

A Mixed Picture: An Inquiry into Geographical Inequalities and Breast Cancer

February 2018



**All-Party Parliamentary Group
on Breast Cancer**

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People with breast cancer in England are experiencing differences in their diagnosis, treatment and care based on where they live, rather than their clinical need.

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1. Foreword

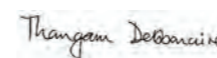
We are delighted to present the final report of the All-Party Parliamentary Group (APPG) on Breast Cancer’s inquiry into geographical inequalities in breast cancer diagnosis, treatment and care across England. We are grateful to the patients, clinicians, charities and NHS planners and commissioners who took the time to contribute evidence to the inquiry.

When compared to other cancers, breast cancer outcomes are good and improving. However, this overall progress masks stark inequalities in diagnosis, treatment and care across the country. These unwarranted variations have an unacceptable impact on the experiences and outcomes of patients.

Each of us has a close connection to breast cancer – one as a patient, one as a breast surgeon, and one who has lost a loved one to the disease. We know just how vital it is that urgent action is taken to reduce this variation and end the mixed picture for breast cancer patients in England.

The report outlines key recommendations to address these disparities. We are particularly concerned about the impact of shortages in the diagnostic workforce on patients’ diagnosis and treatment. We are also eager for new local NHS structures to grasp opportunities to use data to drive service improvements by sharing best practice with one another.

It is likely that some of the issues outlined in the report are also affecting services for other cancers. We hope that the recommendations in this report contribute to the government’s ambition to achieve world-class outcomes not just for breast cancer, but for all cancers.



Thangam Debonnaire MP



Philippa Whitford MP



Craig Tracey MP

2. Executive summary

Outcomes for breast cancer are good and improving, but overall progress is disguising variations across the country. Some women are being diagnosed at an earlier stage of their breast cancer than others, greatly improving their chances of survival. Some women are offered life-saving drugs that reduce the chances of cancer developing or returning, while others are not offered these drugs.

Some women receive the care of specialist nurses; others have no such support to navigate the health and social care system. Some women are given information and services to manage their conditions and make choices that affect their futures, while others are left to fend for themselves after their treatment ends, or are left with reduced fertility unaware there were opportunities to prevent this. These differences exist due to where each woman lives.

As more women are diagnosed with breast cancer and incidence of the disease is set to increase, the NHS faces unprecedented demand while resources are under increasing pressure. At such a time, it is imperative that the focus outlined in the Cancer Strategy of reducing variation is maintained or increase. Otherwise, there is a real risk that inequalities will worsen and outcomes and care for some patients will continue to fall behind those of others. While such differences remain, this country cannot hope to meet the government's ambition of delivering world-class cancer outcomes for all.

Evidence presented to this inquiry showed that, although there are examples of innovative and high performing services, unacceptable differences exist at every level of geography. Some regions of the country perform better in certain areas of care or treatment than others. Stark differences in the availability of services can also occur within very local geographies, from town to town or even within

individual towns and cities. These variations are predominantly due to differences in populations and their needs and the way services are organised locally.

While the new more localised NHS system was established with an objective of removing unwarranted variation by responding to the needs of local populations, the APPG heard warnings from experts that, without urgent action, unwarranted variation could become more entrenched. There is no formal mechanism for good practice to be replicated more widely. There is confusion as to who should be funding what, with a lack of accountability for the commissioning and delivery of breast cancer services.

The inadequate collection and sharing of data is acting as a barrier to service improvement, with some commissioners and services failing to collect or use data and others struggling to access it. Data should be used to spot unwarranted variation, hold services to account, and as a tool to better understand a population and the services it requires.

Much concern was raised about the breast cancer workforce. Current vacancy rates and increasing demand coupled with a workforce approaching retirement is creating pressures in the system that will only worsen with time if not addressed. These problems are hitting certain areas of the country

hardest and are being felt particularly acutely in the diagnostic workforce, specifically among radiologists and radiographers, and in the Clinical Nurse Specialist workforce. This is especially worrying as delays in diagnosis can cause knock-on effects for breast cancer patients along the treatment pathway.

This report sets out recommendations to tackle these problems and address unwarranted geographical inequalities in breast cancer so that treatment and care for breast cancer patients can be improved across the country. The APPG asks that NHS England, Public Health England, Cancer Alliances, commissioners and service providers consider these recommendations and work together to ensure that all those with breast cancer can be sure of world-class treatment and care regardless of where they live.

Recommendations

Targeting interventions

Cancer Alliances should tailor prevention, awareness and screening initiatives to their local populations, targeting specific groups that are most in need of outreach such as Black, Asian and minority ethnic women and women from lower socio-economic groups. Interventions should target groups within the population who are most in need and should use methods that have shown to be effective for each group.

Effective use of data

NHS England and Public Health England should continue to develop the Cancer Dashboard so that data on inequalities can be more easily obtained, working with the National Cancer Registration and Analysis Service where appropriate to identify areas where a strategic analysis could be most useful.

Clinical Commissioning Groups and Cancer Alliances should use the Cancer Dashboard to compare themselves to others and, alongside more detailed data that they hold on their geographical area, ensure that any adverse trends are investigated and steps taken to improve outcomes.

Earlier diagnosis of secondary breast cancer

NHS England should deliver on the ambition of the Cancer Strategy to ensure GPs are able to diagnose secondary breast cancer early, as well as considering other ways patients can get back into the system if secondary breast cancer is suspected (for example open access follow up).

Cancer Alliances should consider how they can work with local GPs to raise awareness of the signs and symptoms of secondary breast cancer.

Recording of data

Public Health England has ensured there is a standardised dataset, the Cancer Outcomes and Services Dataset, where information on breast cancer can be recorded. Local providers must ensure they are recording all information in the dataset by implementing appropriate training and software. Cancer Alliances should support local providers to do so and hold them to account if data is not submitted.

Workforce planning

Each Cancer Alliance should publish a clear workforce plan to deliver the Cancer Strategy in England and set out funding requirements to do this. This should be developed in conjunction with relevant Health Education England offices, Sustainability and Transformation Partnerships and other partners. It should consider all areas in breast cancer care, but in particular breast radiology, radiography and nursing.

Health Education England should publish its upcoming longer term workforce plan proposing sustainable solutions to the workforce crisis at its earliest convenience. This should include:

- Specific planning to address the breast screening workforce, in particular breast radiologists and radiographers
- Plans to recruit more breast cancer Clinical Nurse Specialists in line with patient need
- The view of patients consulted on the proposals.

All patients should have access to a breast Clinical Nurse Specialist. Health Education England and the Royal College of Nursing should work together

to ensure there are enough breast Clinical Nurse Specialists with the requisite skills to serve local patient populations.

NHS structures and the breast cancer treatment pathway

Cancer Alliances should work with providers and patient representatives to develop comprehensive services that meet the needs of patients throughout their breast cancer journey. Those involved in developing Sustainability and Transformation Partnerships, Clinical Commissioning Groups, Local Authorities, Public Health England, and NHS England specialised commissioning should all be included in development of these plans and services. All patients should have access to:

- Medicines they can benefit from at a price the NHS can afford
- Advice and services to help them manage the short and longer term side effects of treatment including fertility treatment
- Support services, including information and psychological support
- Reconstructive surgery with the full range of options offered and discussed.

3. Introduction

People with breast cancer in England are experiencing differences in their diagnosis, treatment and care based on where they live, rather than their clinical need. Recognising that these geographical inequalities exist, the APPG ran an inquiry from October 2016 to November 2017 to discover where and why inequalities arise and what the possible solutions might be.

The inquiry heard from system leaders, medical experts, charity representatives and patients over four evidence sessions, six patient focus groups, and through a call for written evidence.

The focus of this inquiry is particularly pertinent as the independent report published by the Cancer Taskforce in 2015 recognised that there was ‘unacceptable variability’ in access to and experience of care.¹ Both NHS England progress reports on the implementation of the Cancer Strategy have also conceded that there is still unwarranted variation in outcomes across the country.^{2,3} In addition the *Five Year Forward View* and its follow up, *Next Steps on the NHS Five Year Forward View*, recognised that variation in access, treatment, care and outcomes is an issue across England.^{4,5} These reports set out steps to reduce variation, primarily by focusing on introducing new models for commissioning and providing care, such as accountable care systems and the pilot Vanguard sites. Recently, the planning and commissioning of breast cancer services has undergone a transformation in England with 16 Cancer Alliances established to lead and coordinate cancer care in their areas.

