



An independent review of the Sefton Macmillan Right By You Service

December 2020.

Contents

| | |
|--|----|
| Overview of the Sefton Macmillan Right By You Service..... | 3 |
| Healthwatch Sefton. | 5 |
| What we did. | 5 |
| What did clients tell us? | 7 |
| Summary of the feedback we gathered..... | 17 |
| Lets again look at some of the key highlights.... | 19 |
| Thank you..... | 19 |



Overview of the Sefton Macmillan Right By You Service.

The Sefton Macmillan Right By You Project started on 1st December 2019 following on from the south Sefton Macmillan e-HNA Pilot project which had been in place for 2 years. The Sefton Macmillan Right By You Project was designed to support anyone across the whole of Sefton who is living with or affected by Cancer. This involved a working partnership between Sefton CVS and the Southport and Formby Macmillan Information Centre, with Navigators based in the north and south of Sefton.

In total 490 people were referred into the Sefton Macmillan Right By You Project between 1st December 2019 and 30th November 2020. Support from the Navigators also extended to the families and carers of those patients referred into the service. Referrals have been made through the Clinical Nurse Specialists (CNS) and the Virtual Wellbeing Team Lead Nurse at Aintree Liverpool University Hospital NHS Foundation Trust, CNS's at Southport and Ormskirk Hospital, GPs in north Sefton, through Sefton CVS Signposting Service and through self referral.

The objective of the Right by You Project is to provide holistic support to people in the community living with or affected by cancer. This includes:

- Increase awareness of support services available for people and families affected by cancer
- Help to access clinical support
- To give people living with or affected by cancer a voice to raise concerns and have their say
- To support people living with or affected by cancer to be as independent as possible
- Help people living with or affected by cancer to identify concerns or needs through a Holistic Needs Assessment (HNA) and support them to meet those needs.
- To support people to reduce worries, concerns and emotional support to help reduce the likelihood of crisis

The Macmillan Community Navigators provide holistic support for people living with and beyond cancer. The Navigators can assist patients to access services within the hospital including liaising with the clinical nurse specialists and/or the lead nurse in the Virtual Wellbeing Cancer Service. This can provide a faster pathway for the patient to access clinical information and/or support.

Navigators provide support to identify concerns or needs which are recorded in a holistic needs assessment (HNA) and care plan which is provided to the patient and the nurse specialist. The Navigators provide a range of signposting and support with onward referrals as well as providing support in areas including:

Physical – i.e. clinical concerns are fed back to clinical staff to contact the patient or information sheets can be sent to the patient.

Practical – i.e. support to help arrange transport to attend treatments, provide information on shopping services.

Emotional - i.e. Provide a listening ear; refer to counselling, clinical psychology or Macmillan Hope courses.

Financial - i.e. support to access benefits or Macmillan Grants.



Healthwatch Sefton.

Established following the Health and Social Care Act 2012, Healthwatch Sefton, set up in April 2013, has built up both local and national recognition as an organisation which independently engages with local people.

Everything we say and do as an organisation is informed by our connections to local people. Our main aim is to understand the feedback and concerns of people of all ages who use services, and to speak out on their behalf.

Our role is to ensure that local decision makers and health and social care services put the experiences of local people at the heart of their work. We believe that asking people more about their experiences and encouraging them to feedback can identify issues that, if addressed, will make services better.

Healthwatch Sefton is set up as a private company limited by guarantee, a subsidiary company of Sefton Council for Voluntary Service (Sefton CVS). There is a small staff team and a large team of volunteers who work together to ensure the organisation works towards its priorities.

We are uniquely placed, as we have a national body, Healthwatch England. Both organisations have significant statutory powers to ensure that 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 social care services.

Healthwatch Sefton works with Healthwatch England to ensure the voice of Sefton residents is represented at national level. Healthwatch England picks up national issues and works with Healthwatch Sefton to help provide a national picture. We also work as part of a Cheshire & Merseyside and a regional North West Healthwatch network.

