

Cancer Information and Support Services

Summer 2022





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Your Voice in Health and Social Care is an independent organisation which gives people a voice to improve and shape services and help them get the best out of health and social care provisions. YVHSC holds the contract for Healthwatch Bromley (HWB). HWB staff members and volunteers speak to local people about their experiences of health and social care services. Healthwatch engages and involves members of the public in the commissioning of health and social care services, through extensive community engagement and continuous consultation with local people, health services and the local authority.



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Executive Summary

The Cancer Information and Support Survey was a local project run by Healthwatch Bromley. The project aimed to identify and understand trends in the support needs of people, and their loved ones, living with or beyond different types of cancer. We created a survey which asked questions about support wanted, and received, and collected demographic information.

We aimed to correlate findings to determine what support is being provided and what is lacking. Our survey allowed us to establish what patients with various types of cancers consider essential support and how well they feel this was delivered throughout their treatment. Acting on this research could address gaps in provision and support future initiatives to fill them.

The three aims of this project were to:

1. Understand the support needs of people undergoing cancer treatment and how they feel their needs have been met by service providers.
2. Describe the feelings of patients' loved ones and how they were affected by the support provided, or lack thereof.
3. Produce recommendations for addressing the needs of patients diagnosed with cancer, and people close to them such as family, friends and caregivers.

Our report highlights the key findings and we have carefully analysed the 29 responses. Each participant shared their experience of being a cancer patient, or a partner, carer, or family member of a patient, searching for information and support with cancer.

All participants greatly value the support services they currently use, but would welcome more information on sources of emotional support, diet, and managing particular cancers, e.g. skin and prostate cancers.





About Healthwatch

Healthwatch is an independent champion for people who use health and social care services. We exist to ensure that people are at the heart of care. We ask what users like about services, and what could be improved, and share their views with those with the power to make change happen.

Our sole purpose is to help make care better for people by:

- Providing information and advice to the public about accessing health and social care services and choices in relation to those services.
- Obtaining the views of residents about their need for, and experience of, local health and social care services and making these known to those who commission, scrutinise and provide services.
- Publishing reports and recommendations on how those services could or should be improved.
- Promoting and supporting the involvement of local people in the monitoring, commissioning and provision of health and social care services.
- Reporting the views and experiences of local residents to Healthwatch England, helping it perform its role as national champion.
- Making recommendations to Healthwatch England to advise the Care Quality Commission (CQC) to carry out special reviews of or investigations into areas of concern.

Under the General Data Protection Regulations (GDPR) and the Data Protection Act 2018, we have the lawful basis to process information shared with us by services and service users. Confidentiality is important to us, and we will only keep data for as long as necessary. If you would like to know more about how we use the data we collect, our privacy statement is available on our website, www.healthwatchbromley.uk





Introduction and Background

The Cancer Information and Support Services survey was the first cancer research project undertaken by Healthwatch Bromley.

The survey aimed to assess awareness of cancer information and support among Bromley residents.

It was chosen as a research study topic to support strategic priorities across cancer care, public health, and the NHS Long-Term Plan, and to increase Healthwatch Bromley's knowledge of cancer services and patients' experience of these.

Following a series of discussions with the Patient Experience and Engagement Manager at Princess Royal University Hospital (PRUH) and South Sites, King's College Hospital NHS Foundation Trust, the project was proposed by Healthwatch in November 2021.

The study was approved by the Healthwatch Bromley Advisory Committee, to support King's priority workstreams developing new cancer information and support centres in Bromley. As so many people are affected by cancer in its different forms, we wished to take the opportunity to make local voices heard and enable Bromley residents to help shape the future of these vital services.

The National Health Service (NHS) published its 10-year Cancer Long-Term Plan in 2019 (1). The plan's objective is to increase the number of people living at least five years after receiving a cancer diagnosis; the target is at least 55,000 more people by the year 2028.

