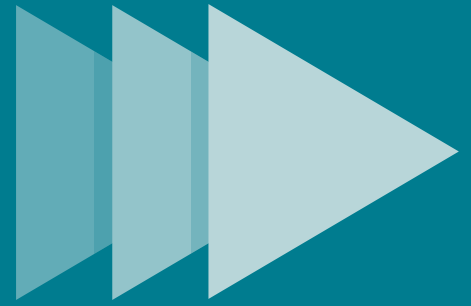


Peer Evaluator Insights Report



Macmillan Transforming Cancer Care Lived Experience Programme



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
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Executive Summary

The Macmillan Transforming Cancer Care Lived Experience Programme has sought creative ways to involve people affected by cancer in the national Transforming Cancer Care Programme (TCC). In order to contribute to TCC effectively, the Peer Evaluator role was created to meaningfully involve people affected by cancer in project design, delivery and analysis.

Peer Evaluators are people who have a lived experience of cancer and are therefore better placed to hold cancer conversations with other people affected by cancer. The purpose of the Peer Evaluator role is to assist in the co-delivery/co-facilitation of the cancer experience focus groups and interviews, co-produce engagement questions and consult on the analysis of themes generated from engagement. In this way, the Peer Evaluator project makes sure that people with a lived experience of cancer are involved at every stage.

The Peer Evaluator role aims to ensure that there are supportive ways for people affected by cancer to meaningfully inform the design of services. A key priority has been to engage with communities affected by cancer who are seldom heard.

Collated experiences

Engagement was conducted with a total of 42 individuals affected by cancer (excluding partly completed surveys). Engagement sought to gather the lived experience of different population groups in relation to overall cancer experiences, evaluation of services and barriers to accessing services. Participants shared the aspects which can positively impact on someone's cancer experience. Personable and empathetic staff, high levels of support and readily available information were three factors that were reported to contribute towards a more positive cancer experience by participants of this engagement. Negative experiences tended to reference themes of negative staff interactions, an absence or lack of support particularly in relation to emotional and psychological support, gaps in information provision and the concept of stigma and its impact when accessing support services.

Through this engagement the team found that the understanding of participants differed in what they considered a 'carer' to be, and this additionally acted as a deterrent to accessing support. Further, a central finding of this engagement was that, among some participants that are affected by cancer through caring for and supporting an individual with cancer, there exists a feeling that they are not entitled to or deserving of support.

Collated evaluations

Across engagement, 24 participants shared positive evaluations of clinical cancer services. Positive evaluations tended to reference kind, helpful and knowledgeable staff and the positive outcome of clinical treatments. 20 participants shared negative evaluations of clinical cancer services. Negative evaluations tended to reference gaps in knowledge in primary care settings, gaps in the provision of signposting to emotional support services and a lack of satisfaction concerning the care provided.

Not everyone who took part in our engagement had accessed cancer support services. For those that did, positive evaluations of cancer support organisations tended to reference supportive staff, high levels of support and comfortable environments. Negative evaluations tended to reference a lack of follow up communications and rigidity in the response to the cancellation of support sessions. Cancer support organisations were predominantly accessed by individuals who have received a diagnosis of cancer, despite the need for support identified by people caring for and supporting someone diagnosed with cancer.

Collated barriers



A total of 29 out of 42 participants reported experiencing at least one barrier when accessing or attempting to access services. The most commonly referenced barriers to accessing cancer services across engagement consisted of:

- **Primary care and receiving a diagnosis (mentioned 29 times during engagement)**
- **Confidence (mentioned 23 times during engagement)**
- **Distance (mentioned 23 times during engagement)**
- **Transport (mentioned 18 times during engagement)**
- **Not knowing that cancer support services existed (mentioned 14 times during engagement)**

Community specific experiences : Sensory loss and visual impairment

Four individuals affected by cancer participated in this engagement who identified with the sensory loss community (VI). Compared to the general population, participants from the sensory loss community (VI) rated support overall more negatively, mentioned the gap in emotional support more often, and reported more negative staff interactions.

Factors determining either a positive or negative experience reported by this community focused on staff interactions, levels of support provided and availability of information. Additionally, the level of understanding that staff displayed on how VI interacts with the cancer experience was important to the individuals who participated in this engagement. One participant reported an overwhelmingly positive experience of receiving care. This was due to the support provided and crucially, the involvement of third sector organisations such as Deafblind Scotland, and receiving care from clinical staff that were experienced in working with VI individuals. Participants who received accessible information, support from third sector organisations and who encountered empathetic and knowledgeable staff provided positive evaluations of clinical cancer services. Only one individual accessed cancer support services and this individual rated this service positively.

Three out of four participants characterised their overall cancer experiences as negative.



This was primarily a result of negative interactions with staff in clinical environments, a lack of understanding among staff of how VI impacts on the cancer experience and a lack of support. Participants spoke of the frustration with feeling unheard and misunderstood throughout their journeys and reported experiencing the following barriers:

- **feeling dismissed and invisible**
- **feeling that the system isn't designed for them**
- **lack of accessibility both in terms of information and in terms of movement**

Community specific experiences : Minority ethnic communities

Eight individuals who identified with a minority ethnic community participated in this engagement. Individuals who identified with a minority ethnic community reported more instances of available information provision, rated cancer support services more positively but also reported more instances of negative staff interactions and rated clinical care more negatively when compared to the general population.

Three participants reported an overwhelmingly positive experience while three participants reported a more negative experience. Two participants provided mixed responses to questions asked during engagement providing both positive and negative reflections to specific topics.

Positive experiences referenced the empathy and kindness of staff in clinical environments and in cancer support settings, referenced high levels of support provided during the cancer experience and the provision of translation services. Individuals who required translation services and who had this form of support organised quickly and, on their behalf, recounted their experiences positively. Negative experiences reported by participants tended to include a lack of available information, a lack of signposting and support, and instances of negative interactions with staff. Participants who shared negative interactions with staff cited a lack of empathy, lack of detail when explaining answers to questions, and a feeling of being “heard but not listened to”.

Only three participants accessed cancer support services and all evaluated cancer support services positively. When it came to clinical cancer services, evaluations were mixed. In terms of providing treatment and treating the diagnosis of cancer, two participants rated clinical services positively. Four participants were unhappy with the clinical care that they had received or the individual they were supporting received, citing the lack of support and lack of information to be the reason for their low evaluation of clinical services.

Engagement with minority ethnic individuals highlighted community specific barriers to accessing services and receiving care. These include understanding the system of the NHS as a whole, language barriers and the impact that culture can have on the cancer experience.



How to improve care

Collated suggestions

All participants were asked what they would change to improve cancer experiences either as someone accessing services for a personal diagnosis, or to provide support and care for an individual with a cancer diagnosis. Suggestions across engagement included:

- More person-centred care (raised 18 times)
 - Accessible information (raised 16 times)
 - Increase in care (raised 13 times)
 - Increased information (raised 13 times)
 - More training for staff (raised 10 times)
 - Increase in local support (raised five times)
 - Changes to hospital policies (raised five times)
 - Organisational changes to cancer support organisations (raised four times)
 - Appointment variety (raised three times)
 - Increased signposting (raised three times)
 - Information videos (raised two times)
 - More collaboration (raised two times)
 - Quicker diagnosis (raised one time)
- 

Sensory loss and visual impairment

The most common suggestions raised by participants who identified with the sensory loss community (VI) included:

- **An increase in accessible information**
- **Increased training on how VI impacts the cancer experience. For example, one participant suggested the use of patient experts**
- **Person-centred care and 'listen to me'**
- **Policy changes (hospital specific)**
- **Organisational changes (cancer support specific)**
- **Information video**
- **Increased signposting.**

Minority ethnic communities

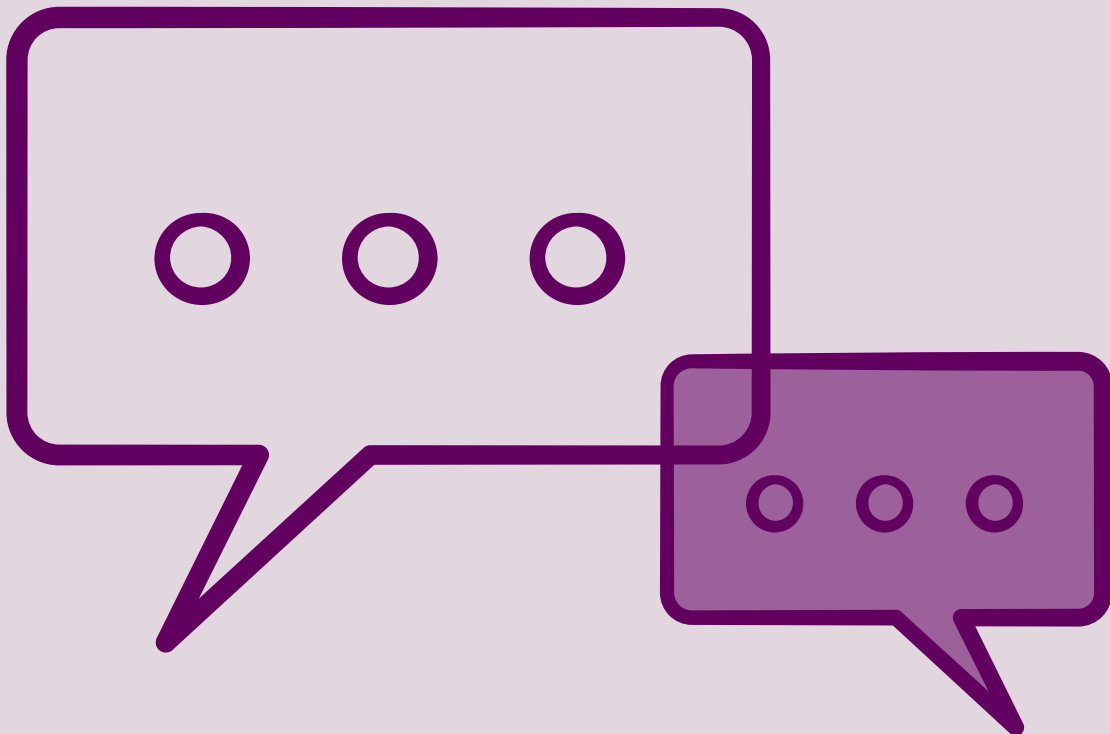
The most commonly raised suggestions by individuals who identified with a minority ethnic community to improve cancer experiences consisted of:

- **Increases in care**
- **Increases in information**
- **More signposting**
- **Changes to policy (hospital policy)**
- **Training for communities regarding healthy lifestyles.**

Recommendations

The individuals affected by cancer who participated in this engagement shared a wealth of information with the Macmillan Transforming Cancer Care Lived Experience Project Team. The experiences documented in this report and in particular the suggestions made by participants as to what they would like to change, have been gathered in order to work towards improving the cancer experience for individuals across Scotland. As a result, the ALLIANCE and the Macmillan Transforming Cancer Care Lived Experience Programme propose the following two recommendations:

- 1.** The Transforming Cancer Care (TCC) Executive Group conscientiously and actively consider the insights presented in this report, and begin the process of considering how these insights can be built upon in practice;
- 2.** Tangible recommendations for cancer care services and national policy are meaningfully co-produced with cancer services and people affected by cancer to embed person centredness into the heart of service design.



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Introduction

The Macmillan Transforming Cancer Care Lived Experience Programme has sought creative ways to involve people affected by cancer in not only project design, but in project delivery and analysis to inform the national Transforming Cancer Care Programme (TCC). The TCC Programme aims to:

- 1. join up support across acute, primary and community settings;**
- 2. ensure everyone's needs are assessed at the point of cancer diagnosis and;**
- 3. ensure people have the opportunity to access services tailored to their individual needs whilst living with and beyond their cancer diagnosis.**

In order to contribute to TCC effectively, specifically to aim three, and to meaningfully involve people affected by cancer in project design, delivery and analysis, the Peer Evaluator role was created; to ensure that there are supportive ways for people affected by cancer from communities which are seldom heard from to meaningfully inform the design of services.

Peer Evaluators are people who have a lived experience of cancer and are therefore better placed to hold cancer conversations with other people affected by cancer. The purpose of the Peer Evaluator role is to assist in the co-delivery/co-facilitation of the cancer experience focus groups and interviews, co-produce engagement questions and consult on the analysis of themes generated from engagement. In this way, the Peer Evaluator project makes sure that people with a lived experience of cancer are involved at every stage.

The rationale for using Peer Evaluators as facilitators of focus groups and interviews was two-fold. Firstly, by including those that have had a similar cancer experience as those participating in the engagement, the setting will promote enhanced psychological safety. Secondly, Peer Evaluators will be facing or will have faced the same socio-economic/structural inequalities as those participating in engagement. With this in common, Peer Evaluators will come from a place of greater understanding which is conducive to gathering insights. To prepare Peer Evaluators for the role, training and capacity building sessions were delivered that included facilitation methods training, trauma awareness training and question design sessions, in addition to regular informal one-to-one support sessions.

As the remit of this project drew special attention to engaging people with a lived experience of cancer from seldom heard communities, specific energy was devoted to scoping out which populations the project should prioritise. An equalities impact assessment (EQIA) provided greater understanding of the barriers to accessing cancer services and barriers to engagement within different communities. It was decided that pro-active action would be taken to prioritise and assure ease of participation for specific communities identified by the EQIA who experienced certain barriers to participation. In addition, as a membership organisation, the Health and Social Care Alliance Scotland (the ALLIANCE) has links with a range of different

organisations that work with, or for individuals from seldom heard communities. As a result, the project prioritised engagement with the LGBTQIA+ community, the sensory loss community, minority ethnic communities, and individuals affected by cancer from areas of rurality and/or low income, as well as the general population.

At the end of December 2022, with the help of a Sensory Loss Peer Evaluator and a Minority Ethnic Peer Evaluator, engagement was conducted with individuals affected by cancer from the sensory loss community with a focus on visual impairment (VI), people affected by cancer from minority ethnic communities, and the general population.

Most recently, Peer Evaluators have been recruited with the help of Dumfries and Galloway Health and Social Care Partnership (HSCP) to not only inform TCC at a national level, but to also inform the ongoing design of the Improving the Cancer Journey (ICJ) service in Dumfries and Galloway. The work of the Peer Evaluators in this area has a specific focus on understanding how rurality and low income can impact the cancer experience in Dumfries and Galloway. The main themes and findings of this cycle of engagement will feature in a separate report towards the end of 2023.

This report contains the main themes and findings from engagement conducted from December 2022 to April 2023.

Section one of this report details the methodology of engagement and demographics of participants. Section two of this report contains an overview of the insights and themes gained from an analysis across the entire engagement sample, and section three details community specific insights and themes gathered from engagement with the sensory loss community and individuals affected by cancer from minority ethnic communities.



Section one: Methodology and demographics

Methods of engagement to gather experiences in December 2022 and March 2023 consisted of focus groups and interviews. The method of engagement employed for the collection of experiences in early April 2023 consisted of a survey.

Both peer evaluators assisted in the creation of the question sets for engagement- bringing their own experiences, knowledge and perspectives. Our Sensory Loss Peer Evaluator was able to use her experiences to inform the design of the questions to focus on the aspects of accessibility, recognising symptoms and attitudes, while our Minority Ethnic Peer Evaluator used her experiences to focus the question set on the impact of culture on cancer services and equality of access.

Questions during focus groups, interviews and in each survey focused on the same broad topics to ensure consistency in responses and to ensure responses across these topics could be comparatively analysed. Questions began with gathering overall experiences of receiving care and experiences of supporting someone with a cancer diagnosis, and then focused specifically on barriers to accessing services. Questioning then focused on asking how well participants felt services met their needs, and what needs remained unmet. Questions and discussions ended with an exercise into thinking about what participants would change to improve service experience.

Focus groups and interviews

Focus groups and interviews were conducted with individuals affected by cancer from the sensory loss community with a focus on visual impairment (VI). Visual impairment (VI) is a term used to describe any sight loss that cannot be corrected using glasses or contact lenses.¹

Interviews and focus groups were also conducted with people affected by cancer from minority ethnic communities. Participation from individuals who identified with any minority ethnic community was encouraged. As the largest minority ethnic population in Scotland, significant work was directed at gathering insights from individuals affected by cancer from the Polish community. Following an intense promotional campaign, an in-person focus group was conducted in Polish to provide participants with a way to engage in their first language, greatly reducing barriers to participation.