Healthwatch Sefton was commissioned by Sefton Council for Voluntary Services (Sefton CVS) to undertake an independent evaluation of this service in November 2020.

What we did.

Developing the survey.

To start the process, we worked closely with the coordinator of the project to review the scope of the work, agree the outcomes and outputs and timescales.

Draft survey questions were developed by Healthwatch Sefton and through input from the Right by You staff team, questions were reviewed and adapted to ensure that the survey would gather feedback that would provide both quantitative and qualitative information which would show how those referred into the service had found the support provided.

The final survey was based on the following:

- a) There were four star rated questions, asking participants to rate; communication, information, support and experience using a star rating (1 being poor and 5 being excellent).
- b) Three open ended questions related to the service and how Macmillan Community navigators listened, understood and acted.
- c) There were a further two questions relating to how the service worked with their clients and how client independence was developed and maintained
- d) A matrix based on 5 statements was used to understand how the service focussed on the person and not the symptoms.

The survey questions were developed to support telephone conversations with each participant and Dawn Thomas from Healthwatch Sefton led on this. Dawn is the Signposting and Information Officer for Healthwatch.

Who we spoke to

The Macmillan Right by You service gained consent by asking participants if they consented to their name and contact number being shared with Healthwatch Sefton (an independent organisation). Participants were informed that Healthwatch Sefton would contact them by phone in order to complete a survey about the support they had received from the service.

Participants were told that the information they shared with Healthwatch Sefton would be included within an evaluation report they would be writing and would be anonymous. Individual quotes would be used within the report to highlight key themes but they would not be identifiable.

We received **24** consent forms from the Macmillan 'Right by You' service. Six Macmillan 'Right by You' navigators had been able to gain consent from their caseloads and therefore this is a good sample of participants who have received support from different individuals.

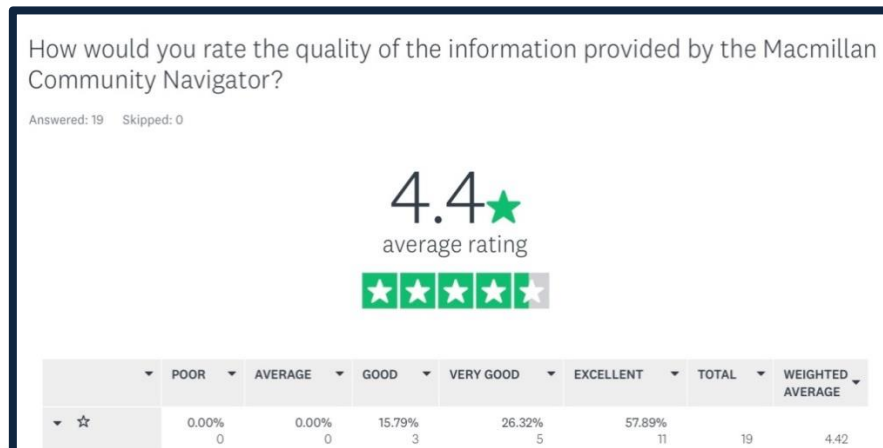
We were only able to engage with **19** of the **24** participants who had provided consent. **2** of those participants who had originally shared their consent, declined to engage when contacted. The additional **3** were unable to take the calls made and did not respond to messages left.

The people who took part all live in the borough of Sefton and were aged between 35 and 105. We spoke to a mix of people living with cancer and carers/family members supporting a person with cancer.

What did clients tell us?