The Long-Term Plan particularly focuses on:

- Cancer prevention
- Early diagnosis
- Faster diagnosis and treatment
- Reducing inequalities
- Personalised care

The NHS has made significant progress in delivering personalised care and support planning to patients, based on holistic needs assessments, led locally by Cancer Alliances. In October 2021, they published the first results of a new, ground-breaking Cancer Quality of Life Survey (2), which helps understand and track the quality of life of patients after treatment. Information and support is one vital element in improving quality of life for cancer patients and their families.

*



Methodology

With the assistance of a clinical nurse specialist (CNS) at PRUH and a Healthwatch Bromley committee member, we produced a survey with qualitative and quantitative questions.

The survey differs from past studies in that it seeks to gather experience from not only patients diagnosed with cancer but also people close to them, such as family, friends and caregivers.

We used SurveyMonkey, an online platform for creating, collecting, and analysing responses. The online survey was promoted on our website and social media platforms. It was shared with key partners and local organisations. We also provided a contact number and email address for people who wished to speak about their experience directly with our staff or volunteers.

We printed hard copies for face-to-face engagement visits as well as designing an Easy Read version for people with sensory impairments to share their experiences.

We met with young adults at the Big Mental Health Day event organised by Advocacy for All. This experience gave us a deeper understanding of people with disabilities who need cancer information and support.

In addition to the survey, we organised an online focus group for people living with or beyond cancer and their friends and family members who wished to share their experiences. We also arranged more than ten meetings with primary care professionals and third sector organisations, to support the distribution of our survey in digital and paper format.

Strengths and Limitations

Several planning meetings and preparation discussions were held with key partners before embarking on this study. King's College Hospital NHS Foundation Trust decided to produce a parallel survey on support needed by cancer patients. Healthwatch surveyed out-patients and their relatives/carers. This separate research was therefore more reliant on online outreach and responses.

In the time available we secured 29 responses from patients, carers, and family members. Though this is a relatively small sample, we believe that the points made in this survey have a wide application.

We understand the King's College Hospital NHS Foundation Trust survey involved talking to patients face-to-face in a medical setting at the PRUH. Our survey used alternative methods to reach patients, carers, and families.

Demographics tell us that over **40%** of our survey respondents are aged 65+ and over **80%** White British. Analysis should therefore take this into consideration. Further information on participant profiles can be found later in the report (Appendix 1). We acknowledge that the feedback provided is a snapshot of the experience of people at the time of the research.



Key Findings

The following section analyses the 29 responses we received. We highlight the key findings which emerged from our survey and take a more detailed look at the different experiences of patients and those close to them when searching for information and support with cancer.

How do you like to receive information and support for your treatment?

The majority of participants said they preferred to receive information and support for cancer treatment one-to-one in person (Appendix 8). This was then followed by in-person at a Cancer Information Centre e.g., Macmillan Cancer Support.

The lowest scoring options for participants were Chat (e.g., texts), Email, and Online (e.g., video call).

Top six services that made a difference

When we asked participants what support made the most difference to a patient's journey, we noticed six recurring services in the responses.

These are highlighted on the right as examples of best practice which impact positively on the lives of those living with and beyond cancer, and their family members.

- Specialists at Guy's Hospital
- St Christopher's Hospice
- Scans at PRUH
- Macmillan Support Group
- Support Groups
- Counselling



Top six services that made a difference Continued....

"**Guy's specialist** prostate cancer unit. Having a named nurse to contact was great."



"**Support groups** were very useful. Talking to people going through a similar experience was life changing."



"The **specialist** cancer urology centre at **Guy's hospital**."



"I was able to get **counselling** following a hospital admission. I was so grateful for that help."



"The breast cancer clinic at **PRUH** with chemo and cancer nurses and amazing specialists to see regularly. The fact that scans can be done in the same hospital was very very useful."





A new Cancer Information & Support Centre

To support King's College Hospital NHS Foundation Trust's plan to develop a new cancer information centre in Bromley, we asked participants where they would like the new centre to be located. This was an open question to which we received several similar responses.

Ease of access, good transport links and a central location were most often mentioned. Residents would like to see a new information centre somewhere in the centre of Bromley, with considerable footfall.