In order for participation not to be overly exclusive or restrictive, engagement was also conducted with the general population. This provided individuals affected by cancer who did not identify with the LGBTQIA+ community, a minority ethnic community, the sensory loss community or who did not identify with experiencing low income or deprivation, to be able to share their views. This also provided an additional avenue of analysis to compare the experience of those that identified with the general population, with those that identified with seldom heard communities.

¹ Sense, 'Blindness and visual impairment' online guide, accessed 10/05/23, available: [Blindness and visual impairment - Sense](#)

Participants in both focus groups and interviews self-selected to participate. Participants were made aware of opportunities to become involved through ALLIANCE communication channels including the ALLIANCE bulletin and social media channels, in addition to utilising the Macmillan Engagement team to share promotional resources. What proved most successful was utilising the relationships that the Macmillan Transforming Cancer Care Lived Experience Programme team had cultivated from the beginning of this project with member organisations, individuals who hold positions of trust within specific communities, and the Peer Evaluators themselves who were able to communicate opportunities to their own communities.

Promotion for the Polish speaking focus group required a more detailed method and a longer period of promotion. In addition to translating resources and materials into Polish and sharing through the ALLIANCE communication and Macmillan communication channels, a member of the Macmillan Transforming Cancer Care Lived Experience Programme team visited a site of religious significance several times, to speak about the project accompanied by a Polish speaking link worker.

In total, across both interviews and focus groups for all community groups 16 individuals participated. These focus groups and interviews were conducted according to the community that individuals identified with to provide a setting of increased trust and sense of safety for participants. A breakdown of participants by community group can be found on **page 8**.

Survey

An outcome of the EQIA was the decision to provide as many ways for individuals to share their views as possible. An additional piece of learning during the relationship building phase of this project with partner organisations and individuals, was that participants may be reluctant to disclose their identities around other people in a focus group environment. As a result, the Cancer Service Experience Survey was created. This was to provide a way for individuals who either did not feel comfortable participating in a focus group or interview, or who did not have the capacity to do so, to be able to provide their views.

Two separate versions of this survey were created. One survey was tailored to individuals who had received a personal diagnosis of cancer, and the other was tailored to individuals who were affected by cancer through caring for and supporting someone who had received a diagnosis. These surveys were created at the ALLIANCE in partnership with two quantitative researchers who specialised in working with statistical information.

The questions in these surveys were informed by our Sensory Loss and Minority Ethnic Peer Evaluators. Sections of these surveys were also co-produced with organisations who had a specific remit in the health and wellbeing of equalities groups, including the LGBTQIA+ community, minority ethnic communities and sensory loss communities. These surveys were available electronically or in hard copy.

As with our focus groups and interviews, respondents to these surveys self-selected to participate.

1

Survey one: Macmillan Transforming Cancer Care Lived Experience Survey- Personal Diagnosis

A total of 22 individuals filled in this survey. 11 individuals fully completed this survey and 11 individuals partially completed this survey- filling in demographic data only without providing responses to any further questions. Information regarding the community identity of respondents has been collated and displayed on **page 8** of this report. For specific information on the demographic data of respondents to this survey, and for further information on non-responses, please consult the quantitative survey analysis paper available separately.

The analysis included in this report features only the 11 individuals who fully completed this survey and excludes the 11 individuals who did not answer any further questions.

2

Survey two: Macmillan Transforming Cancer Care Lived Experience Survey- Individuals supporting and caring for someone with cancer

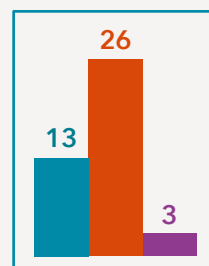
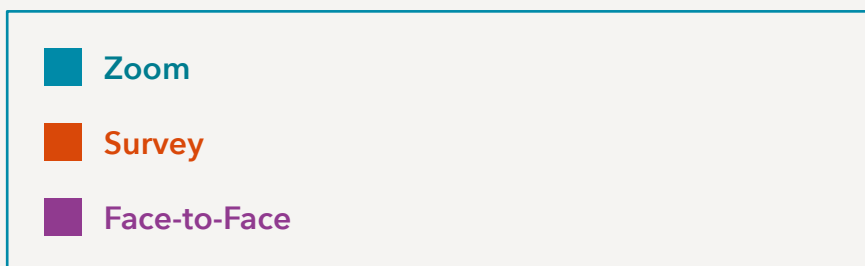
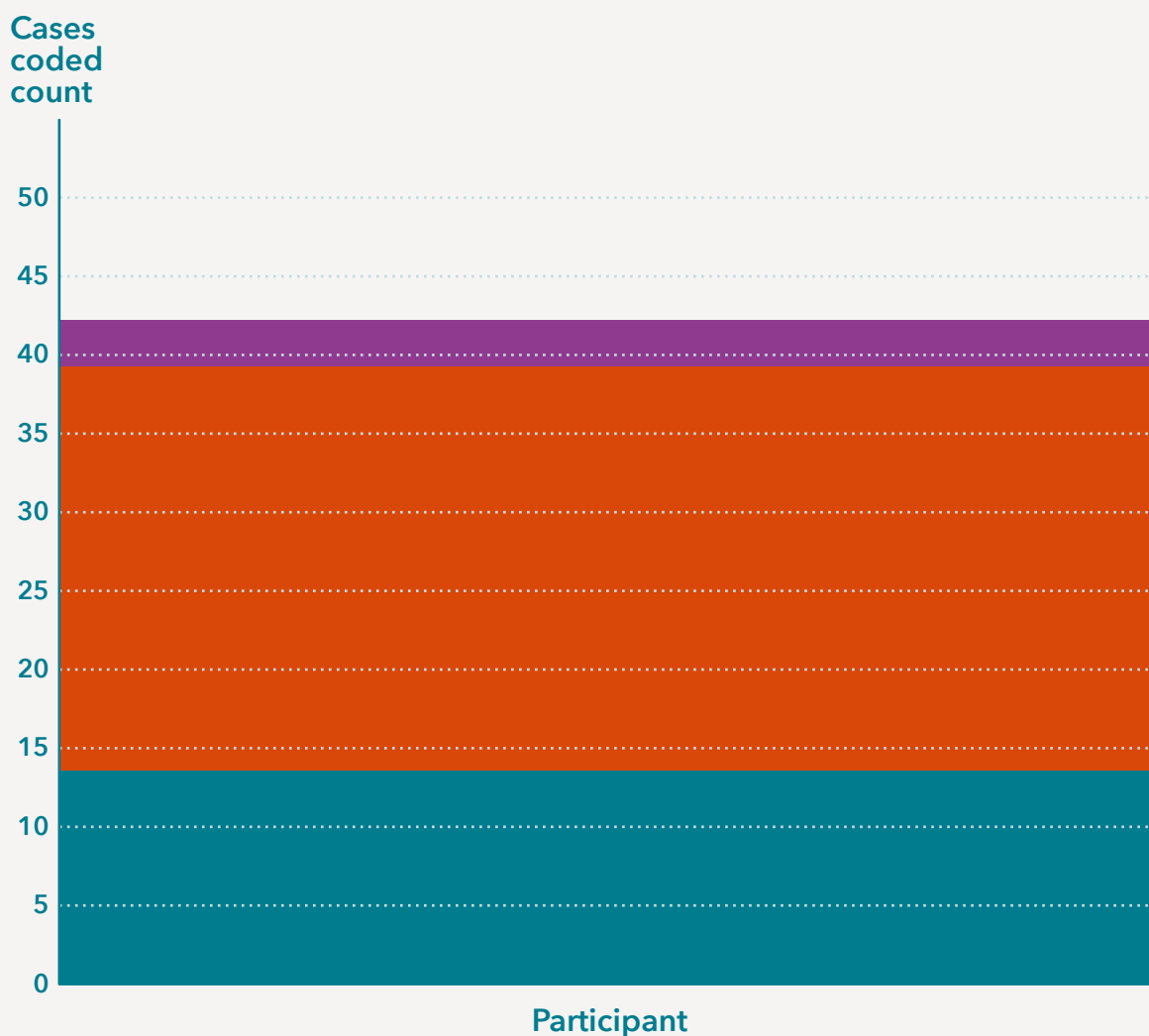
A total of 22 individuals filled in this survey. 15 individuals completed this survey and seven individuals partially completed this survey- three of whom filled in demographic data only, without providing responses to any further questions. For specific information on the demographic data of respondents to this survey, and further information on non-responses please consult the quantitative survey analysis paper available separately.

Analysis included in this report only includes the 15 individuals who completed this survey and excludes the seven individuals who partially completed this survey.

Collated engagement figures

The chart below demonstrates our engagement across all methods. Overall, the Macmillan Transforming Cancer Care Peer Evaluator project with the help of two Peer Evaluators successfully engaged with a total of 42 individuals.

Overall participation count



The chart above demonstrates that 13 individuals participated in a focus group or interview online via Zoom, 26 individuals provided their lived experience via a survey and three individuals participated in a face-to-face focus group.

Health boards

The Peer Evaluator project gathered health board data from participants who were willing to disclose this information. The table below illustrates the different health boards that participants disclosed during engagement.

Health Board	Number of participants
NHS Ayrshire and Arran	1 ■
NHS Dumfries and Galloway	2 ■■
NHS Fife	6 ■■■■■■
NHS Forth Valley	1 ■
NHS Grampian	4 ■■■■
NHS Greater Glasgow and Clyde	4 ■■■■
NHS Lanarkshire	1 ■
NHS Lothian	3 ■■■
NHS Fife + NHS Lothian	2 ■■
NHS Greater Glasgow and Clyde + NHS Lanarkshire	2 ■■
NHS Dumfries and Galloway + NHS Greater Glasgow and Clyde + NHS Lothian	1 ■
NHS Lothian + NHS Dumfries and Galloway	1 ■
Not disclosed	12 ■■■■■■■■■■
NHS Grampian + NHS Lothian	2 ■■

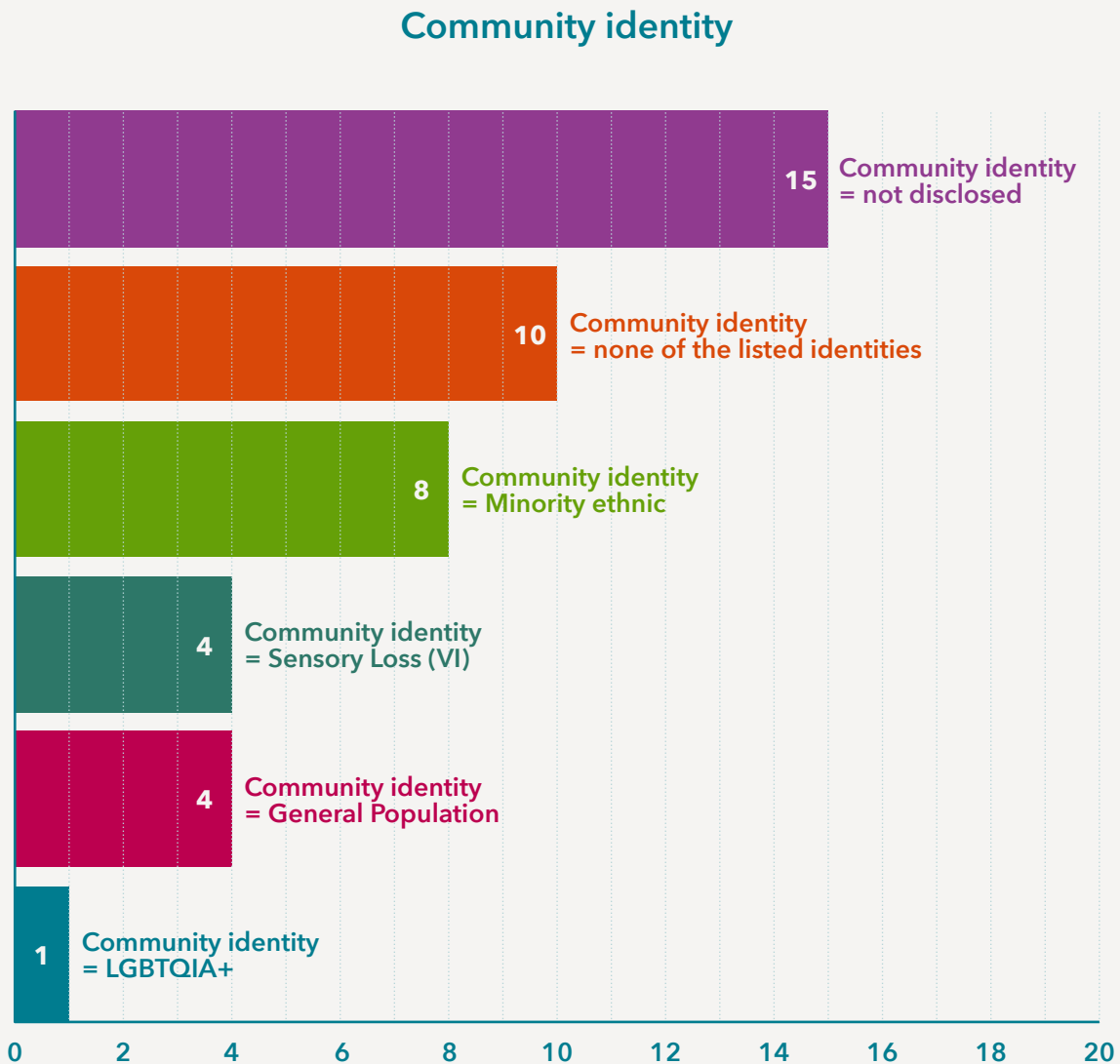
As the table above demonstrates, the experiences documented in this report relate to the health boards of NHS Ayrshire and Arran (one participant), NHS Dumfries and Galloway (two participants), NHS Fife (six participants), NHS Forth Valley (one participant), NHS Grampian (four participants), NHS Greater Glasgow and Clyde (four participants), NHS Lanarkshire (one participant) and NHS Lothian (three participants).

Several participants also reported experiences relating to multiple health boards when accessing cancer services. These combined health board experiences include NHS Fife and NHS Lothian as one grouping (two participants); NHS Greater Glasgow and Clyde and NHS Lanarkshire as a second grouping (two participants); NHS Dumfries and Galloway, NHS Greater Glasgow and Clyde and NHS Lothian as a third grouping (one participant); NHS Dumfries and Galloway and NHS Lothian as a fourth grouping (one participant); and NHS Grampian and NHS Lothian as the fifth grouping (two participants).

The majority of participants (12) did not disclose which health board applied to their cancer experience. Due to the intersectional aspect of this project, disclosing health boards was optional as this did have an impact on the identifiability of participants.

Community breakdown

As this project sought to engage with individuals that are regarded as 'seldom-heard', community identity was gathered from participants that felt comfortable enough to share this information. The breakdown of community identities of participants is plotted in the chart below.

