

Evaluation of the Macmillan Liverpool University Hospitals Foundation Trust Cancer Community Support Service.

2023

Healthwatch Sefton - We believe that health and social care providers can best improve services by listening to people's experiences.

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Who we are?

Healthwatch Sefton is the local health and social care champion for Sefton. Established following the Health and Social Care Act (2012) in April 2013, we have built up both local and national recognition as an organisation which independently engages with people.

We ensure that the experiences of residents are heard for those who access health and care services including; GPs and hospitals, dentists, pharmacies, care homes or other support services. We have the power to make sure leaders and other decision makers listen to feedback and improve standards of care. We also help people to find reliable and trustworthy information and advice and have an Independent Complaints Advocacy Service, to support residents who need support to make a complaint about an NHS service.

Healthwatch Sefton is set up as a company limited by guarantee, a subsidiary company of Sefton Council for Voluntary Service (Sefton CVS). Sefton CVS is a registered charity, operating for 40 years to provide specialist infrastructure and support services to voluntary, community and faith sector organisations (VCF) that encourage and support independent resilience and sustainable communities in the borough of Sefton.

We have a national body, Healthwatch England. Both organisations have statutory duties and powers to ensure the voice of people who want to have a say about health and social care services is strengthened and heard by those who commission, deliver and regulate health and care services.

What are our core beliefs?

- We believe that health and social care providers can best improve services by listening to people's experiences.
- We believe that everyone in society needs to be included in the conversation, especially those whose voices aren't being listened to.
- We believe that comparing lots of different experiences helps us to identify patterns and learn what is and isn't working.
- We believe that feedback has to lead to change, listening for listening's sake is not enough.

Listening to patients and their family members.

During 2023, we were commissioned by Macmillan Cancer Support to independently evaluate the Macmillan Liverpool University Hospitals Foundation Trust (LUHFT) Cancer Community Support Service (CCSS).

Overview of the Cancer Community Support Service.

Liverpool University Hospitals Foundation Trust (LUHFT) Cancer Community Support Service (CCSS) was established in April 2020. Macmillan Cancer Support funded a cancer community support lead nurse (CCSLN) to offer direct support and protected capacity to the Cancer Clinical Nurse Specialists, community services and patients during COVID-19. This post also supported associated recovery plans for cancer services during 2021/2022 and informed the development of a broader, sustainable model to expand personalised care, including holistic need assessments (HNA's) across the wider cancer pathway.

In establishing the service, it was also envisaged that partnerships would be strengthened, mutual education provided and care pathways established with primary and community services. This service was developed to support anyone across Liverpool, Sefton and Knowsley who was living with or affected by cancer.

The service has provided a unique offer of support for patients from suspected cancer referral through to end of life, improving communication and coordination across the healthcare system and supporting people through transition and handovers of care. Due to growth within the service and workforce development, the service is now supported by a personalised care coordinator.

The ambition of establishing the service was to significantly improve communication and coordination across the workforce, improve knowledge about how to refer and navigate to other services, so that people access the most appropriate care and support and to improve confidence and skills in the workforce in engaging with people about their cancer.

870 referrals were made into the service between April 2020 and September 2022. The service supports patients, their families and carers. Referrals from secondary care mainly came from clinical nurse specialists (CNS) and clinical psychologists at LUHFT.

The support offer extended to community cancer navigators, social prescribers and GP cancer care co-ordinators who referred into the service for direct patient support or to utilise knowledge and resources to best support their patients. This provided a faster pathway for patients to access clinical information and/or support. The service was ideally placed to be able to facilitate the continuity and co-ordination of cancer care between primary and secondary care with a strong focus on ensuring patients, family and care givers felt their needs were adequately supported at an unprecedented time.

Objective of the Cancer Community Support Service.

The objective of the service is to provide holistic, personalised support to people when they need it whether the patient is at home or in a hospital setting.

Aims of the evaluation.

- Collect feedback and learning as this is the first service in Merseyside and Cheshire to deliver a system - wide collaborative approach to personalised care for cancer
- Foster a culture of learning and improving a service
- Establish the impact the service has had on patient experience, outcomes, and pathway efficiencies
- Support the delivery of personalised care linking with secondary, community and primary care to improve integration and patient experience and achieve clear pathways of support
- Inform a sustainable model of integrated personalised care, incorporating the role of Macmillan information and support centres, and primary and community services
- Understand the views and experience of patients and staff from stakeholder organisations, to include benefits and challenges: Survey questionnaire / 1:1 interview with patients and staff accessing the service
- Understand the value of the cancer community support lead nurse, in the ongoing clinical oversight of the service and continued development of personalised care at a strategic level.

What we did/ online survey with staff/stakeholders.

We were provided with survey questions developed by the cancer community support lead nurse, to help us to engage with staff/ key stakeholders who had previously accessed the service. Eight **(8)** questions were included within the survey, **six (6)** asked for a rated response using a 5-point scale rating, with **two (2)** questions being open text to capture qualitative feedback (softer intelligence). A copy of this questionnaire can be found in appendix one (1).

Twenty-six **(26)** staff/ stakeholder contact details (email addresses) were provided to Healthwatch Sefton as the sample group. The survey was uploaded onto an online platform (SmartSurvey) and a request to complete the survey, with background information about the evaluation project was emailed to everyone within this group. Respondents were not asked to include any personal details within their online response and responses back into the SmartSurvey system were anonymous.

Roles included within the sample included amongst others: cancer navigators across Knowsley, Liverpool and Sefton, cancer nurse specialists working across LUFHT, members from Cheshire and Merseyside Cancer Alliance, support workers, primary care network care co-ordinators and individuals from community organisations.

During the course of the evaluation two reminder emails were sent out to all staff/stakeholders asking them to complete the survey. Twenty-four **24 (92%)** responses were completed online.

Who we spoke with. Conversations with patients and their family members.

The cancer community support lead nurse gained consent from patients, family members and carers by asking them if they consented to their name, contact telephone number and email address (if applicable) being shared with Healthwatch Sefton. They were informed that they would receive a telephone call from Healthwatch Sefton at a time arranged convenient to them.

Eight **(8)** short questions were developed by the lead nurse to help us to have a conversation about the service. Seven **(7)** questions asked for a rated response using a 5-point scale rating, with one **(1)** question being open text to capture qualitative feedback (softer intelligence). The cancer community support lead nurse provided us with a script to support initial conversations. A copy of the script and the questions we asked can be found in appendix two **(2)**.

