

**Breast Care Services**  
**Southport and Ormskirk Hospital**  
**Engagement Report**  
**March 2015**



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## **1. EXECUTIVE SUMMARY**

The breast care service at Southport and Ormskirk Hospital NHS Trust was closed to new referrals with effect from the 1 September 2014. The hospital was unable to recruit a specialist radiologist and as a result it could no longer continue to run the service safely. NHS Southport and Formby CCG and NHS West Lancashire CCG worked quickly with other nearby hospitals to ensure there was sufficient capacity to receive additional referrals, and GPs were informed of the arrangements for their patients. Southport and Ormskirk Hospital undertook to continue the care of all patients referred to them prior to 1 September 2014.

An engagement programme was launched on 19 January 2015 to seek the opinions, views and suggestions of the local population and enable them to shape the model of future breast care services. This was carried out using a variety of methods to ensure that the programme was as far reaching and inclusive as possible. There were over 3,750 contacts, which generated thousands of comments relating to the local population's thoughts on and experiences of local breast care services.

People were asked what they found positive about breast care services, what they felt could be improved and what they found most valuable in relation to after treatment support. From the feedback the main themes were:

- The vast majority of people who contributed in the engagement programme have had very positive experiences of the breast care services available, no matter which hospital they were treated at and in particular spoke very highly of the breast care nurses.
- People want a local breast care service in the Southport, Formby and West Lancashire areas that at least provides follow up care and support.
- Perceived travel problems if services were to be provided out of the local area. This was from both a practical point of view and also from an emotional and financial aspect.
- Speed of referral into the service, the need for a one stop shop model and then the speed of access to additional diagnostics and treatment is important.
- Better communication, information and consistent messages across the health economy are needed.

An Equality Analysis report was also produced which provides recommendations for consideration to mitigate the difficulties experienced by certain groups within the localities.

## **2. BACKGROUND**

- 2.1 In September 2014, the decision was made by Southport and Ormskirk Hospital Trust to no longer accept referrals for patients requiring breast care services. The two CCGs ensured that GPs were briefed on the availability of other local providers and also that patients continued to have the right to choose from any of these alternative providers. Other local providers were contacted and made aware of the situation and to ensure their capacity to take additional referrals. Southport and Ormskirk Hospital NHS Trust put in place mechanisms to ensure that any referrals made to the Trust would be redirected promptly and the patient's GP informed.

- 2.2 Southport and Ormskirk Hospital NHS Trust made a commitment to write to all patients currently receiving care within the breast service to reassure them that their care would not be affected by the changes.
- 2.3 NHS Southport and Formby CCG with NHS West Lancashire CCG continue to work alongside local providers looking at the options for future commissioning, including best practice pathways of care. To inform this, an extensive engagement programme was launched on 19 January 2015 to seek the views and experiences of patients, carers and the local population. The engagement closed on 2 March 2015.
- 2.4 Updates and reports on the service changes and engagement activity were received and noted by the following health and social care bodies:
- NHS West Lancashire CCG Governing Body, 23 September 2014
  - NHS Southport and Formby CCG Governing Body, 24 September 2014
  - Sefton Overview and Scrutiny Committee for Health and Social Care, 21 October 2014, 6 January 2015, 3 March 2015
  - Lancashire Overview and Scrutiny Committee Steering Group, Friday 28 November 2014
  - Sefton Consultation and Engagement Panel, 23 January 2015
  - Engagement and Patient Experience Group, monthly meetings December 2014 through to March 2015

### **3. ENGAGEMENT PROCESS**

#### **3.1 Aims of Engagement**

Following the closure of breast care services to new patients at Southport and Ormskirk Hospital, NHS Southport and Formby and NHS West Lancashire CCGs undertook a collaborative engagement exercise which aimed to:

- inform patients and other interested groups of the changes
- explain why these have come about
- hear from individuals and groups about their views and experiences of breast care services to help inform how these might be provided in the future

As the service was closed for clinical safety reasons, there was no requirement to hold a formal public consultation. However the CCGs were committed to ensuring patients and local people were involved in future developments. Although there was no opportunity to affect clinical aspects of the service, the CCGs were keen to understand what aspects of the breast care services people found valuable and any suggestions for improvement.

#### **3.2 Methodology**

The methodology was agreed and developed to ensure that the aims of the engagement were met, and to capture the diverse patient experiences and knowledge of the various aspects of the service.

The key aspects of the methodology were as follows:

### **3.3 Focus and Methods of Engagement**

- The process focused primarily on engaging with the various patient groups, including current and former patients, follow-up patients and those patients with a family history of breast cancer, informing them of the recent changes to breast care services and listening to their experiences. Letters were sent to all patients in these groups informing them of the engagement and how they could get involved. The letter was sent to approximately 1,800 patients.
- A survey was developed and was available to complete online and via hard copies. An information leaflet supported the survey and was developed with feedback from Southport and Ormskirk Hospital, other providers and patient representatives
- Other interested individuals and groups were identified e.g. carers, support groups, cancer networks, minority groups, MPs/councillors and local healthcare organisations and groups with an interest in local healthcare. Information and letters of invitation were sent to groups and individuals to cascade where appropriate, and all information was available on the CCGs' websites.
- Focused engagement via meetings/focus group settings was the preferred method of engagement as the changes to the service were varied and in some cases complex; these could be clearly explained and discussed in these settings and patients and others had the opportunity to openly feedback their own experiences and opinions of the service. To facilitate this, a series of meetings were organised mainly via support groups, several of which were open meetings for anyone to attend. These meetings were led by a senior member/s of one or both of the CCGs and, where possible, a clinician.
- To further facilitate focused engagement, the CCGs attended the hospital clinics to discuss the changes with individual patients/carers.
- A news release was issued to all local media.
- Southport and Ormskirk Hospital Trust shadow foundation trust members received an invitation to participate in the engagement: 1,026 members were emailed an invitation and 184 foundation trust members were sent a letter.
- The engagement was further promoted at other local public events which are listed in Appendix A
- The engagement was also supported by the Cheshire and Merseyside Commissioning Support Unit (CSU) Patient Experience Team who provided telephone support for the engagement, including information on how people could get involved, taking bookings for open meetings, completing questionnaires and fielding any queries to the CCGs. Their contact details were included in all information and provided a channel for those who could not access the internet.

### **3.4 Equality Analysis**

- A pre-engagement equality analysis was undertaken and identified several minority groups that would require specific consideration when developing the engagement plan, including the migrant

worker population and Lesbian, Gay, Bisexual and Transgender (LGBT) groups. The assessment also identified higher incidence of breast cancer in specific groups i.e.; the female elder population, Jewish Ashkenazi females and LGBT groups. Due consideration was given to these groups, and bespoke methods of engagement and specific meetings were set-up.

- To ensure that the engagement process was representative of the affected groups, the questionnaire also included an Equality and Diversity monitoring form which captured the profile of the respondents and formed an integral part of the analysis.
- The Equality and Diversity monitoring form also requested postcode information which was used to identify any specific geographic issues, and also enabled the two CCGs to identify their respective CCG residents.

### **3.5 Capturing Feedback**

- To standardise and facilitate a robust approach to engagement, and enable all participants and different patient groups to readily record their views and experiences, a short qualitative questionnaire enabling free text responses was developed. This was used to facilitate all focused discussions and was also available on line to complete.
- To understand the context of individual responses, the questionnaire asked specific information about the respondents' relationship to the service e.g.; patient, carer, personal interest and the name of the provider to which their responses related.
- To ensure accessibility for all, including individuals and groups who were unable to attend a meeting or engage in any other way, all information including the questionnaire was made available via the respective CCG websites.

### **3.6 Analysing Engagement and Feedback**

- During the analysis phase, emerging shared themes and issues were discussed between the two CCGs.
- The CCGs will feedback the outcomes of the engagement publicly and to respondents, indicating how the outcomes will influence the future of the service. 200 respondents provided their contact details so that they can be kept informed of the outcomes of the engagement and future developments.

### **3.7 Stakeholders**

- To maximise the reach of the engagement programme and to ensure that all identified groups were informed, the information such as the dedicated breast care service leaflet and survey, were shared with a wide range of stakeholders as listed in Appendix B.

### **3.8 Engagement/Communication Timeline**

- Staff briefings were held in mid-January with Aintree University Teaching Hospital and Southport and Ormskirk Hospital; these were followed by a range of public events and also attendance at breast care clinics at Southport and Ormskirk Hospital. These ended on 28 February 2015. See Appendix A for a full list of engagement events and clinics.

- An online survey was available on both CCG websites and throughout the engagement period and closed on 2 March 2015.

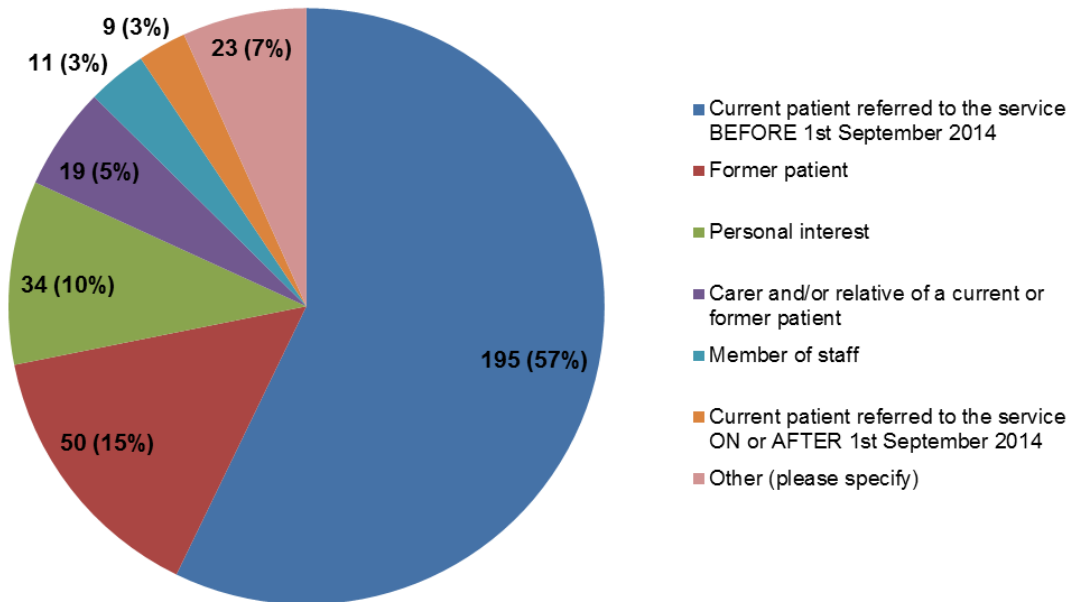
## 4. ENGAGEMENT OUTCOMES

### 4.1 Survey responses and questions

A total of 342 survey responses were received.

People were asked how they knew about breast care services in order to identify the different perspectives e.g. a former or current patient, a carer, a member of staff etc. It was also ascertained which breast care services respondents had experience of:

#### 4.1.1. In terms of the breast care services, which of the following best describes how you know about them?



The majority of the respondents were existing Southport and Ormskirk patients who were referred before 1<sup>st</sup> September 2014 (57%), followed by former patients of a breast service (15%).

