



*Sunderland
Clinical Commissioning Group*

Patient engagement Final report

Sunderland Clinical Commissioning Group –

**Commissioning the best breast-care
services for local people**

September, 2015

Contents

.....	Error! Bookmark not defined.
Executive summary	4
Introduction	4
Aims and objectives of the engagement exercise	4
Summary of insight (conclusions and recommendations)	5
Methodology	7
Key factors in deciding the methodology	7
Limitations within methodology	8
The engagement exercise used the following procedures to engage and involve past-patients.....	10
Phase 1 - for 4 weeks from 21 st June to 24 July:	10
Phase 2 – extension: two weeks from 10 – 21 August	11
The exercise was promoted through a series of channels including	13
The sample	15
Survey results	16
General demographics of the sample.....	16
Results by question.....	17
Welcome on arrival at first hospital appointment.....	17
Before you saw the doctor/specialist.....	17
First consultation	17
Testing and diagnostics.....	18
After diagnosis	18
Arriving for surgery and on the ward	19
Leaving hospital after treatment	20
Focus group and individual interviews.....	21
Summarised feedback.....	21
Consistent themes.....	21
Common issues	22
Patient choice - Advice versus information	22
Privacy, dignity and support.....	23
On the ward	24
Pharmacy service (CHS)	25
Discharge after hospital	25
Parking and transport	25
End of treatment	26
Other issues raised by the minority or individual patients	26

Appendices	27
1. Legal and policy context for consultation on service changes for the NHS	27
The Public Sector Equality Duty	27
The NHS constitution.....	27
The NHS Mandate ‘Nicholson tests’	28
The Gunning Principles	29
2. Initial report including desk research with current know data - attachment	30
3. All data from survey – phase 1 - attachment	30
4. All data from survey – phase 2 - attachment	30

Executive summary

Introduction

In December 2014, the City Hospitals Sunderland made a decision, with the full involvement of Sunderland Clinical Commissioning Group (CCG) as the main commissioner, to temporarily suspend the breast service to new referrals. This difficult decision was made in the interests of patient safety as the Trust is currently unable to provide a consultant-led service for the local population.

Breast surgery for new patients has subsequently been provided by other local Trusts and Sunderland CCG has started the process to develop a new breast-care service model that will deliver a high quality service that best suits the patient; improves outcomes and is cost effective. As the CCG is genuinely committed to putting patients at the centre of service delivery and ensuring patients are key stakeholders in the commissioning cycle, this engagement exercise is recognised as a priority starting point for that development process.

The engagement and subsequent insight will be a key factor in development of requirements within the service specification for prospective new providers and will influence the model.

To be sure we understand 'what good looks like' feedback was sought from Sunderland residents who had been referred for diagnostics or surgery by their GP for any breast condition, including non-cancer and suspected cancer.

There was some input from staff delivering the service, however the meetings were short and provided limited information other than that which supports feedback from patients taking part so no specific insight is drawn from those meetings or recorded in this document.

Aims and objectives of the engagement exercise

- To confirm perceptions of the local service based on any current available, data (primarily from research with cancer patients as there is little published about non-cancer, breast surgery patients).
- To build a picture of the local breast surgery service from past patients before suspension at the end of 2014 and, based on patient insight, identify:
 - which elements should be retained and nurtured
 - which elements can be improved upon
 - which elements should be completely changed or removed
 - any gaps in the service.
- To identify clear recommendations that could potentially be translated into relevant requirements of the service specification.
- To identify opportunities for service improvement outside the service specification which could potentially be implemented by a relevant body or service provider.

It is important to note that this research is not about identifying specific issues with particular service providers but to identify *good practice* across the piece while highlighting areas for *service improvement* with a view to finding out 'what good looks like'. Then articulating these into SMART (specific; measurable; achievable; relevant /resourced timely) requirements of a service specification for providers of a new service model – hence the chosen methodology.

Summary of insight (conclusions and recommendations)

On the whole and, almost without exception, patients reported an excellent or good service with 'no complaints'. When patients did have issues in general the majority were at one stage of treatment of care. Only two people from the total sample of 109 respondents had a problem with their overall experience.

For the purpose of this exercise, elements of feedback from both the survey; focus groups and interviews that can be translated into a requirement of the service specification include:

- **Improved advice over information** – Perhaps the most commonly raised concern.

In the most part, of those who said they needed it said they received a good level of general, easy to understand, information either verbally or in leaflets or factsheets. Nevertheless, the majority of patients all **wanted medical guidance when it came to making important decisions around their treatment**. While they had real confidence and trust in their surgeon/specialist (99%) they did not want – or feel they had the knowledge – to make some decisions alone and literature provided was not enough. Solutions suggested included either encouraging clinicians to be more informative or open about the benefits and risks of each proposed treatment or set up a 'buddy' system where past patients who had had treatments could talk to patients beforehand.

A proportion (13%) felt that family members were not given the opportunity to ask questions, even though patients felt this important.

- **Choice of where treatment was carried out** was important and most patients would prefer to keep services local, however **accepted that for some specialist treatments they may have to go to another hospital**. For most they would prefer a long term and/or regular treatments in a Sunderland hospital or clinic.

Both the survey and focus group/interviews suggested **having [diagnostic] treatment on the same day was more important to them than where the treatment was**.

