The Institute of Cancer Research

ICR-CTSU PPI/E NEWSLETTER

Clinical Trials and Statistics Unit at the Institute of Cancer Research (ICR-CTSU)

Translating cutting-edge science into quality clinical trials that can transform cancer care

Welcome to Issue 2 of the ICR-CTSU Patient and Public Involvement and Engagement (PPI/E) Research Advisory Group (RAG) newsletter, updating patient advocates, staff, members of the public, carers and our community about patient and public involvement and engagement at the ICR-CTSU.

This newsletter is co-produced by the ICR-CTSU RAG and the patient advocates who support us.

Issue 2, 2024

Who are we and what do we do?

The ICR-CTSU is a Cancer Research-UK (CRUK) funded, internationally recognised methodologist led clinical trials unit, providing cancer focussed clinical trial research expertise. We lead pioneering, efficient, high-quality and impactful research across all phases of clinical trials.

NATIONAL NEWS UPDATES

Today, thanks to research, more than 90% of women diagnosed with early-stage invasive breast cancer will survive the disease for 5 years or more.

Patient Advocate Mairead MacKenzie

Between 1993 and 2015, more than half a million women in England were diagnosed with early invasive breast cancer. Not only did they face something life-changing, they also showed us how much things have changed. Here's how:
Patients can choose to share their NHS health data, which researchers can apply to use to track trends over time. 512,447 women contributed their information to a groundbreaking study that CRUK funded into breast cancer mortality in England since the early 1990s. This is the first study of its size to follow up patients for an extended period, and to map out how detailed characteristics of specific patients and their cancers relate to different outcomes: www.cancerresearchuk.org/cancer-statistics

Doctors told Mairead Mackenzie she had breast cancer in 2002. In the years since, Mairead has become a passionate patient advocate and leading members of the charity Independent Cancer Patients' Voice (ICPV). Mairead didn't just feature in this research: but helped shape it, making sure the researchers focused on the questions that matter most to people with breast cancer. Mairead is quoted as saying "studies like this one can give reassurance to patients about their life ahead. And now, women with breast cancer have a much better chance of surviving."

Be Part of Research

The National Institute of Health Research (NIHR) have announced over half a million people from across the UK have now signed up to their flagship 'research matchmaking service', called Be Part of Research.

The free online service matches people to suitable health and care research, based on their interest and where they live.

Be Part of Research is the first UK-wide research volunteer registry covering all health and care specialities. This includes public health and social care studies. It is designed to make it easier for researchers and potential study participants to find each other.

New figures published today show that 528,389 people have registered to Be Part of Research since it launched in July 2022. And 50,000 participants – almost 1 in 10 – have taken part

The People-Centred Clinical Research Project

Earlier this year the Health Research Authority (HRA) carried out a project in partnership with members of the public, researchers, and academics from the University of Lincoln, and asked more than 400 people about their experiences of health and social care research.

The aim of the project was to find out what researchers should do to make sure that the people who take part in clinical research, and those who will be affected by the outcomes of research, are the focus. They decided that research that works in the right way for people should be called 'people-centred' research. More details can be found at: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/people-centred-clinical-research/

The HRA's report makes 19 recommendations to improve clinical research for participants, and calls upon the research community to share and embed the principles and 9 hallmarks of good people centred research: https://www.hra.nhs.uk/planning-and-improving-research/recommendations

LOCAL NEWS UPDATES

Professor Christina Yap and Dr Karen Poole have submitted a grant application to UK Research and Innovation, in partnership with Independent Cancer Patient Voice, University of Surrey and University of Sussex to develop an educational intervention to support patient and public involvement in statistical methodology and artificial intelligence research.

Professor Christina Yap

Dr Karen Poole

We welcome a new patient advocate to the ICR-CTSU PPIE RAG, Andrew Kightley. Based in the Midlands, Andrew brings experience as a carer and is working with Professor Christina Yap on delivering the DEFINE study, developing guidance for early phase dose finding trials and patient outcomes: http://www.icr.ac.uk/DEFINE

The Future of Environmentally Sustainable Research

Ray Gardner

Lisa Fox

PPI-RAG member Ray Gardner participated in a workshop in June about how to support greener research and reduce the impact of clinical trials on climate and the environment.

