What would you change about your local cancer services?

How would you develop your local cancer services?

Healthwatch is a service for people who use health and social care services, our aim is to help you have your say.

We want to know about your experiences of cancer support services. Your feedback will help to develop cancer services in Southampton and West Dorset.

Visit the websites below to complete the online survey or contact us for a face-to-face interview.

it starts with YOU

In partnership with

MACMILLAN CANCER SUPPORT

healthwatch Southampton

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Summary

Wessex Cancer Alliance, supported by Macmillan Cancer Support are testing an integrated care model to improve the effectiveness of assessments and care planning for people affected by cancer. To evidence this Macmillan Cancer Support asked Healthwatch Dorset and Healthwatch Southampton to carry out a baseline engagement to find out people's current experience of getting support, what worked well and not so well. This was done through an online survey (150 responses) and face to face interviews during January & February 2020. In which Southampton had 45 responses on the online survey and 39 in the face to face interviews.

Most of the people Healthwatch spoke to are cancer patients or carers/family members. The majority of people who took part are aged between 54-75, identified as female and White British. Southampton's estimated population is 256,459. This is made up of 50.9% males and 49.1% females. White British individuals take up 62.8% of the Southampton community, leaving 37.2% as other ethnic groups. Southampton has clusters of deprivation in different areas. The areas with 10% most deprived clusters are as followed; Woolston, Bitterne, Harefield, Bargate, Bevois, Swaythling, Coxford, Redbridge, Millbrook and Shirley. Through our engagement Healthwatch aimed to targeted areas of deprivation.

Headlines

- The Southampton population were very appreciative of their NHS System and the clinical work that is carried out by staff.
- The Southampton population appreciated the 24-hour phone line provided by Macmillan.
- 79% of the people in the interviews that we spoke to had had a conversation with an NHS professional surrounding their cancer support care.
- People found support groups very useful.
- Less support available for certain groups; for example, children of cancer patients, single parents and carers.
- People are seeking and developing different support options in their local communities.

This baseline work has allowed for a greater insight of what matters most to people affected by cancer providing a platform for the Right By You pilots to build on.

Recommendations

- People wanted different support options in their local communities.
- People wanted support the whole way through their cancer care journey.
- People effected by cancer would like more support particularly around treatment information, transport and finances.
- People would like to see a range of good quality individualised support provided in community settings and at hospital, throughout their journey, including after treatment. This support should be close to home and easily accessed 24/7.
- There needs to be more signposting of different ways to get support for certain groups such as, single parents and family members.

Introduction

This report outlines the project carried out by Macmillan Cancer Support and the Wessex Cancer Alliance, Wessex Voices, Healthwatch Dorset & Healthwatch Southampton. This was to carry out engagement activities with existing cancer patients, their carers and wider family to inform two ‘Right by You’ pilots in Southampton City and West Dorset. Wessex Voices, an innovative partnership between NHS England and five local Healthwatch organisations in the Wessex area, carried out a literature review in preparation for this project, available on their website: https://www.wessexvoices.org/uploads/9/2/1/6/92161062/right_by_you_literature_review_-_october_2019.pdf.

https://www.wessexvoices.org/wessex-voices-publications.html

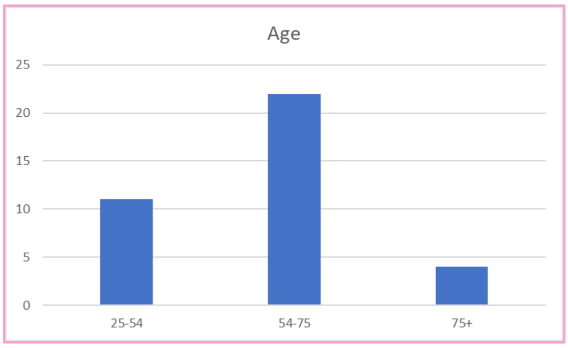
Overall, this will support the development of the pilot Southampton support services for cancer care.

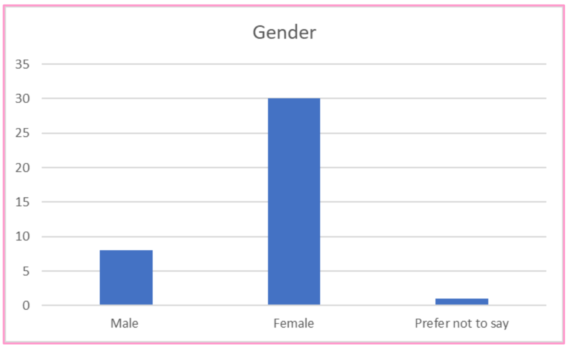
The public engagement involved face to face interviews as well as an online survey. The face to face interviews in Southampton involved two support groups, two organised lunches, Southampton Voluntary Services, a GP surgery, the African Caribbean Club and other members of the public. This came to the sum of 39 individuals. The online survey managed to engage 45 individuals from the Southampton postcode. Healthwatch Southampton are very grateful and appreciate every individual who involved themselves in this public engagement project.