- The level of **support from Breast Clinical Nurse Specialists** is clearly an important factor in the perception of patient care and those who received exceptional support [CHS] implied that it **greatly helped their recovery both physically and emotionally, as well as their overall perception of the level of care received**. There was great anxiety amongst those who thought this service was to be removed, or moved to Gateshead.

Many acknowledge that these nurses seemed to go 'above and beyond' regarding support and care and it was regularly suggested that more support should be provided to them to 'free up' their ability to provide the already excellent service.

- While the survey suggested **privacy and dignity** was overall good (95% said it was respected with only 5 people reporting it was not), this was not always reflected in the in-depth interviews and focus groups.
Most patients reported that at some stage they felt there was issues with privacy or dignity, including; feeling staff were either rude or 'unfeeling'; being able to hear other people's consultations; feeling like they were being 'herded around' or on a 'conveyor belt'; having treatment on a ward when they felt it should have been done in a separate place; being given the wrong notes; not feeling that clinical staff and nurse teams had enough time to spend with them or not considering the weight of emotion that some diagnosis brings.
- Several patients receiving particular diagnostic treatments [biopsy] commented on lack of **pain control** during this procedure.
- **Communication** between medical staff on the ward was mentioned on several occasions. This ranged from issues with teams [clinicians and nurses] providing conflicting information to both each other and to the patient.
- **General levels of in-patient care** were also raised as an issue during, in-depth interviews and focus groups including incidences where patients needed urgent medical attention. There was a perceived lack of knowledge by the staff attending as to what to do or patients being left unattended when support was needed. Participants did question staffing levels on wards and said that staff appeared under pressure.
- **General levels of service on discharge and in the community** were criticised by those receiving care in Sunderland. The clinical pharmacy unit was highlighted as poor for being slow in service delivery and community/district nursing was criticised for lack of ability or sanction to manage post-operative patients.
- **Consistency of service** across the region. Because some past-patients were brought together in a focus group setting or some had had more than one procedure at different times, a question was regularly raised about why services were different in one place compared to another. Particularly around diagnostics in a day.
- There appeared to be a recurrence of issues with patients receiving breast **reconstruction**.
- **Parking and transport**. Some participants commented on having to travel for post-operative care when they 'felt poorly'. Others cited dissatisfaction with patient transport offered – either having to wait for a long time or a poor service offered by contracted taxi-hire firms.
Some people mentioned parking charges and anxieties cause if appointments or treatment ran over and concerns around parking fines.

- **Support from third sector charity and support groups** was greatly appreciated and many patients suggested benefits could be gained for both patients and the NHS if greater partnerships were forged. Both the Macmillan Cancer Support unit at Sunderland and Maggie's Centre at the Freeman hospital were cited as greatly appreciated and successful for cancer patients, as was the local Hug in a Bag charity.

Methodology

Key factors in deciding the methodology

The Trust provided its own estimate of around 3,000 (1.1% of the total population) referrals to breast care services annually. The Trust also estimates that over 90% of those are non-cancer patients. It should be noted that we do not have evidence of this data from the Trust so throughout this document have worked on the average estimate of 3,000.

Over the last six years the average number of patients referred by GPs through Choose and Book or via two week-wait (suspected cancer) for breast surgery is 295 (around 0.1% of the population). An average of 15 men are treated every year.

For the purpose of this analysis we have based results on the percentage of those responding to the survey – i.e. 100 people. But have provided an equivalent figure as a percentage of an estimated 3,000 patient a year for reference.

This sample – 100/3000 – provides a 95% confidence level which translates as providing a statistically significant result from the survey.

Because the potential target sample is a very small and specific group of people, it was agreed the most effective approach to get the greatest response that would provide both quantitative and qualitative feedback was to:

- Appeal for anyone from Sunderland who has had a problem with their breast and subsequent surgery, regardless of when the treatment was or which hospital they attended.
- Survey past patients initially via an online questionnaire (with printed versions available) to attain:
 - quantitative insight and confirm or discount findings from known available national and regional insight and
 - collect tangible; relevant and new local data.
- Conduct focus groups and one-to-one interviews with past patients to further explore experiences, gaining qualitative insight into what was good and bad about the service received and look for patient input into ideas and suggestions for improvements.

We aimed to achieve a statistically significant sample size by:

- Using a promotional campaign to invite relevant participants to respond to the survey.

- Engaging patients directly from those identified by the Trust (to participate in both the survey and focus groups or interview).
- Inviting relevant members of MY NHS to take part.
- Engaging local partner organisations; charities and support groups promote the survey and focus groups.

Limitations within methodology

It should be noted that, for this exercise, while every effort was made to engage with all communities across the city there were some caveats.

Non-cancer patients

Responses from non-cancer patients are not proportionate based on estimates (3,000 patients per year) provided by the Trust and we were unable to get any detailed statistics from there. However, it is likely the majority of non-cancer patients do not go on to have surgery.

It could, however, be argued that breast cancer patients, while in the minority, offer a more qualitative insight to the service as whole as they:

- experience more radical surgery;
- have a more varied range of treatment;
- experience a wider range of related services (e.g. clinical pharmacy; radiology; community nursing) and
- are on a healthcare pathway for longer than non-cancer patients (i.e. 5years).

