to plan our next projects based on the data and findings.
- Ensure information and signposting on where to get support based on the issues raised is available through our website and social media.
- We will work with Macmillan to continue promoting cancer support available in Swindon.

Acknowledgments

Healthwatch Swindon would like to thank all the organisations and individuals that have taken the time to input their views.

We would in particular like to thank DASH and The Nelson Trust for supporting us in completing the surveys.

Appendix

Where we visited or engaged with:

Organisation/event	Location
Swindon Community Fridge (twice)	Gorse Hill (covers Swindon and surrounding areas)
Swindon City of Sanctuary	Central Library
Penhill Community Café	Penhill
Beechcroft Library	Stratton
Bakers Community Café	Railway Village
Bowel Bunch Cancer Group	Tesco Extra (covers Swindon and surrounding areas)
West Swindon District Centre	West Swindon
Coffee and Chat Learning Disability Group	Swindon Town Centre (covers Swindon and surrounding areas)
Swindon Advocacy Movement (Learning Disabilities)	Swindon Town Centre (covers Swindon and surrounding areas)
DASH (Learning Disabilities and Autism)	Sanford House (covers Swindon and surrounding areas)
St Mary's Church Group	Rodbourne Cheney
The Nelson Trust (women with disadvantages)	Old Town (covers Swindon and surrounding areas)
Great Western Hospital Event for Black History Month	GWH (covers Swindon and surrounding areas)

Sahara Fair organised by Changing Suits	Punjabi Centre (covers Swindon and surrounding areas)
Eye Can Conference organised by Wiltshire Sight	STEAM(covers Swindon and surrounding areas)
Diabetic Fair jointly organised by Healthwatch, NHS and National Institute of Health and Care Research	Swindon Town Football Club (covers Swindon and surrounding areas)
The Commonweal School and Sixth Form	Old Town (covers Swindon and surrounding areas)
Women's Health Information session for people with Learning Disabilities	Sanford House (covers Swindon and surrounding areas)

Questionnaire

Cancer information and Support

Where should there be cancer information and support in Swindon?

Healthwatch Swindon who exist to be the voice of the patient are currently undertaking a joint project with Macmillan Cancer looking at the best places in Swindon to share cancer information and support.

It has been identified there is little available for the people of Swindon at the moment.

We want to hear from you to find out how, when and where you would like to receive cancer information and support.

Where would you look first for cancer support and information in Swindon?

1. What kind of information would you want to access?

- Preventative
- Signs and symptoms
- Support during diagnosis
- Other (please specify):

2. Where would you like to find it?

3. How would you like to get the information?

- Leaflets
- QR codes to websites

- Manned information stands
- Drop in sessions
- Other (please specify):

4. Which of the following are important to you when accessing information or support?

- Car Parking close by
- On a bus route
- Can walk to
- Easily accessible
- Week day opening
- Evening opening
- Weekend opening
- Other (please specify):

5. Is there anything you would like to share about your experience of getting information and support for cancer? What went well or could have been done better?

6. Do you have experience of Cancer?

Are you:

- Undergoing tests
- Have a diagnosis
- In remission
- Have family member affected
- Have friend affected

Comments:

7. Please tell us your age

- 13 to 15 years
- 16 - 17 years
- 18 - 24 years
- 25 - 49 years
- 50 - 64 years

- 65 to 79 years
- 80+ years
- Prefer not to say
- Not known

8. Please tell us your gender

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

9. Please select your ethnicity

- 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 group background
- White: British/English/Northern Irish/Scottish/Welsh
- White: Irish
- White: Gypsy, Traveller or Irish Traveller
- White: Roma
- White: Any other White background

- Prefer not to say
- Other (please specify):

10. How well can you understand, speak, read and write English?

Not at all well Not well Well Very well Unsure or don't know Prefer not to say

- I understand spoken English
- I speak English
- I read English
- I write English

11. Please select any of the following that apply to you:

- I have a disability
- I have a long-term health condition
- I am a carer
- None of the above
- I prefer not to say

12. Which of the following disabilities or long-term health condition do you have?

- A physical or mobility impairment
- Deaf or hearing impaired
- Blind or sight impairment
- Learning disability
- Mental health condition
- Asthma, COPD or respiratory condition
- Cancer
- Cardiovascular condition
- Chronic kidney disease
- Dementia
- Epilepsy
- Diabetes

- High blood pressure
- Prefer not to say
- Other (please specify):

13. Do you have access to the internet on a regular basis at any of the following:

- At home wifi/broadband
- On public wifi (e.g. in a café or library)
- At work
- On a mobile network (e.g. smartphone or tablet) with a SIM
- None of the above
- Prefer not to say
- Other (please specify):

14. To what level do you agree or disagree with each of the following statements?

Disagree completely Disagree slightly Neither agree nor disagree Agree slightly
 Agree completely Unsure or don't know Prefer not to say

- I am confident in using apps to carry out day to day tasks (e.g. online banking, booking travel, booking medical appointments)
- I am confident in using online search tools to look for information (e.g. Google)
- I am confident using online written communication such as email, WhatsApp, text
- I am confident using onscreen/video communication such as Facetime, Zoom, Skype or Teams

15. If you would like us to contact you to discuss any of your answers, please add your details below



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