

CANCER RESEARCH UK CLINICAL TRIALS UNIT

Patient and Public Involvement and Engagement (PPIE) Newsletter: Winter 2023



Welcome, from the Director of Precision Medicine Trials, Dr Rowena Sharpe:

The work we do is only made possible by our patients and the public and we would like to tell you more about it before, during and after each trial. This newsletter is for you and needs to be driven by what you would like to see, so please let us know at engage@trials.bham.ac.uk and in the meantime, a massive **thank you** from us; we hope you enjoy reading this edition.

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.

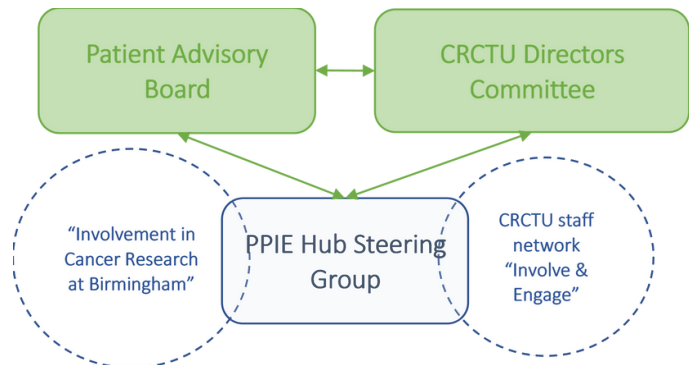
Our Mission:

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.

CANCER RESEARCH UK CLINICAL TRIALS UNIT (CRCTU) PATIENT ADVISORY BOARD

A key part of our CRCTU and PPIE strategy involves forming a Patient Advisory Board, with its membership comprised of patients from across our key disease areas of research. Our Patient Advisory Board aims to ensure that our work is driven in partnership with patients and the public by providing guidance and input to crucial CRCTU strategic and operational areas. The Patient Advisory Board will work closely with the CRCTU Directors' Committee.

The Patient Advisory Board will join several initiatives within the CRCTU, including a PPIE Hub Steering Group (including staff and patient membership), a CRCTU Patient Group (Involvement and Engagement in Cancer Research at Birmingham – ICRB) and a staff network 'Involve and Engage'. A summary of how these groups interact is shown below:



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INVOLVEMENT AND ENGAGEMENT IN CANCER RESEARCH AT BIRMINGHAM (ICRB)

YOUR OPINION

In 2023 we would like to understand those who attend the ICRB a little more, and hopefully 'refresh' the meetings to reflect what you would like to see. If you have the opportunity it would be appreciated if you could complete an online feedback form to provide valuable direction to the group.

COMPLETE SURVEY



In 2018 we established the Patient, Public Involvement and Engagement group, ICRB. It has since developed a greater PPIE presence across both the CRCTU and the Birmingham Experimental Cancer Medicine Centre. The group meets four times a year, and has, to date, reviewed over 24 projects, each time leading to changes that were made to grant applications, protocols and trial documentation.

The ICRB group is a valuable resource allowing patients, carers and members of the public to collaborate with researchers and embed the value of collaboration for our future generation of research leaders.

New members are always very welcome to join the group - please contact us for information.

Next meeting dates (online): 16th March 13:00-14:30 and 7th June 13:00-14:30

LEARN MORE



PPI OPPORTUNITY

Within the CRCTU we have several clinical trials that do not currently have any PPIE collaboration. Some of these are older trials that are now reporting on their results. We are keen to speak to anyone who would like to join the team and read through prepared trial summaries, to ensure the lived experience is included in the reporting of these trials.

APPLY NOW



FOCUS ON TRIALS

National Lung Matrix Trial

THE POWER OF COLLABORATION

The National Lung Matrix Trial (NLMT) is now closed to recruiting patients in clinics and is due to report results from the many treatment arms (after recruiting 423 patients across 26 UK Hospitals, including the Experimental Cancer Medicine Centres). There has been extensive national and international interest in the trial and the CRCTU has shared the experience with clinical, scientific, statistical and trial management communities, with presentations given around the world. The initial trial results were published in the prestigious scientific journal, *Nature* in July 2020. NLMT was highlighted in the recent Department of Health and Social Care (DHSC) document 'Saving and Improving Lives: The Future of UK Clinical Research Delivery' as a trial that "shows the power of collaboration, through the UK's integrated health research system".