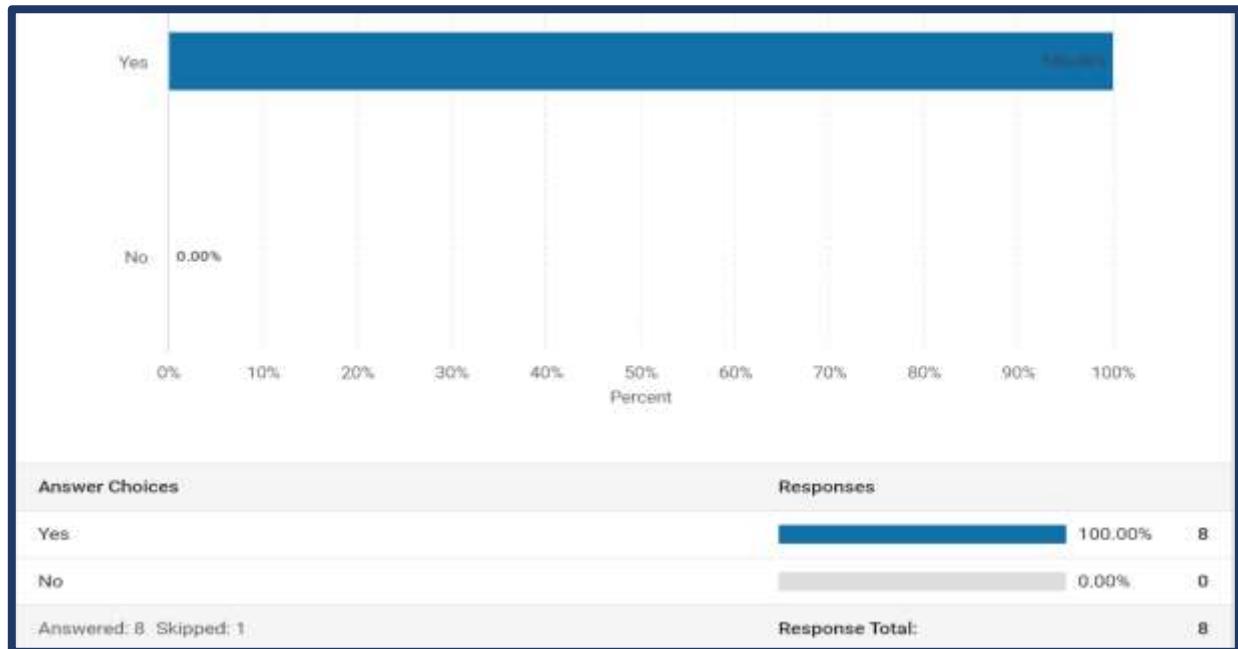
During the course of the evaluation we were provided with contact details for six **(6)** patients and five **(5)** family members. Originally it was anticipated that the sample size would have been larger but when working through patient lists, many patients previously supported by the service had passed away or their health had significantly deteriorated. We were able to speak with nine **(9)** people from this group **(82%)**.

What did patients and their family members tell us about the service?

This section of the report, shares the responses and feedback for each of the questions that were asked during our telephone conversations with patients and family members.

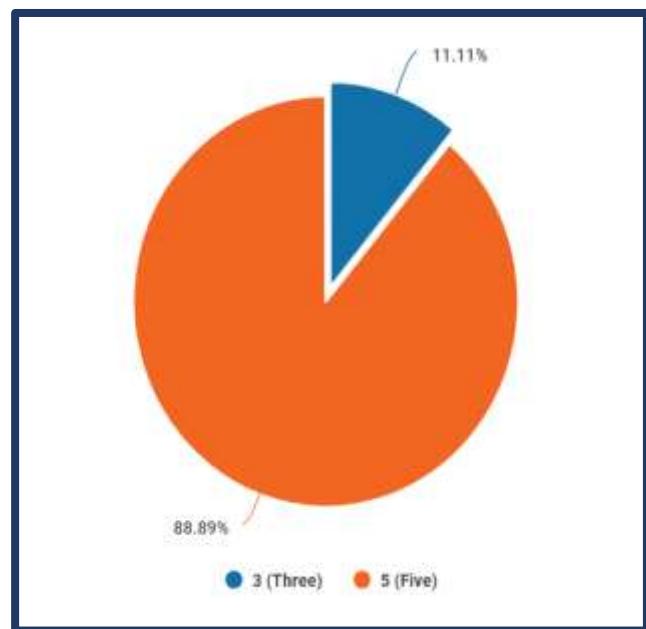
1. Did having access to the Cancer Community Support service and the help they provided improve your experience?

- Eight **(8)** of the nine **(9)** patients/family members answered this question.
- 100% of those responding told us that help provided by the service had improved their experience.



2. On a scale of 1 – 5 (1 being poor and 5 being good), please rate how satisfied you were that your unmet needs were supported by the Cancer Community Support Service?

- All nine (**9**) patients/family members answered the question.
- Eight (**8**) people (**89%**) told us that they were completely satisfied that their unmet needs were supported by the service, rating their satisfaction as a five (**5**), good.
- One person rated their satisfaction as three (**3**).

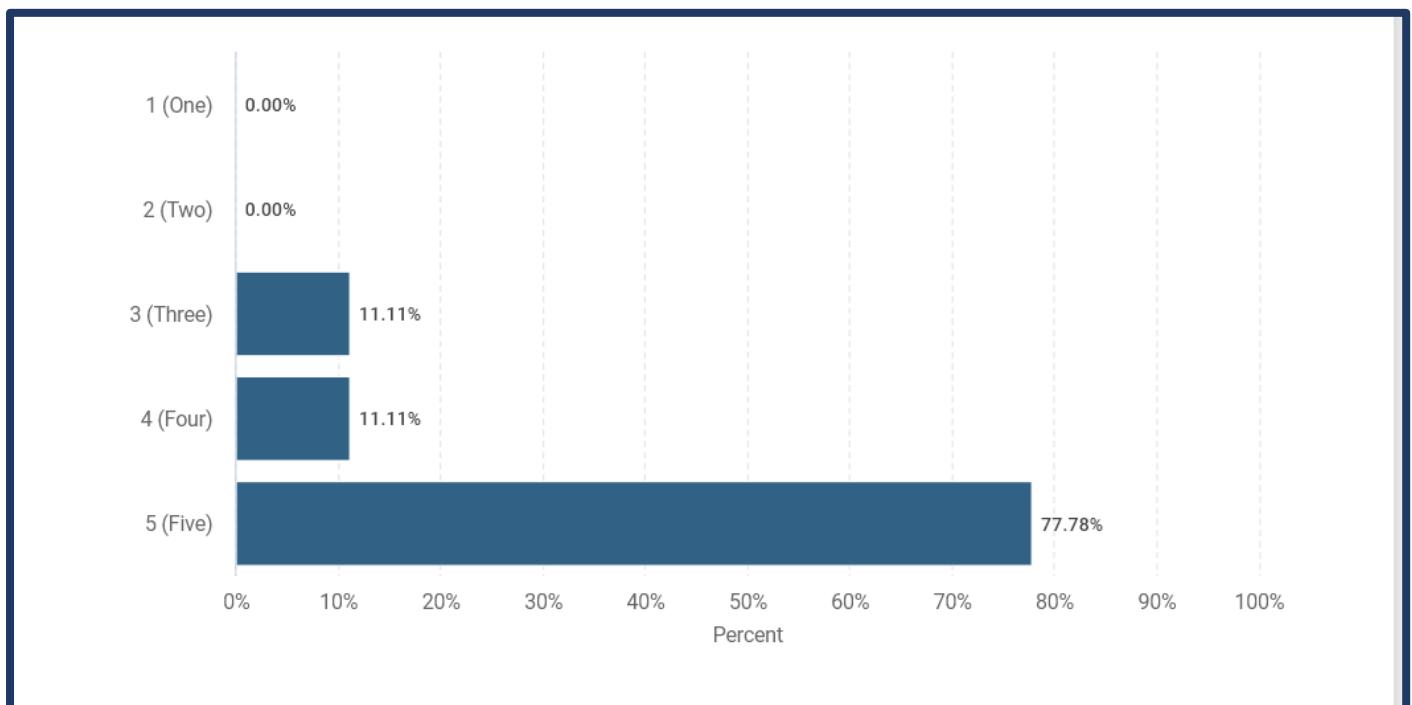


3. On a scale of 1 – 5 (1 being poor and 5 being good), please rate how helpful you found having direct contact details for the Cancer Community Support Service?

