

Participant Information Sheet
Final version 1.1: 23/01/2026

Title of Study: Rural and Coastal Cancer Research Priority Setting

We are inviting you to take part in a research study. Before you decide, it is important that you know why we are doing the study and what is involved. Please read the following information carefully.

What is the purpose of the study?

Despite international recognition that "place" is a key determinant of cancer outcomes, there is no cohesive multi-nation research-led strategy to understand or address the unique challenges faced by millions of people living in rural and coastal areas, including longer travel times, limited access to services and social and economic deprivation.

The Lincoln Institute for Rural and Coastal Health (LIRCH) are working with a range of community and academic partners across the four nations of the UK and the Republic of Ireland to better understand the rural and coastal cancer research priorities across these different nations.

Dr David Nelson and Dr Samuel Cooke from LIRCH have established the Place-based action for Cancer Equity (PLACE) Research network which is a multi-nation approach to tackling cancer inequalities in rural and coastal communities.

As part of the establishment of the PLACE network, we would like to hear from people with an interest in rural and coastal cancer care in England, Scotland, Wales, Northern Ireland and the Republic of Ireland about what matters most to them. This could include health professionals, charities, academics and researchers, policymakers, as well as people with lived experience of cancer and those who support them. The study involves a short online survey as well as some follow up hybrid and online workshops. You do not need to take part in all of these activities but would encourage you to fill in the initial survey so we can get a wide range of experiences.

Am I eligible to take part?

You are being invited to take part because you have experience or expertise relevant to cancer in rural and/or coastal communities. This may be because you have lived experience of a cancer diagnosis, are a carer or family member of someone with cancer, are a health or social care professional, researcher, or work with a community organisation or charity with an interest in rural and coastal cancer care, policy, services, or research.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Your continued care will not be affected if you choose not to take part.

What will I be asked to do?

If you agree to take part, you will be asked to complete a short online survey. The survey will ask you to share your views on the most important **unanswered questions for cancer research in rural and coastal communities**.

We are interested in the research questions you think should be addressed. These may relate to, for example:

- Diagnosis
- Treatment or management
- Prevention
- Support and care

- How services are organised and delivered
- Quality of life
- Living with and beyond cancer (survivorship)
- Emotional and psychosocial support
- Or anything else that you feel is important.

You will be able to list one or more research questions and, if you wish, explain why these matter to you. You will also have the opportunity to add any additional comments or experiences about research needs in rural and coastal cancer that you feel are relevant.

The survey should take approximately **10–15 minutes** to complete.

At the end of the survey, you will be asked if you would be interested in taking part in a follow-on **priority setting workshop**. Some participants will be invited to these workshops to help refine and agree the top 10 research priorities. Workshops will be held in a **hybrid format**, meaning you can attend either in person or online.

You do not have to take part in a workshop to complete the survey.

Use of Artificial Intelligence

We will use artificial intelligence (AI) software (Microsoft Copilot) to help analyse the survey responses. This will be used to support the research team in grouping similar responses, identifying common themes, and summarising the research questions submitted.

No personal information or identifying details will be entered into the AI system. Only the research questions you submit and any explanation of why they matter to you will be analysed using AI.

All data will be handled securely and in line with data protection legislation. The final decisions about how responses are interpreted and used will always be made by the research team.

Will I be paid expenses for taking part?

There is no payment for taking part in the online survey. As the survey is completed online, we do not expect you to incur any costs.

If you are invited to attend a follow-on priority setting workshop, **reasonable travel expenses will be reimbursed**. Light refreshments will also be provided at in-person workshops.

Full details about claiming expenses will be provided to those invited to take part in a workshop.

What are the possible benefits/risks of taking part?

There is no direct personal benefit from taking part in this study. However, by sharing your views and experiences, you will be helping to shape future rural and coastal cancer research priorities. This will help ensure that research, policy, and funding in this area are better aligned with what matters most to people living, working, and receiving care in rural and coastal communities.

Many people also find it valuable to have the opportunity to share their perspective and contribute to improving services and research for others.

