National Cancer Patient Experience Survey 2021

National Results Webinar

CPES@PickerEurope.ac.uk

#pickerworkshops #cpes21

Agenda

Listening to Patient Voices: Reflections on CPES 2021

Ceinwen Giles (Co-CEO, Shine Cancer Support/ Chair, Chair of the Patient Public Voices Forum, NHS Cancer Programme, NHS England)

The National Perspective

David Fitzgerald (Cancer Programme Director, NHS England)

Key Findings

Philippa Fortune (National Programme Lead, Picker)

Kirsty Laing (Associate Insight Director, Explain)

What do we think?

Hanan L'Estrange-Snowden (Insight Manager, Picker)

King's College HNFT: Cancer Improvement Collaborative

Irina Belun-Vieira (Head of Nursing Cancer)

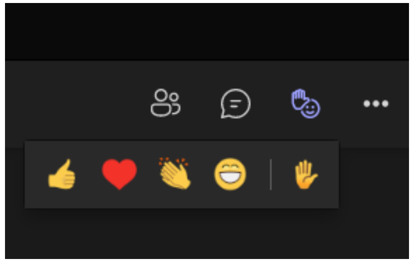
Sola Banjo (Cancer Quality Improvement Manager)

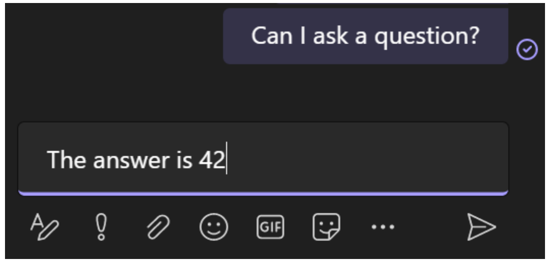
Close

Clare Enston (Deputy Director of Insight and Feedback, NHS England)

Objectives

- Understand the national picture
- To celebrate areas of success in cancer care
- To share improvement learning and experiences
- Answer your questions





Can I ask a question?

The answer is 42

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Listening to Patient Voices: Reflections on CPES21

Ceinwen Giles

(Co-CEO, Shine Cancer Support/ Chair,
Chair of the Patient Public Voices Forum, NHS Cancer Programme, NHS England)

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NHS
England

Listening to Patient Voices

Reflections on CPES 2021

Ceinwen Giles, Co-CEO, Shine Cancer Support

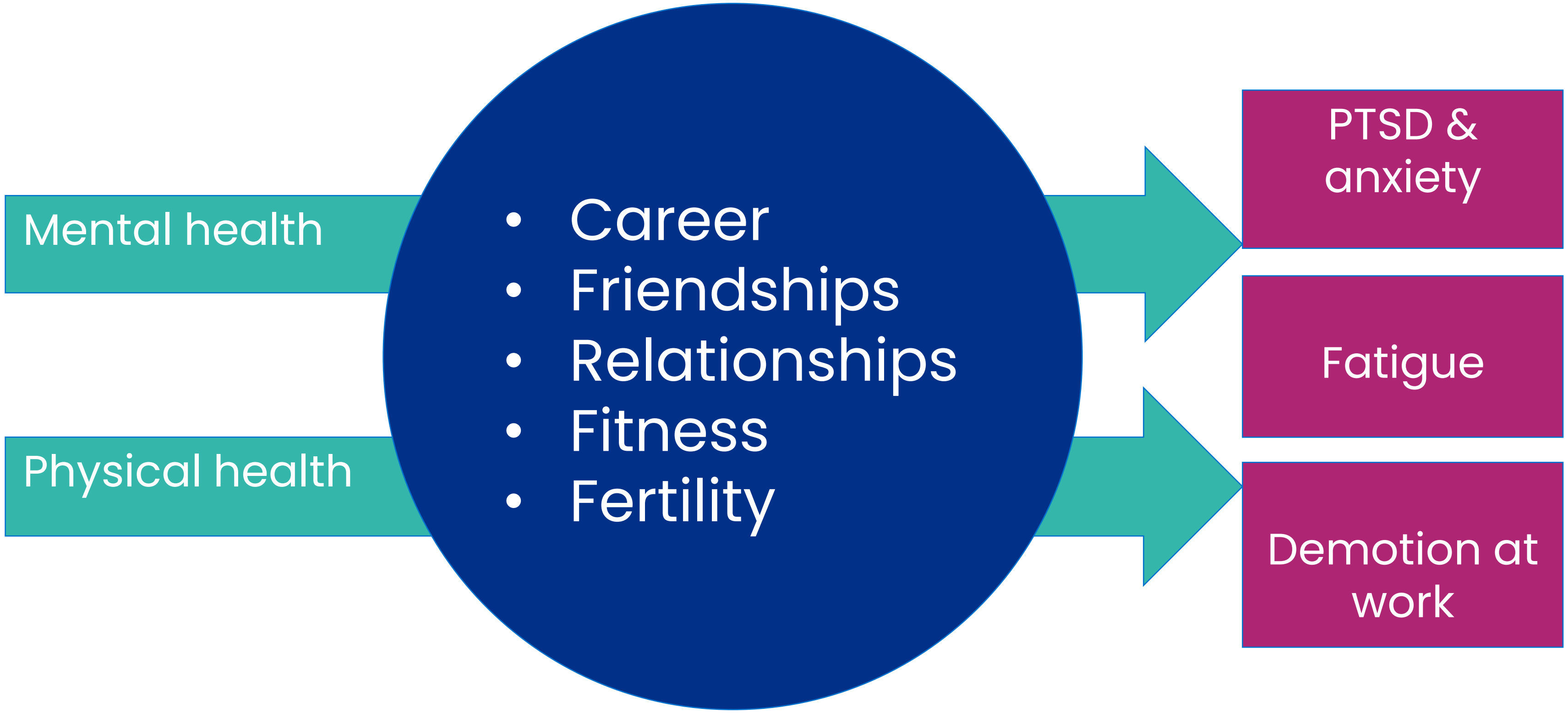
Chair, Patient and Public Voices Forum

Outline

- Why patient experience is important
- Needs to different groups
- How we work with communities
- Links to the Patient and Public Voices forum
- What’s coming next….

Personal experience

- Stage 4 diffuse large b-cell lymphoma
- Six months as an in-patient
- Some amazing care and treatment – some really difficult experiences



Mental health

Physical health

- Career
- Friendships
- Relationships
- Fitness
- Fertility

PTSD & anxiety

Fatigue

Demotion at work

12 years later….


RECOVERY
Expectations
Reality

What should we care about the CPES survey?

- You know how the system *should* work
- Patients can tell you how it *is* working
- A lot of things are working well….

Overall experience

8.92

Respondents' average rating of care scored from very poor to very good (scale from 0 to 10).

Support from a main contact person

91.9%

said they had a main contact person within the team looking after them who would support them through treatment.

Support from hospital staff

89.6%

of respondents said hospital staff gave them information that was relevant to them about support or self-help groups, events or resources for people with cancer.

There is more to do….

Care planning

71.7%

said that before their treatment started, they had a discussion with a member of the team looking after them about their needs or concerns.

Immediate and long-term side effects

59.5%

said the possible long-term side effects, including the impact on their day-to-day activities, were definitely explained in a way they could understand.

Care from your GP practice

43.7%

of respondents who said their GP practice was involved in their care while they were having treatment said they got the right amount of support from staff at their practice.

Living with and beyond cancer

62.5%

said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns.

We also need to look more deeply….

- People from the most deprived groups gave lower average ratings for care received.
- Respondents from white backgrounds gave a higher average rating of care than respondents from mixed, Asian or black ethnic backgrounds.
- We also hear less from people from Asian, mixed and black ethnic backgrounds.
  - 3.5% of the UK population is black, but only 1.5% of respondents are.

Age and gender….

- Respondents in the 35-44 age group were the least likely to say that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns

- Males were the more likely than women to say that before their hormone therapy had started they had all the information they needed in a way they could understand.

When patients tell us what they think…

We already knew that…

That cannot have happened….

There are different ways to get insight and feedback

- Be curious and open
- Think about who is giving you feedback and who isn't
- Think about how you can reach those who aren't giving you feedback
  - Location
  - Time of day
  - Way that they provide feedback (online? Face to face? Written?)

Three issues for the year ahead…

The Cost of Cancer

Ruth Alexander and a panel of experts discuss the financial costs of cancer

Available now

29 minutes

Show more

- The cost of living crisis is going to be tough for everyone – but especially cancer patients.
- Visiting in hospitals – especially if you have children.
- Masking in cancer hospitals and wards.

