

Thurrock Cancer Conversations

healthwatch
Thurrock



**Report
2020**

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About Healthwatch

Healthwatch Thurrock is the independent Health and Social care services champion for the people of Thurrock. We gather and represent views of local residents in order to build up a picture of services that are doing well and where they can be improved.

Along with consultation work and gathering the voices of residents, Healthwatch Thurrock also provide an information guidance and signposting service.

Residents are invited to “speak out” via an online forum as well as through targeted surveys, conversations and face to face engagement within the community.

Healthwatch Thurrock presents the voices of Thurrock to aid in identifying the need for change, considerations before commissioning and to support best practice across services.

Through conversation and engagement with people actually using the services Healthwatch Thurrock highlight and promote improvements.

We know that services are better when people are treated as individuals and are actively involved with shaping support.

To do this, services need to learn from examples of real experiences, how they can be adapted and fit around local needs.

It is also important to understand where services are working well and that should be considered to be a blueprint of change when designing services and support.

Background

Healthwatch Thurrock were commissioned to conduct conversations with individuals to identify the quantity, source and consistency of information received by patients following diagnosis of cancer. Healthwatch Thurrock was supported with the conversations by St Luke's Hospice Information Resource Service.

To retain confidentiality of patients, GPs were asked to contact all individuals who were currently experiencing or had been through a recent diagnosis of cancer following a set criteria. The criteria was individuals on GP cancer registers diagnosed since 2016. The invitation letters invited them to have a conversation with Healthwatch Thurrock. The invitations were targeted based on the date of diagnosis to ensure patients would have gone through diagnosis, assessment, treatment and post treatment stages.

A figure between 30-40 representing 10% of individuals fitting the criteria was agreed as a robust sample group and having reached this number, Healthwatch Thurrock and St Luke's Hospice Information Resource Service began to make arrangements with the individuals to meet and have conversations.

Conversations were held mostly within people's homes with a small number conducted by telephone or at a location as requested by the individual

Background

To guide the conversations, a set of prompt questions were used to maintain consistency and to gather the information required to analyse when and what information was given to support individual journeys.

The majority of individuals responding to the invitations were female (71%), White/British (41%) and did not have a disability (96%). Whilst this is not wholly representative of Thurrock residents living with cancer this was representative of those individuals who wanted to take part in the conversations.

The conversations lasted around one to one and a half hours and although much information was heard, for the purpose of this report, the focus of feedback is around information, support and overall experience received and by whom.

The results, as shown in this report, will be shared to identify gaps, understand where information is given but also whether individuals were able to source their own information and from where.

Healthwatch Thurrock and St Luke's Hospice Information Resource Service would like to thank each and every person they spoke to for sharing their experience and journey. At times conversations were difficult and emotional for both, but sometimes they were positive and gave an opportunity to acknowledge good existing practices and where to improve them.

Executive Summary

The report looks at different stages of a persons cancer journey, diagnosis, assessment, treatment and post treatment and Healthwatch Thurrock sought to understand the level and appropriateness of information given.

From the conversations, the overall experience of people with regard to the information they received came across as mostly positive (66%), with a smaller amount citing they were somewhat supported (14%). A fifth of people (20%), however, said they did not feel supported or informed.

There did not appear to be any correlation between the type of cancer and the availability of information given. Delivery of information between verbal and leaflets was evenly matched in diagnosis with a Consultant being the main source. A little less than a quarter of people felt the information should have been available earlier (23%).

When resourcing information for themselves, individuals used online (22%), family (29%) and other resources such as support groups. Most people (73%) did not look for support groups for themselves, although in various times during their journey, support groups were something people wanted to know about.

In all stages, information was mostly given by a Consultant and this was considered to be the correct person. There were no trends across types of cancer, male or female and the information they received that would suggest a disadvantage to particular groups.

The clearest trend to come from the conversations was that of people skipping or choosing not to answer a particular line of enquiry. Assumptions could be made that this was due to information overload at the time making it difficult to recall or that they simply did not remember.