Those who answered “other” included local residents, patients who attended screening appointments and a former member of staff.

#### 4.1.2 Which breast services do you have experience/knowledge of?

|   | Response Percent | Response Count |
|---|------------------|----------------|
| Ormskirk and District General Hospital                    | 79%              | 240            |
| Southport and Formby District General Hospital            | 64%              | 194            |
| Clatterbridge Cancer Centre                               | 52%              | 157            |
| Linda McCartney Unit, Royal Liverpool University Hospital | 20%              | 62             |
| Christie Hospital NHS Foundation Trust                    | 6%               | 19             |

|  |    |     |
|--|----|-----|
| Royal Edward Albert Infirmary, Wroughtington, Wigan and Leigh NHS Foundation Trust | 5% | 16  |
| Other (please specify)   |    | 82  |
| answered question  |    | 305 |

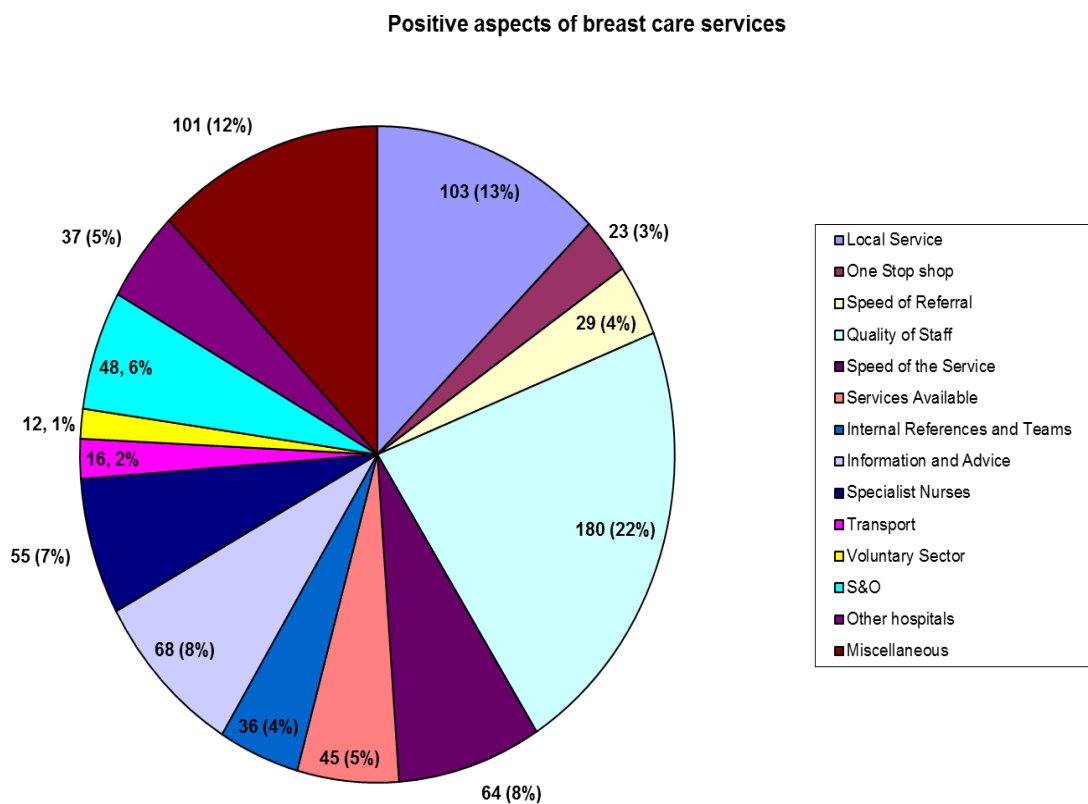
The majority of respondents had experience/knowledge of Ormskirk (79%) and Southport (64%) hospitals, and 52% of the Clatterbridge centre.

The 82 responses in the “other” section included Aintree, the Marina Dalglish centre, the mobile screening units, Royal Preston Hospital and Whiston (St Helens and Knowsley Teaching Hospital NHS Trust).

#### 4.1.3 Please tell us about the positive aspects of your experiences/knowledge of local breast care services.

Over 800 positive experiences were reported from 314 responses. The responses can be grouped into the themes shown in the following diagram:

Diagram 1:





### **Local service and a “one stop shop”**

**Having a local service was seen as very important to 103 respondents, where 23 replies also indicated their preference for the “one stop shop” approach to service provision.**

*“Being close to home when undergoing treatment, such as chemotherapy, cuts down on the negative aspects of travelling when unwell. Transport links and costs can also be a problem if too far away, so travelling to Southport was helpful as I was able to arrange lifts that did not cause inconvenience to others. The mammogram appointments at Ormskirk have been good. No waiting and able to walk there from work. Staff very nice in all local services. Encouraging to have support close to home.”*

*“At a time of great worry and trepidation the fact that all clinics and support was LOCAL was of vital importance. Diagnosis, treatment and follow up clinics, mammograms and check-ups that are local have been a great benefit.”*

*“I had six months of chemotherapy for breast cancer at Southport and Formby District Hospital. Having my treatment and being able to see my oncologist in Southport where I live, made this difficult treatment so much more bearable. Some treatment days could last up to 6 hours and if I then had to travel back home from another hospital further away from my home this would have added to the stress. The team I had at Southport where a constant support at the most difficult time in my life.”*

*“One stop care - I had the mammogram, FNA and core biopsy all at the new patient appointment. I got the results of the first two tests before I left, you don't get the results of the core biopsy at the appointment. It's good to know results before you leave so that you are not going away for a week or two and worrying. You've got consultants, nurses and breast care nurses and you can access these if there are any concerns, at short notice over the phone or in clinic, especially when just starting treatment as very scary. The breast care nurses can also allocate to consultants' clinic list and if it was something they could not deal with. It's close to home.”*

### **Speed of referral and quality of staff**

**Respondents (29) commented on the speed with which people could access the service, with the highest response, 180 replies, highlighting the overall quality of staff providing services, across all locations.**

*“Everything is positive. Doctors, nurses, breast care nurses - all are excellent. we don't want change.”*

*“Team have been excellent, doctors, nurses, surgeons. I have been well informed along the patient journey. Ormskirk is a better hospital in every aspect. It is very clean.”*

*“Familiarity - staff know you, you know them. Friendly, caring Good care received, Peace of mind. They do what they can to fit in with you if you are working regarding appointments.”*

*"Everybody is so nice- you are taken like somebody special from room to room, each service, each person gives you VIP treatment - it was like you were the only one who mattered. Privacy and dignity maintained constantly even in people's volume of speech. The breast care nurse is always there when needed. I had a card with her details on it. She knew me."*

*"Breast care nurses and consultants go that extra yard for you. I saw the GP yesterday and had an appointment 11am today it's been very quick and put my mind at rest. The surgery for breast removal went fantastically well, a really, really good package of care. I received help to bathe, to improve the mobility in my arm as the cancer had a knock on effect on my muscles."*

*"Clinic Apt offered quickly after seeing GP. Results given same day after scan and needle biopsy. Support from Specialist Nurse - excellent support during appointments, checking my understanding, clarifying uncertainties, answering questions - felt like she was my 'advocate', asking questions for me if I forgot or was unsure about something. Also made it clear I could contact anytime or seek help and advice."*

#### **Speed of the service and services available**

**Once services had been accessed, 64 replies, commented upon the speed with which results and a range of services could be provided. Particular reference was made to the scope of services available, where provision across a number of sites was recognised, with the preference for these to be on either the Southport or Ormskirk locations.**

*"Operation Date offered within month but delayed at my request, after asking for advice for." "A friend was fast-tracked after finding a lump. The service was very quick and friendly (Linda McCartney centre)"*

*"Treated very quickly since phoning the doctor both in Southport and Ormskirk hospitals."*

*"Clear treatment plan explained. Quick referral into service initially then shore wait for surgery, results etc. Very trusted and well renowned breast care service at Aintree and trusted surgeons. Availability of the Marina Dalgligh Unit for Chem and MD volunteers for invaluable complimentary therapies."*

*"Excellent and quick treatments once diagnosed. Surgical team very good. Oncologist excellent. Breast care nurses fantastic and so necessary."*

*"Exceptional care and sensitivity throughout. Speed of diagnosis; excellent communication; successful procedure followed by exceptional care on Ward H, Ormskirk. All of the above gives reassurance at what would otherwise be a very worrying time. Thank you."*

#### **Internal communications and team working**

**Service users complimented the way referrals were made across different clinical disciplines and how teams were used to maximise skills and the patient experience.**

*"The breast care service at Ormskirk hospital sent me for physio, addressed my pain relief, arranged a lighter weight prosthesis to help fibromyalgia, sent*

*me for a proper bone scan - I received a fuller package of care at Ormskirk, they addressed all of my needs, not just the immediate ones, e.g. the surgeon was in touch with the pain clinic - it works here!"*

*"Experienced and highly dedicated team, from the Consultants, Specialist Nurses to the admin person booking the target referrals. A huge loss to the local population when it closed."*

*"Very quick diagnosis and got appointments for x- rays/ mammograms/ ultrasound very quickly through the breast care nurses. All very helpful with information and making arrangements."*

### **Information and advice**

***The provision and quality of information was welcomed by 68 respondents, examples of which include:***

*"All staff involved are supportive and answer any questions. I've always felt fully informed every stage of the way, aware of options, possibilities and what might be/might not be?"*

*"The whole process from diagnosis through to treatment could not have been better every process was explained from start to finish and no matter what questions arose there was someone ready and willing to answer and explain and more importantly allay the fears."*

*"Easy read breast screening booklet"*

### **Support from the voluntary sector**

***The role of the voluntary sector in providing support was also recognised in 12 of the responses.***

*"I joined the lift up group after my initial treatment. At the time meetings were held in the hospital which probably slowed my joining of the group as I'd seen enough of the hospital environment. Meetings are now held outside the hospital which is good. I have enjoyed the group support both when I was a new member and could ask how others were coping and am now able to offer help to newer members still in the throes of treatment."*

*"Support provided by charitable organisations such as Big Sista Love which offer an art therapy , less traditional approach to breast cancer survivors."*

*"Sarah's Stars. St Rocco's Hospice provided counselling for my daughter who was 11 years old and took it hard. They also gave me physio when I needed it."*

*"Headstrong Pamper group in Marina Dalglish on Tues am, Reiki, Nails, Facials, Arm Massage, Support Session, Hope Course, Support Group, Own Macmillan nurse, Support and Welcoming staff (talk about anything)"*

### **Specialist nurses**

**Over 50 respondents were highly complementary about the specialist breast care nursing team and the assistance they gave to patients, across all elements of their clinical journey.**

*"I found my treatment which began 12 years ago to be good. From my GP through to surgery and aftercare I felt supported but especially from the breast care nurses."*

*"She came to visit me at home during treatment so I was able to talk in a relaxed and non-pressurized environment about my concerns and fears. As my treatment continued with follow ups at regular intervals at the local hospital, the breast care nurses were always there to support."*