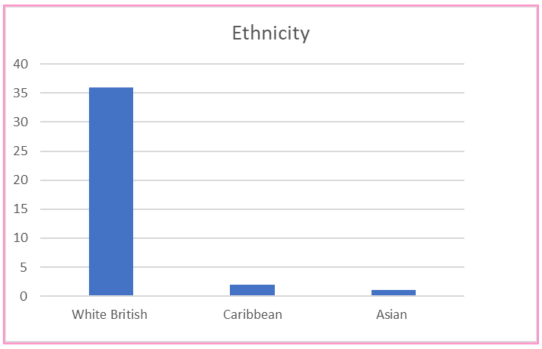
This engagement project has highlighted areas of development for the local cancer support services, as well as shown the areas that are helping to support individuals, carers, family members and friends every day. The people who participated in this engagement were cancer patients, carers, family members or friends. The first half of the report will explain the themes that were found from the Southampton public in the semi-structured interviews, as well as graphs showing the data of age range, category and ethnicity. This report will then lead on to explain the online survey results, using graphs for explanation. Finally, there will be three anonymous case studies to allow the reader to better understand people’s cancer journeys.

Face-to-face Semi-structured Interviews

Data of the protected characteristics involved:

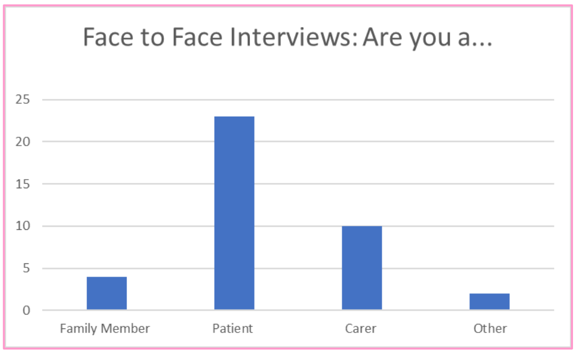






These graphs show the protected characteristics involved with the face to face interviews. It is important to acknowledge that not every participant participated in these questions.

What people told us:



Above shows who Healthwatch Southampton engaged with, as shown the most engagement was with Cancer patients.

Conversations with an NHS professional:

When asking individuals whether they have had a conversation, with an NHS professional, about the support and the needs around care, thirty-one out of thirty-nine individuals responded yes. This shows that a high majority of individuals who were spoken to were offered a discussion with an NHS professional surrounding their cancer support care. Many individuals explained how the conversations were with consultants or at the hospital. Other areas were over the phone and at a GP surgery. However, the stage in which these conversations took place varied. Many expressed how they took place the whole way through the cancer care process, while others stated they were at specific times such as pre-diagnosis, diagnosis, during treatment and after. The results from the interviews show a varied response, which is to be expected given the variation in individual needs. This was shown through quotes such as; “*It very much depends on the individual*”. For example, some may feel that the shock of the symptoms and diagnosis means they need to talk to an individual about how their feeling, whereas others expressed that they’re not ready to talk about their diagnosis straight away.

Yet, some members of the engagement project stated how through treatment and after treatment was the most vital times. This was because through treatment a lot of information is needed for someone to feel they are well understood in what is happening to them. This was shown through an individual stating, *“you have to do a lot of treatment info yourself at home, which is mind boggling”.* Also, after treatment patients can feel lost. The support from the medical healthcare is no longer there due to it no longer being needed. This was shown through people describing it as feeling as being *“dropped”*.

Furthermore, for those already with the resources to travel to appointments, transport support information was expressed to not always be needed straight away, as an individual did not feel unable to travel to appointments until the treatment side effects took effect. The conversations with the Southampton public showed how everyone’s support system is different. A common theme was those who had less family and friends in the area felt they needed earlier access to support, compared to those who expressed they were/are very much reliant on their family and friends.

Opinion on the place support services should be:

The next area of the interview explored if it was the right place for the conversation and if it wasn’t where would have been better suited. As mentioned above the most frequent response to where conversation took place was at the hospital. In the interview participants were asked where they’d prefer the conversation/support to take place; this resulted in the answers being mostly community based. For example, the common responses were; *“the GP”, “in the community”* and *“at home”.* When these responses were given the participants were then asked why these places have been chosen. This gained responses such as; *“I’ve spent enough time at the hospital” and “if I am not feeling well travelling far is awkward”.* These quotes show how individuals can associate the hospital with clinical treatment, as well as showing the fact that being local when someone feels unwell can be best suited to their needs. There were some results stating that the hospital (where most support is given in Southampton) was the best and most appropriately suited for some individuals. When asking why this was the case, it seemed that it was because it was most convenient for patients and family members when coinciding with appointments. Also, people mentioned that *"the hospital has lots of information and leaflets"*. Other contributors to this public engagement were unsure of where was best. One carer stated that *"it depends on the individual".* However, these results suggest that having support both in the community and at the hospital is most likely to fulfil everyone's needs.