BME communities

There is a marked lack of responses from the BME community with only 2 respondents disclosing their ethnicity outside 'white-British'.

Efforts made to engage with the BME community included:

- Meetings with the Unity organisation (Sunderland's BME community liaison organisation) led to significant support to promote the exercise but with no response. Activity included:
 - The organisation's attempt to co-ordinate a focus group
 - Promotion of the online survey on the Unity Organisation's website and news letter
 - Direct email to their own contacts
- Translation of information into 4 languages after a request from the International Community Organisation of Sunderland (ICOS), the Sunderland Bangladeshi Centre and the New City Medical practice

Year of treatment

Because it was agreed we wanted to get the greatest response in order to properly inform service improvement we did not time-limit the date of surgery when inviting responses from past patients.

The engagement exercise used the following procedures to engage and involve past-patients

Phase 1 - for 4 weeks from 21st June to 24 July:

Survey

- A comprehensive, 46 question, survey attracted **100 responses** was designed to establish an overall perception of the level of service from the first appointment with a consultant after GP referral; through diagnostics; surgery and in-patient care; to discharge from hospital. It did not include the appointments process or primary/community care before or after surgery as these elements could not be directly influenced by potential new service providers.
- It was open to anyone who had had a problem with their breast and had gone on to have surgery. In addition to their experiences, respondents were asked if they would be willing to attend a focus group or be interviewed separately to inform the service development process. The survey included questions about their general health and demographic information.
- Was tested before release with patient groups from outside the Sunderland area to gauge its accessibility and relevance. CHS Breast nurses and the Acting Directorate Manager for General Surgery also reviewed the survey to ensure accuracies around the patient pathway.
- The Survey was shared widely through a range of targeted and general channels (detailed pages 11 - 13) allowing respondents the opportunity to provide quantitative information via a 'tick box', multi-choice, online or hard-copy questionnaire.

Focus groups.

- Four planned focus groups were held. Made up of a total of **20 volunteers** sourced from an invitation in the survey; via initiation by the CHS Breast Nurse-Specialists or direct contact with the Sunderland Macmillan Breast Cancer Support Group.

Groups were held over 3 dates and volunteers were offered a choice of a morning or evening session.

Individual interviews.

- Further qualitative insight was gained from **12, one-to-one interviews with individual patients** who volunteered their views but did not want to be part of a focus group, including one male patient. Again, sourced from either a request in the survey or from direct invitation from the Breast Nurse-Specialists

The purpose of the focus group and interviews was to gain further in-depth insight into available national and regional data; via the online survey as well as to invite suggestions for service improvement.

Staff/clinical perspective

- Meetings were held with the Trust's two Breast Clinical Nurse-Specialists and with the Trusts Business Manager to gain their insight into their view of 'what good looks like' in relation to the service.

The Strategic Clinical Network's Macmillan Patient Experience Project Manager also provided input based on a perspective of cancer patients in general from work carried out locally.

Phase 2 – extension: two weeks from 10 – 21 August

While Phase 1 was initially successful, it was agreed to extend the online aspect the engagement exercise. Reasons were multiple:

- Although promotion was extensive during phase 1, it was agreed that the overall response could be enhance with a further two- week digital campaign. This would also allow an increased emphasis on targeting non-cancer patients and other hard to contact communities.
- We also had a commitment from the Sunderland City Council to promote the survey through internal channels to staff.
- Reporting timelines had been relaxed as further negotiation and planning meetings were taking place with partners and providers of the potential new service, allowing a short extension to the engagement programme.
- A previous, internally managed engagement exercise carried out by the CCG (urgent care review) recommended a minimum of 6 weeks engagement with patients and the public.
- It would be an opportunity to compare the effectiveness of an enhanced digital campaign; useful for other engagement exercises in the future.

Phase 2 subsequently included:

- **Facebook advertising** – a potential audience of **44,000 women every day** during the 2-week campaign period
- **Social media conversation creation/engagement** – specialist support was commissioned to schedule key messages; channel and create conversations across all social media platforms based on breast care services to drive more people to the online survey.
- Updated promotional collateral and a revised survey was produced with the new deadline and circulated to the Trust and Council communications leads for distribution internally and externally.
- Focus Group attendees who had not completed the original survey were invited to do so during the extension.

The exercise was promoted through a series of channels including

Channel	Quantity / reach	Response / result*
Link to online survey posted on SCCG 'Get Involved' pages on website	-	102 view to web page 113 people clicked through to survey
Link and promotion of survey posted / tweeted on SCCG social media platforms	Total reach 79,925 Generated 38 Tweets via SCCG Twitter	44 retweets 387 Click through to survey from Twitter
Additional digital promotion including direct posts on relevant organisations' Twitter and Facebook outside the CCG's own. Conversations created using the above channels	5 posts a day for 14 days on 20 twitter accounts and Facebook pages.	See above
Facebook Advertising	38, 472 people reached	1,080 clicked through ad to survey information
Printed version of the survey were made available – Phase 1 only	33 requested	7 returned
Printed literature promoting the survey designed to raise awareness and encourage participation.	Supplies sent to: <ul style="list-style-type: none"> • 51 practices • 68 pharmacies • 4 Urgent Care Centres • 600 community outlets (via the Local Authority Voluntary and Community Network – x 5 localities) • City Hospitals Sunderland • Sunderland City Council 	Direct reach unknown but relates to overall response