This report shows that geographical differences can manifest at regional, Clinical Commissioning Group (CCG) and sub-CCG level, creating a mixed picture for breast cancer across the country. As the new NHS structures are established it is important

that everyone involved in the commissioning and delivery of cancer diagnostic, treatment and support services understands the role they can play in identifying and minimising variation. This report seeks to shine a light on whether progress is being made in achieving this.

The inquiry found that three key themes must be addressed in order to reduce unwarranted geographical inequalities:

1. The effective collection and use of data to drive service improvement
2. National and local workforce planning
3. Improving the consistency, transparency and accountability of commissioning and delivery of cancer services through new NHS improvement and structures.

It is unlikely that these issues affect only breast cancer outcomes. This report may therefore be a warning bell about geographical inequalities in the treatment and care of other cancers.

The APPG would like this report to contribute to the conversation about this wider issue, which requires the development of sensitive, tailored and localised approaches to make progress in addressing cancer outcomes as a whole.

You could not have designed more variation into a system if you tried.

Adrian Hackney, Director of Commissioning, Greater Manchester Cancer Services.
(Oral evidence session 3, October 2017)

4. Geographical variation

The overall good outcomes for breast cancer mask variations in the treatment and care available to patients across England. Unwarranted variations exist at a regional level as well as in small pockets of populations, between or even within neighbouring towns and cities. These discrepancies can be attributed to population demographics, including age, ethnicity, and socio-economic status as well as variation in the services and standards offered by devolved NHS structures in local areas.

It is vital that commissioners, Cancer Alliances and providers ensure the best services are available to all local populations and to all patients. In order to do this, planners must understand local populations and their needs.

Overall outcomes for breast cancer are good and have been improving, whether that is measured in terms of survival rates, early diagnosis, various waiting time standards, or indeed the reported patient experience. The data that we have shows good outcomes in those terms, but – and it is a huge ‘but’ – [there is] variation geographically, demographically and within social groups.

Professor Chris Harrison, National Clinical Director for Cancer, NHS England (Oral evidence session 4, November 2017)

Incidence and Prevalence

Breast cancer is the most common cancer in England: on average, 126 people received a breast cancer diagnosis every day in 2016.⁶

The disease is more common in some areas than others, for example there are 41% more cases of breast cancer in the CCG with the highest incidence compared to the CCG with the lowest incidence.⁷

There are several factors behind geographical differences in breast cancer incidence:

- Breast cancer is less common among women living in the most deprived areas
- The disease is more common among white women than Black, Asian and minority ethnic (BAME) women
- A woman’s risk of breast cancer increases with age, meaning places with older populations are likely to have more cases of the disease.⁸

The best way to improve breast cancer outcomes is to, where possible, prevent it from developing in the first instance. Different groups within the population have different risks of breast cancer so targeted interventions are essential in order to ensure they are effective and cost-efficient. For example, commissioners and providers in more socio-economically advantaged areas, such as the South East (where breast cancer is more common) should consider carefully what interventions they should provide to reduce women’s risk of developing breast cancer.⁹

Risk factors related to incidence that commissioners and providers could work to address include reducing alcohol consumption, reducing the prevalence of people being overweight or obese and lack of physical exercise.

Stage of diagnosis

While nationally more breast cancers are being diagnosed at an early stage, and more CCGs are recording data on stage at diagnosis, even where 90% of this data is collected there are stark differences in the percentages of breast cancer cases diagnosed at an early stage between CCGs (see figure 1).

It is all about excluded populations who do not use services, who do not utilise screening and that is the one that will make the quantum change to outcomes: you change access and you change outcomes.

Dr Rory Harvey, Chair, East of England Cancer Alliance (Oral evidence session 3, October 2017)

The earlier cancer is diagnosed the more successful treatment is likely to be. 90% of breast cancer patients diagnosed at stage one (when the tumour is small and localised) survive for at least five years compared to just 15% diagnosed at stage four (when the tumour is larger and has spread to other parts of the body).¹⁰

Improving the rates at which cancer is diagnosed at stages 1 or 2 is therefore likely to save lives.

Highest	88%	NHS Rushcliffe CCG
Lowest	62%	NHS Gloucestershire CCG

Figure 1: Breast cancers detected at an early stage (1 or 2), (2013)⁷

Some geographical variation in early diagnosis may be linked to population demographics and for this reason commissioners and planners should be targeting interventions accordingly. For example:

- While socio-economically advantaged women are more likely to be diagnosed with breast cancer, women living in disadvantaged areas are more likely to be diagnosed at a later stage with a lower chance of survival^{11,12}
- Although white women are more likely to be diagnosed with breast cancer, BAME women are more likely to be diagnosed at a later stage
- Older women are more likely to be diagnosed later than younger women.¹³

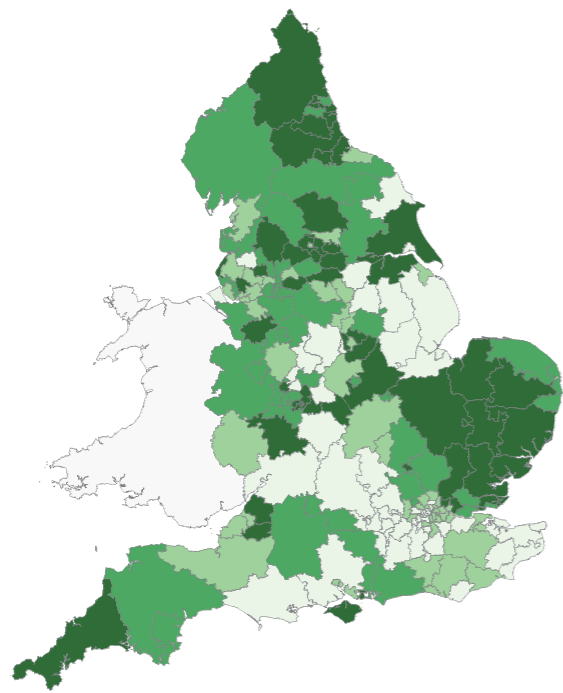
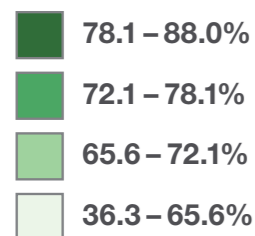


Figure 2: Percentage of breast cancers detected at an early stage (1 or 2), by CCG⁷



National average: 71.0%
Range: 36.3 – 88.0%

Map reproduced with the permission of NHS RightCare

Secondary breast cancer

It is estimated that there are 35,000 people in the UK living with secondary breast cancer,¹³ and that a further 35 out of every 100 people with primary breast cancer will develop secondary breast cancer within ten years of their first breast cancer diagnosis.¹⁴

Women whose primary breast cancer has been successfully treated cannot consider themselves ‘in the clear’ five years after treatment; breast cancer may recur many years after treatment and patients must be advised accordingly. Health services will need to adapt and provide services that meet the distinct needs of these patients. The inquiry found that there is variation across England in the support that women with secondary breast cancer receive.

Mortality

9,554 people died from breast cancer in England in 2014.⁸ Premature deaths differ between CCGs: the mortality rate among people aged under 75 in the worst performing area is more than double that of the best performing area (see figure 3).^{7,15} Differences may be due to differences in the demographic factors outlined above, as well as how well individual services are performing.