Executive Summary

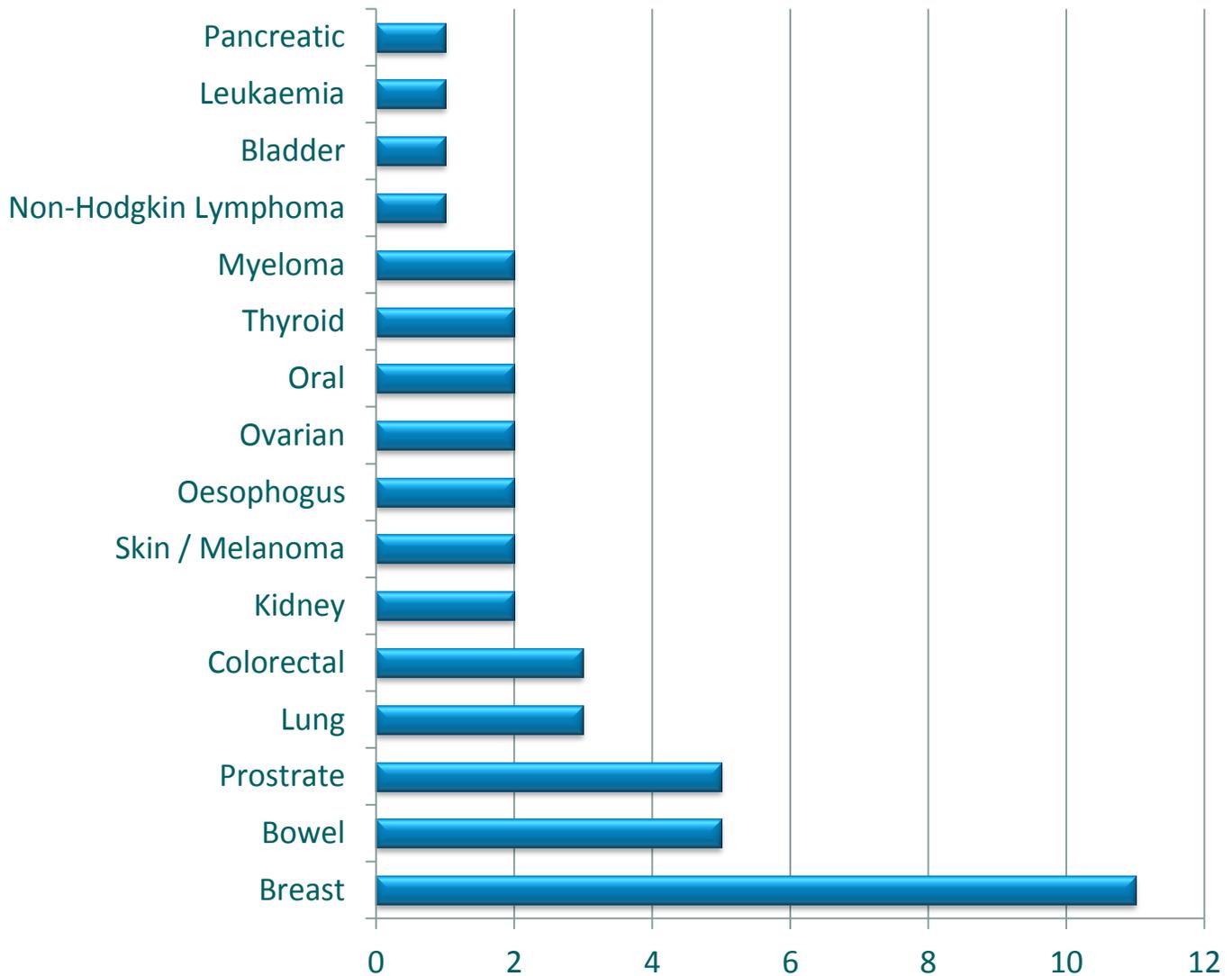
There are opportunities for improvement at all stages so people receive information but also feel able to ask questions about their cancer. There were instances where people still had questions and notably some felt they were rushed and overwhelmed to the point they felt there was no time. This appeared to be where the pace of diagnosis, test and ultimately treatment was very quick.

One of the prompts within the conversations was “What is the most important thing to know at diagnosis” Half of individuals (50%) wanted to know their prognosis and ultimately whether they would survive. Others (38%) wanted to know next steps. Smaller amounts were concerned about side effects (8%) and support available (4%).

