

## Study Newsletter

Issue 2

### To the HORIZONS community – Thank you

Back in September 2016, HORIZONS began inviting people from 110 hospitals all over the UK and by March 2019, a total of **3,442** people had agreed to take part in the study. Since our last newsletter, we have been busy exploring your answers to our first four questionnaires – this is a mammoth task because of how much valuable information you have sent back.

In this newsletter, we will give you a first look at who is in the HORIZONS community and some early results which help build a picture of people's experiences in the first few months after a diagnosis of cancer. We also present findings from our interview study which explored how people sought and used support services after cancer treatment.

Clinical and academic experts from across the UK and internationally are eager to find out what HORIZONS will uncover. Your answers will improve our understanding of what is important which will help make a difference to the lives of people living with and beyond the cancers involved in HORIZONS.



**Professor Claire Foster**  
Chief Investigator of the Macmillan HORIZONS Programme

**We could not have done this without you, thank you.**



*As a cancer patient myself, I have learned so much from this study so far. Thank you for every questionnaire you have returned, every comment you have made, and every experience you have shared. I hope you find this newsletter interesting and useful - after all, it's all about us!*

**Richard Stephens**

Chair of the HORIZONS User Reference Group

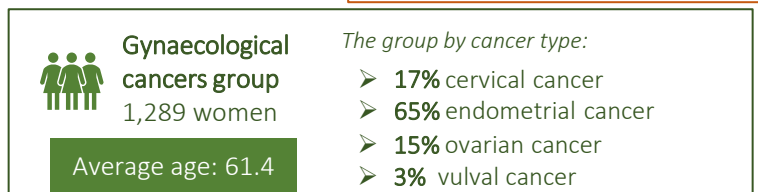
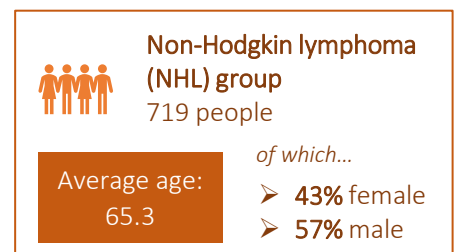
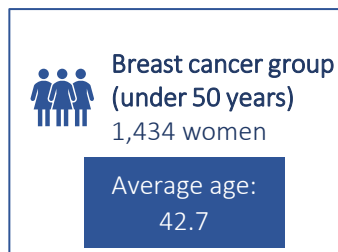


### KEY FINDINGS

#### Who is taking part?

- **3,442 people are in the HORIZONS community**
- 82% are from England, 9% from Wales, 6% from Scotland and 3% from Northern Ireland.
- Most are white British with people of other ethnicities making up 10% of all participants

### FACT FILE: The HORIZONS Groups



## KEY FINDINGS

# Quality of life is lower soon after diagnosis

*Quality of life* can be described as how someone rates their ability to do and enjoy everyday activities.

Ratings of quality of life are lower 3 months after diagnosis, possibly because of side effects from treatment. Overall, the NHL group experienced poorer quality of life compared to the breast and gynaecological cancer groups.

We expect quality of life to recover in time but our work with people diagnosed with bowel cancer (the ColoRECTal Wellbeing [CREW] study\*) showed us that some issues, identified before treatment started, can delay this recovery.

### This includes:



Low confidence to deal with problems linked to health



High level of depression symptoms



Low levels of social support (e.g. having someone dependable who will listen in times of need, be good company, help with daily chores)



Having other health conditions which affect the ability to carry out day-to-day activities



Find out more about CREW here:

<https://www.southampton.ac.uk/msrg/ourresearch/macmillan-crew-cohort/macmillan-crew-cohort.page>

## What we found with your help

### Soon after diagnosis...

- 20% of all participants reported low levels of confidence to deal with health-related problems
- 84% reported they were lacking full social support
- 7% reported high levels of depression symptoms
- 44% have one or more other health conditions that they say affects their day-to-day activities

## What this means

Your answers show that these factors also affect many people living with other types of cancers. Therefore it is important to identify and resolve these issues early to help the recovery of quality of life in the long-term.

Your answers have also shown how these issues are experienced differently between the HORIZONS groups. This helps us to understand how help can be adapted for each group according to individual needs.