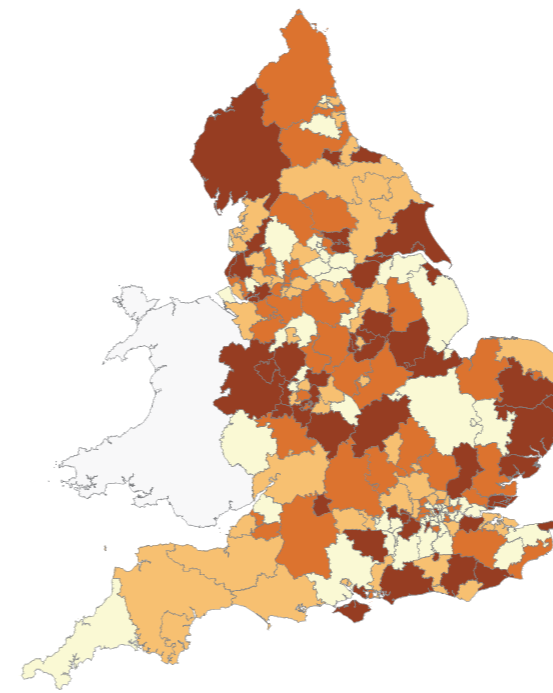
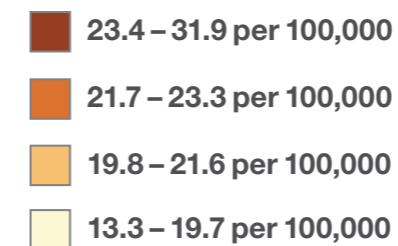


Figure 3: Under-75 breast cancer mortality rate per 100,000 women, by CCG^{7,16}



National average: 19.8 per 100,000 women
Range: 13.3 – 31.9 per 100,000 women

Map reproduced with the permission of NHS RightCare

4.1 Targeting interventions to reduce variations based on population demographics

Early detection and diagnosis of breast cancer can save lives. The earlier breast cancer is detected, the more likely that treatment will be successful. There are three routes to diagnosis: attending routine screening, being referred by a GP and emergency diagnosis at A&E. Those cancers diagnosed through the screening programme are likely to be less advanced, increasing chance of survival.¹⁷ In comparison, by the time patients develop symptoms and therefore present at their GP or in A&E, the cancer is likely to be at a more advanced stage.

In order to improve early diagnosis and, in turn, improve survival rates, local NHS bodies should take steps to improve symptom awareness and screening uptake among specific populations. It is likely that a lack of awareness of the signs and symptoms of breast cancer contributes to later diagnosis among these groups.¹³ Good awareness of the symptoms of breast cancer empowers people to see their GP with any concerns early.

If we look at the screening cohort, at three years relative survival is 100%, fantastic, and that is a mix of screening and also treatment options, which have improved over the last few years. If we look at the two-week wait, three-year survival is 89%; GP referrals goes down to 85%; and emergency presentation is 36%. We need to get women in through screening.

Jacque Jenkins, National Programme Manager, Breast Screening, Public Health England (Oral evidence session 1, March 2017)

Screening uptake is the lowest it has ever been over the last 10 years; 71% of women aged 50-70 went for routine breast screening in 2016/17.¹⁸ The APPG heard that there are geographical variations in screening uptake which are linked to population demographics, including deprivation, ethnicity and language. This is likely to contribute to the lower rates of early detection among these groups, though recent evidence suggests that the gap in screening coverage between socio-economic groups may be decreasing.^{19,20} Targeted interventions (such as the one described in Tower Hamlets CCG below) would improve screening uptake among these women.

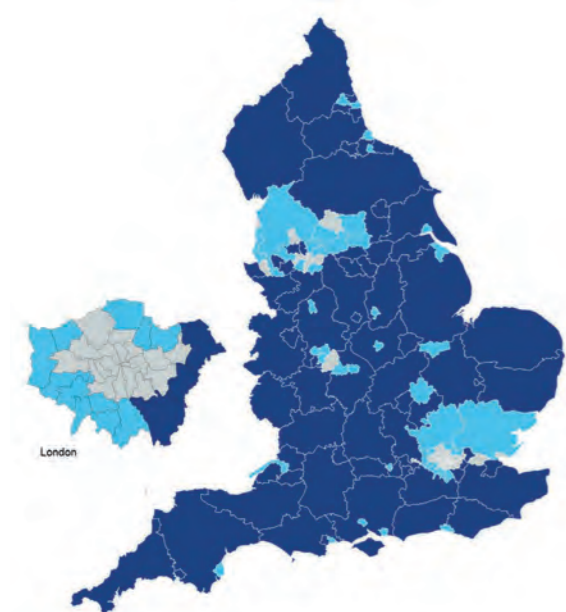


Figure 4: Breast screening coverage among women aged 53-70, by Local Authority²²

- 75% and over
- 70% to less than 75%
- Less than 70%

Map reproduced with the permission of NHS Digital

Statistics at regional level can mask significant differences between screening coverage within regions. Different CCGs within the same Cancer Alliance may have vastly different screening coverage. For example NHS Rushcliffe CCG has the highest screening coverage in England at 82%, whereas NHS Nottingham City CCG has a screening coverage of 71%.²²

Both of these CCGs are part of the East Midlands Cancer Alliance, which has the highest rate of screening coverage. Meanwhile in London, the region with the lowest screening uptake, NHS Bromley CCG has a screening coverage of 75% while the lowest screening coverage in the whole of England is found in NHS West London CCG at 56%.²²

In Liverpool, the APPG heard that the geographical location of screening services in one part of the city may pose a barrier to women who live in the other side of the city.²³

Some CCGs are establishing initiatives to increase screening based on local data. Greater Manchester has started offering a second timed appointment to women who do not attend their first and as a result uptake has gone up by 6%.²⁴

The APPG heard about other initiatives to increase screening uptake, such as those introduced by Tower Hamlets CCG and by Lancashire and South Cumbria Cancer Alliance.²⁵ Features of such initiatives included communication plans using advertising and social media to raise awareness, using health promotion officers to increase uptake and sending invitation letters from GPs instead of other NHS employees.

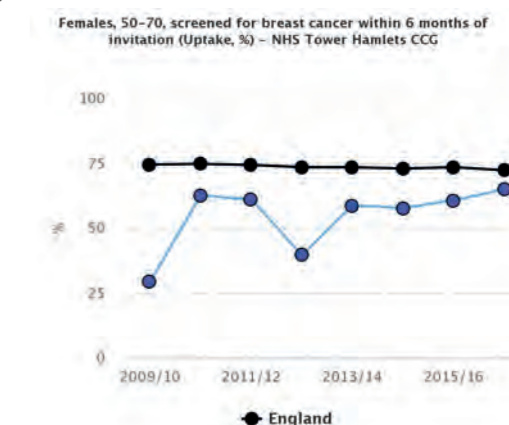
**Case study:
Improving screening uptake in
NHS Tower Hamlets CCG²⁶**

In 2005/6, Tower Hamlets in London had one of the lowest rates of breast screening uptake in the country. Just 51% of eligible women attended screening compared to a national average of 76%. The area had a poor survival rate for breast cancer and NHS Tower Hamlets felt that this might be due to women presenting with later stage cancer.

Screening statistics showed that screening rates were lowest among white/Irish (54%), Bangladeshi (39%) and black women (45%). The CCG decided to target the white/Irish and Bangladeshi populations in order to increase breast screening uptake (the relative black population in the borough was considered small at just 3%). Reasons for low attendance among these women were explored in focus groups, and included language barriers, unfamiliarity with screening, and taboos around breasts and cancer. These insights were used to develop interventions focused on white/Irish and Bangladeshi women, particularly from lower socio-economic groups, such as marketing campaigns tailored to the target populations, community outreach and service improvements.

Interventions that proved particularly successful included an invitation to a second timed appointment for those who did not attend their first appointment. This almost doubled response rates compared to a simple open invitation to call the service and rebook a screening appointment. Text message reminders and pre-appointment phone calls by specialist advocates to those due to attend a breast screening appointment also proved successful.

Between 2006/07 and 2009/10, breast screening rates in Tower Hamlets increased by 14% (from 52% to 66%). Rates varied across participating GP practices, with a high of almost 80% in one practice. However, screening rates dropped again suddenly in 2012/13, when responsibility for screening moved to NHS England. Subsequently, NHS England committed to an improvement plan to increase breast screening coverage in Tower Hamlets. The plan included reintroduction of a targeted telephone outreach service to support women to access screening. The screening rate has since risen again (as shown in the graph below).²⁷



Recommendation

Cancer Alliances should tailor prevention, awareness and screening initiatives to their local populations, targeting specific groups that are most in need of outreach. Interventions should target groups within the population who are most in need, and should use methods that have shown to be effective for each group.

5. Reducing inequalities

Good data can help to improve outcomes and experience by identifying poor performers and highlighting where there are outliers. New NHS structures have the opportunity to facilitate interventions that are tailored to the local population but these need to be based upon analysis of good quality data, such as population demographics, screening uptake and prevalence of secondary breast cancer.

