Participant Information Sheet

Development and testing of a screening tool to identify need for support for people who have had a cancer diagnosis.

Researcher(s): Dr Jane Frankand, Dr Nicola Andrews, Dr David Wright
Ethics/ERGO no: 110170
Version number and date: 1; 04.06.2026

The information in this section is to help you decide whether or not you want to participate in this research study by providing a summary of key points about the study. We have included detailed information after this section.
We are developing a short screening tool to help quickly and accurately tailor care appropriate to an individual cancer patient's needs. We have developed a first version of the tool. We are asking cancer patients to complete an online survey and will use the information provided to test whether the questions are working well.

- We invite you to take part in our research study. Before you decide, please take time to read this information. It explains why we are doing the study and what it will involve.
- If anything is unclear or if you have any questions, please ask.
- You can talk to someone you trust before you decide. It is entirely your choice whether to take part.
- If you decide to take part, you will be asked to provide consent before you can proceed with the online survey.

What is the research about?
It is a priority in the UK that every person diagnosed with cancer has access to personalised care and support. This means that people's needs are fully identified, and individual support planned. It is recognised that some people will need more support than others to manage their illness and its treatment and to maximise their health and wellbeing. We have been funded by the Wessex Cancer Alliance (WCA) to develop a short screening tool that can be used in clinical practice to rapidly and accurately tailor support provided to the individual person with cancer. We have developed version 1 of the screening questions and need to test these to check they are working well.

This study was approved by the Faculty Research Ethics Committee (FREC) at the University of Southampton (Ethics/ERGO Number: 110170).

Why have I been asked to participate?
You are being invited to take part because you have had cancer. We are looking for people who have had a diagnosis of cancer, are aged 18 or older, are able to complete the survey in English and are resident in the UK.

We are aiming to include around 500 people in this study and therefore information about this survey has been widely circulated.

We are advertising the study through posters, newsletters, social media etc. 'Gatekeepers' within organisations and services relevant to the focus of this research have also agreed to circulate an invitation to participate, an information sheet and a link to our online survey through email, posters and/or social media.

If you have received information directly about the study, it is because you are on a circulation list for an organisation or service acting as a gatekeeper or connect with social media or online platforms where the study has been advertised.

What will happen to me if I take part?
This study involves completing an online questionnaire (using the Qualtrics survey platform) which we anticipate will take approximately 10 to 15 minutes of your time. If you leave the questionnaire without completing it, your progress will be saved for up to 7 days and you can automatically continue from your last question, if using the same device and browser. This feature works by placing a cookie on your browser that keeps track of the progress. If you do not return within 7 days your answers will be automatically deleted. All the questions are either multiple-choice questions or require a one- or two-word text answer.

If you are happy to take part in the survey, you will need to tick (check) the boxes in the eligibility and consent sections before you can continue. Completing the survey is anonymous. This means the research team will not know whether you have participated, or what answers you provided. However, we will be inviting a number of participants to take part in further testing of the screening tool, involving an online interview. If you wish to be considered for an interview, you will need to provide your name and email address, in which case the questionnaire would no longer be anonymous. If you complete the questionnaire and do not wish to be involved further, you do not need to provide your name and email address and participation remains completely anonymous.

What are the possible benefits of taking part?
If you decide to take part in this study, you will not receive any direct benefits. However, your participation will contribute to the development of the screening tool, which will be used in clinical practice to improve cancer care.

What are the possible disadvantages and risks of taking part?
It is not expected that taking part in this study will cause you any psychological discomfort and/or distress. However, should you feel uncomfortable you can leave the survey at any time. Following completion of the questionnaire, if any of the questions have raised issues for you which may be upsetting or you have any concerns we recommend that you seek support from your health care providers, such as your GP or specialist nurse, or through the helpline provided by Macmillan Cancer Support, who can be contacted on 0808 808 0000.

What information will be collected?
You will be asked to answer a number of questions about quality of life and wellbeing. You will also be asked some questions about you, such as your age and gender, and about your cancer, such as the type of cancer and how long ago you were diagnosed.

At the end of the survey, you will be asked if you are willing to be involved in further testing of the screening tool as part of an online interview. If you wish to be considered for an interview, you will be asked to provide your name and email address. If you provide your name and contact details your questionnaire responses will no longer be anonymous.

If you provide us with your name and email address to be considered for further involvement in the study, we will store that data separately to any questionnaire answers you provide. Both your questionnaire data and your contact details will be labelled using a unique code. We will use this code to link your survey answers to your contact details only if you are selected for interview.

How will my information and personal details be protected?
Your participation and the information we collect about you during the research will be kept strictly confidential during the study.