<p>Local partner engagement:</p> <p>'e-comms' pack with articles; printable artwork and social media posts sent to communications leads.</p>	<p>Posted on websites and through internal channels</p> <ul style="list-style-type: none"> • Sunderland City Council • HealthWatch Sunderland <p>Support unknown</p> <ul style="list-style-type: none"> • City Hospitals Sunderland 	<p>Sunderland City Council 1,698 staff read their e-newsletter featuring the item on the engagement exercise 52 people clicked through to the survey.</p> <p>HealthWatch Sunderland</p> <ul style="list-style-type: none"> • Direct reach unknown but relates to overall response <p>City Hospitals Sunderland</p> <ul style="list-style-type: none"> • Unknown
<p>Local 3rd sector support group engagement (responding):</p> <p>'e-comms' pack supplied</p>	<p>Posted on social media; digital channels and e-bulletins.</p> <ul style="list-style-type: none"> • Age UK • Mental Health NE • Sunderland Carers Assoc • Breast Cancer Survivors Trust • Hug in a bag charity 	<p>Direct reach unknown but relates to overall response</p>
<p>Local BME communities targeted</p> <p>Translations and alternative format of promotional literature supplied on request.</p>	<p>The Unity Organisation</p> <ul style="list-style-type: none"> • Meetings • e-comms pack supplied • Translated literature supplied (Lithuanian; Polish; Farsi and Urdu) <p>International Community Organisation of Sunderland (IOCS)</p> <ul style="list-style-type: none"> • Translated literature supplied (Lithuanian; Polish; Farsi and Urdu) <p>New City Medical Practice</p> <ul style="list-style-type: none"> • Translated literature supplied (Urdu) 	<p>Direct reach unknown but relates to overall response</p>

	Sunderland Bangladeshi Centre <ul style="list-style-type: none"> Translated literature supplied (Urdu) 	
MY NHS volunteers were contacted to take part. Sunderland residents who: Agreed to complete surveys Interested in: elective surgery / hospital performance	<ul style="list-style-type: none"> 29 By post (letter sent inviting relevant people to call for a survey) 14 By email (as above – but sent link) 	Direct reach unknown but relates to overall response
Sunderland Health Forum meeting	Exercise promoted at 2 June meetings	Direct reach unknown but relates to overall response

The sample

Channel	Total number of respondents		%*	%**
Phase 1: Online survey	34	100	34	3.6%
Phase 1: Online survey	66			
Focus groups	20 participants	32	11	1.1%
Interviews	12 participants			
Printed surveys returned	7 (included in P1 online results above)			

*% based on an average of 295 patients a year through CAB or 2WW

** based on 3,000 referrals a year

A total of **100** people completed the online survey.

Twenty people took part in the Focus Groups and 12 people volunteered to be interviewed. Of that 32 person total, 23 volunteered through the survey and nine were initiated by the Trust's Breast Clinical Nurse Specialists. Results below are based on the 100 survey respondents only.

Survey results

General demographics of the sample

For the purpose of this report % are rounded up. Results indicated in (brackets) are the % of respondents to the survey. Results indicated in *[square, italic brackets]* indicated the % or a potential 3,000 patient sample, per year, referred through the service.

Of those responding to the survey, 51 were treated for cancer while the remaining 49 were non-cancer patients – a near 50/50 split. All nine people nominated by the breast nurses had been treated for cancer.

The overall sample was predominantly made up of women with 1 male respondent and 1 participant not stating gender.

The age range was between 27 years and 79 years, with the majority of respondents being aged between 46 – 55 years old (43 %).

AGE	% of survey sample
16-25 years	0
26-35 years	9
36-45 years	11
46-55 years	43
56-65 years	23
66-75 years	12
Over 75 years	2

Fig1: age range and percentage response

Most survey respondents (71 *[2.4%]*) had all or the majority of their treatment at City Hospitals Sunderland. The remaining said the majority of their treatment was at the Queen Elizabeth Hospital in Gateshead (14 *[0.5%]*); the University Hospital, Durham (4) at the Freeman or Royal Victoria Hospitals, Newcastle (3). One patients said they chose South Tyneside hospital (as the only trust who could offer a female doctor) and one patient stated they had opted for private healthcare. The remaining six respondents did not answer.

Respondents had treatment was carried out between 2002 and 2015.

The majority (98%) were White British.

The majority of respondents (77%) did not consider themselves to have a long-standing condition.

Results by question

Welcome on arrival at first hospital appointment

The majority of respondents said they found the clinic easily (88% [3%]) and that staff on reception made it clear what they had to do and where they had to wait (89% [3%]). Six people said they had difficulty finding the clinic and 8 said the receptionist didn't make it clear what they had to do. The remaining people couldn't remember.

Before you saw the doctor/specialist

If they needed to do something (like get weighed or changed into a gown) before seeing the doctor, the majority (80% [2.6%]) said they understood fully what was expected and why. 12% said they understood but were not told why. Five respondents said they did not need to do anything and three people said it was not clear what they had to do or why.

The vast majority (93% [3.1%]) of respondents said their nurse assisting this process was pleasant and friendly with only one person saying they were not. 88% [3%] reported their privacy and dignity was respected at this stage, while 7% felt it was not.