Support which is given:

The next part of the interviews covered the type of support which is currently given through cancer care. Emotional support was highlighted as important by many people (14/31). Although a couple of individuals said that emotional support was focused on sometimes a little too much, which meant for them other types of support was forgotten about. However, even though these opinions were discussed most individuals were happy with the emotional support that they had been offered. Treatment support was also seen to have been offered frequently (7/31). When exploring what types of support was given it gave a good overview that some individuals felt they received all types (6/31). Yet, other types of support that was lowly noted through the interviews were financial, information, caring responsibilities and diet, meaning not everyone had access to the support they needed. This left only a few stating that they had received/were receiving none.

The conversations then led on to explore what is seen to be the best support provided.

The most popular results involved the emotional support provided by different services; this was stated because the emotional support service was offered to people 24 hours a day. Participants expressed how being able to contact nurses and support workers through their phone, support groups and having an online community (e.g through Facebook groups) meant that support was always available. Some patients expressed how it helped them to feel less alone. Quotes such as *"knowing I can call and get information the same day really helped"* were stated. Financial support was mentioned in terms of lowering the price for parking at the General Hospital, for cancer patients, carers or relatives with a patient. This was said to help "*majorly*". However, negatives were mentioned about other types of support such as housing, diet and exercise. Current and previous cancer patients explained how there was less emphases on these areas by services.

Family members support:

When participants were asked about if the family members were offered support twenty responded yes and fifteen individuals responded with no. Leaving four individuals responding with N/A. The participants who stated yes to the family members being offered support had quotes such as; *"Yes, absolutely", "They have but didn't want it"* and *"Of course".*

However, when exploring into the fifteen individuals who stated no, ten were family members or carers themselves. For example, one individual stated *"There isn't many support groups for family members".* This can make family members feel isolated. One participant specifically mentioned their teenage child only being able to access support from school. This was because there was no information about cancer specifically directed towards a teenage age range. Therefore, making awareness around everyone feeling support is available is essential.

Organisations/Support workers who's care shone:

When participants were asked what organisation/who gave the best cancer care support, suggestions were: the consultant, support groups, breast cancer team, Hope and Dietitians. However, Macmillan was mentioned by over half the participants in a positive light and was described as having the *"gold standard support treatment".* This shows how Macmillan has a big influence on many individuals in Southampton when cancer is involved in their lives. Participants also mentioned their personal consultants' and support groups being centre of support throughout the cancer treatment process.

The last question, which was specifically explored, asked if anything could overall be improved. This brought in a mixture of responses. 16/31 stated that they didn't think their cancer care support services needed improvement. Two quotes from these results are *"It's the gold standard of cancer care support"* and *"Macmillan are outstanding".* Individuals acknowledged how the high demand for cancer care means staff are working to the highest of their ability with what's available to them. For example, one participant stated, *"I am very happy with how I've been treated considering the pressures they are under".* These conversations even brought up specific people or specific places who they believed were integral to their support. For example, Matt Hobbs an individual who runs a support group, the organisation Macmillan was named several times, personal breast care nurses and even clinical consultants. This shows the importance of what and who can impact and change a cancer journey in a positive way. Also, demonstrates how the healthcare workforce are integral to individuals' positive experiences.

However, others stated that there was room for improvement. There was a variety of reasons as to why people thought the support should be improved. The quotes gave an insight as to what people feel is important and is currently being missed by the service. One individual stated they waited for *"5 months to be able to access support"* to access any type of support. This response was not solitary, as others had said they were in similar positions. This left individuals feeling isolated and neglected. Another reason was that the cancer support services focused solely on emotional support. This left financial, housing and transport needs unmet, which was described to go together with maintaining healthy emotional wellbeing. One individual stated that there needs to be *"less focus on emotional and improve other areas!".*

When speaking to individuals who were single parents one area became apparent. This was that *"There isn't any support for single parents. If you have little family to help you are still left to do day to day tasks (e.g. cleaning) and looking after a child".* This shows how management of day to day activities were not seen by the public to be included in the support services.

Finally, another issue was some contributors felt there was not enough access to information access about the treatments. Having treatments more specifically explained in person without too much *“medical jargon”* was needed. This was seen to be able to improve the knowledge of the carers, family members and patients at each stage of the treatment processes, as many participants felt overwhelmed with the medical treatment knowledge.

Overall, this showed some positive aspects of the support services that were acknowledged, and many were happy with the services they had received. However, it is important to acknowledge the public’s opinion of how the support services could be improved.