*"Really good experience I've felt as if I've been' looked after' the nurses are really good they explained everything and the follow up care has been really good."*

*"With the breast care nurses you don't feel like there are any stupid questions."*

### **Transport**

**Where services were provided away from Southport and Ormskirk the provision of either transport assistance or the facilities on these other sites was regarded as important (16 responses).**

*"Transport – Patient Transport Service has really helped to get to Clatterbridge and Ormskirk. Everything else is fine too."*

*"Attended Aintree daily for 1 month. Transport excellent Treatment at Aintree excellent"*

### **Hospital sites**

**Respondents indicated 48 positive comments about services on the Southport and Ormskirk sites with 37 indicating positive experiences at the other sites contributing to the overall service offer.**

*"Surgery at Southport, it's local and not difficult for relatives to visit." Aintree was excellent. I was impressed with the radiotherapy service, how the staff explained things - so pleasant and very personal. Ormskirk is good too."*

### **Miscellaneous**

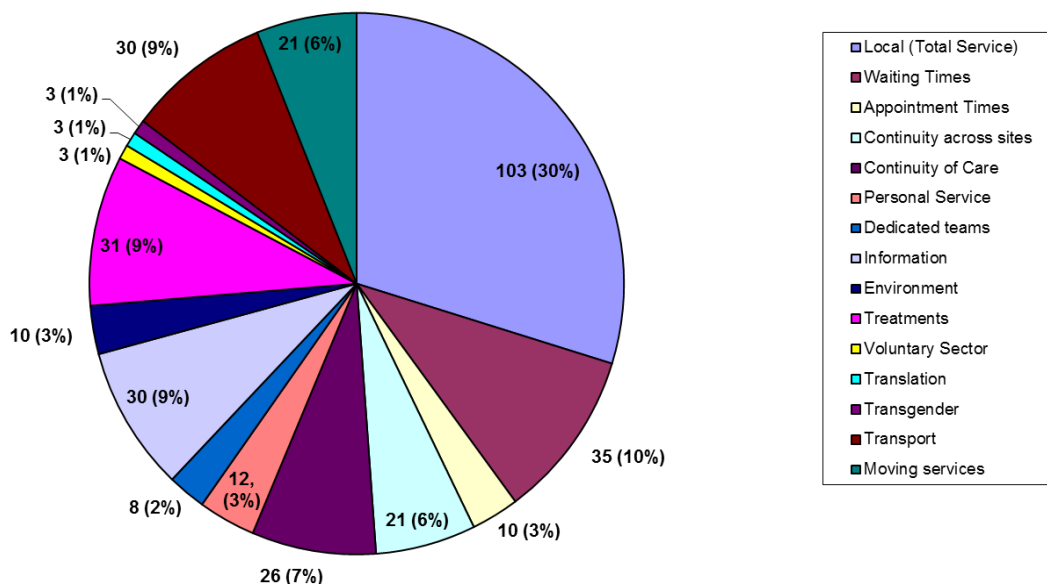
**In the miscellaneous comments, most of these related to single entries where patients commented on the overall provision of service**

#### **4.1.4. Please tell us what aspects of the services could be improved.**

**Over 300 suggestions were made from nearly 260 responses to the survey. The following themes were noted:**

**Diagram 2**

**Areas for Improvement**



**Local service and movement of services**

The majority response was the need to ensure that there was a strong local service, 103 responses, with a further 21 responses challenging the movement of services away from the Southport and Ormskirk sites.

*“A more dedicated team offering the fullest range of services. More services delivered from Ormskirk and Southport.”*

*“To have more services locally e.g. having radiotherapy at Southport and Ormskirk rather than Clatterbridge.”*

*“Please keep aftercare local with full support from people we can learn to know and trust so can talk freely and easily about our concerns and feelings.”*

*“I received a follow up appointment at Wigan. A local, Ormskirk clinic would be more convenient. However, Wigan staff & DR were fantastic. I had utmost trust in their experience.”*

*“Maintain all services at Ormskirk Hospital and Fazakerley Hospital for any current treatment.”*

*“It would be ideal to keep review appointments at Ormskirk in the future it’s good that it’s local”*

*“Being kept local! If you have been told you have CANCER you don’t need the extra trauma of having to travel, for treatment. Ops and clinics.”*

*“The distance travelled and the time it took to get to my daily treatments at the Marina Dalglish centre was on occasions very tiring.”*

*“Retain the breast care service at Southport & Ormskirk - for distance / congestion reasons - travel to either Preston or Liverpool takes a large portion of the day and when trying to work full time is not feasible.”*

### **Waiting times and appointment times**

**Patients were looking for improved waiting times, especially for follow ups and more regular screening. They were looking for longer appointment times and greater flexibility with appointment times. (35 and 10 responses)**

*“After my check up with the Oncologist (after Operation) I waited quite a number of weeks before I had to ring Ormskirk hospital to remind them about my follow up appointment with the surgeon - that probably was because of the closure of the department and my surgeon left the hospital.”*

*“Reduce the waiting time for diagnostics e.g. I was advised I needed an MRI scan but I was initially advised this would take place in 3-4 weeks. For peace of mind I would have liked this sooner.”*

*“Waiting times. Chemotherapy and consultant appointments, and sometimes blood testing, always involved a long wait at Southport. Some follow up appointments for consultation at Ormskirk (2013/14) involved many hours of waiting prior to seeing a consultant for an appointment that lasted five minutes. Being local to home though meant I was able to pop home for a cuppa and drive back in time for my place in the queue!”*

*“When I was going through my Chemotherapy treatment I found the waiting around very difficult I had to wait for the drugs to arrive each time before I could start”*

*“Occasionally consultant appointments in the afternoon can be up to 2 hours after scheduled time due to over-running clinics in the morning at other NHS locations.”*

*“Waiting times for results is an issue. I was waiting in the consultant’s room for what felt like ages waiting for results of a test it looked like everyone knew it was bad news but no one wanted to tell me they left me waiting instead.”*

### **Continuity, personalised service and dedicated teams**

**Respondents are asking for priority to be given to ensuring continuity of care when services are provided across a number of sites (21 replies) with 26 patients stressing the need for continuity of care based on a person centred approach (12 replies) provided by dedicated teams (8 replies)**

*“I feel you need continuity with the team of consultant and staff who were with you from the start.”*

*“Continuity when staff are on leave/off sick - I experienced a gap during a period of staff sickness. Not being told when mammograms are due - I attended today and was told I should have already had a mammogram. Mr*

*Haq has now left and gone to Birmingham as there is no work for him here - it should be a priority to keep doctors."*

*"Post-surgery I was upset that I did not receive a phone call to follow up. It would have been good to talk to someone."*

### **More follow ups/contact/ appointments with breast nurse.**

*"The Royal, Liverpool. Three years ago I went there for breast surgery. I was shovelled into a side room to wait, other patients were allowed their husbands to stay but my sister wasn't allowed to stay. I went for the injection, then went back in to the waiting room. Seven hours passed until I got a bed.*

*There was then a two hour wait before surgery - no real explanation was offered, no-one checked on me I was just advised I "was last on the list". I was discharged later than planned so I hadn't ordered any lunch, but they would not get me any. There was nobody around at the time of discharge so when my lift arrived other visitors helped me put my coat on and carry my bags. I have a lot of pain from the fibromyalgia, in addition to the pain from surgery. The team there didn't acknowledge the fibromyalgia. I had problems with pain relief and my regular medication was not sorted out. I am allergic to lignocaine, but there were no other alternatives available and so I was advised to come back another time. From March to November I did not have a prosthesis as the invite letter was not sent to me to go for a fitting. The staff were off hand with me at the bra fitting service."*

*"Communication between departments, support after treatment finished - felt "left to get on with it" - I sort out support group but not everyone would do this."*

*"Communications between hospital, GP, District Nurses and patient need improvement. Protocols appear different between different sectors providing care. There was confusion re anticoagulant administration as different surgeons used different protocols. District Nurses used different drain rate to indicate time to remove - not same as hospital."*

### **Information and environment**

**The provision of appropriate and supportive information was highlighted by 30 respondents where 10 people felt that adjustments were needed to the environment in which services were delivered.**

*"More information from breast surgeon or breast care nurse tailored to individual needs. e.g. for me - services available for younger women - Facebook group (YBCN), Willow Foundation."*

*"Signposting to free support services, complimentary therapies, support groups etc."*

*"More specific short-term information i.e. The process of "What's going to happen next?" "how long do I wait in the hospital room, who and what am I waiting for, what do I wear, why/ when should I contact a nurse, what should I try to do by myself, when can I go home..."*

*“From point of finding out about my diagnosis up to my actual surgery information and communication from breast nurses and doctors was limited. Also the aftercare was limited; leaflets were the only information that I could source help. So information and communication needs to improve.”*

*“I was admitted to Southport hospital over a weekend due to a high temp through casualty. This experience was frightening as I was alone in a side-ward as a range of different doctors came and went and stuck needles in me. They were friendly but I got little explanation of what they were doing and why or if I would need to stay in or for how long. I was put in 2 different wards and was very unhappy and worried that, due to low immunity (following chemo) I would catch something from the other patients and the smell of patients using commodes in the bays surrounding me seemed to linger and was really unpleasant. Nurses were busy ""handing over"" and filling in forms and had little time to see to patients. At night, doors and curtains were closed and restricted their vision of what was going on in the wards. Patients were waiting for help to go to the loo etc. and my drips remained attached for long periods of time after they were finished. "Ring the bell when it's finished and I'll come and take it out for you" would have helped. Rather than feeling like I was an inconvenience when I did ask or ring the bell.”*

*“A walk in centre where people could meet and just talk when the terrors of the disease got the better of them.”*

*“Routes for advice were very unclear and no one seemed sure how to deal with queries. Each time I seemed to go around the houses to get an answer.”*

*“Patients leaving after receiving their results may well be extremely distressed. They had to walk out through the waiting area this is embarrassing for them and very scary for those walking up to you. Another exit or a private room would be made available.”*

*“Southport isn't clean and seems a bit of a mismatch - I had to see Dr Hyatt and needed to walk through patient treatment areas - not good for privacy.”*

*“to have all units wheelchair accessible”*

*“Would like bright waiting areas and refreshments and magazines.”*

### **Personalised support and issues relating to translation, gender and sexuality**

**Over 30 replies asked for a comprehensive provision of services, including psychological support, with consideration being given to translation services, the needs of single sex relationships and the requirements of the transgender community.**

*“Emotional support - need someone to talk to. Difficulties using the telephone. Surgeons - abrupt; could improve bed-side manner (Southport).”*

*“Health records do not reflect transgender information causing embarrassment and inappropriate breast screening invitations, or no invite for screening. Some individuals fall out of the system. Unsupportive and uneducated GP's and health professionals – have no understanding or*



*knowledge of transgender issues. Tailored support throughout treatment and after treatment especially as this group more likely to be vulnerable and isolated to have all units wheelchair accessible.”*

*“I want a local service. Public transport is difficult to Aintree. I would also like a translator.”*

