

What is the study about?

You are invited to take part in a research study in the form of an anonymous survey which aims to better understand the needs of patients with metastatic breast cancer (including secondary breast cancer, stage IV breast cancer and advanced breast cancer), with a particular focus on information and communication needs. The survey includes questions on patients experiences with metastatic breastcancer, as well as questions about your demographics, your diagnosis, your experience of living with metastatic breast cancer, prognosis, your personal diagnosis story and communication, sexual / intimacy / fertility impact, exercise, palliative care, financial burden and time toxicity.

The study has been developed by a patient with metastatic breast cancer in conjunction with a cohort of patients with the same disease and an interdisciplinary steering committee comprised of medical and radiation oncologists, allied health professionals, palliative care staff and doctors in training. The co Chief – Investigators of this study are Ms. Siobhan Gaynor (Patient Consultant Committee, Cancer Trials Ireland) and Prof. Seamus O'Reilly (Medical Oncologist, Cork University Hospital and Vice-Clinical lead Cancer Trials Ireland). This study is being conducted with Cancer Trials Ireland (<http://www.cancertrials.ie>) as part of their public patient involvement (PPI) initiative in cancer clinical research. This partnership will increase the reach of the study and facilitate analysis of the data received and dissemination of the findings. We plan for a total of 300 patients living with metastatic breast cancer to complete the survey so that we gather information on a broad range of experiences across the island of Ireland.

What will I have to do?

As part of this study, you will be required to answer questions in an anonymous online survey relating to your experiences of having metastatic breast cancer. Your full participation will take approximately 30 minutes (which includes reading this information sheet, reading and filling in the questionnaire).

What are the benefits?

The study's findings will help improve and understand further the impact that metastatic breast cancer has on the lives of patients in Ireland. It will investigate information and communication needs of patients. We hope that the results of this survey will be used to guide evidence-based changes in service provision and to also guide the implementation of new health and social care resources to optimise care for patients with metastatic breast cancer with particular emphasis on psychosocial and palliative care needs.

What are the risks?

As the survey contains questions of a personal nature reading and answering the questions may lead to increased anxiety. If you feel upset, distressed, or uncomfortable, you may withdraw from this study without any consequence. Simply discontinue and close the survey without answering any more questions. Support is available from cancer support groups and charities. Contact details and further information can be found at <https://www.hse.ie/eng/services/list/5/cancer/patient/patlinks/>

What if I do not want to take part?

Participation in this study is voluntary, and you can choose not to take part. It is entirely up to you.

What happens if I change my mind during the study?

If you begin the survey, you can stop answering the questions at any time with no consequence. You can simply close your browser and the responses you entered up until that point will be discarded. If you complete and submit the full survey, it will not be possible to withdraw your response at a later date because no personal identifying information will be collected and therefore, your response cannot be associated with you.

What happens to the information? Will my identity and my answers to the survey be kept private?

The collected information will be kept private and stored securely and safely on a SurveyMonkey® single password protected account managed by Cancer Trials Ireland. As you will not be asked to provide any identifying details, the data you provide will be anonymous. No personal data related to the device on which you complete the survey will be collected. At regular intervals during the survey, and following completion of the study the anonymous data will be downloaded from the SurveyMonkey® platform and saved as a database on a secure server at Cancer Trials Ireland. The anonymous data gathered in the study will be kept for ten years.

Who can take part?

You can take part if you are aged 18 years or older and have been diagnosed with metastatic breast cancer and are able to complete the online questionnaire independently or with the help of a friend or relative.

What happens at the end of the study?

The information you provide will be pooled together with the information completed by other survey participants and the results may contribute to research publications and/or conference presentations. As detailed above, because no personal identifiable information will be collected, the information published will never be linked with any individual person.

What if I have more questions or need help understanding something?

If you have any questions or need help understanding something before deciding whether or not to take part, please feel free to contact the researchers Ms Siobhan Gaynor or Prof. Seamus O'Reilly via: mbcsurvey@cancertrials.ie

This study has obtained ethical approval from the RCSI Research Ethics Committee.

Thank you for taking the time to read this information. We would be grateful if you participated in this study.