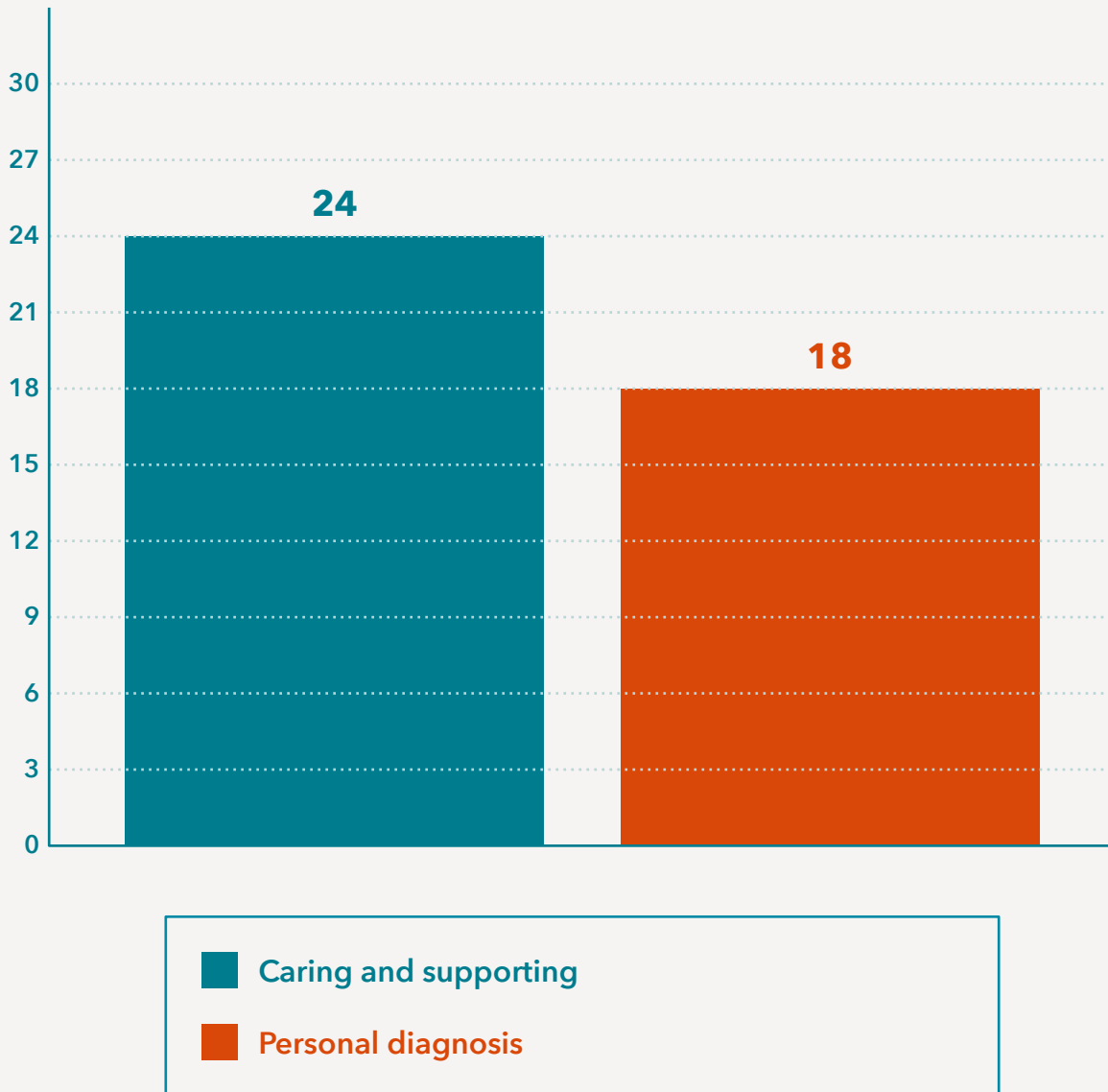


As the chart demonstrates, one participant identified with the LGBTQIA+ community, four individuals identified with the general population, four participants identified with the sensory loss community impacted by visual impairment, and eight participants identified with a minority ethnic community. 10 participants disclosed that the community that they identified with was not listed on either the survey form or the focus group/interview registration form, and 15 participants preferred not to disclose their community identity and so were marked as 'not disclosed'.

Cancer grouping

The chart below demonstrates the breakdown in how participants were affected by cancer across engagement.

Demographics: Cancer Grouping



The chart above documents that there were more individuals taking part in this engagement who were affected by cancer through caring for and supporting an individual with cancer (24), than individuals who had received a diagnosis of cancer (18).

Approach to analysis

A mixed methods approach was utilised to analyse the experiences collected during engagement. The focus group and interview transcripts, as well as the information provided in the open questions of the surveys, were analysed qualitatively with the use of Nvivo. Nvivo is a qualitative analysis software that can be used to generate core themes and store data. Nvivo also provided the opportunity to identify patterns and trends in the data across demographic categories. The closed questions of the survey were quantitatively analysed and can be found in a separate report.

Additionally, Peer Evaluators were provided with an opportunity to assist in the analysis of findings. Peer Evaluators accompanied the Development Officer in reading over interview, focus group and survey transcripts and were provided with the opportunity to sense check the coding criteria and initial themes generated during this stage. Peer Evaluators were then offered the chance to read and submit notes on all versions of reports produced allowing them the opportunity to input their unique insights.

Limitations

Throughout the project life span, challenges in securing participants were experienced. This can partly be due to the intersectional remit and scope of the work. Rather than seeking to engage with anyone affected by cancer, this project had a specific focus on engaging with people with protected characteristics in addition to being affected by cancer. Efforts to reduce barriers to participation were taken where possible.

As a result of the small sample size (42), the information contained within this report is not generalisable to broader populations and instead should be read and interpreted as reflective of individual experiences only.



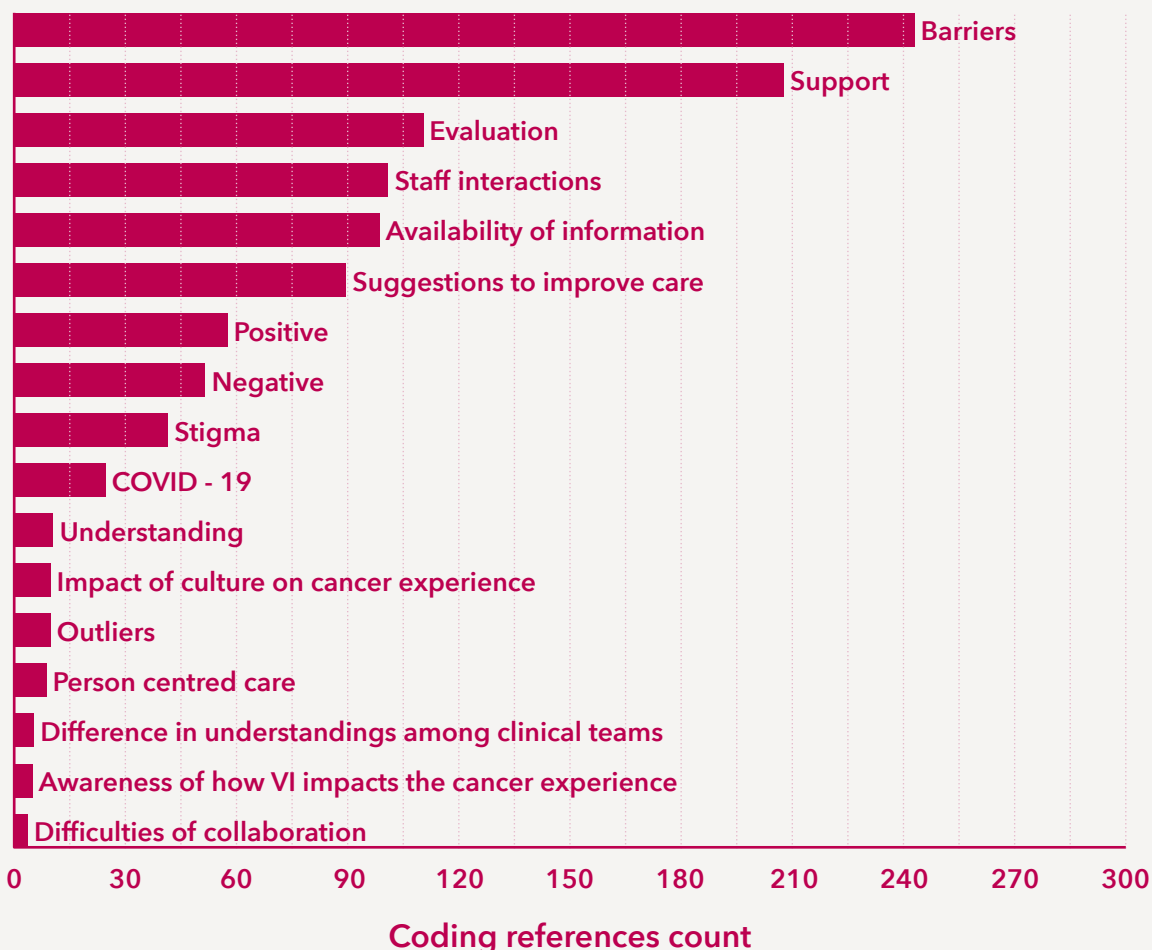
Section two: Generalised themes and insights

This engagement sought to gather the lived experience of different population groups in relation to overall cancer experiences, evaluation of services and barriers to accessing services. These three themes therefore represent the main themes contained in this report. However, engagement also generated additional sub-themes concerning other factors that impact on overall cancer experiences. These subthemes include levels of support offered and provided to individuals, the availability of information and how this can impact on levels of understanding, the importance of staff interactions including an awareness of how different conditions can impact the cancer experience, and finally stigma and its impact on attitudes to accessing support.

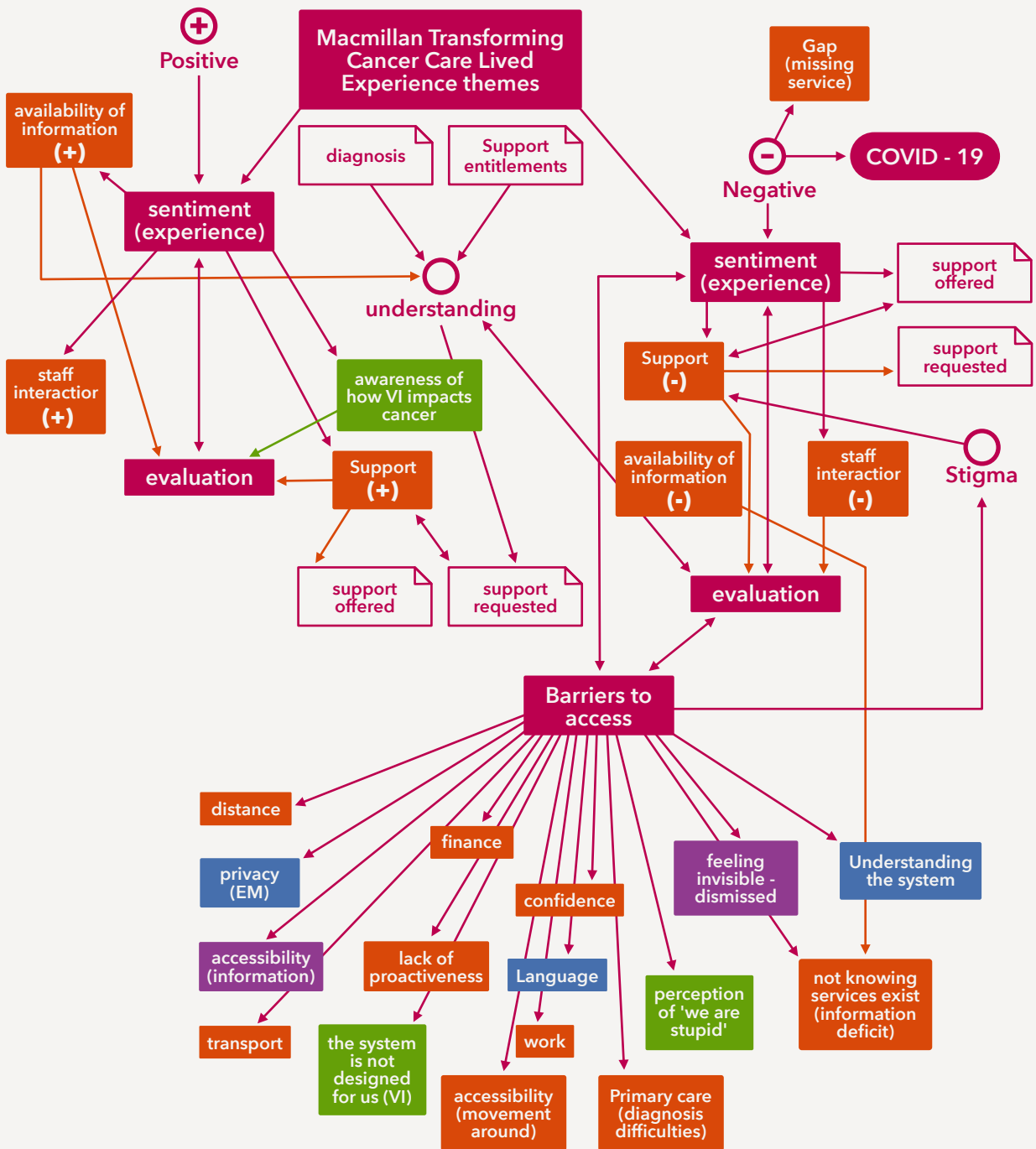
This section of the report looks only at general themes reported across engagement for all participants and omits any community specific themes at this stage. This is to ensure that participants that provided their experiences during engagement are not reduced to a community identity and are considered as part of the wider population to ensure inclusivity.

The chart below illustrates the number of times each theme and sub-theme was referenced by participants during engagement, illustrating how important each theme was to participants.

Distribution of codes across all cases



The thematic map below graphically depicts the relationships between themes, sub-themes and dependencies across engagement.



- Green coded items= codes specific to sensory loss and visual impairment (VI)
- Purple coded items = codes present across all community groups but VI weighted
- Blue coded items = codes specific to minority ethnic communities
- Orange coded items = not community specific

Theme one: Cancer experiences

Positive experiences

Participants shared examples of both positive and negative experiences whether that was when accessing services, receiving care or both. Whether affected by cancer through a direct diagnosis, or by supporting and caring for someone with cancer, positive experiences tended to reference the empathy of clinical staff and cancer support staff that individuals interacted with, the levels of support offered to them, and the availability of information.

The impact of staff interactions

During the analysis stage of this project, the importance of everyday interactions was something that one of our Peer Evaluators found to be of considerable importance for participants, and it is therefore important to draw attention to the impact that staff interactions can have for individuals during their cancer experiences.

19 participants commended the clinical staff and cancer support staff that they had interacted with. Throughout engagement, and in particular during the focus groups and interviews, participants emphasised that these positive interactions could have significant impact on the cancer experience. For example, participants commented that:



From the moment the cancer nurse took my hand and took me into the room, it was quite, not personal but, in that moment when you are told you have cancer and all those big words that are thrown around at you, it was just nice to have that human touch and say wait a minute, we are human here, we understand what you are going through



I would rate Maggie's (location redacted) centre 10/10. I would give it 100 if I could



I found the care, empathy and attention was the most beneficial element in my ongoing treatment

Levels of support

26 participants shared different examples of the support that they had been offered by both clinical staff and by cancer support staff. 26 participants were provided with support early in their experiences which cast a positive light on their overall cancer experience, and others were not. In the latter scenario, participants reported feeling more isolated and confused during this time. This is a theme which will be returned to later in this report.

Examples of positive experiences concerning support include:



I'm lucky because I have a lot of people around me, district nurse, support worker, GP



(during the pandemic) At the end of every communication there was- if you are feeling isolated or lonely phone this number, or text this number, or email. I was never left alone



When I accessed the head and neck group three years ago (Maggie's Centre) we still meet once a month today, you've got kind of beginning, middle and end of the story so to say. There was somebody there 24 hours a day that you could talk to you, I've put a post up online at 2/3am and someone has responded

Availability of information

From clinical information regarding diagnosis and treatment to information on where to access support, 17 participants focused on how the levels of information shared with them during appointments, and in particular after diagnosis, impacted on their experiences. Participants shared the following examples of the positive impact that availability of information had on experiences:



from day one at the ENT department I was given all that (information about cancer diagnosis), my cancer nurses followed me right through, if I couldn't get a hold of one I got a hold of the other.....at (one of my appointments) I got like a diary type thing and it had everything in it. It had a bit where you could ask questions and things, it was brilliant



Each individually (each consultant) gave a good and clear perspective of the options they could offer whilst being part of the bigger team

For individuals in a caring and supporting capacity, instances of good information sharing were less common. Only four individuals rated the availability of information positively, reporting that they were signposted to organisations and services that could provide support. For example:



When I started crying, she gave me a list of places I could contact and speak to people

When reflecting on overall cancer experiences, this section has shown the aspects which can positively impact on someone's cancer experience whether that is as someone who has received a diagnosis of cancer or as someone who is there to support and care for someone with a diagnosis. Personable and empathetic staff, high levels of support and readily available information were three factors that were reported to contribute towards a more positive cancer experience by participants of this engagement. The following section takes a look at those aspects which were reported to contribute to a more negative cancer experience.