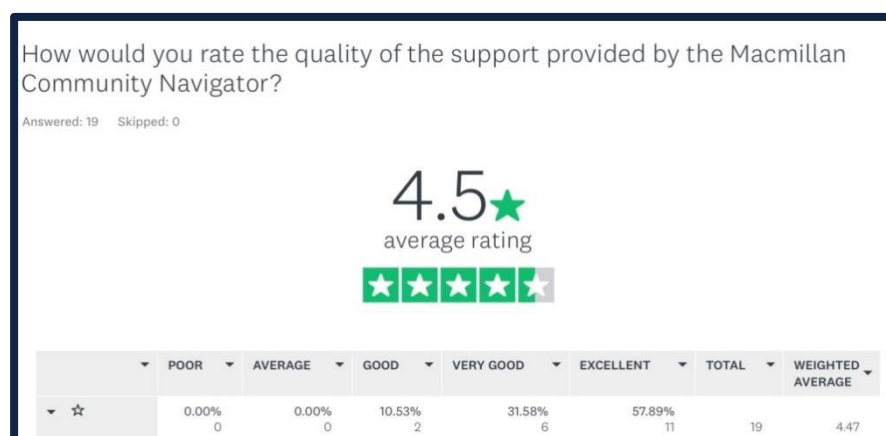
This section shares the feedback for each of the questions that were asked within the telephone survey and includes examples of feedback which was shared.

1. How would you rate the quality of the information provided by the Macmillan Community Navigator?



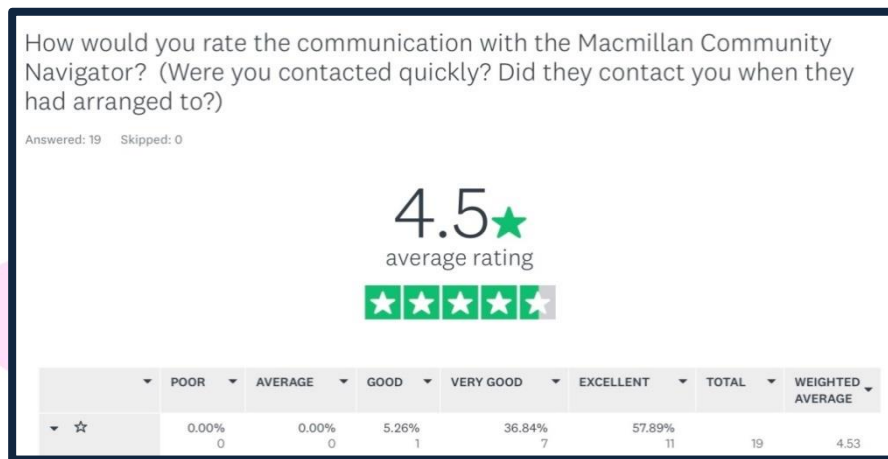
- All **19** clients responded to this question and as you can see, the quality of information provided by navigators was viewed as an average rating of **4.4**.
- **11** of the **19** clients rated the quality of information as **excellent (58%)**, with **5** rating information as **very good (26%)** and **3** rating is as **good (16%)**.
- **No** clients rated the quality of information as average or poor.

2. How would you rate the quality of the support provided by the Macmillan Community Navigator?



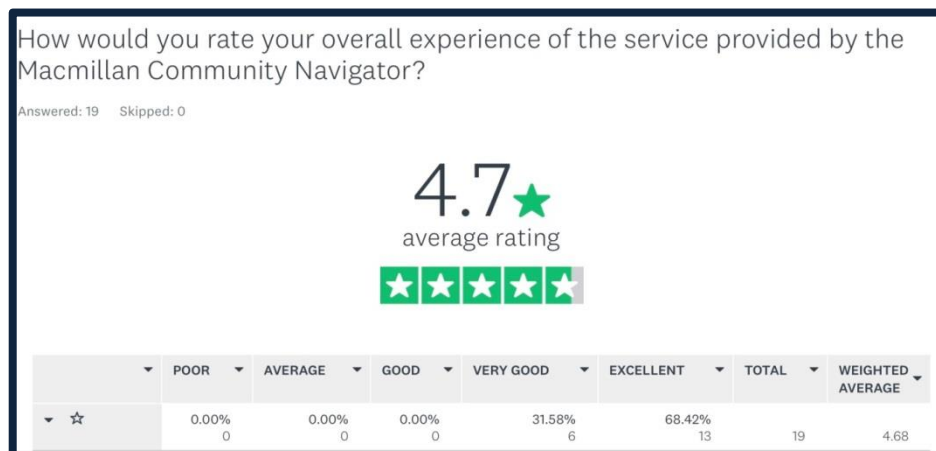
- All **19** clients responded to this question and as you can see, the quality of the support provided by navigators was viewed as an average rating of **4.5**.
- **11** of the **19** clients rated the quality of the support received as **excellent (58%)**, with **6** sharing that the quality of support was **very good (32%)**. **2** clients rated the support they had received as **good (10%)**.
- **No** clients rated the quality of support as average or poor.

