CURIE

Collecting, Understanding,
Reporting, Interpreting and Exploring

PIS_v0.8

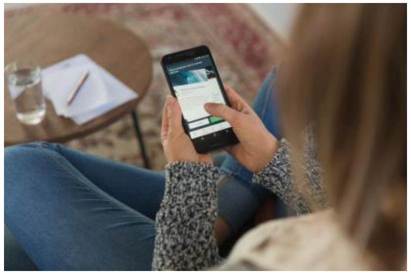
To improve services, we want to be able to collect and make use of your information on your symptoms and experience of cancer treatment.

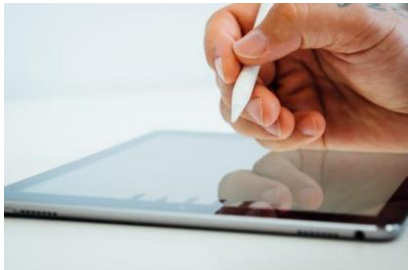
SUMMARY

The aim of this research is to understand how patient reported information is collected and to use this to improve services. It also provides you access to your completed forms which can be printed out for your clinical appointments and links to relevant support 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).

You are invited to take part as you are over the age of 16 and are starting a new cancer treatment.





You will be asked to fill in the questionnaires on a safe & secure online platform.

If you want to join, these are the next steps:

CONNECT to [the online questionnaire]()

COMPLETE the form to tell us about you, your illness, quality of life, symptoms and experience

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Multi-Centre Quality Improvement

CURIE is a quality improvement study which aims to understand and improve the collection of patient reported information on quality of life, symptoms and experience during treatment.

You will occasionally be asked to complete an online form with some questions about you and your illness. We will also ask you questions about your treatment, symptoms, quality of life as well as some optional additional information (i.e., ethnicity, sexual orientation).

We will then help summarise the information so that you can discuss it with your clinical team, and we will feed this information, if you agree, back to the team treating you.

The platform will also link you with local sources of community support, such as Macmillan and Maggie's Centres.

The main aim of CURIE is to work out HOW to do this best – how do we make it easy for people to collect information, and how do we feed that information back to the treating teams?

Why does this matter? We try to be fair in the way we treat people and encourage them to be well again. We want to take into account your voice as we have very little data on quality of life and patient experience for patients having treatment for cancer. CURIE is trying to understand how best to collect this information and improve the way this feedback is brought back to the treating teams by this bettering the services to cancer patients.

What are the benefits? You will be able to print out summarised information on your experience that you can take to your treating team. The online platform will link you with relevant community support services. You will help future patients as the study ultimately aims to improve services and to better the way patient experience and outcome information is collected.

What are the downsides of taking part? We do not foresee any downsides to you signing up to this study.

Is my data secure? We are using a secure platform; all information is encrypted. We will only share your personal data with your treating team, the NHS, and the National Cancer Registration Service (part of Public Health England). Anonymous information might be shared in the future with non-commercial third parties.

For more information visit computationaloncology.net/curie