Collecting data will help local commissioners and providers plan services for their population; making the data publicly available will enable them to compare their performance and find out where they might learn from others' best practice to drive service improvement. Data should also be used to provide an overview of the success of both local NHS organisations and NHS England, in terms of breast cancer services and outcomes.

Data is essential to all of this. Cancer waiting times tell us a lot. They give us a good overarching picture of how the NHS is performing when it comes to cancer, but we need a huge amount more data to really understand more about inequities, geographical variation and the reasons behind geographical variation and access to treatments, but also – remembering the picture on diagnostics – how we can improve that early diagnosis side as well.

Emlyn Samuel, Senior Policy Manager, Cancer Research UK (Oral evidence session 2, September 2017)

5.1 Using data to understand performance on a geographical basis

The APPG heard that data is available but that it is not always accessible; there is no national strategy

for collecting and reporting data, so opportunities to use data to gain useful insights are missed. Those giving evidence agreed that data can be used to drive improvements but there is not always timely access to data and information about how individual teams are performing is not pulled together.²⁸

The collection of cancer data by NHS services appears to be patchy. For example in NHS West Essex CCG (the best performing CCG) the stage at which breast cancer had been diagnosed was recorded for 98% of new breast cancers cases, compared to just 42% of breast cancer cases in NHS Slough CCG (the worst performer).²⁹ Collection of data for secondary breast cancer is particularly poor and this is examined in more detail below.

We should absolutely know how I compare in Liverpool to how you compare in Westminster, and is it better or worse, and then of course, why. Completion of the cancer outcome services dataset... should be mandatory and that is the basis of good quality data moving forward.

Professor Chris Holcombe, Deputy Chair, Breast Cancer Clinical Expert Group (Oral evidence session 4, November 2017)

Progress has been made in developing accessible datasets that bring together cancer data but these services do not always prioritise providing data on a geographic basis.

One of these tools is the Cancer Dashboard, which has been developed by NHS England and Public Health England (PHE) after being recommended by the Cancer Taskforce.³⁰ It allows data on survival, treatment, patient experience, quality of life, operational performance, incidence and mortality to be viewed at CCG level and, in the future, at Alliance level. It does not provide an analysis of geographical inequalities itself, but makes the data available so that CCGs, Alliances and researchers can do so themselves.

Another service available to all is the National Cancer Registration and Analysis Service (NCRAS), which ensures that data on cancer is collected and collated. The service produces reports and analyses of cancer data to help policy makers and practitioners. Its most recent report on inequalities was in 2016.

We hope the NCRAS will continue to analyse data on geographical inequalities so that it remains a source of insight for the cancer community, and does not become solely a repository of data. The APPG heard that a more strategic approach to the collection of data and its analysis could benefit the

NHS by helping to reduce variation and improve efficiencies, as sharing data has helped improve practice in Scotland.

Case study: Sharing data in NHS Scotland

The three managed clinical networks in Scotland organise cancer services across the country to a set of national quality performance indicators.³¹ Since 2007, clinicians from the three networks have come together to share and discuss their data in order to compare themselves and learn from each other. Performance against the national standards is also reported in annual reports.

In this way data sharing is used to drive up performance as well as being published in a transparent manner so that everyone is able to see how cancer services are performing. Data sharing has been effective in reducing variation and improving services according to key indicators.³²

Recommendations

NHS England and Public Health England should continue to develop the Cancer Dashboard so that data on inequalities can be more easily obtained, working with the NCRAS where appropriate to identify where a strategic analysis could be most useful.

CCGs and Cancer Alliances should use the Cancer Dashboard to compare themselves to others and, alongside more detailed data that they hold on their geographical area, ensure that any adverse trends are investigated and steps are taken to improve outcomes.

5.2 Collecting data to support people with secondary breast cancer

In some areas, people with secondary breast cancer are not getting the treatment, support and care they need. The Cancer Taskforce identified gaps in the support and services offered to people with secondary breast cancer, including:

- Variation in access to a Clinical Nurse Specialist (CNS)
- Some multidisciplinary teams not routinely discussing their secondary breast cancer patients
- Patchy provision of information for patients
- Patients' psychosocial needs not being met
- A lack of prompt and timely access to specialist palliative care services.¹

Part of the problem is that there is currently no published data on the number of secondary breast cancer diagnoses each year, how many people are living with the disease or length of survival following diagnosis or treatments.

This is despite the fact that collection of data on people with secondary breast cancer has been mandatory since 2012 in England. Lack of accurate and easily accessible data makes it difficult for commissioners and healthcare providers to understand their local patient populations, what their needs are and how to plan services and support to adequately meet these.

Where data on secondary breast cancer is collected, there is variation in what is recorded. In 2016, only 33% of trusts were collecting data in full, 47% were partially collecting data, while 20% were not collecting any data at all (see figure 6).^{33,34,35} In order to reduce these variations and improve diagnosis of breast cancer as a whole,

comprehensive data about the diagnosis and treatment of breast cancer must be collected and made publicly available, for example, as part of the development of the Cancer Dashboard and as separate groups within a continued Cancer Patient Experience Survey. This would allow Cancer Alliances and providers to compare their performance with others and be able to plan services for their patient populations.

5.3 Supporting GPs to quickly diagnose secondary breast cancer

Delays in the diagnosis of secondary breast cancer vary across England. Earlier diagnosis is beneficial as it offers opportunities to begin treatment more quickly. In England, 21% of women with previous experience of primary breast cancer are treated for another condition before secondary breast cancer is eventually diagnosed.³³ Many women in the inquiry focus groups approached their GPs several times with symptoms such as backache and tiredness before they were referred for diagnosis of secondary cancer.

The inquiry understands that, while this remains a problem across England, there is also variation across regions. One reason for this is the varying levels of symptom awareness among GPs. For example, in Yorkshire and Humber 29% of people were treated for another condition before diagnosis with secondary breast cancer while in the South West it was only 11%.³³

Awareness among GPs needs to improve so that patients attending appointments with symptoms that may be secondary breast cancer are quickly referred to specialist services. In addition, commissioners and planners should consider open access follow up, which allows patients to attend specialist services without having to first see a GP if they suspect their cancer has returned.

Recommendations

NHS England should deliver on the ambition of the Cancer Strategy to ensure GPs are able to diagnose secondary breast cancer early, as well as considering other ways patients can get back into the system if secondary breast cancer is suspected (for example open access follow up).

Cancer Alliances should consider how they can work with local GPs to raise awareness of the signs and symptoms of secondary breast cancer.

A close-up portrait of a woman with dark, curly hair, looking upwards and to the left. She is wearing a dark blue top. The background is a blurred wooden lattice structure.

Joanne, Manchester

“I was diagnosed with primary breast cancer in 2006, age 30. During the three years prior to my diagnosis of secondary breast cancer, I sought medical help for depression, sudden stoppage of my periods, acute indigestion and occasional unexplained vomiting. Neither the specialists nor my GP ever connected my symptoms to my initial breast cancer diagnosis, which I always highlighted. I trusted the ‘experts’ and often felt like a hypochondriac.”

“Following a couple of bouts of sickness, I again sought GP support which eventually resulted in an abnormal liver function test. My GP asked me if I drank a lot, before it was confirmed I had extensive secondary breast cancer in my liver and bones. He informed me of my secondary diagnosis on a Friday night with no offer of any support or advice, and things did not improve greatly going forward. In an instant, my lovely imperfect life was stopped in its tracks – I seriously considered whether I’d be better off dead.”

“My hospital later told me they don’t like to talk about secondary breast cancer as it frightens people. All medical professionals and patients must be able to recognise the symptoms, so patients can access treatment and support, and their condition can be stabilised for as long as possible. It’s not about frightening people – it’s about education.”

6. Workforce planning

Workforce capacity issues were a recurring and urgent theme of this inquiry. The APPG heard worrying evidence that workforce vacancies coupled with increasing demands on the NHS may impact on speed of diagnosis and therefore survival. Urgent action is required to address these issues so that patients can continue to benefit from high standards of treatment and care wherever they live.

These current and pressing workforce issues are unlikely to dissipate in the future. As the general population ages and people live longer, the numbers of women and men developing breast cancer will increase. With more effective treatments being developed, more people than ever will survive the disease but some will have ongoing needs and people with secondary breast cancer may live an increasing number of years with the disease. At the same time technology continues to develop at pace, offering new opportunities to treat and manage patients and their cancer.