3. How would you rate the **communication** with the Macmillan Community Navigator?



- All **19** clients responded to this question and as you can see, the quality of the support provided by navigators was viewed as an average rating of **4.5**.
- **11** of the **19** clients rated the quality of the support received as **excellent (58%)**, with **7** sharing that the quality of support was **very good (37%)**. **1** client rated the support they had received as **good (5%)**.
- **No** clients rated the quality of support as average or poor.

4. How would you rate your **overall experience** of the service provided by the Macmillan Community navigator?



- All **19** clients responded to this question and as you can see, the rating for overall experience was viewed as an average rating of **4.7**.
- **Overall experience was rated as excellent/ very good.**
- **13** of the **19** clients rated their overall experience as **excellent (68%)**, with **6** sharing that the quality of support was **very good (32%)**.
- **No** clients rated the quality of support as average or poor.

5. **Have you felt comfortable to have your say and felt involved in choosing what will support your needs? If so, how?** (i.e. was the Navigator easy to talk to? Did they listen? Did they give you confidence that they could help?)

- All **19** clients responded to this question.
- **100%** of clients who we spoke to shared that they **had felt comfortable** in having their say and felt involved in discussing their support needs.
- Clients shared their feedback about how navigators took the time to **listen**:

We were told about how helpful and caring navigators were. **One** client shared how one navigator had gone the extra mile to support them:

"She was very easy to talk to. She was amazing. She always checked in when she said she would, it helped to keep me going. She really cared and listened to everything I said. She even kept things in mind even after I had not needed that support. I care for my mother who is 105 and my heating went off, I had fan heaters but they were not good enough so she helped me to get an oil heater so both me and my mum were warm. If everyone was like her this world would be an incredible place."

The **information, advice** which navigators were able to provide their clients to support them to make informed choices and decisions was another key theme which was picked up from responses. Navigators were also able to share information and advice in a way that was **easy to understand**.

Clients shared how they had been made to feel comfortable as it had been easy to have conversations with their navigator '**how easy it had been to talk**'.

"She was excellent and did a lot of it for me. She made it simple and easy for me".

"The whole experience for the family member/patient and the rest of the family was very supportive. She was there when we needed her for any questions or follow ups and explained any technical or medical terms into language my father in law could understand."

"....helped me with her kind and common sense approach."

"Yes, I live on my own and was worried when I was first diagnosed but she really put me at ease."

"She was very easy to talk to and made us very comfortable."

"Yes, she was very easy to talk to and helped me with her kind and common sense approach. My friends were sympathetic but I needed the encouragement and support from someone independent."

"Yes she was easy to talk to and listened to all I had to say".

"She listened to anything I needed. She was absolutely wonderful."

"She was a very good listener"

Two clients shared how support from navigators had been prompt, with them responding to queries **quickly**.

"She really was excellent at her job. We had a laugh too. Any queries, she took them away and was back to me quickly with the answers."

"She was very good to talk to, a very good listener. I can't fault her. She did anything I needed and did it very quickly."

"She had a very reassuring manner and such a calming voice. She provided solutions to our problems."

"Gave me a lot of help and followed up when needed with the correct information".

"Yes, she was great with the advice and helped me to express how I was feeling."

"Yes, she helped me to apply for benefits I didn't know about."

"She sorted out his benefits and got things backdated. She was excellent."