Answer Choices	Responses		
1 (One)	<div style="width: 0.00%;"> </div>	0.00%	0
2 (Two)	<div style="width: 0.00%;"> </div>	0.00%	0
3 (Three)	<div style="width: 0.00%;"> </div>	0.00%	0
4 (Four)	<div style="width: 0.00%;"> </div>	0.00%	0
5 (Five)	<div style="width: 100.00%;"> </div>	100.00%	9
Answered: 9 Skipped: 0	Response Total:		9

- This question was answered by everyone we contacted.
- All nine (**9**) people responding to this question told us that having direct contact details for the service was really helpful (**100%**).
- All responses were rated as five (**5**), good.

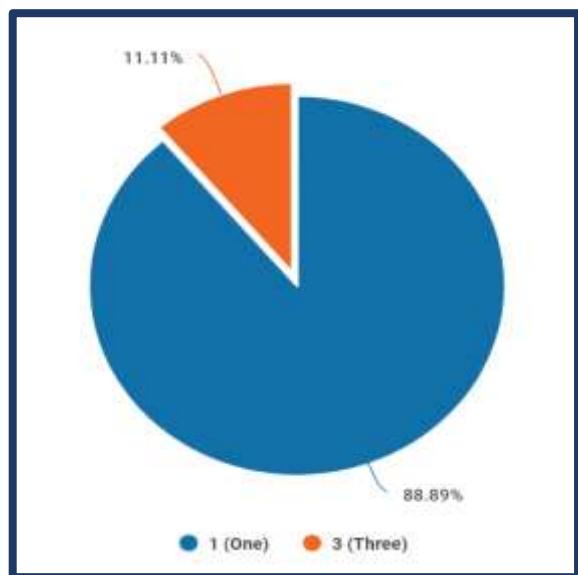
4. On a scale of 1 – 5 (1 being not important and 5 being very important), please rate how important it is for you to have support provided and be linked in to services local to where you live?



- This question was answered by everyone we contacted.
- Seven (7) people (78%) rated their response to this question as 5 (very important), one (1) rating importance as four (4) and one rated it as three (3).
- Therefore, patients and family members rated having a service available, which has links with other local services who can support further, as important.

5. On a scale of 1-5, (1 being poor and 5 being good), how comfortable did you feel to have your say and feel involved in choosing what would support your needs?

- All nine (9) people we spoke to answered this question.
- 100% of people we spoke to, shared that they had been **comfortable** having their say and **felt involved** in choosing support needs.
- All responses were rated as five (5).



6. How likely would you be to recommend the Cancer Community Support Service to others? (1 being likely, 5 being very unlikely)

- Eight (8) of the people we spoke with told us that they would be **very likely** to recommend the service to others (89%).
- One (1) person rated their response to this question as three (3).

7. Please share any feedback you have about your experience of using the cancer community support service and the support provided either directly by them or through them?

Feedback about experiences of accessing the service was provided from eight (**8**) people, one (**1**) person had to end their conversation earlier than expected.

The following word cloud shows some of the key themes which people told us about in their general feedback about their experiences. The importance of each word is shown with larger font size:

The word cloud consists of several words in varying sizes. The largest words are 'Support' (top left), 'feel' (top center), 'family' (top right), 'needed' (middle left), 'service' (middle right), 'Team' (bottom left), 'Gill' (bottom center), 'Helped' (bottom right), 'Answered' (bottom left), 'Diagnosis' (bottom center), and 'Scary' (bottom right). The size of each word indicates its relative importance in the feedback.

Support

Support is important to people. We received positive feedback about the support provided by the team working within the cancer information support service and their support in providing information or signposting onto other services which would support them.

This shows how the incorporation of Macmillan information and support centres improves access to the most appropriate support, treatment and care and improves the experience of those with a cancer diagnosis or their family members.

Below are some of the direct quotes shared with us.



"I feel at the end of my tether, muddling through. I have waited for services and feel some have paid lip service. The cancer support service have guided me through."



"They helped me to get more support in place and give me really useful bits and bobs of info which have really helped me. They are angels"



"Without the support they provided to my family, I dont think we would have got through this."



"It was good to find out about this service and that they were there to support me. It was good to know that support was there when I needed it."



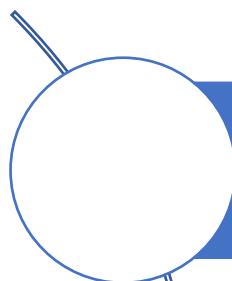
"Gill was really friendly, and knowledgeable and understood what was going on. She gave me lots of good feedback about where to go for support."



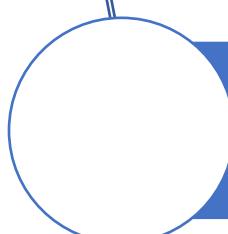
"The support I have had from the service has been out of this world, I didn't know where to start on this journey but the practical and emotional support which has been provided to date has been really helpful."

Providing support at the time of need.

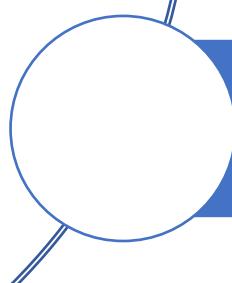
Feedback shared shows how this service and those working to support patients and their families, were able to provide support at a time when additional support was **needed**.



"It was good to find out about this service and that they were there to support me. It was just good to know that support was there when I needed it."



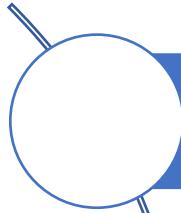
"Just knowing they were there if I needed help was just the reassurance I needed at this worrying time."



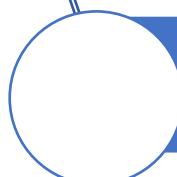
"Thank you for asking me for my views on this service. Without the support they provided to my family, I don't think we would have got through this. They were there to rely on when we really needed it."