Where people did not have a conversation with an NHS professional

Individuals who said no to the first question about having a conversation with a healthcare professional, led the semi-structured interviews in a different direction. There was a total of eight individuals who stated they had not had a conversation about support with an NHS healthcare professional.

All eight participants explained that they thought a conversation surrounding what support was available would have helped them. Two individuals explained how at each stage a conversation would have been appropriate (at diagnosis, before, during and after treatment), as it would have made them feel they could access support whenever it was right for them. Whereas the other participants felt that before the treatment and during the treatment would have best suited them. However, all contributors felt that making sure the conversation happened at the right time for them was integral. This was shown through quotes such as *“yes, but only when I was ready”.* This again shows how everyone has a different process when needing/accessing support.

When asked about which support would have been best for individuals to access the responses surrounded emotional, financial and transport.

Opinions on the best place to access support:

The results with this question brought out how five individuals wished to have the support services within the community. This was shown by:

- Two individuals stating the GP
- Three others saying in the community.

Whereas, one individual expressed how the hospital would be best suited for them. This was because the participant was a family member and thought when their family member is having treatment that it would be more practical to access support at the same time. The other two contributors stated they were unsure were the best place to get support services would be. This was down to the fact they haven’t received any to know what to compare it with.

Finally, since these participants expressed they did not have a conversation with their healthcare professional about the support available, conversations led to what other support they did/do have through their cancer process. This conversation brought up how many who did not use support services relied fully on their friends and family. Unfortunately, though it needs to be remembered that not everyone has access/opportunity to this type of support.

Other comments people added:

At the end of the interview every participant was asked if they had any other comments or wanted any points to be specifically noted. One theme which was apparent was how grateful the participants were of the NHS. This was from people who were involved in the engagement or individuals who were at events and spoke to Healthwatch colleagues but were not in the category to take part in the interview. This is a positive thing to acknowledge. One person explained their NHS story and said, *"the NHS are just brilliant!".* This reflects the publics high regard for the NHS.

Online Survey:

The next section of the report will explore into the online survey and will show similarities and differences. Much like the face-to-face semi-structured interviews the online survey brought in similar findings and these will be explained below.

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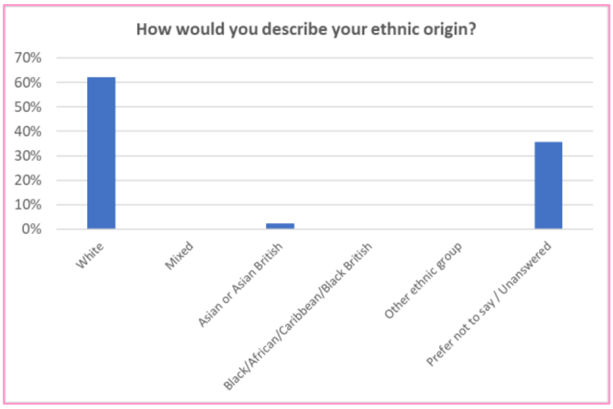
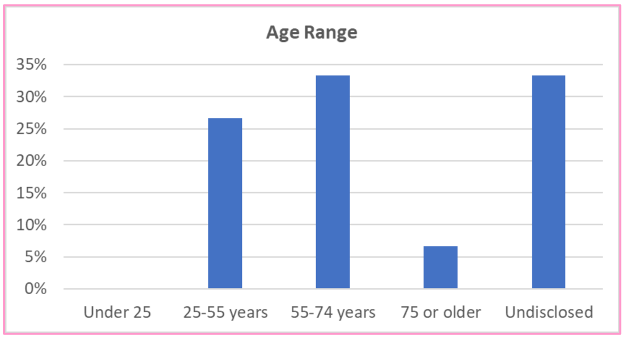
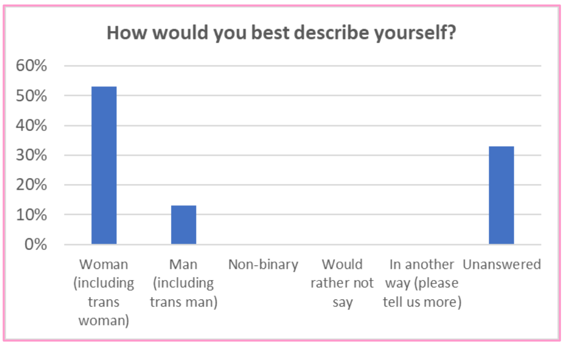
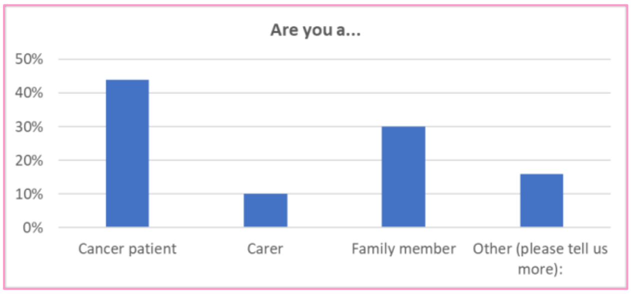