By carrying out these conversations Healthwatch Thurrock has identified that most people are happy and informed at different stages of a cancer journey.

Improvements can be made across all stages including making sure individuals have the chance to ask more questions, even at a later time when they have had time to come to terms with their diagnosis.

What cancer were you diagnosed with?



The chart above shows all the different types of cancer within the sample group. Breast Cancer was the most common cancer suffered from people in conversations. All the individuals suffering /having suffered from Breast Cancer in the sample group were female. This type of cancer was an expected output from the conversations due to high female response and that it reflects Breast Cancer being the most common type nationally.

Prostate Cancer was the most common cancer reported by males in the sample group, again reflecting the national picture.

Information

Information - the accessibility, understanding and receiving was a key element to the conversations. What information was given, who gave it to you and was it the correct amount as well as whether people had sought their own information was asked.

There was no prior measure of what was the correct amount or person to give information and at what point. However, it is assumed that all individuals should be given adequate information noting that this is relative to the persons needs or preference.

Information at diagnosis

People reported that they had received various types of information at the point of diagnosis including:

- Verbal
- Leaflets / brochure
- Support group information
- Signposting to online resources

At the point of diagnosis, a large number (84% / 38 individuals) were given information in one form or another. The highest delivery of information was verbally (43%) with leaflets (41%) a high second.

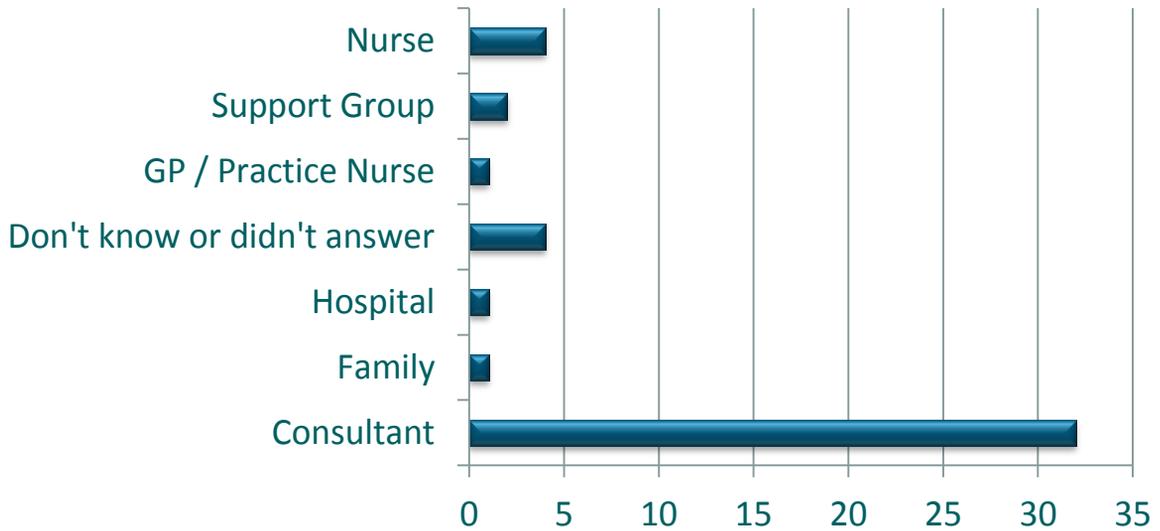
Only one person (2%) was given information about support groups and no-one was directed to online resources.

Some people (14%/6) said they were given no information at the point of diagnosis. There was no theme to specific cancers and not receiving information as they were unique in this response set.

Information at diagnosis

Generally most people received information about their diagnosis from a Consultant within an hospital or clinic (71%).

Who gave you information at diagnosis



The information at diagnosis was timely for the majority of people (41%), however, nearly 1 in 4 people would have liked it earlier. A number of people (36%) did not answer this question.

Half of the responders felt the information was adequate to answer any questions or address any initial fears, however nearly a quarter (23%) felt they wanted more.

A large majority (73%) felt there was additional information they would have liked.