The PPV Forum

- The Cancer Programme have worked hard to establish a structure for ensuring patients are engaged
- Patient & Public Engagement Manager to specifically focus on ensuring effective engagement- Rachel Lovesy from March 22
- Establishment of the Cancer Programme PPV with Terms of Reference and patient representative Chair

Our objectives:

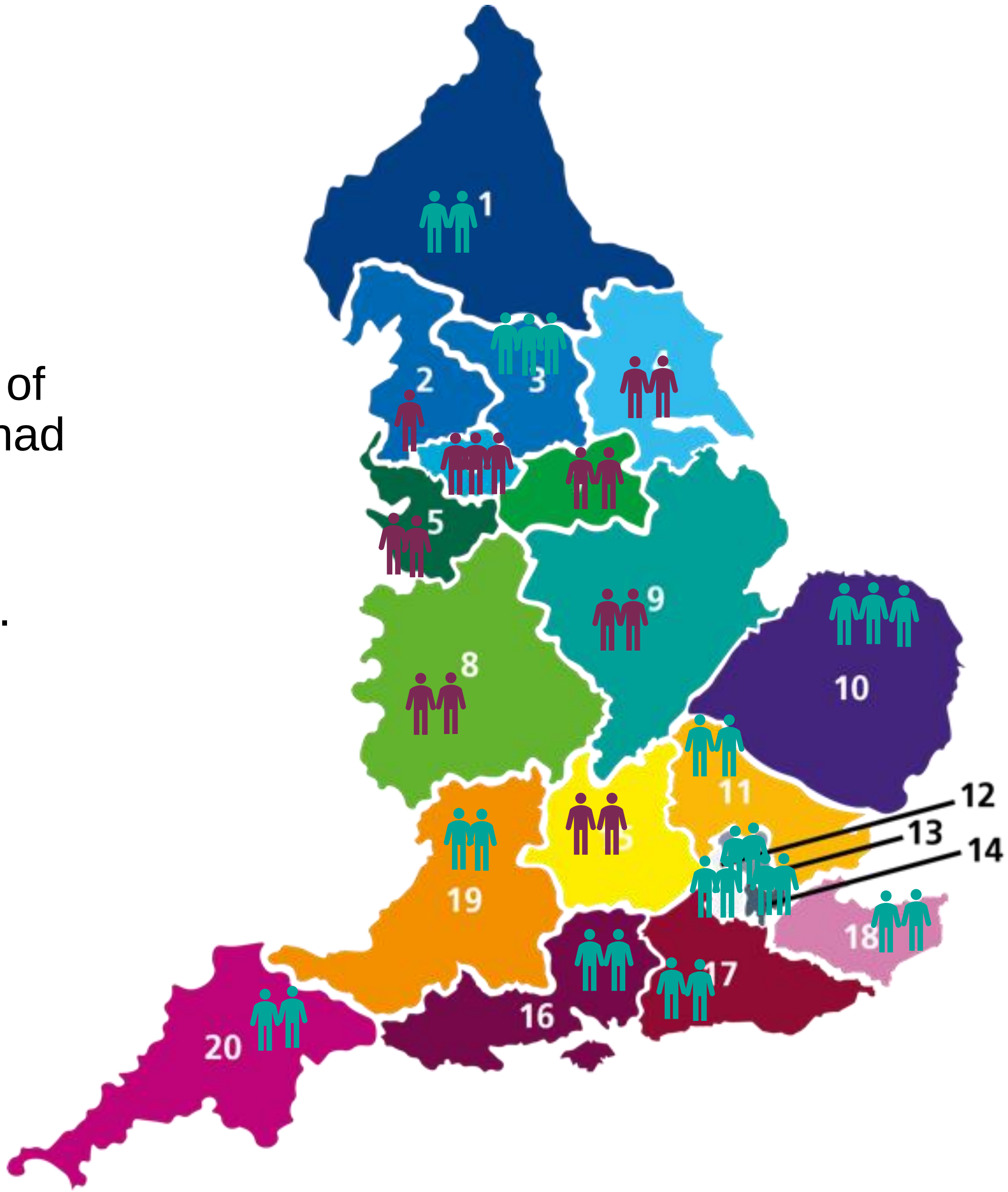
- To bring actionable on-the-ground intelligence from communities and people affected by cancer into the Cancer Programme and to relevant decision-makers
- To deliver advice, guidance and support to add value to the success of nationally-led programme, projects, and policy
- To generate mutual learning between project teams, communities, and people affected by cancer

Our Members

There are currently 35 PPV members.

All members have a personal experience of cancer, or supporting someone who has had cancer.

Members are based across the country, many are aligned to their Cancer Alliance.



The PPV Forum – what we do

- We represent patients and the public voice within the National Cancer Programme
- We actively support programmes by joining project teams, meetings, workshops as many other activities, as equal partners and decision makers
- At present, we are involved in over 15 projects including;
    - *Task and Finish Groups – Psychosocial and Treatment Interruption*
    - *GRAIL Implementation*
    - *CPES Awards*
    - *Health Inequalities Sub-Group*
    - *Experience of Care*
    - *Faster Diagnosis Quality Markers*

The PPV Forum – how to involve us

- **We want to better linked to Cancer Alliances and ICS structures**
- We have a range of personal experiences and perspectives which we can bring - and would love to be involved from the start of projects.
- Many of us have experience beyond our own cancer experience and can guide and advise on how to involve communities
- We are passionate about health inequalities, particularly within our own communities

"What I hear when I'm being yelled at is people caring loudly at me."

Thank you!

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@ceineken

The National Perspective

David Fitzgerald

(Cancer Programme Director, NHS England)

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Key Findings

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CPES 2021
Quantitative Results

Key sources of data for CPES21

National Reports

- Quantitative overview of national results (standard)
- Quantitative overview of national results (Easy Read version) (new for 2021)
- Qualitative report presenting a thematic analysis of free text comments (new for 2021)
- National level data tables – Excel

Alliance Reports

- Cancer Alliance Level Reports – PDF – Quantitative
- Cancer Alliance data tables – Excel

ICS Reports (new for 2021)

- ICS Reports – PDF – Quantitative
- ICS data tables – Excel

Trust Reports

- Trust Reports – PDF – Quantitative
- Trust data tables – Excel
- Free text workbooks - Excel

Delve deeper using the interactive reporting tool on the ncpes.co.uk website!

New Survey for 2021 – Trend Data

- The survey had not been reviewed since 2015, when the last full review took place.
- The survey was updated for 2021 and the CPES Advisory Group oversaw the review of the questionnaire
- There had been significant changes in service delivery, clinical practice and policy, which the survey now reflects
- As such there is no historic trend data in the 2021 Reporting

CPES – who is eligible

- All acute and speciality NHS Trusts in England that provide adult cancer services
  - Adults > 16 years
  - Confirmed primary diagnosis of cancer

  Adults who were:
  - EITHER: Admitted to hospital as an inpatient
  - OR: a day case patient
  - For cancer related treatment

- Discharged between **1 April 2021 and 30th June 2021**

- Response rate of 55%

59,352 out of 107,412 patients surveyed responded

Headline Findings (Quantitative)

Headline Findings

Overall experience

8.92

Respondents' average rating of care scored from very poor to very good (scale from 0 to 10).

Support from your GP practice

64.1%

of respondents who had contacted their GP practice said that the referral for diagnosis was explained in a way they could completely understand.

Diagnostic tests

94.4%

always had enough privacy when receiving diagnostic test results.

Finding out that you had cancer

71.4%

said that when they were first told that they had cancer, they had been given the option of having a family member, carer or friend with them.

Headline Findings

Support from a main contact person

91.9%

said they had a main contact person within the team looking after them who would support them through treatment.

Deciding on the best treatment

79.2%

said they were definitely involved as much as they wanted to be in decisions about treatment options.

Care planning

71.7%

said that before their treatment started, they had a discussion with a member of the team looking after them about their needs or concerns.

Support from hospital staff

89.6%

of respondents said hospital staff gave them information that was relevant to them about support or self-help groups, events or resources for people with cancer.

Headline Findings

Hospital care

80.9%

of respondents who had an overnight stay said they had confidence and trust in all of the team looking after them.

Your treatment

79.1%

said they felt the length of waiting time at the clinic or day unit used for cancer treatment was about right.

Immediate and long-term side effects

59.5%

said the possible long-term side effects, including the impact on their day-to-day activities, were definitely explained in a way they could understand.

Support while at home

55.4%

said their family or someone else close to them were given all the information necessary to help care for them at home.

Headline Findings

Care from your GP practice

43.7%

of respondents who said their GP practice was involved in their care while they were having treatment said they got the right amount of support from staff at their practice.

Living with and beyond cancer

62.5%

said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns.

Finding out that you had Cancer

Just under three quarters of all respondents **(71%)** said that when they were first told that they had cancer they had been given the option of having a family member, carer or friend with them (Q12).

Respondents in the 16-24 age group were the **.** The 35-44 age group were the least likely to say this was the case (Q12).

When asked how they felt about the way they were told they had cancer, **74%** said they were told sensitively (Q13). Overall, **84%** said that they were definitely told about their diagnosis in a place that was appropriate for them (Q15).

Hospital Care

89% of respondents felt that they were always treated with respect and dignity while they were in the hospital (Q37).

When asked ‘Did the hospital staff do everything you wanted to help control your pain?’, **86%** of respondents said this was definitely the case (Q36)

When asked whether they were given clear written information about what they should or should not do after leaving hospital, **89%** of respondents felt they were and that this information was easy to understand (Q38).

Hospital Care

However in some areas of hospital care respondents reported a more negative experience.

With only six out of ten **(61%)** respondents who had stayed overnight saying family or someone else close to them were definitely able to talk to someone on the team looking after them if they wanted to (Q32).

67% of respondents answering that during their stay in hospital they could always talk to the hospital staff about their worries and fears if they needed to (Q35).

Care Planning

93% of respondents who had a discussion with staff about their needs or concerns said a member of their care team helped them create a care plan to address these (Q25).

And **99%** of respondents who had a care plan, said that a member of the team looking after them reviewed the plan with them to make sure it continued to reflect their needs or concerns (Q26).

