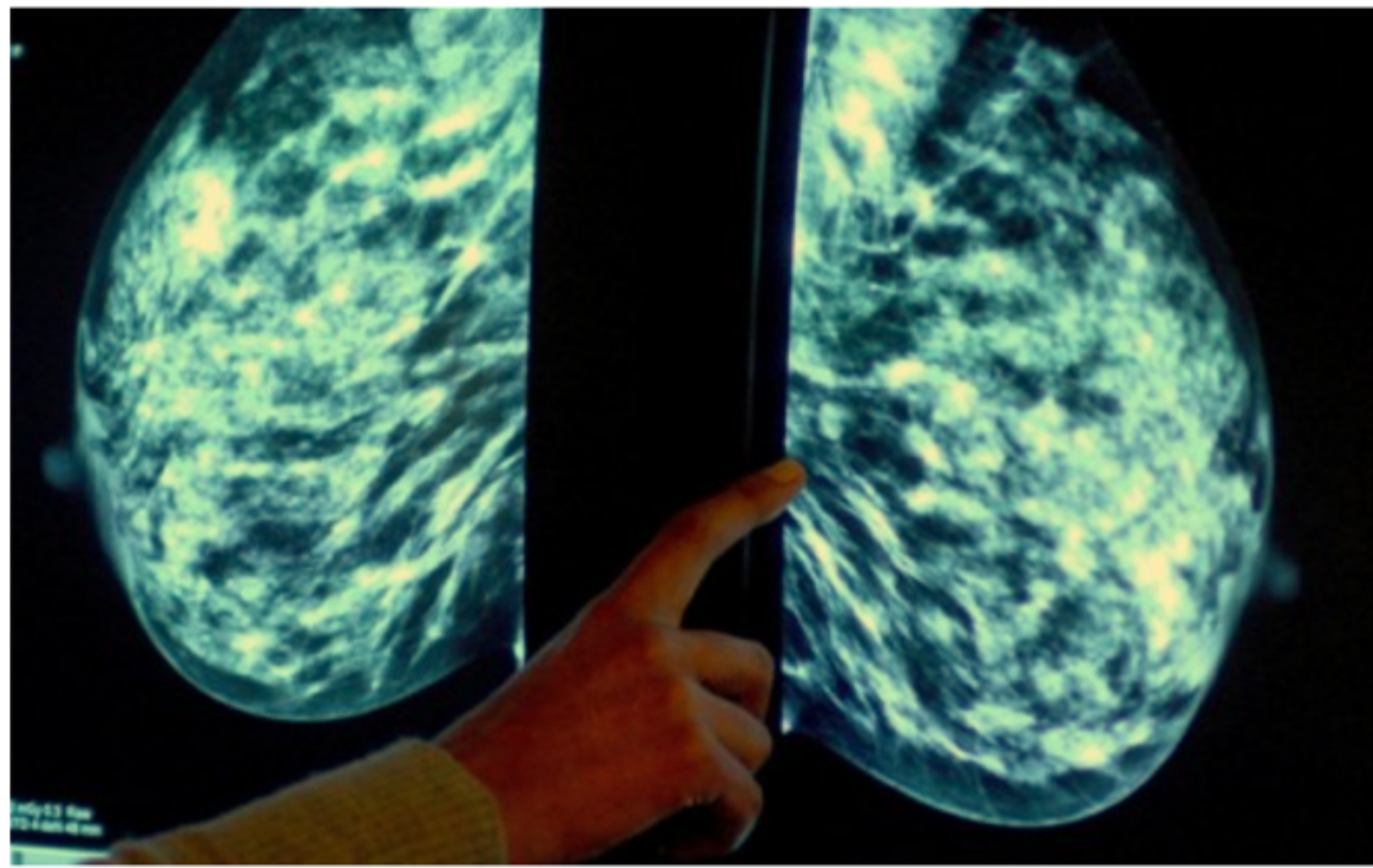


'I am not the cancer' illustrates the psycho-social impact of advanced breast cancer



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Last year, the photographer Tim Wainwright and sound artist John Wynne – experienced in working within the medical world – were commissioned by Novartis Oncology to find a way of illustrating the emotional, social, psychological – and sometimes financial – implications of a secondary breast cancer diagnosis. This coincided with the results of Novartis' "Here and Now" patient survey – distributed by Breast Cancer Care.

