

National Audit of Primary Breast Cancer State of the Nation Patient and Public Report 2024

A summary of findings for patients and the public

An audit of care received by people diagnosed with primary breast cancer
in England and Wales during 2019 to 2021



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1. Glossary

Term	Definition
Adjuvant treatment	Cancer treatment, such as chemotherapy, endocrine therapy or radiotherapy, given after surgery.
Bilateral breast cancer	Breast cancer which, when diagnosed, was found in both breasts.
Breast-conserving surgery (BCS)	Surgery to remove the breast cancer without removing all of the breast. Also known as a 'lumpectomy' or 'wide local excision' (WLE).
Breast reconstruction	Surgery which aims to create a breast shape after mastectomy.
Cancer Outcomes and Services Data set (COSD)	The COSD sets out the data that NHS England must record for all cancer patients. For more information, visit https://digital.nhs.uk/ndrs/data/data-sets/cosd .
Chemotherapy	Treatment with drugs that kill cancer cells. This is a type of systemic anti-cancer therapy.
Clinical nurse specialist (CNS)	A highly experienced nurse who plays a crucial role in supporting patients throughout their diagnosis, treatment and follow-up care for breast cancer.
Early invasive breast cancer	Invasive breast cancer stages 1 to 3A.
Endocrine therapy	Drug therapy used to treat 'hormone positive' breast cancer. It is a type of systemic anti-cancer therapy (SACT). Also known as 'hormone therapy'. This stops oestrogen from helping the cancer to grow.
Human epidermal growth factor receptor-2 (HER2)	A protein found on the surface of cancer cells which helps them to grow.
Human epidermal growth factor receptor-2 (HER2) status	This helps determine whether a breast cancer has a higher-than-normal level of HER-2. If the status is HER2-positive, specific systemic anti-cancer therapies can be used.
Immediate reconstruction	Breast reconstruction surgery performed during the same surgery as a mastectomy.
Invasive breast cancer	This is when cancerous cells have spread to other breast tissue beyond the original breast duct or glands.
Mastectomy	Surgery to remove the breast.

Term	Definition
Metastatic breast cancer	Breast cancer that has spread beyond the breast and nearby lymph nodes to other parts of the body such as the bones, lungs, liver or brain. Also called advanced breast cancer, secondary breast cancer or stage 4 breast cancer.
Neo-adjuvant treatment	Cancer treatment, such as chemotherapy or radiotherapy, given before surgery. For example, neo-adjuvant chemotherapy (NACT) is chemotherapy given before surgery.
Non-invasive breast cancer	This is when cancerous cells are only in the ducts or lobules of the breast and haven't spread to surrounding breast tissue. The most common type of non-invasive breast cancer is called ductal carcinoma in-situ (DCIS).
Oestrogen receptor (ER) status	This helps determine whether there are or not oestrogen receptors within a breast cancer. Breast cancers which are ER-positive are sensitive to oestrogen and can be treated with endocrine therapy.
Primary breast cancer	Breast cancer which, when diagnosed, was found only in the breast or nearby lymph nodes.
Progesterone receptor (PR) status	This helps determine whether there are or not progesterone receptors within a breast cancer. Breast cancers which are PR-positive are sensitive to oestrogen and can be treated with endocrine therapy.
Radiotherapy	High energy X-rays used to kill cancer cells. This is generally used as an adjuvant treatment following surgery. For example, post-mastectomy radiotherapy (PMRT) is radiotherapy given to the chest wall following a mastectomy.
Systemic anti-cancer therapy (SACT)	Drug treatment for cancer.
Systemic treatments	These are cancer treatments which aim to treat the whole body (for example, chemotherapy and endocrine therapy).
Triple diagnostic assessment (TDA)	An assessment which includes a physical examination, scans and biopsies (as needed) during a single visit to get a quick breast cancer diagnosis. Some people need more complex diagnostic investigations, which would happen at a different time.
Triple negative breast cancer	Breast cancer that is HER2-negative, ER-negative and PR-negative.

2. What is the NAOpri?

The National Audit of Primary Breast Cancer (NAOpri) is a national clinical audit. It aims to find out about the health and healthcare of people with primary breast cancer in England and Wales, and to improve patient care by highlighting areas where improvements could be made. The NAOpri builds on work from the National Audit of Breast Cancer in Older Patients (NABCOP), which ran from 2016 to 2022, but it has been expanded to include younger people and men with breast cancer.