Information at diagnosis

Through the conversations, nearly three quarters of individuals (73%) said they would have liked more information at diagnosis. The type of information ranged from wanting to know whether they would die to saying “everything” (19%). Notably from participants that were given information by a nurse at diagnosis, only one person said they wanted more.

There was again, no correlation to the type of cancer and those feeling they were not given enough information.

For several people, they acknowledged that due to speed of everything going on, they didn't either have or understand the information given.

“Support information would have been helpful”

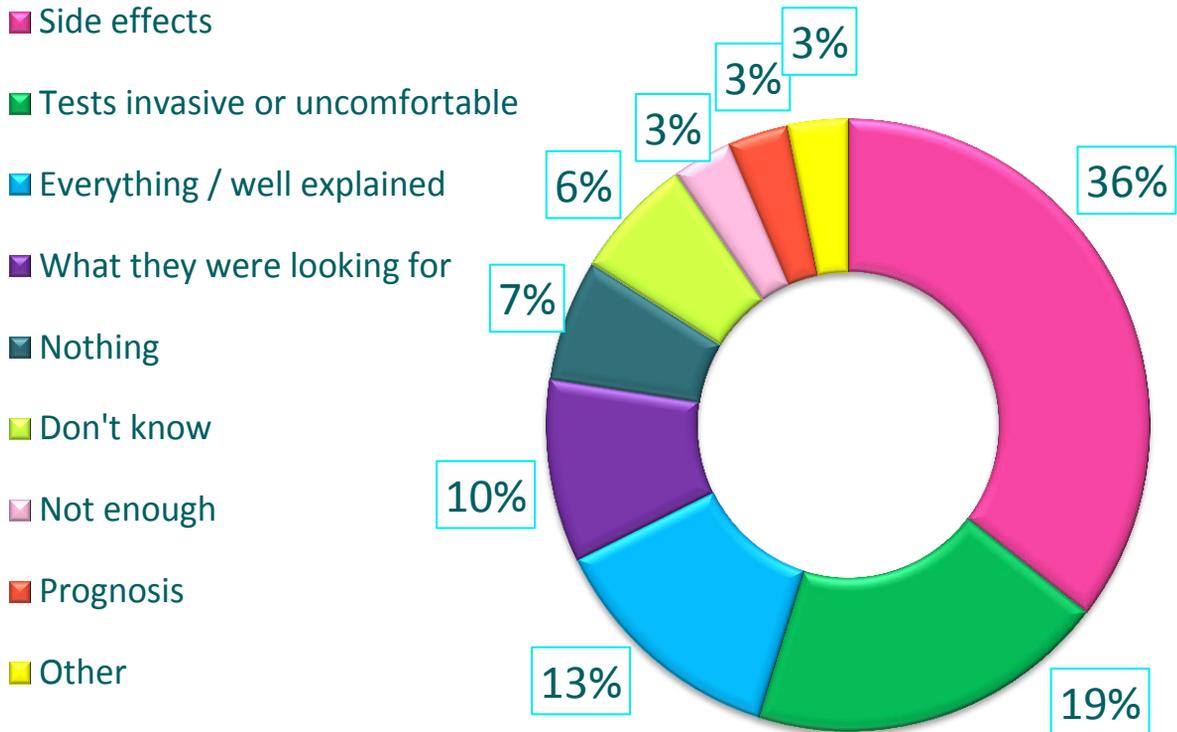
Diagnosis 2017. At diagnosis information was given verbally by a Consultant and timing plus amount of information was considered adequate to address initial fears and answer questions. However, she told Healthwatch Thurrock that she would have liked more support group information. She researched her cancer online and sourced a support group herself. The most important thing she wanted to know when diagnosed was “Am I going to survive?”

Female, Breast Cancer

 ***Not a chance to ask questions, everything happened so quick*** 

Information at point of assessment / tests

At the point when people were being told about next steps and what further assessments were required after diagnosis, over a third (36%) were told about side affects. Conversations also revealed just under a fifth (19%) received information about whether the tests were invasive or uncomfortable.



Diagnosis 2016. At assessment / test stage, patient was given information about where tests would take place. A nurse gave the patient the information and he felt this was the correct person to do so. He felt fully informed about the tests and did not require any further information.