Negative experiences



it was very difficult, unpleasant experience

Negative experiences reported across engagement tended to reference themes of negative staff interactions, an absence of support or a lack of support, gaps in information provision and the concept of stigma and its interaction in accessing support services.

Impact of staff interactions

A total of 20 participants referenced difficulties when interacting with staff members whether in clinical settings or in cancer support settings. Similarly to what has been reported above, these interactions played a significant role in shaping the overall experience for participants. Examples provided by participants are included below:



I get that they are busy, they are under strain but they are also dealing with a very fragile situation where people are either losing people or going through quite traumatic things- shouldn't you have that calmness and patience to you, to break things down slowly



My mum phoned the council to get some kind of benefits for reasonable adjustment in the home and she was told he (her husband) is not sick enough and they were asking her how sick is he? The questions they were asking were ridiculous, and my mum was like how sick does he have to be, he is not enabled in any way



Compassionate communication and respect is everything and it was completely absent at every turn

Gaps in support provision

There was a reported lack of signposting to services regardless of whether the participant had received a diagnosis of cancer or whether they were caring for and supporting someone who had been diagnosed with cancer. A total of 31 participants provided examples of gaps in support that they have experienced. For example:



For this period of time, the 4 months and the day I discovered she had cancer, there was no support at all. At all

Across engagement, when asked 'were you ever signposted to emotional, practical or financial support services?' the most common response was 'no'. A key recurring theme is the gap in the provision of emotional and psychological support for individuals affected by cancer. For example, participants commented that:



I can't say that the NHS offered emotional support really



if you have cancer, you should be offered emotional support but that just isn't there



I'd explained to the doctors that I would like to be put on the list for some counselling but you just never heard back



left feeling confused, upset and unsupported

This was particularly evident with individuals who were caring for and supporting an individual with cancer. For example:



when I was having a bit of a melt (meltdown), they (medical professionals) were like we know, we understand that your partner is going through a difficult time, we guess that would affect you a bit...There was no understanding that I was falling apart as well and there was none of that in the process. I kind of brushed off my need for support because everyone else was brushing it off

Gaps in information provision

While there were some respondents that had a positive experience when it came to information provision, several other respondents shared their difficulties when attempting to obtain information. 18 participants shared their difficulties in attempting to gain information concerning an understanding of their cancer diagnosis and who to contact for support. For example:



see trying to find numbers and trying to get through, you just end up getting passed from pillar to post

Linked to the availability of information was the concept of understanding. This concept was only mentioned by three participants but its relationship to support services merits inclusion. The greater the availability of information, the more that individuals understood about their diagnosis and, importantly, what support they could access. For example:



I remember being at my appointments and being in the waiting rooms and I kept asking them, what did they say again, I just wasn't taking the information in during the appointments. I don't remember them saying that



you are not in a position to fully understand what is going on, and have the questions there prepared for the clinician who is in a hurry

To see a graphic depiction of the relationship between these two themes, please **see appendix one**.

Stigma: "A Rubik's cube of emotions"

The quote above demonstrates the complexity of navigating the myriad of emotions that come with receiving a diagnosis of cancer, and of caring for an individual who has been diagnosed with cancer. A key theme that was present in this engagement across all cohorts and communities participating was that of stigma.² The concept of stigma was operationalised in discussions of experiences in various ways. A total of 12 participants mentioned the word stigma while many more touched on the topic of stigma to some degree.

Some individuals operationalised the concept of stigma as a reluctance to talk about cancer and expressed the negative connotations associated with cancer. Others expressed the concept of stigma as some cancers being regarded as less serious than others, and as a result feeling less deserving of care. Finally, those that were affected by cancer through caring for and supporting an individual, explained the feeling of being 'undeserving' of care because they themselves had not received a cancer diagnosis.

For example, some participants spoke of how cancer has been associated with certain topics that can deter conversations from taking place:



Cancer is associated with death, and perceived in a really negative way



it's that word cancer, and I never thought I'd be like that. I could talk about it quite openly before the diagnosis but when it was myself.... yeah I couldn't



it's this whole, everything's got to be a secret, and god forbid I mean 'cancer' that's the worst thing ever, you can't talk about it



So sometimes we, sick people, don't want to tell the family. I know what I have, it is incurable, it is inoperable. Non-treatable

²Stigma has been defined as "a set of negative and often unfair beliefs that a society or group of people have about something" (I Stop Stigma by... | NAMI: National Alliance on Mental Illness)

Others provided examples of some cancers being regarded as less serious than others, which caused feelings of being less deserving of care:



at the time, I didn't think I had a right to contact Macmillan because I have (type of cancer redacted) cancer, it's a strange one, I don't think I felt worthy of receiving care. I'm thinking if it's someone with a different form of cancer would they feel more entitled to access those services? I think the stigma thing is a big issue

Finally, in focus groups, interviews and in the survey, participants shared their experience of navigating complex feelings that were linked to caring for and supporting an individual with cancer. For example:



I feel a bit of a fraud because I am a carer....I didn't have cancer

Further, when asked about experiences of accessing cancer support services, several participants commented that they "didn't feel it was appropriate to access services" because they had not received a diagnosis of cancer. As a result, it became apparent that among some participants that are caring for and supporting an individual with cancer, there exists a feeling that they are not entitled to or deserving of support.

The topic of stigma was not one that the team expected to find, at least to this extent during engagement. The examples contained within this section perhaps demonstrate the need to understand stigma as it relates to cancer more thoroughly. Finally, through this engagement the team found that participants differed in what they considered a 'carer' to be, and this additionally acted as a deterrent to accessing support.

This section has demonstrated that there are various elements of the cancer journey that can influence the overall experience for individuals. Participants have provided insights into what some of these elements might be. From everyday encounters with staff members in clinical and cancer support environments, to the availability of information and the degree of support offered these factors can heavily influence the experience of individuals who are affected by cancer. This section has also highlighted the enduring impact that stigma continues to play in the cancer sphere.

Theme two: Evaluation of services

In an effort to understand not just the overall experience of people when accessing cancer services and to determine what contributed to these experiences, this project also sought to understand who accessed cancer services, who did not and what participants thought of these services as a whole. Both individuals who had received a diagnosis of cancer and those who cared for and supported an individual with cancer reflected on their experience of accessing clinical cancer services either themselves or to support an individual. Feedback on experiences of utilising clinical cancer services were mixed and can be broken down into positive and negative evaluations- although more heavily weighted in the positive direction.

Positive evaluations of clinical cancer services

Across engagement, 24 participants shared positive evaluations of clinical cancer services. Similarly to overall cancer experiences, positive evaluations tended to reference kind, helpful and knowledgeable staff. For example:



The out of hours cancer team, em when you start your chemo you get a wee red card...My husband had to phone them when I was unwell, they do everything behind the scenes and they phoned the hospital to let them know I was coming in. By the time I got to the hospital there was already a bed made up for me



took into account relevant information from family members about the patients health and wellbeing



In [hospital redacted], the support my Husband and I received was exemplary

More importantly however for participants when evaluating clinical services, was the outcome of clinical treatments. Those that evaluated clinical services positively, overwhelmingly referenced the positive outcome of treatment that they had received or witnessed. For example:



I needed to be cured of cancer, I needed to recover well and I needed to recover safely and they did put in place mechanisms



the treatment /options for treatment were clear and treatment started quickly. This is a good thing

Negative evaluations of clinical cancer services

20 participants shared negative evaluations of clinical cancer services. Negative evaluations tended to reference gaps in knowledge in primary care settings, gaps in the provision of signposting to emotional support services and a lack of satisfaction concerning the care provided. For example, participants shared the following comments during engagement:



I don't think the level of care or quality of care has been sufficient



unmet need- emotional needs, pragmatic needs i.e. how to actually care for (partner) at home, information in terms of what symptoms I was meant to look out for throughout the process



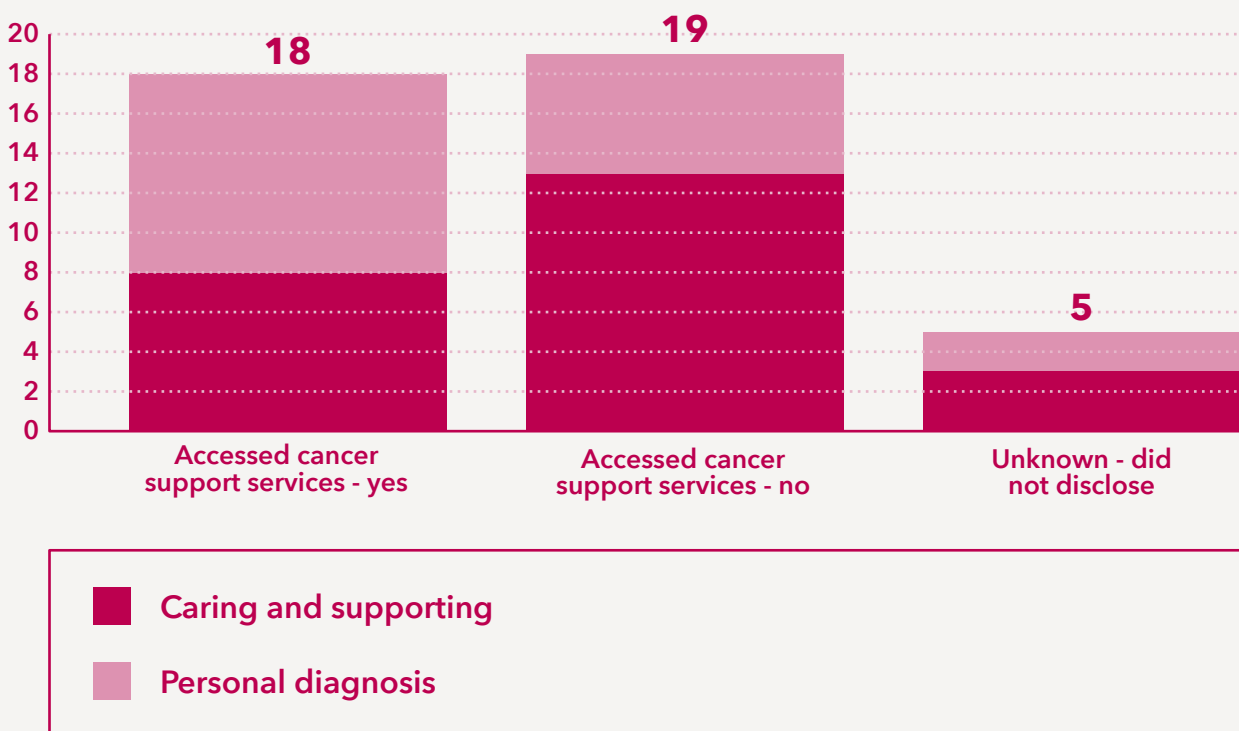
From misdiagnosis to accidents during end of life care, the experience was traumatic

Overall, during engagement there were more instances of positive evaluations of clinical services than negative evaluations when looking across the engagement sample. However, this does begin to slightly differ when we look at the experiences of specific communities in more detail. This will be picked up in section three of this report.

Cancer support organisations

The chart below breaks down participants into who accessed cancer support services and who did not. The dark pink bars represent individuals who were affected by cancer through caring for and supporting an individual who had been diagnosed with cancer, and the light pink bars represent individuals who had received a diagnosis of cancer. The column on the left represents participants who have accessed cancer support services, the column in the middle represents participants who did not access cancer support services and the column on the right represents participants who did not disclose an answer to whether they accessed cancer support services.

Who accessed cancer support services and who did not

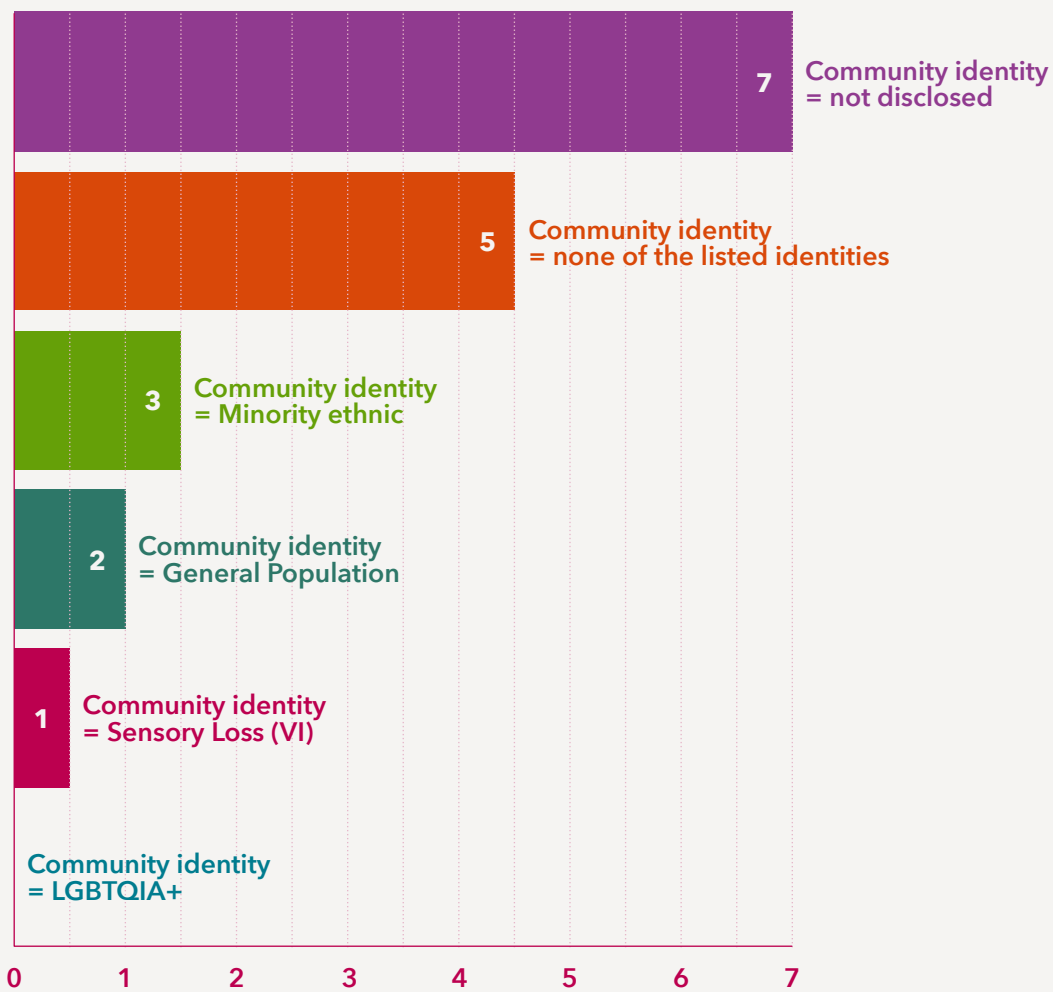


This chart illustrates that not everyone who took part in our engagement had accessed cancer support services. 18 participants reported that they had accessed cancer support services, 19 participants reported that they had not accessed cancer support services and five participants declined to provide an answer.

The chart above illustrates that participants caring for and supporting an individual diagnosed with cancer were less likely to access cancer support services, than individuals with a diagnosis of cancer. The chart above shows that 10 of the individuals who accessed cancer support services were affected by cancer by personal diagnosis and eight individuals who accessed cancer support services were affected by cancer from caring for and supporting someone with a cancer diagnosis.

Furthermore, of the 18 individuals who accessed cancer support services, three individuals identified with a minority ethnic community, two individuals came from the general population, one individual identified with sensory loss community (VI), five participants answered that their identity was not listed, and seven participants preferred not to disclose. This is demonstrated in the chart below.