Support from a main contact person

85% of respondents found it very or quite easy to contact their main contact person (Q18).

Respondents from white ethnic backgrounds were the most likely to say it was ‘very’ or ‘quite easy’ to contact their main contact person. Respondents from Asian ethnic backgrounds were the least likely to say it was ‘very’ or ‘quite easy’ to contact their main contact person (Q18).

96% of respondents said that they found the advice from their main contact person to be ‘very’ or ‘quite helpful’ (Q19).

Support while at home

Only **55%** of respondents said that their family or someone else close to them were given all the information they needed to help care for them at home (Q49).

Respondents with a mental health condition were the least likely to say their family or someone else close to them were given all the information they needed from the team looking after them to help care for them at home (Q49).

Care from your GP Practice

Of those that said their GP practice was involved in their cancer treatment, **44%** said they got the right amount of support from staff at their GP practice while they were having cancer treatment (Q51).

Respondents in the most deprived group (based on IMD quintile) were the least likely to say that they got the right amount of support (Q51).

18% of all respondents said they had a review of their cancer care by a member of staff at their GP practice (Q52).

Further Guidance

For further guidance on scoring, suppression and how to use the reports please refer to the Technical Document on the NCPES website

https://www.ncpes.co.uk/supporting-documents/

Or email the team

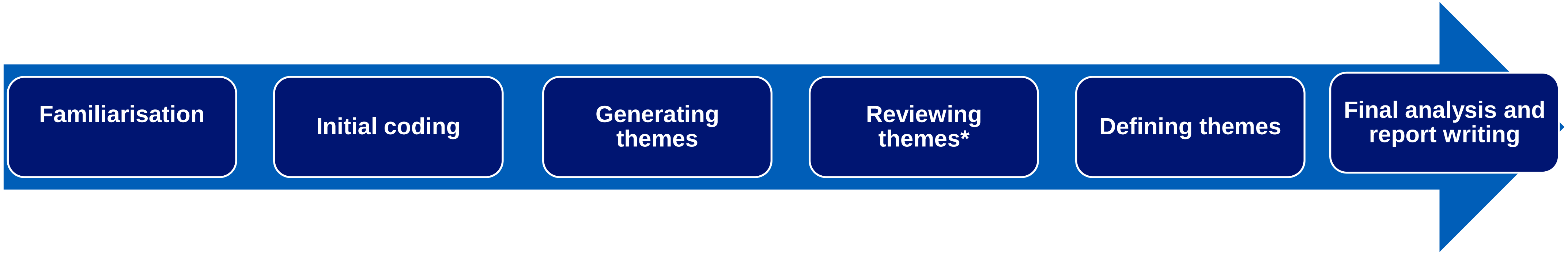
CPES@pickereurope.ac.uk

National Cancer Patient Experience Survey 2021 – Qualitative

Qualitative analysis - approach

- Thematic analysis was undertaken to achieve a deep understanding of the written feedback from two open questions asked at the end of the survey.
  - This sought to facilitate reflection and learning across services delivering NHS cancer care for adults in England.
- To analyse this data, the standard six steps of thematic analysis were used to identify pattern and meaning within the data.

Figure 1: Thematic Analysis Approach



Familiarisation

Initial coding

Generating themes

Reviewing themes*

Defining themes

Final analysis and report writing

Qualitative analysis – questions

QA: Overall, how would you describe your care and treatment? (**84%** responded)

QB: Was there anything that could have been improved? (**62%** responded)

- *Note – a third open question was asked 'QC - any other comments?' (44% responded) but this was not included in analysis as the majority were found to be a repetition of comments provided in QA and QB.*

Qualitative analysis - sampling

- A two pronged sampling approach was taken, ensuring the sample was representative and the principle of data saturation was applied.

Stage 1

  - A random sampling technique to ensure that the sample was representative of the population as a whole (95% confidence level with a margin of 3%, sample size 1501 respondents)

Stage 2

  - Data saturation was used to ensure the sample encapsulated as fully as possible the range of experiences within the data (i.e., the point at which no new themes emerged from the data)

- *A full copy of the qualitative report and sampling information can be found here: https://www.ncpes.co.uk/wp-content/uploads/2022/07/20220701-NCPES-Qualitative-National-Report-FINAL.pdf*

Findings – gratitude

- An overwhelmingly strong theme was gratitude. Respondents discussed their care as excellent and highlighted positive experiences with staff members who were praised for their kindness and compassion.
- Care was described as being;

Progressive

Efficient

Brilliant

Outstanding

> *“Treatment and care couldn’t have been better. All staff have been very caring, informative and genuinely concerned. All possible tests have been completed..."*

> *“My care and treatment were excellent and I was well looked after throughout. The nurses and staff were very helpful”*

- This echoes the positive overall experience of care quantitative scores.

What does the quantitative survey data tell us?

Respondents were asked to rate their overall care on a scale of 0 (very poor) to 10 (very good). The average rating of care given by respondents was **8.92**.

89.2% of respondents felt that they were always treated with respect and dignity while they were in the hospital.

Findings – negative experiences with General Practice

- Respondents often felt support from their GP did not meet their expectations. Concerns included:

Initial symptoms not taken seriously = delayed diagnosis

A lack of proactive follow-up by GP after diagnosis and/or treatment

Difficulty with access to GP appointments

"When one goes to the GP with lumps...they should be biopsied/investigated as soon as possible and taken seriously. I would have been treated for cancer 7 months earlier if my lump in my armpit had been biopsied the first time I went to GP"

"I have had no contact from my GP practice, I think it's important that my GP makes contact to offer further support"

What does the quantitative survey data tell us?

64.1% of respondents who had contacted their GP practice said that the referral for diagnosis was explained in a way they could completely understand (Q3).

18.0% of all respondents said they had a review of their cancer care by a member of staff at their GP practice (Q52).

Respondents were asked if they got the right amount of support from staff at their GP practice while they were having cancer treatment. Of those that said their GP practice was involved in their cancer treatment, **43.7%** said this was definitely the case (Q51)

Findings – communication for patients

- Respondents felt inadequately informed about some aspects of their care and commented on a lack of effective follow-up. They suggested the following as examples of areas in which more information would be useful:

Detailed information on cancer type

Information on type of treatment

Information on side effects of treatment

Do's and don'ts after surgery

"More explanation of my illness & any future care that would help me"

"Perhaps, a little more information during the hospital stay regarding the treatment given"

"I have a rare form of cancer and wasn't provided anywhere near enough information on this or any direction where to find it. I had to do the research myself"

What does the quantitative survey data tell us?

82.2% of respondents said their treatment options were completely explained to them in a way they could understand before their cancer treatment started (Q20).

71.7% said that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24).

62.5% said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns (Q55).

Findings – communication for patients

- They also expressed a desire for face to face communication and emphasised the importance of a single point of contact

"Having 1 point of contact in the beginning would have been much better as it was confusing to know who to speak with, I felt a bit being sent from pillar to post, obviously when worrying about my condition. It would have helped if it was better co-ordinated"

"Given that it was during Covid lockdown, care was mostly done by phone, even checking the wound was by video link. It was ok but I didn't feel I was able to share my thoughts adequately"

"I would have preferred being told I had cancer face to face rather than in a telephone call"

What does the quantitative survey data tell us?

Respondents were asked whether once their cancer treatment had finished, they could get emotional support at home from community or voluntary services. **31.8%** of respondents that needed care and support said this was definitely the case (Q53)

91.9% said they had a main contact person within the team looking after them who would support them through treatment, with **81.5%** saying that this person was a specialist nurse (Q17).

55.4% said their family or someone else close to them were given all the information they needed to help care for them at home (Q49).

85.0% said it was 'very' or 'quite easy' to contact their main contact person (Q18).

Findings – waiting times

- Long wait times were mentioned in many different contexts.

To start treatment

To start treatment once in hospital

To be seen at appointments

To receive an appointment

Receiving information

Prescriptions/ medicines

Being discharged

Follow ups

Transport

- The most prominent example was waiting longer than anticipated for tests and treatment. Some understood this wait to be associated with poorer prognosis.

"There was a 3/4-month delay in starting treatment. A matter of concern if my cancer was time sensitive"

"It did feel to me that it was a long time before I actually got to treatment, especially when my cancer had spread so rapidly with a poor prognosis"

What does the quantitative survey data tell us?

When asked how they felt about the length of time they had to wait for their test results, **81.9%** felt the length of time was about right (Q7).

79.1% of respondents felt the length of waiting time at the clinic or day unit for cancer treatment was about right (Q43).

Findings – negative experiences with hospital staff

- Reflecting the pivotal role of staff, when a negative interaction was experienced it stood out to respondents.
- There were isolated incidents of staff being unprofessional or inconsiderate, as well as a common feeling staff were 'too busy' and wards were 'understaffed' which impacted care.
- Specific to cancer care, a small number of respondents highlighted they felt there was a need for staff to undergo more specialist training.

"Maybe more training for nurses with regard to blood taking and canular insertion"

"Good overall apart from a few individuals who were rude to me / just ignored me when waiting for treatment. However, some nurses were outstanding and very kind, knew exactly what to say when I have been upset and gave me lots of time, never rushed me"

What does the quantitative survey data tell us?

76.2% said they could always get help from hospital staff when they needed it (Q34).

During their hospital stay, **66.9%** of respondents said they could always talk to the hospital staff about their worries and fears if they needed to (Q35).