The APPG would like to emphasise the need for long term workforce solutions that can meet these future challenges and opportunities as well as short term urgent action.

*I was one of the first people appointed under the Forrest Report³⁶ to set up screening in Scotland and in the UK and there was a whole army of us fresh-faced youngsters. Surprise, surprise, we were all appointed at the same time and we are all going to retire at the same time. This demographic time bomb has really been sitting there; it has been well documented and could have been predicted for a long time. We are actually now in the midst of it.**

Dr Hilary Dobson, Chair, British Society of Breast Radiology (Oral evidence session 1, March 2017)

In December 2017, Health Education England (HEE) published its long overdue Cancer Workforce Plan.³⁷ The APPG welcomes this plan to address immediate short term issues. For this new plan to be successful it must receive adequate funding and swift political commitment to both support and hold to account the bodies involved. In addition, while this plan addresses short term issues, a strategy is required that looks beyond 2021 to develop a workforce capable of meeting the opportunities and challenges of the future. HEE has indicated that such a strategy will be published in summer 2018. The APPG urges that this plan is not delayed so that work on longer term planning can begin as soon as possible.

6.1 Shortages in the radiography and radiology workforce

Radiographers and radiologists

Radiographers and radiologists play an extremely important role in the diagnosis of breast cancer, performing and interpreting mammograms respectively. This workforce also performs ultrasounds and guided biopsies, and locates impalpable breast lesions to allow surgical excision to be performed. Mammograms are given to those taking part in the breast screening programme and are also likely to be one of a number of tests given to patients who are referred via the urgent pathway.

There is a national shortage of radiologists but this shortage is even higher among breast specialists. Currently 13% of breast radiology consultant posts across the UK are unfilled.³⁸ Compared to the general radiology workforce, breast radiologists are more likely to be female (female to male ratio 2:1 for breast compared to 1:1.8 for general) and more likely to work less than full time.³⁹ This presents particular challenges in terms of recruitment and retention.

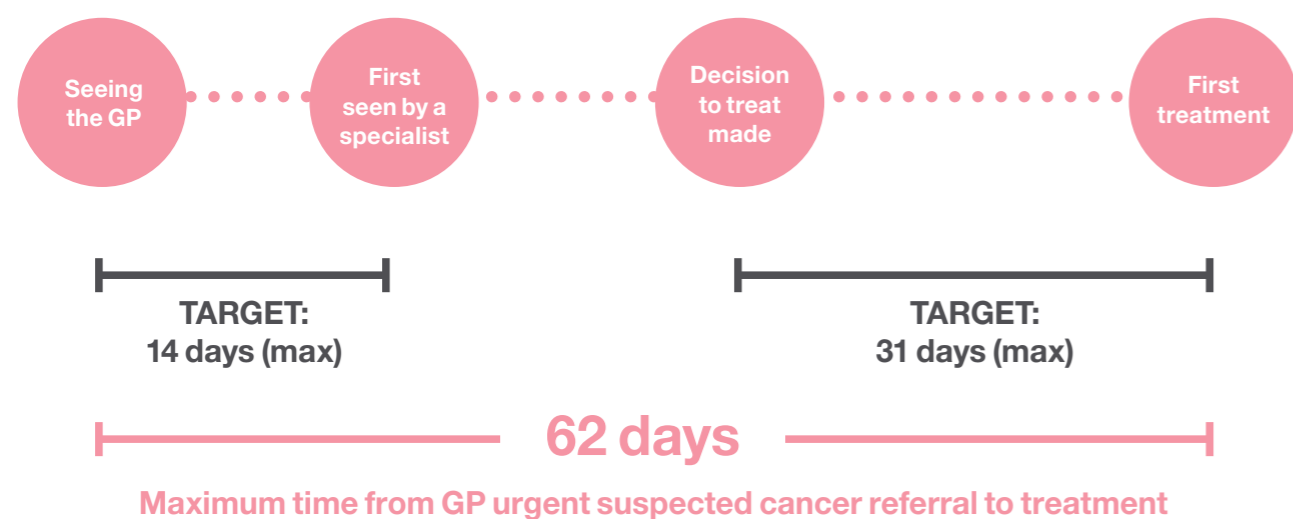
Further pressures will arise as 21% of breast radiologists are due to retire in the next five years, with half the breast radiologist workforce lost in the next 15.³⁹ Vacancy and retirement rates differ across the country and are therefore contributing to geographical variation in waiting times for diagnosis. For example, in the North East of England 33% of breast radiologists are due to retire compared to 20% average across the rest of the country.³⁹

A Public Health England (PHE) survey of the mammography workforce in 2017 found that actual staffing levels were not meeting recommended ratios for mammography across the country; only 18% of mammography units are adequately resourced. Staffing pressures are particularly acute in the North East, Yorkshire and Humber region, the West Midlands and London.⁴⁰

A lack of capacity in the radiology, radiography and mammography workforce has an impact on the speed at which patients are diagnosed. When a woman is concerned she may have breast cancer, speedy diagnosis is essential so that she can either be reassured nothing is amiss or treatment can start quickly. This inquiry welcomes action proposed in the Cancer Workforce Plan to increase training for specialists in diagnostics. In particular the APPG welcomes an increase in the number of reporting radiographers which will help to free up clinical radiologists' time, as well as investment to increase the recruitment and retention of radiologists.

The APPG welcomes the proposal of the establishment of a National Breast Imaging Academy. Providing multidisciplinary training for all healthcare professionals involved in breast imaging, the Academy would include an apprenticeship scheme for radiographers and mammographers, fellowships for breast radiologists and work to raise the profile of a career in breast imaging. A business case has been developed, funded by HEE North West, and the initiative is supported by a range of institutions including PHE, the NHS Breast Screening Programme, The Royal College of Radiologists, The Society of Radiographers, The Association of Breast Clinicians and Greater Manchester Commissioners. The APPG hopes to see the Academy rolled out nationally in the future.

Waiting time targets for breast cancer



The impact of diagnostic workforce shortages on patients

Cancer waiting time targets were introduced in 2000 with the aim of speeding up both diagnosis and the start of treatment. Waiting for a diagnosis or for treatment to start can cause psychological distress for the woman with breast cancer or suspected breast cancer. Diagnostic pathways rely on radiographers, radiologists and pathologists to meet these targets.

It was absolute hell. I have heard other people making the same comment about the long wait for diagnosis and feel that this is something that can really be improved upon.

Andrea, London (Written evidence)

According to the two week wait target, 93% of people with suspected breast cancer or those with breast symptoms where cancer is not initially suspected should be seen by a specialist in two weeks after being referred by a GP. This is being phased out in favour of a new target: by 2020 all patients will wait no longer than 28 days after a GP referral for suspected cancer to hear whether they do or do not have cancer.

The APPG believes that the two week wait target gives an indication of how well the system is operating. In the year 2015/16, 95% of breast cancer patients referred by their GP via the urgent pathway were seen within two weeks.⁴² However, this varied across the country, with the best performers seeing 99% and the worst 71% in the same time frame.⁴²

The proportion of patients being seen by a specialist within two weeks in England had been slipping over the last year, but most recently achievement against the target improved. This improvement has been attributed to increased transformation funding and is welcomed by the APPG as a sound use of such investment.

Evidence suggests there are two key reasons why the two week wait is under strain: shortages in the diagnostic workforce and increasing numbers of people being referred.

Unfortunately as workforce capacity is falling, demand is rising. The number of women in England referred to a specialist with suspected breast cancer increased by more than 50% to 333,195 in the last four years.⁴³ In the same time frame, the number of women referred with symptoms but where breast cancer was not suspected increased from 194,718 to 209,791.⁴³

The reasons for increasing referrals are threefold: (1) more women are developing breast cancer as the general population ages, (2) efforts to raise awareness of the signs and symptoms of breast cancer are taking effect and (3) NICE guidance has lowered the threshold at which a GP can refer a patient to specialists. This means more women are coming forward with suspected cancer which, in the end, is identified as non-cancerous. The APPG heard that when one-stop diagnostic breast clinics were set up three decades ago, 1 in 7 cases seen were found to be cancerous, whereas this is now 1 in 20.⁴⁴

The difficulty for us is that we have to deliver the 31/62 day treatment targets and if a patient then spends a long time in the assessment process, you may have eaten up 50 days of that 62 day target. So we are running to keep still at the moment because the diagnostic pathway and treatment planning process are becoming more complex with extended imaging assessments and breast reconstruction.

