

Frequently Asked Questions

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Version 1.0

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Why the need for CURIE?

Cancer patients, their carers and treating teams have questions about quality of life and patient experience during and after treatments. This information is often missing, however it could be captured using commonly used technologies (i.e., phone, tablet, computer) to provide a more complete overview of the patient experience.

Although there is some information on patient experience, it often comes from clinical trials. This has a few downsides - patients enter clinical trials based on certain criteria (i.e., fitness, age) and they do not represent the standard patient population. Furthermore, patients with rarer cancers or those who receive treatments to ease pain and symptoms caused by cancer might not be captured by clinical trials as well.

Recent improvements in technology allow patients to access their electronic health records online and to answer questionnaires (e.g., on service quality) at a time and place that is comfortable for them. To improve services for cancer patients, we want to be able to collect and make use of your information on your symptoms and experience of cancer treatment.

What is CURIE trying to achieve?

The aim of CURIE is to understand how patient reported information is collected and to use this to improve services.

Patient reported outcome measures (PROMS) are standard questions that help collect information on symptoms or side-effects of your treatment. Patient reported experience measures (PREMS) collect information on your experience on treatment and overall care. In this research, we will capture both as "Patient Reported Data" (PRD).

CURIE aims to collect patient reported data from multiple hospitals nationally, understand how patient experience and the collection of this information varies across different centres and use this to improve services. The aim is to work out how to best help patients and their treating teams in the use of patient reported data.

What will I be expected to do?

When you sign up to CURIE, you will be asked to complete some questions about you (some are optional). This should not take any longer than 10 minutes to complete.

When you join CURIE, you will receive the first "core" questionnaire. It aims to capture information about your quality-of-life, your experience, and your treatment. This should take less than 10 minutes to complete.

You will get the same questions at specific timings during and after your treatment. It will be before you start a new treatment, 4 and 8 weeks later, and every 3 months following the end of your treatment.

During the project, you will be able to access additional questionnaires focusing on your specific diagnosis (e.g., a questionnaire specifically designed for breast cancer patients that focuses on psychological and social well-being, among other things).

Why do you ask me questions that can be answered from my medical records?

We are aware that there are questions in CURIE which can be answered through accessing your clinical records (e.g., the aim of your treatment). But we want to ensure that your understanding is the same as what the clinicians have entered in your records.

When I give feedback on my experience, will I see changes made to my care?

~~By agreeing to use CURIE, your treating team would have agreed to wisely use your answers to improve the services, departments, and care given to future patients. Although your treating team~~ They might not be able to fix all some of the issues you raise, ~~d.~~ But we hope that they will be able to communicate and acknowledge your concerns ~~you raised~~. We also hope they plan to improve your and future patients' ~~local~~ experience ~~locally~~ and future patients'. For smaller issues, or where there is a "quick fix", we hope that they can put in place a change on time.

How will you know the CURIE project is successful?

The impact and success of this project ~~are~~ depend ~~ant~~ on ~~f~~ many factors. To assess the success, we will look at how many patients are using the online system to provide their feedback, what is the impact of the project on each participating centre, what are the improvements to patient care delivered. The main parameters are the use of the platform by the patients, the impact of CURIE on the centres, and the improvement of the patients' care.

If you would like further information, please get in contact with us on imperial.curie.project@nhs.net. A member of our team will be happy to share any details with you.

Will you be sending or providing information updates about the project?

We would like to share our results and learnings with you. We will do this in various forms, including webinars, posters, and other publications. You'll find the latest communication on CURIE official website (www.radiotherapyoutcomes.org).

Does this project have the same approvals as clinical trials?

The CURIE project is a Quality Improvement (QI) project, ~~thus~~, it does not need the same approvals as clinical trials. Your data will be treated with the utmost care. All confidential information will be securely held by each treating Trust, using a ~~the~~ secure platform.

Who are the National Cancer Registration and Analysis Service and why will you be sharing my information with them?

Your personal data will be shared with the national cancer registry. It is known as the National Cancer Registration and Analysis Service (NCRAS) and is run by NHS Digital ~~runs~~ NCRAS. Agreements are already in place between the NHS Trusts and NCRAS. The national cancer registry collects identifiable information about cancer patients diagnosed in England.

~~Public Health England formed NCRAS in 2016 and NHS Digital has taken over in 2021. Their aim is “to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research”.~~

~~Thus, W~~we would like to share your answers with NCRAS to allow a national linkage with clinical data. This would help to provide a representation of the “normal” cancer population in England.

I would like to know more about the technical side of things – how do I get more information?

Please contact us on imperial.curie.project@nhs.net with the information you would like, and we will do our best to provide you with this.

My question has not been answered. What should I do?

You can see if your question was answered from our Frequently Asked Questions sheet on our webpage (www.radiotherapyoutcomes.org). You can also send your question on imperial.curie.project@nhs.net and we will do our best to answer.

Project management group

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