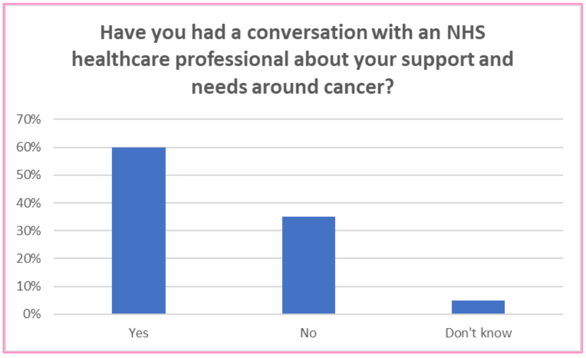
What people completed on the survey



Above shows a graph of what participants categorised themselves into when taking part in the online survey. It is important to note that individuals could choose more than one option; for example, a friend (other) may also be a carer of the same individual. When exploring the other category, it included friends and health and social care professionals.

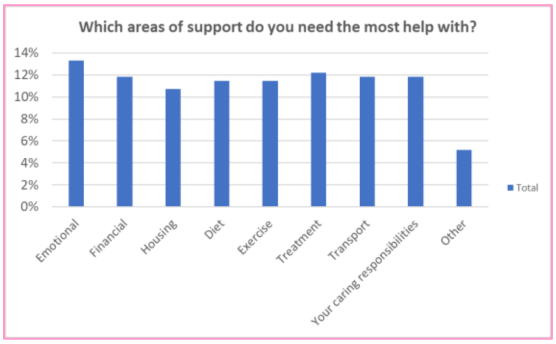
- Cancer patient: 22
- Carer: 5
- Family member: 15
- Other: 8

Conversations with an NHS professional:



Much like the face-to-face semi-structed interviews, the online survey also came out with a high majority having talked about the cancer support care services with a healthcare professional (24 individuals). The result showed that for many individuals this took place at the hospital or with a consultant. For example: *“so I have regularly talked to my consultant about support”.* Once again this was very similar to the results found by the semi-structured interviews. Clinical nurse specialists were also written about as the first point of support conversation. When exploring the comments, most individuals had their conversations at the hospital at the point of diagnosis and then continued throughout the treatment process.

What support is felt to be most needed:

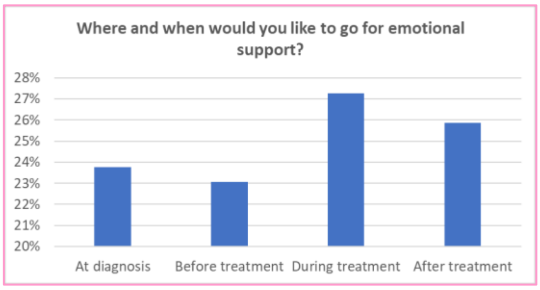


The top five (in order of highest to lowest) support categories which the Southampton public felt was most needed when going through cancer support care was; emotional (36 individuals), treatment(33 individuals), financial (32 individuals), transport (32 individuals) and care responsibilities (32 individuals). The emotional support was stated to be most needed, yet in some semi-structured interviews a few described that it was focused on too much. This shows some differences. Yet, the other support mentioned also came up in the interview themes.

When exploring the comments, caring was a strong theme. For example, people mentioned their children which needed to be accommodated for *(“childcare duties”*), caring for a relative in their home and their partners. This also came up in the interviews where individuals mentioned about having to adapt for illness and the support which is needed. This shows how the Southampton population feels that their family lives are central, so being supported in this area is important.

The next section will explore specific types of support and what is viewed to be the best place that participants thought support could provide through. These locations or access to support are out of websites, GP surgeries, Community Venues, Hospitals, Cancer support groups and other. This also looked at the time of when the support was wanted; for example, at diagnosis, before treatment, during treatment or after treatment.

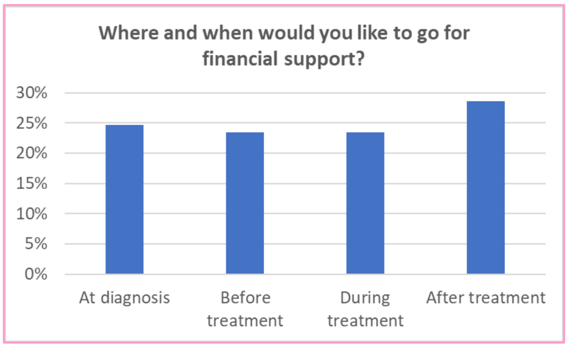
Emotional Support:



As the graph shows individuals feel they mostly need emotional support during treatment (39 individuals). For the emotional support the majority stated they wanted it at the hospital in the times of diagnosis, before treatment and during treatment. Emotional support was also seen to be wanted in support groups at the stages of before and after treatment. One individual said that *"I would like to be supported by people who have been through Cancer and have a great understanding of how Cancer effects every part of your life and family/friend's life".* This result also links with the face-to-face semi-structured interview.