*“From a lesbian and gay perspective, lesbians are more likely to suffer from or be at risk of breast cancer as there is a correlation with having children. Lesbians are still less likely to have children. I think this is a need which is hidden or not promoted and there needs to be some specific awareness raising.” [Further info provided]*

### **Transport**

**Accessing services was seen as a key element of the service where transport, particularly public transport availability, and car parking needed to be improved to enhance the patient experience. Here some responses asked for more services in Southport rather than having to travel to the Ormskirk site.**

*“I am fortunate in having family locally in Liverpool with whom I stayed the night before chemo treatment and a couple of days after to recover from sickness etc, otherwise would have found it difficult travelling to and from appointments.”*

*“Perhaps not having to go to another hospital for other things like Isotope injection.”*

*“Transport - not the wait, but the discomfort.”*

*“Attending Clatterbridge for chemo/radiotherapy - if you don't drive it's a long day especially when feeling unwell.”*

*“I had all my treatment at the Royal & Clatterbridge. I would say transport could be a problem for quite a few people. I had to travel by train and public transport, which when you are feeling not too good is not very satisfactory.”*

*“Having to keep answering the same questions when booking Patient Transport Service.”*

*“Would have been good if oncologist could have clinics in Southport instead of just Ormskirk.”*

*“Have mammograms at Southport again rather than just at Ormskirk”*

*“Should be available in Southport.”*

### **Treatments**

**Respondents made the following suggestions for improvement to treatments:**

*“Increase number of breast care nurses (with training in helping/ counselling skills)”*

*“Use of dressings post op that less people are allergic to.”*

*“More urgent care in A&E at Southport when neutropenic. Someone in A&E who can use a picc line. Separate ward in hospital for cancer patients. 24hr 7 days specialist cancer nurse.”*

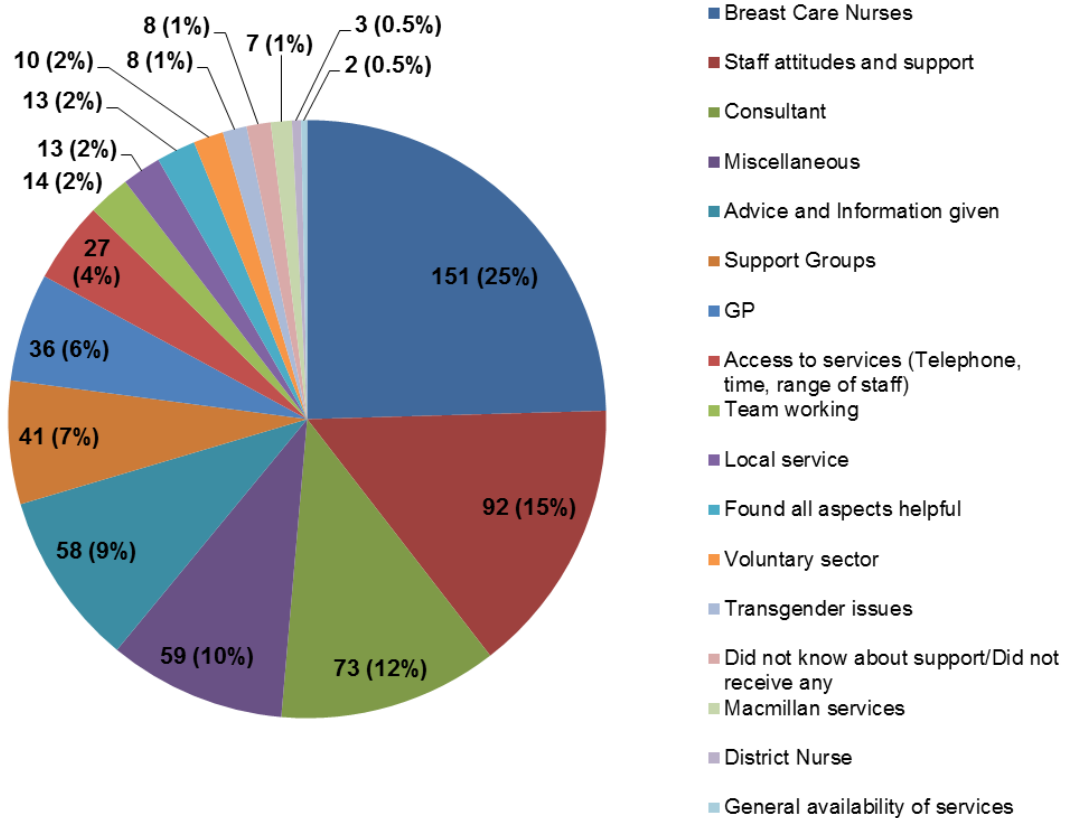
*“Mammogram process is painful wish there was a different way of doing the test.”*

**4.1.5. If you are, or have been, a patient of the service what aspects of after treatment support have you found most helpful e.g. consultant advice, breast nurse support/advice, support groups, GP support?**

There were 246 responses to this question generating almost 600 comments. The main themes are as follows

**Diagram 3**

### After treatment support that was found most useful



The most popular response for what after treatment support people had found most useful was “Consultant advice, breast nurse support” with 151 of the responses mentioning the service provided by the breast care nurses and 73 mentioning their consultant. Respondents valued the staff attitude and support, and advice and information provided by these two staff groups.

### **Breast care nurses**

**The value of the support and advice provided by the breast care team was strongly recognised by respondents, and they appreciated the relatively easy access to this:**

*“Breast care nurse - you know they are always at the end of the phone and if you leave a message they always get back to you ASAP. It's having a point of contact rather than a vague department.”*

*“Breast care nurse was excellent I was given leaflets and books that were useful. The breast care nurse even came to my house to see me this gave me reassurance and confidence”*

*“The breast nurses provided an invaluable role, always available to reply to queries if they were unable to help they knew which direction to point me for appropriate advice.”*

*“To know I only need to ring the breast care nurse about a concern rather than possibly having to ring the GP and start at point 1 is very valuable.”*

*“Consultant advice; breast nurses fantastic e.g. lymphoedema spotted by a breast care nurse - referral to lymphoedema nurse - also excellent.”*

### **Team working**

**Respondents recognised the benefits from the health care staff working as a team, and also valued seeing the same team/individuals on a regular basis:**

*“Follow up services are excellent, Even though I have my MRI and Mammogram every year it's still really worrying to go for the results.”*

*“The breast care nurses and Clatterbridge radiotherapists - the way they speak to you and allay your fears - the teams are second to none. And they work as a team. Seeing the same surgeon for check ups means a lot too.”*

*“I found the consultant advice, breast nurse support/ advice and GP support most reassuring. All these work well together at Ormskirk and makes attending clinics less daunting.”*

*“Continuity of Consultant care - maintaining a direct line with my healthcare team.”*

*“A week after completing my radiotherapy I was concerned that my skin may have become infected. Having called the number I was given to discuss my concerns I was then contacted by Clatterbridge Centre, Aintree and given an appointment on the same day to have my wound looked at, which was reassuring.”*

### **Support groups**

**The benefits of a support group were acknowledged by 41 of the respondents, including the therapies and courses they offer:**

*"Support group Sarah's Stars".*

*"Complimentary services were good I attended a session at the Linda McCartney unit about makeup and how to tie a scarf your self-image really suffers when you have treatment like this but these sessions really helped."*

*"Occasional telephone calls from BCN. Attending hospital support group. Attending 'pamper sessions' weekly at Marina Dalglish in Aintree for on-going support."*

*"Support groups - I found the retreat at Aintree unit very helpful. did not find much formal support after treatment finished. No real support by my own GP?"*

*"Even after 12 years I still greatly value the support of lift up to help quell fears that still arise."*

*"Starting Over course at Halton Hospital.GP support"*

*"Breast care support group including therapies such as rekei/reflexology - really helpful."*

### **GP**

**The GP was mentioned as being a helpful resource following treatment by 36 respondents:**

*"It's all been good. GP been excellent."*

*"GP support from my local GP practice."*

*"The consultants have been most reassuring, as my GP."*

### **Other and miscellaneous**

**Other helpful resources for after treatment support were district nurses and Macmillan services, oncologists, radiology team and volunteer drivers:**

*"District nurse made regular visits and checked on drains. Macmillan nurse community centre - Scarisbrick Avenue was helpful to go and talk about experience."*

*Volunteer drivers for transport to Clatterbridge/radiotherapy invaluable."*

### **Members of the In-Trust transgender support group commented:**

*"GPs supportive of transgender population makes all the difference to mental and physical health and wellbeing. Less traditional typed of aftercare such as art therapy sessions provided by Big Sista Love which are held in the community."*

**Just 8 respondents (1%) did not know about the availability of or how to access after treatment support.**

#### **4.1.6. Do you have any other comments about local breast care services?**

The main themes emerging in the responses to this question were:

- to keep the service local for emotional and practical reasons
- the need for other supporting, complementary services
- the importance of continuity
- concerns around the lack of information
- suggestions for improvement

Specific examples of the above themes are as follows:

##### **A local service**

*“Keep it local for patients who are unable to travel, breast care is an important service for women which is better closer to home.”*

*“Don't want to go to Liverpool, getting there is a problem especially when you're unwell. It is difficult enough time, but if you've faith and know the people who are treating you it helps.”*

*“Appreciate not having some specialist staff is a problem and therefore the acute elements of the service may have to be provided elsewhere, but as breast cancer is such a common condition, it's a shame not to have the 'outpatient' elements kept locally. Especially as numerous visits to clinic are required, some people do not have access to cars for easy transport to other non-local hospitals at such a stressful time.”*

*“Patients have enough worry and anxiety when attending the breast service and moving it further afield just puts added stress and anxiety that is not needed when there is a perfect local service.”*

*“I am concerned at how far any patients will have to travel for treatment given that Ormskirk & Southport won't have a service. My experience was one of ten months filled with appts across three hospitals, I was incredibly tired, so weary, I used hospital transport and sometimes friends took me, despite a generally excellent service, the parts that let it down to me seemed so avoidable, down to poor admin, breakdown in communication, depts out of touch with each other etc.”*

*“I have been extremely impressed with all the local services provided by Southport and Ormskirk hospital. The access to local hospitals means that there is not the added stress of a long journey at what is a very difficult time. I would like to see this local service retained. I travelled to Aintree for radiotherapy but this was a short term, time-limited activity and I prefer to have a local continuity of care.”*

*“It's atrocious that the service could be going as far afield as Aintree. This would be very difficult. I have a young family, if you are going to be introducing extra travel it will make it very difficult. I've still got to meet my*

*family's needs. It will be harder for my mum who is going to be moving into this area - the train from Burscough to Ormskirk and then onto wherever. The train from Burscough to Ormskirk is only every hour and 45 minutes. The hospital destinations are not near. Southport and Ormskirk Hospital Trust is friendlier and more personal. If you are transferred into a massive service are you going to have the same personal experience, especially for something that is so life changing for the patient and their family? It's difficult to make a choice when local provision is not available. If people start to use more Patient Transport Service to get further away, The Patient Transport Service are already in demand but this will increase demand."*