Emotional Support

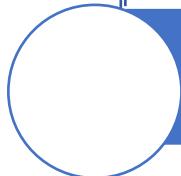
Going through cancer can be very emotional, with many ups and downs. This is often true for the person who has cancer and the people close to them. Feedback received from those we spoke to, shared their experiences of how they were **feeling** and how the service guided them, helped with their emotions and feelings and were there to listen. Two (2) people told us how they had been scared by the diagnosis.



"I feel at the end of my tether, muddling through. I have waited for services and feel some have paid lip service. The cancer support service have guided me through, but I am tired with it all."



"They were there to rely on when we really needed it, such a scary time but they made us feel safe and protected."



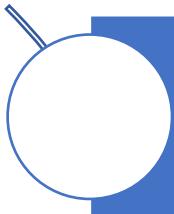
"They really encouraged me, motivating me and making sure what I asked didn't feel silly, always putting me at ease with the worries and scary moments encountered."



"They helped me so much. You feel really stuck as a carer as you want to look after the one you love whilst not getting stressed about everything and before i was supported by these lovely people, i felt as though i was sinking and my blood pressure rising. They helped me to get more support in place and give me really useful bits and bobs of info which have really helped me. They are angels."

Supporting Families.

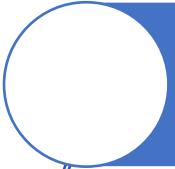
It is evident from the feedback we have received that the service provides support not just to those with a cancer diagnosis but their family members/carers, answering questions, providing encouragement, providing holistic care and support to the wider family.



"To be honest, it was good to know that there was someone on the end of the phone to listen to me, although i think at the time, i was so worried about what the diagnosis and treatment would mean to my family and the person i care for i probably wasn't making much sense. It was just good to know that support was there when i needed it."



"The encouragement to keep going when you really want to give up from Gill and the team was the key thing for me, they really helped me and my family. Just knowing they were there if i needed help was just the reassurance I needed at this worrying time."



"Without the support they provided to my family, i dont think we would have got through this. Every question I had was answered and if they didnt know something they would find out and always got back to me."



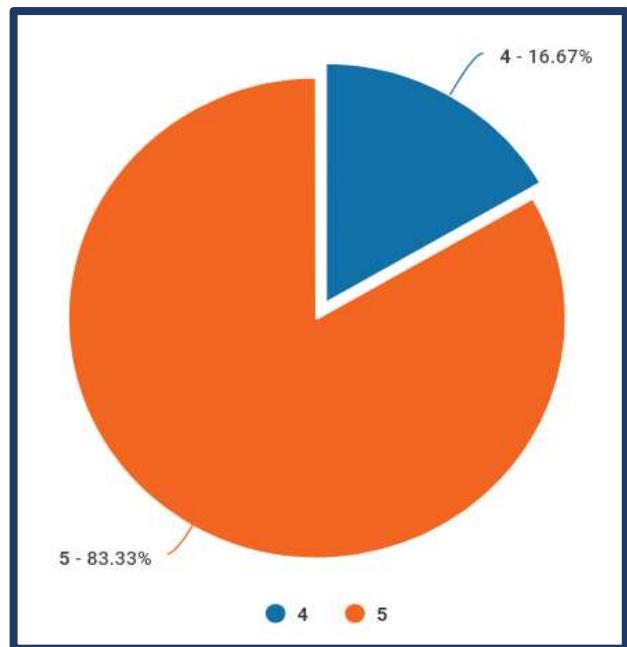
"I am so grateful for the help they have given me and the family. You should all be so proud of yourselves."

What did staff/professionals tell us about accessing the service?

This section of the report, shares the feedback for each of the questions that were asked in the online survey, which was sent out to staff/stakeholder who had previously engaged/been in contact with the service. Twenty-four (**24**) members of staff/stakeholders completed the survey online.

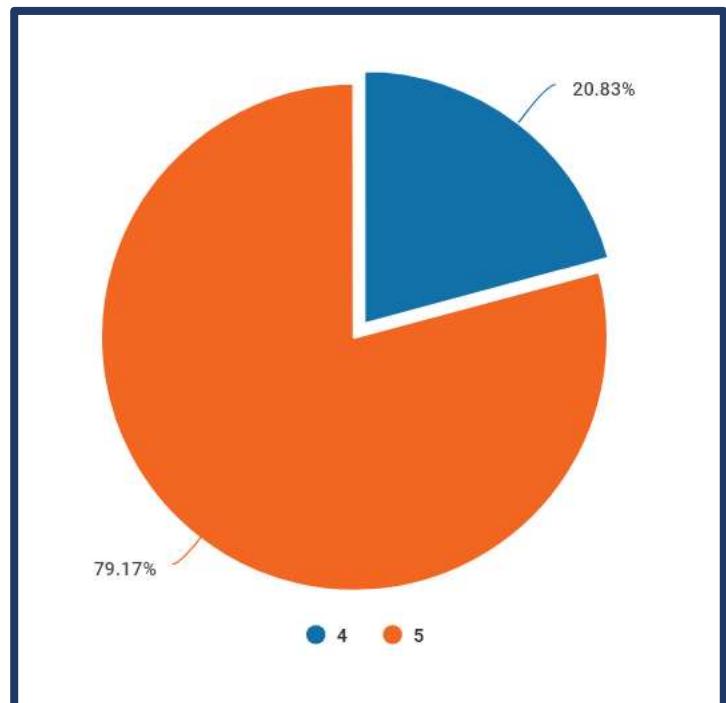
1. On a scale of 1 - 5 (1 being poor, 5 being good), how important to you is it to have access to a service which bridges the gap and integrates support and communication between secondary, primary/community care and the positive impact this can have on patient experience?

- All twenty-four (24) staff/stakeholders responded to this question.
- 83% of staff responding (**20**) rated their response as five (**5**) 'good', with 17% (**4**) rating their response as four (**4**).
- Therefore there was an overall agreement that having access to this service bridges the gap and integrates support and communication between secondary, primary and community care.

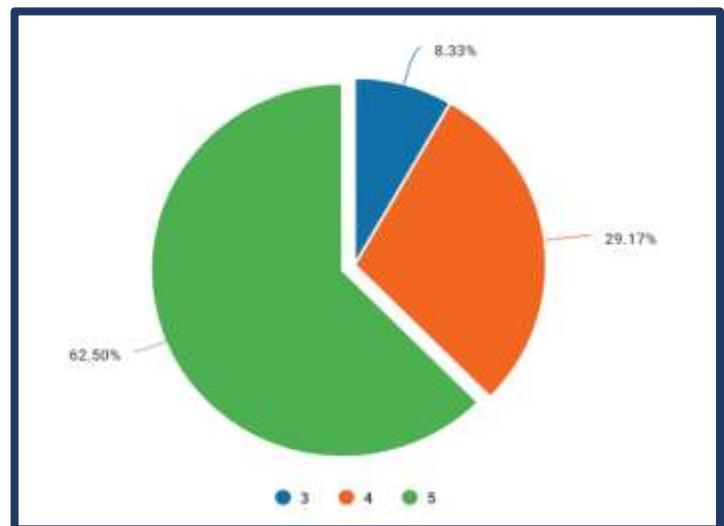


2. On a scale of 1 to 5 (1 being poor, 5 being good), how valuable to your service do you find having access to a single point of integrated cancer support?