First consultation

On first meeting the doctor patients were asked if he/she made it clear what was going to happen in this initial examination. 76% [2.5%]) felt they completely understood; 15% [0.5%]) said they understood some of it, but 8% reported that the doctor simply asked about symptoms. One person could not remember.

They were then asked if the doctor explained what initial symptoms might be. Just over half (56% [1.9%]) said they completely understood with a further 20% [0.7%]) saying they understood some of it. 11% said the doctor was unsure themselves and 9% said it was really unclear what might be wrong.

When asked if they understood what diagnostics might be required when it was explained to them, most completely understood (75% [2.5%]) or understood some of it (21% [0.7%]). Only two people felt it was really unclear and a further two said they couldn't remember.

Patients were asked if they felt their privacy and dignity were respected during the diagnostics stage of their examination. The majority (95% [3.2%]) said they felt it was with five people saying it was not and two people could not remember.

When asked if they staff invited any questions; respondents said 78% [2.6%] said they were asked. 10% said they were not asked and two people said they were not but would have liked to ask questions. 10 people could not remember.

Immediately after seeing the doctor 94% [3.1%] of patients were given information about what would happen next. 4% were not and two people said they were not but would have liked more information.

Testing and diagnostics

Most patients (88 out of 100) said they were invited for further tests after their initial appointment.

Of those 88 [3%], 49 people (56% [1.6%]) said reasons for the tests were explained completely with 34 people (39% [1.1%]) saying they were explained to some extent. Three people said it was not explained, one said they did not need an explanation and the remaining 2 people did not answer this question.

We asked how many people getting test had them on the same day. Just over half of those responding, 57 people (65% [1.9%]) said they did and with just over a quarter, 29 people (30% [1%]) said they had to wait for a separate appointment. Six people could not remember.

When asked if they would have preferred to have tests on the same day only a third (29 people [1%]) of the 88 respondents replied. The majority (24 people [0.8%]) said they would have preferred tests on the same day with five people saying they did not mind having to wait.

Regarding information supplied about the tests, 18 people were given enough, easy-to-understand information. Four people said they were given information but it was difficult to understand. Three people said they were not given information but would have liked some. Two people felt they didn't need anything and a further three could not remember.

Those 88 having tests were asked if they got test in the same place. Of those, 58 people (66% [2%]) said they did and the remaining 29 said they had to go to another clinic or site. Of those who had to go to another site 24 people (83% [0.8%]) said they did not mind with the remaining seven people saying they would have preferred tests on the same site.

When those patients receiving tests where asked if medical staff fully explained what would happen during tests, the majority (95% [2.8%]) said they got a complete or at least some explanation (61% and 34% respectively). Four people said they did not get an explanation but would have liked some. One person could not remember. When asked if it was explained that it may take several days for test results and that they would be called back, the majority (88% [2.6%]) of respondents said they understood fully; 12% (11 people) said they would take time but not told how long they would wait. One said they were not told but would have liked to have known and four people could not remember.

After diagnosis

We asked all 100 respondents to the survey if they felt they left knowing enough about their condition and planned treatment after initial diagnosis. While the majority (83% [2.8%]) said they did, 12% said they did not but would have liked to know more. 3 people felt they didn't need any more information and two people could not remember.

Just over half of patients (52% [1.7%]) were given easy-to-understand information about their condition after diagnosis. 4% people got information but found it difficult to understand. 20 people said they didn't feel they needed anything but 17% [0.6%] said they didn't get any information but would have liked some. Six people could not remember.

Just over half of patients (58% [2%]) said they were given details of a Breast Clinical Nurse Specialist after treatment. It should be noted that non-cancer patients would not always need this level of support and this response correlates with the number of non-cancer patients responding to the survey.

There was an almost equal split of people responding to say they were given information about support agencies relating to their condition with 53% [1.8%] saying they were given information at some point and 40% [1.3%] saying they were not but did not feel they needed it. The latter are likely to be non-cancer patients. Seven people could not remember.

Arriving for surgery and on the ward

The majority – 89% [3%] – of patients arriving for surgery found the ward easily (and found staff greeted them pleasantly. 4% people said they struggle to find the ward and 2% people felt they did not receive a pleasant welcome.

We asked patients if the medical staff made it clear what they had to do initially on arrival (such as get changed into a gown). The majority (93% [3.1%]) said they were told. Two people said they were not and it was not clear what they had to do and nine people said they could not remember. A similar majority (92%) said medical staff were pleasant and friendly during this process. Two people felt they were not. Six could not remember.

During this initial process 92% of people felt their privacy and dignity were considered with the remaining 8% feeling it was not.

When asked if medical staff explained what would happen during the procedure the majority said it was either fully or to some extent explained (72% [2.4%] and 20% [0.7%] respectively). Six people got no explanation but would have liked one. One person said they didn't feel they needed an explanation and two people could not remember.

The majority of respondents said they felt they saw enough of their doctor/specialist before treatment (81% [2.7%]) with the remaining 19% [0.6%] saying they did not, with almost all (99% [3.3%]) expressing confidence and trust in them.

When asked if patients had confidence and trust in nursing staff on the ward 61% [2%] said yes, in all of them; 35% [1.2%] said yes in some of them and 4% people said they did not have trust or confidence in them.

