



What is the Patient Trials Advocate (PTA) service?

The PTA service is led by a number of nurses and was launched in early 2021 by Make 2nds Count as a pilot service for men and women with secondary breast cancer. The PTA service supports patients by enabling them to better understand how clinical trials work and assists patients in finding potentially suitable clinical trials that may be appropriate to consider as a treatment option. Any clinical trials that are found using the various UK trials databases are sent directly to the patient, allowing them to decide if they wish to share these trials with their clinical team.

Following extremely positive feedback from users the PTA service is now a fully funded, permanent service and is available to patients across the UK.

Why is Make 2nds Count providing this new service?

Evidence shows that patients significantly benefit from the opportunity to take part in research 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, either alongside or instead of their standard of care giving them access to innovative new treatments.

How does the service work?

The PTA service is an advisory, informative and supportive service but does not offer clinical guidance or replace the expertise of a patient's clinical team. The service aims to help find suitable clinical trials for patients based on eligibility criteria and to support them in discussing trials with their clinician. Our PTA nurses can search for trials locally and across the UK. If suitable trial(s) are identified, the patients' clinician should be the designated individual to contact the coordinating trial center for further support and information.

Whilst every effort is made to ensure that the most up to date information is provided, we can be limited by whether databases are being regularly updated by the companies and universities running the trials.

What can the PTA service not help with?

The PTA service is not able to provide clinical 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 secondary breast cancer will exclude patients with brain metastasis, others might exclude patients if they have already been on a similar class or type of drug. There is no guarantee that the PTA service will be able to find a trial for every patient.

Who is the service open to?

From 2022 the service has been open to anyone with secondary breast cancer who lives in the UK.

Can I use the service if I only have questions and I'm unsure if a trial is something I wish to consider?

Yes, the PTA service can be used to answer questions in relation to clinical trials as well as having a trial search completed, if the patient would like one conducted. The service can be accessed as often as is helpful.

We have a dedicated [informational section on our website on clinical trials](#) and publish a [UK registry of available trials](#). We also have [an information booklet](#) which explains how to find and access trials and how they work. Contacting the PTA service to discuss trials may be helpful, as navigating the complex information around trials can be confusing. If you are interested in accessing a clinical trial, it's important to talk to your medical team. They are best placed to help you make an informed decision on what is appropriate to consider as a potential treatment option.

Do you contact my Oncologist about me before or after the call to the PTA Service?

We don't have any contact with your oncologist and what is discussed during the call with our PTA nurses is kept confidential. There is a letter we can send to your oncologist, with your consent which highlights you have approached Make 2nds Count to request information about trials. Other than your name this will have no personal information. Some people find this letter being sent is helpful in initiating a conversation with the oncologist about trials and future treatment options.

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

We are happy for you to get in touch on behalf of your loved one. Ideally, it would be useful to have them on the call to share information. However, if this is not possible we would advise that they are aware the call is taking place.

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

To maintain patient safety and ensure the correct patients receive appropriate treatment, clinical trials have very specific eligibility criteria. This could result in you being excluded from a trial. If this happens, your medical team would decide what was appropriate for you to have instead. It may be possible to be considered for another trial or standard of care. New treatments and trials for secondary breast cancer are constantly developing so other options may become available in the future. You can use the service as many times as is helpful and there may be a suitable trial available in the future.

Do you have access to patient medical records?

Our PTA nurses do not have access to medical records. When booking an appointment, a referral form is completed giving sufficient medical information to allow a trial search to be conducted. Based on the information provided and with a telephone conversation with the patient, our PTA Nurses are able to conduct a database search to see if there are any trials running in the UK that may be suitable to consider with the help and expertise of your consultant.

Will my data be shared?

Make 2nds Count will store the information collected in the referral form securely, following General Data Protection Regulation (GDPR) guidelines. We will share this information with the relevant PTA nurse, allowing them to assist patients in the search for a clinical trial. As with GDPR guidelines all information will be stored for a maximum of 12 months and then destroyed. Make 2nds Count do not have access to the medical record of any patient. Make 2nds Count Privacy Policy is available to view [here](#).

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