However, others felt that the location wasn't essential. It was the quality of support and the cost for attendance. For example, one individual wrote *"For me it is not the place so much, it's the people who offer support. Obviously, it would be helpful to people if the venue that the support is at doesn't cost people anything to park. The place needs to be bright and welcoming".* This was also seen in the interviews with the mention of the parking charges at the Southampton General Hospital.

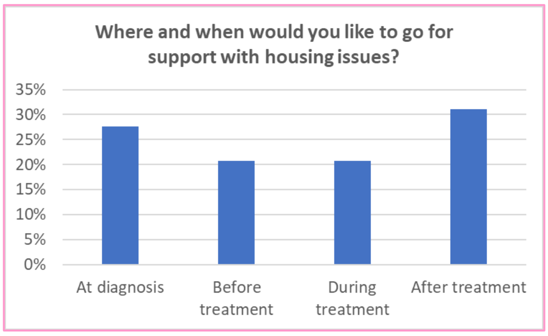
Financial Support:



The graph above shows how financial support is wanted the most at diagnosis (19 individuals) and after treatment (22 individuals). Yet, the percentages are very similar, and it shows how many want it throughout the cancer process. The main place individuals wanted to access this support was at support groups. The comments show this is because the participants feel that they could get the most advice from others around them. As well as this, it allows conversation to flow around the subject area. Although community venues where not rated higher than the other options the comments did explore the concept of financial support being in the community. For example, *"somewhere like the job centre"* was reported and easier venue options were suggested.

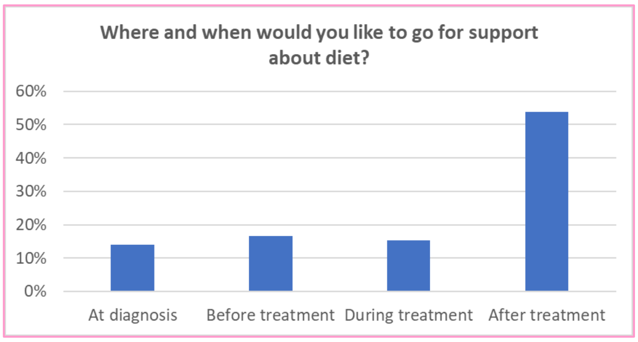
It is important to note that not everyone answered this question, as many individuals said it was not applicable for them.

Housing Support:



Many individuals felt this wasn't applicable for them, but as shown above the housing support is mostly wanted at diagnosis (8 individuals) and after treatment (9 individuals). The three highest results for place was the GP surgery, community venues and support groups. At diagnosis the highest response was the cancer support groups and then after treatment the GP surgery and community venues were seen to be the best location. The comments below linked to worrying about mortgage payments; this was something associated with the diagnosis stage. However, during and after treatment there was comments about *"adaptations that are necessary"* for houses. This could suggest why local support were viewed as better because they were nearer to an individual's home.

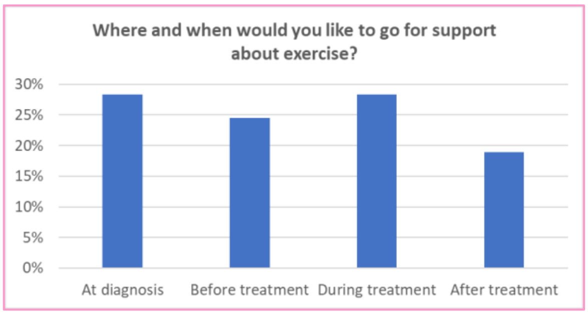
Diet Support:



As shown above the diet support is mostly wanted after treatment by some majority (42 individuals). This compares with the diet issues found after chemotherapy. With diet support the most popular response throughout the cancer care process was the hospital.

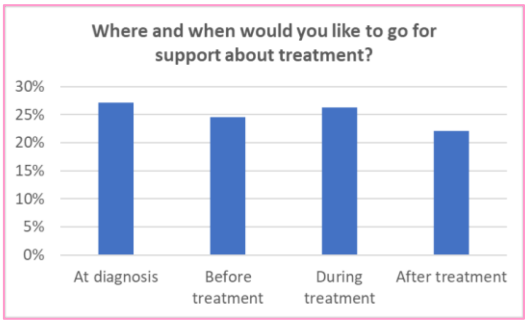
Comments left on this question showed a theme of having no support with diet throughout the cancer care process. It was also stated that the dietitian time was so limited that the help wasn't seen as helpful. Again however, not everyone felt they needed diet support so not every participant responded to this question. The theme of lacking support in this area was brought up in the face-to-face semi-structured interviews.