3. What is primary breast cancer?

Primary breast cancer is breast cancer which, when diagnosed, was only found in the breast or nearby lymph nodes with no spread to other parts of the body. This includes non-invasive (stage 0) and invasive (stage 1A to 3C) breast cancer. The National Audit of Metastatic Breast Cancer (NaoMe) reports on patients who have breast cancer which has spread beyond the breast and nearby lymph nodes (stage 4). You can read more about the NAOme at <https://www.natcan.org.uk/audits/metastatic-breast/>. We do not currently report any specific information for bilateral breast cancer cases. This is because analysis becomes very complex and difficult to interpret when someone has more than one treatment or set of tumour characteristics, for example, the ER status and HER2 status may be different in each breast.

4. What is this report about?

This is a summary of the main findings and recommendations from the first NAOpri State of the Nation report (the SotN report). You can download the full report from our website at <https://www.natcan.org.uk/reports/naopri-state-of-the-nation-report-2024/>. You can also use this link to get additional information. This includes data from individual NHS organisations, which allows you to see results from your own hospital.

The purpose of this clinical audit is to assess the patterns of care and outcomes for people with primary breast cancer in England and Wales, and help NHS services to improve the quality of their data and the care they provide. The results of this audit are based on people in England and Wales diagnosed and treated for primary breast cancer between 2019 and 2021. The breast cancer care described for this period of time includes changes introduced in the NHS during

the Covid-19 pandemic. As a result, data for 2020 to 2021 may be different.

We produced this report with the NAOpri Patient and Public Involvement Forum, who represent and support the rights and interests of patients.

In this summary, speech bubbles (like this one) tell you which pages in the SotN report give more information.

SotN report page

5. What data does the NAOpri use?

SotN report page 5

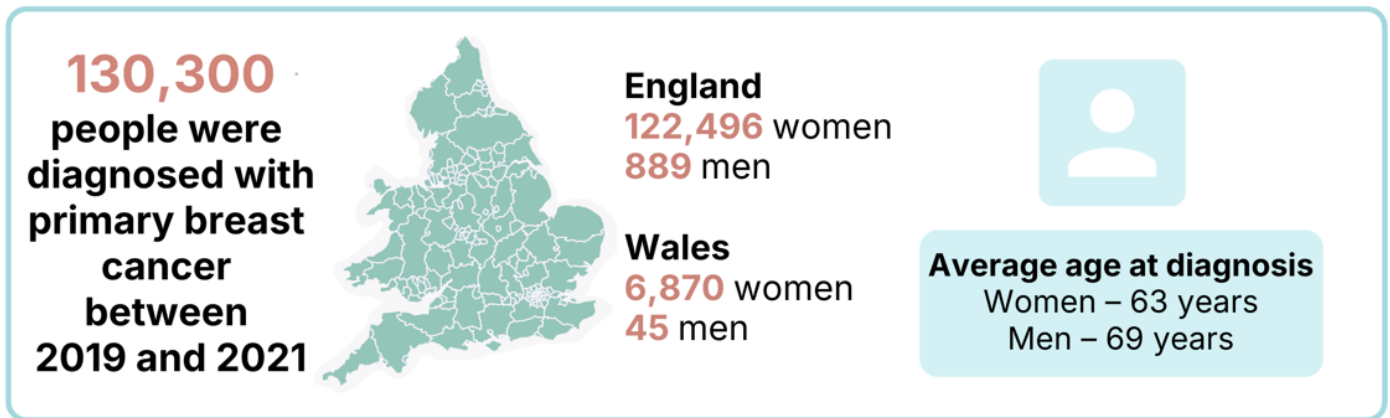
The NAOpri uses information from electronic medical records routinely recorded as part of patient care in English and Welsh hospitals.