Breakdown of who accessed cancer support services



Positive evaluations of cancer support services

During engagement 17 participants who accessed cancer support services shared some positive evaluations. Similarly to the discussion on overall cancer experiences, positive evaluations of cancer support organisations tended to reference supportive staff, high levels of support and comfortable environments. For example, participants shared the following comments:



Macmillan's online services, after my chemo, I slept on the recliner chair in the living room, and the online support from Macmillan was absolutely amazing



I got a lot of emotional support from [location redacted] I went to see her every couple of weeks. During lock down she phoned me right up until she retired. She recommended a lot of good books. [Community organisation redacted] was much more relaxed about if you can't make it they understand. They dealt with long term illnesses not just cancer

Negative evaluations of cancer support services

Eight participants out of the 18 that accessed cancer support services shared negative evaluations. These tended to reference a lack of follow up communications and rigidity in the response to the cancellation of support sessions. For example, participants shared the following comments:



(I suffer from) chronic severe migraines and so had to cancel some appointments. This was not received well by staff at the service



I had one call with a Macmillan professional [regarding a holistic need assessment] for minutes and there was no follow up. I think I was expecting some form of follow up from a cancer service and when nothing happened and I was actually surprised by that

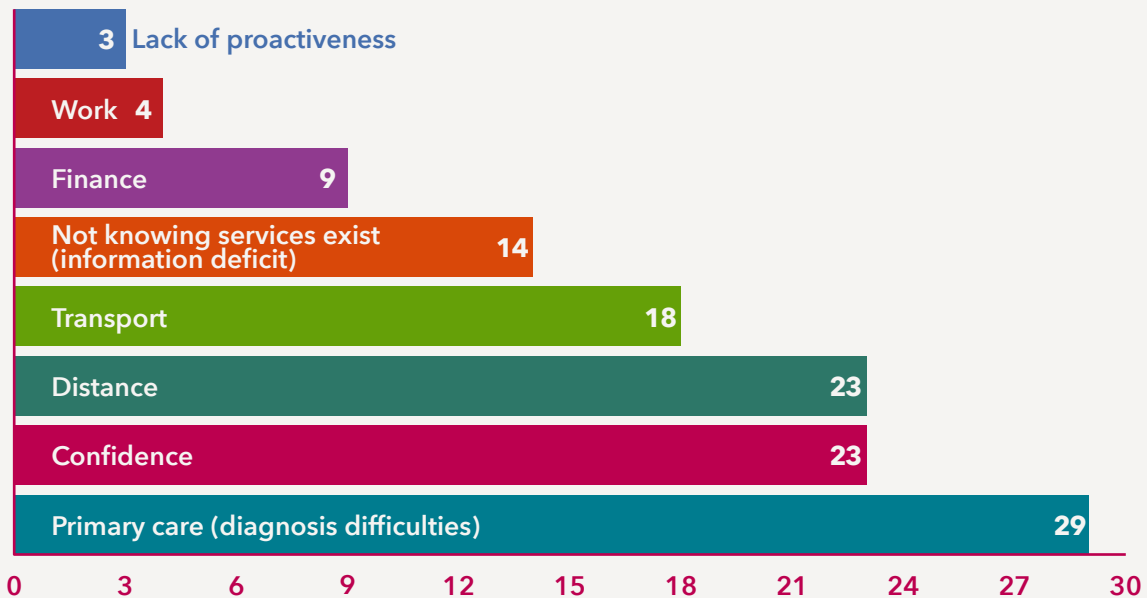
Overall, participants shared both positive and negative experiences of accessing cancer support services. A key take away from this engagement was that of those that participated, cancer support organisations were predominantly accessed by individuals who have received a diagnosis of cancer. The possible reasons for this gap in support uptake for individuals caring for and supporting an individual with cancer was reflected in the discussion of stigma. This topic will be picked up again in the following section on barriers.

Theme three: Barriers across engagement

One of the key aims of this work was to investigate what barriers people face when accessing or attempting to access services. The following section addresses the theme of barriers across the engagement sample. There are some barriers that are unique and specific to minority ethnic communities and the sensory loss community and as a result, will be addressed separately in section three of this report.

A total of 29 out of 42 participants reported experiencing at least one barrier when accessing or attempting to access services. The chart below plots the barriers according to how often they were referenced by participants during discussions and in survey responses.

Barriers across engagement

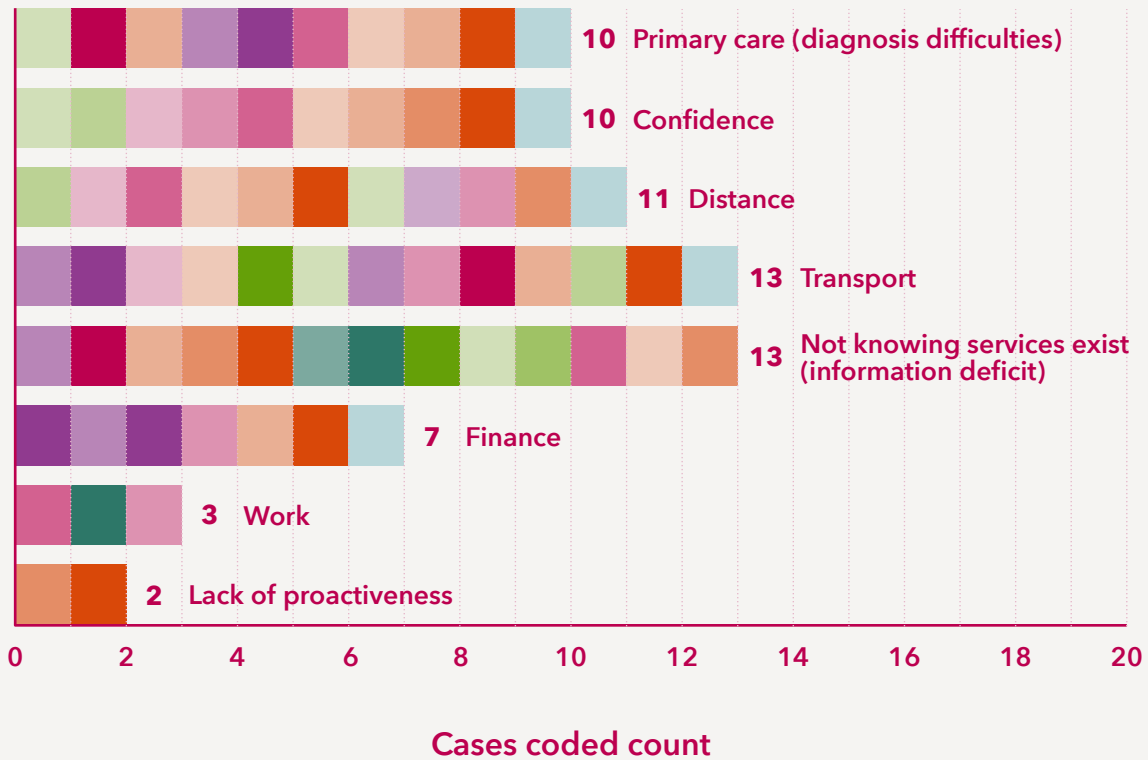


The chart above shows that the most commonly referenced barriers to accessing cancer services across engagement consisted of:

- Primary care and receiving a diagnosis (mentioned 29 times during engagement)
- Confidence (mentioned 23 times during engagement)
- Distance (mentioned 23 times during engagement)
- Transport (mentioned 18 times during engagement)
- Not knowing that cancer support services existed (mentioned 14 times during engagement)

Additionally, the chart below demonstrates how many individuals referenced a given barrier, rather than how often the barrier was brought up in conversation or during survey responses. Each box in the chart represents a participant.

Barriers across engagement: Participant breakdown



A comparison of these two charts shows that while primary care and difficulties with diagnosis was the most frequently referenced barrier and dominated certain discussions, it was only referenced by 10 participants out of 29, demonstrating the importance of the issue to these 10 participants. Conversely, although the barrier of not knowing services existed was mentioned 14 times, it was mentioned by the greatest number of participants (13 out of 29) along with transport (13 out of 29 participants). Each key barrier will be discussed in turn below.

Confidence and primary care barriers when receiving a diagnosis

10 participants shared their frustrations 23 times during engagement with the difficulties they encountered when receiving a diagnosis of cancer, and when supporting an individual who was receiving that diagnosis.

For example, participants fed back that they had to push and “fight” to receive a diagnosis, and that primary care almost acted as an initial barrier in their journeys that they had to overcome. However, following diagnosis, the interactions with secondary care and specialist services appeared to be more pleasant and much more positive. Participants shared the following examples:



my issue was, I really had to push at the GP, you know push, push, push and I think, what if someone didn't have that confidence?



eventually you just get to the stage where you go off the handle and you get treated like you are a nuisance. But you are pushed to that stage where you have to fight



he went back and forth to the doctors so many times...the next time we went we asked for a blood test. The GP didn't delve deeper, didn't ask questions

Some participants shared examples of having to attend A&E after seeing GPs for months before receiving a diagnosis:



my daughter was unwell for four months and I kept taking her to the GP. The GP kept prescribing antibiotics for tonsillitis and would not take a blood sample. I was so worried that I took her to A&E and refused to leave until they saw my daughter. Finally, they came and told me that my daughter has leukaemia. It was a very difficult unpleasant experience

Transport and distance

The issues of transport and distance to appointments were also commonly referenced barriers for individuals affected by cancer when attending clinical appointments or cancer support services. 11 participants shared experiences of travelling long distances and 13 participants shared experiences of encountering difficulties sourcing transport when unwell. For example, participants commented that:



By the end of my treatment I was ill, I had lost a lot of weight and the last thing you want to think about at the end is I've got to sit on a bus. I would have missed an appointment rather than have travelled in by bus again



Transport to the department (was difficult) because the buses were only every 4 hours (if you are coming outside of [health board area redacted]), if you missed a bus you had a real problem there



they (parents) are at a pensionable age, they can get on a bus for a pound and get down the road, but they aren't really able (due to mobility restrictions)

Not knowing cancer support services exist (information deficit)

13 out of 29 participants cited the main reason for not accessing services was due to not knowing that cancer support services existed, what they offered and where to find them. Of this 13, six participants were affected by cancer through caring for and supporting an individual with cancer and seven participants had received a diagnosis of cancer. Participants voiced that they did not know where to go or who to speak to. Some examples are provided below:



(what stopped you from accessing support services?) not knowing they were there really



We aren't actually aware of where to go



I was unaware that cancer support organisations existed



I struggled to find a condition specific support organisation local to me due to being a rarer tumour type

The barriers of confidence, primary care and difficulties receiving a diagnosis, distance and transport to appointments and not knowing that services existed, represent the four main barriers reported by participants. However, there were several other barriers mentioned during engagement. For further information on lesser mentioned barriers please consult appendix two and for barriers by clinical appointments, please consult appendix three.

Finally, all participants were asked what they would change to improve cancer experiences either as someone accessing services for a personal diagnosis or to provide support and care for an individual with a cancer diagnosis. A word cloud has been generated below to graphically depict the strength of suggestions raised by participants. The larger the word, the more participants suggested the change.

Person-centred

accessible

location collaboration person-centred better
 braill check clear clinic videos communicate conditions contact
 appointments diagnosis different dog done easy education email ensure
 every experience signposting information local happen
 helpful policy training support team

The word cloud above shows the following suggestions raised by participants in order of strength.

- **More person-centred care (raised 18 times)**
- **Accessible information (raised 16 times)**
- **Increase in care (raised 13 times)**
- **Increased information (raised 13 times)**
- **More training for staff (raised 10 times)**
- **Increase in local support (raised five times)**
- **Changes to hospital policies (raised five times)**
- **Organisational changes to cancer support organisations (raised four times)**
- **Appointment variety (raised three times)**
- **Increased signposting (raised three times)**
- **Information videos (raised two times)**
- **More collaboration (raised two times)**
- **Quicker diagnosis (raised one time)**

The following section of this report looks at community specific experiences and barriers beginning with insights reported by individuals affected by cancer from the sensory loss community who are specifically impacted by VI. This is followed by insights reported by individuals affected by cancer who identify with a minority ethnic community.

Section three: Community specific insights

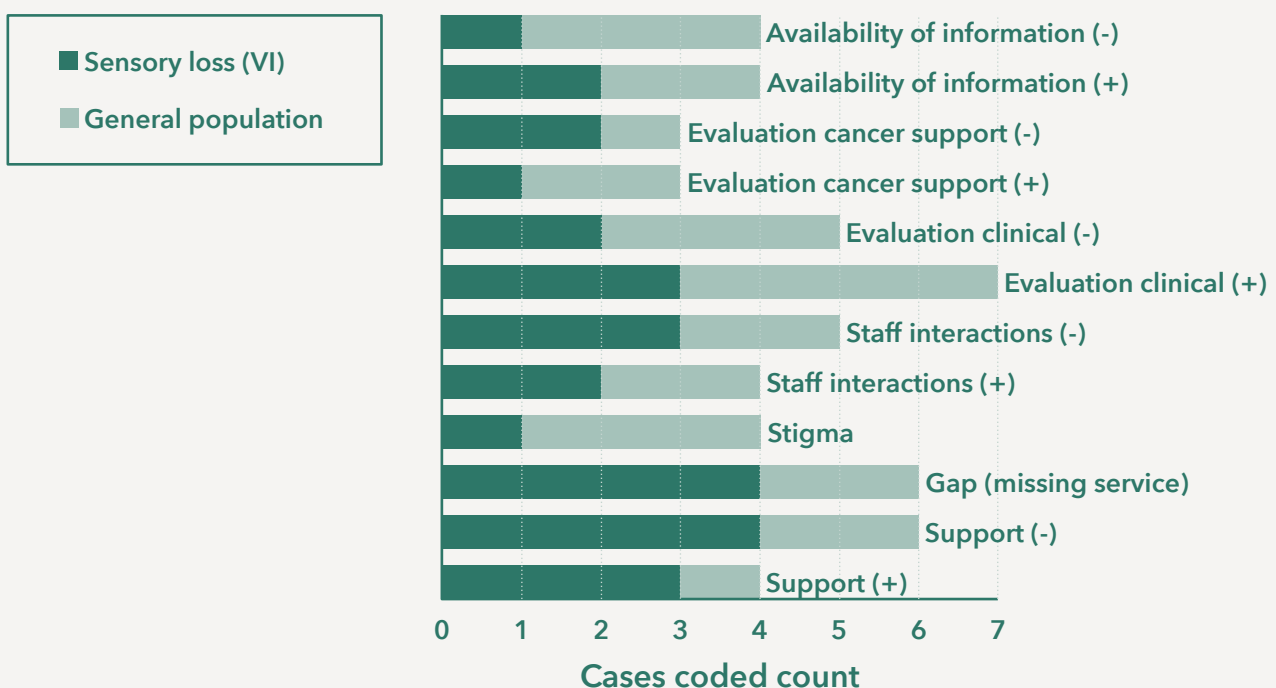
This project had a special focus and emphasis on gathering experiences from seldom heard communities. Engagement was conducted with the sensory loss community focusing on the experience of those who have been affected by cancer who have visual impairment (VI). Engagement was also conducted with those who have been affected by cancer who identify with a minority ethnic community. As a result, during engagement emphasis was placed on the additional barriers faced by minority ethnic communities and individuals with sensory loss. This section of the report begins with the insights gained from engagement with individuals living with sensory loss and, in particular VI, who have been affected by cancer, before moving on to detail the insights gained from engagement with individuals who identify a minority ethnic community.

Sensory loss, visual impairment and cancer

Visual impairment (VI) is a term used to describe any sight loss that cannot be corrected using glasses or contact lenses.³ Participants self-disclosed their VI status. Four individuals affected by cancer participated in this engagement who identified with the sensory loss community (VI). One individual was affected by cancer through caring for and supporting an individual who had received a diagnosis of cancer, and three individuals had received a cancer diagnosis.

The chart below plots the experience of participants who identified with the sensory loss community (VI) who have been affected by cancer, compared to the experience of the general population.