6. **How did the Macmillan Community Navigator help you to identify any concerns you have/had?** (Did they offer a Holistic Needs Assessment HNA? Did you tell them your concerns and they discussed these with you?)

Every client taking part had something to share when asked this question. **Well being checks** were mentioned by many clients and various examples were shared of what this process and support had led to.

We were told that concerns relating to support for practical items and issues had been of concern and examples were shared. **Two** clients shared how they had been supported to access a **Macmillan grant**; *"In the beginning she helped me get a grant for under clothes as I had messed up my old ones"*. Another shared; *"....a Macmillan grant for a mattress"*.

Finances were another concern with navigators being able to provide information about benefits and also practical help in applying for benefits. In answering this question, **5** of the **19** clients shared that navigators had supported them to **access benefits**.

2 clients spoke about their **living conditions** and how navigators had been able to **provide practical support** to them, as they were living in

accommodation without heat. **One** client shared: ***“She offered quite a bit of support but I didn't need much. I was cold in my living room and she helped me to apply to get a fire installed.”***

For those of us with pets, we know that it's difficult to leave them in the house for long periods of time. **One** client shared that they had concerns about the volume of appointments they had and how long they would not be at home and how a navigator had been able to **offer information** which had helped them: ***“We had concerns over leaving our dog when we went for hospital appointments and the navigator found numbers to help. She also signposted us to Sunflowers and various other groups.”***

In terms of other practical support, **one** client told us that a navigator had been able to help them access a **Carers assessment** and another shared how they had been supported to **apply for a blue badge** to help them with their concerns about using their own car. A client shared how they had been offered support in getting **back into education**.

Support for people's **emotional health and well being** and their **mental health** was one of the key concerns which navigators were able to help their clients with. In being able to spend time to **listen** to client and carers concerns, navigators were able to **support** and **signpost to appropriate services**. You can read some of the comments which were shared with us below. **Dawn from the team, who spoke to all of the participants, shared how grateful clients and carers had been for the support which had been provided.**

“She helped she listened and was there for me. She made such a difference, I was depressed but bit by bit she helped me to sort everything I needed and to lift my spirits. I can't fault her at all. She really altered my life in an amazing way.”

“She looked into any information to make my situation better including my mental health support.”

“When someone tells you have cancer its horrifying until you find there's lots of different types. The support I received was great though.”

“Very good listener. Lots of health and well being support.”

“Yes she was a very good listener and helped me get all the information I needed about anything.”

“We discussed everything I needed, she listened and was amazingly helpful.”

“I was in a void trying to take everything in, she helped to do everything.”

7. What were your needs/situation when you first came into contact with your Macmillan Community Navigator? How has the support provided by the Macmillan Community Navigator helped you to meet your needs?

You will see from the responses from the previous question that many clients had already shared what support had been provided by the Macmillan Community navigators.

When looking at the needs/situation when **first being in contact or referred into the Macmillan Right by You service** they were categorised below (the larger the text, the more the need/situation was shared)

Emotional support

Financial support: welfare benefits

Financial support: access to a Macmillan grant

Information and support about a diagnosis

Financial support: clothing grants

Financial support: support with travel expenses

Access to transport for regular hospital appointments.

Not sure....

Emotional support and **support to access welfare benefits** were the top 2 areas of need which were shared by people accessing the service.

In terms of **emotional support**, people shared how the support offered had valued.

"I was scared and lonely and she really helped to get things in order. She never let me down. It was nice to know that there was somebody out there that I could rely on to help me when I needed them."

"Yes, she helped us to get attendance allowance."

"She also helped with benefits forms."

"She found out lots of financial help I could get and helped me to complete forms."

One person shared how they had received their Cancer diagnosis during the COVID-19 pandemic and how the support from a navigator had helped them. **Another client** shared their experience of being diagnosed after attending an Accident & Emergency department.

"The absolute shock of the diagnosis after going into A+E for one thing but finding you have leukemia was awful. She listened so well to all my concerns and explained anything I needed clarifying."