*"If you've got a long way to travel and then get bad news, it will be very difficult to get back home."*

*"People will need more time off work with increased travel, not all employers would allow this, so they could postpone their appointments or it could lead to Did Not Attends."*

*"It's wrong what has happened with the breast care services and its move to Preston, Liverpool, Wigan, Whiston etc. It's detrimental to patients. Vascular services have been consolidated so that major surgery takes place at a Liverpool hospital but all your investigations, specialist nurses, consultations etc. take place locally, this model makes services more accessible."*

*"We've been told the service is closing 31st March - I can't understand why they are closing it. Cancer is not uncommon. 1 in 3 women are affected by breast cancer therefore there should be full services in all local hospitals. As I have a physical disability I needed the Patient Transport Service to get to radiotherapy - the Patient Transport Service have rickety old vehicles which cause a lot of pain due to my muscle problem. The Patient Transport Service is a good service and amazing if you just needed to use it once a month but every day for three months was horrendous. At one point during radiotherapy I was thinking of giving up due to the additional pain. Requesting a car via the Patient Transport Service was very stressful. I had a reoccurrence of cancer and I've just had a scare, I found a lump. If I had to go to Wigan or Liverpool this would be too much of a trek for me. I have no family in the area. Transport is a problem. The care from the breast service is faultless. It's disgraceful that it is being closed down. I've petitioned my MP John Pugh. We've got to have local services. It really upsets me that if I have another scare I might have to go to Wigan, I can't bear the thought of Patient Transport Service due to the discomfort and the follow up as well. The follow up can be for five years."*

*"Elderly people, amongst others, will not be able to travel easily. This could result in an increase in the number of Patient Transport Service bookings and a corresponding increase in cost. Also a lot won't go if services are moved. People may decide not to come thinking "that's my lot". It's very off putting the thought of more travel. If you are an inpatient you need visitors, but extra travel and fuel may reduce the number of visitors. Will the so called "super centres" be able to cope with the extra numbers? Will people get the time and attention that is needed? They may have to take time off work too to accommodate the extra travel time."*

*"Why do people have to travel to Liverpool - this incurs cost and time at a time when you are vulnerable?"*

*“My niece has just had to travel to Liverpool at age 18 to be seen for breast screening. This was very traumatic for her as again she felt communication was poor. Staff need to be reminded that not everyone is able to ask the correct questions or are even aware of questions to ask. The need for kindness is paramount.”*

*“I am saddened and disgusted by the closure of this excellent service in my local community. I could understand if the service was deemed "not fit for purpose" but I have not heard a bad word about the breast care services in either Southport or Ormskirk. I worry about the travelling distance for new patients, in particular elderly women, having to go to Aintree, The Royal Liverpool, Wigan or St Helens if they do not drive or have somebody to drive them there. I am not aware if there is a direct public transport facility to these hospitals. Also, I am amazed that in this day and age of high technology why was digital x-rays with another local hospital not put in place in the interim period until a consultant radiologist had been appointed? Another point that concerns me, should a public consultation period on the closure of this service, been put in place?”*

*“Initially I was receiving appointments for different clinics at different hospitals on the same day, meaning that some would have to be rearranged. A local service, "one stop shop" would have been far easier to deal with and I am sure would result in less wasted appointments where people do not attend due to clashes with appointments at other hospitals which are some distance away.”*

*“The population of West Lancs is big enough to have its own breast care service.”*

*“Follow up clinics must still be offered at Ormskirk Hospital. Breast care nurses must still be based at Ormskirk. Diagnosis clinics could still be offered at Ormskirk with support from another local unit eg Whiston Hospital.”*

*“To be kept in Southport- difficult to fit appointments in around work commitments. (Family History Patient)”*

*“I've attended Aintree and find the treatment at Ormskirk a lot more personal. At Aintree I felt like a number on a conveyor belt. It was also more difficult to get there I don't drive and had to get someone to take me and parking is difficult. Even the consultant didn't seem to have enough time for you.”*

*“People who don't drive will have difficulties there are limited bus services in most of the rural areas and it is even worse if you're feeling poorly”*

*“It would be most helpful to patients to have the breast services "local" no excuses about difficulty recruiting specialist/Radiographer. A lot of people find that excuse hard to believe. The NHS is said to be for patients, not bonuses. It has been decided that other hospitals will be used for diagnosis, i.e. Aintree hospital, if some form of transport were available it would soften the blow, especially for those without private transport.”*

### **Other supporting/complementary services:**

*"I have concerns about the future of the bra service. Now, I go to Southport Hospital. I knock on the breast care nurses' room, don't need an appointment, say I've brought my bras to have a pocket sewn in and leave my details. The altered bras are posted back to me. What's going to happen with this service in the future? This service isn't available at Wigan. My friend is given pockets to sew herself. Now the safety net has gone if the service is not running anymore."*

*"If the breast-care nurses are not going to be here after March where do we get a prosthesis from when they burst? Who will be the point of contact for patients?"*

*"I'm concerned about the Prosthesis service were will this be I would have difficulty traveling to Aintree and am concerned about possible waiting times there"*

*"Regular screening is important, especially when you have had experience of breast cancer. Southport calls us for mammogram and X-ray in between appointments. That will stop. It's now self-referral. I was discharged today so advised to ring Houghton St regarding screening, the next appointment is 2018 - I would prefer annual screening for peace of mind."*

*"Hopefully aftercare will be able to be local and that the service of the complementary massage therapies will be continued. To have help to reduce stress and tension in this way is most important. The breast care nurse role is vital, as she knows her patients very well. Breast cancer is very emotive and it is important not to feel on a treadmill as a number rather than an individual. Please don't lose the knowledge and skills of the local breast care nurse, one has already left."*

*"The small local caring setting at Ormskirk and Southport is vital to BC Services. The range of support services provided, groups and particularly 'pink pamper days' at Hurlston Hall (arranged by BC Nurses, Sarah, Trish and Janet) provided a unique sharing and support experience. This involved a social gathering of about 100 bodies who were treated free of charge to a lovely buffet, manicures, foot massages, Reiki treatment, etc. A very personal touch. Just a measure of the extra mile this BC service has provided."*

*"I think there is a need for support for families this could be through voluntary organisations it would also be good if we could have complimentary therapies at Southport."*

*"The vital support of a local breast cancer nurse is being removed. In the community she can quickly answer questions/give advice over the phone/direct who you need to see/provide new prosthesis etc. I think this is a HUGE loss. Also communication from different hospitals to district nurses about new patients and differences in care need thinking about."*



### **The importance of continuity**

*“How many times can you flash your boobs to new people? Part of my breast is missing. I feel very uncomfortable when there are new people there in clinic. It's the psychological effect as well as the physical ones, for years after the surgery I felt uncomfortable about going out and did people know? The radiotherapy alters the appearance of the breast too. If you go to one of these super centres will you see the same surgeon for all appointments?”*

*“It's a good service. I want it to be kept here. I've received really good care. I don't want to go anywhere else. I worry about longer waiting times if using Trusts in another area as they've already got their patients, there will be more people on the waiting list and things could get missed due to the increase in volume of patients.”*

*“As a patient at the end of my treatment (5yrs) I was told that I would now go onto routine checks every 3 years I feel this is too long to go and am concerned something would be missed. Feel it would be better if we had a phone number we could ring or a drop in surgery”*

*“I am worried that I will not get good after care. I am on tamoxifen for possibly 10 years but if staff are made redundant due to no new patients, I will not get the support that I might need. I am not in favour of phoning a number for anything or discussing personal information with a stranger so the one to one support and discussions from all staff (consultant and nurse) is important.”*

### **Concerns around the lack of information:**

*“Today I have been to see my Oncologist at S/port Hosp; and to my horror I have been told by my Oncologist that he will NOT be seeing me again. He was unsure whether I would be seeing ANY OTHER ONCOLOGIST in the future. Now that is, for me and I suggest many other Cancer sufferers, very, very bad news. Having undergone a full Mastectomy and subsequently diagnosed with secondary cancer of the Femur I was lead to believe that I would be seeing an Oncologist at regular six monthly intervals. Knowing this has been very important to me mentally as I battle with this dreadful disease. To have this service taken away is almost as deflating as being diagnosed with the disease. Not only is it the knowledge that you will be seeing a Specialist that helps you to be positive it is the help and medication that goes with each consultation.”*

*“Having brought my concerns to the meeting with trust CEO and co, I was advised that J Parry would write to me regarding prosthetics, his reply said I would be put in touch with the breast care nurses. I spoke to my breast care nurse who wasn't able to shine any light on the problem. I feel that the CEO has not considered the effect this closure is having on patients, past and present. I feel that those of us who are just completing our treatment and follow up are being left out of the information loop.”*

*“I will be extremely sorry to lose this wonderful service, after re-assurances at a public meeting in December by Jonathan Parry that he would do his best to ensure follow-ups etc. stay in Southport and yet only a month later I hear we are to lose these at the end of March too. Once again this appears to have*

*been decided behind closed doors, as there is no mention of it in the last Trust Board Minutes for December I accessed on line! I spoke to my Breast care nurse last week, who confirmed that we would lose the rest of the service at end of March 2015! She has not been informed what provision will be made for follow up appointments etc. so I am now unclear where or when I shall be followed up. My next appointment with the Oncologist is due in mid March, I hope this will take place at Ormskirk Hospital as planned."*

*"Concerned that if any patient should have concerns reoccurrence etc who do we go to? I feel we've been abandoned."*

*"I believe that the support I get from the breast care nurse is to be discontinued from the end of March ?? Firstly this is disgusting as I will no longer have any support person to turn to. Secondly were am I to get my prosthesis from I didn't ask for cancer to strike me & to have my breast removed so why should I & many other people suffer , so answers would be grateful or are we to find out about another service to be lost via the newspaper!!!!"*

*"Would like to know where I am likely to be sent now to see the doctors."*

*"This confusion about Ormskirk hospital we the patients are in the dark and don't know how things are going to be. Please keep me informed. Don't Desert Ormskirk. Very confused about what future holds. Appointment etc. April appointment at Ormskirk with regular consultant, I will still go and hope to be seen."*

*"I have been a patient since 2008, lately I have found things quite distressing as first my breast nurse left, now I have been told my oncologist is going these are people who have cared for me for seven years, however when I ask what the future holds no one seems to be able to answer the question. I feel the trust is waiting for all us long term patients to ask for another trust, so it does not reflect badly on them as if they have forced us out. At the moment there is no continuity of care we are seeing different doctors and have no idea how long these will be around for. We trust these oncologists with our lives and I feel it takes time to build this trust which is never going to happen when we are getting passed from person to person."*

*"It isn't what you had to do it was the way it was done - it was ill-planned and ill-judged. You treated the medical staff shamefully. Why has no-one's head rolled? You had a great service and now the patients undergoing treatment don't know what is going on. You talk about choices - have any of them had a personal letter asking them where they would like to go?"*

*"The whole process of closing the service to new patients at Ormskirk, has a questionable timescale and communication systems in place to inform the population are flawed. The breast care services leaflet is full of incorrect and misleading information, this must be addressed and an apology and correct information published in the Ormskirk Advertiser and local Champion newspaper. Only then can it be stated that local consultation taken place."*