Some participants went further by telling us exactly where they would like to see a new centre. The Glades, Bromley Civic Centre, and near Beckenham Beacon Hospital were the top three locations.

The Glades in central Bromley, a shopping centre with a total of 135 trading stores and a floor space of 464,000 sq. ft, was mentioned three times.





A new Cancer Information & Support Centre Continued....

"In **central Bromley** so it is accessible from all areas of the borough."

"Anywhere that is **accessible** with public transport."

"In **The Glades** because it has the most footfall."

"Attached to one of the hospitals. I suggest **Beckenham Beacon** as it is not huge and would be safer for patients and family to visit."

"I think it should be **central to the whole borough** with **easy transportation** links, so probably Bromley Town."



Cancer Groups

To understand how important different types of support were to people with different types of cancers, we asked participants to rate each type of support on a scale of 1 to 5; 5 being “Very Important” and 1 being “Not Important.” We then grouped the data by type of cancer diagnosed and studied the data trends. The following sections highlight support by each cancer group/type.

Prostate

The seven respondents affected by prostate cancer (Appendix 2) placed a consistently high value on all types of support, particularly ‘Emotional’ (focusing on the individual feelings of the patient) and ‘Relationship’ (the relationship with a patient’s partner and the broader family), with both earning similar ratings. **86%** rated them as “Very Important”, **14%** as “Not Important”.

All seven respondents said they were aware of the ‘Emotional’ support given by a hospital and the services available to them for prostate cancer. However, when asked if they were aware of ‘Relationship’ support, only one respondent said yes. This suggests there is still work to be done to cover intimate and sexual topics effectively.

The next highest ratings were for ‘Physiotherapy’ (**71%**), ‘Psychological’ (**67%**) and ‘Support Group’ (**57%**) (Appendix 3). **67%** of participants said they strongly value the support of a Cancer Psychologist. However, **71%** of participants diagnosed with prostate cancer were unaware of any available Cancer Psychologist support (Appendix 4). Since this area is highly valued, lack of support can make the treatment experience more difficult.

In the U.K., prostate cancer is the most common cancer among men (3) yet nationally there is still a significant gap in emotional support.

Post-treatment, prostate cancer patients are known to experience difficulties with body image, masculinity, self-esteem, impaired quality of partner/marital relationships and sexual intimacy (4). This could be addressed by relationship support.

The National Institute of Health Research found that although prostate cancer is the second most diagnosed cancer in men globally, there is still a critical lack of guidance available to practitioners to provide supportive care for sufferers (5). These unmet needs included support for side effects such as incontinence and erectile dysfunction, which can heavily affect patients and partners.

A previous survey conducted in seven European countries and involving over 1000 men discovered that 81% of respondents had some unmet psychological needs (6).

Prostate continued...

Another support considered “Very Important” among prostate cancer patients, and their carers, is a cancer support group service, with **57%** ranking this a five and all respondents being aware of the existence of these groups. **14%** said that group support is somewhat important, **28%** were neutral.

Four of the seven responses for prostate cancer were from family members or carers. We found that often the wife or partner, of a person living with prostate cancer reaches for help for ‘Relationship’ support or is willing to participate in a ‘Support Group’.

When asked, “What has made the most significant difference to you and your family/friends? Is there a particular service you would like to highlight?” one family member/ carer stated “Support groups were very useful. Talking to people going through a similar experience was life-changing”. This insight demonstrates the value of providing and promoting a cancer support group to partners, family members, and carers of patients.

The only support with the lowest rating, from the prostate cancer respondents, is ‘Financial Aid’. Out of all the survey responses, no one rated this area “Very Important”. We note that seven of the respondents are age 45+. Every respondent who said they had children stated they were adults.

Age can significantly impact financial responsibility and the need for financial support. Younger patients, especially with younger children, may need more financial help and value this more highly.

“There should be more support for partners of patients with prostate cancer. It’s in place for patients only.”



Breast

In our survey, the four participants, **(100%)**, diagnosed with breast cancer rated 'Body Change Support' as "Very Important". (Appendix 5 and 7). A woman's physical sensations and experiences can change drastically due to surgery, chemotherapy, and radiation.

