

# 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 our first 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 in the ICR-CTSU.

This Newsletter is co-produced by the ICR-CTSU (RAG) team and patient advocates who support us.

*Issue 1, 2024*



## Who are we, and what do we do?

The ICR-CTSU is a Cancer Research-UK funded, internationally recognised methodologist led clinical trials unit, specialising in cancer-focused clinical trial research expertise. We lead pioneering, efficient, high-quality, and impactful trials across all phases of clinical trials. Our expertise ranges from experimental medicine early phase studies to trials which may deliver widespread change to routine practice.

## Meet the Leads

The ICR-CTSU is led by Director Professor Judith Bliss (NIHR Senior Investigator), Co-Director Professor Emma Hall and Deputy Director and Operations Director Claire Snowdon. They are supported by a senior leadership and management team overseeing around 100 staff (including statisticians, trial and data managers, IT specialists and PhD students). Together with patient advocates the ICR-CTSU works to deliver ICR-CTSU research projects and clinical trials addressing the unmet needs of patients. Karen Poole coordinates the patient advocates involved with the CTSU activities.



*Prof. Judith Bliss,  
CTSU Director*



*Karen Poole  
PPI/E Lead*



## How did the Research Advisory Group come about

The ICR-CTSU PPI/E group had been running for many years but circumstances such as COVID and the retirement of the chair suspended the group. In 2022, Dr Karen Poole was appointed to get the ICR-CTSU PPI/E group up and running again. An invitation was sent to previous group members to determine whether patient advocates and research staff had any interest in re-establishing the group.

During a meeting in January 2023, it was decided that the activities of the group should reflect the expanding role of PPI/E at the ICR-CTSU and the ICR-CTSU PPI/E Research Advisory Group (RAG) was born. We meet regularly, have ambitious goals for the next few years, and have a clear strategy on how to deliver them. The group continues to expand (necessary to cope with the workload!) with an increase in both research staff and patient advocates.



### ICR-CTSU Patient Advocate Survey

In Autumn 2023, the PPIE RAG distributed a survey to the 50 advocates involved in ICR-CTSU trials to find out more about our advocates' experiences in life and PPI. Responses were provided by 43 advocates. Thank you for sharing your personal data as part of this survey.

The findings revealed that most advocates were of white ethnicity, identified as heterosexual, had previously held high socio-economic job roles, and had more than 5 years of PPI experience. It was also found that advocates are residing in various parts of the UK. The PPIE RAG is keen to use this research to address current gaps in ICR-CTSU's pool of advocates moving forward.

The results collected serve as an initial database on the demographics and vast experience held by the current CTSU advocates. This will inform future recruitment of advocates and allow the CTSU to recommend current advocates for trials that they are already suited too. Of the 43 (86%) respondents, 17 (39.5%) expressed interest in joining the PPIE RAG.

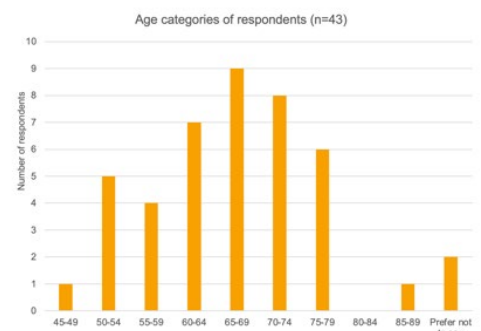
The working group will evaluate how to expand its membership with some of these respondents as it looks to continue its working developing patient and public involvement within the CTSU for 2024.

The survey provides a real insight of the patient advocates that we work with. It shows a good distribution of diversity by age and region within the UK. It also highlights the lack of current diversity in our patient advocates – something we are currently addressing.

By Matthew Tyler, ICR-CTSU Medical statistician

#### Online survey link sent to 49 PPI advocates on TMGs/TSCs by Trial Managers

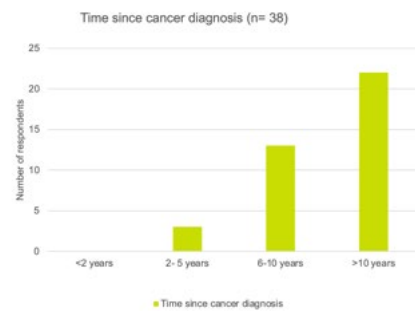
- 43/50 (86%) respondents
- 21 female, 22 male (all same gender as sex assigned at birth)
- 40 heterosexual, 2 gay/lesbian, 1 prefer not to say
- 41 white, 1 black/black British/Caribbean or African, 1 no response



