PARTICIPANT NEWSLETTER - FIRST EDITION

DECEMBER 2017



POsitive Sentinel NOde: adjuvant therapy alone versus adjuvant therapy plus Clearance or axillary radiotherapy

Welcome

Welcome to the first newsletter for women participating in the POSNOC Trial. Some of you may have been involved in the trial for some time and some of you may have joined the trial more recently. Either way, we hope you will find this newsletter interesting, enjoyable and informative. We will send you a newsletter from time to time to keep you updated about the study and give you any other important information you need to know about POSNOC.

POSNOC is the largest UK led International breast cancer surgical trial

A reminder as to why we are doing this study

We now know that drug treatments in early breast cancer are more advanced and very good at preventing the cancer from coming back compared to before. Current NHS standard care is to offer armpit treatment to patients when a small amount of disease is found in the 'sentinel' gland. However, as the drug treatment is more advanced than before the armpit treatment may no longer be

needed. If armpit treatment is no longer needed, it is important to know this. We could then spare women unnecessary treatment, and avoid the long term problems it causes.



(recruitment figure as of December 2017)

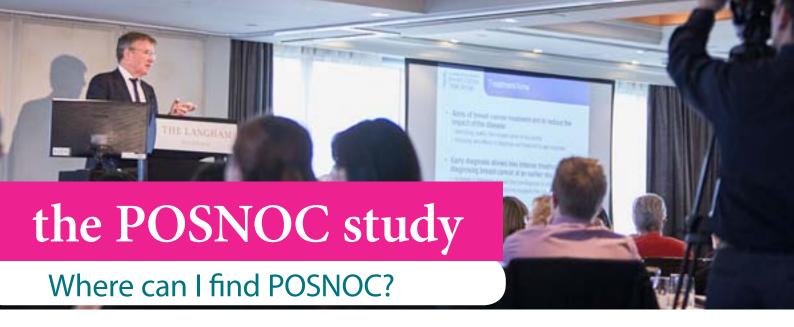












The POSNOC study is open in **97** hospitals across the UK and **17** hospitals in Australia and New Zealand.

This means should you move home or if you were to transfer your care to a different hospital, you can still remain within the trial at one of the other hospitals involved in POSNOC. For more information please discuss this with your research nurse.



3658 patients screened



900 participants enrolled into the study (recruitment figure as of December 2017)



hospitals open to POSNOC in Australia and New Zealand



hospitals open to POSNOC in United Kingdom

Thank you all for taking part in the POSNOC study. In order to answer the important study question we need to involve **1900** women, just like you. So far **900** women have signed up. It is your enthusiasm and dedication to help create a better standard of care for all women that is making this study happen.

POSNOC study follow-up

We appreciate that since your diagnosis you will have had a lot of information given to you. As part of the study your care will be monitored for 5 years and for the first 3 years we will be asking you to complete some questionnaires. If you are in the UK you will be sent questionnaires directly to



your home and once completed you should post them back to the team based in Sussex (SHORE-C). Other questionnaires will be conducted via the research team in clinic or over the telephone. We really hope you can complete these in the required timeframes as this is important data to help answer the research question and may in the future help implement positive changes for breast cancer care.

What you have to say about POSNOC

We would love to hear from women who are taking part in the POSNOC study and start to use these newsletters as a forum for the POSNOC community. This time, we hear from Daphne who has been involved in the trial since **August 2014**

"When I was diagnosed with breast cancer 18 months ago, I was told about the POSNOC trial. My consultant explained what the trial was about and what was involved, including all the risks. He gave me information, including a DVD, to take home and study. I was then able to make my own informed decision about committing to the trial, which was important to me at that time."



Daphne

Chief Investigator

I recently met the first two women who had said YES to the study as part of their 3 year follow up visit. It is hard to believe 3 years have passed!

Women may experience arm swelling, shoulder problems, nerve pain, and numbness if all the lymph glands in the armpit are removed or treated with radiotherapy. However, if the treatment is not resulting in any benefit, should we be offering those treatments to women?

POSNOC will find out if armpit treatment is 'OVERTREATMENT' and reduce the side-effects for future women whose lives are changed by the word CANCER.

Together, we can #makelymphoedemahistory



Amit Goyal



Australia and New Zealand Investigator

We are pleased to be contributing to this very important trial.

The questions being addressed by POSNOC are faced by women around the world every day, and through POSNOC, we will have better answers to them in the future.

Congratulations to Amit and the team leading POSNOC, and deep thanks to all those women who have chosen to participate.

A chance to have your say

Would you like to tell your POSNOC story? We would be very interested to hear about how you are getting on with the study. If you would like to contribute to our next newsletter or be featured on our website, please contact one of the coordinating centres using the details provided below.





Please be sure to get in touch with your local research team if you have any concerns about your treatment.

For any general trial queries please get in touch with your study coordinating team:



UK:

Nottingham Clinical Trials Unit Email: POSNOC@nottingham.ac.uk

ANZ:

Breast Cancer Trials breastcancertrials.org.au



Be sure to follow us on Twitter @POSNOC

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