Of the breast cancer responses we received, **80%** are aware of 'Body Change Support' being offered during their treatment. This is significant, as all respondents considered it "Very Important".

"No amount of money could have helped me more, in my opinion. With breast cancer your body changes a lot."



In a year, approximately 55,920 women in the U.K. will be diagnosed with breast cancer (9). Of patients at all stages, 81.2% have surgery to remove the tumour in their breast or breast area (10). Due to the location of the surgery, and what might need to be removed, the patient's body can be deeply affected.

The Oncology Nursing forum stated in a report (11) that "healthcare providers need to better understand the sexuality and intimacy needs of women with breast cancer and their partners. To open the lines of communication, healthcare providers must have an understanding of the importance of discussing the sexuality issues of patients with breast cancer."

Skin

In our survey, of those who said they had skin cancer, **80%** are female, with half in the 45-54 age group and the rest aged 65+.

The five respondents affected by skin cancer considered nearly all support services "Very Important" (Appendix 6 and 7).

From these responses, we identified that information might have been less available to people with skin cancer than breast cancer.

Around 8,400 new cases of melanoma skin cancer are diagnosed annually in women in the UK, making it the fifth most frequent form of cancer (7).

People 75 and older make up more than a quarter, 29%, of all new instances of melanoma skin cancer in the UK each year (8).



Cancer support for people with a disability

Of the 29 participants in our survey, three stated they are autistic. We engaged with them in May at the Big Mental Health Day. We discovered no significant differences between the experiences of these people and the respondents who said they do not have a disability.

At the event, we had the pleasure of speaking with a person who is autistic and beyond prostate cancer. During our conversation, the only negative issue identified was with diet and its challenges for some people with autism. The person confessed that they could not implement their dietitian's recommendations due to a lack of cooking skills. They had to carry on with microwavable meals despite knowing they might not have the best nutritional value.

We note that eating a healthy and balanced diet is essential for optimising cancer treatments (13).

Healthwatch Bromley's 2020 report, 'Autism Care Pathway in Bromley 18+' (12), identified a need to raise awareness of varying levels of stigma and discrimination faced by some autistic people across health, social care, and educational settings. When looking at the responses we received for the cancer survey, we think that further research studies, primarily focusing on autism awareness, would be beneficial.

“I'd love to speak to a cancer dietician – I didn't know one existed.”



Recommendations

1. Local Authority Public Health and NHS partners should review current cancer awareness activities across Bromley, with a view to establishing an annual event, well publicised and with practical demonstrations, e.g. identifying the signs and symptoms of skin cancer, utilising national cancer awareness days/weeks where appropriate.
2. Primary care professionals should continue to collaborate with third-sector organisations to explore solutions to assist partners, relatives or caregivers of cancer patients who have undergone bodily changes.
3. Partners such as King's College Hospital NHS Foundation Trust and Macmillan Support Line should review websites, leaflets and other resources with a view to encouraging people to seek help when facing personal or intimate difficulties in their relationships as a result of cancer diagnosis, treatments and bodily changes.
4. Clinicians e.g. dieticians should work closely with local healthcare organisations to make dietary plans more easily achievable by individuals needing extra support due to learning difficulty or disability, particularly because eating a healthy and balanced diet is essential for optimising cancer treatments.
5. Support services for cancer patients should be designed for and publicised to family members, carers and partners, as well as patients, to increase their awareness and involvement and help improve patient outcomes.
6. King's College Hospital NHS Foundation Trust should consider locating its proposed new Bromley cancer information centre in the Glades, Bromley Civic Centre, or in/near Beckenham Beacon. This was a clear view from our respondents.