## COVID-19 Pandemic



No one could have predicted the unusual times we are living in but your answers and experiences have helped us and Macmillan Cancer Support understand the possible impact of the COVID-19 pandemic on people living with and beyond cancer.

### Your answers told us

14% of people live alone

20% of people reported feeling extremely anxious after a diagnosis of cancer

### What this could mean

Stay at home restrictions have been difficult for many but this shows the potential level of need for services that help people living with cancer who live alone or who have a limited support network

Services supporting mental wellbeing for people living with cancer will be more vital as uncertainty from the pandemic may increase the number of people who feel highly anxious

## KEY FINDINGS

# Finding and getting support after treatment for cancer

We spoke to 30 members of the HORIZONS community to understand more about how they got support to help them live with cancer and its after effects because we know this is important.



We were told about the many different types of help and support people used.

Friends and family    Group activities (e.g. walking groups)    Online resources  
Help from healthcare professionals    Complementary and alternative therapies  
Wellbeing courses    Using occupational health services at work

Many used existing connections (e.g. family, friends, health professionals) and activities (e.g. yoga, massage) to help them cope with problems and concerns related to living with cancer

*...I'd seen him on and off for a number of years anyway but when I got back on my feet, I was still getting problems with my neck and shoulder which, I think, was a lot to do with the stress of having cancer and the treatment. So, I went to him and he relieved the stress in my shoulders and neck and it was wonderful.*

*Mandy\*, age 70s, NHL*

*...they said: "do you want to go and see the psychologist?" and, I thought well: "I'll try anything". And, I did. And, I had a couple of sessions with her.*

*David\*, age 70s, NHL*

We were told about the many different ways they found support. For example: being referred, their own research, other's recommendations, finding things by chance.

We were also told about the emotional challenges in getting support. For example:

- Feeling nervous when attending a support group
- Finding it hard to hear people doing less well
- Not wanting to relive their past experiences because they have 'moved on'

*...the first time I went in, because I had known about this charity but it, I just didn't really know what to expect. So I was a bit nervous about going and it was just a spur of the moment thing because I think, I had been putting it off and off because I was thinking, 'I don't know what it will be like'.*

*Helena\*, age 40s, breast cancer*

## What this means

By talking to you, we discovered the types of support people used but also the challenges some people experienced when getting support. This shines a light on these important issues and will help support services to find ways to overcome challenges faced. That will then help to promote these helpful services and encourage people who need them to use them.



\*Pseudonyms used (not their true names)

# COVID-19 research from HORIZONS

The HORIZONS team have been busy working on new studies interested in understanding your experiences during the pandemic.



## COVID-19 questionnaire insert

You will be given the opportunity to answer questions related to COVID-19 in your next questionnaire

## An opportunity to chat

Some of you will be given the opportunity to take part in telephone interviews to tell us your experiences in more detail.



## Please let us know if your situation has changed



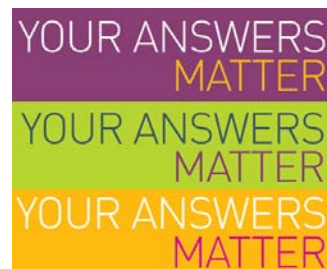
Before we contact you, we do our best to check with your hospital and GP that it is still OK to do so. Recently, it has become more difficult to do this due to the pandemic.

To avoid you missing out, we may have sent your questionnaire without this information. However, we sincerely apologise if your situation has changed. Please contact the research office (see our details below) if you have any questions or if you would like to update your details or let us know of any changes in your circumstances.

## We want to hear from you

We know everyone will have different experiences of cancer and its treatment and so it is important we get to hear from **everyone**. Even if you've finished treatment, don't have symptoms or moved on with your life we still want to hear from you.

**All experiences are important!**



## You can complete your questionnaire online

Around **14%** of the HORIZONS community are completing their questionnaires online. If this is something you would like to try out, please contact us for more information (see our details below).



- You will see the same questions as the paper questionnaires
- You can use your PC/laptop or a tablet device
- Your answers are automatically saved so you can start and stop at any time

## Please keep in touch

If you have any questions or comments about taking part in HORIZONS, we would really like to hear them.

For questions about HORIZONS or newsletter feedback:



**Email us:** [HORIZONS@soton.ac.uk](mailto:HORIZONS@soton.ac.uk)

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



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

We will be on hand to help you speak to the right study team member

For study updates and the latest news please:



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