

# Celebrating great patient and public involvement in the National Audit of Breast Cancer in Older Patients (NABCOP)

Richard Driscoll Memorial Award 2022 – Nomination

## What is the NABCOP?

- Commissioned by Healthcare Quality Improvement Partnership (HQIP) as one of five national cancer audits
- A collaboration between Clinical Effectiveness Unit of Royal College of Surgeons (RCS) of England with the Association of Breast Surgery (ABS), established in April 2016
- To evaluate the process of care and outcomes for women diagnosed with breast cancer, in NHS hospitals within England and Wales, aged 70 years and over compared with 50-69 year olds (includes >70% of all breast cancers)

## Why focus on the care and outcomes for women aged 70 years and over compared with 50-69 year olds ?

- There are unexplained differences and variation in the care of older patients with breast cancer in the UK
- Survival rates are lower in the UK for older patients after a diagnosis of breast cancer than in other comparable countries
- Therefore, the NABCOP explored these issues through the coalescence of information from many national datasets which are aligned at individual patient level

# How NABCOP patients and patient advocates experienced the following throughout the audit...

- Involvement



- Communication and Dissemination



- Accessibility



- Sustainability



- Impact



...in their own words

# Involvement – 1 of 2



## Patients and carers:

1. Feel listened to, taken seriously and valued
2. Value the priority the project has placed on the views of patients and carers – the importance of involving patient representatives has always been at the forefront

Note: Three patient representatives, as well as patient advocates and charity representatives, have steered and provided governance for the audit, since the beginning of the audit in 2016.

“I feel that the NABCOP team and health professionals involved us, listened to us, treated us as equals, and with respect at all times. I felt very much involved and part of the team... [the] patient voice has always been listened to. Our presence is valued by clinicians on the group and the NABCOP team alike.” **Patient feedback**

“All of my ideas were taken seriously and responded to - from referencing CPES [the National Cancer Patient Experience Survey] in the report, to accessing the data at Trust level, to requesting [Triple-Negative Breast Cancer] chemo analysis, to offering my services as a 'Secret Shopper' at MDT.” **Patient feedback**

“From the audit’s inception... [the audit] always had 3 patients present and were careful not to let that slip, putting it as a key agenda notice etc when they needed a new one... This shows the importance NABCOP placed on having Patient Representatives involved” **Patient feedback**

# Involvement – 2 of 2



Patients' involvement has been key to the production of audit summaries and other resources for patients.

3. Patients and carers suggested producing 'something simpler' than audit summaries, to increase accessibility and provide a practical resource. In 2020 we co-created the [NABCOP guide to the breast cancer pathway for older women](#), for health professionals to use with patients in clinics

"Credit was given to those who collaborated (us patient representatives) in creating it by including the organisations [logos] we represent at the bottom of the Guide. This demonstrates NABCOP are keen to have us involved and value our participation" Patient feedback

"The [guide] first published in 2020 is an excellent example of something coming from a patient with support from the team to benefit patients, carers, clinicians alike" Patient feedback

The front provides a visual representation of the typical BC pathway.

On the back, there is an explanation of the BC pathway, with paragraphs explaining what a patient might expect at each step, alongside a box of useful questions for patients to consider.

Space is provided for patients to write thoughts or questions.

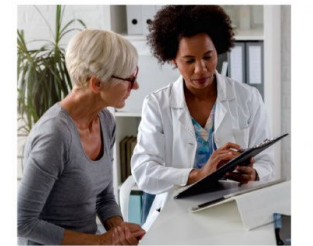
# Accessibility – 1 of 3

Audit reports, guides and forms were disseminated widely and actively by patient representatives and advocates, as well as other stakeholders and the audit team.

1. Downloads from the NABCOP website of the reports and guides co-created with patients and carers have increased year on year. This provides a measure of patients' and carers' growing awareness of the project, its findings and resources.

Note: Feedback on publications and resources has been made possible via live surveys and the audit's web-based 'contact us' form.

