ICR The Institute of Cancer Research

Equality, Diversity and Inclusion (EDI) at ICR-CTSU

What we do at ICR-CTSU

At The Clinical Trials and Statistics Unit at the Institute of Cancer Research (ICR-CTSU) we work to improve cancer treatment. We do this by designing and running research to determine the best treatments for patients. These research studies are called clinical trials.

Why is EDI important in cancer research?

Research participants should reflect the diversity of cancer patients in age, ethnicity, and background. This makes sure the results of the research apply to everyone and that no-one is excluded.

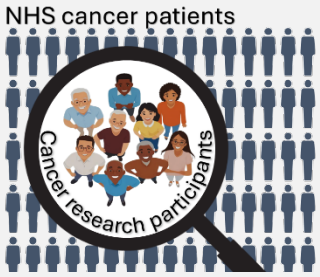
This flyer outlines some of our projects aiming to improve the inclusivity of our research.

Is anyone being excluded from cancer research?

In the past, clinical trials in the UK have not always collected information about people's personal characteristics. Therefore, we don't know whether any groups of people are being excluded. At ICR-CTSU we are running projects to try to change this.

Using NHS data to find out who has not been taking part in cancer clinical trials

The **INTERACT** project aims to find out:



Are there any differences between people who took part in cancer research in the past and those who didn't?

Who is less likely to take part in cancer research in hospitals today? Is this because they don't know about the research or because they choose not to take part?

Once we know who is less likely to take part, we can work with people to better understand why and how we can support their needs.

Improving how we collect information about people who take part in our future research

The **DISTINCT** project* brought together a set of questions to collect information about research participants' characteristics.

The information can be sensitive so the questions were discussed with people from different backgrounds to make sure we collect the right information in the right way.

Using these questions will help us to see who is not taking part in research. We can then design our clinical trials to better include everyone.

*In collaboration with the Cancer Prevention Trials Unit at Queen Mary University of London.

Our patient and public advocates

We work with over 50 people with lived experience of cancer. Our advocates are consulted and advise us at every stage of our research, giving us insights into their needs and priorities.

We wanted to know if we had advisors from all backgrounds as it is important that we consider different perspectives when designing and running our clinical trials.

Getting advice from people from all backgrounds

We asked our advocates to complete a survey and found that:

- Many of our advocates have similar backgrounds, being White, from affluent backgrounds, with a university education.
- This means people from different backgrounds may be underserved.

We are reaching out to include more people to work with us from all backgrounds.

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Making our clinical trials more inclusive

We have a range of different projects working to improve the inclusivity of our research.

Improving the inclusivity of bladder cancer research

COBRA is a clinical trial looking at a new treatment for people with bladder cancer. Bladder cancer is most common in people who are from disadvantaged backgrounds.

1. Hospital staff will provide information on who is or isn't taking part in COBRA.
2. This will help us to identify if any groups of people are being excluded.
3. We will discuss the barriers to taking part with people from the underrepresented groups identified.
4. Together, we will develop a tool or method that will support people.
5. The new tool or method will be used within COBRA and we will assess whether it works.

Improving how we assess skin reactions related to radiotherapy treatment

Radiotherapy uses radiation to treat cancer. Radiotherapy can lead to changes in people's skin.

Historically, these skin changes have been measured using scores based on the reaction of white skin.

As part of the FAST-Forward Boost trial, we will look at improving the way skin reactions are assessed for people with a range of skin tones.

Can we collect information from people electronically?

Clinical trial participants are often asked to complete questionnaires about the side effects of their treatment.

Paper questionnaires are often used. We want to find out if electronic questionnaires might be better.

However, this might leave out people who aren't able to use a computer or smart phone, or access the internet.

In a study called SPRUCE, we are asking people if they would be happy to be assigned to use either paper or electronic questionnaires or if they would prefer to use one or the other.

We aim to find out which method gets the most complete data and which method people prefer.

Changes to the way we work at ICR-CTSU

- We have reviewed the language we use in our information sheets for patients and removed gendered terms (e.g. he/she).
- We have altered our contraception guidelines to make sure these are inclusive.
- We are collecting information about the commonly spoken languages at each NHS hospital. We are working towards providing clinical trial information in these languages.
- If taking part in a clinical trial means extra costs (e.g. additional hospital appointments) we are re-imbursing people whenever possible.
- We ensure that ethnicity data is published alongside our trial results.

Want to find out more?

To find out more about our equality, diversity and inclusion work at ICR-CTSU visit our website.

This leaflet was produced by the Clinical Trials and Statistics Unit at the Institute of Cancer Research (ICR-CTSU), Sutton in collaboration with patient advisors.

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