60.6% of respondents who had stayed overnight said family/someone close to them were definitely able to talk to someone on the team looking after them if they wanted to (Q32).

Findings – wider hospital issues

- Anticipated to impact patients widely, issues were cited with;

“Bedding is poor, sheets are too heavy and do not keep one warm. Adding sheets didn’t help as weight was uncomfortable. Thank heavens for a home delivered quilt”

“No privacy when talking to medical staff about my conditions or treatment in hospital settings on a ward is always a problem”

- Food quality and variety
- Parking access and costs
- A lack of privacy
- Noise disturbance at night
- Décor needing an update
- Beds being uncomfortable
- Restrictions linked to COVID-19

“The food is difficult for people with a number of eating difficulties. It is very hard to find anything that would allow multiple diet requirements to be met which does not help recovery. During my hospital stay I became malnourished”

“Car Park fees are excessive”

Questions?

What do we think?

Hanan L’Estrange-Snowden (Insight Manager, Picker)

CPES@PickerEurope.ac.uk

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Picker

NHS England

Regional break out rooms

What do we think about the feedback?

What should we be celebrating?

What do we want to focus on going forward?

Contact CPES@PickerEurope.ac.uk to access breakout room notes

King’s College HNFT: Cancer Improvement Collaborative

Irina Belun-Vieira (Head of Nursing Cancer)
Sola Banjo (Cancer Quality Improvement Manager)

CPES@PickerEurope.ac.uk
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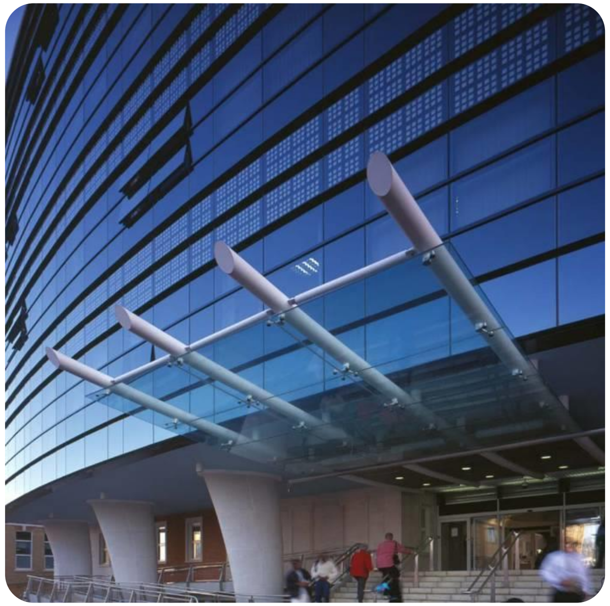
Cancer Improvement Collaborative (NHSE/I):

To improve the explanation of diagnostic test results in a completely understandable way for breast adult cancer patients in ethnically diverse communities

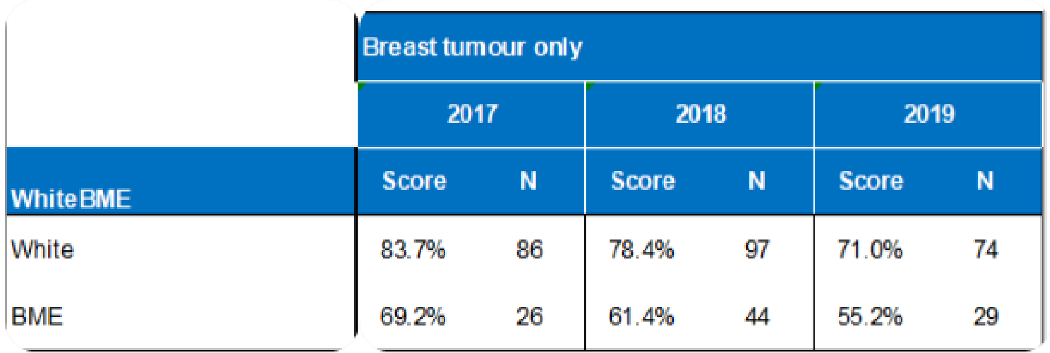
Kings Cancer Collaborative Project Team

King's

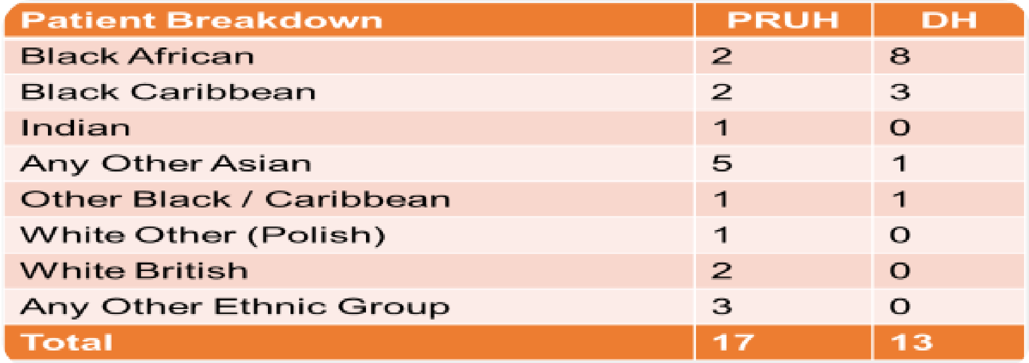


Project Overview

Improve the experience of Kings College Hospital BAME adult breast cancer patients, as measured by for the NCPES Q7, with a target improvement of 10%



	Breast tumour only					
	2017		2018		2019	
White BME	Score	N	Score	N	Score	N
White	83.7%	86	78.4%	97	71.0%	74
BME	69.2%	26	61.4%	44	55.2%	29



Patient Breakdown	PRUH	DH
Black African	2	8
Black Caribbean	2	3
Indian	1	0
Any Other Asian	5	1
Other Black / Caribbean	1	1
White Other (Polish)	1	0
White British	2	0
Any Other Ethnic Group	3	0
Total	**17**	**13**

Main findings

Overall CNS and Consultant explanation of diagnostic testing, care and compassion is great!!!! 89% of our patients commended this aspect of care

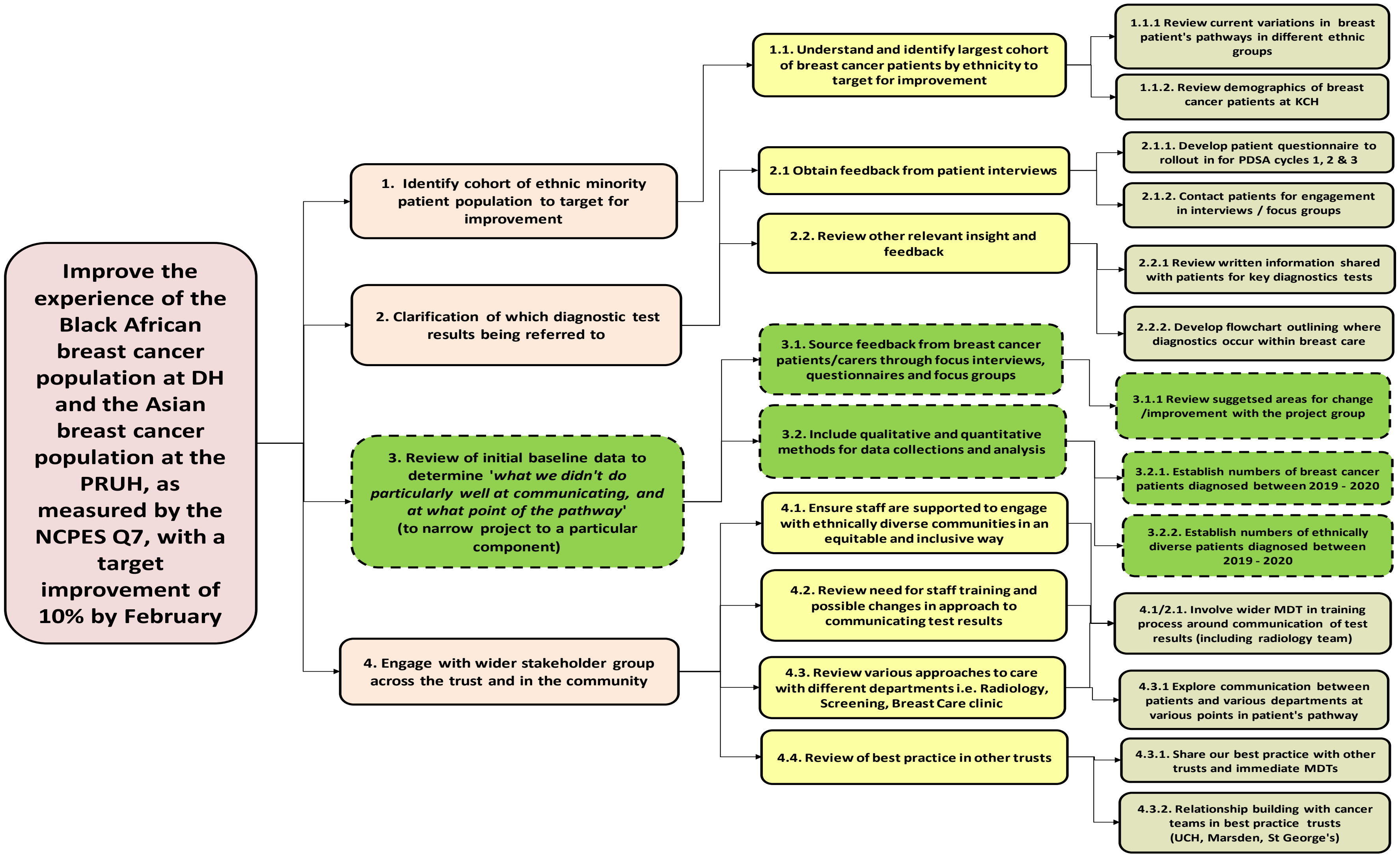
The wider experience of care (including access to information and support) was an area identified for improvement for 11% of our patients