"I shared information about NABCOP Reports, Patient Reports, Patient [Guide] with consumer members of [the National Cancer Research Institute] NCRI and NCRI Breast Group Clinicians. NABCOP Team checked the slides for me that I presented...I linked with my local and regional hospitals - oncologists, radiologists, surgeons, breast care nurse team - checked that they knew about NABCOP - referenced Frailty Score, Frailty Index as well as reports and the patient form" **Patient feedback**



This report has been prepared with:

**NA BCOP** | **ABCS** | **HQIP** | **Royal College of Surgeons in England**

**FITNESS ASSESSMENT FOR PATIENTS 70+ YEARS OLD IN BREAST CLINIC**

Does the patient already have a known diagnosis of dementia?  No (complete all the assessments)  Yes (complete AMT5 assessment)

**Clinical Frailty Scale\*** (Please circle the appropriate number)

- 1 Very fit - People who are robust, active, energetic and motivated. These people experience no or few health problems. They are among the fittest in their age group.
- 2 Well - People who have no other disease symptoms but are not fit for heavy work. They are active and can walk without assistance, e.g. occasionally beyond routine walking.
- 3 Managing Well - People whose medical problems are well controlled, but no one expects active beyond routine walking.
- 4 Vulnerable - People who are dependent on others for help, often experience some activities, a common example being 'Shower cap' or 'Hanging coat' during the day.
- 5 Mildly frail - People who have been recently hospitalised, and need help to get up stairs, dress, bathe, shop, travel, etc. They usually need help to get up stairs, dress, bathe, shop, travel, etc. They usually need help to get up stairs, dress, bathe, shop, travel, etc.
- 6 Moderately frail - People need help with all activities and need help with walking, bathing, dressing, shopping, etc. They often have problems with stairs and need help with bathing and night need minimal assistance during the day.
- 7 Severely frail - People who are almost entirely dependent on others for help with all activities and need help with walking, bathing, dressing, shopping, etc. They often have problems with stairs and need help with bathing and night need minimal assistance during the day.
- 8 Completely frail - People who are almost entirely dependent on others for help with all activities and need help with walking, bathing, dressing, shopping, etc. They often have problems with stairs and need help with bathing and night need minimal assistance during the day.

**Abbreviated Mental Test Score**

Ask the following questions to the patient. Each question that is correctly answered scores one point:

1. What is your age?
2. What is the name of the nearest town?
3. Give the patient an address, ask her/him to repeat it and the first part (e.g. What street?
4. What is the year?
5. What is the name of the hospital? number of incidences where the patient is hospitalised?
6. Can the patient recognise two persons (e.g. the doctor, the nurse)?
7. What is your date of birth (day and month)?
8. In what year did World War II begin?
9. Name the present monarch (give full name)?
10. Count backwards from 20 to 1.

Total score = / 10

Score: A score of 6 or less suggests delirium or dementia, although further tests are necessary to confirm the diagnosis.

Does the patient have severe\* Cardiorespiratory disease? Yes / No

\* severe = less than ordinary physical activity or not causing breathlessness, palpitations or shortness of breath

Does the patient have any other non-breast locally advanced / metastatic malignancy? Yes / No

**NA BCOP** | **ABCS** | **HQIP** | **Royal College of Surgeons in England**

**A guide to asking important questions about the breast cancer pathway of particular relevance to women aged 70+ diagnosed with breast cancer**

What have you heard that a treatment plan for patients with breast cancer is different to that of younger patients? What are the differences? What are the differences between the different types of breast cancer? What are the differences between the different types of breast cancer? What are the differences between the different types of breast cancer?

