

Patient and Public Involvement Focus

Welcome to our PPI newsletter!

Welcome to our winter issue of the King's Clinical Research Facility (CRF) Patient and Public Involvement (PPI) newsletter.

In the latter part of this year, we've been working towards meeting our strategy goals for 2023, which are outlined in the [CRF public involvement strategy](#). For the first time we invited public members to the UKCRF Network Conference and our Annual Research Strategy Meeting. It was a great opportunity to meet in person and to learn about the future direction of clinical research.

In this issue we will reflect on these events, and we will update you on some other projects happening across the CRF.

We would like to thank for all your hard work and support this year. We hope you have a wonderful holiday period and a good start to the New Year. We're looking forward to what 2024 brings.

The Public Involvement Team, on behalf of the King's CRF

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Meet the team at King's CRF!

Each newsletter we'll introduce you to a member of the King's CRF staff, and a member of our PPI group. We hope you enjoy getting to know a little bit more about these individuals and why they enjoy their roles.

Upcoming Celebrations Our 10 year anniversary

King's CRF turns 10 years old in May 2024. Since opening our doors we've hosted over 1,100 studies! Look out for information about celebration events, and special communications pieces next year.



What is the UKCRF Network?

UKCRF NETWORK

The UKCRF Network was established in 2008 and it is made up of 54 CRFs across the UK and Ireland.

The Network aims to provide support and share good practice in clinical research. It is led by a Senior Leadership and Management Team and there are four key areas of work the Network is currently focusing on:

- (1) **Operational Delivery**, tackling barriers to clinical research
- (2) **Strategic Leadership**, building partnerships with research funders
- (3) **Workforce Development**, meeting the needs of employees
- (4) **Involvement and Inclusion**, promoting PPI and improving patient experience

Find out more by visiting the UKCRF Network [website](#).

The UKCRF Network hosts a conference every year, which you can read more about on page 2-3!

Albert – Clinical Research Practitioner



Albert is a Clinical Research Practitioner (CRP), and he plays a crucial role in conducting and managing clinical trials at the CRF. Overall the role of a CRP is to make sure we stick to ethical and regulatory standards, collect study data and do procedures such as take blood, and help to develop new treatments. CRPs work closely with other healthcare professionals, researchers, and regulatory authorities like the [Health Research Authority](#).

For Albert, the rewards of his job include improving patient care and being at the heart of scientific innovation. He enjoys the stimulating environment in research. He feels that his role offers opportunities for professional growth, and provides a sense of fulfilment as he positively impacts the health and care of patients.

Sonia – PPI member

Sonia is a graduate in public health and health promotion and has primarily focused her work on health and wellbeing. Sonia joined the PPI group at the CRF to advocate for patient healthcare and represent the public. As a PPI member, she enjoys collaborating with researchers to introduce new ideas and contribute to the wellbeing of others. Sonia also appreciates the opportunity to meet like-minded individuals who share the same interest.



UKCRF Network Conference



In July 2023, we attended the UKCRF Network Conference in Nottingham. The theme of the Conference was 'Leading life-changing research: realising the potential of experimental medicine.' Experimental medicine, also known as early-phase clinical research, is undertaken in people to better understand the cause of disease or to test new treatments.

On the first day we heard from national and international speakers on interesting topics such as the role of Artificial Intelligence (AI) in clinical research, and the challenges of conducting research in prison populations. On the second day the focus was on 'summer school' sessions with in-depth discussions on the following key areas: research inclusion in a CRF, social media and diversity, managing student placements within a CRF and applying management skills to setting up studies.

December awareness days

National Grief Awareness Week 02/12-08/12

Encourages empathy and support for those who are grieving. The week aims to show that grief is a natural response to loss and is a very personal experience. Read more [here](#).

International Volunteer Day 05/12

This day aims to celebrate and recognise the contributions of volunteers across the globe. It highlights that volunteering contributes to a better and more inclusive world. Read more [here](#).

Christmas Jumper Day 07/12

This is Save the Children's annual event to raise money for children who need it most. At the CRF we'll be putting on festive knits and donating to show our support. Read more [here](#).

We'd like to feature blogs on our website with your stories to honour and celebrate these awareness days.

If you're interested in sharing your experiences with us, please email catherine.harvey15@nhs.net

You can read some of the excellent blogs written by PPI members [here](#)

These blogs cover a range of topics: inclusion in research settings, raising awareness about mouth cancer, stress and tips on how to deal with it, and living with disabilities.

Thanks so much to all our authors.

For the first time a PPI member, Firoza, attended the conference with us (seen in the photo bottom row, second from the right). It was great for CRF staff to meet Firoza in person, and Firoza made really valuable contributions to the summer school session about research inclusion.

The 2024 Conference will be held on 4th – 5th July in Leicester and will be about ‘Making the Invisible, Visible: Equal Access to Clinical Trials for All’. Look out for emails from us in the New Year about how you can express your interest to attend.

“I had a really good time at the conference! I was made to feel very welcome by the King’s CRF team, and I felt like a part of the team which meant a lot to me. I also felt brave and spoke out during one of the afternoon sessions, which was a big deal for me - but the other researchers in the room really listened to what I had to say, and took on board my comments; which for me is what PPI is all about.”