Improve the experience of the Black African breast cancer population at DH and the Asian breast cancer population at the PRUH, as measured by the NCPES Q7, with a target improvement of 10%

KCH Cancer Collaborative
Driver Diagram

King's College Hospital
NHS Foundation Trust

	Add aim	Add primary driver	Add secondary driver	Add intervention
Key:	In order to achieve this aim..	We need to ensure...	Which requires...	Ideas to ensure this happens



Improve the experience of the Black African breast cancer population at DH and the Asian breast cancer population at the PRUH, as measured by the NCPES Q7, with a target improvement of 10% by February

1. Identify cohort of ethnic minority patient population to target for improvement

2. Clarification of which diagnostic test results being referred to

3. Review of initial baseline data to determine '*what we didn't do particularly well at previously, and at what point of the pathway*' (to narrow project to a particular component)

4. Engage with wider stakeholder group across the trust and in the community

1.1. Understand and identify largest cohort of breast cancer patients by ethnicity to target for improvement

2.1 Obtain feedback from patient interviews

2.2. Review other relevant insight and feedback

3.1. Source feedback from breast cancer patients/carers through focus interviews, questionnaires and focus groups

3.2. Include qualitative and quantitative methods for data collections and analysis

4.1. Ensure staff are supported to engage with ethnically diverse communities in an equitable and inclusive way

4.2. Review need for staff training and possible changes in approach to communicating test results

4.3. Review various approaches to care with different departments i.e. Radiology, Screening, Breast Care clinic

4.4. Review of best practice in other trusts

1.1.1 Review current variations in breast patient's pathways in different ethnic groups

1.1.2. Review demographics of breast cancer patients at KCH

2.1.1. Develop patient questionnaire to rollout in for PDSA cycles 1, 2 & 3

2.1.2. Contact patients for engagement in interviews / focus groups

2.2.1 Review written information shared with patients for key diagnostics tests

2.2.2. Develop flowchart outlining where diagnostics occur within breast care

3.1.1 Review suggetsed areas for change /improvement with the project group

3.2.1. Establish numbers of breast cancer patients diagnosed between 2019 - 2020

3.2.2. Establish numbers of ethnically diverse patients diagnosed between 2019 - 2020

4.1/2.1. Involve wider MDT in training process around communication of test results (including radiology team)

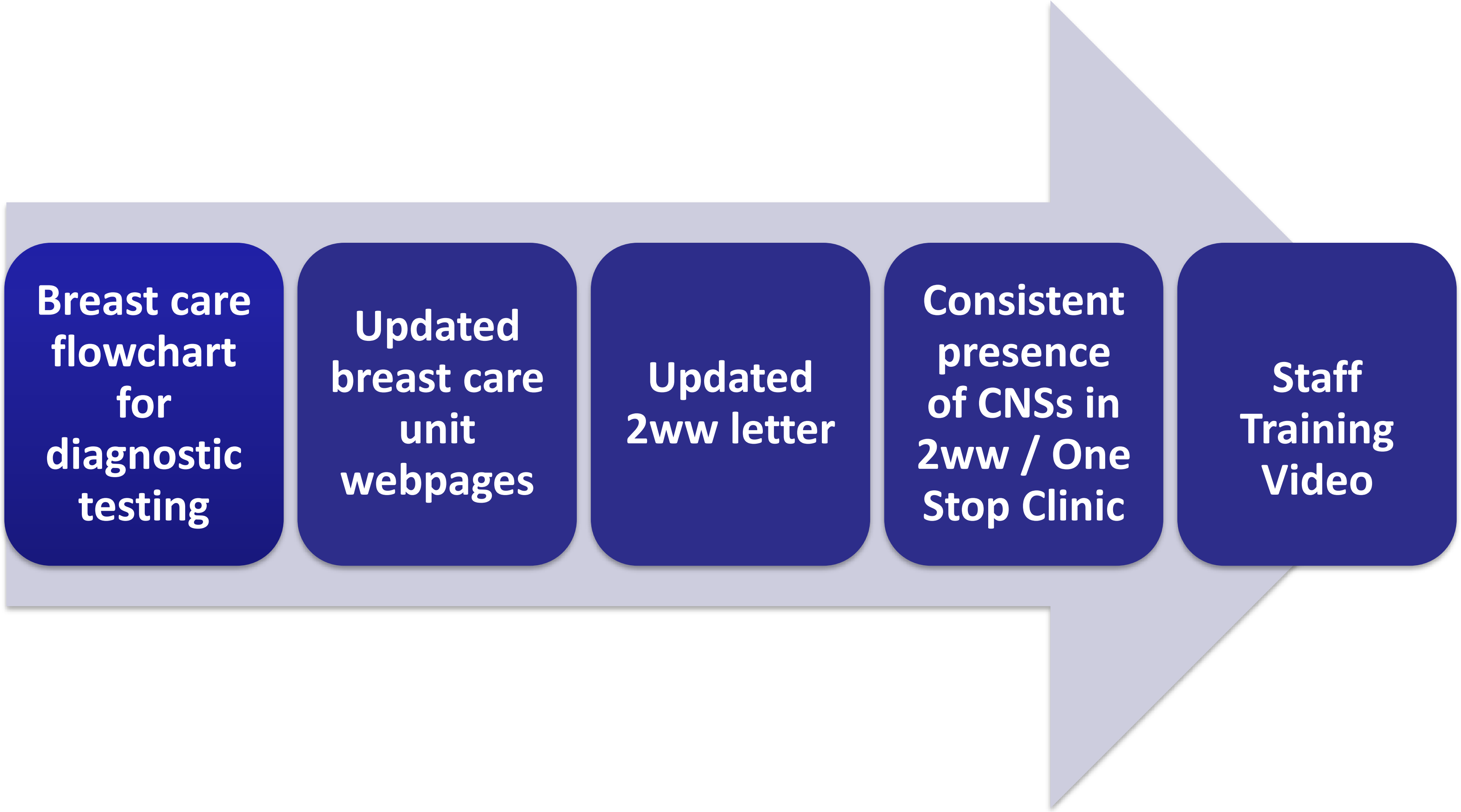
4.3.1 Explore communication between patients and various departments at various points in patient's pathway

4.3.1. Share our best practice with other trusts and immediate MDTs

4.3.2. Relationship building with cancer teams in best practice trusts (UCH, Marsden, St George's)

Our Change Ideas

Piloting change…….



- Breast care flowchart for diagnostic testing
- Updated breast care unit webpages
- Updated 2ww letter
- Consistent presence of CNSs in 2ww / One Stop Clinic
- Staff Training Video

Patient Video has been removed for copyright purposes.

To access please contact CPES@PickerEurope.ac.uk

Top Tips

1. **Secure backing from trust executive leadership, internal and external partners**

2. **Get the right people round the table**
   - ✓ Set up a project group team, including recruiting patient representatives lived experience, CNSs, Cancer Clinical Lead, Comms, Patient engagement and experience, South East London Cancer Alliance breast cancer improvement, Radiology colleagues, Equality and Diversity Team

3. **Understand your CPES results**
   - ✓ Use results in the way to demonstrate there is an issue and link in how it affects outcomes
   - ✓ Link data to experience of care and pathway you are focusing on to inform

4. **Understand your population demographics**
   - ✓ Review and understand ethnic representation in your community
   - ✓ Link to the clinical outcomes team for better data analyses
   - ✓ Use PALs data
   - ✓ Use Public Health Data

Top Tips

5. **Wider team engagement**
   - ✓ Cross site engagement events to update on aims and present change ideas being discussed with all MDM
   - ✓ Allow wider team to feed into changes
   - ✓ Present at the cancer alliance tumor group level
   - ✓ Share success with all who are interested to hear!

