

Autumn 2022

## CRCTU Patient and Public Involvement and Engagement

A taskforce was established in September 2020 to develop an ambitious strategy for Patient, Public Involvement and Engagement (PPIE) in cancer research across the University of Birmingham. The taskforce included patients, staff from the Birmingham Cancer Research UK Clinical Trials Unit (CRCTU), Cancer Research UK Centre, Experimental Cancer Medicine Centre (ECMC) and PPIE experts from across the University.

One of the key recommendations in the strategy is to hear the views of our patients and the public and shape our plans based on this. We recently distributed a PPIE Survey to PPI collaborators on our clinical trials. The aim of the survey was to understand the needs in terms of involvement and engagement with those we already collaborate with, to establish their needs in terms of involvement and engagement. This newsletter will share the results of the survey and highlight what we do well and what PPIE practice we will develop across the unit.

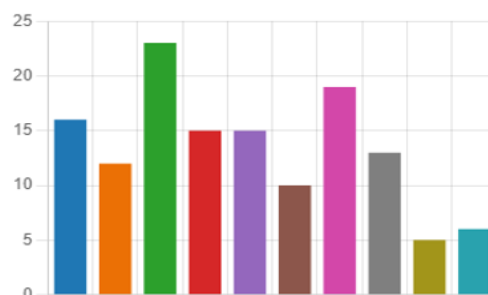
Invites sent to 38 PPIE collaborators across all CRCTU trial management teams  
We had 31 responses

**We asked how contributors heard about an opportunity to work with CRCTU on clinical trials:**

1. Most common contact from PI or research team directly
2. Recruiting through charities
3. General email or newsletter
4. Events

Patients, Parents, Carers and the Public are involved in activities across the journey of a clinical trial.

● Trial design and development	16
● Grant funding submission	12
● Patient facing documents (infor...	23
● Producing a lay summary	15
● Attend focus group or patient/c...	15
● Attend investigator meeting	10
● Member of Trial Management G...	19
● Member of Trial Steering Group ...	13
● Writing up of trial results/public...	5
● Other	6



### ABOUT CRCTU

An **Internationally** leading centre for the design and delivery of high-quality, **practice-changing** trials for **children, young people and adults** with cancer.

### OUR MISSION

Improve the lives of patients with cancer by developing **innovative, efficient and biology rich clinical trials**, with a **patient-centric approach** to trial design and delivery.

*“Thank you to all who took part in our survey”*

## EVIDENCE OF GOOD PRACTICE

14 responses showed that collaborators are part of Trial Management Groups (TMG) and Trial Steering Groups (TSG). 8 responders highlighted that they have a pre-meeting with the trial management staff and PPIE is an item on the agenda to be discussed. 5 people mentioned having a follow up meeting with trial staff, this is an area we would like to see develop. It is our aim to offer Pre and Post meetings with all PPI collaborators who take part in our TMG and TSC's.

A focus of the CRCTU PPIE strategy is to engage with PPIE representatives throughout the life cycle of the clinical trial. The survey asked how

involved contributors felt. It was exciting to hear 23 responses to say they feel involved throughout the trial.

Reflecting on the impact our collaborators have on a clinical trial is often informal through email/ phone contact with trial management staff. However, the survey showed that a large portion of collaborators would consider maintaining a reflection log.

**Ensuring patient, carer and public contributors are involved in each stage of the clinical trial is a focus of the CRCTU PPIE strategy.**

*When attending meetings with CRCTU does the chair of the meeting ensure you are welcomed and included throughout the meeting? (Rate from 1-5 with 5 being most satisfied)*



### ACCESSING

### TRAINING

Whilst many of the responses admit that they have received no formal training from CRCTU, collaborators access a wide range of existing training opportunities:

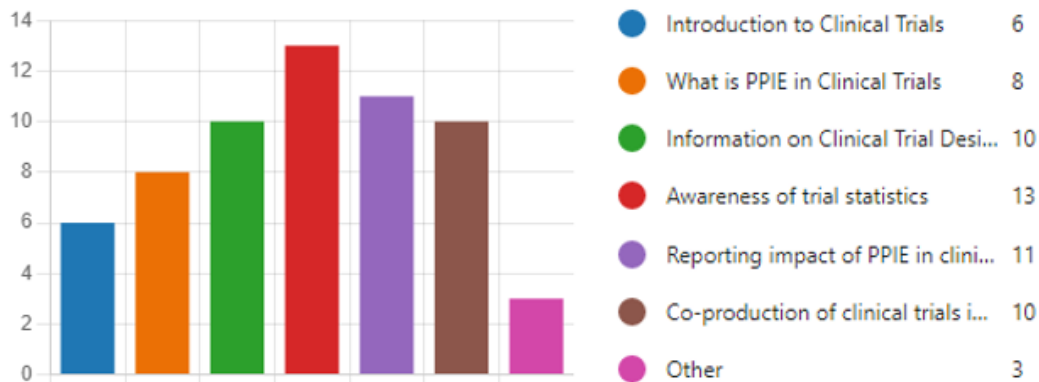
- Future learn
- Cancer Research UK
- Marie Curie
- NIHR
- NCRI
- VOICE
- Elaine Vickers
- ESMO

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### TRAINING

The CRCTU adopts a trial-specific approach to training, led by the patient and the team they work with. We are in an excellent position to deliver more formal and relevant training to our patient and public contributors.

**When we asked what would be the most relevant topics a clear priority was an awareness of clinical trial statistics.** We are running our first virtual session on 8th December at 3pm - please ask us to find out



## Preferences for events, training and meetings



Mid Morning	19
Early Afternoon	18
Late Afternoon	12
Early Evening	7
Other	5



Face to Face	9
On-line	24
Small focus groups	11
1:1 with trial staff	8
Other	2

### Do you have any feedback on how the information about a trial is presented to patients and their families?

*"I have experienced how the researchers and clinical experts can quite literally forget they are talking to someone with no medical or research expertise or knowledge of trials and rush through everything, or not even think about it, because to them it is all second nature.*

*I liken it to, for example, a police officer attending a household who has been burgled, all very mundane to the officer and bordering on boring/not exciting but is a massive crisis for the household bringing all kinds of unthought of emotions and handling of that crisis."*

*"Raise awareness amongst lead researchers of the importance and value of PPI and not just having them on board to meet funding requirements"*

**We are so grateful to all of the contributors who took part in the CRCTU survey. There was a variety of trials and trial management teams represented, including the following:**

STAR TREK medicine programme  
 Study RATInG Glo-BNHL VICTOR OCTAVE and OCTAVE  
 OCTAVE-Duo STAR TREC trial Lung Matrix clinical trial  
 Patient representative Brain Matrix BNHL trial  
 SIOP-HRMB acute GvHD placebo in patients  
 previously involved

### FEEDBACK...

Use trial website to communicate

Simpler language with less acronyms

Main issue is with the lip service given to having PPI involvement in this trail. It is not valued by the key investigator.

When I was involved with De-escalate the patient reps on the TSC wrote a summary of the outcomes for patients and families. This worked well.

It's like an IT technician who whizzes through showing you what to do if something goes wrong with your computer. It is so commonplace to them they forget that the person being shown is still grappling with the first button that was pressed.

Would be useful to ask patients/relatives to reflect back what they understand about the trial to assess if they've really given informed consent or just rushed through a process.

Usually PPIE collaborators make a substantial change to documents. In my experience being involved sooner rather later is better, maybe as part of the drafting group.

Many people have fixed ideas about what research is—lab rat, guinea pig, experimental, etc. They don't understand additional interventions to Improve quality of life etc.

**YOUR FEEDBACK IS CRITICAL TO US AND WE VALUE YOUR INPUT INTO IMPROVING OUR PRACTICE.**

**WE ARE IMPLEMENTING INFORMAL DEBRIEFING POST ALL TMG/TSC MEETINGS TO AID COMMUNICATION.**

**WE ARE PLANNING A THANK YOU EVENT TO RECOGNISE YOUR INVOLVEMENT.**

## INVOLVEMENT AND ENGAGEMENT IN CANCER RESEARCH AT BIRMINGHAM—ICRB

### INPUT FROM THE ICRB GROUP INTO...

Contributions to PhD grant submissions:

- Childhood Cancer
- Living with relapsed cancer
- Robotic Surgery
- Prostate Cancer
- Pain management in children's cancer

Circulating DNA study—shaping questionnaire and perceptions patients may have.