- **79% (19)** of staff/stakeholders responding, rated having a single point of integrated cancer support as '**good**'.
- Five (**5**) staff members (**21%**) rated their response to this question as '**4**'.
- Overall, responses show that having access to a single point of integrated cancer support is valuable to staff who are in contact with the service.



3. On a scale of 1 to 5 (1 being poor and 5 being good), have the interventions provided by the service positively impacted on your area of work?

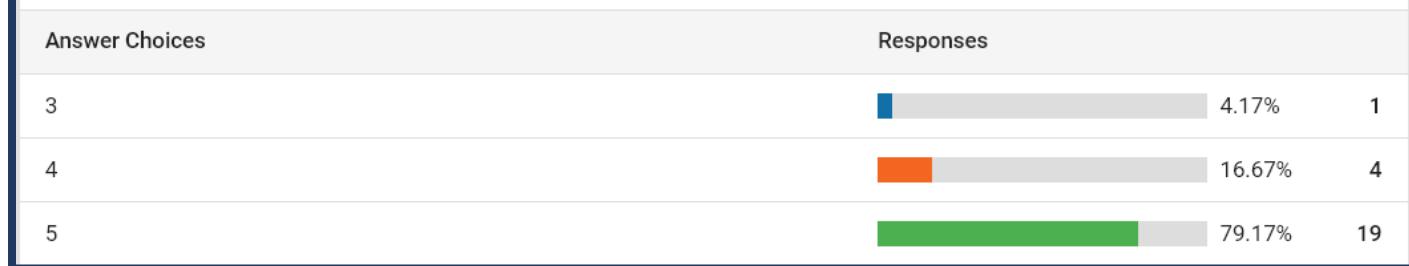
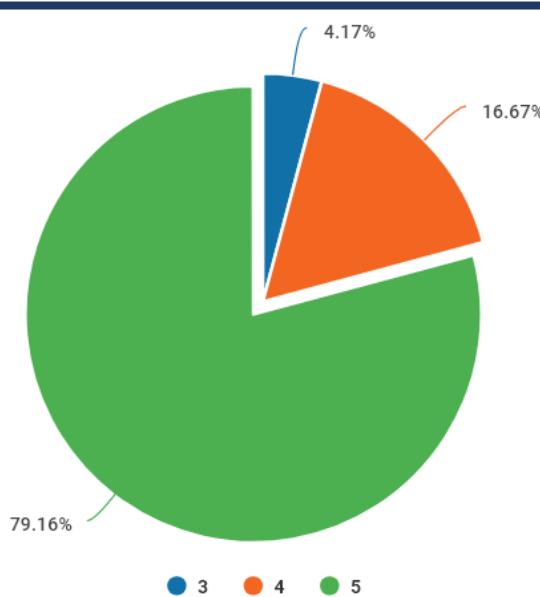


Answer Choices	Responses	
3	<div style="width: 8.33%;"></div>	8.33% 2
4	<div style="width: 29.17%;"></div>	29.17% 7
5	<div style="width: 62.50%;"></div>	62.50% 15
Answered: 24 Skipped: 0	Response Total:	24

- As you can see from the results above, fifteen (15) of the 24 responses (63%) rated their response as five (5) 'good', with seven (7) people (29%) rating their response as four (4). Two (2) people (8%) rated their response as three (3).
- The responses indicate that having contact/support from this service has positively impacted on their own work areas.

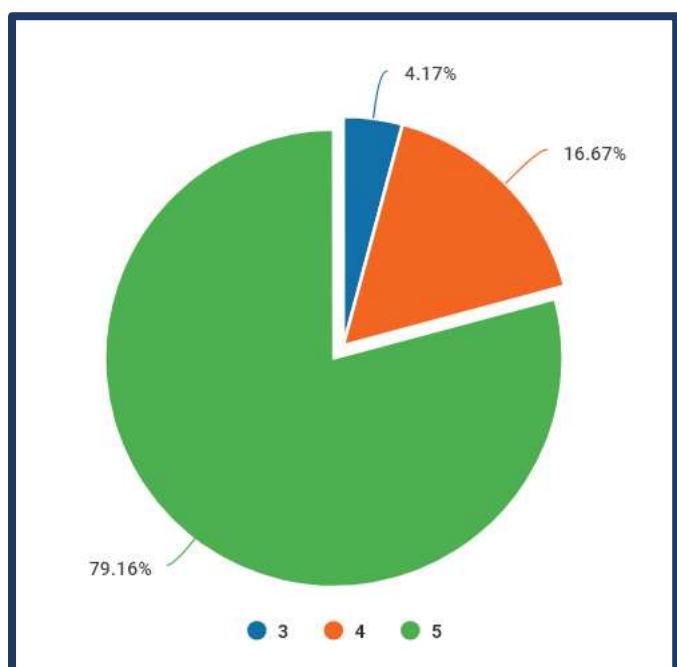
One member of staff/ stakeholder told us that their own service support offer has expanded with them recruiting an early diagnosis navigator who works from the Aintree Hospital site. This navigator accesses the community cancer support service for guidance and support on a regular basis.

4. On a scale of 1 to 5 (1 being poor and 5 being good), how essential is it to have the cancer community support service (CCSS) that can provide additional personalised support locally, close to where a patient lives, in order to respond to their identified unmet needs?



- Nineteen (19) staff members/stakeholders (79%), rated their response as five (5) 'good', 4 rating their response as four (4) (17%) and one (1) person rated their response as three (3), (4%). As you can see from the above pie chart, the responses show that staff think it's essential to have the cancer community support service in place, which provides local personalised support, close to where a patient lives. This ensures that they can respond to their patients identified unmet needs.
- One member of staff/stakeholder told us that patients will often engage where support is local. This can often be at various times of their treatment. As we are a regional unit we rely on community-based support services to link patient in to community initiatives and services.

5. How do you rate your overall experience of the cancer community support service on a scale of 1 to 5 (1 being poor and 5 being good)?



- All 24 staff/stakeholders responded to this question.
 - 79% nineteen (19) people rated their response to this question as 'good'.
- 17%, four (4) people rated their response as 'four', with one (1) person indicating their rating as '3'.
- Staff/stakeholders report a positive experience of being in contact/utilising the support of the service.

6. Does the integrated approach of the cancer community support service improve or enhance your offer of support to your patients? Briefly explain your reasons why.

We received information from all twenty-four (24) staff/ stakeholders.

Below are the key themes which featured within the feedback received, along with some direct quotes from those responding. In analysing the sentiment of the responses, this can be broken down as follows:



From reviewing the feedback, it was evident that the integrated approach has been able to enhance relationships, referral pathways and **strengthen partnerships**. There is particular evidence that the 'cancer community support service' and 'community cancer navigators' across south Sefton, built a strong working partnership which meant that patients could access the support of the navigators during the time that many of the clinical nurse specialists (CNS) were deployed to work on the Covid wards.