*"They need to be retained at Southport & Ormskirk however this does not appear to be the case and without any consultation with the public."*

### **Suggestions for improvement:**

*“There may be a national shortage of specialist radiographers but the laws of supply and demand would say that if you offer an excellent remuneration package you will attract high calibre, suitable applicants. I have raised £2000 this year for Clatterbridge Cancer care. I am one individual who isn't even firing on all cylinders due to my own Cancer treatment. If I had been given the chance I could have easily raised this amount towards the cost of a specialist radiographer and I am sure there are plenty more current or past patients who feel the same.”*

*“How do the travelling clinics work? Is that not an option?”*

*“Needs to be more disabled friendly, particularly Learning Disabilities.”*

*“Would like more advice on healthy lifestyle, fitness.”*

*“If you would like some training on Lesbian, Gay, Bisexual and Transgender issues, please get in touch. There are quite a lot of available resources.”*

*“Transgender education programme required for all NHS employees, particularly GPs and Clinicians.”*

*“Should investigate more about alternative medicines I used Chinese medicine to help me with the side effects of the Chemo it really helped.”*

*“We need a satellite breast clinic run from the centre of excellence with experienced up to date breast nurses , this is a paramount need.”*

*“It's a vital service, especially to those over the age of 50, which MUST be kept local, even if this is only by providing Satellite clinics!!”*

*“Would prefer local diagnostics on site adopting a 1 stop shop approach with service coordinated via one organisation.”*

*“I believe that the mobile breast scanning unit should be made accessible to women less mobile.”*

*“Improvements are required to the Ambulance travel service which is essential to elderly patients and to anyone with other health or painful problems.”*

*“District nurses could be more helpful after discharge, the hospital nurse said the district nurse would remove my drains when they were ready to come out, but they refused, so I had to go back to hospital to have them removed.”*

*“We need LESS managers and executives and MORE clinical staff.”*

### **4.2 Profile of survey respondents**

A detailed demographic breakdown of the survey respondents is found in Appendix C.

The data is reflective of the reach of the engagement and also the targeted engagement as recommended by the initial equality analysis.

### **4.3 Meeting and event feedback**

During the course of the engagement, the CCGs attended 26 meetings/events and engaged with 627 people. They also attended 9 breast care clinics and spoke to 69 follow-up and family history patients.

Overall, the feedback reflected the themes as outlined in Section 3.1 of this report (Survey Response), but as with the survey responses, these differed across stakeholder groups. Examples of these differences are as follows:

- Breast Care Support Groups included a high number of current follow-up patients who praised the care they had received at Southport and Ormskirk Hospital, expressed concerns about the future of their individual care and the lack of communication they had received in this regard, the importance of continuity of care and clinicians, and the support provided by the breast care nurses.
- Family history patient clinics praised the convenience and accessibility of the local service as especially as this enabled them to fit appointments in around work and family commitments.
- Older People Forums were concerned with travel and transport, ease of access, support/advocacy at appointments and valued the friendliness of a smaller hospital setting.
- Disability groups/migrant worker groups also were very concerned about travel and public transport, the availability of information in various formats and interpreters.
- Lesbian, Gay, Bisexual and Transgender groups expressed concerns about the accuracy of medical records and patient history and the impact on appropriate/inappropriate screening referrals; lack of education and the need for more innovative forms of aftercare support (one size does not fit all).

A full list of the engagement events and their related themes are included in Appendix A.

### **4.4 Patient Experience Team**

The Patient Experience Team received 87 enquiries ranging from people booking onto public meetings, callers wishing to log their comments on the service changes, people wanting to complete surveys over the telephone and general enquiries regarding the engagement. This feedback has been captured in the overall analysis.

### **4.5 Website comments**

NHS Southport and Formby CCG's website received 5 extensive comments from patients of the service expressing the excellent treatment they had received at Southport and Ormskirk Hospital and their upset at the sudden change to the service and impact on the continuity of their care. All comments

praised the professionalism and support of the staff, particularly the breast care nurses.

#### **4.6 Petition**

Initiated by the West Lancashire Councilor, Elizabeth Savage over a thousand people signed an online petition to Southport and Ormskirk Hospital asking that the trust: *“continues to recruit a radiologist for the Breast Care Services to prevent closure to this important unit at the Trust”*.

Each person signing the publically available online petition was asked if they wished to give their reasons for signing. Below is a resume of the main themes, which also reflect the engagement outcomes:

- **Travel and Transport:** concerns were expressed that the stress and tiredness of patients having to travel longer distances when feeling unwell was unacceptable, causing greater psychological impact. Cost implications were a concern, especially for those on low incomes and with no family support. A forty mile round trip to alternative providers was seen as an issue, particularly for those in more rural parts of the borough and for those using what was termed a “difficult” public transport system. Juggling work and caring commitments was also mentioned by patients and carers when travelling increased distances.
- **Local Service:** people said this was a vital, much needed service that they didn’t want to lose. Many commented on the excellent quality of the service that they had received at Southport and Ormskirk. There were concerns that services in Southport across the board were being reduced and that this closure was linked to cost savings.
- **Lack of consultation:** complaints were voiced that there was a lack of consultation when the hospital knew it was having difficulty recruiting and that patient choice had been removed. Concerns were expressed that the changes would put a strain on other hospitals.
- **Breast care nurses:** the level of support provided by the nurses was greatly appreciated and valued, particularly in helping patients to cope during a difficult time. Concerns were raised that support groups would fold if breast nurses were re-deployed.

#### **4.7 Equality Analysis**

Following the completion of the engagement, a full Equality Analysis was undertaken by the Equality and Diversity lead and can be found in Appendix 2.

The key issues and recommendations of the analysis are as follows:

- **Travel and transport:** consider the views and experiences of patients in relation to travel, as identified in the Equality Assessment and which responds to the report’s recommendations
- **Provision of local service:** provide access to elements of the breast care service in the Southport and West Lancashire areas

- **Accessibility:** ensure access to treatments for new patients are cognisant of patient need and develop reasonable adjustments, particularly for the frail elderly and disabled
- **Continuity of care:** to be addressed for existing patients as soon as possible and details/arrangements fully communicated to patients and providers
- **Communication and engagement:** a comprehensive engagement feedback and communications plan is required to ensure that all stakeholders are fully briefed on decisions and changes; target minority groups as listed and consider providing information in different formats and languages; engage with local CVS and minority group networks in communications.
- **Support services/groups:** ensure that these continue to be available in local community and are suitably resourced
- **Public Sector Equality Duty (PSED) requirements:** ensure staff are fully trained to deal with different ethnicity, sexuality and transgendered patients and that providers can demonstrate their compliance with PSED. As part of their Public Sector Equality Duties, the CCGs are required to address the key analysis recommendations.

#### **4.8 Other considerations**

The following issues arose during the course of the engagement, presenting some challenges and barriers to the progress and aims of the engagement:

- **Communication with patients** – follow-up patients expressed concerns about the lack of communication from Southport and Ormskirk Hospital around the initial closure of the service to new patients, and many were anxious about the trust's ongoing lack of communication regarding the future of their care.
- **Reasons for closure of the service** – scepticism was expressed regarding the reason for the sudden changes to the service with some people believing that it was a cost-saving exercise and/or that a specialist radiologist was a temporary problem which could be addressed.
- **Patient perception of service** – since the closure of the service to new patients, some patients perceived the service remaining at Southport and Ormskirk Hospital as second rate.
- **Engagement information and materials** – some people felt that the engagement materials implied that the quality of the original breast care service at Southport and Ormskirk Hospital was questionable; a few people commented on the complexity of the information leaflet and pathway diagrams and that, in part, these were difficult to understand.

These issues were expressed by individuals and groups and were captured in meeting feedback, survey responses, petition comments etc. The majority of these issues were addressed with the individuals and groups throughout our engagement activities and where appropriate, feedback to service providers

## 5. CONCLUSION

The aims of this engagement programme were to inform local patients, carers and the wider local community of the changes to local breast care services, explain why these have come about and to hear people's views and experiences of breast care services to help inform how these services might be provided in the future.

A variety of communication and engagement methods were used in order to reach as many people and be as inclusive as possible.

The aim of the engagement was to help the CCGs understand what matters most to patients about breast care services and to help shape future services. However, respondents also used the opportunity to share their disappointment and frustration around the sudden closure of the service at Southport and Ormskirk Hospital NHS Trust to new patients. They were also felt there was a lack of certainty about their future care - who it would be delivered by and where it would be provided from.

The vast majority of people who gave their views as part of this exercise had very positive experiences, no matter which hospital they had received care from. There was an overwhelming sense of gratitude, importance and passion when views were shared by both former and current patients of all breast care services and their carers.

The themes that emerged from the findings are that people want local service provision in the Southport, Formby and West Lancashire areas that offers at least follow up support and care, and ideally a complete service. There was some acceptance that certain services could not be delivered from the Southport and Ormskirk hospital sites but participants would certainly like to access the breast care nurses, prosthesis service, bra fitting service, support groups, review appointments, family history clinics, and mammography appointments locally.

Associated with the need for a local service were the perceived travel problems if services were to be provided out of the local area. This was from both a practical point of view in terms of the cost, extra time it would take, time needed off work and experiencing difficulties with public transport, and also from an emotional aspect in terms of having further to travel when already feeling tired, unwell or if receiving bad news, and having to also factor in carers'/family responsibilities. The Equality Analysis report makes recommendations for consideration around transport issues to mitigate the difficulties experienced. See Appendix 2.

The majority of responses – a high number of which were Southport and Ormskirk patients - spoke very highly of the support of their breast care nurses. In particular, they highlighted the personal nature of the service, the level of support and information that is provided and the accessibility of the service. People really valued being able to phone the breast care nurses and have a single point of contact. Participants also identified continuity of care and team working as being a real positive when undergoing treatment. They valued their relationships with the team and the relationships the team had with other health professionals/departments.

Speed of referral into the service and then to access to diagnostics and treatment was important to participants, and participants highlighted the "one stop shop" model to minimise the wait for results.

Participants requested better communication and information. Consistent messages are needed across the healthcare economy. From the survey responses 200 people

provided their contact details to be kept informed of future developments of local breast services. This resource will be an additional way to communicate plans going forward. Suggestions for ways to be more involved have also been received from LGBT and migrant groups.

This extensive communications and engagement programme has resulted in over 3,750 contacts and generated thousands of comments relating to the local population's thoughts on and experiences of local breast care services. It is recommended that this insight is considered and used to shape future breast care services. A further piece of communications and engagement work will be needed to inform people of how the future models of care will look and how their feedback has been used to arrive at these, and to also explain where it has not been possible to incorporate suggestions and why.