Male, Skin / Melanoma Cancer

Information at point of assessment / tests

Additional information required as recorded by patient voice

“Not told enough, should have been told more about thrush. Would like a pathway to A&E, did not know about that”

“Body image/reconstruction/impact of radiotherapy/pain surgery”

“Would like to have known that they were looking for cancer, but also being oblivious was good”

“Needed to know how painful procedures would be. Not informed when next appointment would be”

“Would have like to have spoken to Dr’s more, was allergic to chemo”

In the majority, it was a nurse (27%) giving the patient information about the tests or assessments that was going to take place. In other instances (22%) the information came directly by a Consultant / Surgeon and in other situations (17%) a Consultant/Surgeon supported by a nurse gave the information.

A third of respondents chose “other” as an option when asked about what they were told at the point of assessment. This was a free text response and conversations revealed about the same amount of people felt they were told what they needed (36%) to those that felt they should have been told more (37%).

Information during treatment

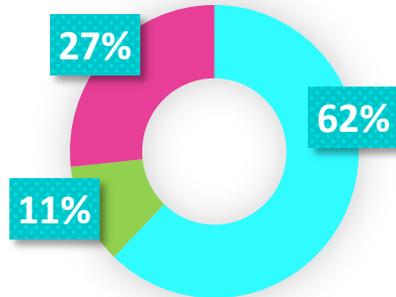
Over two thirds (62%) of conversations revealed that patients understood their treatment and they were fully informed.

Treatment information was mostly given by a consultant (85%).

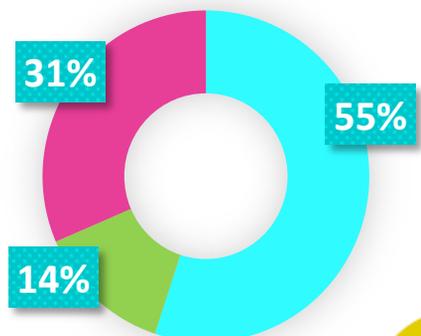
Over half (55%) knew who to talk to or to find further information.

A quarter (25%) felt there was information available for family members / friends.

Understand treatment and fully informed?



Did you know who to speak to for further information?



Information post treatment

Over two fifths (43%) of people were informed about what to expect after treatment to maintain their health and wellbeing.

A similar amount (44%) felt they did not have any further questions following cancer treatment. However a large number (40%) said they did not know or did not answer the question.

A small number (17%) felt they still required further support or information following treatment.

Additional advice given post treatment



When asked about additional information, various responses were given, however, 22 from the sample group of 45 individuals declined to answer.

Information post treatment

Further support of information wanted as recorded by patient voice

“Information should be given earlier, at the beginning, given by a person who understands whats going to happen and whats available”

“Given information but more needed”

“Felt let down for ongoing support, felt alone”

“I don’t know what information I needed, it is very confusing when you are going through trauma”

“Better follow up”

“Pain management”

“People in the same situation as me”

“Someone to understand / talk to / listen / counselling”

“Someone to understand / talk to / listen / counselling”

Information post treatment

Diagnosis 2018. At diagnosis, patient was given verbal information from a Consultant, however, she would have liked the information earlier. The amount of information was considered adequate and addressed initial fears or answered questions. The patient was unsure how the diagnosis was then followed up and did not research anything as she “didn’t want to know”.

The patient did not find or access any support groups and the most important thing to know was “Is it treatable?”.

When she reached assessment / test stage she wanted to know how much discomfort and invasive the procedures was and was given information from a Consultant. In her opinion, this was the right person and she felt the information was comprehensive.

Patient felt that she understood the treatment she was to have and was fully informed again by a Consultant.

On two occasions the patient felt she would have liked more information and advice about pain relief.

Patient felt her diagnosis took too long and it would have been helpful for the pharmacy to be open 24 hours.

Overall, she felt supported by information throughout her cancer journey and felt this came from her Consultant.