"One of the main reasons why the integrated approach provided by the service improves or enhances support to patients, is the support provided by the team."

"The referral process from the CCC to our service is very efficient and the quality of referrals are excellent."

"There are so many benefits to this service including building better working relationships between hospitals and support services which can only benefit patients and their families."



It is evident from the feedback that the service is **responsive** and **helpful** to those staff and professionals who engage with the service and provides a **holistic** service to patients and their family members. The service provides up to date information, and provides interventions which have positive impacts.

“The CCSS provide up to date and relevant information on other cancer and none cancer related community services for the benefit of all patients. The CCC are in regular contact and easy to access.”

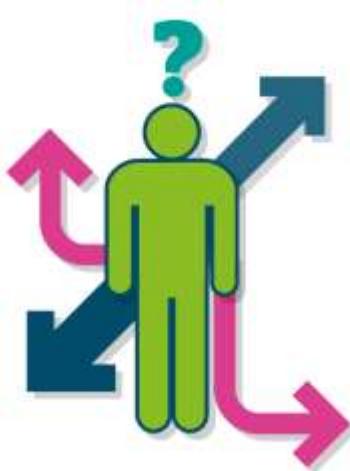
“Yes its really helpful for a patient during their pathway to have cancer community support, its a point of contact that act holistically and can sign post to the relevant services”

“Gill and Jo are so helpful, approachable and supportive not just to patients but have been to me too and its just so re-assuring to have this service in place.”

“Just knowing about this service and having a single point of access makes all the difference. The team are great, and when I have personally had to be in touch with them, they have been so helpful and supportive. They really do make a difference and I know from my experience that patients I have supported have really valued the warmth, the information and support which has been provided.”

“We have examples of interventions which have had positive impacts for our patients when this service has been able to support us. The single point of access is extremely beneficial and works really well. It makes all the difference when the staff are so friendly, approachable and knowledgeable.”

“During Covid, the service was in valuable although i now have less contact with the service. However on the occasions I have liaised the input has been very worthwhile and much more timely for patients.”



Feedback showed evidence of staff engaging with the service, **utilising** the **knowledge** of the team and its connection to Macmillan cancer support to learn about those non-medical issues which affect patients and their families and as part of the service offer provide opportunities for peer support.

"They have provided the opportunity for and facilitated the meetings of the community cancer support teams from across Liverpool and Merseyside which has supported joined up working and peer support as well as a good community of practice."

"The cancer community support service bridges the gap between medical and our non medical services , helping patients feel supported in every aspect of their cancer journey, addressing any concerns after a cancer diagnosis .This is turn helps reduce the non-medical worries a patient might have when they have had a diagnosis of cancer, helping them concentrate on their cancer journey rather than other life / practical concerns."

"Yes its really helpful for a patient during their pathway to have cancer community support, its a point of contact that act holistically and can sign post to the relevant services."

"They are able to provide additional resources and support that is not available within our service by strengthening all aspects of community care."

"If the Macmillan Cancer Community Support Service had not been in place at this time, many people with a cancer would have not been given the support to access the Navigator Service, which provides vital support such as delivery of food parcels, help to access benefits and grants and emotional support."



The integrated approach has **enhanced care pathways** with **community** and **primary care** providers, feedback shared providing evidence that there have been **improvements** in communication, continuity of care, and preventing patients to slip through the net. The Macmillan cancer community support service also provided a crucial link between the hospital and community cancer teams in Cheshire and Merseyside to ensure that clinical information was available for patients and that the hospital teams were aware of the ongoing support being provided by cancer navigators for their patients. The Macmillan cancer community support service also helped liaise with GPs and primary Care teams to ensure the best outcomes for patients being supported by the Navigators.

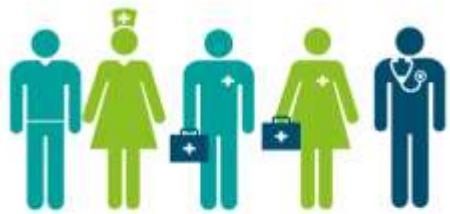
"They are able to provide additional resources and support that is not available within our service by strengthening all aspects of community care."

"The integrated approach of the CCSS team has vastly improved communications between primary care networks, GP practices and LUFHT. This has really enhanced the support offered to patients being able to explore queries and resources via the CCSS team who are always prompt and concise with responding to requests. A great quality improvement to patients."

"The integrated approach enhances our support to patients by providing a timely response to a patient enquiry, particularly when the enquiry is regarding fast-tracking a patient's benefits claims. Patients benefit from having continuity of care by our services working integrated."

"The integrated approach of the Cancer Community Support Services is an integral part of linking the services available for Cancer patients in secondary, primary and community care, without this service patients wouldn't know what support is available to them and could quite often slip through the net."

"The CCSS service is a vital connection bridging a gap between primary and secondary care."



Feedback on **improved communication** and **co-ordination** between services and the workforce was shared.

"CCSS at Aintree hospital is a valuable link between the acute setting, Clinical Nurse Specialist Teams and the Community Cancer Navigators in south Sefton. Without this service, there would be a gap in communication between the hospital cancer services and the community cancer support services."

"There have been occasions when we have had trouble engaging people to attend their appointments and haven't necessarily taken the time to understand the barriers but this service has been an intermediary in supporting both patients and us to ensure treatment has been offered in the best way."



There is evidence that the integrated approach has **improved staff knowledge** on how to **refer** and **navigate services** so that the most **appropriate care** is accessed for their patients.

"Jo and Gill always respond to requests for information and support which has expedited care and support for many people affected by cancer in south Sefton."

"Up until recently; following the merger of LUHFT I was a lone worker on the Aintree site. My support and guidance from the CCSS was, and still is invaluable to both myself and my patients."

"It definitely helps me support our patients better, knowing when I reach the point of not being able to advise or support further, that I have a team who can provide the additional support, and hopefully further link in for ongoing help."



Feedback shared how the integrated approach provides much needed **practical support** to other members of staff to ensure **timely support**, including **non-medical support and interventions**.

"My God yes! There have been times when they have been able to support our service to ensure that our offer supports both the patient and their Carer/Family members to actually understand the impact a treatment plan will have, and i mean those issues which we sometimes forget, how they will get to their appointments, can they afford it, what impact will this have on families etc and also the emotional support. Having the connections with wider Macmillan support those broader aspects. Having the team in place and knowing that there is a single point of access has been so useful. I know the service was really useful during the pandemic and this really needs to be a long term sustainable service."

"Certainly, this service is much needed and i know it is used by many. Having the integration with Macmillan too just helps with those issues which patients and families have and supports them to access the support they need. I know from infromation provided to patients and families this has helped them immensly."

"Yes its really helpful for a patient during their pathway to have cancer community support, its a point of contact that act holistically and can sign post to the relevant services."