Taking part will not affect the care or support you receive now or in the future.

The risks of taking part are low. Some people may find it emotional to talk about cancer-related experiences, particularly in workshops. You can choose not to answer any questions, take a break, or withdraw at any time.

Will anyone know I have taken part?

The University of Lincoln (UoL) is the sponsor for this study based in the United Kingdom. We will be using information from you to undertake the research and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The research team will keep your name and contact details confidential and secure. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from UoL may look at your research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

Your participation will be confidential unless you reveal that you or someone you know is at serious risk of harm. We will talk about it with you so that we can work out together how best to handle this.

Where will my data be stored?

The data obtained from the study will be stored securely on the university OneDrive in password protected files. Only the researchers will have access to it. The data from this study *may* be put in an Open Access repository for other researchers to use in future research. If so, responses will be anonymised and any personal data (e.g. contact details) will be removed.

We will keep identifiable information (e.g. email address) about you for 12 months after the study has finished. This information may be used in relation to further projects – you will be asked to provide your consent if this is the case.

What will happen if I don't want to carry on with the study?

You are free to withdraw from this study, without having to give a reason, by contacting Dr David Nelson at dnelson@lincoln.ac.uk. This can be done during the completion of the survey or during the workshop if you decide to take part, but not once the survey or the workshop has finished, because you have completed the study anonymously. It will not be possible to remove the data provided, as we will not be able to identify you in any way.

What will happen to the results of the research study?

The results of this study will be used to produce a **top 10 list of research priorities for rural and coastal cancer** across the UK and the Republic of Ireland. We intend to have priorities across all the nations as well as a list of those that are country specific. These priorities will be shared with researchers, funders, policymakers, and relevant organisations to help inform future research, strategy, and funding decisions.

We plan to share the findings through reports, presentations, and academic publications. A summary of the results will also be made available to participants and via the University of Lincoln and partner organisation websites.

Who is organising and funding the research?

This research is being organised by Dr David Nelson at the University of Lincoln and is being funded and supported by UK Research and Innovation (UKRI) Expanding Excellence in England (E3) startup funds awarded to the Lincoln Institute for Rural and Coastal Health.

Who has reviewed the study?

All research conducted by the University of Lincoln is looked at by an independent group of people, called a Research Ethics Committee, to protect your rights, dignity and wellbeing. This study has been reviewed and given favourable opinion by a University of Lincoln Research Ethics Committee (Ref: 2026_22767)

What if there is a problem?

It is very unlikely that this study would cause you any harm. If you have a concern or a complaint about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet.

If you remain unhappy and wish to complain formally, you can make a formal complaint through the University complaints procedure or by contacting ethics@lincoln.ac.uk.

Further information and contact details

Contact details

Dr David Nelson

Study Lead and Chair of Place-based Action for Cancer Equity Research Network
Lincoln Institute for Rural and Coastal Health, University of Lincoln, Lincoln, UK.
Email: dnelson@lincoln.ac.uk

Dr Samuel Cooke

Study Co-Lead and Deputy Chair of Place-based Action for Cancer Equity Research Network
Lincoln Institute for Rural and Coastal Health, University of Lincoln, Lincoln, UK.
Email: Scooke@lincoln.ac.uk

Information compliance

The University of Lincoln is the lead organisation and will be the data controller for this study. This means that we are responsible for looking after your information and using it properly.

The university's **Research Participant Privacy Notice** (<https://ethics.lincoln.ac.uk/research-privacy-notice/>) explains how we will be using information from you in order to undertake this study.

If you feel that we have let you down in relation to your information rights then please contact the Information Compliance Team by email on compliance@lincoln.ac.uk or by post at Information Compliance, Legal and Compliance Services, Lawress Hall, Riseholme Park, Lincoln, LN2 2LG.

You can also make complaints directly to the Information Commissioner's Office (ICO). The ICO is the independent authority upholding information rights for the UK. Their website is ico.org.uk and their telephone helpline number is 0303 123 1113.