Female, Ovarian Cancer

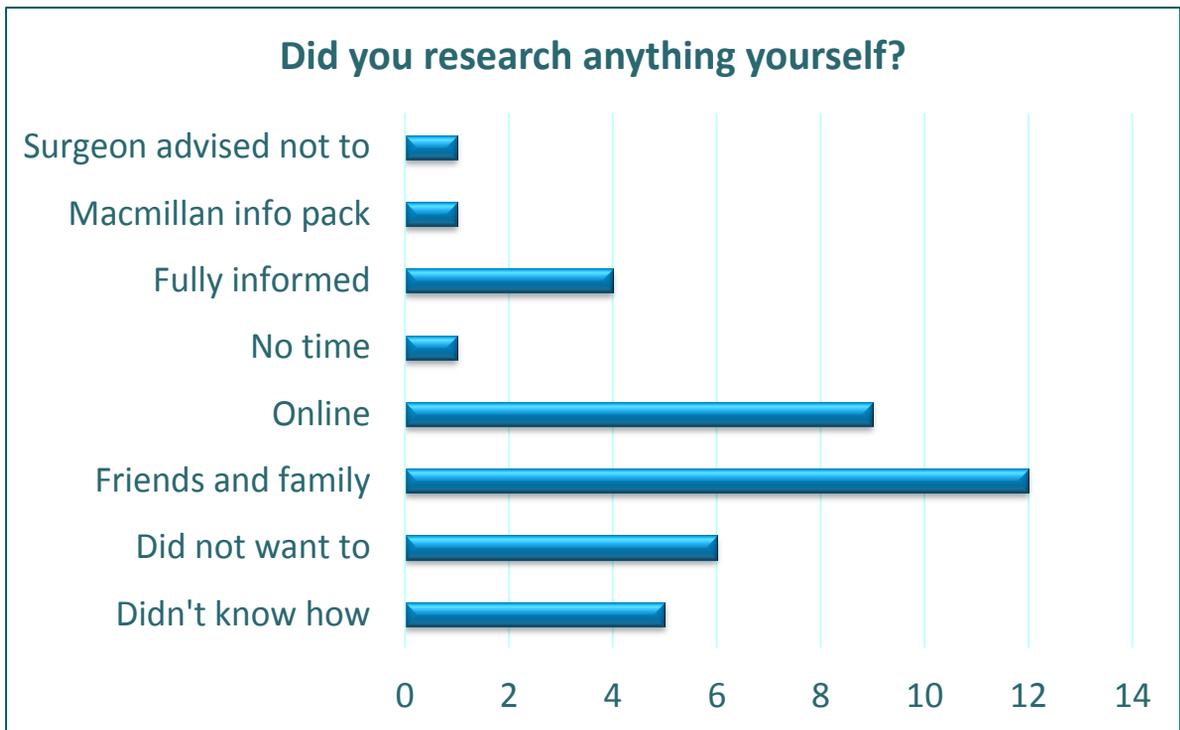
Support and self directed information

People were asked whether they were signposted or given information about support groups at various stages of treatment.

Only one person was told about support groups at the point of diagnosis. However, eleven people sourced support groups themselves.

Three people cited that it was a support group that gave them information about their illness and support for family members at diagnosis rather than a professional.

Six people said that they wanted more information about support at various stages.

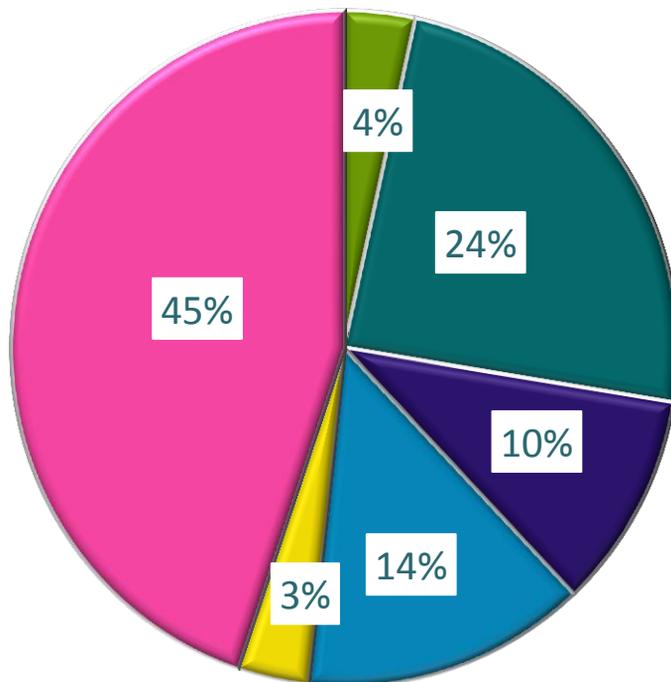


What was the most important thing to know?