Only the research team and approved staff from the University of Southampton may see your data to help monitor the study. They may also check the study to make sure it complies with research regulations. People from regulatory organisations (who make sure the study follows proper rules) might also need access to your data. Everyone who sees your information is required to keep it confidential.

Questionnaire responses will be held securely on the Qualtrics platform until downloaded by the research team. Questionnaires that have been partially completed and not submitted will be automatically deleted by Qualtrics 7 days after the questionnaire was commenced. Only the research team will be able to download data from the Qualtrics platform.

If you opt to share your name and email address to be considered for an interview these data will be separated from the questionnaire data and will only be re-linked to survey data if the research team identify you as a respondent they would like to interview.

Downloaded questionnaire responses and all other data will be stored securely on the study specific SharePoint established on the University of Southampton password protected and encrypted system, backed up on secure platforms. The files stored in this location are encrypted at rest, and all data is held in secure centres within the UK. Only the research team will have access to this information.

The information collected will be analysed and used to inform the development of the screening tool that can be used in clinical practice.

At the end of the study, all identifiable data will be destroyed and the questionnaire data retained as an anonymous dataset. This anonymous dataset and outputs of the analysis will be retained for 10 years after the study has finished and then securely destroyed, in accordance with the University of Southampton Research Data Management Policy.

Do I have to take part?
No, it is entirely up to you to decide whether to take part. If you decide to take part, you will need to complete the consent section of the online survey to show you have agreed to take part.

What happens if I change my mind?
You have the right to change your mind and are free to withdraw at any time without giving a reason. You can withdraw from the survey at any point before final submission, by closing the survey window. Your data will be automatically deleted 7 days after you close the window. However, any anonymous data cannot be withdrawn after they have been submitted.

What will happen to the results of the research?
On completion of the study, reports of the study findings will be written for Wessex Cancer Alliance, the study funder, which they may wish to promote and circulate. Results are likely be published in health care journals and presented at national and international conferences. Reports and publications will not directly identify you without your specific consent.

Where can I get more information?
If you have further questions after reading this information sheet, please contact a member of the research team (023 8059 0539, perscare@soton.ac.uk).

What happens if there is a problem?
If you are concerned or unhappy about any part of the study, please contact the researcher team (023 8059 0539, perscare@soton.ac.uk). They will do their best to answer your questions.

If you remain unhappy or have a complaint about any part of this study, please contact the Head of Research Ethics and Governance, University of Southampton (023 8059 5058, rgoinfo@soton.ac.uk), University of Southampton.

Data Protection Privacy Notice

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

How will we use information about you?

Any personal data we collect in this study will be used only for the purposes of carrying out our research. Contact details will not be retained beyond the end of the study or used for future studies. Your personal data will be handled according to the University's relevant policies.

The University of Southampton is the 'Data Controller' for the personal information we collect from you for this research project.

Information that may identify you, such as name and email address, if provided, will be used to carry out the research or to check your records to make sure that the research is being done properly.

For clarity, different types of data are collected in this study:

Admin Data, which is necessary such as name, email address, etc. These are used to organise and manage your participation in the study.

Research data such as interview recordings, transcripts, etc. which are used for analysis and to produce research outputs. Where possible, the University will make every effort to make sure research data will be pseudonymised and stored separately from identifying information.

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.

We will keep all information about you safe and secure.

Once the study is finished, your identifiable information will be deleted.

We will write our reports in a way that no-one can work out that you took part in the study.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect. We will keep all information about you safe and secure.

What is our lawful basis for using your data?

Our lawful basis for using your personal data is your consent. This means we will only collect, use, and store your information if you choose to take part and give clear permission for us to do so. You can withdraw your consent at any time, without giving a reason, and this will not affect your rights or your standard of care. Any data collected before withdrawal may still be used in line with good research practice and ethical requirements.

What are your choices about how your information is used?

- You can stop being part of the study at any time, during the study, without giving a reason, but we will keep all information about you that we already have, in line with the study description in the Participant Information Sheet, and consent form.
- You have the right to access, rectify, or request restriction of your personal data. However, these rights may be limited where this is necessary to ensure research remains accurate.

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

You can find out more about how we use your information:

- by sending an email to University's Data Protection Officer (data.protection@soton.ac.uk).
- by asking one of the research team or from our general privacy policy.
- by sending an email to perscare@soton.ac.uk or by ringing us on 023 8059 0539.

How long we keep your data?
Your contact details, if provided, will be retained for the duration of the study and will be destroyed within six months of the end of the study. The anonymised questionnaire dataset will be retained for 10 years after the study has finished

Thank you.
Thank you for taking the time to read the information sheet and considering taking part in the research.