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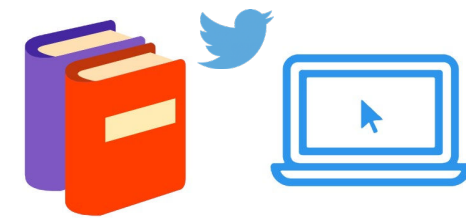
Patients have played a key role in ensuring NABCOP resources are as accessible as possible:

2. The Plain English Campaign provides input into the audit summaries for patients, which have gained Crystal Mark accreditation each year
3. Guides are printed by health professionals and made available to patients, “ensuring the Guide is accessible to all, ESPECIALLY to its target audience (the older women) who are a group that doesn't rely on technology as much as their [younger] counterparts”



“[Independent Cancer Patients' Voice] ICPV circulated links to the reports on the NABCOP website...Patient Report[s] and Patient [Guide] on the NABCOP website - can print out and read off screen, large font for visually impaired people...We were involved in commenting on the language used in the reports and form - plain English - clear, brief”  
**Patient feedback**

# Accessibility – 3 of 3



Patients and carers reflected on the materials produced by the audit with respect to their inclusivity and accessibility:

4. Particularly the [NABCOP guide to the breast cancer pathway for older women](#), for health professionals to use with patients – which will continue to have a life beyond the audit
5. The Data Viewer, which contains granular information about the performance of each NHS organisation, is freely available to patients and has been used and promoted by NABCOP patient representatives

“With regards to the accessibility of the audit's findings, the charity I'm closely linked to (força-strength against cancer) has included [the Patient Guide on their website](#), an additional channel to get the information disseminated. Also, I have personally signposted older patients (or their carers) to the Patient Guide” **Patient feedback**

**NABCOP 2022 Annual Report: NHS Organisation Data Viewer**

| Report Chapter      | Topic  |
|---------------------|--|
| Chapter 3.2         | <a href="#">Data Quality</a>   |
| DQ_Summary          | <a href="#">Data Quality (DQ) summary, by NHS Organisation</a>   |
| DQ_Time             | <a href="#">Data Quality (DQ) over time, by NHS Organisation</a>                                       |
| Ind_Summary         | <a href="#">Individual summaries, by NHS Organisation, of figures from Chapter 3.4 to 3.8</a>          |
| Ind_Summary_Compare | <a href="#">A summary that allows for comparison of two selected NHS Organisations</a>                 |
| Summary             | <a href="#">Individual summaries, by NHS Organisation, of figures from Chapter 3.9 &amp; Chapter 4</a> |
| Chapter 3.4         | <a href="#">Triple diagnostic assessment in a single visit</a>   |
| Chapter 3.5         | <a href="#">Involvement of a breast clinical nurse specialist (CNS) or key worker</a>                  |
| Chapter 3.6         | <a href="#">Surgical treatment for DCIS</a>  |
| Chapter 3.6         | <a href="#">Radiotherapy treatment for DCIS</a>  |
| Chapter 3.7         | <a href="#">Surgical treatment for early invasive breast cancer</a>                                    |
| Chapter 3.7         | <a href="#">Radiotherapy treatment for early invasive breast cancer treated with surgery</a>           |
| Chapter 3.7         | <a href="#">Adjuvant chemotherapy plus trastuzumab for HER2 positive early invasive breast cancer</a>  |
| Chapter 3.8         | <a href="#">Chemotherapy for metastatic breast cancer at initial presentation</a>                      |
| Chapter 3.9         | <a href="#">Reoperation rates following initial BCS for DCIS</a>                                       |

**CONTENTS** | Data Quality | DQ\_Summary | DQ\_Time | Ind\_Summary | Ind\_Summary\_Compare | Summary | Ch3\_4\_TDA | Ch3\_5\_CNS | Ch3\_6\_DCIS\_Surgery | ...

Click in the cell below to scroll & pick the NHS organisation you want to be highlighted in the subsequent tabs:  
\* Click here (on CONTENTS tab) to scroll & select NHS Organisation \*

Click in the cell below to scroll & pick an NHS organisation you would like to compare the above organisation with in the "Ind\_Summary\_Compare" tab:  
\* Click here (on CONTENTS tab) to scroll & select NHS Organisation \*



Previous slides make clear that patients' and carers' role in communication and dissemination is key to making audit materials accessible; further reflections are shared here...