Firoza, public member, conference attendee and conference representative for the CRF

Equality, Diversity and Inclusion



At the King’s CRF we aim to ensure our staff members and public members feel included and like they belong. We have produced an Equality, Diversity and Inclusion (EDI) strategy in partnership with King’s College Hospital EDI team as a step towards this goal. You can read the strategy here: <https://maudsleybrc.nihr.ac.uk/nihr-kings-clinical-research-facility/our-edi-strategy/>

We held an initial training session for all staff in July 2023, to try to understand what they already know about EDI, their experiences, and what they would like more support on. This training session was informed by survey results gathered in June 2023. The training session was co-delivered with a public member, Peter, who recently participated in a clinical trial at the CRF and who is passionate about making research spaces inclusive. During the session, Peter highlighted the importance of:

- ✓ *Using inclusive language when speaking with diverse research participants*
- ✓ *Providing safe spaces for individuals, not presuming where certain communities will feel psychologically safe (and where they won’t)*
- ✓ *Taking time to explain research clearly to all research participants. This includes telling participants exactly what will happen to them as part of the study, and how it might make them feel*
- ✓ *Being aware of research participants’ unique experiences and backgrounds. Staff, where possible, should be flexible in their approach, and adapt the environment for individuals’ needs.*

We now aim to develop a clear EDI action plan, in collaboration with 3 public members. We will also submit an abstract to an NHS Research & Development Conference in 2024 about our EDI plans and work. We will keep you all updated with our progress!

Chemotherapy trials at King’s CRF

We have been working hard to gather the views of healthcare professionals and public members about whether the King’s CRF would be a good or not-so-good place to host chemotherapy trials in the future. Chemotherapy uses anti-

cancer medicine to erase cancer cells. Despite best efforts, sometimes chemotherapy does not work, and this is why more research is needed.

In order to gather everyone's views on this topic, we produced a survey alongside 3 of our public members. Their input ensured the survey questions were relevant, understandable and in a suitable format. We're very grateful for their involvement in this piece of work.

"It's been great to co-produce this survey with the CRF and it demonstrates an understanding by the CRF that the voice of PPI lay persons is of paramount importance"

Manos, public member and part of the survey development team

The survey closed in November 2023, and we received 274 responses from PPI members at the CRF, the Cicely Saunders Institute (which focuses on Palliative Care Research), and the wider King's College Hospital PPI members and volunteers.

The initial results show that approximately 65% of respondents **strongly agree** or **agree** that King's CRF can appropriately arrange and host chemotherapy trials, and approximately 70% **strongly agree** or **agree** that staff can positively support chemotherapy trials.

The free text comments provided us with some really useful insights about the strengths and areas for improvement for the CRF. The comments from PPI members broadly fall under the following categories:

- 1) The need for collaborative working:** between the CRF, support centres such as Macmillan, and the hospital cancer teams.
- 2) The need for high quality participant information and greater publicity of the CRF:** some respondents who had a lot of experience in cancer and chemotherapy trials were not aware of the CRF.
- 3) The importance of diversity and inclusion:** many respondents highlighted the diverse community King's College Hospital (KCH) serves, and that all communities should have access to clinical trials.
- 4) The reputation of KCH:** respondents who had good experiences in other departments at KCH, inferred that their experience at the CRF would be just as good.
- 5) The importance of excellent staff care:** respondents noted that the CRF team are close and care about their work and participants.
- 6) The quality of existing infrastructure:** the CRF was identified as containing excellent, modern, and safe facilities.
- 7) Practicalities including transport:** many respondents stated that Denmark Hill is not easy to get to, and that parking is limited.

These results, alongside the results from the healthcare professionals' survey, will be included in an internal report.

A huge thank you to everyone who completed the survey! If you'd like to find out more about this project please email Sergio Munoz-Villaverde, the CRF Chemotherapy Research Services Information Analyst on: s.munoz-villaverde1@nhs.net

Annual Research Strategy Meeting

In October 2023, the Research and Development (R&D) Office at King's College Hospital hosted the Annual Research Strategy Meeting. The R&D Office supports the work of the King's CRF and the researchers who use our facilities.

The five-year R&D strategy was launched in 2019, and every year the R&D Office has provided updates on their progress. This year was the first time we all met together since COVID-19, and it was also the first time patients and members of the public were invited to attend. We were delighted that 6 PPI members from the King's CRF joined us on the day. The first session of the meeting focused on 'Research highlights' and Professor Peter Goadsby, the Director of King's CRF spoke about our accomplishments. These include exciting studies in the following areas: addiction research including opioid overuse, Paroxysmal Nocturnal Haemoglobinuria (PNH, a rare blood condition), and psychosis.



"The attendance of patients at the meeting reflects the crucial importance of their direct involvement in all aspects of the investigative journey, and our commitment that their views will be heard and implemented"

Professor Peter Goadsby, Director of King's CRF

The second part of the day was all about patient voices. There was a powerful presentation from members of the [Red Ribbon Living Well Foundation](#), and they spoke about how HIV research had made a personal impact on their lives and in their communities.

Training needs survey



It has been almost a year since we established our public involvement network at the King's CRF. Thank you so much for your patience and honest feedback while we've all been on this journey together.

We'd really like to know how we can support you and improve your experience as public members as we go into 2024. For this reason we've co-produced a survey with 2 public members which includes questions about whether you'd like training on particular topics, and if you know how to access information and support currently.

We'd be very grateful if you could please complete this anonymous survey: <https://forms.office.com/e/YFm31694ry> it should take you about 15 minutes to complete. None of the questions are mandatory and all results are anonymous to us. Thank you so much in advance!

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Have a virtual tour of our facilities:

<https://www.maudsleybrc.nihr.ac.uk/nihr-kings-clinical-research-facility/about-crf/>

Thank you to everyone who contributed to our website by carefully reviewing and authoring content. It is greatly appreciated and the website is much better and more user-friendly thanks to your efforts.