



# Online discussions of Oncotype DX testing in early-stage breast cancer

**Emily Ross, Julia Swallow, Anne Kerr and Sarah Cunningham-Burley**

The University of Edinburgh and the University of Leeds

©Gatawa/Getty Images

## Who we are and what we did

We are university researchers working on a project exploring experiences of novel research and treatments within cancer care. With assistance from two cancer charities, we undertook a small study of women's experiences of a gene expression profiling test (Oncotype DX). These tests are sometimes used to guide chemotherapy decision-making in early stage breast cancer. Following surgery, Oncotype DX may be offered to some patients with early-stage cancer, when this has not spread to the lymph nodes. The test is used to predict the benefit of adjuvant chemotherapy in protecting against breast cancer recurrence.

We looked at online forums where women discussed their experiences of Oncotype DX. Many women share their experiences in this way and also seek advice and opinion from others, especially for quite a novel test such as this one.

Two cancer charities kindly granted us permission to use online forum data in our research. We analysed a total of 132 discussion threads from these two charities, drawn from a total of 7 online forums. We made sure to protect the confidentiality of forum users by changing names and not using other personal information.

## What we found

Our research found that women mostly wrote in positive ways about Oncotype DX. Many saw the test as providing "specific" and "personalised" information about their cancer and treatment recommendations. Some contrasted this with more commonly used methods of predicting chemotherapy benefit, which were described as more "general".

Many forum users welcomed the numerical estimate of chemotherapy benefit provided by Oncotype DX testing. When they received a 'low risk' score, which indicated a small benefit of chemotherapy, many represented the test as determining their decision not to

proceed to chemotherapy. Equally, for high scores, some reflected that they would then “have to” undergo chemotherapy, even though they did not want to.

However, for those receiving an ‘intermediate’ score, decisions about chemotherapy could be difficult. Some called this score the “grey zone”. In these cases, forum users appealed to other women for opinions about whether to have chemotherapy, and also reported asking their doctors for advice about what they would do e.g. by imagining what they would advise if it were a family member in this position. In lots of the forum posts we analysed, the decision to proceed or not to chemotherapy was discussed as very difficult. This was because though women wanted to do “all they could” to avoid their cancer recurring in the future, they also feared chemotherapy. Many had difficult memories of family members going through the treatment, and some also discussed not wanting to become sick, which could interrupt working and family life.

Though many were positive about the availability of Oncotype DX to help chemotherapy decision-making, some users also discussed uncertainty about whether their cancer would return, something which could not be resolved by clinical care or medical tests. Women said things like, “there are no crystal balls”, suggesting that a degree of uncertainty was always present.

Oncotype DX did not always lessen uncertainty and anxiety for some of the women writing on these forums. For example, some shared stories of other women who had experienced chemotherapy but gone on to have a recurrence later in life. In some cases, in addition to Oncotype DX scores, women encouraged other users to think about a possible recurrence and how they would feel in the future if they had said no to chemotherapy.

We concluded that though Oncotype DX was viewed very positively by many users, it did not always easily resolve the decisions faced by women with early-stage cancer about whether to proceed to adjuvant chemotherapy. These decisions were very difficult and emotional. They were influenced by family members’ experiences of cancer and chemotherapy, the suffering associated with cancer treatment but also by a sense of needing to ‘fight’ cancer. For a minority of users, notably those with an ‘intermediate’ score, Oncotype DX could present even more difficulties for decision-making.

## Why is the study important?

The results of this study have implications for how clinicians discuss predictive tests and techniques with patients. These results are also important for patients and their families, so that they remain informed about the benefits of novel tests, but also their limitations.



@CancerandSoc21C

<http://www.cancerandsociety.ac.uk/>



This work was supported  
by the Wellcome Trust  
(grant number  
104831/Z/14/Z).



THE UNIVERSITY  
of EDINBURGH



UNIVERSITY OF LEEDS