Over all most people had important questions answered in a way they could understand most of the time (64% [2.1%]) or some of the time (24% [0.8%]). Four people felt they did not understand answers to questions and the remaining eight said they could not remember.

When asked if they felt doctors talk about them as if they were not there 70% said they did not. Nevertheless, nearly a quarter (21% [0.7%]) said they did sometimes (19% [0.6%]) or often (2%). Nine people couldn't remember.

We asked if patients ever felt they were given conflicting information from different health professionals. The majority (74% [2.5%]) said they were not, 21% [0.7%] said they were sometimes and 5% people said it happened often.

When asked if family members could ask the doctor questions during treatment, 22% [0.7%] said they definitely and the same number (22%) said they were to some extent. Others said either no family were involved (20% [0.7%]) or that they did not want family involvement (15%). 13% people said family members were not given the opportunity to talk to staff and eight could not remember.

Leaving hospital after treatment

Finally, we asked about the process on leaving hospital after treatment starting with how long they had to wait after being told they could go and actually being discharged. Most patients (66% [2.2%]) said they had no wait and left as soon as their transport home arrived. However, 18% [0.6%] said they waited a long time for prescription drugs and 2 people felt it was disorganised and it was unclear when they could leave. Fourteen people could not remember.

When asked if they were given clear information about what they should and should not do when after leaving hospital 60% [2%] of patients said they were. 5% said they were not but would have liked some information and 9% said they were not but didn't feel they needed any. Six people could not remember.

We also asked if they were told who to contact if worried about their condition after leaving hospital. Most (69% [2.3%]) said they were but 19% [0.6%] said they were not. Twelve people could not remember.

Focus group and individual interviews

At total of 20 people attended four focus groups and 12 people volunteered for individual interviews – including one male patient. (32 people represents approximately 1.1% patients through the service annually). The majority of participants had had breast cancer (27 people – 84% [0.9%]) the remaining six had not. This influenced the responses as the majority of feedback was provided about breast cancer services.

After general introduction to the purpose of the meeting and background to the project, including an explanation of confidentiality; participants were asked to recount their experiences in brief, highlighting their reasons for taking part in this element of the research.

Participants were then encourage to talk about their experiences of the **actual process** of each stage as well as their **perceived care**, focussing on both good and bad experiences. Aspects of participants' responses were explored in more depth depending on comments; examples of experience given and issues raised.

These focus group members and interviewees were specifically asked for ideas of what 'good looks like' for a future service and to offer their own ideas and suggestions for service improvement.

Across all four focus groups the general feeling was one of a shared experience and members talked amongst themselves in a supportive way, even when opinions or experiences differed.

Similarly, past patients who volunteered to be interviewed separately offered the same candid responses.

Perhaps most beneficial from this qualitative feedback exercise is the readiness of participants to offer solutions.

Summarised feedback

There was clearly identifiable and shared experiences across all groups and interviews. Some of which may not be implementable in a service specification, however the CCG and / or Trust may choose to act on the solutions and suggestions offered by patients interviewed.

Consistent themes

In general, overall, the majority of the participants and interviewees praised the service offering positive comments and highly commending both the staff and the process.

The majority offered comments such as:

I could not fault the service (all Trusts/services)

No complaints (all Trusts/services)

The nurses were fantastic (predominantly CHS patients)

I could pick up the phone at any point and got really good advice (predominantly CHS patients)

I got a full list of appointments in advance which was great (Freeman)

I couldn't believe who quickly everything happened – it was excellent

The doctors and nurses were marvellous

The most satisfaction was within specific areas of the pathway:

Diagnostics services

- The speed of the service - how quickly tests were carried out, including those having all tests in a day or those waiting a few days were impressed that, in the majority of cases, they had tests and a diagnosis within a short space of time.
- The level of care, support and information offered by staff in diagnostic teams.

Post-operative specialist treatment

- Similarly positive feedback was offered about staff providing post-operative care in centres providing radiotherapy and chemotherapy including both the level of care and information provided.

Breast nurse specialists

- The nurses at CHS attracted a great deal of praise from the vast majority of those who had access to their support.

Third party support

- All those receiving support from charities and support groups found the service and support helpful.

Two out of the 33 participants cited major dissatisfaction throughout their experience. In both those cases the women did, however, suggest solutions to many of the issues raised.

Common issues

The most common service areas coming under criticism were to do with clinical engagement at the first appointment and then as an in-patient.

Patient choice - Advice versus information

The majority of participants highlighted issues around choices relating to treatment. While they agreed they were all given lots of information in the form of leaflets or from the breast nurses after diagnosis, many were 'left' to decide what level of surgery they should have or whether or not to follow a drug-treatment regime.

I was told to go away and think about and tell him what I had decided when I came back – I wanted his advice, what do I know. I was really panicked by this and had a terrible few days.

I was given the choice between a lumpectomy and a mastectomy. I decided to have it all taken away, a full mastectomy. Then on the morning of my surgery, when I was just about to go down, my husband asked the surgeon, 'if it was your wife what would you say'. He said 'have a lumpectomy'. So I changed my mind and I am glad it did now.

I wanted the doctors to tell me what they think. Even if they still say it is up to me a bit of guidance would be really helpful. I don't know how you are supposed to decide yourself, we're not the experts.