"I am not the Cancer" is an exploration of three women, all of whom are living with the disease.

I entered the huge, darkened room and saw six armchairs set opposite six screens. On each screen was, either, a woman's face or the back of her head. Sitting in the first armchair, I realised that the "head" was not doing the talking – the sound of the woman's voice came from a speaker above the armchair. As each woman described how she coped with the diagnosis, with trying to lead a normal life and with the knowledge that, medically, no more could be done, I was struck by the matter-of-fact quality of each woman's voice – very little emotion came through and this made for an even greater impact on the audience.

The three faces barely smiled but, as you watched and listened, it was impossible to draw your eyes from the screen – even when you were looking at the back of the head. As each script came to its end, you moved to the next armchair until you had heard each woman speaking twice, once while watching her face and once with purely the back of her head on view.

Three points resonated with me. One woman explained that it would seem she had fallen through some organisational net and no follow-up appointments were ever made. A second woman spoke of not wanting to know the type of her breast cancer, because "I probably wouldn't understand it all anyway" (at this point, I wanted to intervene and reassure her that of course she would understand if sometime had taken the trouble to explain it to her.)

Returning to the first woman, I heard how she had tried to join a breast cancer internet forum, only to be thwarted by the statement on the forum which said: "If you have secondary breast cancer you will be asked to leave this site".

Secondary breast cancer/metastatic breast cancer/advanced breast cancer (ABC) are all terms used to describe the disease when it has spread to other parts of the body. An estimated 30,000 women are affected each year and their life expectancy is two to four years – compared to ten, for early detected breast cancer. Far too many with ABC feel isolated – clearly not helped by internet forums.

Listening to the three women, representing those 30,000 – all of whom will be undergoing similar experiences – the words of Breast Cancer Campaign's CEO, Baroness Delyth Morgan, stayed in my mind. Speaking to us before we ventured into the installation, Delyth said "There is an undercurrent in the policy world at the moment, that we can't talk about breast cancer – or even cancer – anymore. That we should think of all conditions together. I disagree". She then reminded us that: "No longer is there a dedicated cancer team in the Department of Health and the change from Cancer Networks to Strategic Cancer Networks has reduced the resources for cancer support locally. For common cancers, commissioning is now split between local Clinical Commissioning Groups and NHS England."

Last year, Breast Cancer Campaign called on the Government to make it easier for charities to benefit from Gift Aid and to continue with the Cancer Research Support Fund – the organisation which meets the indirect costs of research (eg heating and lighting etc), so that all the money raised by the charities can fund the direct costs. The call was acknowledged in the Chancellor's spending round speech for 2015-16. The Higher Education Funding Council for England, who distributes the money, has maintained the CRSP's award of £198 million for 2014-15.

Delyth also reminded us that the UK survival rates for ABC lag behind the rest of Europe. Surely it is not good enough for our Government's target to be simply to match the average European rate? We must strive to hit it and never lose sight of what is needed by those with ABC.

The Nice Breast Cancer Quality Standard states that all women with ABC should have access to a Clinical Nurse Specialist. Sadly, there are no figures to show how many women with ABC actually receive access to such a Nurse – but, if no one has thought about it before, listening to the three women on "I am not the Cancer", will illustrate exactly why we need to retain The Breast Network Site Specific Groups, which work at a local level to improve the treatment and support that people with breast cancer receive.

Please join Breast Cancer Campaign's "Spread the Word" campaign. Log onto its website, where you can send an email to your local MP.

If we set in place a template for understanding the psychosocial impact of ABC, could it not be used for those with other advanced cancers?