Fiona MacNeill, President, UK Association of Breast Surgeons (Oral evidence session 1, March 2017)

Increased pressure on diagnostic capacity is likely to be affecting how long patients wait before they are able to start treatment. The 62 day target acts as a useful indicator of how well services are performing, with 85% of patients expected to start first treatment within 62 days of an urgent GP referral and 90% expected to start first treatment within 62 days of a referral from the NHS screening programme. This target was set to ensure that patients do not face delays to the start of their treatment, which can lead to psychological distress and the possibility that a patient's cancer may become more difficult to treat successfully.

The 62 day waiting time target from urgent GP referral for all cancers has not been met across England for the last three years. Urgent GP referrals for breast cancer have performed better with 95% patients receiving treatment within the 62 day target for 2016/17.⁴⁵

There is variation across the country with the best performing CCGs achieving 100% and the worst 82%.⁴⁶ The percentage of patients treated within this target has been slipping over time, with 97% of patients being treated within the target in Q1

2011/12 compared to 93.5% in Q1 2017/18.⁴⁷ The APPG believes differences in diagnostic workforce capacity contribute to the geographical variation in healthcare providers meeting the 62 day target.

Once you are diagnosed you are desperate to find out the stage and treatment plan, so four weeks was agonising. The whole process is a waiting game. Recall to screening, await biopsy results, wait for surgery, wait for surgery results, wait for treatment.

Jackie, Swindon (Written evidence)

Recommendations

Each Cancer Alliance should publish a clear workforce plan to deliver the Cancer Strategy in England and set out funding requirements to do this. This should be developed in conjunction with relevant HEE offices, Sustainability and Transformation Partnerships (STPs) and other partners. It should consider all areas in breast cancer care but, in particular, diagnostics and nursing.

HEE should publish its upcoming longer term workforce plan proposing sustainable solutions to the workforce crisis at its earliest convenience. This should include:

- The breast screening workforce addressed as a distinct subgroup of cancer diagnostics for analysis and future planning
- Plans to recruit more breast cancer CNSs in line with patient need
- The view of patients consulted on the proposals.

6.2 Shortages in the nursing workforce

The inquiry heard from women with breast cancer about the positive impact a Clinical Nurse Specialist (CNS) can make. CNSs provide support and information to patients, helping them to manage side effects of treatment, give psychological support and information. Managerial, research and specialist expertise and skills are required and evidence supports the cost effectiveness of the role.^{48,49} The Cancer Patient Experience Survey (CPES) shows that patients with a CNS are:

- 55% more likely to be told about the long term side effects of treatment
- 48% more likely to be given written information about their cancer
- more than twice as likely to be given information about financial help or benefits.⁵⁰

However, there is variation in the percentages of breast cancer patients being given the name of a CNS (76% to 100%) and in their ability to contact them easily (58% to 100%).⁵¹ The APPG heard evidence that this variation was partly explained by the differences in the role and job title across the country. With no job title protection or standardised job specification, the nature of the role and those chosen to fill them varies across the country.

Job titles don't necessarily reflect the education level or competence of those practitioners, or what they are being asked to do in those roles. There is at times a poor understanding of the meaning of the title and the role expectation. That can vary from hospital to hospital. Patients are therefore getting a different service even though they are having a specialist nurse.

Nikki Morris, Royal College of Nursing (Oral evidence session 2, September 2017)

CNSs face an increased workload due to the increasing numbers of those with breast cancer, those referred and those in follow up. This means CNSs have less time for each patient than they've had in the past.⁵² In addition, one in three specialist nurses is over the age of 50, presenting a capacity problem for the near future.⁵²

The APPG heard financial constraints have led to shortages in some areas, particularly for services where senior management may not appreciate the benefits that a CNS can bring and perceive these roles as expensive.⁵² The third sector has played an important role in providing funding for CNS positions. This has added to geographical variation because healthcare services with active third sector funders have benefited and areas without have been left behind.

There is evidence to show that particular groups of patients are receiving differing levels of support and care from a CNS. There is a particular variation in the availability of CNSs to women with secondary breast cancer: some have access to a specialist secondary breast cancer CNS, some have access to a more general breast cancer CNS, and others no access to a CNS at all. Three quarters of trusts across the UK do not have enough CNSs for secondary breast cancer.⁵³

The APPG believes all women with breast cancer, including those with secondary, should be able to benefit from the support of a CNS regardless of where they live. Workforce planning is therefore crucial to ensure future patients benefit from the support and care of a CNS.

Recommendation

All patients should have access to a breast CNS. HEE and the Royal College of Nursing should work together to ensure there are enough breast CNSs with the requisite skills to serve local patient populations.

Eleanor, Folkestone

“I was diagnosed with primary breast cancer in 2001 and with secondary breast cancer in February 2008. Initially I didn’t have a secondary clinical nurse specialist but when my care was moved to a different hospital I met one for the first time.”

“She transformed my experience of the disease and treatment, making the whole thing bearable. Whenever possible she has been present at key appointments, staying behind for as long as necessary to ensure I fully understand what is happening. She is always available over the phone and by email, coordinating my care.”

“My clinical nurse specialist “gets me” because she has seen me through so much. The problem is that there is only one of her, and if she’s in with me she can’t be with someone else. Her priority must be that if someone is being given a diagnosis of secondary breast cancer she should be there.”



7. NHS structures

The inquiry received mixed evidence about the impact of the new structures within the NHS, including CCGs and Cancer Alliances, on the planning and commissioning of services. A more localised system brings new opportunities, such as the ability to tailor services to specific population needs. The APPG learned of local innovations to improve the experience and outcomes of local patients like the new approach at The Christie outlined below.

Case study: Secondary breast cancer at The Christie NHS Foundation Trust, Manchester

The Christie Hospital is the largest single site cancer centre in Europe, and employs a dedicated Macmillan Secondary Breast Care Nursing team. In collaboration with the Secondary Service Pledge led by Breast Cancer Now and Breast Cancer Care, the nursing team has introduced nurse-led clinics for all patients with new diagnoses of secondary breast cancer.

Newly diagnosed patients are invited to appointments with a CNS a month after diagnosis, at which time they have had time to consider their diagnosis and treatment plan and may have questions or concerns. The nurse carries out Holistic Needs Assessments, and the patients' needs inform the follow-up pathway they are allocated to.

Through this new system, the nursing team is better able to offer patients the help and information they need in a proactive manner, using the CNS' time more effectively and providing better support for patients.

The APPG heard evidence that the system for commissioning cancer treatments and services is disjointed, with a lack of clear accountability for delivery and outcomes of treatment.

[There is] a lack of joined up thinking we feel is happening within the structures of the NHS and... lack of leadership of these particular difficult issues.

Dr Catherine Harper-Wynne, Consultant Medical Oncologist and Secretary of the UK Breast Cancer Group (Oral evidence session 2, September 2017)

Indeed, the current commissioning system has been designed to allow for local decision making but early indications are that this is failing to address variation across the country in access to treatments and services for breast cancer patients. While the inquiry heard that NHS England holds CCGs to account for their decision making, how this is done in practice seems unclear and, on the basis of the variation observed by this inquiry, unsatisfactory.

Furthermore, there is a lack of transparency within the system. The reporting responsibilities of the new structures appear unclear and there is a lack of understanding as to who is undertaking what role or how to access them. Fears were also expressed about delays in allocation of transformation funding

to Cancer Alliances and whether this could also delay further efforts to tackle geographical variation locally. Concerns were also raised that services located within Vanguard receive more funding than others.

The Alliances are something different. They are leadership and coordination mechanisms at a local level ... [so that] at a more local level we have the coordinating mechanism for cancer care to provide that strategic planning and delivery of cancer services. That is very much intended to be a mechanism for being able to see inequalities and deal with those differences.

Professor Chris Harrison, National Clinical Director for Cancer, NHS England (Oral evidence session 4, November 2017)

The APPG welcomes the publication of the Clinical Advice for Cancer Alliances by the Breast Cancer Clinical Expert Group that sets out best practice in the treatment and care of breast cancer.⁵⁴ It is to be used by both commissioners and providers as a tool to evaluate breast cancer services. The Clinical Expert Group plans to turn this guidance into standards and will begin this work in early 2018. The APPG hopes that this may assist in ensuring consistent standards and outcomes in treatment and care across the country.

