

Study Newsletter

Issue 1



Thank you for taking part in this important study

Welcome to the first newsletter for the HORIZONS study. Our aim with these annual newsletters is to keep you up to date with the study and how we are getting on.

HORIZONS follows a large group of recently diagnosed cancer patients over time to find out how cancer and its treatment affects people's everyday lives. By sharing your experiences we can learn how to improve the care that cancer patients receive in the future.

We are delighted with the support since the study started in September 2016. So far, over 1,644 patients are taking part from all over the UK. We are hoping to gather as many patients' views as possible to get a whole range of experiences.

Up to now, around 80% of you have returned your first questionnaire which is really encouraging but we would love to see this increase. The more of your experiences we have, the better the picture we will be able to create and this will help to inform care and support services to make important decisions.

We hope you will continue to support the study by completing questionnaires in the future. We want to know how cancer and its treatment affects the lives of people living with and beyond cancer. Thank you again for your time and support.

With best wishes,

Professor Claire Foster, Chief Investigator for the HORIZONS Study

Who is taking part:

1,644
patients taking
part in HORIZONS

641

Breast cancer
Patients (under
50 years old)

317

Non-Hodgkin's
lymphoma
Patients

686

Gynaecological
cancer
Patients

Cervical cancer

Endometrial cancer

Ovarian cancer
(including Fallopian
Tube & Primary
Peritoneal cancers)

Vulval cancer

Taking part in HORIZONS helps us to study the questions that patients want answers to



The aims of the HORIZONS study are guided by the **Macmillan Listening Study**. The Listening Study was carried out in partnership with people affected by cancer. We asked what the priorities for cancer research should be. Patients wanted to:

- Better understand the impacts of cancer and its treatment
- Find ways to help manage these impacts

If you would like to find out more about this or about our other projects, please visit: https://horizons-hub.org.uk/prev_projects.html

Thanks for asking

Why are the questionnaires long?

Our questionnaires include a range of different topics that patients, health professionals and experts have told us are important to ask.

Some of these questions might seem repetitive but they measure slightly different things so it's very helpful if you answer all of these questions.

Are my answers still useful even if I've finished treatment?

We know people will have different experiences of cancer so it's very important to hear a whole range of these.

Whether or not you've finished treatment, don't have any symptoms or have moved on from cancer, we still very much want to hear from you because all your experiences are important!



“ This questionnaire has been helpful in that:

- it has helped me to understand what symptoms can be expected
- to find reassurance that what I am experiencing is normal + predictable
- and to know that my experience can be helpful to improve the process for others
- it has helped to complete the questionnaire in stages as it is quite long, but all very relevant

Ovarian cancer patient

Patients are taking part from 69 NHS trusts & boards across the UK



HORIZONS started at six hospital trusts including Southampton, Winchester and Basingstoke, Norfolk, East Surrey, and Ipswich. We hope to have over 70 health trusts and boards across the UK asking patients to take part.

If you would like to find out more, please visit: https://horizons-hub.org.uk/participating_sites.html

You can now complete our follow-up questionnaires online



If you would like to try this out, please contact us for more information (see our details below).

Please keep in touch

If you have any questions or comments about taking part in HORIZONS, we would really like to hear them. We also want to make sure that these newsletters are as useful as possible so please let us know what you think of this edition and if there is anything you would like to see in our next one.

For questions about HORIZONS or newsletter feedback please:



Email us: HORIZONS@soton.ac.uk

Our office is open Mon-Fri (9am-5pm) and is closed on public holidays



Call us: 02380 59 26885 (standard call charges apply)

Helen Clegg, the study's administrator, will be on hand to help you speak to the right study team member

For study updates and the latest news please:



Visit our website:

www.HORIZONS-hub.org.uk



Follow us on Twitter:

[@HORIZONS_MSRC](https://twitter.com/HORIZONS_MSRC)

In each newsletter, we would like to highlight some additional information we think might be of interest to you. This issue's insert features an introduction to the study team.

MACMILLAN SURVIVORSHIP RESEARCH GROUP



HORIZONS is carried out by the Macmillan Survivorship Research Group (MSRG) at the University of Southampton and is led by Professor Claire Foster.

- We are a team of researchers and study administrators who work closely with people affected by cancer and try to include those often not represented in research
- Our research mainly explores how health and wellbeing recovers after cancer diagnosis and treatment and ways to support patients manage the impact of cancer after treatment
- For more information about us and our other research projects, please visit our website: <https://www.southampton.ac.uk/msrg>

The HORIZONS Study Team



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