Exercise Support:



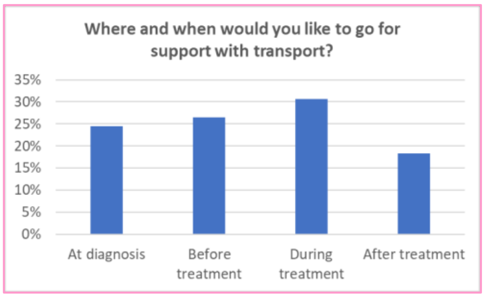
With regards to support with exercise the most popular location was the GP surgery in every stage of the cancer support, apart from during treatment. During the treatment stage 15 individuals thought the GP surgery, the hospital and support groups were equally as suited, in terms of being the best place to get support. However, this question was poorly answered as some believed it was not required or attending an exercise session was too hard; this was shown through the comments below. This was either down to affording sessions or healthiness. However, there was also some positive comments saying how exercise really helped them "*mentally and physically*" throughout. Interestingly, this was not reported through any of the semi-structured interviews.

Treatment Support:



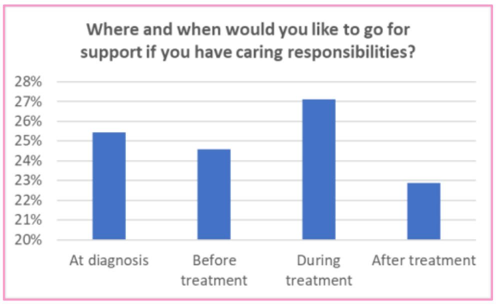
The graph above shows how this support is felt to be needed throughout the cancer care process. Treatment support gained a lot of responses (30 responses). At diagnosis treatment support was seen to be mostly needed at the hospital. Through the comments this was seen to be because any worries could then be discussed there and then *("to be able to discuss any worries")*. Before and during treatment, again, the hospital was the most popular response. However, cancer support groups were also highly acknowledged and came in at a close second. At the after-treatment stage cancer support groups were viewed to be the best place to access support. When exploring the comments themes came up around discussion, advice and sharing experiences. For example, *“many people have side effects and I would benefit from some sound advice”* and *“reducing the feeling of complete isolation”*. This theme was similar to the semi-structured interviews.

Transport Support:



The graph shows how individuals feel this support is needed until the after-treatment stage. This question was not answered highly by participants. The reason for this is unknown, nevertheless, there was a comment below stating “*we didn’t know such thing was available*”. This suggests that signposting to support treatment services needs to be carried out more in practice. This was also a theme in the semi-structured interviews, where individuals were not accessing support. Overall, the cancer support groups, and the hospital were most seen to be the place to provide the best transport support throughout the cancer care process.

Caring Support:



As shown above caring support is mostly wanted through treatment (32 individuals). The caring support was viewed to be best suited to cancer support groups, with GP surgeries closely running second place. Both these places were seen to be popular throughout the cancer care process. At diagnosis, before treatment and during treatment cancer support groups were the most popular over GP surgeries. Whereas, after treatment the GP surgery was thought to be the same as support groups in terms of location. This was no surprise considering that in the face-to-face semi structured interviews family members who cared for their loved ones felt there should be more support groups for them to attend.

Case Studies:

Case Study one:

This White-British individual is aged between 55-74 and had recently been diagnosed with a brain tumour. Before this diagnosis he saw himself as fit and healthy, as he worked full time and had a busy lifestyle. This diagnosis was felt to have come out of nowhere. After diagnosis the individual explained how his conversation about support services was first discussed with a consultant at Southampton General Hospital. He felt the conversations about support which were carried out was at the correct times since they were in his appointments. However, the support which was offered was only emotional, although he described himself to be financially stable and well supported by his family and friends. He felt the best support he was given was through support groups, as this allowed him to discuss similar issues with other people. This allowed the social connection and understanding which isn't always felt when others are not in the same situation. He expressed how his family member (wife) had been offered support as she attends every appointment with him.

When explaining the support in more detail he said how he visited the Macmillan centre in the hospital and he also had a specialist nurse come to appointments and explain anything he didn't understand. He expressed how every support assistant with his care was very kind and friendly. This helped him to feel at ease and comfortable. When asked where he would prefer his cancer care support, he stated at the GP surgery, as this was most practical for him and his wife in terms of travelling. Overall, this gentleman stated that the care he has received has been great, especially when considering the high demand and pressure the staff are under.