"The integrated approach enhances our support to patients by providing a timely response to a patient Inquiry, particularly when the enquiry is regarding fast-tracking a patient's benefits claims."

"The cancer community support service bridges the gap between medical and our non-medical services, helping patients feel supposed in every aspect of their cancer journey, addressing any concerns after a cancer diagnosis .This is turn helps reduce the non-medical worries a patient might have."

"This service enables patients to be fully supported physically, practically, emotionally and financially. A Cancer Diagnosis is hard enough to deal with without all the other concerns it brings like other health problems, the impact it has on family members, mental health concerns and financial problems to name a few, the integrated approach the Cancer Community Support Service provides helps patients navigate through their cancer journey and beyond.

"I believe this support service is absolutely vital to both patients and services providing support in the community to people with cancer. I have seen first hand on many occasions how much quicker it is to get answers for patients instead of having to go round the houses and waiting often days for responses, this is incredibly difficult for patients and adds significantly to the stress, worry and anxiety that patients and their families are already experiencing. It is also very frustrating and time consuming for services trying to support people in the community."

7. Please share any suggestions you may have that could improve or enhance the cancer community support service.

Nineteen (19) staff members/stakeholders completed this question, sharing their suggestions on how the service could be improved/enhanced. In reviewing the feedback, the following areas were raised for the cancer community support service to look at, as possible areas of service improvement.

Promotion of the service offer/ educating the workforce.

The following suggestions were made to ensure that staff fully utilise the service:

- Training/update sessions to be held to inform staff of services available for patients in the community and what support is available.
- The sessions which are held could include more clarity about referral pathways for other services which may be useful to patients and families.
- Case studies could be developed and circulated to support staff to understand how the service works with patients and their families and the benefits working in partnership with the cancer support service can bring to the workforce.

Improvements in communication/ co-ordinated approach.

The following suggestions were made to ensure there are opportunities for regular dialogue/communication across teams and so that staff working within the cancer support service have stronger relationships with the wider workforce:

- Suggestion that quarterly integrated team meetings could be held between staff working in the cancer support service and other services in and around LUHFT so that everyone can be kept up to date on service developments and issues. Meetings which had previously been in place were described as informative and staff would like to see them re-instated.
- It appears from feedback that the Macmillan cancer support service had previously arranged for regional peer support sessions to take place during 2012/2022, which linked community cancer navigators and cancer support workers across Knowsley, Liverpool and Sefton. The teams had found the sessions beneficial in sharing information and supporting cohesion between the teams and would benefit from them starting up again.
- Annual team building session could be funded so that teams can meet with the cancer community support service team, and this would help to build stronger relationships and for some, put a face to an email/telephone call.
- Revisit the relationship with the community cancer navigator service in Sefton (and similar services) to ensure appropriate referrals into this care pathway. (From the end of 2022 and throughout 2023, there had been reduced contact from the Macmillan cancer community support service, the number of referrals received seeing a significant decline.)

Promotion with primary care/ community services.

The following suggestions were made to consider how to broaden the service offer and engage with primary care and community services, acknowledging that this work may generate additional pressures for the service and the team and this would need to be considered:

- Promote the service with GP practices as they are increasingly employing care co-ordinators and sometimes dedicated cancer care co-ordinators to help support patients and it would be great to promote the service offer within general practice.
- Build relationships with primary care networks (PCNs) to ensure they know more about the service and its offer.
- There was a suggestion that communication between community and hospital teams could be improved but there were no suggestions on how this could be achieved.
- The community cancer navigator service in Sefton would be keen to have more contact from the support service. In addition, they would value support from the service to facilitate navigators having a presence in acute settings within appropriate clinics with clinical nurse specialist teams. The team feels that the Macmillan cancer community support service plays an important role in the link between the acute trust and the patient and supporting teams in the community.

Expansion of the service/ extension of funding.

There were a number of comments/ suggestions with the main suggestion being that plans need to be in place to ensure the longevity of the service. It was largely agreed that the service should be valued by being an embedded partner service within the NHS which is appropriately funded. It was noted that when speaking with colleagues in other areas, staff they spoke to had been envious about the service and how it supports locally. There was one specific suggestion and this is shared below:

- It would be good to have a service like this at Clatterbridge hospital and other hospitals that patients are likely to use, particularly now that we have Mersey and West Lancashire Teaching Hospitals NHS Trust as one of our local NHS Partners.

Q8. Please share any additional comments you may have about the service.

This was the last question included in the survey for staff/stakeholders and thirteen (13) responses were provided. This question was optional. In analysing the sentiment of the responses, this can be broken down as follows:



We have included all of the responses to this question as they provide evidence of the value placed on the service and the staff working in the team and demonstrate how the service has strengthened partnerships and communication. It is also evident from the feedback that staff have valued having access to information from the service which has improved knowledge of non-medical pathways. There is one comment about how the service doesn't cover the full catchment area for one of the organisations/services and this links to one of the suggestions earlier within this report that it would be beneficial for the service to be expanded so more patients and their family members benefit from their expertise.

“From my experience, it’s just a really good service to be able to access and knowing that the team are there has been extremely useful in my role. They have also helped me to understand certain aspects of the Cancer pathway/treatment and the wider social issues and how patients have access to wider offers of support.”

“Only to say, its great having the support from this service and i hope this evaluation goes well as it’s a much needed service.”

“Interactions with the service have been good, great friendly staff.”

“It is just fab and has made such a difference to patients, their families and services that support them.”

"The CCSS team are always pleasant and helpful, providing prompt information on request."

"I feel they have been a great asset, and they have been so invaluable to me in supporting my patients. They are also great for being on the end of the phone for advice, support and guidance for me as well as they patients."

"Thank you so much for your ongoing support :)."

"Gill is very supportive and approachable and response promptly to all requests and is complete in her all aspects of community care she is engaged in."

"The CCSS team are very helpful and prompt when responding to requests."

"The service we have at LUHFT is amazing, they have enhanced the care of patients, they are always there for a listening ear and also offer to help problem solve when patients have a difficult pathway. Thank you, Gill and Jo, for all your hard work."

"Excellent Service. The service and support from Gill and Jo is always very reliable and professional. This service enables us to provide holistic support to the patients we support."

"Very helpful when contacted, but this service doesn't cover our catchment area, so the support this service can offer is limited due to the large geographical area that we cover."

"Cancer community support is important in helping identify patients that may need non-medical support such as help applying for benefits, wellbeing or transport etc. CAL and cancer community support work together in the best interest of those who have had a cancer diagnosis, communicating to ensure they receive wrap around care- medical and non-medical."

Summary of the feedback we gathered.

During 2023, Healthwatch Sefton was commissioned by Macmillan cancer support to independently evaluate the Macmillan Liverpool University Hospitals Foundation Trust (LUHFT) Cancer Community Support Service (CCSS).

The qualitative feedback has allowed the evaluation to ask questions that cannot be easily put into numbers in a way that we can understand the human experience that individuals have had when accessing the CCSS. It is these experiences that should be used to inform future service design.