The workshop, organised by Lisa Fox (ICR-CTSU Sustainability Lead and Chair of the Medical Research Council National Institute of Health Research (MRC-NIHR) Trials Methodology Research Partnership (TMRP) Greener Trials Working Group), Professor Paula Williamson (University of Liverpool) and Gabby Samual (Kings College London), was funded by Innovate UK.

The aim of the workshop was to share knowledge between regulators, funders, publishers, researchers and patient advocates about how to make clinical research more environmentally sustainable. The focus was very much on how these groups could help shape change in approach. Many ideas emerged about how to ensure that future research is environmentally sustainable, whilst also acknowledging that capacity and knowledge within the sector would be key to driving change.

The full report will be made available on the TMRP Greener Trials website: [Network Hubs :: Enabling Lower Carbon Clinical Trials (CiCT) Project]

Patient-Centric Dose Finding Early Phase Trials

ICR-CTSU PhD student Emily Alger's recent paper **'Patient and public involvement and engagement in the development of innovative patient-centric early phase dose-finding trial designs'** highlights the importance of involving patients in creating advanced dose-finding trial designs, particularly using Patient Reported Outcomes (PROs) to help decide whether a dose is tolerable for patients.

Click [here] to read the full paper.

What is a dose finding trial?

The aim of dose-finding oncology trials is to make sure a treatment is safe, understand its side effects, and recommend the right dose (or doses) for future clinical trials. Traditionally, a patient's tolerance to treatment is assessed by doctors who evaluate toxicities (side-effects) using established grading guidelines.

Emily Alger

'In a dose-finding trial, we start with a low dose of a drug and increase it until too many patients have severe side effects. The highest safe dose is then investigated in a later phase trial. We are suggesting a new way to do these trials. We want to look at both what doctors see as severe side effects and what patients say.'

STAFF SPOTLIGHT

Hannah Gribble joined the ICR-CTSU as a Trial Manager in March 2019 specialising in bladder cancer trials, joining the ICR-CTSU PPI RAG in June this year. She has a particular interest in improving equality, diversity, and inclusion of our clinical trial participants. As such, Hannah will be the day-to-day project lead on INTERACT which aims to broaden our understanding of who is underrepresented amongst our clinical trial participants, how hospitals collect data about people's characteristics and how we can make links with specific organisations to help address any underrepresentation.

Outside work Hannah is enthusiastic about almost anything fitness or adventure related, usually spending her annual leave climbing mountains. She is a big fan of the Olympics and previously worked as part of the anti-doping team in Rio in 2016.

Hannah Gribble

OUR AIMS FOR PPI AT THE ICR-CTSU

Governance	• Deliver appropriate strategy, policy and procedure documentation to govern and record PPIE activities in ICR-CTSU that draws on ICR strategy and policy
Learning	• Support the learning and development needs of Patient Advocates and ICR-CTSU staff to enable effective involvement • Introduce a process to ascertain the learning from involving Patient Advocates
Communication	• Re-establish ICR-CTSU Patient Advocate Forum and regular communication activities • Develop best practice guidance for co-production of patient facing documentation, consultation activities and involvement after trial participation
Outreach	• Work with other CTUs, national cancer charities, cancer organisations to learn from and contribute to PPI standards, activities and resources.
Equality, Diversity & Inclusivity	• Facilitate the recruitment of appropriately diverse patients as participants and patient advocates
Collaboration	• Expand Patient Advocate membership of ICR-CTSU groups (with guidance for enabling involvement) • Develop a programme of work on patient-prioritised endpoints

CONTACTS and LINKS

Webpage: https://www.icr.ac.uk/our-research/centres-and-collaborations/centres-at-the-icr/clinical-trials-and-statistics-unit/patients-and-public

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