6. **Listen to your patients**
   - ✓ Baseline data collection from patients (1:1 and focus groups)
   - ✓ Work with live experience patients as partners to identify areas of concern, even if they are not answering a question you trying to understand
   - ✓ Share success and final work with all who contributed

7. **Be flexible and responsive**
   - ✓ Allow your improvements to be lead by what your learned from patients
   - ✓ Offer a platform for patients and staff to design what good look like

Questions

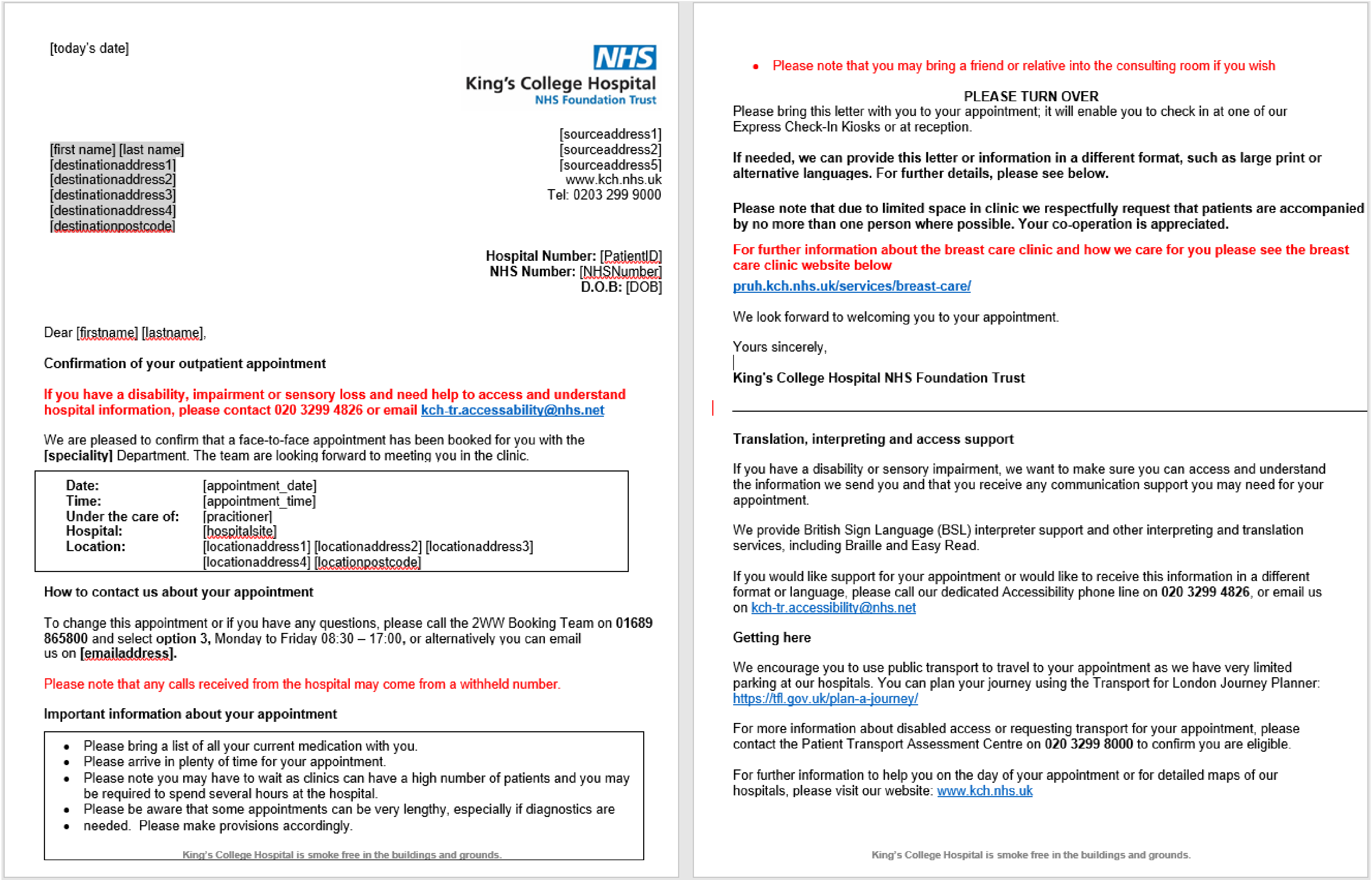
King's Cancer Collaborative

Appendices - Ideas for change / improvement

King's

Appendix 1 - 2ww Clinic Letter

NHS
King's College Hospital
NHS Foundation Trust



[today's date]

NHS
King's College Hospital
NHS Foundation Trust

[first name] [last name]
[destinationaddress1]
[destinationaddress2]
[destinationaddress3]
[destinationaddress4]
[destinationpostcode]

[sourceaddress1]
[sourceaddress2]
[sourceaddress5]
www.kch.nhs.uk
Tel: 0203 299 9000

Hospital Number: [PatientID]
NHS Number: [NHSNumber]
D.O.B: [DOB]

Dear [firstname] [lastname],

Confirmation of your outpatient appointment

If you have a disability, impairment or sensory loss and need help to access and understand hospital information, please contact 020 3299 4826 or email kch-tr.accessability@nhs.net

We are pleased to confirm that a face-to-face appointment has been booked for you with the **[speciality]** Department. The team are looking forward to meeting you in the clinic.

Date:	[appointment_date]
Time:	[appointment_time]
Under the care of:	[pracitioner]
Hospital:	[hospitalsite]
Location:	[locationaddress1] [locationaddress2] [locationaddress3] [locationaddress4] [locationpostcode]

How to contact us about your appointment

To change this appointment or if you have any questions, please call the 2WW Booking Team on **01689 865800** and select **option 3**, Monday to Friday 08:30 – 17:00, or alternatively you can email us on **[emailaddress].**

Please note that any calls received from the hospital may come from a withheld number.

Important information about your appointment

- Please bring a list of all your current medication with you.
- Please arrive in plenty of time for your appointment.
- Please note you may have to wait as clinics can have a high number of patients and you may be required to spend several hours at the hospital.
- Please be aware that some appointments can be very lengthy, especially if diagnostics are
- needed. Please make provisions accordingly.

King's College Hospital is smoke free in the buildings and grounds.

- Please note that you may bring a friend or relative into the consulting room if you wish

PLEASE TURN OVER

Please bring this letter with you to your appointment; it will enable you to check in at one of our Express Check-In Kiosks or at reception.

If needed, we can provide this letter or information in a different format, such as large print or alternative languages. For further details, please see below.

Please note that due to limited space in clinic we respectfully request that patients are accompanied by no more than one person where possible. Your co-operation is appreciated.

For further information about the breast care clinic and how we care for you please see the breast care clinic website below

pruh.kch.nhs.uk/services/breast-care/

We look forward to welcoming you to your appointment.

Yours sincerely,

King's College Hospital NHS Foundation Trust

Translation, interpreting and access support

If you have a disability or sensory impairment, we want to make sure you can access and understand the information we send you and that you receive any communication support you may need for your appointment.

We provide British Sign Language (BSL) interpreter support and other interpreting and translation services, including Braille and Easy Read.

If you would like support for your appointment or would like to receive this information in a different format or language, please call our dedicated Accessibility phone line on **020 3299 4826**, or email us on kch-tr.accessibility@nhs.net

Getting here

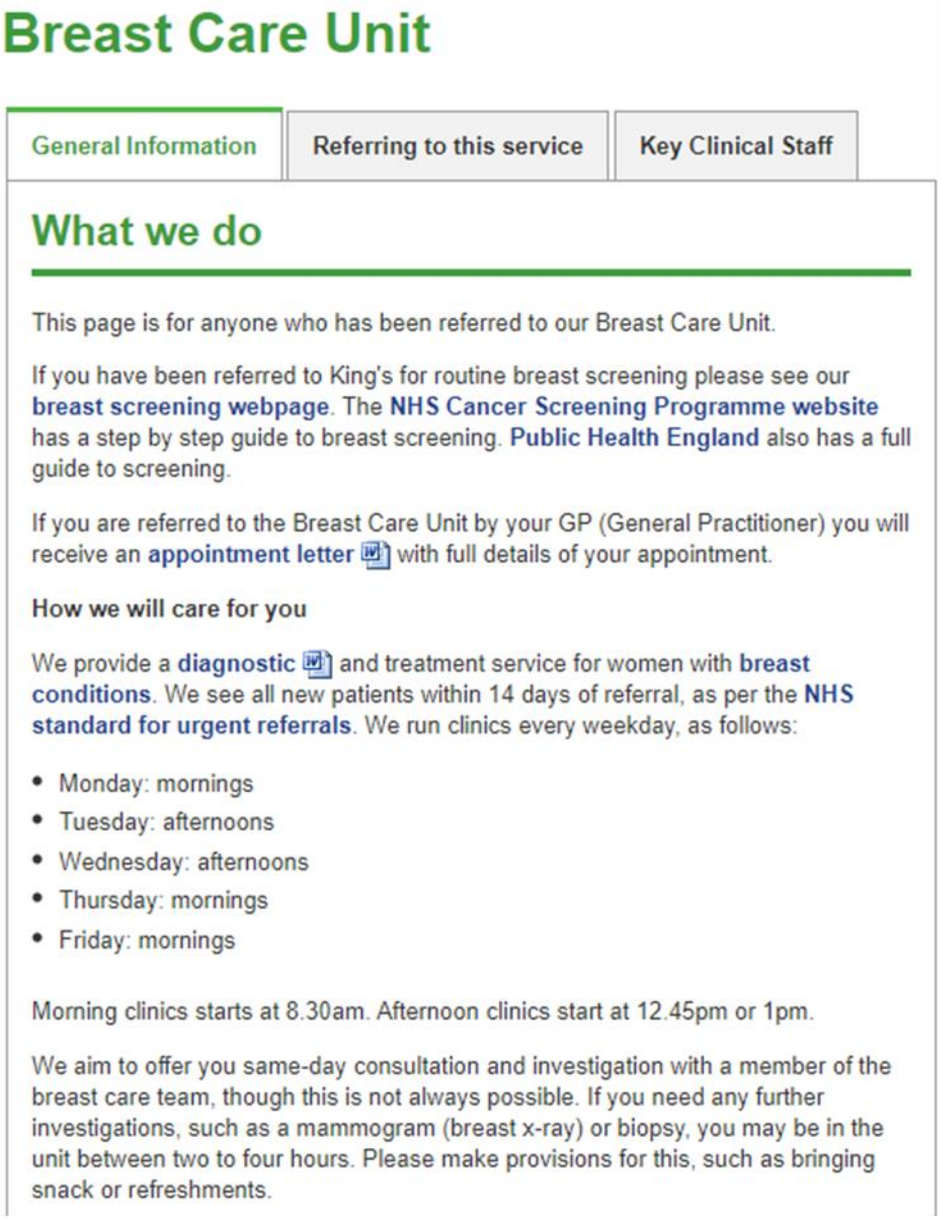
We encourage you to use public transport to travel to your appointment as we have very limited parking at our hospitals. You can plan your journey using the Transport for London Journey Planner: https://tfl.gov.uk/plan-a-journey/

For more information about disabled access or requesting transport for your appointment, please contact the Patient Transport Assessment Centre on **020 3299 8000** to confirm you are eligible.