This was a complex innovative design with multiple industry collaborations, integrated biology and personalised medicine. NLMT is our flagship precision medicine trial for patients with non-small cell lung cancer (NSCLC).



PATIENT REPORTED EXPERIENCE MEASURE (PREM)

AMMO is a randomised phase 2 study of a drug called ASTX727 versus best supportive care in types of blood cancers called myelodysplastic syndrome (MDS)/Myeloproliferative neoplasm (MPN) overlap syndromes. In addition to comparing how well patients respond to the trial treatment, the trial also includes a PREM sub-study. This sub-study aims to better understand why patients choose to take part in clinical trials, what obstacles they face and how trials might be designed better in the future, specifically for patients with these diseases.

This will be measured using questionnaires given at the start of the study, following treatment and 12 months after entering the trial. At these time points, patients will also be invited to interviews with nurses to discuss their experience further. Feedback will also be requested from patients who decline to enter the study or subsequently withdraw.

The sub-study is in collaboration with the University of Manchester and The Christie NHS Foundation Trust.

PRACTICE CHANGING IN CHILDREN'S CANCER

The EE2012 clinical trial is an international practice-changing randomised controlled phase III trial in children's cancer.

Looking at Ewing Sarcoma, a rare bone sarcoma most commonly diagnosed in teenagers and young adults for which, at the time of trial inception, there were no novel therapeutic options nor was their international agreement on the most effective backbone induction chemotherapy. EE2012 was an international randomised controlled trial (RCT) for newly diagnosed Ewing Sarcoma, and in keeping with CRCTU's age-inclusive approach was open to patients aged 5 years to 50 years. The trial was a core part of the EU FP7 funded Euro Ewing Consortium (EEC) and was developed in close collaboration with the EEC Patient Advocacy Group.

Over a period of 51/2 years, 640 patients were recruited from 112 sites in 10 countries, and randomly assigned to receive either vincristine, ifosfamide, doxorubin and etoposide (VIDE) or vincristine, doxorubicin, and cyclophosphamide alternating with ifosfamide and etoposide (VDC/IE).

The trial used Bayesian design to answer an important treatment question with as few patients as possible, showing preference for VDC/IE which also has no excess toxicity with VDC/IE, and the regime duration is 3 months shorter in treatment length.

The outcome has already changed practice in Europe and informed the design of CRCTU's current CRUK-funded 'InterEwings1' trial.




THE SMALL TRIAL

The SMALL study will recruit 800 women whose breast cancer is early-stage and has been detected through the NHS screening programme, with 500 of those women assigned to the test treatment. The trial will test the standard treatment versus the use of radiotherapy-guided 'minimally invasive vacuum incision'.

COLLABORATION AT THE ROYAL COLLEGE OF SURGEONS

The SMALL trial team took part in an information day for healthcare professionals working across approximately six trials, including the SMALL trial. This was held at the Royal College of Surgeons, London in January 2023, initiated and organised by the SMALL Trial Chief Investigator and the QRI team. 70 active researchers from across the UK attended, as well as the SMALL trial patient representative.



PATIENT ADVOCATE, HILARY STOBART'S VIEW

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Last week, 16th January 2023, I was able to attend a Breast Surgical Trials Day held at the Royal College of Surgeons (RCS). It was very well-attended with about 80 people with different hospital roles from units up and down the country. There were also two patient advocates there including myself. There should have been two or three more, I think, but the flu season took its toll!