7.1 Access to preventative medicines

Preventative medicines such as tamoxifen and bisphosphonates can help to stop the development or spread of breast cancer. These medicines have contributed incremental steps towards the improvement of survival rates for breast cancer that have led to generous gains in overall survival rates over the last 30 years.⁵⁵ However, the current NHS commissioning structures are leading to variation across England in the availability of preventative medicines.

One reason for variable access to these life-saving and potentially cost-saving drugs may be that commissioners do not reap the financial benefit of providing the drugs. For example, CCGs may invest in offering a drug to patients who would benefit from it, but NHS England might save money from the resulting fewer cases of breast cancer. There also appears to be a lack of awareness among commissioners about what they should be funding and of the clinical and financial benefits of preventative medicines. The APPG heard that there is a lack of leadership in ensuring consistency among commissioners and in tackling some of the system issues that the inconsistent use of medicines highlights. Many patients are aware of what drugs are available, and being unable to access them adds to feelings of anxiety at an already difficult time.

Bisphosphonates improve the outcomes of postmenopausal women with breast cancer, reducing the risk of the disease spreading to the bone within ten years by nearly a third (28%) and reduce the risk of death from breast cancer by nearly a fifth (18%).⁵⁶ Bisphosphonates are available cheaply as they have been repurposed from their original use of treating osteoporosis.

New guidance from the National Institute for Health and Care Excellence (NICE) for early and locally advanced breast cancer is currently under consultation and due to be published in July 2018. The APPG welcomes this updated guidance, which recommends that clinicians offer bisphosphonates to postmenopausal women at high risk of breast cancer recurrence. However, the APPG would like the guidance to ensure that bisphosphonates are offered to all postmenopausal women who could benefit and, while we know that many CCGs will look to NICE guidance to drive commissioning, this is only part of the picture.

Funding is a further barrier to the widespread use of bisphosphonates. A survey of oncologists showed only about a half of hospitals are providing bisphosphonates to breast cancer patients.⁵⁷

A Freedom of Information request sent to all CCGs by Breast Cancer Now in 2017 found the majority (117 out of 208) were not funding bisphosphonates and this was primarily due to confusion about responsibility for funding.⁵⁸ CCG funding of bisphosphonates appears to vary regionally, for example in Yorkshire and Humber almost two thirds of the CCGs are providing funding for bisphosphonates compared to none in the North East, which may be leading to unacceptable regional differences in treatment provided to

patients.⁵⁸ Each woman's opportunity to benefit from the increased survival these drugs provide is dependent on the individual funding decision of her CCG or trust.

I've read that bisphosphonates could stop cancer spreading to the bone, but they are not offered in our area. I wanted to ask if I could have them, maybe even pay for them if I have to.

Gerry, Worcestershire (Primary breast cancer focus group)

Those giving evidence to this inquiry stressed that NHS England should act to issue clear guidance to CCGs on the funding of bisphosphonates.

The inquiry also heard evidence about the geographical variation in the use of hormonal therapies such as tamoxifen and faslodex, which block the hormone oestrogen that some forms of breast cancer rely on to grow. This can help to prevent the return or spread of breast cancer after treatment and increase the time women with secondary breast cancer are able to live without their condition progressing. Tamoxifen is usually given to pre-menopausal women for up to ten years after treatment in order to prevent recurrence. Faslodex is given when other hormonal treatments have been found to no longer be controlling the cancer.

Tamoxifen can also be given as a preventative treatment to women who have a high risk of developing breast cancer. These women usually have a strong history of breast cancer in their family and account for about 15% of women who develop the disease. Another 5% have inherited a gene which makes developing breast cancer more likely.⁵⁹ NICE has recommended that women

at high or moderate risk are offered tamoxifen or other chemopreventive drugs, anastrozole or raloxifene, depending on their medical history.⁵⁹

There is a lack of data about the use of these treatments across the UK. Cancer Research UK presented evidence that nearly half of GPs were unaware that tamoxifen could be used to prevent breast cancer and only 77% of GPs were willing to prescribe it.⁶⁰ The inquiry heard that funding of faslodex was sporadic across the country: "the North East of England gets faslodex and the South East does not, and there are various parts of the West that do and do not get it."⁶¹

The inquiry was told that this was because this treatment was originally approved for use by the Cancer Drugs Fund but was then removed and has never gained NICE approval. There is also a big difference in spend on primary care prescribing for breast cancer between CCGs, with the highest spending CCG spending four times as much as the lowest.⁶² It is clear that local commissioning arrangements should be improved to significantly increase access to preventative medicines across the country.

7.2 Side effects of treatments

The treatment of breast cancer can lead to short and long term effects for patients, from physical and body image changes to lymphedema. When patients are made aware of these possible consequences they may be able to proactively reduce their risk of side effects and make choices about their care and treatment that are right for them. One possible consequence is temporary or permanent infertility. In some cases there are options available that can protect fertility or minimize potential damage. Alternatively,

measures may be taken to preserve fertility such as the freezing of eggs or embryos in advance of treatment.

However, the inquiry found that there was variation as to whether patients were told about the impact of treatment on their fertility. Some patients appear to be left unaware of this impact or that action can be taken to preserve fertility and options to preserve fertility may not be offered routinely across the country. Whether or not a patient has to pay for such treatment may also depend on where they live.⁶³ Not having advice or treatment to preserve a woman's fertility can have the long term impact of affecting a woman's choices in life, long after the cancer has been treated.

I didn't get offered fertility treatment at all but I would have definitely taken them up on the offer.

Kimberley, London (Primary breast cancer focus group)

7.3 Psychosocial support services

People with breast cancer may need support to understand their diagnosis and its impact on their life, advice on how to manage short term and long term side effects, along with help to cope with the emotional and psychological impact of the disease. Providing the right support can help to deliver a positive experience of treatment and care.

Evidence suggests that access to such support varies across the country. Innovative services and pathways are being developed in some parts of the country but in many cases these innovations are not being replicated elsewhere.

Poorer performing services should look to best performers to consider how they might improve and commissioners should use performance data to hold services to account.

The end of active treatment can be difficult for patients, who may need help to manage emotional, financial and physical consequences of their condition. Almost a third (30%) of breast cancer recurrences could be prevented with the right lifestyle changes.⁶⁴ Good post-treatment support includes helping patients to make choices which could reduce the risk of recurrence.

Charities have developed courses for patients who are finishing treatment to give them information and advice, enabling them to manage their condition and make healthy lifestyle choices. However, Breast Cancer Care told the inquiry that one reason for the patchy provision of their 'Moving Forward' course across England was that some nursing teams do not have the resources to take part. Some NHS services offer similar support, such as the Recovery Packages in Greater Manchester, described in more detail in the case study below.

Psychological and emotional support have clear benefits for breast cancer patients. For example, Cognitive Behavioural Therapy has been shown to help to reduce the impact of common side effects associated with hormone treatments and chemotherapy. Many participants in the focus groups also lauded the benefits that support groups provide, some citing it as the factor which made the most positive impact on their experience of cancer.

That support network completely changed things for me, and by happy coincidence a new support group was setting up in Sutton for women with secondary breast cancer and I was able to transfer straight to that in the end. I would say that for me, the thing that has been the life-changer, apart from the fact that the drugs are keeping me alive and I'm very grateful for that, but it's one thing existing and it's another living, and I've been able to live because of the support that I get from my peers.

Eleanor, Kent (Secondary breast cancer focus group)

The APPG understands there is variation in whether patients are told about emotional and psychological support services, including peer support groups and counselling. Only 34% of secondary breast cancer patients were made aware of counselling across the UK, ranging from 48% in the North West to 29% in the West Midlands and Yorkshire and Humber.³⁴ Similarly, only 36% were made aware of opportunities to speak to others with secondary breast cancer, ranging from 47% in the South West to 17% in the East Midlands.³³

Case study: Implementing the Recovery Package in Greater Manchester²⁴

NHS Greater Manchester is engaging in activity to ensure that Recovery Packages are available to all patients finishing treatment by 2019. The Recovery Package is a combination of different interventions, which when delivered together, can greatly improve the outcomes and coordination of cancer care, including better and earlier identification of consequences of treatment. Recovery packages include:

- Holistic Needs Assessment and care planning, at diagnosis and at other significant points in the patient pathway.
- Treatment summaries, after significant phases of treatment.
- Cancer care reviews, in primary care.
- Health and wellbeing events, providing information and support.