6. Where can I find more information about the NAOpri?

- Follow us on X using our handle [@NAOpri_News](https://twitter.com/NAOpri_News)
- Read our newsletters on the National Cancer Audit Collaborating Centre (NATCAN) website at <https://www.natcan.org.uk/news/>
- Email us at breastcancer audits@rcseng.ac.uk

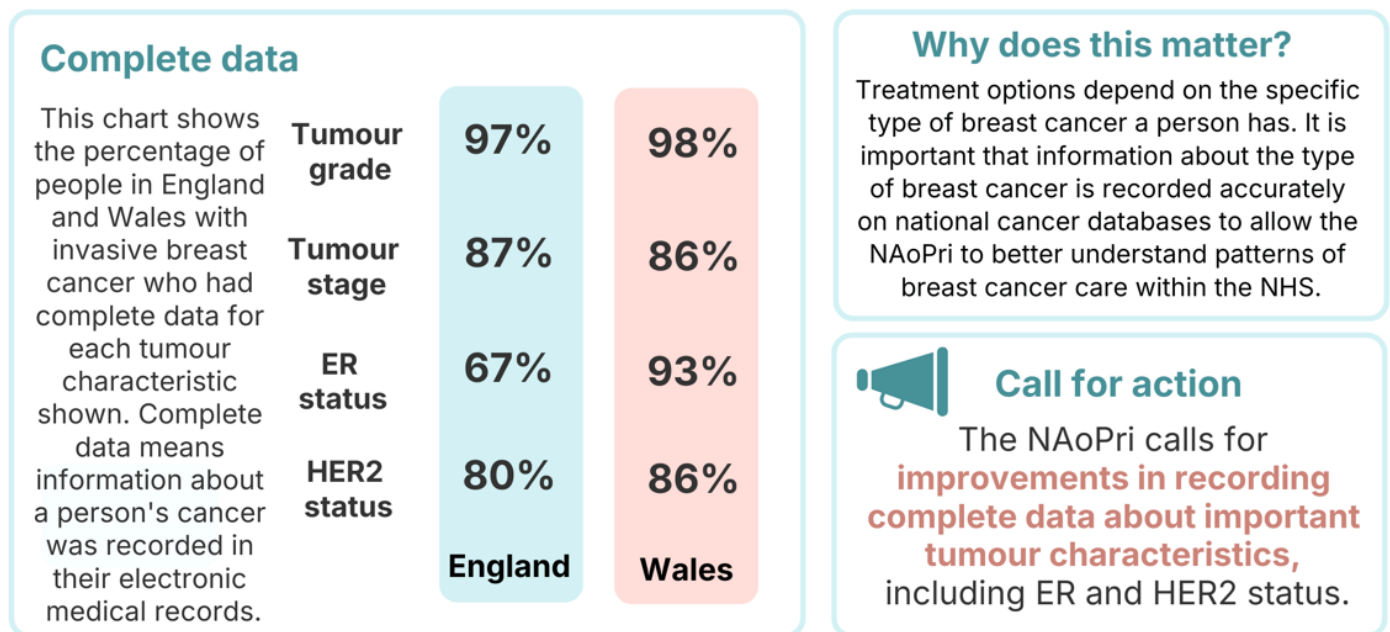
7. Who is the SotN report about?