## 6. APPENDICES

### Appendix A

#### Timetable of public meetings/events/clinics and feedback

(Those meetings highlighted in yellow were open to the public and places on these events were bookable via the CSU Patient Experience Team)

| Event details<br>(for both CCG areas in date order)  | Feedback: main themes  |
|--|--|
| Wednesday 19 Nov – Southport and Formby CCG Big Chat, Royal Clifton Hotel, Southport                         | <ul style="list-style-type: none"> <li>• Service update</li> <li>• Plans for engagement</li> </ul>   |
| Wednesday 14 Jan – Aintree staff briefing<br>12 noon<br>Aintree Hospital                                     | <ul style="list-style-type: none"> <li>• Increase in number of new patient referrals</li> <li>• Distance and travel for patients from Southport and Formby/West Lancashire CCG areas</li> </ul>  |
| Thursday 15 Jan – staff briefing<br>4.30pm onwards<br>Ormskirk Hospital                                      | <ul style="list-style-type: none"> <li>• Unhappy with the wording of the leaflet, feel it reads as if there are no current benefits to the services at SOHT.</li> <li>• Felt that by removing service from SOHT working relationships would be lost - trying to keep cohesiveness of teams across different sites could be problematic and could result in communication problems.</li> <li>• Suggested the following services could be kept on site: pre-op teaching and information, ongoing support, prosthetic clinic, local support groups, post op wound checks, seroma management, post treatment holistic needs assessment.</li> <li>• Patients very worried due to not knowing when and where they will be seen next.</li> <li>• Lack of consultation with staff around the future of the service.</li> </ul> |
| Tuesday 27 Jan – SPAC forum (Maghull)<br>1.30 - 3.30pm<br>St Andrew's Church Hall, 22 Damfield Lane, L31 6DD | <ul style="list-style-type: none"> <li>• Value of screening service and accessibility</li> <li>• Access to screening for over 70s</li> <li>• Importance of support attending hospital appts</li> </ul>   |
| Tuesday 27 Jan – Migrant worker group<br>6pm – 8pm<br>Parenting 2000, Morningson Road, Southport PR9 0TS     | <ul style="list-style-type: none"> <li>• Transport and distance</li> <li>• Understanding the changes to service/clinical benefits</li> <li>• Availability of information in other languages</li> <li>• Availability of interpreters during</li> </ul>  |

|   |  |
|---|--|
|   | treatment  |
| <p>Wednesday 28 Jan - SPAC Forum (Southport)<br/>1.30 – 3.30pm<br/>Lord Street West Church, PR8 2BH</p>   | <ul style="list-style-type: none"> <li>• Availability of screening</li> <li>• Access to alternative hospitals by public transport</li> <li>• Continuing role of breast care nurses.</li> </ul>   |
| <p>Wednesday 28 Jan - Aintree Breast Cancer Support group<br/>6pm – 8pm<br/>Marina Dalglish Centre, Aintree hospital</p>                                  | <ul style="list-style-type: none"> <li>• Future of Southport and Ormskirk services</li> <li>• Lack of co-ordination and information sharing between different aspects of service</li> </ul>  |
| <p>Thursday 29 Jan – In Stitch<br/>10 – 12noon<br/>Macmillan Cancer Support Centre, 23-35 Scarisbrick Avenue (off Lord Street), Southport<br/>PR8 1NW</p> | <ul style="list-style-type: none"> <li>• Communication with f/up patients</li> <li>• Service now perceived by patients as 2nd rate and fragmented</li> <li>• Importance of relationship with/support provided by breast care nurses</li> <li>• Travel issues for older patients</li> <li>• Some patients prepared to travel for a 'better' service</li> <li>• Importance of environment in helping to relieve anxiety (Aintree does this very well)</li> </ul>   |
| <p>Friday 30 Jan – Firm Roots<br/>1.30pm – 3pm<br/>St John's Church Hall, School Lance, Burscough</p>   | <ul style="list-style-type: none"> <li>• Questions around future provision of services and issues around lack of communication concerning the changes only information most participants had was hearsay.</li> <li>• If follow up clinics were held on other sites it may lead to more non attendances because of the difficulty getting there. It's a lot easier to get to Ormskirk so patients are more likely to turn up.</li> <li>• Unhappy when having to travel between sites as part of treatment process e.g. patient was injected with a dye at the hospital she attended and then told she had to get herself to Wigan Hospital for the next part of her treatment.</li> </ul> |
| <p>Wednesday 4 Feb – Migrant worker support group<br/>3pm – 4.30pm<br/>Holy Trinity School, Southport</p>   | <ul style="list-style-type: none"> <li>• Attendees unsure of women's health services in the area - a leaflet outlining these or something on line would be useful.</li> <li>• One attendee described how in Poland ladies are routinely called for health checks even if there are no known symptoms or family history. There was a delay in this lady's referral reaching the hospital. The lady had been unsure though how long these things normally took.</li> </ul>   |

|   |  |
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|   | <ul style="list-style-type: none"> <li>• Surveys and information taken away by attendees and left at the school too.</li> </ul>  |
| Thursday 5 Feb – Health and Social Care Forum, 10 – 12 noon, Netherton Feelgood Factory                         | <ul style="list-style-type: none"> <li>• Information on engagement and how to get involved</li> </ul>  |
| Thursday 5 Feb - Ormskirk Support Group<br>7pm – 9pm<br>Ormskirk Hospital Out Patients department               | <ul style="list-style-type: none"> <li>• Uncertainty of their future follow up appointments</li> <li>• Emotional distress</li> <li>• Conflicting messages from trust and consultants themselves e.g. oncology</li> <li>• Not all patients had received letter from trust announcing engagement</li> <li>• Concerns over patients managing to cope change of teams/service</li> <li>• Value locally based team even if have to travel further for some treatment</li> <li>• Liked consistency of getting to know local nurses who support throughout journey</li> <li>• Concerns over transport</li> <li>• Overwhelming support for existing service at S&amp;O</li> <li>• Lack of understanding why trust not engaged</li> </ul> |
| Saturday 7 Feb – In Trust transgender group<br>3pm – 5pm<br>Waterloo Community Centre, St Georges Road Waterloo | <ul style="list-style-type: none"> <li>• Health records that do not record background and transition</li> <li>• Transgender individuals being incorrectly called for screening or falling out of the system</li> <li>• Unsupportive and uninformed clinicians – training requirement</li> <li>• Tailored /innovative aftercare and support groups required</li> </ul>  |
| Monday 9 Feb – Sefton Cancer Support Group<br>10.30 – 12.30<br>1 Duke Street, Formby, Merseyside L37 4AL        | <ul style="list-style-type: none"> <li>• Continuity of care for current follow up patients</li> <li>• Poor communication with current patients and related anxiety</li> <li>• Importance of other cancer care consultations to inform development of service</li> <li>• Importance of empowerment to make decisions on care choices.</li> <li>• Scepticism re. inability to recruit radiologist</li> <li>• Importance of support groups in "recovery package"</li> </ul>   |
| Tuesday 10 Feb Big Sista Love,<br>3 - 5pm   | <ul style="list-style-type: none"> <li>• Support offered to patients should be varied and less "traditional",</li> </ul>   |

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| Hanover Street, Liverpool   | particularly valued by LGTBI community.   |
| Tuesday 10 Feb SAFE event (Sexual Awareness For Everyone), Edge Hill University                                     | <ul style="list-style-type: none"> <li>Information and surveys taken to event</li> </ul>  |
| Thursday 12 Feb – Sefton Equalities Partnership<br>5 – 6pm, CVS, Burlington House, Crosby                           | <ul style="list-style-type: none"> <li>Satisfied that engagement was inclusive</li> <li>Further support offered with engagement</li> </ul>  |
| Thursday 12 Feb –Lift-up Cancer Support Group,<br>7 – 9pm<br>Lakeside Christian Centre, Fairway, Southport, PR9 0LA | <ul style="list-style-type: none"> <li>Continuity of care for follow up patients</li> <li>Improved communications for follow up patients</li> <li>Transport - cost / difficulty of getting to alternative providers</li> <li>Scepticism re. inability to recruit a radiologist</li> <li>Importance of communication for joined up after care</li> <li>Importance of relationship with/support provided by breast care nurses</li> <li>Accountability of Southport and Ormskirk Trust and lack of representation at meeting</li> </ul> |
| Tuesday 17 Feb – SPAC Forum (Formby)<br>1.30 – 3pm<br>Formby Methodist Church, Elbow Lane, L37 4AF                  | <ul style="list-style-type: none"> <li>Positive comments about quality of service at Southport and Ormskirk and other hospitals</li> <li>Importance of support at appointments, either family, friends or advocate – providers should welcome and encourage</li> <li>Transport</li> <li>Poor communication between hospital and patients</li> </ul>   |
| Tuesday 17 Feb – West Lancs Pensioners Forum<br>community centre at The Galleries, St Helen’s Road, Ormskirk        | <ul style="list-style-type: none"> <li>Changes to the breast care services were discussed as part of a wider presentation to the group</li> <li>Surveys and information were given to the group to complete</li> </ul>  |
| Wednesday 18 Feb - West Lancs CVS Health Network Event  | <ul style="list-style-type: none"> <li>Information and surveys taken to event</li> </ul>  |
| Friday 20 Feb – Skelmersdale library<br>10am – 12pm   | <ul style="list-style-type: none"> <li>Issues with mobile screening - turned away from scheduled appointment twice due to machine not working due to a replacement part being needed - not contacted beforehand.</li> <li>Parking at Wrightington not good, neither is public transport to get there.</li> <li>Positives of current service: speed, manner, one stop shop, work as a</li> </ul>   |

|   |  |
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|   | <p>team. Quality of support extended to relatives too e.g. support for husband</p> <ul style="list-style-type: none"> <li>• Marina Dalglish centre - radiotherapy - marvelous</li> <li>• Volunteer driver - amazing service</li> <li>• Suggested improvement: can be waiting too long between surgery and radiotherapy</li> <li>• Leaflet could be misleading in that it may imply that one stop clinics do not happen at Ormskirk and that SOHT do not have modern up to date services</li> </ul>   |
| 24 Feb - Sarah's Stars Breast Cancer Support Group,<br>7 – 9pm, The Olive Tree, Community Centre, Penketh | Feedback recorded on surveys   |
| 25 Feb – Ability Group (disabilities network)<br>10-12noon<br>Sing Plus Litherland                        | <ul style="list-style-type: none"> <li>• Travel and transport - difficulties using public transport and distance from bus/train to hospitals</li> <li>• Communications between hospitals</li> <li>• Accessibility - some old buildings have poor access</li> <li>• Confusing signage and information - needs to be in accessible formats e.g; audio appointment letters for the visually impaired</li> <li>• Health passports are good</li> <li>• Allowing support dogs to attend appointments</li> <li>• Advocacy</li> <li>• Continuity/joined up care for those with multiple conditions.</li> </ul> |
| 25 Feb – Southport Rest Home (for Jewish community)<br>3-4pm<br>Albert Road Southport                     | <ul style="list-style-type: none"> <li>• Travel and transport - residents unable to use public transport and travel time/distance magnified for those with long term conditions</li> <li>• Costs - most would require the support of a paid care to attend appointments</li> <li>• Preference for smaller, friendlier hospitals</li> <li>• Difficulties in hearing and understanding what is being said by clinicians</li> </ul>   |
| 28 Feb - NHS West Lancashire CCG's Burscough Listening Event  | <ul style="list-style-type: none"> <li>• Information and surveys taken to event</li> </ul>   |