Crucially, NHS Greater Manchester is ensuring that recovery packages will be included in commissioning specifications to ensure speedy implementation.

The national Cancer Patient Experience Survey (CPES), a valuable survey that provides a snapshot of the experiences of people with cancer across England, shows that people with primary breast cancer generally have a good experience of cancer care.

However, the inquiry received information about the varied experience of care of secondary breast cancer patients. Two thirds (64%) of secondary

breast cancer patients in the UK rate the quality of their care as excellent or very good, but this varied from 45% in the East Midlands to nearly three quarters (73%) in the East of England.³⁴ The kinds of differences patients are experiencing include whether they felt that healthcare professionals listened to concerns they had about secondary breast cancer, which varied from 100% in the North East of England to just 47% in the East Midlands.³³

Ultimately we have uncovered huge variations in care for secondary breast cancer across the whole pathway, which are simply dependent on where a patient lives.

Breast Cancer Care (Written evidence)

From the evidence submitted to this inquiry, it is clear that women with breast cancer highly value a holistic approach to their treatment and care. Access to support groups, good information, help to manage their fertility, and courses to ease the transition from active treatment back to a normal life are valued by patients. Women with secondary cancer also need to have access to specialised support services.

It is heartening that some commissioners are taking steps to ensure these services are provided. Commissioners and Cancer Alliances have a role to play in ensuring that pathways for breast cancer encompass these vital forms of support. It is important that every woman with breast cancer in England is offered access to psychosocial services regardless of where they live.

7.4 Reconstructive surgery

The inquiry was informed that there is worrying variation across the country in the availability of certain types of reconstructive surgery, as well as whether patients are offered reconstruction at the same time as their tumour-removal surgery.⁶⁵

There is widespread variation in the availability of reconstructive surgery as a result of decisions made by CCGs. These decisions appear to be made for financial reasons rather than on clinical grounds, and result in a postcode lottery for patients and a tendency for patients not to be offered the gold standard of reconstruction, with reversion to procedures that give poorer results, or even no reconstruction.

British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS) (Written evidence)

There is currently a lack of evidence to show how widespread this practise is, but these reports are deeply concerning.

Current guidance from NICE states that clinicians should ‘discuss immediate breast reconstruction with all patients being advised to have a mastectomy, and offer it except in cases of significant comorbidity or (the need for) adjuvant therapy may preclude this option. All appropriate breast reconstruction options should be offered and discussed with patients, irrespective of whether they are all available locally’.⁶⁶ New guidance is currently under consultation and due to be published in July 2018. The APPG welcomes this updated guidance, under which clinicians should discuss the benefits and risks of the timing of breast reconstruction with patients, and what different surgery options involve.⁶⁷

Lauren, London

“When I was diagnosed with breast cancer at age 31, I thought they were joking. A grade 3 cancerous tumour had set up residence in my breast without my consent and sent my world into a tail spin. The physical impact of cancer treatment was terrifying, but I was in no way prepared for the emotional upheaval I was about to face. As somebody who had always been life and soul of the party, I began to feel completely isolated and lonely.”

“Luckily I had the option of counselling at my hospital, which provided no end of support when I slipped into distress and anxiety. I also put the skills I acquired from CBT sessions I’d previously had to good use, which is something I think should be offered to patients at the point of diagnosis. I hands down would not have handled my cancer treatment without it.”

“The recovery process is long and complicated, yet access to psychological care tends to be extremely limited post-treatment; it feels as though all the support just drops off a cliff edge. Some days you may be feeling a little lost, whereas others you’re crippled with anxiety and feeling low. There is no service to support you in these moments; it’s not beneficial booking onto a course of counselling for 3 months’ time when what you need is some support to get you through today.”

Recommendations

Cancer Alliances should work with providers and patient representatives to develop breast cancer services and care that meet the needs of patients throughout their breast cancer journey. Those involved in developing STPs, CCGs, Local Authorities, PHE, and NHS England Specialised Commissioning should all be included in development of these plans and services. All patients should have access to:

- Medicines they can benefit from at a price the NHS can afford
- Advice and services to help them manage the short and longer term side effects of treatment including lymphedema and fertility treatment
- Support services, including information, psychological support
- Reconstructive surgery with the full range of options offered and discussed.

8. Conclusion

New NHS structures such as Cancer Alliances present opportunities and challenges that could drive innovative practice and improve breast cancer outcomes across England, while tackling variation. However the report of this inquiry finds that there is still geographical variation in screening uptake, access to medicines and essential health services to support fertility, recovery and mental health which may be contributing to differences in outcomes.

New commissioning arrangements and a lack of accountability may be exacerbating these differences. The impact of variation across the country is that no woman with breast cancer can be sure that they are receiving treatment and care that is either most suited to them or of the highest standard. This is unacceptable.

Current workforce pressures pose a worrying threat to the good progress made in breast cancer treatment and outcomes seen over the past decades. Different geographical areas will face their own workforce issues and local planning coupled with national action is required to ensure the workforce is not only fit for today but also for tomorrow. This action must be accompanied by funding and investment.

The data gap, particularly in secondary breast cancer, means that inequalities could deepen if steps are not taken to fix them. That there is now more data available provides the opportunity for Cancer Alliances, providers and commissioners to ensure that services are tailored to meet the needs of their local populations.

Indeed, to solve the inequality gap, this inquiry finds that a sophisticated and tailored approach, which takes into account the variation that can exist within an area and does not translate into wholesale solutions, is essential. Not only will this approach be more efficient and cost-effective for the NHS, it is the approach most likely to help achieve the ambition of delivering world-class cancer outcomes and better meet the needs of women with breast cancer.

9. Appendices

List of respondents to the call for written evidence

- British Association of Plastic, Reconstructive and Aesthetic Surgeons
- Breast Cancer Care
- Breast Cancer Now
- Cancer Research UK
- Dr Mary Wilson
- NHS Greater Manchester
- Lancashire & South Cumbria Cancer Alliance
- Leicester Breast Unit
- Liverpool City Council
- Macmillan Cancer Support
- Pink Ribbon
- Royal College of Nursing
- Simon Holt, Consultant Surgical Oncologist and Head of Department at The Prince Philip Hospital Breast Care Unit
- Siobhan Laws, Consultant Surgeon, NHS Hampshire Hospitals Foundation Trust
- UK Breast Cancer Group

The APPG also received written evidence from nine people with experience of breast cancer. The Group would like to thank everybody who submitted evidence.

Focus groups

34 people attended six focus groups, which were held in Birmingham, London and Manchester. In each city one focus group involved people who had had a primary diagnosis of breast cancer and another involved people with a diagnosis of secondary breast cancer. The APPG extends its grateful thanks to everyone who participated.

List of oral sessions held and witnesses

Oral Session 1, 22 March 2017

Witnesses:

- Jacquie Jenkins, National Programme Manager, Breast Screening, Public Health England
- Dr Hilary Dobson, Chair, British Society of Breast Radiology (BSBR)
- Dr Nisha Sharma, Secretary, BSBR
- Fiona MacNeill, President, UK Association of Breast Surgeons
- Danni Manzi, Head of Policy and Campaigns at Breast Cancer Care

Oral Session 2, 12 September 2017

Witnesses:

- Dr Catherine Harper-Wynne, Consultant Medical Oncologist, Kent Oncology Centre, UK Breast Cancer Group, NHS England Breast Cancer Expert Group
- Emlyn Samuel, Cancer Research UK
- Nikki Morris, Royal College of Nursing

Oral Session 3, 17 October 2017

Witnesses:

- Dr Virginia Wolstenholme, UCH London
- Adrian Hackney, Director of Commissioning, Greater Manchester Cancer Services
- Dr Rory Harvey, East of England Cancer Alliance

Oral session 4, 29 November 2017

Witnesses:

- Professor Chris Harrison, NHS England, National Clinical Director for Cancer
- Professor Chris Holcombe, Deputy Chair, Breast Clinical Expert Group

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