SotN report page 10



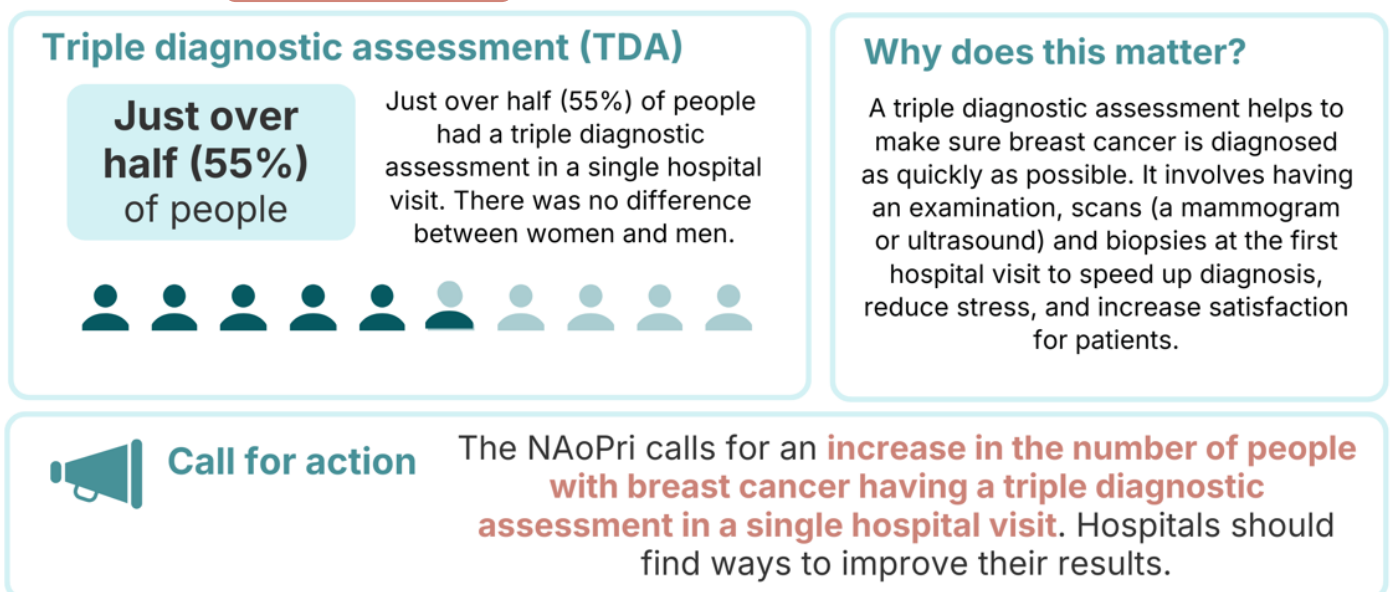
8. How complete is primary breast cancer data?

SotN report page 9



9. How are people diagnosed and supported with primary breast cancer?

SotN report page 12



Clinical nurse specialists (CNS)

Nearly everyone (98%)

Nearly everyone (98% of people) who had their data recorded, saw a clinical nurse specialist when they were diagnosed. There were no differences between women and men.

In England, this information was only recorded for 76% of people, which made it difficult to interpret.

Why does this matter?

The National Institute of Health and Care Excellence (NICE) include contact with a clinical nurse specialist in their quality standards of breast cancer care.

Assigning a clinical nurse specialist to people with primary breast cancer leads to better health outcomes.

Having a dedicated clinical nurse specialist promotes continuity of care, as they can give information and support for the person with breast cancer throughout their treatment. They can improve the patient's experience and make sure the patient's views are taken into account.



Call for action

The NAOpri calls for **recording of clinical nurse specialist data** on national cancer databases to be improved by making sure hospitals assign a healthcare professional to be responsible for checking data.

10. How is primary breast cancer treated?

SotN report pages 13 to 17

Breast surgery

8 in 10 people



Eight in 10 people with early invasive breast cancer had breast surgery to remove their cancer within 12 months of their diagnosis. There was no difference between women and men. However, of those having surgery, 28% of women had a mastectomy compared with 94% of men.

Why does this matter?

Breast surgery is an important part of treatment for early invasive breast cancer. Surgical options are breast-conserving surgery or a mastectomy. The type of surgery as person has depends on many factors, including the extent of the disease and individual's choice.

Everyone should be offered surgery for early invasive breast cancer unless they have a significant health problem that would make surgery too risky.

Breast reconstruction

2 in 10 women



Two in 10 women had immediate breast reconstruction when having a mastectomy for non-invasive or early invasive breast cancer. This does not take into account patient preference or suitability, for example, patients who were offered but chose not to have reconstruction, and those who weren't able to have reconstruction. Very few men had reconstruction.

In England, 24% of women had immediate breast reconstruction compared with 14% in Wales. The number of women who had breast reconstruction varied between different types of breast cancer. In cases of non-invasive breast cancer, 41% of women had reconstruction and in cases of early invasive breast cancer, 21% had reconstruction.

Why does this matter?

The National Institute for Health and Care Excellence (NICE) recommends that all patients should be offered breast reconstruction unless it can't be done because of poor fitness or other health problems.



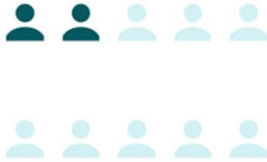
Call for action

The NAOpri calls for **better access to immediate breast reconstruction** for patients in all NHS hospitals.