It was great to see some of the range of surgical trials that are available to patients and the very collaborative nature of the research and the meeting. Six trials were presented by their Chief Investigators at this event, explaining the criteria, the purpose, and the progress so far. This left time for everyone to discuss and ask questions. For example, challenges to recruitment were raised from a number of units with others suggesting solutions. There was a question from one of the patient advocates about how black participants might be better engaged, and she offered some ideas. The afternoon session then built on these discussions with a session from the University of Bristol QuinteT group about conveying equipoise and engaging with treatment preferences.

RCS put on a very tasty lunch so there was plenty of time to speak to people during the breaks to carry on the conversations. The meeting was an excellent opportunity for multiple disciplines, including patients, to meet together to discuss trials. I look forward to the next one.

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World
Cancer Day
4 February

Close 
 the care
gap 

WORLD CANCER DAY - 4TH FEB

The theme for this year's international cancer awareness day is #CloseTheCareGap, with a message that everyone deserves access to cancer care.

This year you can follow the campaign online to unite your voice and take action to spread the word.

LEARN MORE



This international awareness event gives everyone the chance to play a part in creating a cancer-free world. Last year the campaign highlighted the inequalities in cancer care around the world and shared the reality that:

- Inequality in cancer care costs lives
- People who seek cancer care hit barriers at every turn
- Income, education, location and discrimination based on ethnicity, gender, sexual orientation, age, disability and lifestyle are just a few of the factors that can negatively affect care
- The gap affects everyone
- These barriers are not set in stone, they can be changed

JOIN THE 21 DAY CHALLENGE

Commit for 21 days to raising awareness about cancer and closing the care gap. You can choose from one of the three challenges (improving your personal health; making history by helping to eliminate cervical cancer; educating yourself and speaking out about the inequalities that exist in accessing cancer services) – one day at a time for 21 days.

Simply sign up to receive daily inspiration and practical guidance at the 21 Days to Impact Challenge.

SIGN UP



CRCTU HIDDEN HEROES

FROM RESEARCH NURSES TO STATISTICIANS, MEET THE PEOPLE WORKING HARD BEHIND THE SCENES TO DELIVER THE CRCTU'S PIONEERING CLINICAL TRIAL PORTFOLIO. PATIENT COLLABORATOR, SHAUN BOWDEN CHATTED TO CRUK SENIOR RESEARCH NURSE, KAREN TURNER



SB: CAN YOU TELL US EXACTLY WHAT YOUR ROLE AND RESPONSIBILITIES ARE WITHIN CRCTU?

KT: As the CRUK Senior Research Nurse I am the team leader for the nursing team, who deliver trials locally at the University Hospital Birmingham NHS Trust. The team are specialised and they deliver the treatments of early phase cancer treatments in the local NHS Trust.

KT: In addition to this I support Cancer Research UK, to showcase the local research to supporters and members of the public. From a press interview to helping one of the local fundraising teams reach out to one of the groups that they work with. I really love working with these teams as it's a privilege to thank supporters, meet them and talk about the science. Explain what's happening locally, how credible it is, but also just hear their story and link what we're doing in the lab to what we're doing with patients as having an impact.

KT: A part of my role I enjoy is working with the wonderful CRUK Senior Research Nurses around the country from most of the major centres. We get together regularly and look at where the gaps are in our areas and work together as a whole. This also includes a key part of my role, including the living voice of patients and carers in our research.

SB: DID YOU SET OUT TO WORK IN CANCER RESEARCH, OR DID IT JUST HAPPEN?

KT: I enjoyed the complexity of balancing the care, psychological support and the holistic care of cancer patients. So when I qualified as a registered general nurse I went down to the Royal Marsden Hospital in London, and worked on many wards, which was a wonderful experience. Working across different wards I noticed that people were experiencing the same things; there were those commonalities, and that led to an interest in cancer fatigue that patients experience. I followed this up for my dissertation when on my Degree in Cancer Nursing course.

KT: I did fall into clinical research nursing mostly from a dislike of night shifts anymore. I soon found it was incredible to have that sort of role where you played a part in new treatments and discoveries. Every day was different, and that's where I got the research bug, coming back to Birmingham in 2000 as an Oncology Clinical Nurse Specialist it didn't take long for me to find my way down the road to the University of Birmingham and the Cancer Research UK Clinical Trials Unit in 2002.