I can come off the tamoxifen if I have an oophorectomy [ovary removal] but I don't know what to do and no one seems able to offer advice. They just tell me I will have an instant menopause and I don't know what is worse – how I feel on the drugs or what an early menopause will do to me.

Another issue debated was the relating to when patients were given a cancer diagnosis. The majority said they were in shock and didn't listen to what they were being told.

I was just numb. I couldn't hear what he was saying to me.

I just couldn't take it all in. I was in shock.

I heard cancer and that was it.

Suggested solutions offered by participants

- GPs, diagnostic clinicians and consultants should make patients aware of suspected cancer to alleviate the shock. Many patients want this basic information that 'it might be cancer' but understood clinicians could not say for definite. One patient said she had no idea after having previous non-cancer treatment and assumed it was just the same. She even delayed her test result appointment as '*it was the last thing she expected*'.
- Partners or a family members should be allowed to accompany the patient throughout the whole process including during diagnostics to help absorb important information.
- A 'buddy system' could be set up so patients who have been through various treatments or procedures can talk through their experiences.

Privacy, dignity and support

Overall most patients suggested privacy and dignity was considered throughout. However, there were some very specific and significant issues raised:

We were herded like cattle in the main reception and had to queue to get our wrist bands. Then just stood around feeling lost and bemused until a nurse shouted our name – not the best way to feel just before you go in for surgery. (QE arrival on day of surgery)

We were all together in cubicles side by side and you could hear what he was saying to other people as he dashed from one to the next. (CHS patient follow up with surgeon)

I was handed my notes by the nurse to hold onto while I waited, then realised they weren't my notes. The nurse was clearly rushed off her feet and stressed out but I didn't think it was very good. (Phoenix unit CHS)

I had to get changed three times in and out of gowns for different tests and wandered around to different departments with my notes. (Durham University Hospital)

I screamed so loud when they put the needle in the cyst I must have terrified the other women next to me. They had only pulled the curtains round my bed. I thought they should have taken me to a treatment room. (Non-cancer in-patient CHS)

I called the breast nurse to ask about my drains on Saturday and she didn't call back until the following Wednesday – I had been to my GP by then and see a practice nurse who sorted me out. (QE)

Participants were asked if having men accompanying women throughout the process including diagnostics was an issue. The vast majority suggested it was, in fact, extremely important to them their husband, partner or family member was with them. However, when probed some participants suggested giving any male patients the choice of an appointment privately or at the beginning of the clinic to avoid any potential privacy or dignity issues for the male patient. The male respondent did not support this personally.

Suggested solutions offered by participants

- Always allow patients to be accompanied at every possible stage.
- Treat people as individuals and consider their feelings – particularly if they are in shock (at diagnosis) or frightened (on arrival for surgery).
- Train up 'auxiliaries' to do some tasks to relieve the pressure on breast nurses. Possibly volunteers, health trainers or similar if there is no money for more trained clinical staff.

On the ward

Some participants cited issues relating to in-patient care. Communication between staff and general level of care was criticised.

My drip was bone dry and my arm was red and sore I called and called and still the nurse didn't do anything until a doctor came in and went mad.

I felt really ill and my blood pressure was dropping. No one seemed to know what to do. When the surgeon came in on the morning he rushed me straight to the operating theatre as I had a massive internal bleed from a nicked vein. I was ill for days and had to stay in [hospital] for a week – longer than I should have.

Suggested solutions offered by the patients

- Be consistent – don't say one thing one day then something else the next
- Improve communication between clinicians and health care staff – administration of prescribed drugs on the ward

- Improve pain management

Pharmacy service (CHS)

There was also a consistent issue with the pharmacy service at CHS – all those using it felt the service was poor.

You wait ages when you feel really poorly after your chemo

It is a horrible waiting area and the staff are miserable

Two participants said they were not given clear instruction on how to administer their own drugs (abdominal injections) and had to either go back to the clinic or manage on their own.

I thought someone would have shown us how to do it.

Suggested solutions offered by the patients

- Have chemo drugs taken to patients at the phoenix unit
- Improve the waiting area and speed up dispensing

Discharge after hospital

Several people mentioned issues on their first few days out of hospital, particularly with drains.

Several people had problems with their drains and had been told to contact their district/ community nurses. In all instances when a patient contacted this service they were told the nurse could not help and to go back to hospital.

Suggested solutions offered by the patients

- Train district/community nurses to deal with drains
- Provide more guidance on aftercare – don't let anyone leave any stage of the pathway without being really clear of what to do or what will happen. Provide a comprehensive back up – breast nurses under pressure to constantly provide excellent advice and support.

Parking and transport

Some participants commented on having to travel for post-operative care when they 'felt poorly'. Others cited dissatisfaction with patient transport offered – either having to wait for a long time or a poor service offered by contracted taxi-hire firms.

Some people mentioned parking charges and anxieties cause if appointments or treatment ran over and concerns around parking fines.

Suggested solutions offered by the patients

- Make parking free for those having regular treatment
- Properly vet and brief contracted taxi firms to ensure they understand that people may be sick after treatment and that all funds should be covered by the contractor - *I was asked to pay the toll through the Tyne Tunnel and I didn't have any money.*

End of treatment

The vast majority of breast cancer patients (some prompted by comments when part of a group) said they all felt a sense of loss or insecurity at the end of treatment.