During conversations, people were asked “what was the most important thing to know when you were first diagnosed?”

Most people wanted to know their prognosis and if they were going to be okay. Other themes were around next steps and side effects to be expected.

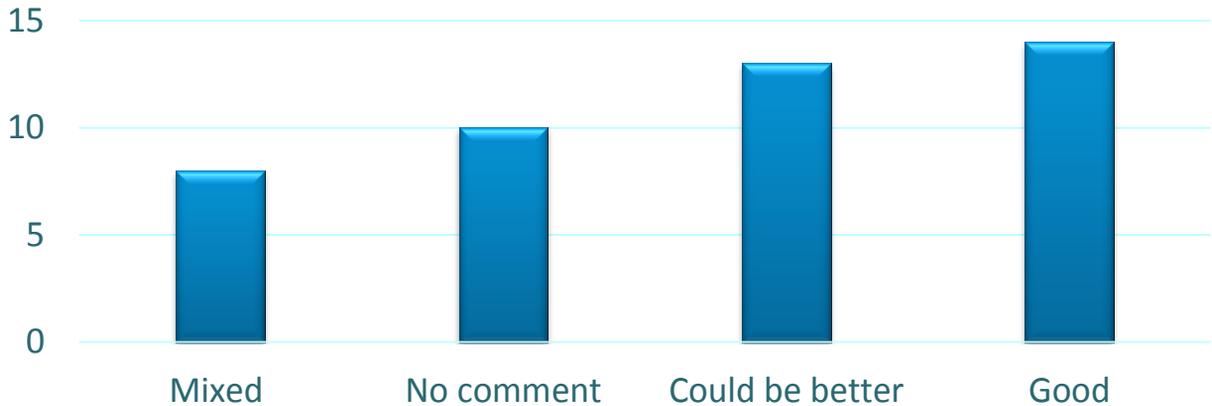
Most important thing to know at diagnosis



- My support
- Next steps
- Side effects
- Treatment options
- Support for family
- Will I be okay

Any other comments?

People were asked for any other comments and whilst this was not specifically focused on information given, their experiences were:



“Very poor support for family members”

“Very little information during treatment, only found out at the end”

“Pharmacy should be open 24 hours. Diagnosis took too long. Excellent treatment once diagnosed”