SO IN TERMS OF WHAT YOU DO, YOU SEEM TO HAVE A MIXTURE OF ROLES AS A MANAGER, CRUK NURSE AND A RESEARCHER. IS THERE AN AREA THAT YOU ENJOY MOST? OR IS IT A BLEND THAT YOU REALLY ENJOY?

KT: I think it's the blend, because as a manager I look after the most amazing team. I'm very privileged to get feedback from them on current clinical trials and they can have input into the trials. You could have the best science in the world, but if it isn't going to work practically patients will not go into the trial.

KT: I love the patient involvement and that's a part of what keeps me going, even on a bad day, you'll meet somebody who just floors you completely with their story and support. It is very rare, I think, at my age now to be in a job in a position that can take you back to day one of your passion.

CRCTU HIDDEN HEROES

SB: IF I ASKED YOU WHAT YOU FOUND THE MOST DIFFICULT PART OF YOUR JOB, WHAT WOULD YOU SAY ABOUT THAT?

KT: Probably all the hats I've got to wear, and the order you've got to keep them on and off. Also, it's no secret that the NHS is having lots of problems at the moment. It's under enormous strain, and the service delivery is difficult enough without us coming along with a clinical trial adding to what needs to be done.

SB: IN THE TIME THAT YOU'VE BEEN DOING THIS. WHAT ARE THE MOST IMPORTANT CHANGES THAT YOU'VE ACTUALLY SEEN HAPPEN?

KT: A lot of my early research was in haematology, with a disease called multiple myeloma. At the time patients would get diagnosed quite late and we had few options for treatment. At the time we did research on some really intense high-dose treatments, which was a lot for people, and it could often have severe problems due to infection. And if we had a patient that we saw for 3 or 4 years, that was good, but now in the clinic, these patients are in 10+ years of treatment with it becoming more of a chronic condition almost like diabetes.

SB: JUST TAKING THAT A STEP FURTHER THEN, WHAT DO YOU EXPECT THE CHANGES IN THE FUTURE TO BE?

KT: I think the next generation is really going to see the progress of the advances we're making now with targeted cancer treatment. To look at somebody's cancer in a more individual way, discovering what makes that cancer grow/what drives that cancer. What is making it disobey the rules that the other cells in the body listen to?

SB: WHAT WOULD YOU PUT DOWN AS YOUR GREATEST OR MOST MEMORABLE ACHIEVEMENT?

KT: Recently it is working with researchers and scientists to reach out to patients and carers to have input into the research. Sometimes the researchers are quite young/early in their careers, and they've never been exposed to collaborating with patients in this way. I just love sitting back and introducing them to each other, the scientists can talk about the research they're doing. But patients and carers can comment on so many aspects of the research, some of which are very practical elements. I enjoy watching the researchers really listen to you and think maybe they should try that. When they really listen to you, it can have a dramatic, real impact.



SB: YOU FACILITATE A GROUP OF PATIENTS, CARERS AND THE PUBLIC TO BE INVOLVED WITH RESEARCH, CALLED THE INVOLVEMENT AND ENGAGEMENT IN CANCER RESEARCH AT BIRMINGHAM (ICRB). WHERE DO YOU SEE THE ICRB GOING OVER THE NEXT FEW YEARS?

KT: I'd like to see it grow in its power and influence. We are going through a 'refresh' to see what works, what people would like to see more of, and less of, and raise the profile of the group. It's not an exclusive group, the more people who'd like to join in to come along and listen the better. I'd like to see the group become more diverse and really start to identify problems that you all experience. Really show researchers that if you collaborate with those who have the lived experience of cancer you are going to have a project that is robust and well-designed for the patients who will actually want to go into it. We have to make clinical trials that are patient-friendly.