Cancer experience: Sensory loss community and general population

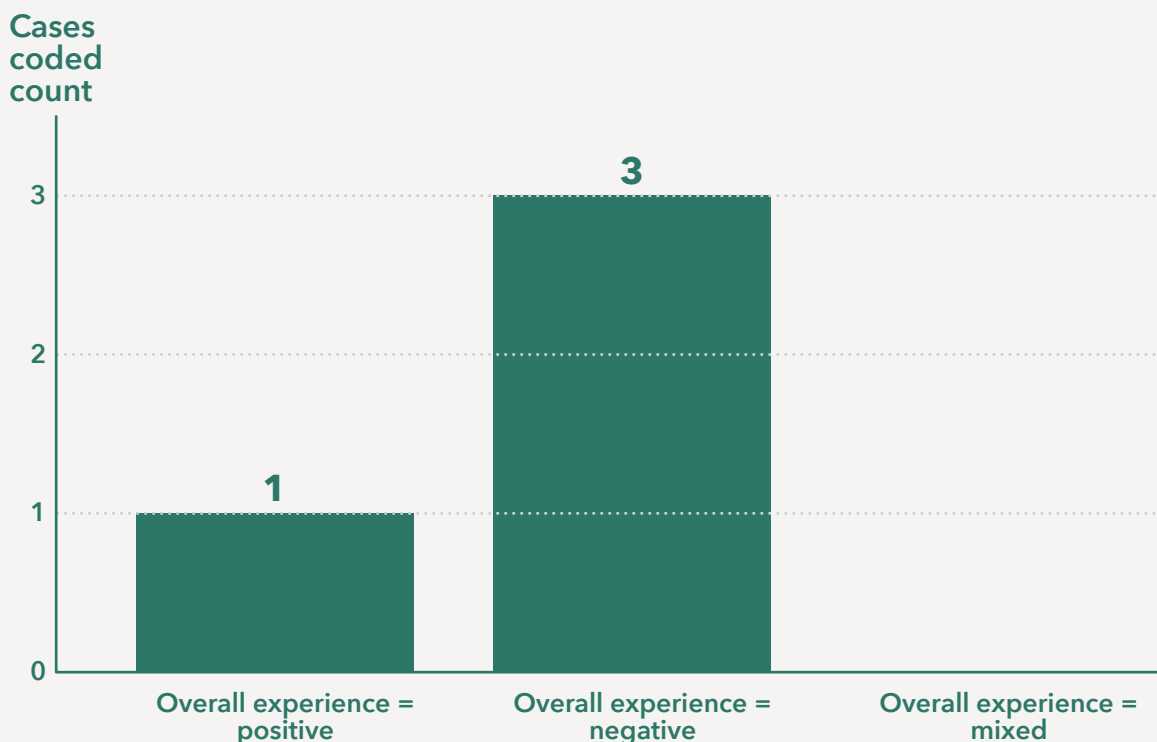


³Sense, 'Blindness and visual impairment' online guide, accessed 10/05/23, available: [Blindness and visual impairment - Sense](#)

The chart above demonstrates that compared to the general population, participants from the sensory loss community (VI) rated support overall more negatively, mentioned the gap in emotional support more often and had more negative staff experiences than the general population.

During focus groups and interviews, recording the overall tone of discussion was an important identifier of experience. The overall sentiment of discussions were recorded and have been plotted in the chart below.

Overall experience - Sensory loss (VI) and cancer



The chart above demonstrates that out of the four participants who had been affected by cancer with VI, three individuals reported an overall negative experience while one individual reported an overall positive experience.

Factors determining either a positive or negative experience reported by this community focused on staff interactions, levels of support provided and availability of information. Additionally, the level of understanding that staff displayed on how VI interacts with the cancer experience was important to the individuals who participated in this engagement.

Overall positive experience

One of our participants reported an overwhelmingly positive experience of receiving care. This was due to the support provided and crucially, the involvement of third sector organisations such as Deafblind Scotland, and receiving care from clinical staff that were experienced in working with VI individuals. For example, this participant commented that:



Deafblind Scotland guides are invaluable and I don't know how I would have gotten to appointments without them



The chemo nurses worked hard to try and combat the side effect of numb fingers

This individual gave an example where prior to treatment that would require her to be in hospital for a prolonged period of time, she was permitted to come in the day before to get used to the room, to the environment, and its layout. She commented that this reduced the pressure she felt, made the whole process easier and reduced her "pre surgery fear and anxiety".

While the other three participants characterised their overall experience as negative, they did reflect positively on two attributes of care that they received and observed. This included positive interactions with staff and the availability and accessibility of information.

Positive reflections and evaluations

Two participants provided examples of positive interactions that they had experienced with staff during their cancer experience. For example:



He was the only surgeon I have ever met who actually read the consent form out to me instead of delegating it for someone else to do. It instantly made me feel better, made me feel recognised



well I met some very very helpful people, people in the NHS, people in um charities

Two participants referenced the availability of information that they received during their cancer experience. For example:



They knew I could use the web so they gave me Macmillan websites so I could download information and read it



I think we were given a lot of helpline numbers that I then copied into my computer phone book

One participant referenced the accessibility of the information they received commenting that:



Got a sheet of paper that said this is what is available, ticked them all and they sent the whole lot (in braille), took a wee while but that's okay

Participants who received accessible information, support from third sector organisations and who encountered empathetic and knowledgeable staff provided positive evaluations of clinical cancer services. Only one individual accessed cancer support services and this individual rated this service positively.

Negative experiences and evaluation

Three out of four participants characterised their overall cancer experiences as negative. This was primarily a result of negative interactions with staff in clinical environments, and a lack of understanding among staff of how VI impacts on the cancer experience. All three individuals provided examples of interactions that they had with staff that negatively impacted their cancer experience. Participants spoke of the frustration with feeling unheard and misunderstood throughout their journeys. For example, one participant commented that:



perception that being blind, I wouldn't know what I looked like and a comment was made by the surgeon that it would be much easier for me because I wouldn't know what I looked like post-surgery, so it wouldn't make any difference and so I wouldn't need counselling and that it was a benefit of being blind because I wouldn't see anyone's looks to me; you know he was giving that to me as positive- because you are blind it will be an advantage because you won't see anyone looking at you

Participants felt that cancer care professionals whether that is in a clinical environment or in a holistic environment, do not adequately understand how sensory loss and VI in particular, impacts the cancer experience. For example, participants commented that:

“ they didn't know how to, they didn't have the words, the vocabulary, or the awareness, their systems and processes in place weren't for me, they were for sighted people

“ do I have to tell guide dogs I have cancer, will they take the dog away? It's things like, if I've had treatment will I be able to stand upright and move successfully? Will I be able to use my long cane?

One participant spoke of the importance of touch and of tactile memories and how important this concept was for the grieving process. This participant emphasised that this is not something that medical professionals often consider. As a result, the experience reported by individuals affected by cancer from the VI community in this engagement, has identified a more complex pathway to receiving care and accessing services. For some, this complex experience was present at the start of their journeys. For example:

“ (At the) breast scan (my partner) wasn't allowed with me, they wouldn't let (my partner) in and I didn't have my cane with me. People were trying their best to guide but they weren't experienced in it so I was bouncing off door frames, having to be man handled into the position for the scan. They were lovely people but they just didn't know what to do, or how to explain the position to be in so I could do things myself

And for others, the impact that these interactions had, resulted in a decision to disengage. For example:

“ so many times we do not get understanding or double checking the impact of sight loss on XYZ, so many of us just disengage, we become passive, we allow things to be done to us that we put up with

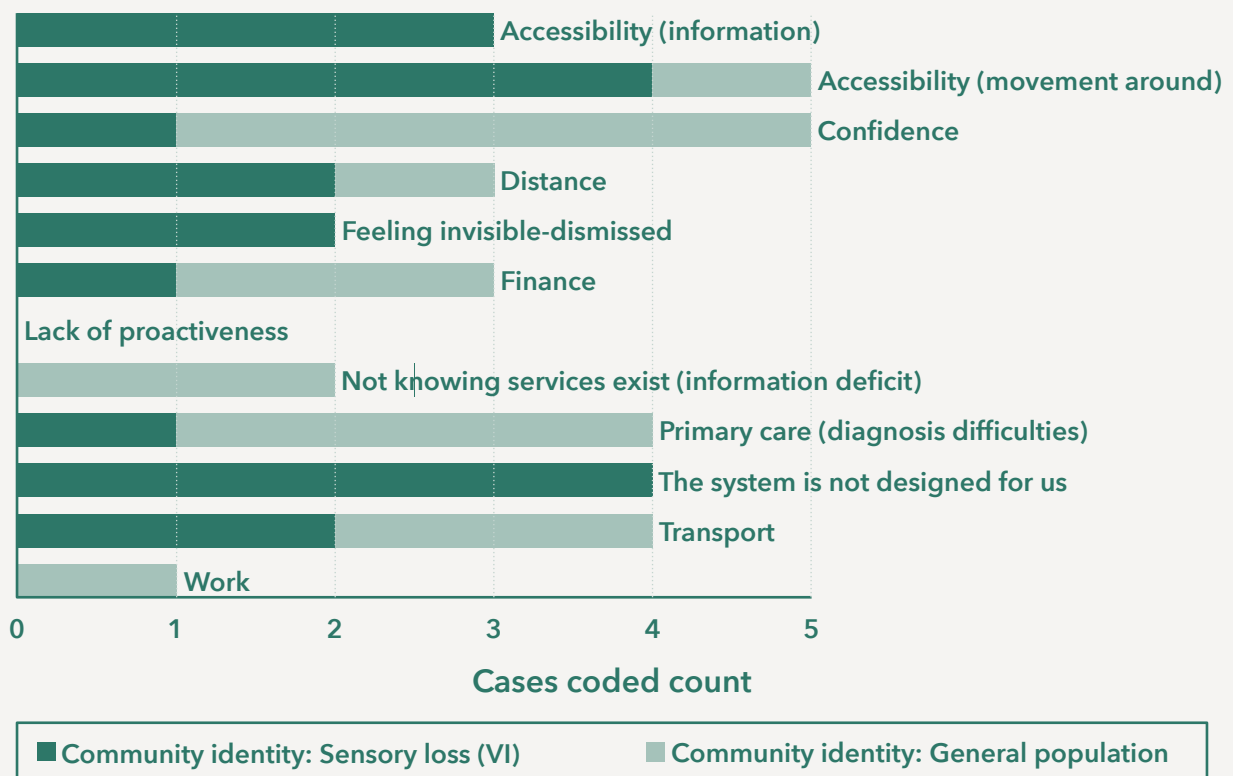
All four participants in this cohort felt that more could have been done to support their emotional and psychological health during the cancer journey. Again, the most common response to the question ‘were you signposted to emotional, financial or practical support services?’ was ‘no’. Due to this perceived support gap, participants from this community rated cancer support organisations negatively feeling that they were under supported throughout their journeys and provided comments such as the one below:

“ I would like a bigger support network

Barriers to services and the sensory loss community (VI)

Engagement with individuals affected by cancer from the sensory loss community who have been impacted by VI highlighted a range of barriers to accessing services. The chart below demonstrates the barriers faced by the VI community reported during engagement, in comparison to those that identified with the general population.

Barriers: VI compared to the general population



The chart above illustrates that participants who identified with the sensory loss community experienced the same barriers as the general population including confidence, distance to appointments, financial concerns, challenges in receiving a diagnosis and transport. Each of these barriers have been discussed earlier in this report and for more information on these barriers please consult **pages 26-30**.

The chart additionally illustrates several additional barriers that are unique to this community. These barriers include feeling dismissed and invisible, feeling that the system isn't designed for individuals with VI and accessibility both in terms of information and in terms of movement. Each of these barriers will be discussed in turn.

Feeling dismissed and invisible

Participants reported that they often felt invisible during clinical appointments. Participants explained that there can be a trade-off and a choice to be made when attending an appointment with a sighted person who is there for support. On the one hand, attending an appointment with a sighted person can leave the VI individual who is affected by cancer, feeling invisible and dismissed during interactions with staff. Participants reported that this is due to the majority of interactions and communications being directed towards the sighted individual. This can leave the VI individual feeling *talked about* rather than *talked to*. One participant explained that attending an appointment alone can force staff to interact with you, but at a cost, as navigating environments is harder and often dangerous. Examples provided by participants include:



We can hear when voices are being directed at us...you know sound travels, and the consultant wouldn't look at us, he kept looking at our support worker



sometimes the medical profession aren't used to us as VI people having a voice about our medical needs, they just expect us to take passively what we're given, but actually we do know stuff, we have been given information and that disconnect is actually really hard



when receiving the DNR letter, I was taken into a room, given this letter and then immediately taken to see my partner. I didn't have any time to process that information. If you are sighted, you can go off and get a cup of tea or something. None of that was given to me. You feel shunted from A to B without knowing what your rights are and all of that makes it difficult to get through the minefield of the clinical world

“The system isn’t designed for us”

Through engagement with individuals who were affected by cancer from the VI community, a key insight was the belief that the health care system and cancer care services are not designed for individuals with sensory loss, and that this hinders their ability to use services effectively. For example, participants commented that:

“ the system is only really equipped for an able-bodied person

Examples of this provided by participants are included below:

“ From the beginning to the end, the experience isn’t made for us. It’s always about if you’ve seen blood in your poo, if you’ve seen blood in your urine, fair enough you can feel a lump that’s true, but then it’s like as a VI person you’re not taught how to check your breasts properly

“ during chemotherapy for example, I kept taking my hearing aids out because they were amplifying the sound of the chemo machines and I didn’t like it

“ the tests are always complicated. Like for a stool sample it isn’t accessible so you don’t do it, so you are missed

Accessibility of movement

All four individuals reported accessibility of movement to be a barrier when accessing services whether that be clinical cancer services or cancer support services. In a clinical setting, participants raised a range of challenges surrounding physically accessing appointments. This included length of appointment times, difficulties arranging support and the practices of specific hospitals and health care environments. One participant explained that arranging assistance to certain cancer treatment appointments is challenging due to the length of time assistance would be required. For example:



I wouldn't have wanted to ask a guide to come to the chemo appointments because they last for over three hours. If the clinic is running late, the guide will have to leave to go to another appointment. That caused problems occasionally

Another participant spoke of challenges surrounding the policies of certain hospitals regarding guide dogs and accessibility. For example:



They wouldn't let the dog in. When I explained what a guide dog was, they immediately said well we have people who are allergic to dogs and when I asked well are they people I will come in contact with? They said no they might be people that will come into the area and we don't want the dog hairs. In the end you just give up and you don't want to argue any more so I was without support

All four participants referenced the difficulties of interacting with staff who were inexperienced in their accessibility requirements. Participants spoke of the consequences both physically and psychology that this can have. For example:



One time I was taken to a different toilet, and no one explained that everything was the other way around and I hit myself and opened my breast stitches and had to go back to theatre, and people were saying to me well why didn't you give yourself more space and I would say, I'm blind I have no concept of space



We are reliant on people to take us around to where we need to be. We are reliant on that person either having the knowledge if they are member of staff, if it's a member of family we are reliant on their good will to get you to where you need to go to. I found this always difficult

Accessibility of information

Several participants spoke about a lack of accessibility when it came to receiving information and how this can act as a barrier to accessing services. While one participant had received some accessible information, others recalled the difficulties that accompanied receiving information that was in-accessible. For example:



It would have been nice if there were braille copies of breast cancer things in the actual chemo ward for the chemo clinic...what I did at the end was, I left my braille copies at the clinic that I no longer needed, so that the next person has information they can read



its all 'this is what things look like'



when you say my preferred format is braille, you then have to explain the level of braille that you read at, so whether you need heightened braille which is on thicker paper so that the dots are easier to read. Most people, if you say I need that in braille, they say that's fine we'll get that done. So even if I request it in braille, and I receive it in braille, if they haven't checked which type of braille I need I won't be able to understand it

One participant elaborated on the emotional difficulties that can accompany not having accessible information and in particular relying on friends or family to read aloud information related to a cancer diagnosis. For example:



if you have a relative, loved one or a friend, they may not be the person you would want to give you the information, because if they are really close to you and they are reading out these things, it heightens their fear and then you get caught up not only in your own fear but theirs

Individuals who identified with the sensory loss community (VI) who participated in this engagement, shared a considerable amount of lived experience concerning their overall cancer experience and the barriers that they face regularly when attempting to access services. Despite the small sample size of the participants who identified with this community, participants provided rich and detailed information about their experiences.

Finally, all participants across this engagement were provided with the opportunity to voice what they felt could be done to improve cancer services. Participants from the sensory loss community were the most vocal and suggested a range of ideas. A word cloud has been generated below that captures the most common words used in response to this question.