For further information to help you on the day of your appointment or for detailed maps of our hospitals, please visit our website: www.kch.nhs.uk

King's College Hospital is smoke free in the buildings and grounds.

Appendix 2 - Breast Care Unit Webpages



Breast Care Unit

What we do

This page is for anyone who has been referred to our Breast Care Unit.

If you have been referred to King's for routine breast screening please see our **breast screening webpage**. The **NHS Cancer Screening Programme website** has a step by step guide to breast screening. **Public Health England** also has a full guide to screening.

If you are referred to the Breast Care Unit by your GP (General Practitioner) you will receive an **appointment letter** with full details of your appointment.

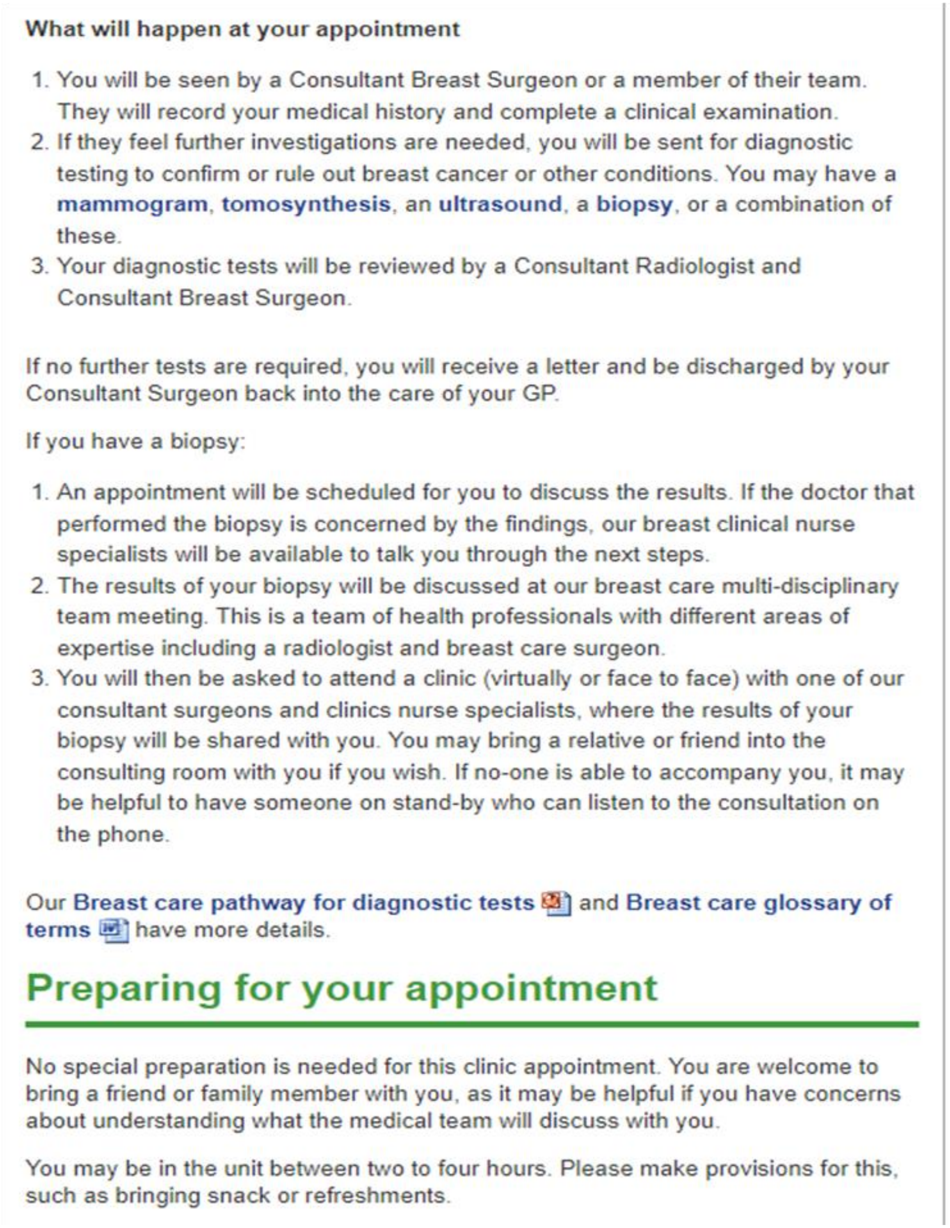
How we will care for you

We provide a **diagnostic** and treatment service for women with **breast conditions**. We see all new patients within 14 days of referral, as per the **NHS standard for urgent referrals**. We run clinics every weekday, as follows:

- Monday: mornings
- Tuesday: afternoons
- Wednesday: afternoons
- Thursday: mornings
- Friday: mornings

Morning clinics starts at 8.30am. Afternoon clinics start at 12.45pm or 1pm.

We aim to offer you same-day consultation and investigation with a member of the breast care team, though this is not always possible. If you need any further investigations, such as a mammogram (breast x-ray) or biopsy, you may be in the unit between two to four hours. Please make provisions for this, such as bringing snack or refreshments.



What will happen at your appointment

1. You will be seen by a Consultant Breast Surgeon or a member of their team. They will record your medical history and complete a clinical examination.
2. If they feel further investigations are needed, you will be sent for diagnostic testing to confirm or rule out breast cancer or other conditions. You may have a **mammogram**, **tomosynthesis**, an **ultrasound**, a **biopsy**, or a combination of these.
3. Your diagnostic tests will be reviewed by a Consultant Radiologist and Consultant Breast Surgeon.

If no further tests are required, you will receive a letter and be discharged by your Consultant Surgeon back into the care of your GP.

If you have a biopsy:

1. An appointment will be scheduled for you to discuss the results. If the doctor that performed the biopsy is concerned by the findings, our breast clinical nurse specialists will be available to talk you through the next steps.
2. The results of your biopsy will be discussed at our breast care multi-disciplinary team meeting. This is a team of health professionals with different areas of expertise including a radiologist and breast care surgeon.
3. You will then be asked to attend a clinic (virtually or face to face) with one of our consultant surgeons and clinics nurse specialists, where the results of your biopsy will be shared with you. You may bring a relative or friend into the consulting room with you if you wish. If no-one is able to accompany you, it may be helpful to have someone on stand-by who can listen to the consultation on the phone.

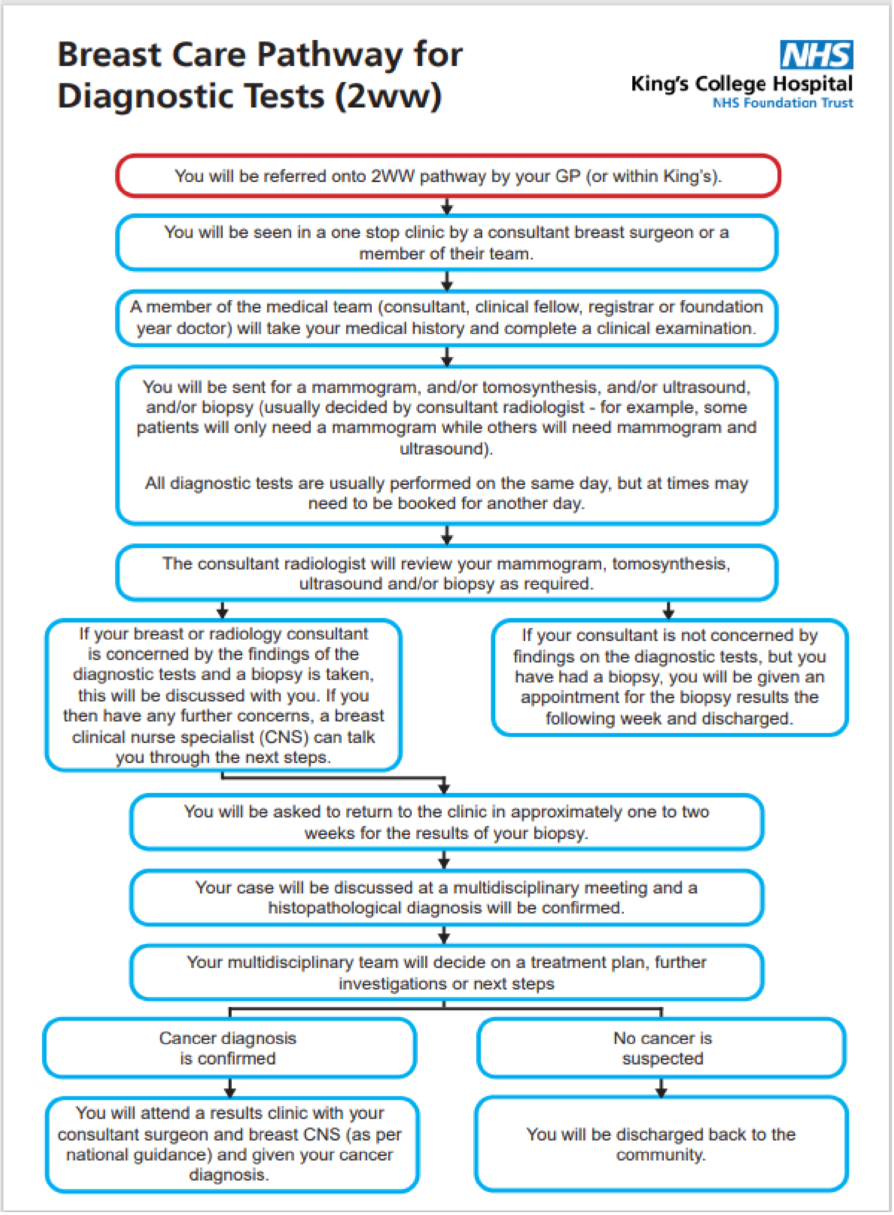
Our **Breast care pathway for diagnostic tests** and **Breast care glossary of terms** have more details.

