CURIE

Collecting, Understanding, Reporting, Interpreting and Exploring Patient-Reported Outcomes and Experience in adult cancer patients: a coordinated multi-centre quality improvement project

Computational Oncology Laboratory – Radiotherapy department, Charing Cross Hospital, Imperial College Healthcare NHS Trust, London, UK
FAQ, version 1.0

Frequently Asked Questions

Getting started

There are a lot of documents on the CURIE webpage, and I am not sure in which order I should read them?

We would recommend you read in this order:

1. Introduction *(to have a broad idea of the project)*
2. Extended introduction *(to have a better idea of the project)*
3. Patients' testimonials *(to get a better understand of why this project is important to patients)*
4. Outline of the questionnaires *(to know what questions are being asked to patients and when)*
5. Manual for staff *(if you got hooked and wished to open this study in your own Trust)*

Why is this project important to patients?

CURIE was designed with help from (former) patients, charities, and clinical staff. Charities and former patients all agreed that their treating teams focused first on the treatment but its impact on the quality of life was rarely the main discussion during the clinic appointments.

Eligibility criteria

Why is this project only for adult patients when paediatric patients are the ones more susceptible to have long-term side effects?

We wish to focus on acute toxicity and side-effects in the major cancer population (adults). Each year, there are less than 2,000 new cases of cancer in the paediatric population, compared to almost 400,000 new cases in the adult cancer population. We do not think involving children and teenagers will make a difference in the adult population.

Why is it open only to patients having radiotherapy and / or chemotherapy? What about patients undergoing surgery?

We wish to focus on acute side-effects and the side-effects observed following surgery are usually linked to the procedure and not to the toxicity caused by the surgery.

Patient-portal

I do not know if my Trust have a patient-portal, what should I do if nothing is implemented locally?

We can provide a list of patient-portals and the Trusts where they are already implemented (when applicable). If your centre is not on the list, we advise you to ask your managers, divisional directors, and heads of departments as they might know. In the case where no patient-portal is available in your Trust, we can provide a list of vendors and help you with discussion.

Any other questions?

If the staff manual and the previous questions still do not answer your question, feel free to contact us on imperial.curie.project@nhs.net.