



What is the Patient Trials Advocate service?

Make 2nds Count has launched a pilot service, led by a Patient Trials Advocate nurse, to enable people with secondary breast cancer to understand and potentially access clinical trials. The pilot service is initially open to patients diagnosed with secondary breast cancer who live in the Lothians, Borders, Livingston, Fife and Dumfries and Galloway. It will run for 3 months to assess patient demand and interest and ensure all enquiries and referrals are managed effectively. Assuming it's successful, Make 2nds Count will look to roll it out to additional areas by the end of 2021.

Why is Make 2nds Count providing this new service?

Evidence shows that being given the opportunity to take part in research benefits patients significantly and their experience of being involved is overwhelmingly positive. However, for various reasons many patients choose not to participate in a trial or aren't aware of their trial options. For patients with incurable secondary breast cancer, trials can potentially give them access to an alternative therapy alongside their standard of care and access to innovative new treatments.

How does the service work?

The Patient Trials Advocate service is an advisory, information and support service and does not replace clinical guidance and the expertise of a patient's clinical team.

The pilot service is led by our patient advocate, Vivienne Wilson, a Senior Research Nurse based at the Western General Hospital in Edinburgh. She has worked in a number of cancer research nurse roles for over 17 years and has a wealth of experience and knowledge of clinical trials.

Vivienne's aim is to help find suitable clinical trials for patients based on eligibility criteria and to support them in discussing trials with their clinician. She will look at trials locally but also UK wide, however ultimately, it is a clinician who will make the referral for a patient.

Whilst every effort is made to ensure that the most up to date information is provided, we can be limited by databases that are not constantly being updated.

What can the Patient Trials Advocate not help with?

The patient advocate is not able to provide guidance or expertise on a patient's current treatment for secondary breast cancer.

It is also possible that after conducting a search, there may be no clinical trials that the patient is eligible for in the UK. Clinical trials have eligibility criteria that can be complex and may exclude participation. For example, some trials for metastatic breast cancer will exclude patients with brain

mets, others might exclude patients if they have already been on a similar class or type of drug. There is no guarantee that the Patient Trial Advocate will be able to find a trial for every patient.

Who is the service open to?

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What if I don't live within the pilot area and want to find out more?

We have a dedicated section on our website on [trials](#) which explains how they work and provides information on how to find and access them. However the best route is to talk to your oncologist or clinician if you are interested in trials and they should be able to help.

What if I am a family member interested in finding our more?

We are happy for you to get in touch but before we can start researching trials we will need to speak to a patient directly and have their authority to proceed.

What will it mean if I'm not eligible for a trial?

The current clinical trials may have eligibility criteria that exclude participation by a patient. However new treatment and trials for secondary breast cancer are constantly developing so other options may become available in the future.

Do you have access to patient medical records?

Our Patient Trials Advocate nurse does not have access to medical records and plans to understand past treatments and trial requirements through a phone call or email conversation with the patient. Based on the information that the patient provides, our advocate will then conduct a search to see if there are any suitable UK trials

Will my data be shared?

Make 2nds Count will store the basic data collected in the referral form securely and following GDPR guidelines. We will share it with the relevant Patient Trials Advocate where it will also be stored on an NHS database to allow them to assist patients in the search for a clinical trial.

In accordance with the EU and UK's General Data Protection Regulation, all information will be stored for a maximum of 12 months then deleted.

Make 2nds Count will not have access to any patients medical data.

For further information please see our privacy policy
<https://www.make2ndscount.co.uk/privacy-policy/>