"I found my cancer during lockdown. Speaking to my navigator was a massive help it was nice to have someone to talk to about the real stuff, she was really nice and gave me lots of encouragement - it meant the world."

In needing **financial support**, we were told about **access to Macmillan grants** which supported with both the **practical issues** people faced and to support in overall **health and well being**.

"There was a need for a new mattress due to the cancer, having the Macmillan grant helped us to get one and help my father in law to sleep."

"She helped instantly with benefits. She helped me get a wig and a grant for a washing machine too."

8. What services has the Macmillan Community Navigator helped you to access?

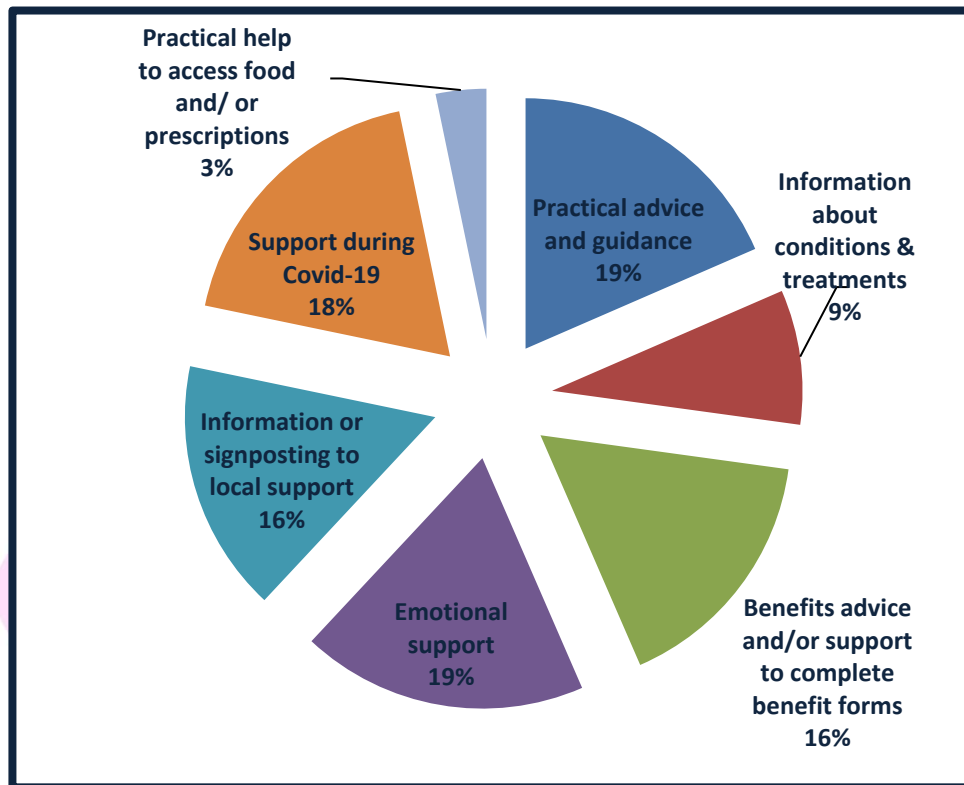
When asked the question about, clients gave multiple answers, showing that navigators were able to deal with a broad range of issues which a client required support with. The chart on the next page shares the responses.

In line with the responses to the previous question, it is clear to see that the community navigators helped clients and their carers to access the services which they had initially contacted the service for/ referred for.

18 clients had received invaluable support during the covid-19 pandemic with **3** clients also gaining practical help to access food or prescriptions.

16 clients had also received help to access other local support services, with community navigators being able to **signpost them** or **provide information** about other services.

2 clients shared further comments and both stated that they had been supported to apply for and access **“Macmillan grants”**



9. Has the information or support provided by the Macmillan Community Navigator helped you to remain or be more independent? If so, How?

All 19 clients (100%) told us resoundingly that the information/ support provided by the community navigators **had helped them to remain or be more independent**.