Adjuvant chemotherapy

2 in 10 people

Two in 10 people who had surgery for early invasive breast cancer had adjuvant chemotherapy. Rates were similar for women and men.



Why does this matter?

Adjuvant chemotherapy can reduce the risk of the breast cancer coming back in the future and increase survival.

Chemotherapy is often offered to people with ER-negative or HER2-positive breast cancer, people whose cancer is also in their lymph nodes, and people with ER-positive breast cancer who are considered to have a high risk of their breast cancer returning.

The benefits of chemotherapy have to be weighed up against the risks. This is particularly important for people with other health conditions.

Overall chemotherapy

3 in 10 people

Three in 10 people who had surgery for early invasive breast cancer had chemotherapy at some point in their treatment.



Neo-adjuvant chemotherapy (NACT)

1 in 10 people



One in 10 people with early invasive breast cancer had neo-adjuvant chemotherapy. Few men had NACT.

Women with stage 2 or 3A breast cancer were most likely to be offered NACT. Of this group, NACT was more often given to younger women and those with HER2-positive or triple negative breast cancer.

There was lots of variation in how NACT was used across different hospitals.

Why does this matter?

National guidelines recommend using NACT for people where it may help to try to shrink the breast cancer or treat involved lymph nodes in the armpit.

NACT is recommended for people with HER2-positive and ER-negative breast cancer if they are likely to be offered chemotherapy after their surgery as it allows doctors to see how the tumour responds to certain chemotherapy drugs.



Call for action

The NAOpri calls for **NACT to be used more consistently** across different hospitals.

Radiotherapy after breast-conserving surgery

8 in 10 women

Eight in 10 women with early invasive breast cancer had radiotherapy after breast-conserving surgery. There was more variation in older women. There were not enough men who had breast-conserving surgery to be able to include data on men having radiotherapy after breast-conserving surgery in the SotN report.



Radiotherapy after mastectomy

5 in 10 people

Five in 10 people with early invasive breast cancer had post-mastectomy radiotherapy (PMRT). The rates for women and men were similar.

There were large differences in whether PMRT was used according to the risk of breast cancer returning. PMRT was used in 85% of high-risk cases, 67% of intermediate-risk cases and 18% of low-risk cases.



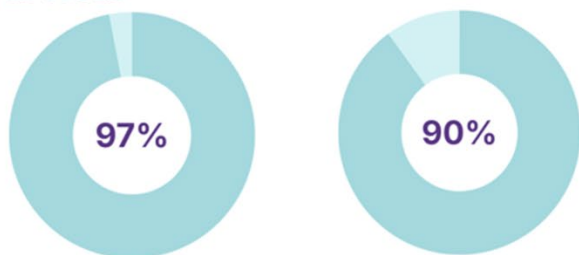
Why does this matter?

Radiotherapy plays a key role in reducing the risk of breast cancer returning in the future. It is recommended for most people who have breast-conserving surgery. PMRT is recommended to those with high-risk breast cancer, but not those with low-risk breast cancer. For those with intermediate-risk breast cancer, guidelines recommend that PMRT is considered.

11. What are the outcomes for people with primary breast cancer?

SotN report page 18

Survival



Year one

Year three

In England and Wales, 97% of people survived primary breast cancer for one year after their initial diagnosis, and 90% survived for three years. There were differences relating to the stage of the breast cancer and patient characteristics (for example, their age and other health problems).

Future NAOpri outcomes

We will be working towards publishing information about the following.

- People who need **additional breast surgery** within 12 months of their original surgery (known as re-excision of margins).
- People who are admitted to hospital because of a **complication with their chemotherapy treatment**.
- **Five-year survival** after an initial diagnosis of primary breast cancer.
- **Breast cancer recurrence** (that is, when breast cancer comes back) – currently data is only available for less than 1% of people.



Call for action

The NAOpri calls for **improvements in how breast cancer recurrence is recorded** on national cancer databases. This will help patients understand how different breast cancer types and treatments affect recurrence.

12. What you can do

Accurate information is important for achieving healthcare equality for all patients and across regions. Ask your breast cancer team to record information about your breast cancer on national cancer databases. You can find data for the NHS organisation where you are receiving care at <https://www.natcan.org.uk/reports/naopri-state-of-the-nation-report-2024/>.