Case Study two:

This White-British individual is aged between 25-55 and previously had had breast cancer. She is now in remission. She explained how she did have a conversation with a healthcare professional surrounding the support services available to her. This conversation took place after diagnosis and during the treatment. She explained how accepting the diagnosis was difficult but there was no time to stop because she is a single mum, which means she has a busy lifestyle. The support she was offered was emotional and information surrounding the cancer care process. This meant she used services such as, the Breast Care team, Hope and support groups online. She stated how the "*Breast Care nurses were amazing and having someone to help with emotional support was essential*". She didn't get offered the financial or diet support. Yet, she worked throughout her treatment, as her work was described as very supportive and flexible. She did mention how she found finding food that didn't taste of metallic was difficult, due to the chemo. Therefore, more diet support was thought to have helped during this time.

When asked if family members had been offered support, she explained how she did not have much family locally and the main individual who needed her support was her child. The child's age however, seemed to cause some support issues because she explained how the information seemed to be directed at a younger age range or an adult. Nothing for teenage years. This meant that the support for her child very much came from the school and their health and wellbeing team. She also explained that for single parents there was no support at home. This meant day to day tasks became challenging and this left the individual struggling to cope with parenting, household keeping, cooking and working. Overall, this affected her mood negatively.

Furthermore, she stated that the most important time for support is after the all clear or cancer treatment has been carried out. This is because she said *"it feels as though you're chucked back into the normal world again after having to adapt. It can be very overwhelming".* She did have support from the moving forward care team and a counsellor, yet this was sought out by her. Overall, she is happy the support she was provided with and thinks the team does an excellent job. Though, can see areas for improvement.

Case Study three:

This Black Caribbean individual, aged between 55-74, was a patient of the oncology cancer unit. The diagnosis was explained to him at the hospital; however, support was offered before, during and after treatment. The support he was offered was treatment information. This he thought was good as it helped him understand the cancer treatment journey. Yet, he did explain how diet and exercise support would have been useful. This was because he did not receive any support from elsewhere. When asked if his family was offered support, he replied no. This gentleman shows that he was offered very little in terms of the support he was offered, which is why he explained that the cancer care support services could be improved. The individual stated how if it was his choice then more support at the hospital oncology unit would have been best for him. This is because it would coincide with appointments.

Conclusion:

This engagement project has showed how there are areas of development for local support cancer services. The specific areas are discussed below in recommendations.

Recommendations:

- More social prescribing signposting for individuals, as it seems that the support services which are available are unknown to many individuals. This means that individuals who do not have the resources to seek out the services end-up slipping through the net. This overall creates individuals to feel unsupported in certain areas through their, their family members or their carers cancer care process.

- More support groups for family members. This was noted in the interviews and online survey as a direct need throughout the cancer care support process. Developing this aspect will allow every individual involved in a cancer care journey to feel more supported.
- More awareness of support groups for different ages. As mentioned above information is directed at different age ranges. Having more understanding around targeting information at the correct age range for health and social care professionals will allow everyone to have a good understanding of cancer information.
- Awareness for support groups for those lacking in personal support. This was flagged because of the single parent theme. Making sure that support groups in the local area are known about for signposting will ensure that there is a type of social support for individuals lacking in that resource.

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Appendix 1 (who we spoke to)

- Southampton City library
- 2x Carers Lunch- 154-158 Portswood Road
- Southampton Voluntary Services
- Brain Tumour Support Group- Greenways, Chandlers Ford
- Stoneham Lane Surgery
- Priory Road Luncheon club- African Caribbean Club

Appendix 2 (lessons learnt)

Three potential limitations of the public engagement are mentioned below. This is good to reflect on as it will help us with future work and public engagement.

The carer and family category can become confusing for participants because some would state that they are both. Therefore, some people when being interviewed may have felt they were not able to choose both. This then effected the analysis by potentially not knowing the maximum number of carers or family members, if only one was chosen.

There were more negative responses on the online survey than through the face-to-face semi-structured interviews. There are potential causes for this. One could be that the face-to-face semi-structured interviews were mostly held at either a support group, a health and social care setting or an event about cancer. This can mean that because of the setting they were in, they felt more supported as they had support around them. Therefore, for further engagement other settings will be explored more to see if this impacts responses. Another reason could be that being face to face with an individual can cause people to hold back their opinion in fear of judgement. Though, this is a general limitation of face-to-face interviews.

Healthwatch Southampton heard from a low number of males and other ethnicity's apart from White-British. This needs to be considered for further engagement to inform the pilots. Other issues like gender, disability, sexuality and specific issues like fertility also need to be considered in offering support to people so further investigation of existing patient and public feedback and engagement on these issues may also be necessary.

Overall, the lessons learnt from this project is that cancer care support is needed throughout the cancer care process. This is because many individuals rely on this to help them get through their cancer care process. However, signposting to support areas needs to be improved, as many individuals are slipping through the net on certain support areas (especially financial, transport and housing). Overall, however the public are very grateful for the help they receive.