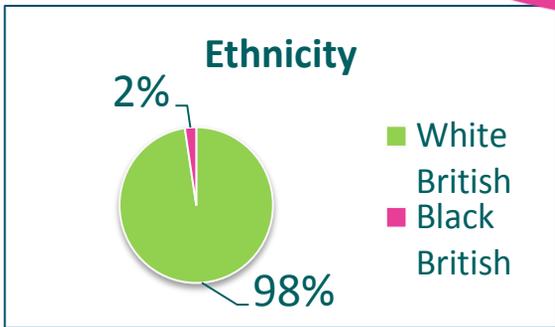
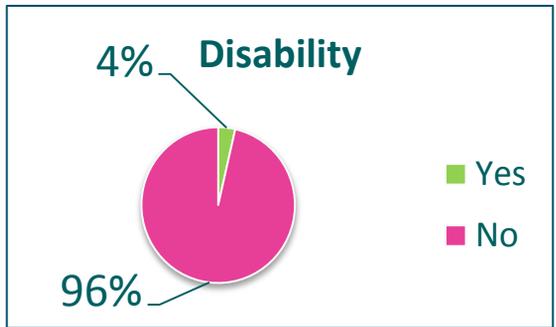
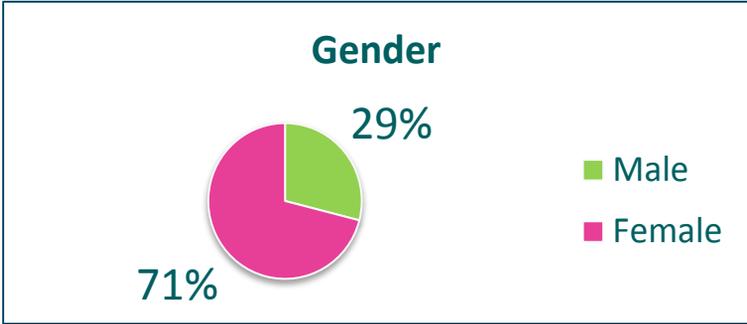
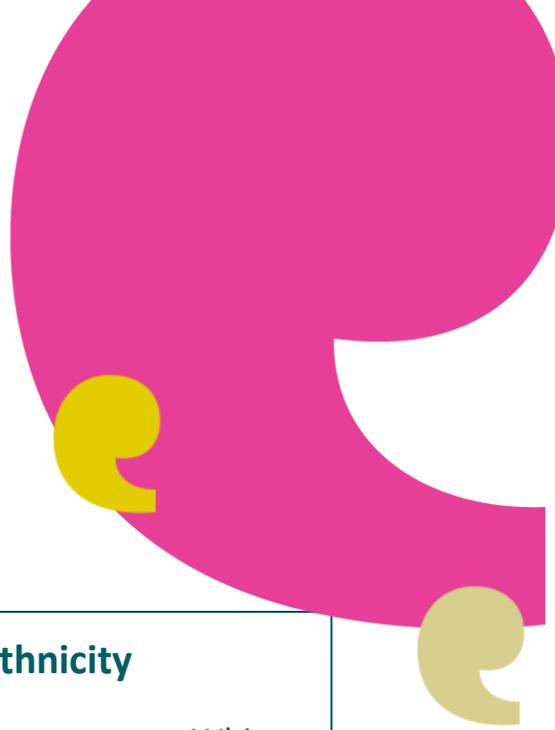
“Consultant was very blunt at diagnosis but cancer nurse was very good”

“Don’t feel that I could have had better treatment than I had”

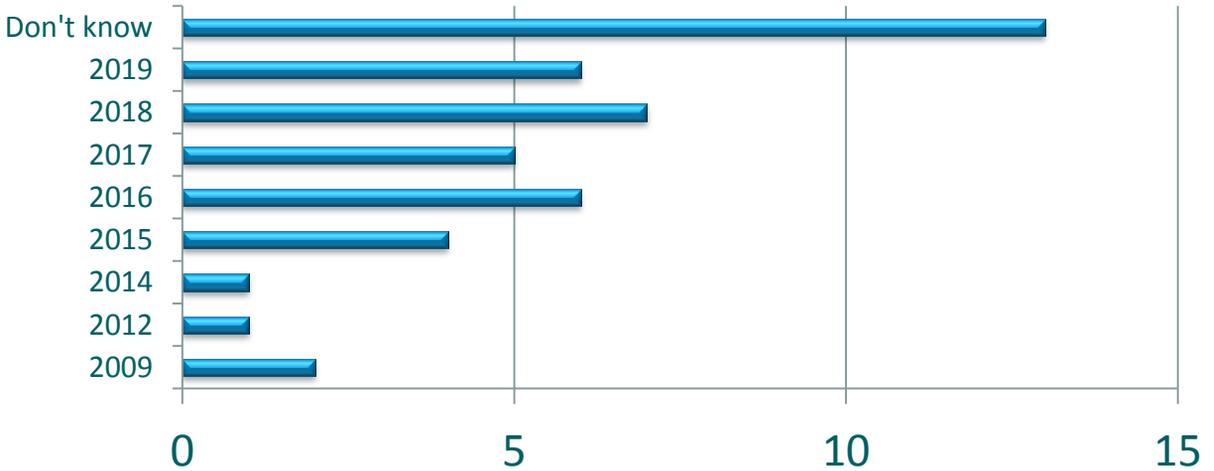
“The whole of my diagnosis and treatment has been excellent from start to finish”

“Macmillan nurse very good at Southend, she explained what was going to happen. Saw her every week”

Demographics



Date of Diagnosis



The majority of people could not remember when they were diagnosed or chose not to answer. (29%).

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