SB: ONE OF THE THINGS I'VE NOTICED IS THAT THE TERM CLINICAL RESEARCH OR CANCER RESEARCH, CAN STILL CAUSE FEAR IN SOME PEOPLE. HOW DO WE OVERCOME THAT FEELING OF FEAR OR OF UNCERTAINTY?

KT: It's about demystifying what it means to be in a clinical trial. We have to talk to people and make sure we don't keep our research a really well-kept secret. We have to bridge that gap and let people know what we do, especially in the area. There's a lot to be proud of in Birmingham/West Midlands. We do an awful lot of research, and we've improved things for people with cancer.

KT: As a CRUK Senior Research Nurse I attend engagement events and we have several tabletop demonstrations to try and demystify this a little bit. But the more we could hear from people like yourself, and what it means to be on a clinical trial the easier it will be to remove the fear.



THE BIRMINGHAM EXPERIMENTAL CANCER MEDICINE CENTRE (ECMC) FUNDED FOR A FURTHER FIVE YEARS

The Birmingham ECMC, jointly funded by Cancer Research UK and the National Institute for Health and Care Research in England, provides world-leading expertise in the development of innovative cancer trials. New funding will enable researchers from the centre to continue to conduct the highest quality trials into experimental treatments for cancer, focusing specifically on precision medicine, cancer immunotherapy and biomarker-driven patient stratification.

Congratulations to the team and the patient contributors who developed the funding application for the Birmingham ECMC to be an integrated translational hub for cancer research in Birmingham.

HAVING THE PATIENT, LIVED-EXPERIENCE SUPPORTING THE FUNDING APPLICATION WAS A KEY PART OF THE SUCCESS.

SHAUN AND DEREK ARE TWO OF OUR PATIENT COLLABORATORS WHO MET WITH THE TEAM AND WERE INVOLVED IN THE APPLICATION, WE ASKED THEM WHAT THIS INVOLVEMENT MEANT TO THEM

“Personalised medicine is vitally important in ensuring that individual treatment is targeted - in order that it is effective and that side effects are reduced.

We believe that the Birmingham group has a vital role to play in research which is laboratory based initially but can then be translated to the clinic.

As the funding application progressed we were able to see and comment upon the significant scope for PPIE within the proposals and within the whole philosophy of the group.

As patient representatives, we are pleased to see the serious consideration that the Birmingham ECMC bid is giving to PPIE principles. The desire to embed these principles within the operation is reassuring and should significantly enhance outcomes for both patients and researchers.”

LEARN MORE



TRAINING

“WHAT AN AMAZING PRESENTATION. I HAVE BEEN DOING PPI FOR 9 YEARS AND HAVE LEARNT SO MUCH TODAY. THANKS, PETER AND WOULD LOVE FURTHER OPPORTUNITIES TO LEARN”

ON 8TH DECEMBER PETER FLETCHER, SENIOR BIOSTATISTICIAN, TOOK US ON A TOUR OF THE WORLD BELONGING TO CLINICAL TRIAL STATISTICS.

21 delegates joined us as Peter gave an introduction to clinical trials and the background to statistics in health research. Peter is keen to deliver more sessions and we are really interested in hearing your thoughts.

TALK TO US 

SAVE THE DATE

Midlands Health Alliance is celebrating PPIE in the Midlands with free events between 16th - 18th May.

Providing researchers with the opportunity to understand the impact that PPIE can have across the research infrastructure from initial ideas through to grant submission. For PPIE managers, the chance to understand more about the NIHR, other research landscapes and how to share best practice. For members of the public: Become involved and learn how to support your NHS and its research priorities.

SIGN UP 

BRAINSTRUST

There are a series of opportunities for those affected by brain cancer, all available to book on Eventbrite.

Coming up on 15th February 2023 is a Hypnotherapy Webinar for calmness and confidence around medical processes and procedures.

SIGN UP 

FUTURE LEARN

Talking About Cancer: Reducing Risk, Early Detection and Myth-busting.

Learn from experts at Cancer Research UK about how you could save lives by talking about cancer prevention and early detection.

SIGN UP 

IF YOU WOULD LIKE TO FEEDBACK 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.