



ACRE Study

Assessing Supportive Care Needs in Advanced Colorectal Cancer

Carer Information Leaflet

Chief Investigator:

Dale Vimalachandran
University of Liverpool
dalevim@liverpool.ac.uk

Study Co-ordinator:

Dheepa Nair
University of Liverpool
dnair@liverpool.ac.uk

What is the purpose of this leaflet?

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. A member of the research team can help you with any questions you may have. You should ensure that all your questions are fully addressed before giving your permission to participate in this study. We encourage you to take time to discuss your options with family or friends.

Should you decide to take part, you will be required to sign a consent document.

This “informed consent” form provides the necessary information you need prior to agreeing to participate. A copy of the signed form will be provided for your records.

What is the ACRE study?

Understanding your experience; supporting someone who is living with bowel cancer, often involves many practical, physical, and emotional adjustments. People describe changes in their daily routines, their energy levels, and the kinds of support they need from healthcare teams. Carers may take on new responsibilities and may also have needs of their own.

The ACRE Study has been created to better understand these experiences and will take place over a year and a half.

We want to learn what support helps, what is missing, and how services across Cheshire and Merseyside could be improved so that care feels more consistent, timely, and appropriate.

This leaflet explains what the study involves and what taking part would mean for you. Participation is completely voluntary and will not affect you or your loved ones care in any way.

Why this study is important

Across our region, support for people with advanced colorectal cancer varies. Some people find that services fit their needs well, while others encounter barriers or feel unsure where to turn for help.

By listening to patients and carers, we hope to understand:

- The needs that are most important
- How these needs differ between individuals and groups
- Whether the support available matches what people feel they need
- What could be done differently or better

Your experience, whatever it has been, can help shape better care in the future.

Why have you been invited?

You have been invited because you are a carer of a person with advanced colorectal cancer. You are not being asked because of anything specific in their medical care or because of any concerns you may have raised.

You are being asked simply because your perspective is valuable.

Who is organising and funding the study?

The study is sponsored by the University of Liverpool and funded by Northwest Cancer Research.

Who has reviewed the study?

This study has been reviewed and approved by a Research Ethics Committee and the Health Research Authority (HRA).

What taking part involves

Taking part includes one or two possible components. You may choose to take part in either or both.

1. Completing questionnaires

If you agree, we will ask you to complete questionnaires that explore carer's own support needs.

You can fill these in:

- Online
- On paper
- Or with help by phone or video call

Most people complete them in 10–15 minutes.

2. Taking part in an interview (optional)

Some participants will be invited to a one-to-one conversation with a researcher. This is a chance to speak more openly about:

- What is working well
- What feels challenging
- What support you would find helpful

These conversations can take place:

- Over the phone
- Online via a Microsoft Teams link
- Or face to face in a private confidential room in the hospital of your recruitment.

They usually last around 60 minutes, but this is flexible.

You will be allowed to bring someone to support you during the interview process if you wish. If the person you have initially chosen is also recruited into the study, we ask you to choose another person. You will not be interviewed with the person you care for in order to promote an open and confidential environment. If you require someone to bring you to the interview, there will be an appropriate space where they can wait for you.

If you travel to an in-person interview, we will reimburse reasonable travel costs.

Some people may find that discussing their situation brings up strong feelings. If that happens, you can pause, skip a question, or stop entirely. The research team can also help signpost to further psychological, social or clinical support if needed.

Will the person you care for medical journey be affected?

Taking part, or choosing not to take part, will NOT influence medical care in any way. Their clinical team will not know your questionnaire answers or interview comments unless you choose to share them yourself.

Possible benefits

You may not benefit directly.

However, many people find that reflecting on their experience helps them identify what support matters most.

Your contribution will also help us understand how to improve services for others in the future.

Possible risks

There are no medical risks in this study. Please remember that you can pause, skip topics or stop the interview at any point. If you require help or assistance during or after the interview process, the research team can signpost you to the most appropriate team.

What happens if the person I care for is very ill or dies during the study?

During the study it may be a possibility that the person you are caring for unfortunately becomes unwell and in some cases, may die. The research team can support you and signpost you to teams that may be useful in that very difficult time.

If the person you care for becomes more unwell during the study, they may no longer be able to continue taking part. If they lose the ability to make decisions about participation (capacity), no further study activities (such as questionnaires or interviews) will be carried out with them, but information already collected may still be used in an anonymised form.

If you have agreed to take part as a carer, you may be able to continue your participation in the study even if the person you care for can no longer take part, including if they lose capacity or die. This will depend on what was agreed in the consent process. You are free to withdraw at any time without giving a reason

If the person you care for dies during the study, any information already collected from them may still be included in the research.

Taking part in the study will not affect the care or treatment provided to the person you care for at any stage.

Withdrawal from the Study

If you choose to withdraw, no further data will be collected from you. Data already collected may still be used in an anonymised form for research purposes.

What will happen to the results?

The findings will be shared with:

- NHS teams across Cheshire and Merseyside
- Professionals who plan supportive and palliative care
- National and international researchers via publication

Results may be published or presented at conferences, but no individual will be identifiable.

The aim is to use what we learn to develop supportive care that is fair, accessible, and shaped by the experiences of the people who rely on it.

A summary of findings will be available. If you would like a copy to be sent to you we will be happy to do so. Your contact details may be retained for this purpose if you have consented to this.

Will I be paid for donating my time or participating in interviews?

You will not be paid for donating your time or participating in interviews however we will reimburse reasonable travel expenses. This can be checked prior to you consenting to the study.

How will we use information about you?

We will need to use information from you and from your hospital medical records for this research project.

This information will include your

- Name
- Date of Birth
- NHS number
- Diagnoses and clinical details
- Contact details
- Postcode of your address.

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Who is running the study?

The ACRE Study is sponsored by the University of Liverpool and funded by Northwest Cancer Research. The University's registration number is **Z6390975**. The University Of Liverpool is looking after your information. We will not share your information related to this research project with any other organisations. We will keep all information about safe and secure by anonymising any information stored on University of Liverpool managed systems, including approved research databases such as REDCap.

International Transfers

Your data will not be shared outside the UK.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for a maximum of **10** of years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- At www.hra.nhs.uk/information-about-patients/
- By asking one of the research team
- By sending an email to dnair@liverpool.ac.uk

Who can I ask for advice on whether to take part?

We recommend that you speak to your friends and family before you decide whether or not to take part in this study. You can also ask to speak to a doctor who is not involved in the study to get independent advice on whether to take part. If you would like to speak to somebody independent, please ask your GP.

What if I have a complaint about the study?

If you have a complaint or are not happy with the general care and treatment you receive during the study, please first contact d.nair@liverpool.ac.uk or your nurse specialist. They will try to resolve any issues however if this is unsatisfactory you can take matters further. This can be done by contacting your local PALS office. If you are unsure about these details the research team will happily provide you with them. You can also contact the sponsor of the study (The University of Liverpool) at legal@liverpool.ac.uk.

Thank you for considering taking part

Your experiences carer offer insight that cannot be gained from medical records or clinical data alone.

Thank you for taking the time to read this leaflet and for considering whether this study might be right for you.