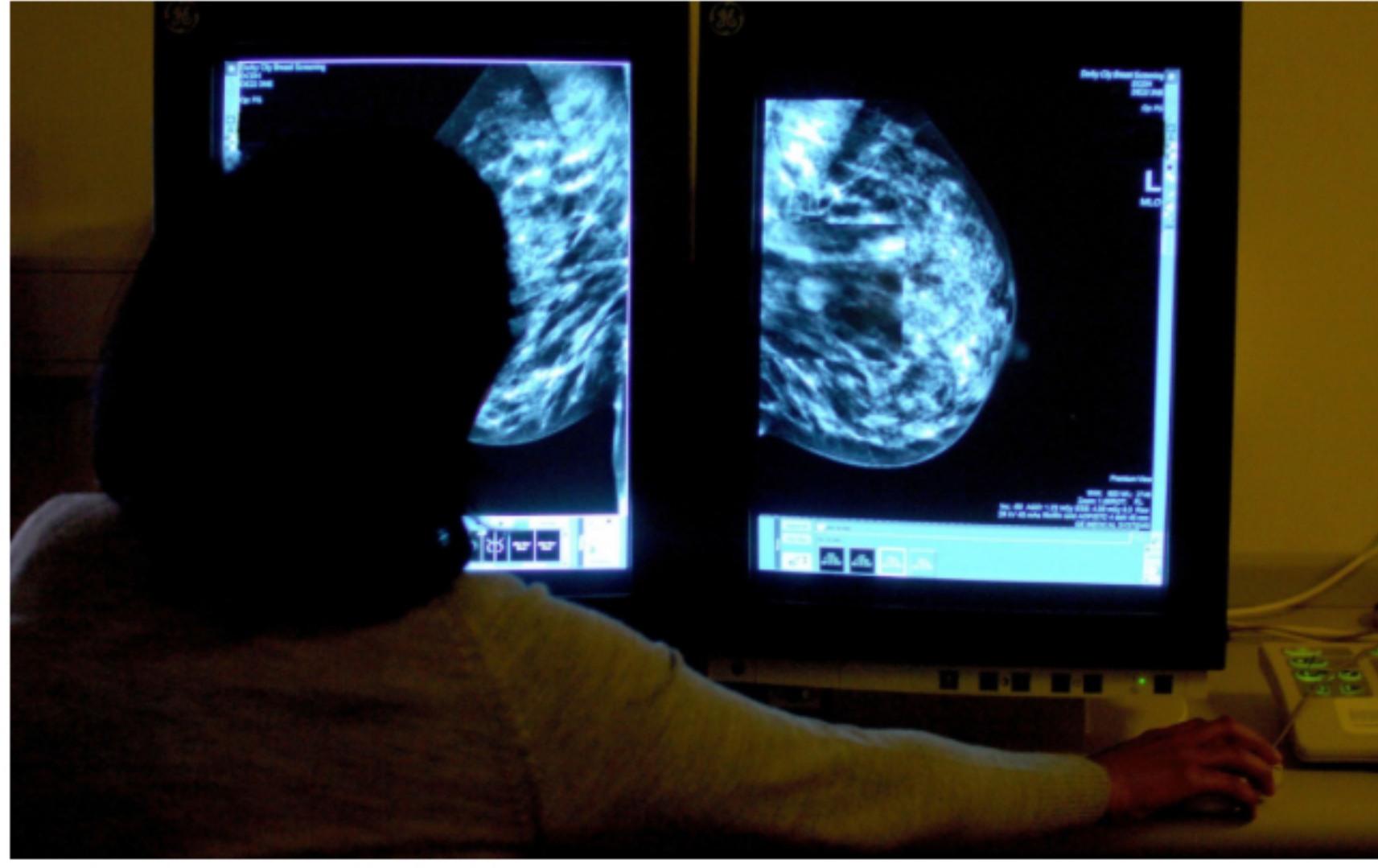


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It is time to end the post-code lottery for secondary cancer care



A consultant studying a mammogram CREDIT: PA

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By **Judith Potts**

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Almost four years ago, in June 2014, I attended the inaugural showing of ‘I am not the cancer’. This art installation – created by British artists Tim Wainwright and John Wynne – used the disembodied voices of three women whose breast cancer had metastasised. The three talked openly and starkly about the realities of living with secondary breast cancer, as the viewer watched only the women’s unspeaking faces in close up. As people emerged from the darkened room, some people – who had perhaps not entirely appreciated that ‘secondary’ actually meant incurable – were shocked into anger at the lack of awareness, care and treatment. I remember talking to Clinical Nurse Specialist (CNS) Gill Donovan from the Velindre Cancer Centre in Cardiff, who was one of too few CNS’s giving care to those with advanced breast cancer.

I thought again of Gill when I read the report from the All Party Parliamentary Group on Breast Cancer into geographical inequalities – i.e. the postcode lottery – in the diagnosis, treatment and care of people with breast cancer. Part of the report reads: ‘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 CNS.’

The report also highlighted that some multidisciplinary teams are not routinely discussing their secondary breast cancer patients; there is patchy provision of information for patients; patients’ psychosocial needs are not being met and there is a lack of prompt and timely access to specialist palliative care services.

It appears that four years later we are still in the same situation.

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Even worse – despite the fact that collection of data on people with secondary breast cancer has been mandatory since 2012 in England – the report goes on to say ‘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. 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 data at all.’

This is shocking. In October last year [I wrote about exactly this problem](#) and I would reiterate now my question. Surely it is not beyond the NHS Trusts to comply with this very necessary instruction? Considering just how many managers are employed by the NHS Trusts – more than there are beds in the NHS – I find it hard to believe that one from each Trust could not be seconded to provide this information. How many other mandatory instructions are being ignored?



Medical technician positioning young woman for mammogram CREDIT: GETTY

Many women who gave evidence to the Inquiry’s focus groups reported approaching their GPs several times with symptoms such as backache and tiredness before the GP referred them on to the breast clinic for a secondary diagnosis. Regions varied enormously. In Yorkshire and Humber, 29% of people were treated for another condition first, while in the South West it was only 11%.

Following the publication of the report, [Breast Cancer Now](#) is campaigning to end this completely unacceptable postcode lottery by encouraging you to email your MP to ask him or her to write to your local Cancer Alliance. Please complete the form on Breast Cancer Now’s [website](#).

You may be wondering what Cancer Alliances do. According to their [website](#) they are ‘a way to bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography. Together with the [National Cancer Vanguard](#), they will lead the local delivery of the Independent Cancer Taskforce’s ambitions for improving services, care and outcomes for everyone with cancer.’

Yet, it has taken Breast Cancer Now – a charity – to point out the six ways in which the Cancer Alliances need to step up to the job. These include holding local providers to account if data is not recorded; working with GPs to raise awareness of the signs and symptoms of secondary breast cancer; conducting gap analysis to ensure adverse trends are investigated and addressed; developing a local workforce plan which considers all staff along the pathway in breast cancer care; developing a model pathway to ensure all patients have fair access to medicines, fertility services, breast reconstruction services – without time restrictions – and appropriate psychological support services; and tailoring prevention, awareness and screening initiatives to their local populations.

Why is it always down to a charity to take the bull by the horns? Considering the Cancer Alliances have been in position – led by Cally Palmer, NHS England’s national cancer director – for over two years, what exactly have they been addressing? Clearly, not the injustices in diagnosis, treatment and care of patients with breast cancer in England.