Appendices

Appendix 1: Participant Profiles

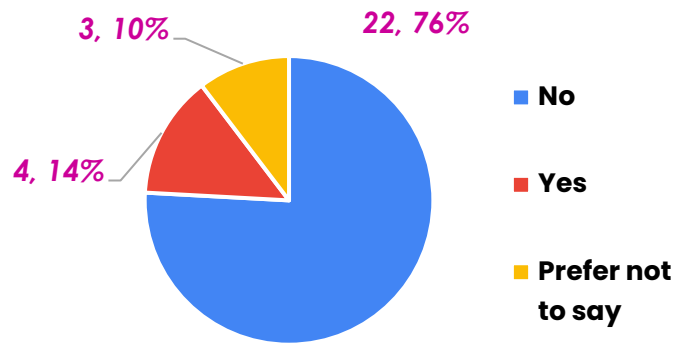
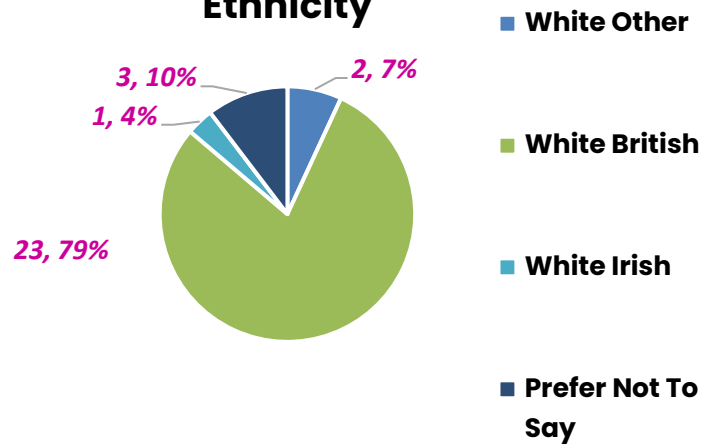
Healthwatch Bromley received a total of 29 responses from residents between March – June 2022. When we promoted the survey, we requested that only Bromley residents participate. This was difficult to monitor online. We are aware that some respondents may not be Bromley residents. However, we try to gather monitoring information with every survey to improve our research studies.

56% are cancer patients and 44% family members or carers of cancer patients.

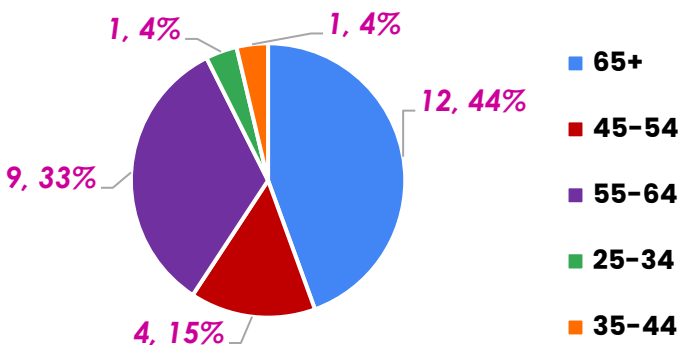


65% female 35% male

Ethnicity



Do you have a physical or mental disability or impairment?



