



All-Party Parliamentary Group on Breast Cancer

A mixed picture: an inquiry into geographical inequalities and breast cancer

Terms of Reference

About the APPGBC

The All-Party Parliamentary Group on Breast Cancer (APPGBC) exists to raise the profile of breast cancer issues within Parliament. It provides a forum for MPs and Peers to discuss the most important issues affecting women and men with breast cancer and to encourage a dialogue between Parliamentarians, Government, the NHS and, most importantly, those living with or affected by the disease.

Introduction and background to inquiry

In October 2016, the APPGBC announced it was undertaking an inquiry into geographical inequalities and breast cancer, and the steps that could be taken to ensure that everyone with breast cancer receives the same high level of treatment and care, irrespective of where they live.

More people are developing breast cancer than ever before. In England, 42,000 women and around 300 men are diagnosed, and almost 10,000 patients still lose their lives to the disease, each year.

While breast cancer patients across England should receive the same high level of treatment and care, unfortunately this is often not the case and patients have varying experiences depending on where they live. Inequalities exist throughout the patient pathway from diagnosis through to treatment and care, and survival.

Recent years have seen dramatic changes to the way that health services are structured, funded and commissioned, including the introduction of clinical commissioning groups (CCGs) and the split in commissioning in the breast cancer pathway between NHS England and CCGs. Over the course of 2016 we have seen the development of Sustainability and Transformation Plans (STPs) in 44 'footprint' areas. In Greater Manchester responsibility for health and care services, including funding, is being devolved to local bodies. This all impacts on the way that services are provided and potentially on the treatment and care experienced by patients.

The purpose of the APPGBC inquiry is to establish the extent of the geographical variations that exist in England – including, where possible, whether variation has changed significantly over time - and the reasons for these variations, as well as the impact they have on patients. The inquiry will make recommendations to address the inequalities highlighted, including considering the opportunities presented by new NHS structures and plans.

The inquiry will use data available through a range of sources including NHS Right Care, NHS England, Office for National Statistics, the National Cancer Registry and Analysis Service (NCRAS) and the Cancer Patient Experience Survey (CPES) as well as taking evidence from those with expertise in, or experience of, breast cancer - including patients, clinicians, commissioners, health bodies and others.

Themes of the inquiry

The inquiry will focus on geographical variation across four key themes: diagnosis; treatment and care; outcomes; and NHS structures and plans.

Diagnosis

The earlier breast cancer is diagnosed, the better the chance of successful treatment. The most common ways people are diagnosed are as a result of attendance at screening, and referral to a specialist by their GP. Although far fewer people are diagnosed as a result of presenting as an emergency, for example at Accident and Emergency, survival rates for people diagnosed through this route are much lower.¹ The inquiry will look at geographical differences in diagnosis and delivery of services, including:

- **Screening.** All women between the ages of 50 and 70 should be offered breast cancer screening every three years. However, the percentage of women screened has declined steadily over recent years.² The percentage of women screened in the three years from 2012 to 2014 varied from 50.8% to 81.5% across CCGs.³
- **Emergency presentation.** The number of women diagnosed with breast cancer as a result of presenting as an emergency varied from 3.2 to 19.8 per 100,000 women between 2006 and 2013 across CCGs.⁴
- **Stage of diagnosis.** The percentage of breast cancers diagnosed at an early stage (stages 1 and 2, when it is most treatable) in 2013 varied from 36.3% to 88.0% across CCGs.⁵
- **The promptness with which patients are diagnosed.** In terms of service delivery, NHS England has a target that everyone that presents at their GP with a symptom of breast cancer, whether cancer is suspected or not, be seen by a specialist within two weeks of referral. The percentage of women with suspected breast cancer referred urgently that saw a specialist within 2 weeks in 2015/16 varied from 71.3% to 100% across CCGs, and for women with a symptom where breast cancer was not initially suspected referred non-urgently from 66.7% to 100%. The operational standard is 93%.⁶

Treatment and care

The exact treatment that people with breast cancer receive will depend on a number of factors, including the type of breast cancer they have. But there are a number of aspects of treatment and care that can particularly impact on people's outcomes and their experience of their care. The inquiry will look at geographical differences in some of these, including:

- **The promptness with which patients receive treatment.** In terms of service delivery, NHS England has targets for the time within which people diagnosed with cancer should receive their first treatment. The percentage of people diagnosed with breast cancer that started their first treatment within 31 days of agreeing a treatment plan with their doctor in 2015/16 varied between 88% and 100% across CCGs. The operational standard for this target is 96%. However, the percentage of people that started their first treatment within 62 days of being referred by their GP varied between 82% and 100%. The operational standard for this target is 85%.⁷
- **Access to some treatments.** Access to some treatments can vary across the country. This is often the case for medicines that have not been through the National Institute for Health and Care Excellence (NICE) appraisal process, as where this recommends a treatment CCGs are required to fund it. Off-licence, off-patent medicines, such as bisphosphonates, are a good example of this. Bisphosphonates are licenced for treatment of osteoporosis and advanced cancer, but in July 2015 evidence that they were effective in preventing the development of

secondary breast cancer was published in medical journal The Lancet. Whilst data is not collected nationally on which CCGs commission such medicines, a UK Breast Cancer Group survey in early 2016 suggested that most clinicians are unable to offer bisphosphonates to their patients.