### Timetable of clinics and feedback (existing patients only)

| <b>Clinics<br/>(for both CCGs in date order)</b>                              | <b>Feedback: main themes</b>  |
|---|---|
| Friday 23 Jan – Ormskirk Hospital<br>Outpatients<br>AM<br>Ormskirk Hospital   | Comments recorded on surveys but main themes were <ul style="list-style-type: none"> <li>• Concerns around the future of the existing service bra fitting, prosthesis service, breast care nurses etc</li> <li>• Increased travel if service moved</li> </ul>   |
| Friday 23 Jan –Family History Outpatients<br>PM<br>Ormskirk Hospital          | Comments recorded on surveys <ul style="list-style-type: none"> <li>• People may FTA if service moved further away</li> </ul>   |
| Monday 26 Jan – Ormskirk Hospital<br>Outpatients<br>AM<br>Ormskirk Hospital   | Comments recorded on surveys but main themes were: <ul style="list-style-type: none"> <li>• Putting more stress on families/workers by increasing travel at an already very stressful time</li> <li>• A local service is needed</li> </ul>  |
| Monday, 2 Feb – Ormskirk Hospital<br>Outpatients<br>AM<br>Ormskirk Hospital   | <ul style="list-style-type: none"> <li>• Limited feedback</li> <li>• Comments re. late running of clinic and increased waiting times</li> <li>• Information requested in Romanian</li> </ul>  |
| Tuesday, 10 Feb – Ormskirk Hospital<br>Outpatients<br>AM<br>Ormskirk Hospital | <ul style="list-style-type: none"> <li>• Lack of continuity/poor communication in transition to a new service - unsettling</li> <li>• Lack of choice of alternative provider</li> <li>• Importance of a named breast care nurse for support</li> <li>• Like the intimacy of a small service/hospital</li> </ul> |
| Wednesday 11 Feb – Mammography clinic,<br>Ormskirk hospital                   | <ul style="list-style-type: none"> <li>• Need for a local service that offers a variety of support</li> </ul>   |
| Thursday 12 Feb – Mammography clinic,<br>Ormskirk Hospital                    | <ul style="list-style-type: none"> <li>• Receiving a holistic service – not treating just the breast cancer but taking into account long term conditions too.</li> </ul>  |
| Friday, 13 Feb – Family History Outpatients<br>PM<br>Southport Hospital       | <ul style="list-style-type: none"> <li>• Positive comments on the efficiency, friendliness, supportive and discreet nature of the service</li> <li>• Local and easy to access for those with work and family commitments</li> </ul>   |
| Wednesday 18 Feb – Mammography clinic,<br>Ormskirk Hospital                   | <ul style="list-style-type: none"> <li>• Concerns over increased travel if services moved</li> <li>• Need for local service</li> </ul>  |

## **Appendix B**

### **Breast care services engagement stakeholders**

#### **West Lancashire**

|  |
|--|
| West Lancashire Age UK                                     |
| Age UK's Older and Out                                     |
| Aughton Community Together                                 |
| Boiler Room  |
| Burscough Older People's Club                              |
| Central and West Lancashire Carers                         |
| Corum (Supporting Young parents)                           |
| Families and babies team                                   |
| Firm Roots   |
| Homestart Lancashire                                       |
| Lancashire LGBT  |
| Liverpool Road Hall Community Centre                       |
| "My View" – NHS West Lancashire CCG's membership scheme    |
| North West Breast Cancer Telephone Buddies                 |
| Ormskirk Community Partnership                             |
| Ormskirk Support Group                                     |
| Parent Carer Network West Lancashire                       |
| Parkinson's Disease Society                                |
| Quarry Bank Community Association                          |
| SAFE, (Sexual Awareness for Everyone) Edge Hill University |
| Skelmersdale Writers Group                                 |
| South Lancashire Disability Partnership                    |
| Southport Mums in the know                                 |
| Aughton & Ormskirk U3A                                     |
| Burscough & District U3A                                   |
| Parbold, Newburgh & District U3A                           |
| Southport Alzheimer's team                                 |
| West Lancashire Borough Council                            |
| West Lancashire CVS  |
| West Lancashire CVS Health MNetwork                        |
| West Lancashire Disability Helpline                        |
| West Lancashire Multiple Sclerosis Society                 |
| West Lancashire Pensioners Forum                           |

## Southport and Formby

|  |
|--|
| Ability Group                                    |
| Age Concern                                      |
| Aintree Breast Cancer Support Group              |
| Aintree University Hospital NHS Foundation Trust |
| Big Sista Love                                   |
| Chinese Carers Network                           |
| Embrace (Sefton)                                 |
| EPEG   |
| Health and Social Care Forum                     |
| HealthWatch Sefton                               |
| In Stitch Support group                          |
| In Trust   |
| Jewish Community Care                            |
| Lift Up Cancer Support group                     |
| Macmillan Cancer Support                         |
| Migrant Worker Group                             |
| Migrant Worker Group (ESOL)                      |
| Public Health Sefton                             |
| Sarahs Stars Breast Cancer Support group         |
| Sefton Cancer Support                            |
| Sefton Carers Centre                             |
| Sefton Consultation and Engagement Panel         |
| Sefton Council                                   |
| Sefton CVS                                       |
| Sefton Disability Network                        |
| Sefton Equalities Partnership                    |
| Sefton Pensioners Advocacy Centre                |
| Southport and Ormskirk Hospital NHS trust        |
| Southport Rest Home                              |



## **Appendix C**

### **Breast Care Services engagement feedback report**

#### **Diversity and Equality monitoring data**

##### **What is your age?**

|                   | <b>Response Percent</b> | <b>Response Count</b> |
|-------------------|-------------------------|-----------------------|
| 16 or under       | 0%                      | 0                     |
| 17 - 25           | 2%                      | 5                     |
| 26 - 35           | 3%                      | 9                     |
| 36 - 45           | 13%                     | 44                    |
| 46 - 55           | 27%                     | 88                    |
| 56 - 65           | 22%                     | 72                    |
| 66 - 75           | 19%                     | 64                    |
| Over 75           | 14%                     | 46                    |
| Prefer not to say | 1%                      | 2                     |
| answered question | 330                     | 330                   |

##### **How would you describe your gender?**

|                   | <b>Response Percent</b> | <b>Response Count</b> |
|-------------------|-------------------------|-----------------------|
| Male              | 5%                      | 17                    |
| Female            | 95%                     | 309                   |
| answered question | 326                     | 326                   |

##### **Is this the same gender you were born with?**

|                   | <b>Response Percent</b> | <b>Response Count</b> |
|-------------------|-------------------------|-----------------------|
| Yes               | 96%                     | 315                   |
| No                | 2%                      | 6                     |
| Prefer not to say | 2%                      | 6                     |
| answered question | 327                     | 327                   |

### Which area do you live in?

|                              | Response Percent | Response Count |
|------------------------------|------------------|----------------|
| Southport and Formby         | 46%              | 154            |
| West Lancashire              | 41%              | 136            |
| Somewhere else, please state | 13%              | 43             |

Of the 43 respondents who answered that they lived somewhere else, the breakdown of locations is as follows:

|            |    |
|------------|----|
| Maghull    | 9  |
| Sefton     | 3  |
| Lancs      | 3  |
| Wigan      | 2  |
| Liverpool  | 2  |
| Berkshire  | 1  |
| Blackburn  | 1  |
| Bootle     | 1  |
| Chorley    | 1  |
| Halton     | 1  |
| Knowsley   | 1  |
| Lydiate    | 1  |
| Manchester | 1  |
| Netherton  | 1  |
| St. Helens | 1  |
| Wigan      | 1  |
| Wirral     | 1  |
| Warrington | 0  |
| Not stated | 12 |
| Total      | 43 |

### Are you a carer?

|                   | Response Percent | Response Count |
|-------------------|------------------|----------------|
| Yes               | 11%              | 34             |
| No                | 89%              | 284            |
| answered question | 318              | 318            |

**Do you have a long term condition that affects your day to day activity?**

|                   | <b>Response Percent</b> | <b>Response Count</b> |
|-------------------|-------------------------|-----------------------|
| Yes               | 26%                     | 80                    |
| No                | 74%                     | 228                   |
| answered question | 308                     | 308                   |

**What is your ethnic group/background?**

|                       | <b>Response Percent</b> | <b>Response Count</b> |
|-----------------------|-------------------------|-----------------------|
| White British         | 92.9%                   | 302                   |
| White East European   | 2.5%                    | 8                     |
| White Other           | 2.5%                    | 8                     |
| White Irish           | 0.6%                    | 2                     |
| White/Black African   | 0.3%                    | 1                     |
| Other ethnicity       | 0.3%                    | 1                     |
| Gypsy/Roma/Traveller  | 0.0%                    | 0                     |
| White/Black Caribbean | 0.0%                    | 0                     |
| White/Asian           | 0.0%                    | 0                     |
| Mixed other           | 0.0%                    | 0                     |
| Indian                | 0.0%                    | 0                     |
| Pakistani             | 0.0%                    | 0                     |
| Bangladeshi           | 0.0%                    | 0                     |
| Black Caribbean       | 0.0%                    | 0                     |
| Black African         | 0.0%                    | 0                     |
| Chinese               | 0.0%                    | 0                     |
| Prefer not to say     | 0.9%                    | 3                     |
| Total                 |                         | 325                   |

**Please choose a category that best describes your level of disability**

|                      | <b>Response Percent</b> | <b>Response Count</b> |
|----------------------|-------------------------|-----------------------|
| No disability        | 68%                     | 182                   |
| Physical impairment  | 14%                     | 38                    |
| Multiple impairments | 6%                      | 15                    |
| Hearing impairment   | 5%                      | 12                    |
| Mental health        | 2%                      | 5                     |
| Learning disability  | 1%                      | 2                     |
| Wheelchair user      | 1%                      | 2                     |

|                   |     |     |
|-------------------|-----|-----|
| Visual impairment | 1%  | 2   |
| Prefer not to say | 3%  | 8   |
| answered question | 266 | 266 |

#### What is your religion/faith?

|  | Response Percent | Response Count |
|--|------------------|----------------|
| Christian (C Of E, Catholic, Protestant and all denominations) | 80%              | 256            |
| No religion/belief   | 13%              | 41             |
| Other  | 3%               | 8              |
| Sikh   | 0%               | 1              |
| Hindu  | 0%               | 0              |
| Jewish   | 0%               | 0              |
| Muslim   | 0%               | 0              |
| Prefer not to say  | 4%               | 13             |
| answered question  | 319              | 319            |

#### What is your sexual orientation?

|  | Response Percent | Response Count |
|--|------------------|----------------|
| Heterosexual /straight (attracted to the opposite sex) | 92.7%            | 292            |
| Gay/Lesbian (attracted to the same sex)                | 1.6%             | 5              |
| Bisexual (attracted to both sexes)                     | 0.6%             | 2              |
| Prefer not to say                                      | 5.1%             | 16             |
| answered question                                      | 315              | 315            |