As the word cloud shows, the most common suggestions voiced by participants include:

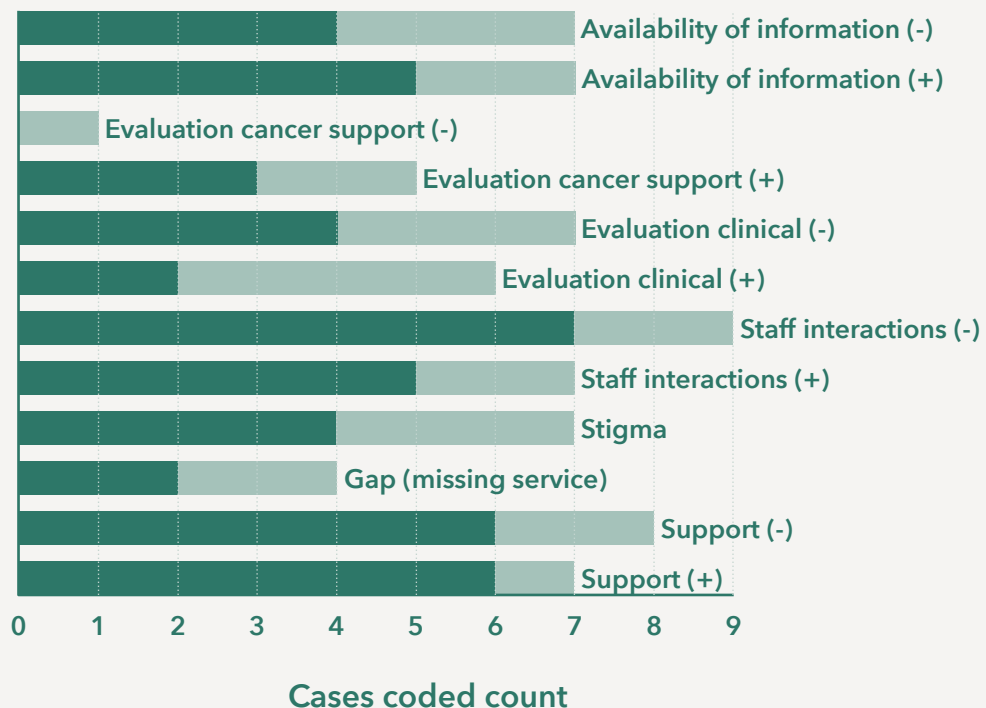
- An increase in accessible information
- Increased training on how VI impacts the cancer experience. For example, one participant suggestion was the use of patient experts
- Person-centred care and 'listen to me'
- Policy changes (hospital specific)
- Organisational changes (cancer support specific)
- Information video
- Increased signposting

Minority ethnic communities

Eight individuals took part in this engagement that identified with a minority ethnic community. The following information is presented to highlight the voices of participants that are often not provided with a platform to do so. Importantly, the experiences presented in this section are not simply confined to that of minority ethnic communities. Individuals across a range of population groups will experience similar challenges and experiences that are outlined in this section. What this section aims to do is simply report what individuals who participated in our engagement that identify with a minority ethnic community told us about their cancer experience. This section contains a documentation of the unique experiences and barriers faced by individuals who identify with a minority ethnic community who have been affected by cancer. For a general overview of themes and barriers reported across the entirety of engagement, that includes minority ethnic participants but omits community specific experiences and barriers, please consult section two of this report.

Of the eight individuals that participated in this engagement, two individuals had been affected by cancer through a personal diagnosis of cancer, and six individuals had been affected by cancer through caring for and supporting an individual with cancer. The chart below plots the experience of participants in this engagement who identified with a minority ethnic community compared to participants who identified with the general population.

Experience: Minority ethnic communities and the general population



■ Community identity= Minority ethnic ■ Community identity= General population

The chart above illustrates that individuals who identified with a minority ethnic community reported more instances of available information provision, rated cancer support services more positively but also reported more instances of negative staff interactions and rated clinical care more negatively when compared to the general population.⁴

Overall experience of participants was recorded according to the overall tone and sentiment of discussions during engagement. This is demonstrated in the chart below.



As the chart above illustrates, three participants reported an overwhelmingly positive experience while three participants reported a more negative experience. Two participants provided mixed responses to questions asked during engagement providing both positive and negative reflections to specific topics. Positive experiences reported by participants are provided below.

Positive experiences

For individuals who identified with a minority ethnic community, positive experiences referenced the empathy and kindness of staff in clinical environments and in cancer support settings. Although only three participants reported having an overwhelmingly positive experience, four participants shared some positive examples of interacting with staff during their experiences. For example:



I think most of that was the doctors and nurses were fantastic

⁴General population refers only to participants who disclosed that they identified with this community and does not include participants who selected 'not disclosed' or 'none of the listed identities'



It was always reassuring, this is what I was seeing in the cancer wards. There are worried faces and seeing how staff reassured them and gave them hope and positivity. It's what got me through it

Additionally positive experiences referenced high levels of support provided during the cancer experience and the provision of translation services. Individuals who required this form of support, and who had this form of support organised quickly and on their behalf, recounted their experiences positively. For example:



We just asked the hospital....we need interpreter and everything was done



She then called me with an interpreter. And then she asked me if I wanted to have the letter in Polish. I said yes. I also have the information about the (cancer) journey in Polish

Five participants reported being satisfied with the level of information that they were provided with. Finally, all three individuals who reported an overall positive experience disclosed that they had attended cancer support organisations, and reported positive evaluations. For example:



Lovely meetings, for example, for skills and how to do make-up without hair. So there was this one about make-up. Very nice, we were given nice cosmetics

Two individuals who accessed cancer support organisations accessed emotional support, and spoke of the benefits of doing so. An example is provided below:



I just cried like hell, and I never cried through the whole journey but in that moment I'm telling this complete stranger what had happened and what I'm going through. It opened the door to waves of emotion and I let it rip, and I am glad I did that

Participants who reported positive aspects of their experiences- regardless of their overall experience- reported positive interactions with staff in clinical and cancer support environments, a strong support network and the provision of translation services on request. However, there were also aspects of the cancer experience which participants reflected on much more negatively. The negative experiences reported during engagement are included in the section below.

Negative experiences

Negative experiences reported by participants tended to include a lack of available information, a lack of signposting and support, and instances of negative interactions with staff. While five individuals reported positive experiences relating to receiving information, three participants focused heavily on the impact that a lack of information had on their cancer experiences. These participants commented that they had experienced not only a lack of information, but a lack of clarity relating to treatment options and support during their cancer experiences. For example, participants commented that:

“ There is just no knowledge of what is happening and what the options are. It’s normal not to have clarity over what is going on with your body when you have cancer as a condition right, but every time you make a decision, you should have all the information there for you. It’s really serious stuff, and there is no proactivity

“ there is simply no information as you leave the ward, about what you should do

Seven participants also shared experiences of negative staff interactions which impacted on their overall cancer experiences. These participants cited a lack of empathy, lack of detail when explaining answers to questions, and a feeling of being “heard but not listened to”. This insight again drives home the importance of everyday staff interaction for participants in both clinical environments and cancer support settings. For example:

“ (consultant was) under pressure and so I didn’t get answers in as much detail as I wanted or with as much empathy as I would have liked

“ It was draining. Conflict between myself, the GP and the hospital team

“ for the first appointment, I walked out of there. It was so negative, he described everything, very negatively, how many percent of people die, etc

Support

Finally, six participants referenced a lack of local support and a lack of signposting to support services during engagement to be a particularly negative aspect of their cancer experiences. For example participants shared comments such as:



We aren't actually aware of where to go



in terms of clinicians when I've attended appointments, they have alluded to oh you could reach out to this (like the organisations) but what is there locally? For us, no not really had any support



I wasn't signposted to anything

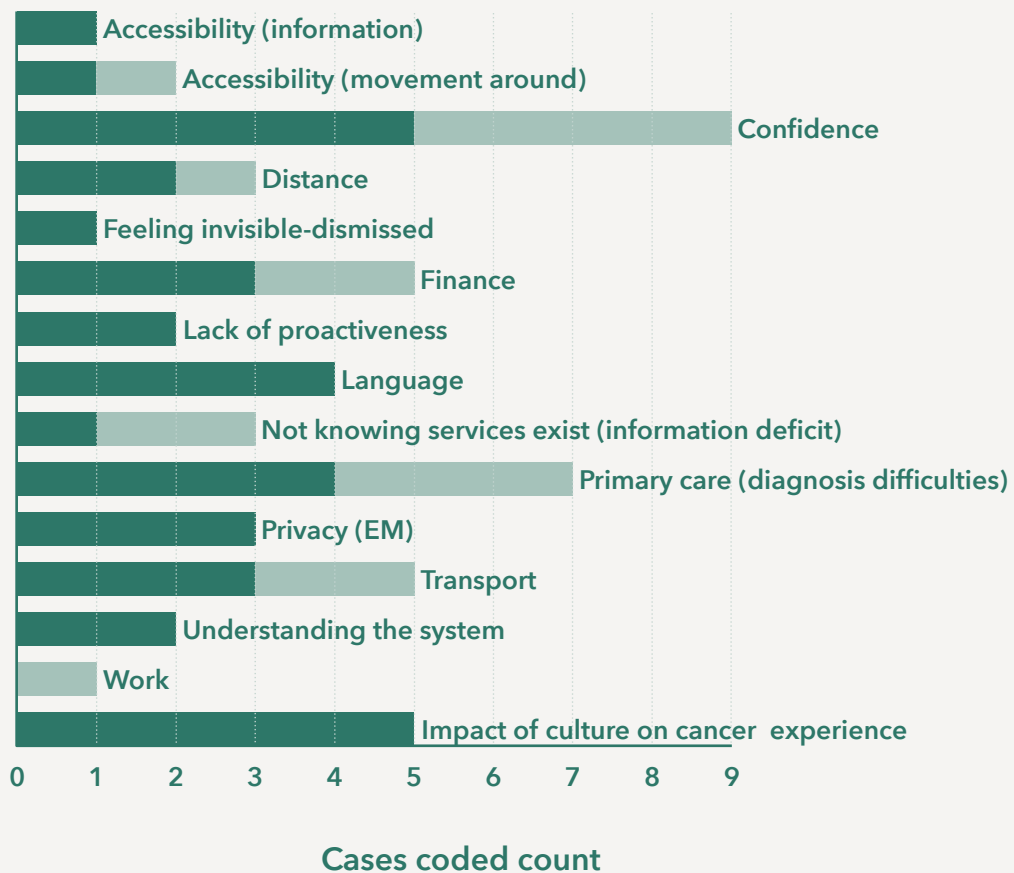
Evaluation

Only three participants accessed cancer support services and all evaluated cancer support services positively. When it came to clinical cancer services, evaluations were mixed. In terms of providing treatment and treating the diagnosis of cancer, two participants rated clinical services positively. Four participants were unhappy with the clinical care that they had received or the individual they were supporting received, citing the lack of support and lack of information to be the reason for their low evaluation of clinical services. Two participants did not provide evaluations for clinical cancer services.

Barriers

A key aim of this project was to ascertain what barriers to services specific community groups encountered. This next section of this report details the insights shared by participants who identified with a minority ethnic community when accessing or attempting to access cancer services. The chart below compares the barriers reported by those that identified with the general population to the barriers reported by those that identified with a minority ethnic community.

Barriers: Minority ethnic communities compared to the general population



As the chart above shows, engagement with minority ethnic individuals highlighted community specific barriers to accessing services and receiving care. These include understanding the system of the NHS as a whole, language barriers and the impact that culture can have on the cancer experience. In addition to sharing their own experiences, several participants used their interview and focus groups session to advocate for and to ‘be a voice for minority ethnic people’.

Understanding the system and 'no one is listening'

Participants explained that a particular barrier when receiving a cancer diagnosis, and attempting to access cancer services, was how well they understood the health care system and specifically, the NHS. For example, one participant provided the following comment:

“ when I received the news and when I started crying I was given a list of places I could contact and speak to people. But we don't have any social worker or anyone, we don't know the system well, so I was a bit hesitant to ask for help. Because I didn't understand the system, I kept everything in

Similarly to the concept of feeling invisible among the sensory loss community, the feeling of 'no one is listening' was discussed during engagement. Participants reflected that one of the most difficult aspects of the cancer experience was the feeling that no one was taking their concerns seriously, a particular difficulty before diagnosis. For example, one participant commented that:

“ no one was listening to me. I felt like the doctors felt like I was exaggerating

Language barriers

Language also featured as a barrier for several participants. For example, participants commented that:

“ I'd say a barrier for us was language. When we arrived in the UK our English was bad

“ Only the language barrier was the most (difficult)

For one individual, despite being provided with a translator and informing the hospital that her first language was not English, letters continued to be sent in English and this represented a point of frustration for this individual. This individual would send photographs

of the appointment letter to a support worker who would translate the written information back to her in order for the individual to understand what was being sent.

Another participant explained that despite speaking English well, understanding what medications to take, when, and for what purpose was confusing. Several participants felt strongly that these processes are even more difficult for individuals who do not speak English. For example:



the struggle for minority ethnic people is doubled. They are alone, without support or family and some of them don't speak the language at all. We can struggle to sometimes make appointments, we can struggle to express our feelings



for minority ethnic people, they need the clarification about the system early and all the way through

These participants felt strongly that they had a duty to use their engagement session not just to talk about their own experiences, but to advocate and to represent the voices of individuals who could not take part in this project.

Impact of culture on the cancer experience : Perceptions of privacy

An aim of this engagement was to understand the impact of culture on cancer experiences. This aim was derived from the input of our Minority Ethnic Peer Evaluator who helped to create the question sets for engagement. However, not many participants felt that they could provide an answer to this question. The impact that culture can have on the cancer experience represents a separate research question in its own right, and is outwith the scope of this report to provide possible answers to this question. However, an example of responses that we did receive during engagement are included below:



I think culture, it has an impact in terms of maybe misunderstandings, it creates a lack of communication between both parties



context is important, (person participant supports) is from an ethnic minority background that culturally speaking they are not as open or receptive to hearing certain messages around health or care

Therefore, given the responses to this question, a barrier called 'Privacy' was added to the data set. As the chart on **page 48** shows, two participants felt that the impact that culture can have on the concept of privacy and communication, can act as a barrier to accessing cancer services among some individuals who identify with a minority ethnic community.

Finally, all participants across this engagement were provided with the opportunity to voice what they felt could be done to improve cancer services. A word cloud has been generated below that captures the most common words used in response to this question:



As the word cloud demonstrates, the most common raised suggested to improve cancer experiences consisted of:

- **Increases in care**
- **Increases in information**
- **More signposting**
- **Changes to policy (hospital policy)**
- **Training for communities regarding health lifestyles**

LGBTQIA+ community

This engagement also sought to gather insights and experiences from individuals affected by cancer from the LGBTQIA+ community. However, efforts to gain an LGBTQIA+ Peer Evaluator to co-facilitate engagement were unsuccessful. As a result, engagement with this community took the form of the cancer experience surveys, questions of which were informed by partner organisations working in the field of LGBTQIA+ health and wellbeing. However, only one survey respondent identified as belonging to the LGBTQIA+ community. To protect the identity of this participant, results have not been broken down into community specific experiences or barriers for this cohort and engagement with this community continues to be a priority for further projects.

Conclusions

When reflecting on overall cancer experiences, this report has shown the aspects which can positively impact on someone's cancer experience, whether that is as someone who has received a diagnosis of cancer or as someone who is there to support and care for someone with a diagnosis. Participants of this engagement have provided insights into what some of these aspects might be. From everyday encounters with staff members in clinical and cancer support environments, to the availability of information and the degree of support offered, these factors can heavily influence the experience of individuals who are affected by cancer. Overall, during engagement there were more instances of positive evaluations of clinical services than negative evaluations when looking across the engagement sample. Additionally, participants shared both positive and negative experiences of accessing cancer support services. A key take away, was that cancer support organisations were predominantly accessed by individuals who have received a diagnosis of cancer, despite the need for support identified by people caring for and supporting someone diagnosed with cancer. The barriers of confidence, primary care and difficulties receiving a diagnosis, distance and transport to appointments, and not knowing that services existed represent the four main barriers reported by participants during this engagement. Finally, this engagement has also highlighted the continuing impact of stigma and its interaction with accessing cancer support services particularly for individuals affected by cancer through caring for and supporting an individual, largely hindering access to these essential services.