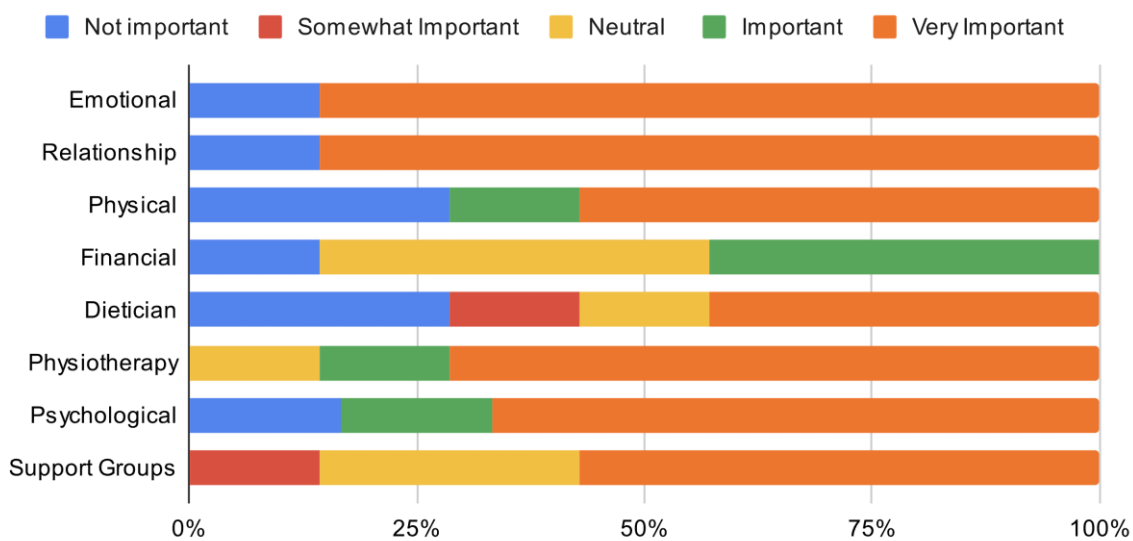
Age groups



Appendix 2: Type of cancer groups

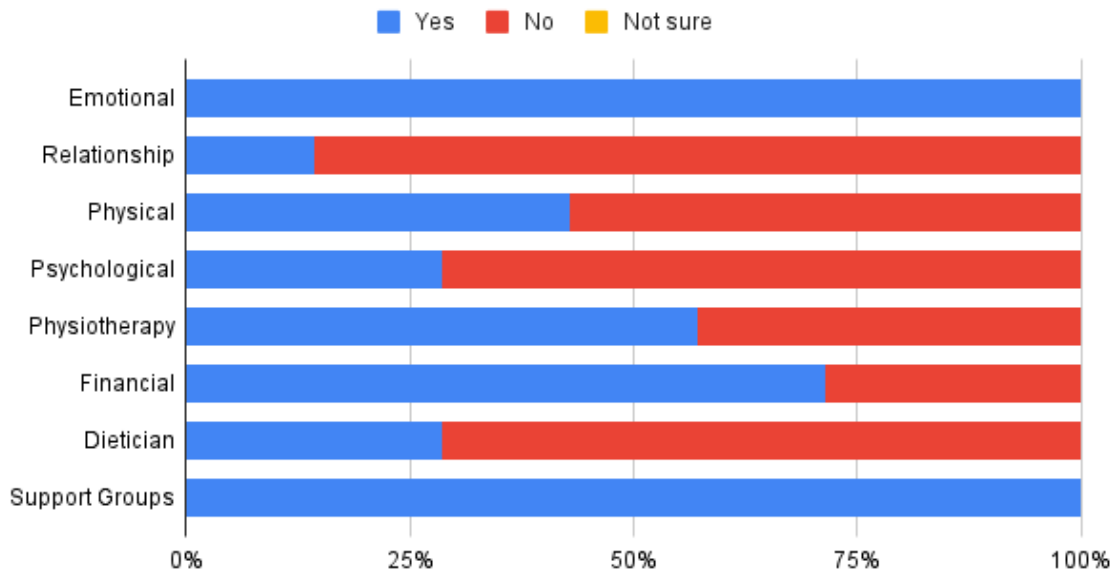
With what cancer/s have you/your friend or relative been diagnosed?	Record Count
Prostate Cancer	7
Skin Cancer	5
Breast Cancer	4
Bowel Cancer	2
Ovarian Cancer	2
Liver Cancer and Bile Duct Cancer	2
Bone Cancer	2
Pancreas and Liver Cancer	1
Uterine Cancer	1
Lung Cancer and Brain Tumours	1
Breast Cancer Bladder Cancer Ovarian Cancer and Breast Cancer	1
null	1
Grand total	29