\* use MY data



“Always more to do BUT we have reached out to charities [Independent Cancer Patients' Voice] ICPV, [the National Cancer Research Institute] NCRI, Breast Cancer Now, Local Hospitals information centre, Breast Care Nurses”  
**Patient feedback**

“There have been so many 'opportunities to disseminate and provide input' over the last 5 years... My selection emphasizes the mutual respect and the relationships that exist between the patients and the NABCOP team...”  
The team “proof-read, edited and contributed to articles [and presentations, referencing or reflecting on the audit's work] for the Annals of Breast Surgery... for a Macmillan update [to the] Breast Cancer brochure so that older women could be represented alongside younger women... the Wales Breast Cancer Conference ... and UseMyData. The team supported me on shaping and delivering a question, based on NABCOP data gaps, in front of an audience of about 300 to the national statistician in the Houses of Parliament.” **Patient feedback**



The audit communicates and disseminates its findings via a range of channels:

1. [NABCOP website](#)
2. Direct targeted emails
3. Newsletters
4. Social media (@NABCOP\_news, and re-tweets via @ABSGBI, @RCSNews and charities)



5. Presentations at conferences and meetings provide an opportunity to share audit messages and materials
6. Steering group members disseminate via local hospital intranets, sites and Newsletters
7. Input is sought from other (broader) patient groups, such as HQIP's Service User Network (SUN) members

# Sustainability – 1 of 2



Reflections on how the learning is being shared and implemented are reflected in previous slides.

Furthermore...

1. Patient involvement is at the forefront of the audit's work
2. This has included meetings between the audit team and only patient representatives and advocates, to focus on patient-led products
3. Ensuring patients are embedded in the work of the audit **“from the audit's inception”**

“Patient Representatives are always included in emails sharing Agendas and Minutes of meetings and are kept up-to-date regularly. Also, we are given "save the date" well in advance of meetings so that we can arrange our calendars to attend - in other words, we aren't just an after-thought. We are kept well informed throughout” **Patient feedback**

“Questions raised by us as patients are addressed and answered with respect. We comment on documents via email, NABCOP team check with us, ask our thoughts. Collecting data as NABCOP have done takes time but ultimately it is having a benefit to patients in getting the right treatment for them irrespective of their age” **Patient feedback**

## Sustainability – 2 of 2



Learning from the NABCOP, including the importance of patient and public involvement, is already informing the two new breast cancer audits.

4. The newly commissioned audits have been championed by patients and advocates including Breast Cancer Now – who have steered and contributed to the NABCOP's governance since it started in 2016
5. The voice of patients, carers and the public will be central to the new audits

Regarding “the two newly commissioned audits, there already was interest in involving patient representatives - demonstrating that our input was an added value to the audit and NABCOP want to continue this involvement in future audits” **Patient feedback**

“The National Cancer Audit Collaborating Centre will collaborate closely with professional groups and patient charities. Patient forums will be established to ensure that patients inform the quality improvement goals of each audit. The audits are committed to engaging widely with charities and experts involved in cancer care, delivering for patients and their families, as well as healthcare professionals and the health service.”  
**RCS press release about the new audits, 31 August 2022**

# Impact – 1 of 4



Through the NABCOP's reporting we have seen

1. an increase in the use of a reliable, consistent measure of patient fitness and cognition, and
2. an increase in surgery rates for fit older women over the audit period.

The impact of this achievement is reflected on in these quotes.

Note: Both Quality Improvement (QI) goals for the audit.

“Fitness Assessment Form was created as a tool to standardise how frailty and cognition are measured for an older patient in breast clinics...it paves the way for the medical team to discuss the best and most appropriate treatment for a patient. The assessment enables patients to be treated as individuals and not just according to their age, hence treating the older and younger women equally and fairly...a phenomenal impact!” **Patient feedback**

The “NABCOP has pushed forward the message that women in the over 70's age group have not been receiving the same treatment options as those in the younger age group - for me as a professional caring for women and men with breast cancer this is a most timely intervention. In the Trust in which I work 'Frailty scores' have been integrated into our normal breast cancer diagnostic pathways and allows for initial significant assessment of each patient over 70- years of age” **Breast Nurse Specialist / Carer**

“NABCOP data is showing more older patients get surgery than previously did before the NABCOP data collected. More work to do” **Patient feedback**



## The impact of the NABCOP's work

3. 'Improving completeness of key clinical data items, specific to the audit'\* was achieved by increasing awareness of ways to improve the quality of the data that is integral to understanding treatment decisions, such as tumour size.