The experience reported by individuals affected by cancer from the sensory loss community (VI) in this engagement, has identified a more complex pathway to receiving care and accessing services. Participants from the sensory loss community (VI) rated support overall more negatively, mentioned the gap in emotional support more often and had more negative staff experiences compared to the general population. Factors determining either a positive or negative experience reported by this community focused on staff interactions, levels of support provided and availability of information. Additionally, the level of understanding that staff displayed on how VI interacts with the cancer experience was important to the individuals who participated in this engagement. Participants who received accessible information, support from third sector organisations and who encountered empathetic and knowledgeable staff provided positive evaluations of clinical cancer services. However, participants from this community rated cancer support organisations negatively feeling that they were under supported throughout their journeys. This report has shown that participants affected by cancer who identified with the sensory loss community, experienced the same barriers as the general population including confidence, distance to appointments, financial concerns, challenges in receiving a diagnosis and transport. This report has also shown that participants who identified with this community face additional barriers that are unique. These barriers include feeling dismissed and invisible, feeling that the system isn't designed for individuals with sensory loss, and accessibility both in terms of information and in terms of movement.

This report has shown that individuals who identified with a minority ethnic community reported more instances of both positive and negative staff interactions, information provision and support compared to the general population, demonstrating a much more mixed and nuanced experience on these themes. For individuals who identified with a minority ethnic community, positive experiences referenced the empathy and kindness of staff in clinical environments and in cancer support settings. Additionally positive experiences referenced high levels of support provided during the cancer experience and the provision of translation services. Individuals who required this form of support and who had this form of support organised quickly and on their behalf, recounted their experiences positively. Negative

experiences reported by participants tended to include a lack of available information, a lack of signposting and support, instances of negative interactions with staff and a feeling of being heard but not listened to. This report has detailed the specific barriers that can impact on individuals who have been affected by cancer that identify with a minority ethnic community. These barriers include understanding the system of the NHS as a whole, language barriers and the impact that culture can have on the cancer experience.

Recommendations

The individuals affected by cancer who participated in this engagement shared a wealth of information with the Macmillan Transforming Cancer Care Lived Experience Project Team. The experiences documented in this report and in particular the suggestions made by participants as to what they would like to change, have been gathered in order to work towards improving the cancer experience for individuals across Scotland. As a result, the ALLIANCE and the Macmillan Transforming Cancer Care Lived Experience Programme propose the following two recommendations:

- 1.** The Transforming Cancer Care (TCC) Executive Group conscientiously and actively consider the insights presented in this report, and begin the process of considering how these insights can be built upon in practice;
- 2.** Tangible recommendations for cancer care services and national policy are meaningfully co-produced with cancer services and people affected by cancer to embed person centredness into the heart of service design.

Acknowledgements

The Macmillan Transforming Cancer Care Lived Experience Programme on behalf of the ALLIANCE, would like to thank our dedicated Peer Evaluators and the following organisations for their continued support, advice and guidance throughout this project:

- Aberdeen interfaith group
- African Challenge Scotland
- Amina (Muslim Women's Resource Centre)
- Andalus
- BEMIS
- Bridges Programme
- Coalition for Racial Equality and Rights
- Deafblind Scotland
- Empower women for change
- Feniks
- Govan Hill Community Development
- Hidayah
- Highland Pride
- LGBT Health and Wellbeing
- Macmillan Improving the Cancer Journey Practitioner, Midlothian Wellbeing Team
- NKS (Networking Key Services)
- Pink Saltire
- Polish Family Support
- Polish Men's Action Group
- RNIB (Royal National Institute of the Blind)

- **Sandyford Gender Identity Clinic**
- **Scottish Cancer Coalition**
- **Sense Scotland**
- **Shetland LGBTQ**
- **The Language Room**
- **WsREC (West of Scotland Regional Equality Council)**



About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level. Our vision is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.



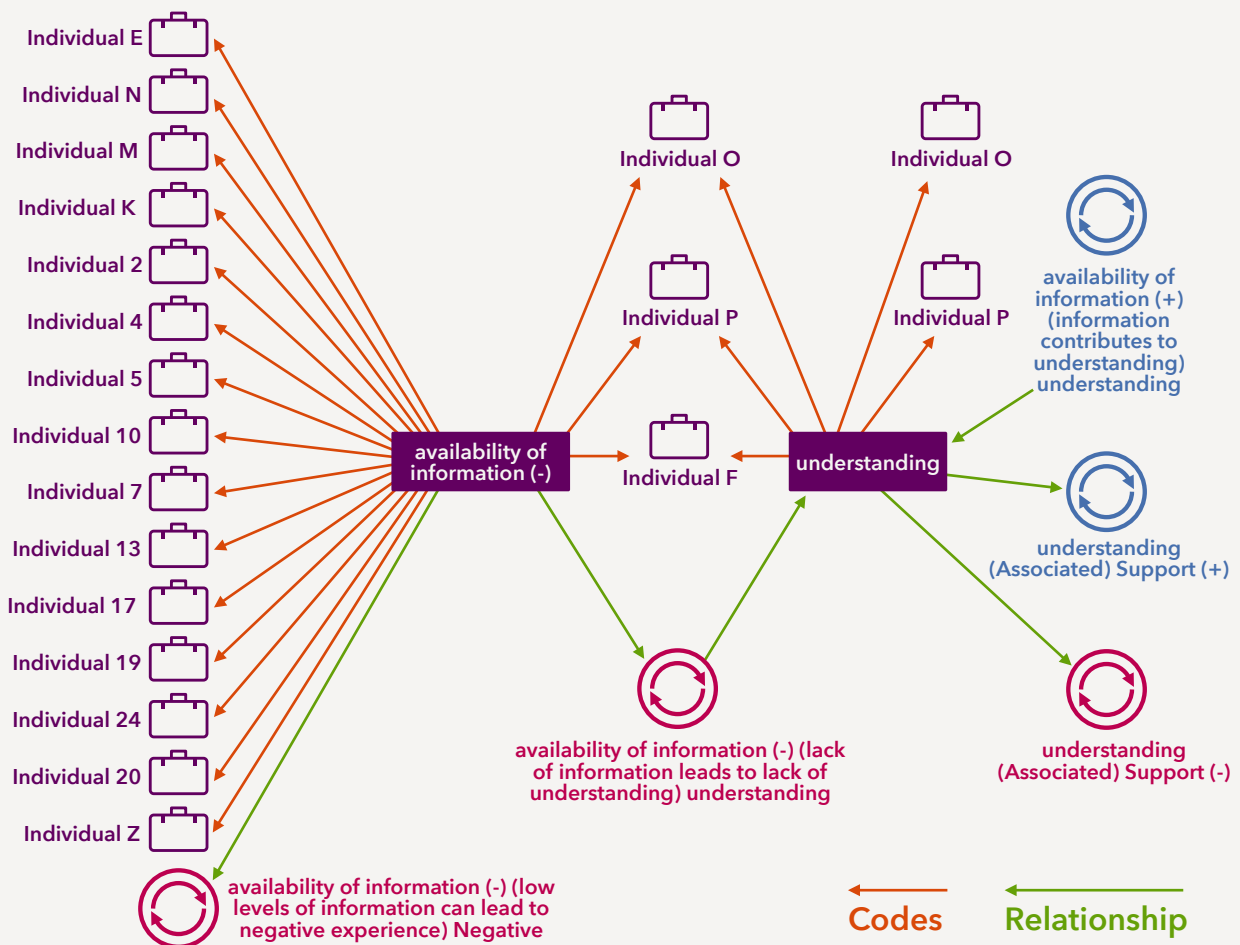
ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Appendices

Appendix one - The relationship between the availability of information and understanding

The briefcase icons represent cases. Each case represents an engagement participant. The purple boxes represent codes. The code on the left hand side is 'availability of information (-)' and the code on the right hand side is 'understanding'. The circles with directional arrows in the middle show relationships generated by Nvivo.

The cases on the far left hand side show all the participants who mentioned a lack of information. The cases on the far right hand side show all the participants who mentioned a lack of understanding. The three cases in the middle show all the participants who attributed a lack of understanding to come from a lack of information.



Appendix two: Lesser barriers

Finance

“ it was costing me a lot

“ Yeah finance, em what actually happened was because I recently changed jobs I wasn't entitled to sick pay and because of my husbands wages

“ It was quite a worrying time you know the heating constantly had to be up, you've got the chemo, and the travel every day and yeah it was a worry that nobody should need to have at that point

“ couldn't use public transport because of the risks which would have been the cheaper option

Work

Participants that referenced the barrier of finance provided the following comments:

“ On week 4 or 5, my husband works shifts and em, because I wasn't working he had to keep working

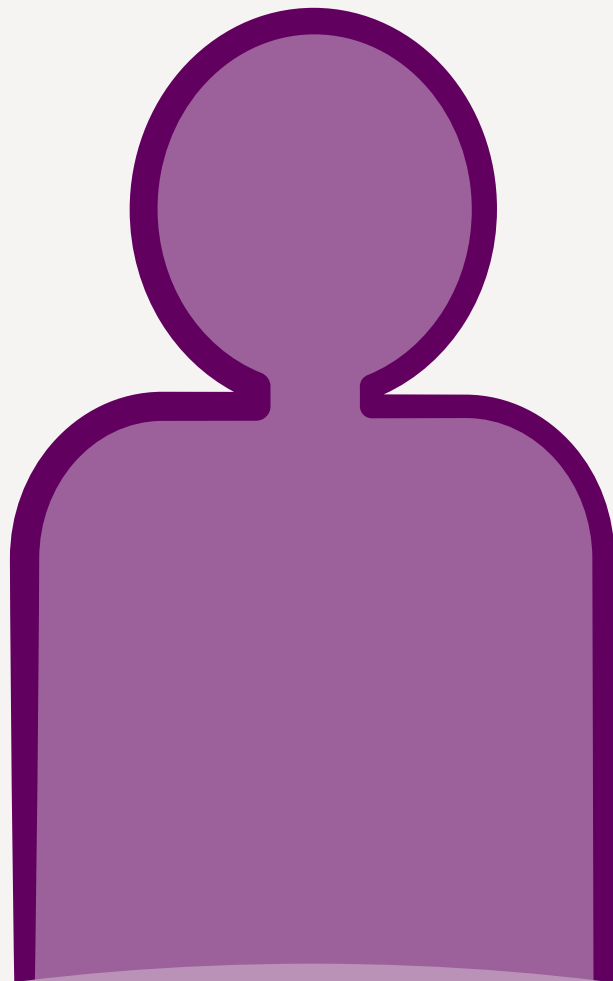
“ found it difficult to access Maggie's, as much of their support pre-surgery was during the day and I was still working

Lack of proactiveness

Participants that referenced the barrier of lack of proactiveness provided the following comments:



why don't they take out one day a week and heck in with those patients, you and ask "how are you doing, can we sign post you anywhere, would you like referred anywhere, do you need someone to come and check on you" and have some proactiveness



Appendix three: Barriers by appointment type

1

Survey One: Macmillan Transforming Cancer Care Lived Experience Survey- Person Diagnosis

Consultations

A total of 64% (7 respondents) received consultations as their form of care. The barriers reported for accessing consultation appointments consisted of:

- Other barriers (1 respondent)
- Not allowed to attend consultation with someone who was there to provide support due to COVID-19 (3)
- Not allowed to attend consultation with someone who was there to provide support NOT due to COVID1-19 (1 respondents)
- Consultations appointments far away (1 respondent)

Out of 7 respondents, a total of 6 faced barriers when attempting to access their consultation appointments.

Diagnostic tests

A total of 64% (7 respondents) indicated that they receive diagnostic testing as part of their clinical cancer care. The barriers reported for this type of appointment are as follows:

- Other barriers (1 respondent)
- Transport (1 respondent)
- Not given information in an accessible format (1 respondent)
- Not given information in an LGBTQIA+ friendly format (1 respondent)
- Not allowed to attend appointment with someone who was there to provide support NOT due to COVID-19 (1 respondent)
- Appointment was far away from where I lived (1 respondent)

Out of a total of 7 respondents 6 faced barriers when attempting to access their diagnostic testing appointments.

Surgery

A total of 73% (8 respondents) indicated that they accessed surgical appointments as a method of cancer care. The barriers reported for surgical appointments are detailed below:

- Other barriers (1 respondent)
- Transport (2 respondents)
- Not allowed to attend my appointment with someone I knew who was there to provide support due to COVID-19 (2 respondents)
- Not allowed to attend my appointment with someone I knew who was there to provide support NOT due to COVID-19 (1 respondents)
- Finance/money concerns (2 respondents)

Out of a total of 8 respondents all 8 indicated that they experienced the above barriers.

Radiotherapy

A total of 18% (2 respondents) indicated that they received radiotherapy as part of their clinical cancer care. The barriers reported for this type of care are as follows:

- Other barriers (1 respondent)
- Not allowed to attend my appointment with someone who was there to provide support due to COVID-19 (1 respondent)

Out of a total of 2 respondents one respondent answer that they faced both of these barriers when attempting to access their radiotherapy appointments.

Chemotherapy

27% (3 respondents) indicated that they accessed this type of care. No barriers were reported by survey participants when accessing chemotherapy appointments.

Biological and immunological therapy

One respondent indicated that they accessed this form of care. This respondent did not report any barriers when accessing biological and immunological therapy.

Other care or treatment

A total of 27% (3 respondents) indicated that as part of their clinical cancer care they attended the category of 'other clinical appointments'. The barriers reported when accessing this type of appointment are detailed below:

- Other barriers (1 respondent)
- Transport (1 respondent)

Out of a total of 3 respondents two respondents faced these barriers when attempting to access their clinical appointments.

2

Survey Two: Macmillan Transforming Cancer Care Lived Experience Survey- Individuals supporting and caring for someone with cancer

The following appointment types have been listed with what barriers respondents faced when accessing these appointments along with the total number of respondents that reported this barrier.

Chemotherapy

A total of four respondents indicated that they faced barriers when they accompanied the individual they supported at chemotherapy appointments. The barriers reported for chemotherapy are as follows:

- COVID-19 6% (1 respondents)
- Finance 7% (1 respondents)
- Location 6% (2 respondents)

Consultations

A total of 12 respondents indicated that they faced barriers when they accompanied the individual they supported at consultation appointments. The barriers reported for consultation appointments are as follows:

- COVID-19 6% (1 respondent)
- Transport 18% (4 respondents)
- Location 22% (7 respondents)

Diagnostic testing

A total of nine respondents indicated that they faced barriers when they accompanied the individual they supported at diagnostic testing appointments. The barriers reported for diagnostic testing appointments are as follows:

- COVID-19 6% (1 respondent)
- Transport 18% (4 respondents)
- Location 13% (4 respondents)

Palliative care

A total of eight respondents indicated that they faced barriers when accessing palliative care. The barriers reported are as follows:

- COVID-19 6% (1 respondent)
- Not COVID-19 8% (1 respondent)
- Finance 7% (1 respondent)
- Transport 9% (2 respondents)
- Location 9% (3 respondents)

Radiotherapy

A total of 12 respondents indicated that they faced barriers when they accompanied the individual they supported at radiotherapy appointments. The barriers reported for radiotherapy appointments are as follows:

- COVID-19 6% (1 respondent)
- Finance 7% (1 respondent)
- Transport 14% (3 respondents)
- Location 22% (7 respondents)

Surgery

A total of five respondents indicated that they faced barriers when they accompanied the individual they supported at surgical appointments. The barriers reported for surgical appointments are as follows:

- Finance 7% (1 respondent)
- Transport 5% (1 respondent)
- Location 9% (3 respondent)

Other clinical appointment

A total of three respondents indicated that they accompanied the individual they supported at 'other clinical appointment' signifying that the clinical appointment was not listed. The barriers reported for 'other clinical appointments' are as follows.

- I was not allowed to attend the appointment with the individual I was supporting (not due To COVID19 restrictions)' . (1 respondent)
- Transport 5% (1 respondent)
- Location 5% (1 respondent)