Appendix 3: Ratings across the prostate cancer group

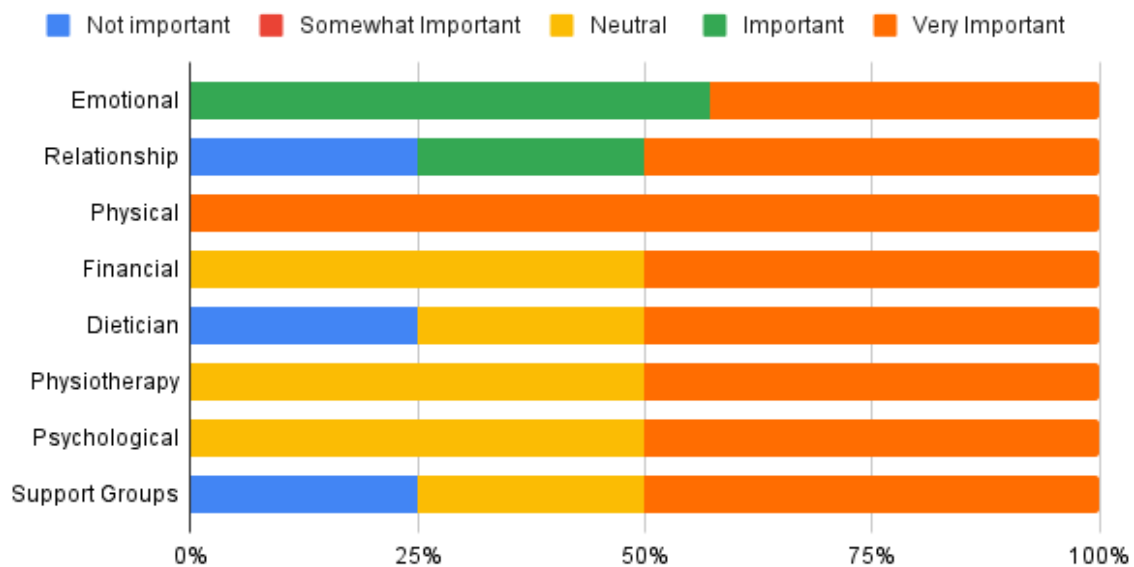




Appendix 4: Awareness of support services amongst prostate cancer group

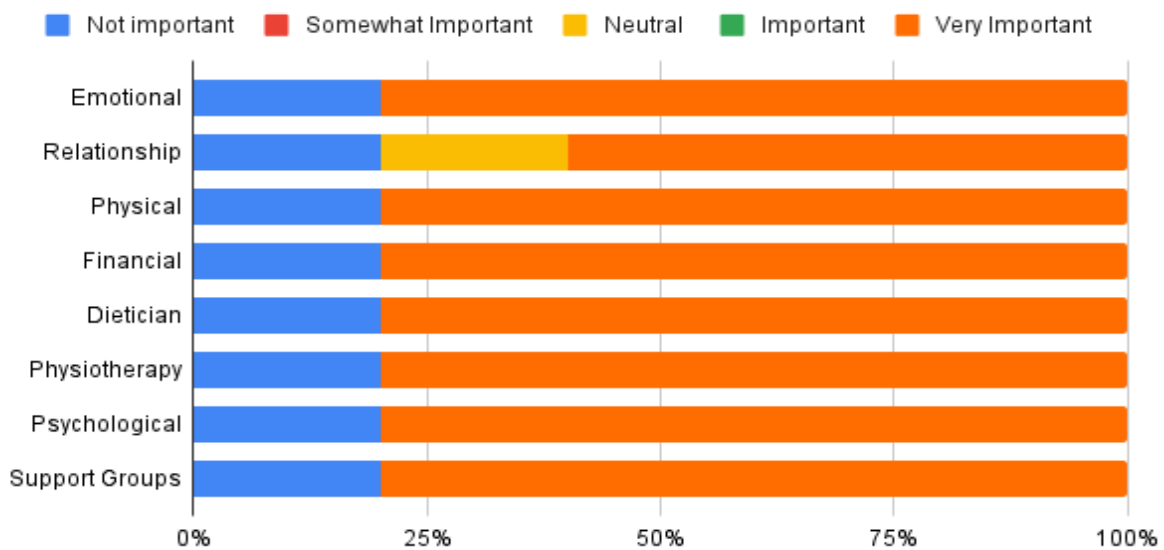


Appendix 5: Ratings across the breast cancer group





Appendix 6: Ratings across the skin cancer group

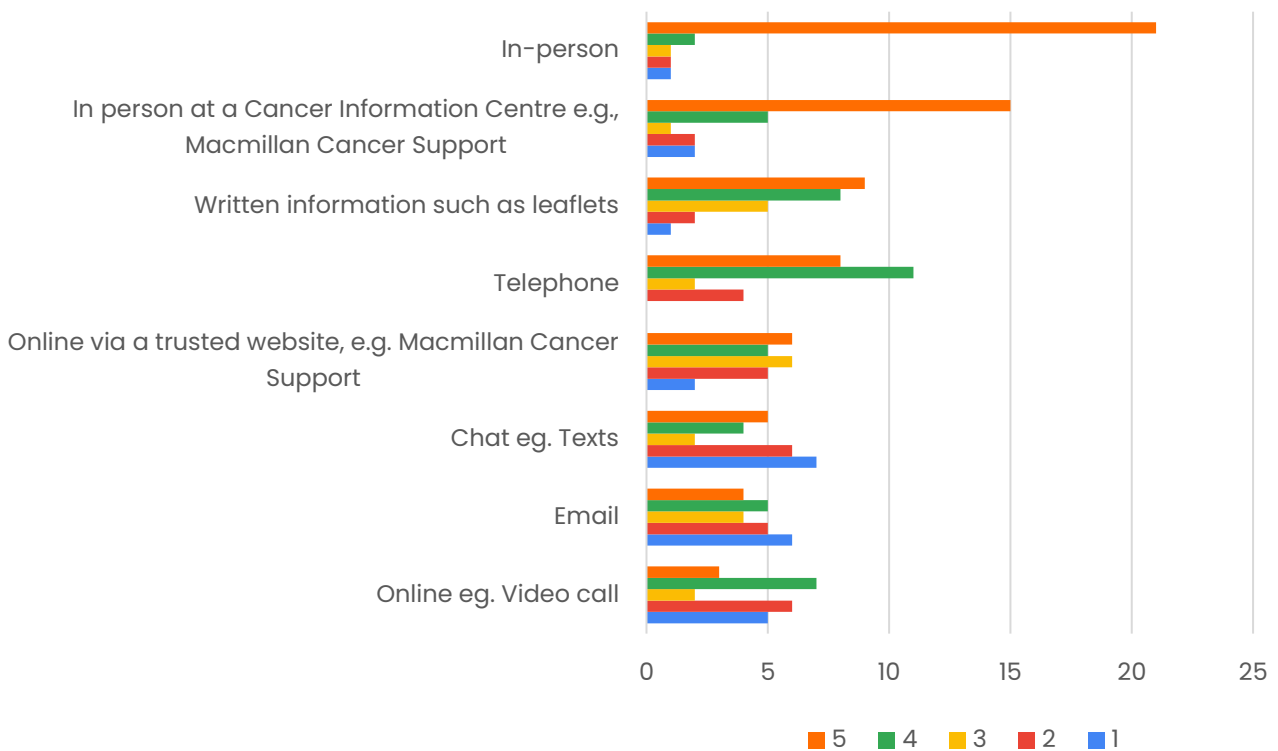


Appendix 7: Percentage of “Very Important” across different types of support between breast and skin cancer.

Support	Skin Cancer	Breast Cancer
Emotional	80%	43%
Relationship	60%	50%
Physiotherapist	80%	20%
Body Change	80%	100%
Cancer Dietitian	80%	15%
Financial Aid	80%	50%
Cancer Group support	80%	50%
Cancer Psychologist	80%	50%



Appendix 8: Percentage of “Very Important” across different types of support between breast and skin cancer.





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- Chislehurst Medical Practice
- Community House
- Community Links Bromley
- Cotmandene Community Resource Centre
- Dimpleby Cancer Care
- Healthwatch Greenwich
- Macmillan Cancer
- Mencap
- Mottingham Community & Learning Shop
- NHS South East London Clinical Commissioning Group (NHS SEL CCG)
- One Bromley
- South East London Cancer Alliance
- St Christopher's Hospice
- The Pink Ribbon Foundation
- VCSE Health and Wellbeing Transformation Project