13. Information and support about breast cancer



Find out more

You can find more information about the NAOpri at

<https://www.natcan.org.uk/audits/primary-breast/>

For general information about breast cancer, and how patient information is used to improve outcomes, you can visit the following websites.

Where to find information and support about breast cancer

Breast Cancer Now	https://breastcancernow.org/ Helpline - 0808 800 6000
NHS England breast screening for women aged 71 or over	www.gov.uk/government/publications/breast-screening-for-women-aged-71-or-over
Cancer Research UK	www.cancerresearchuk.org
Flat Friends UK	www.flatfriends.org.uk
Independent Cancer Patients' Voice (ICPV)	www.independentcancerpatientsvoice.org.uk
Macmillan Cancer Support	https://www.macmillan.org.uk/cancer-information-and-support/breast-cancer
NHS choices	www.nhs.uk/conditions/breast-cancer/
Lobular Breast Cancer UK	https://lobularbreastcancer.org.uk/
Inflammatory Breast Cancer Network UK	www.ibcnetworkuk.org
Men's Virtual Meet-Up (VMU)	https://www.themensvmu.org/

Where to find information on how patient information is securely collected and shared

use MY data	www.usemydata.org
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This report was co-produced by the members of the NAOpri project team and Patient and Public Involvement (PPI) forum

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The National Cancer Audit Collaborating Centre (NATCAN) is a national centre of excellence set up to evaluate cancer care in England and Wales. It is part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP) and is funded by NHS England and the Welsh Government.



The Royal College of Surgeons of England is an independent professional body committed to supporting surgeons to help them achieve and maintain the highest standards of surgical practice and patient care. As part of this, it helps with carrying out audits and evaluating clinical effectiveness for surgery. Registered charity number: 212808



The Association of Breast Surgery is a registered charity that is dedicated to improving breast surgery and how breast conditions are managed for the benefit of the public. For more information, visit www.associationofbreastsurgery.org.uk. Registered charity number: 1135699



The UK Breast Cancer Group (UKBCG) is a forum for clinical and medical oncologists. The UKBCG acts as a stakeholder to NICE, NHS England and other organisations and carries out key pieces of work (with other organisations when necessary) with the aim of improving patient care. For more information, visit <https://ukbcg.org/>. Registered charity number: 1177296

Patient groups represented on the NAOme Patient and Public Involvement (PPI) forum



Breast Cancer Now is a charity that's led by world-class research which works towards providing life-changing care. They help anyone affected by breast cancer, the whole way through their care and treatment, providing support for today and hope for the future. For more information, visit <https://breastcancernow.org/>. Registered charity numbers: 1160558 (England and Wales), SC045584 (Scotland) and 1200 (The Isle of Man)



Independent Cancer Patients' Voice (ICPV) is a patient advocate group that is not linked to established UK cancer charities. They know how valuable medical research is to both public healthcare and the national economy. For more information, visit www.independentcancerpatientsvoice.org.uk. Registered charity number: 1138456



Men's Virtual Meet-Up (VMU) are a patient advocacy group for men diagnosed with breast cancer, to help them feel seen and heard, and to know they are not alone. For more information, visit <https://www.themensvmu.org/>. Registered charity number: 1196494



Flat Friends UK is dedicated to supporting women who have had mastectomy surgery without breast reconstruction (including those who may face decisions about reconstruction in the future). For more information, visit <https://flatfriends.org.uk/>. Registered charity number: 1168730



Lobular Breast Cancer work to save more lives by campaigning for more information and targeted research, quicker diagnosis and more effective treatment guidelines across the UK. For more information, visit <https://lobularbreastcancer.org.uk/>. Registered charity number: 1191402

Commissioner



The Healthcare Quality Improvement Partnership (HQIP) is led by a group from the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. It aims to promote quality improvement in patient outcomes and increase the effect that clinical audits, outcome review programmes and registries have on the quality of healthcare in England and Wales. For more information visit <https://www.hqip.org.uk/national-programmes>.

Acknowledgements

This report uses information which was provided by patients and collected as part of their care and support.



For patients diagnosed in England, information was collected, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS Digital.



For patients diagnosed in Wales, information was collected, maintained and quality assured by the Wales Cancer Network (WCN), which is part of Public Health Wales.

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