Design and reporting of dose finding trials, discussion and input into experience and beliefs around participating in a phase I clinical trial

Haematology Accelerated Trial platforms

Early Phase Clinical Trials

Inflammation—Advanced and Cellular Therapy Trials

Drug discontinuation in Clinical Trials

CRUK Accelerator Award

Input into A PPIE Strategy for Birmingham

New clinical trial for those with intracranial germinoma

'Can we predict which patients with BRAF-mutated colorectal cancer will benefit from the new treatment?'

In 2018, we established the PPIE group, ICRB. Currently with over 40 patient and public contributors, it has developed a greater PPIE presence across both the CRCTU and Birmingham ECMC. The group has met 14 times (between 2-4 meetings per year) and reviewed 24 projects, either pre-grant or during recruitment (15 clinical trials, 5 PhD projects and 4 strategic initiatives). Each review has led to changes that were incorporated into the grant application or protocol and many of these projects were led by junior investigators, embedding the value of PPIE into our future generation of leaders.

Please join us at the next ICRB meetings, which will be held on-line:

15th November	2022	12:30-14:00
19th January	2023	13:00-14:30
16th March	2023	13:00-14:30
7th June	2023	13:00-14:30

**If you would like to be included in emails about the ICRB group please contact**

**Karen Turner:**  
**[k.turner.1@bham.ac.uk](mailto:k.turner.1@bham.ac.uk)**



### NEXT STEPS...

Results from the CRCTU PPIE Collaborator Survey will guide us on the areas to develop best practice and focus on ensuring our collaborators are at the heart of the world class research at CRCTU. We plan to hold a thank you event to recognise your involvement and to share our progress in delivering our ambitious PPIE strategy.

Understanding and increasing the diversity of our collaborators and ensuring we are inclusive to all views will deliver an ambitious PPIE strategy for the CRCTU.

If you have any views shared within the newsletter or wish to reach out and talk about your experience as a PPIE collaborator with us please email: **[Engage@trials.bham.ac.uk](mailto:Engage@trials.bham.ac.uk)**

## ASKING THE PUBLIC FOR THEIR THOUGHTS ON PPIE...

### We want to hear from you...

Share your thoughts on the inclusion and engagement of patient, parents, carers and members of the public in the development and progress of our clinical trials

#### **Your voice matters to us and will shape our research**

Please take a few minutes to share your thoughts in our survey:  
<https://forms.office.com/r/7bYEz1kAui>

Or you can scan our QR code:  
Open the camera app  
Focus the camera on the QR code  
by gently tapping the code.  
Follow the instructions on the screen  
to complete the survey.



Please share the link for our General Public Survey with community groups.

Based around questions we asked our collaborators this general survey has no end date and is available for any member of the public to share their thoughts.



*Research WITH and BY patients, carers, parents and members of the public, not TO and FOR them*

## OPPORTUNITY TO GET INVOLVED

### Research participation opportunity



**Have you been diagnosed with CANCER?**

**Would you like to take part in a research project?**

What is our study about?	What will happen?	What will I have to do?
We are testing a new app to report your symptoms	You will take part in a one hour testing session	1. Download an app 2. Complete some questionnaires 3. Give us feedback



Email [Dr Christel McMullan](mailto:c.mcmullan@bham.ac.uk) for more information: [c.mcmullan@bham.ac.uk](mailto:c.mcmullan@bham.ac.uk)

Could you help our colleagues assess how easy app is to use?

The app being developed is called 'CIS Oncology ChemoPRO' and the team are keen to know how easy it is to use.

Share your thoughts and impressions of the technology to help develop this for patients.

Please contact Dr Christel McMullan at

[C.mcmullan@bham.ac.uk](mailto:C.mcmullan@bham.ac.uk)

# TRAINING OPPORTUNITIES

Join us on 8th December for an Introduction to Clinical Trial Statistics. This will be on-line from 3-4pm and is aimed at a lay audience who would like to understand more about how we use statistics in clinical trials.



Please email [Engage@trials.bham.ac.uk](mailto:Engage@trials.bham.ac.uk) if you would be interested in this event.



## Introduction to Randomised Controlled Trials

Discover the importance of trials in evidence based medicine and learn about the trial lifecycle from conception to publication.

Free on-line training opportunity at [Futurelearn.com](http://Futurelearn.com)

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Website: [birmingham.ac.uk/research/crctu](http://birmingham.ac.uk/research/crctu)

If you would like to feedback any comments or have any questions please contact us at: **Engage@trials.bham.ac.uk**

We would love to know if you found this newsletter interesting and if you have any requests for future issues.

Join us on Twitter @CRCTU