Preparing for your appointment

No special preparation is needed for this clinic appointment. You are welcome to bring a friend or family member with you, as it may be helpful if you have concerns about understanding what the medical team will discuss with you.

You may be in the unit between two to four hours. Please make provisions for this, such as bringing snack or refreshments.

Appendix 3 - Breast Care Flowcharts



Breast Care Pathway for Diagnostic Tests (2ww)

King's College Hospital
NHS Foundation Trust

You will be referred onto 2WW pathway by your GP (or within King's).

You will be seen in a one stop clinic by a consultant breast surgeon or a member of their team.

A member of the medical team (consultant, clinical fellow, registrar or foundation year doctor) will take your medical history and complete a clinical examination.

You will be sent for a mammogram, and/or tomosynthesis, and/or ultrasound, and/or biopsy (usually decided by consultant radiologist - for example, some patients will only need a mammogram while others will need mammogram and ultrasound).

All diagnostic tests are usually performed on the same day, but at times may need to be booked for another day.

The consultant radiologist will review your mammogram, tomosynthesis, ultrasound and/or biopsy as required.

If your breast or radiology consultant is concerned by the findings of the diagnostic tests and a biopsy is taken, this will be discussed with you. If you then have any further concerns, a breast clinical nurse specialist (CNS) can talk you through the next steps.

If your consultant is not concerned by findings on the diagnostic tests, but you have had a biopsy, you will be given an appointment for the biopsy results the following week and discharged.

You will be asked to return to the clinic in approximately one to two weeks for the results of your biopsy.

Your case will be discussed at a multidisciplinary meeting and a histopathological diagnosis will be confirmed.

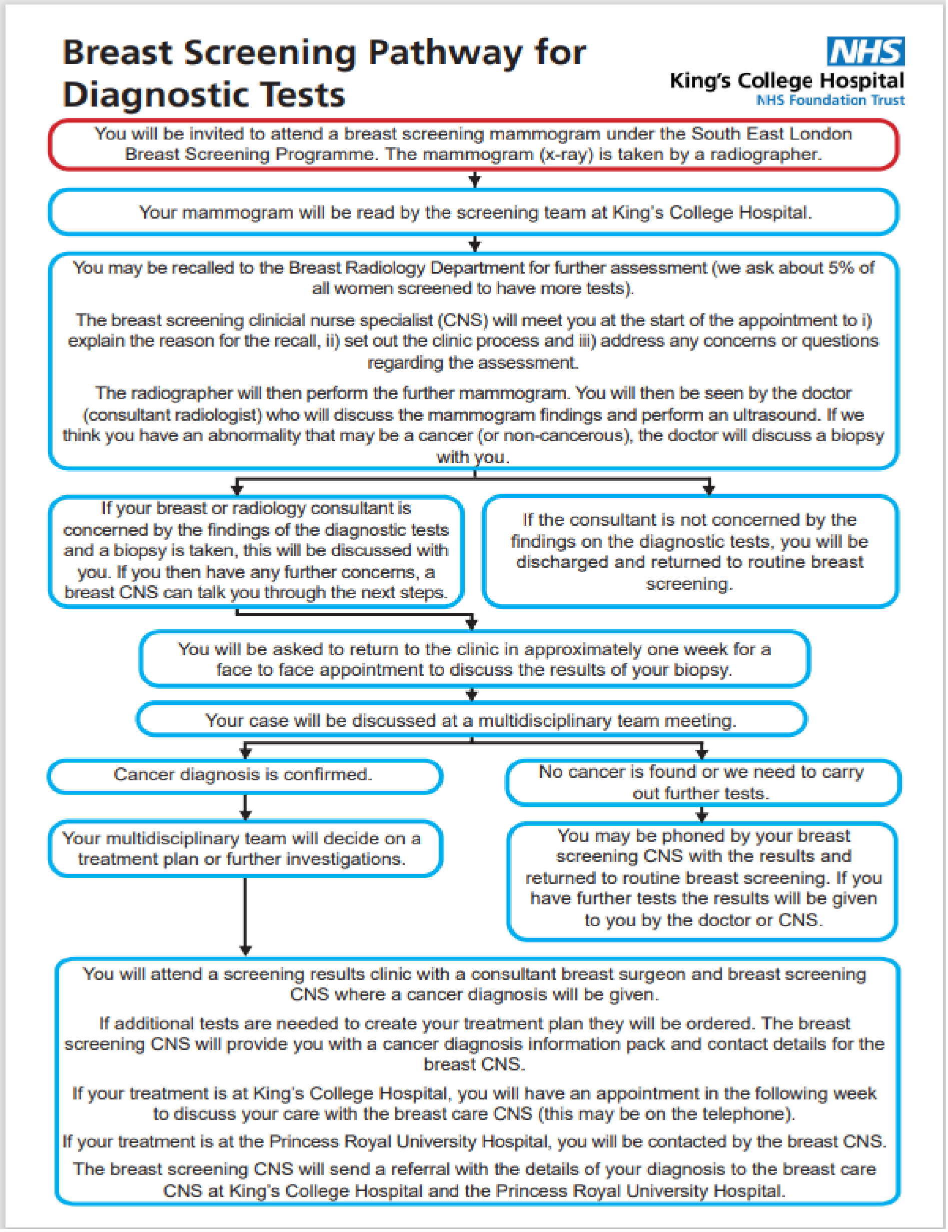
Your multidisciplinary team will decide on a treatment plan, further investigations or next steps

Cancer diagnosis is confirmed

You will attend a results clinic with your consultant surgeon and breast CNS (as per national guidance) and given your cancer diagnosis.

No cancer is suspected

You will be discharged back to the community.



Breast Screening Pathway for Diagnostic Tests

King's College Hospital
NHS Foundation Trust

You will be invited to attend a breast screening mammogram under the South East London Breast Screening Programme. The mammogram (x-ray) is taken by a radiographer.

Your mammogram will be read by the screening team at King's College Hospital.

You may be recalled to the Breast Radiology Department for further assessment (we ask about 5% of all women screened to have more tests).

The breast screening clinicial nurse specialist (CNS) will meet you at the start of the appointment to i) explain the reason for the recall, ii) set out the clinic process and iii) address any concerns or questions regarding the assessment.

The radiographer will then perform the further mammogram. You will then be seen by the doctor (consultant radiologist) who will discuss the mammogram findings and perform an ultrasound. If we think you have an abnormality that may be a cancer (or non-cancerous), the doctor will discuss a biopsy with you.

If your breast or radiology consultant is concerned by the findings of the diagnostic tests and a biopsy is taken, this will be discussed with you. If you then have any further concerns, a breast CNS can talk you through the next steps.

If the consultant is not concerned by the findings on the diagnostic tests, you will be discharged and returned to routine breast screening.

You will be asked to return to the clinic in approximately one week for a face to face appointment to discuss the results of your biopsy.

Your case will be discussed at a multidisciplinary team meeting.

Cancer diagnosis is confirmed.

Your multidisciplinary team will decide on a treatment plan or further investigations.

No cancer is found or we need to carry out further tests.

You may be phoned by your breast screening CNS with the results and returned to routine breast screening. If you have further tests the results will be given to you by the doctor or CNS.

You will attend a screening results clinic with a consultant breast surgeon and breast screening CNS where a cancer diagnosis will be given.

If additional tests are needed to create your treatment plan they will be ordered. The breast screening CNS will provide you with a cancer diagnosis information pack and contact details for the breast CNS.

If your treatment is at King's College Hospital, you will have an appointment in the following week to discuss your care with the breast care CNS (this may be on the telephone).

If your treatment is at the Princess Royal University Hospital, you will be contacted by the breast CNS.

The breast screening CNS will send a referral with the details of your diagnosis to the breast care CNS at King's College Hospital and the Princess Royal University Hospital.

Close and thank you

Clare Enston (Deputy Director of Insight and Feedback, NHS England)

CPES@PickerEurope.ac.uk

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