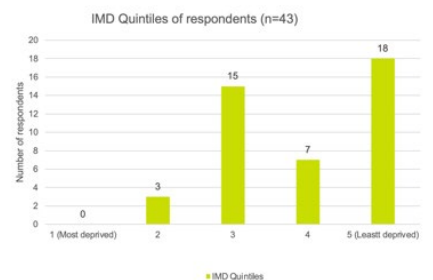
#### PPI Advocates involved with ICR-CTSU

- 4 people affected by cancer but not directly experienced cancer
- 29/43 (67.4%) have more than 5 years advocacy experience; 2 with less than 1 year
  - 22 NCRI Consumers
  - 17 ICPV members
  - 16 usemydata.org members
  - 5 NIHR Champions
  - 9 also involved with RM

(4 individuals involved in ICPV and NCRI and usemydata and are NIHR Champions (and one v. busy person is involved with RM committees too!))
- 17/43 (39.5%) have experience of trial participation



#### PPI Advocates involved with ICR-CTSU



- 35/42 (83.3%) completed qualification at degree level or above (3 with PhD)
- 37/43 (86%) had held jobs in ONS 2010 categories 1 or 2 (managerial/professional occupations)
  - 20 with occupation in STEM field

### Christmas Jingle & Mingle Event 2023

To the uninitiated a Jingle and Mingle suggests a campanologists' convention! However, attendees found it a well organised festive event for those new to PPI, the ICR and the ICR-CTSU or all three, PPI advocates and professionals alike. Having been brought up to speed with the ICR-CTSU achievements and future plans we got down to the serious business of mingling, sharing PPI stories and opportunities.

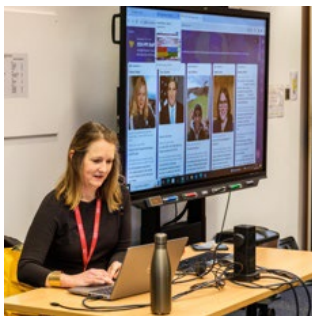
What was encouraging was to know that diversification is a significant future agenda item.

The main take home was that PPI is alive, well and expanding in the ICR-CTSU. If you're interested in joining, just drop us a line at: [ppi-icrcts@icr.ac.uk](mailto:ppi-icrcts@icr.ac.uk)

*By Monica Jefford, Patient Advocate.*



### Staff Training Session February 2024



*A combination of professional ICR-CTSU staff and patient advocates attended the training session chaired by Dr. Karen Poole*



I and four other Patient Advocates of the ICT-CTSU RAG PPI/E attended the latest staff training event. The event was interactive with front room talks undertaken by Karen Poole and Martin Lee. This seemed to benefit both staff and patient advocates. Each advocate sat at a table with ICR-CTSU staff members, enabling informative interaction and the exchanges of both ideas and experiences.

Both advocates and staff came away with ideas of doing things differently, and a better understanding of each other.

There was some terrific feedback on the day and the room was buzzing during discussions' – not only about advocacy, but also about crochet!

*By Mairead MacKenzie, Patient Advocate*

## ICR-CTSU Advocate Profile

Ray Gardner was diagnosed with prostate cancer in 2018 and, following successful treatment at The Royal Marsden, is now in remission.

He was invited to join the Patient/Carer Advisory Group at the RM in early 2019. He subsequently became involved in patient advocacy in clinical services at the RM and then cancer research at the ICR. He has been an advocate on cancer research trials, trial steering committees, advisory groups, and is a keen supporter of pre-doctoral research applications and the Senior Adult Oncology Program at the RM.

He is currently co-chair of the ICR-CTSU PPIE Research Advisory Group.



*Ray Gardner  
ICR-CTSU PPI/E RAG Co-Chair*

## Our Plans for 2024

We have developed our activities into six themes that are aligned with the NIHR UK Standards for Public Involvement (2019). Project teams have then been created to ensure that cross-theme initiatives are properly managed. Our focus for 2024 is on learning, increasing both the numbers and diversity of our advocate representation, and communication. Our plans are guided by the NIHR Standards for Patient and Public Involvement. If you would like to be involved in any of these areas, please contact Karen Poole on [ppi-icrctsu@icr.ac.uk](mailto:ppi-icrctsu@icr.ac.uk).

### 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

## Our ICR-CTSU Contacts

**Our 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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