5 clients told us that their community navigator had been able to **provide them with the contact details and telephone numbers for organisations who could help them**.

“She has given me lots of contact details to use.”

“She left me with numbers to call in the future”

“Yes, I have numbers to call.”

“I am now aware of all the support out there should I need it.

Examples of how the support provided, **improved peoples confidence levels** were shared, as well as how having the support from the navigator helped them **to get through difficult times**:

“Yes, she gave me the confidence to deal with things with her support and then on my own again once I was feeling better.”

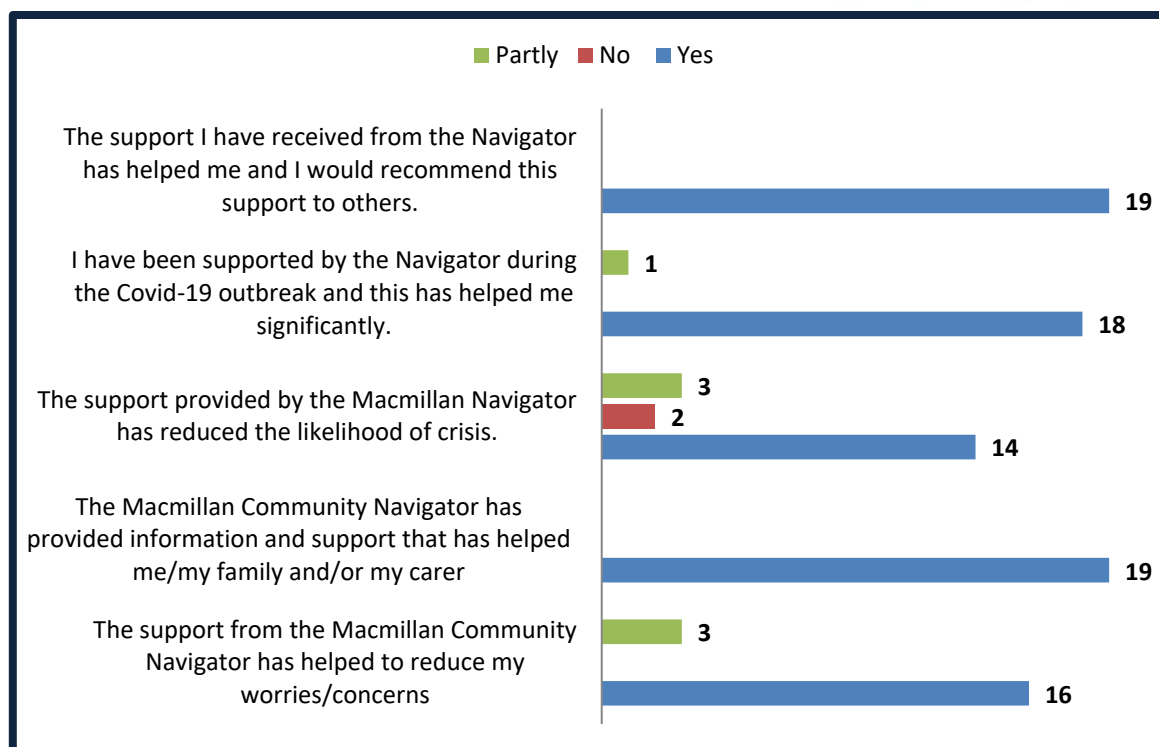
“Yes, I feel more confident for talking.”

Yes, it’s helped him to recover quicker.

The support has helped me to get through, having someone to talk to has helped a lot.

Yes. She helped put me ease when I was stressed.

In the final question we shared **4** statements with participants and asked them to tell us if they agreed, disagreed or partly agreed with them.



All **19** clients (**100%**) shared that they **would recommend** the support provided from the Macmillan Community Navigators to others.

Again, all **19** clients (**100%**) shared that the **information and support** provided by the navigators **had helped them**, their family or their carer.