This is reflected on in these quotes.

Note: \*A Quality Improvement (QI) goal for the audit.

“NABCOP prompted others to have more inclusive audits with vast improvements in the data being collected. Also, the frailty test has increasingly become a part of the pathway questionnaire and not a sporadic tool used once in a while. There has also been a "push" to remind clinicians to record information, something that up to this point leaves a lot to be desired” **Patient feedback**

“NABCOP has also had an impact in cancer care because it has prompted IT people who redesign programmes to come up with innovative, user-friendly, time-efficient ways to record data” **Patient feedback**



4. The work of the NABCOP provided evidence that “we can do better for older patients with breast cancer”\*

A Breast Nurse Specialist and patient advocate / carers reflects on the impact of this...

Note: \*Professor Kieran Horgan, Age Anaesthesia Association meeting, 13 May 2022.

“As a Breast Nurse Specialist caring for breast patients for 30 years I have strived to be part of improving patient treatment options, communication skills and understanding of elderly patients. I have worked specifically with older women with breast cancer since... As I have got to know patients I realised that for various reasons people were not being seen as who they really were and decisions about their ability to go for treatments have been hindered by this lack of knowledge and understanding about the patient... Decisions about treatment and choices come down to good communication and awareness and NABCOP has brought to the forefront of our thinking these specific needs and problems and clearly striving for the best outcome is central to this project. It is and continues to be a starting point for best practice.” **Breast Nurse Specialist / Carer**

## Impact – 4 of 4



The impact of the NABCOP is further reflected on with regards to

5. The valuable guide co-created by patients and carers and the NABCOP team – for use throughout and beyond the life of the audit, and
6. Future breast cancer audits – which will be run by the same team as the NABCOP

“In 2020, the NABCOP team developed the ‘Guide to the Breast Cancer Pathway for Older Women’ as a way to guide patients to ask important questions along the breast cancer care pathway. This guide emerged from an idea put forward by the patient representatives who were involved in the design and content of this guide. It can provide the basis for discussion of key elements of a woman’s treatment enabling decisions to take place between the older patient and the health professionals as to appropriate treatment. We have played a role in disseminating the NABCOP reports to our patient networks linking with patients, health professionals and charities.” **Patient feedback**

“The two new audits starting in 2022, Primary Breast Cancer and Metastatic Breast Cancer, will build on NABCOP data. NABCOP has demonstrated the benefit of good data being collected. It is invaluable to improve outcomes for patients. It allows for hospital Trusts to compare themselves and learn from one another” **Breast Nurse Specialist / Carer**

Great patient and public involvement will be central to the **two new audits**

- one on primary breast cancer, and
- a second focusing on secondary (metastatic) breast cancer, for women and men of all ages

Commencing October 2022

- The work of the NABCOP and lessons learned will be used to inform the planning and delivery of the two new audits
- The Clinical Leads and RCS staff who have worked for the NABCOP will also continue to be involved in the two new audits, helping to ensure a smooth transition and continuity of expertise in breast cancer audit

The image shows two screenshots of news articles. The top screenshot is from the HQIP (Healthcare Quality Improvement Partnership) website, dated 31 Aug 2022. The article is titled "HQIP commissions new set of cancer programmes" and mentions that HQIP has commissioned a set of new cancer programmes. The bottom screenshot is from the Royal College of Surgeons of England website, also dated 31 Aug 2022. The article is titled "RCS England partners with NHS England to evaluate cancer treatments and strengthen services for patients" and states that a new national centre of excellence will be established at the Royal College of Surgeons of England (RCS England) to strengthen NHS cancer services.

# Thank you for considering our Richard Driscoll Memorial Award nomination!

This nomination was co-created by patient representatives, patient advocates, and the NABCOP team.

Special thanks and appreciation to all members of our Clinical Steering Group, Project Board and all stakeholders who contributed generously to the life and aims of this audit.