This report details the findings from our telephone interviews with nine **(9)** patients and family members who have accessed the service for support and responses to an online survey from twenty-four **(24)** members of staff/stakeholders who have previously engaged with the service. Despite the sample size being relatively small, the richness of the experiences and feedback provided from the open-ended questions has provided the opportunity to gain a real insight into the service offer and its impact.

This independent report shares key themes and issues from feedback provided to us by patients and their family members and staff/stakeholders who have previously engaged with the Macmillan cancer community support service.

In reviewing the feedback, this report demonstrates the value placed on the service by those it supports and engages with, with particular emphasis on the non-medical support and information that is provided alongside the support to navigate care pathways which is provided through this partnership work between Macmillan cancer support and Liverpool University Hospitals NHS Foundation Trust.

Patients and family members told us that they valued the support provided by the service, particularly timeliness of the support, as prior to being put in touch with/finding out about the service, they had often been struggling to cope/ didn't know who they could turn to. The emotional support provided by the team was also found to be a vital role which the service provides.

Staff and stakeholders told us the service bridges gaps and improves communication and co-ordination. There is value in having this single point of integrated cancer support, the service being perceived as being responsive and helpful, providing holistic support. Positive impacts on both staff/stakeholder's experience and patient experience were noted, with the provision of localised knowledge and being able to utilise this, providing additionality.

Feedback shared, demonstrates not only the quality of support provided by having this partnership/service in place but the qualities of the staff team, which as you can read within the report ensure the service has the current standing it has in the experiences of those using/accessing the service.

The responses provided by staff/stakeholders to question 7, which can be found within this report on pages 26 – 28, share suggestions and recommendations on how the service could improve. Recommendations for consideration have been grouped under the following headings and should be considered as ways to enhance the service offer:

- Promotion of the service/educating the workforce
- Improvements in communication/co-ordinated approach
- Promotion with primary care and community services
- Expansion of the service/ extension of funding.

Who we would like to thank

We would like to thank a number of people and organisation's for supporting us to undertake this independent evaluation of the service.

Firstly, and most importantly we would like to thank the people we spoke to, both patients and family members for agreeing to be part of this evaluation and for taking the time to engage with us and for your honest feedback about the support you have received from the service.

We would also like to thank those staff/ stakeholders who agreed to take part in the evaluation by completing an online survey and again for your honestly and suggestions in how the service can enhance its offer.

Special thanks to Joanne Kinsey, Gill Nolan and Rebecca Sedgwick for engaging with us at Healthwatch Sefton to lead on this independent evaluation of the service. Thank you for the support provided to get everything in place ready prior to the launch date, and for the meetings held to support us in our understanding of the service.

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Appendix 1: Online survey for staff/stakeholders.

LUHFT Cancer Community Support Service Evaluation - Feedback from organisations and staff

Background

Healthwatch Sefton is independently evaluating the Cancer Community Support Service (CCSS) based with Liverpool University Hospitals NHS Foundation Trust.

As a previous user of the service, we would be extremely grateful if you could spare a few minutes of your time to help with this evaluation by completing this short survey.

The aim of the evaluation is to inform a sustainable model of integrated personalised care, incorporating Macmillan Information centres, Primary and Community services

1. On a scale of 1 - 5 (1 being poor, 5 being good), how important to you is it to have access to a service which bridges the gap and integrates support and communication between secondary, primary/community care and the positive impact this can have on patient experience? *

- 1
- 2
- 3
- 4
- 5

2. On a scale of 1 to 5 (1 being poor, 5 being good), how valuable to your service do you find having access to a single point of integrated cancer support? *

- 1
- 2
- 3
- 4
- 5

3. On a scale of 1 to 5 (1 being poor and 5 being good), have the interventions provided by the service positively impacted on your area of work?

- 1
- 2
- 3
- 4
- 5

4. On a scale of 1 to 5 (1 being poor and 5 being good), how essential is it to have the Cancer Community Support Service (CCSS) that can provide additional personalised support locally, close to where a patient lives, in order to respond to their identified unmet needs? *

- 1
- 2
- 3
- 4
- 5

5. How do you rate your overall experience of the Cancer Community Support Service on a scale of 1 to 5 (1 being poor and 5 being good)? *

- 1
- 2
- 3
- 4
- 5

Does the integrated approach of the Cancer Community Support Service improve or enhance your offer of support to your patients? Briefly explain your reasons why? *

Please share any suggestions you may have that could improve or enhance the Cancer Community Support Service.

6. Please share any additional comments you may have about the service.

Appendix 2: Script and questions for patients and family members.

Liverpool University Hospitals NHS Foundation Trust. Cancer Community Support Service Evaluation. Questionnaire for Patients, Family Members and Carers.

Healthwatch Sefton has been commissioned to independently evaluate the Cancer Community Support Service (CCSS) based with Liverpool University Hospitals NHS Foundation Trust. Healthwatch Sefton is an independent health and social care champion. We have the power to make sure NHS leaders and other decision makers listen to your feedback and improve standards of care. We also help people to find reliable and trustworthy information and advice.

You may have been contacted by Gill or Jo to gain your consent for us to speak with you about how you or a family member have been supported by the service.

Gill and Jo who run the Cancer Community Support Service at Liverpool University Hospitals NHS Foundation Trust, have helped you with your care or helped a family member recently. They have asked us to get in touch to gather some information about your experience of their support.

We would be extremely grateful if you could spare a few minutes of your time to help with this evaluation by completing this short survey.

1. Did having access to the Cancer Community Support service and the help they provided improve your experience?

- Yes
- No

2. On a scale of 1 – 5 (1 being poor and 5 being good), please rate how satisfied you were that your unmet needs were supported by the Cancer Community Support Service?

- 1 (One)
- 2 (Two)
- 3 (Three)
- 4 (Four)
- 5 (Five)

3. On a scale of 1 – 5 (1 being poor and 5 being good), please rate how helpful you found having direct contact details for the Cancer Community Support Service?

- 1 (One)
- 2 (Two)
- 3 (Three)
- 4 (Four)
- 5 (Five)

4. On a scale of 1 – 5 (1 being not important and 5 being very important), please rate how important it is for you to have support provided and be linked in to services local to where you live?

- 1 (One)
- 2 (Two)
- 3 (Three)
- 4 (Four)
- 5 (Five)

5. On a scale of 1-5, how comfortable did you feel to have your say and feel involved in choosing what would support your needs?

- 1 (One)
- 2 (Two)
- 3 (Three)
- 4 (Four)
- 5 (Five)

6. How likely would you be to recommend the Cancer Community Support Service to others (1 being likely, 5 being very unlikely)

- 1 (One)
- 2 (Two)
- 3 (Three)
- 4 (Four)
- 5 (Five)

7. Please share any feedback you have about your experience of using the Cancer Community Support Service and the support provided either directly by them or through them?

8. How would you rate your overall experience of the Cancer Community Support Service? (5 being good and 1 being not good)

- 1 (One)
- 2 (Two)
- 3 (Three)
- 4 (Four)
- 5 (Five)