- **Aspects of care that people with breast cancer particularly value.** For example, we know that having a clinical nurse specialist (CNS) who is easy to contact is very important to patients. The percentage of breast cancer patients that said they were given the name of a CNS to support them through their treatment as part of National Cancer Patient Experience Survey 2015 ranged from 78.3% to 100% across CCGs in England, and the percentage that said that their CNS was very easy or quite easy to contact ranged from 64% to 100%. The percentage of patients that said they were told who to contact if they had any concerns after they were discharged from hospital ranged from between 78.3% to 100% across CCGs.⁸

Outcomes

Outcomes for breast cancer patients vary across England. As indicators for quality of life are currently being developed, the inquiry will focus on geographical differences in survival and mortality:

- There is less variation in one and five year survival rates for breast cancer patients across England than for some other types of cancer. **One year survival** varied between 95.7% and 97.3% across NHS England Area Teams for women diagnosed in 2012. **Five year survival** varied between 82.6% and 86.5% for women diagnosed in 2007.⁹
- **Premature mortality** (under 75) from breast cancer varied from 13.3 to 31.9 per 100,000 of the population across CCGs between 2011 and 2013.¹⁰

NHS structures and plans

There have been a number of changes to NHS structures over recent years that impact on the services provided and potentially the treatment and care experienced by patients. The inquiry will consider a number of recent developments and the opportunities that they present to address geographical inequalities and improve outcomes and experience for breast cancer patients, including:

- the development and implementation of STPs, and the role of the Cancer Alliances in taking forward work on cancer in these Plans;
- devolution of health services to local bodies in Greater Manchester;
- the work of the Cancer Vanguard in developing new models of care for cancer; and
- the availability of data and how it is being used to improve quality of treatment and care (including, for example, the move from peer review for cancer services to quality surveillance).

Scope of the inquiry

While the APPGBC is a cross-UK group, health services are devolved to each of the nations and data are not necessarily comparable across the nations. The inquiry will therefore focus on geographic inequalities within England. However, the APPGBC is keen to learn from examples of good practice in Scotland, Wales and Northern Ireland and therefore encourages representatives in the devolved nations to contribute to the inquiry.

Structure of the inquiry

Call for written evidence

The APPGBC will issue a call for written evidence from organisations and individuals with expertise in, or experience of, breast cancer, including patients and carers, clinicians, commissioners, health bodies and others.

Oral evidence

There will be an oral evidence session for each of the key themes of the inquiry at which patients and carers, clinicians, commissioners, and representatives of health bodies will be invited to give evidence to the APPGBC.

Patient focus groups

The APPGBC understands that people with breast cancer may prefer to share their experiences in different ways. Whilst the inquiry welcomes written evidence from patients and carers about their experiences and the impact these have had on them, and we hope that they will also be willing to give oral evidence, we are also proposing to hold some focus groups to ensure that we hear from as wide a range of patients and carers as possible.

Report

A report, based on the written and oral evidence, and the patient focus groups, will be produced which makes recommendations to address the inequalities highlighted and ensure that all breast cancer patients receive the same high level of treatment and care wherever they live in England.

Timetable for the inquiry

Stage of inquiry	Date
Call for written evidence	Week commencing 16 January 2017
Deadline for written evidence	Wednesday 15 March 2017
Patient focus groups	March/April 2017
Oral evidence sessions	End March – May 2017
Publication of report	Autumn 2017 (date tbc)

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References

¹ Please see publications on routes to diagnosis published by Public Health England available at:

www.ncin.org.uk/publications/routes_to_diagnosis.

² Breast Screening Programme, England 2014-15, NHS Digital. Available at:

content.digital.nhs.uk/catalogue/PUB20018.

³ This data is part of the Cancer and Tumours Focus Pack made available by Public Health England and NHS England as part of Commissioning for Value. It is available at:

ccgtools.england.nhs.uk/cfv2016/cancer/atlas.html

⁴ Ibid.

⁵ Ibid.

⁶ Data provided by NHS England, and available [here](#).

⁷ Ibid.

⁸ Data from the Cancer Patient Experience Survey 2015. Available at:

<http://www.ncpes.co.uk/index.php/reports/local-reports/data-tables>

⁹ Cancer Survival by NHS England Area Team – Adults diagnosed: 1997-2012, followed up to 2013, Office of National Statistics. Available at:

www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalbynhsenglandareateamadultsdiagnosed/2014-12-16#breast-cancer-women

¹⁰ This data is part of the Cancer and Tumours Focus Pack made available by Public Health England and NHS England as part of Commissioning for Value. It is available at:

<http://ccgtools.england.nhs.uk/cfv2016/cancer/atlas.html>