18 people had been **supported** by a community navigator **during the covid-19 Pandemic** and that the **support provided** had **significantly supported them**.

When asked if the support provided by the service had **reduced the likelihood of crisis**, **14 (74%)** clients shared that **it had**. **3** felt that the support had partly reduced the likelihood, with **2** disagreeing.

16 (84%) clients shared that the support had from the service **had helped to reduce** their **worries and concerns**.

Summary of the feedback we gathered.

Healthwatch Sefton was commissioned to undertake an independent evaluation of the Sefton Macmillan 'Right by You' service during December 2020. From a sample of **24** clients shared by **6** Community Navigators, **19** clients were engaged and were able to share their feedback with Healthwatch Sefton.

10 questions were asked, with all **19** clients engaged. Dawn Thomas from our team, who is our Signposting and Information officer, supported the review by contacting the clients by phone. Dawn shared; ***"Completing the Macmillan calls was a very positive experience for myself and the participants. Each call was filled with praise for the Macmillan workers that supported the clients. From help to get blue badges or benefits to general information or simply having someone to talk to, each staff member were appreciated for their invaluable part in the client's journey with their cancer."***

It was clear from talking to clients, that the service and the support provided by the Macmillan community navigators was greatly valued, with many getting emotional when talking to us about how the service had supported them. This is supported with all clients sharing that they would recommend this service to others.

Emotional support and support with finances were highlighted as key areas in which they had initially required support with and it is clear from the feedback shared, that clients had been supported with those initial concerns and then had gone on to gain further support from their community navigator. **17** clients told us about the invaluable support which they had received from the service during the covid-19 pandemic.

When clients spoke about their community navigator, they again became emotional. Clients spoke about their experience of having someone who took the time to listen to them, someone who engaged with them regularly, and someone who looked out for them in terms of emotional and practical support. It was clear that the navigators listened to their clients, understood what their support needs were and acted upon them. Access and the support to get Macmillan grants were important to a number of clients, helping them to access clothing, wigs and washing machines. We were also told about the practical support to ensure clients had access to heating in their homes.

The information provided by navigators and the signposting to other local services for a variety of support needs was spoken about by clients and how this would help them with future support.

Increased confidence was another key area which was fed back with all of the clients we spoke to, telling us that they felt comfortable in being able to speak up and also importantly, how they felt involved in discussing their support needs. There was clear evidence that the service works with their clients, engaging them to support themselves, rather than doing everything for them. This is further evidenced below.

Every client told us that the information and support provided by the community navigators had helped them to remain to be more independent.

There was nothing but positive feedback about each of the community navigators and the support that they had provided. You will have seen this feedback in the comments which were shared with us which we have included throughout this report. The feedback from clients, shows how the navigators employed by the service and the service provided see people and not the symptoms.

Lets again look at some of the key highlights....

100%

of clients engaged would recommend this service to others.



100%

of clients felt comfortable in having a say and felt involved in discussing their support needs.



Overall experience

... this was rated as 'excellent' and 'very good'.



17 of the 19 clients had received support during the covid-19 pandemic.

100%

of clients told us that the information and support provided had helped them to remain or be more independent.



Thank you

Healthwatch Sefton would like to thank a number of organisations and people for supporting us to undertake this independent review.

Firstly and most importantly, we would like to thank the 24 clients who gave their initial consent for us to contact them and those 19 clients who we spoke to. We would like to thank you for your time and your honest feedback about the support you have received from the Sefton Macmillan Right by You service.

We would also like to thank Sefton Council for Voluntary services (Sefton CVS) for commissioning us to undertake this review and Adele Thompson and the team of Macmillan Community Navigators for supporting us in this process.



Healthwatch Sefton
3rd Floor, Suite 3B,
North Wing,
Burlington House,
Crosby Road North,
Waterloo, L22 0LG

w: www.healthwatchsefton.co.uk
t: 0800 206 1304
e: info@healthwatchsefton.co.uk
tw: @HWatchSefton
fb: facebook.com/HealthwatchSefton