You go through so much for so long then suddenly that's it, it is your last radiotherapy treatment or your last annual check-up and you're done.

I felt like I'd been dropped – everyone was very nice and it was like a celebration at first as you think 'I am cancer-free' but then you're lost.

You have so much attention for so long and so much happiness then it's gone.

My medicine [tamoxifen] was like a prop or crutch. When they said I could stop taking it I was like, 'eeehhh no I can't, I need it'.

Suggested solutions offered by participants

- Elicit engagement with local 3rd sector and/or public health staff or volunteers to develop a support group for 'end of treatment'

Other issues raised by the minority or individual patients

Some CHS patients attending during a particular time period (2012 – 2014) commented on their dissatisfaction with their surgeon. Primarily more attitude than clinical knowledge or results of surgery.

Appendices

1. Legal and policy context for consultation on service changes for the NHS

Any reconfiguration of services requires a robust and comprehensive engagement and consultation process. NHS organisations are required to ensure that local people, stakeholder and partners are informed, involved and have an opportunity to influence any changes.

The process for involving people requires a clear action plan and audit trail, including evidence of how the public have influenced decisions at every stage of the process and the mechanisms used.

Section 242 of the NHS Act 2006 (as included in the Health and Social Care Act 2012) sets out the statutory requirement for NHS organisations to involve and consult patients and the public in:

- The planning and provision of services
- The development and consideration of proposals for changes in the way services are provided
- Decisions to be made by NHS organisations that affect the operation of services

Section 244 of the NHS Act 2006 requires NHS organisations to consult relevant Overview and Scrutiny Committees (OSC) on any proposals for a substantial development of the health service in the area of the Local Authority, or a substantial variation in the provision of services.

The Public Sector Equality Duty

S149 of the Equality Act 2010 states that a public body must, in exercise of its functions, have due regard to the need to:

- Eliminate discrimination
- Advance equality of opportunity
- Foster good relations
- Remove or minimise disadvantage
- Take steps to meet needs
- Encourage people to participate

Public bodies must also take into account the protected characteristics of:

- Age
- Disability
- Gender re-assignment
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

The NHS constitution

NHS Constitution gives the following rights and pledges to patients:

“You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.”

“The NHS commits to provide convenient, easy access to services within the waiting times set out in the Handbook to the NHS Constitution (pledge).

“The NHS commits to make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered (pledge).

“You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences.”

The NHS Mandate ‘Nicholson tests’

Additionally, CCGs have further duties which have been set out through the NHS Mandate 2013-15, which sets out the ‘4 tests’ to be met in services reconfiguration (known as the Nicholson tests).

This exercise fulfilled the highlighted elements below:

Support from GP Commissioners	Engagement with GPs, particularly with practices whose patients might be significantly affected by proposed service changes
Clear clinical evidence base	The strength of the clinical evidence to be reviewed, along with support from senior clinicians from services where changes are proposed, against clinical best practice and current and future needs of patients
Strengthened patient and public engagement	Ensure that the public, patients, staff, HealthWatch and Health Overview and Scrutiny Committees are engaged and consulted on the proposed changes
Supporting patient choice	Central principle underpinning service reconfigurations is that patients should have access to the right treatment, at the right place and the right time. There should be a strong case for the quality of proposed service and improvements in the patient experience

The Gunning Principles

Before 1985 there was little consideration given to consultations until a landmark case of *Regina v London Borough of Brent ex parte Gunning*. This case sparked the need for change in the process of consultations when Stephen Sedley QC proposed a set of principles that were then adopted by the presiding judge. These principles, known as Gunning or Sedley, were later confirmed by the Court of Appeal in 2001 (*Coughlan* case) and are now applicable to all public consultations that take place in the UK.

The principles and where this exercise fit within them are:

- **Consultation must take place when proposals are still at a formative stage**
This engagement exercise formed the primary activity and responses will clearly define the requirements of the service specification for prospective providers.
- **Sufficient reasons must be put forward for the proposals to allow for intelligent consideration and an intelligent response.**
The survey; focus group plans; all promotional collateral and digital media activity clearly outlined the basis for this engagement exercise – explaining the current situation; background; why this stage is vital and the genuine commitment to patient involvement.

The elements have been tested with patients, partners and clinical staff to ensure any participants understood the purpose of the exercise and the value of resulting insight.

Participants in the engagement were provided with information and given the opportunity to ask questions.

While the survey provided in the most part a one-way opportunity for response on past experiences; focus group and one-to-one interviews will allow for a more two-way process of information sharing and opportunities to ask questions. The views of those in focus groups or one-to-one interviews will be formally recorded and shared back to ensure accuracy and provide an opportunity for re-evaluation.

- **Adequate time must be given for consideration and response**
A clearly defined project plan was put in place with key milestones. The engagement exercise in fact influenced the overall service planning process to ensure adequate time for public involvement and evaluation of their responses.
- **The outcome of the consultation must be conscientiously taken into account**
Based on the feedback from the engagement activity, decision-makers will be able to show they have taken the outcome of the consultation into account – they will be able to demonstrate good reasons and evidence for their decision.

Should decision-makers disagree with the majority response, they must be able to set out why the majority view was not followed.

- 2. Initial report including desk research with current know data - attachment**
- 3. All data from survey – phase 1 - attachment**
- 4. All data from survey – phase 2 - attachment**