

Patient and Public Involvement Focus

Welcome to our PPI newsletter!

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

In this newsletter we will continue to keep you updated on our work, this includes working towards our goals in both our [PPI](#) and [Equality, Diversity, and Inclusion \(EDI\)](#) strategies. We are extremely pleased that we have held PPI workshops collaboratively with Guy's and St. Thomas' CRF in January and April, and hosted EDI training for staff in March and May. We have included updates on these events in this issue.

As always, we are very grateful for your hard work and support. We appreciate your openness and flexibility as we try new events and different styles of meetings. We wish you a happy summer and look forward to the rest of 2024 with you!

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

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Meet the team at King's CRF!

In each newsletter, we will 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 Events

Annual Research Strategy Meeting

King's College Hospital (KCH) Research & Development will be hosting their Annual Research Strategy Meeting on **Thursday 19 September in a venue near KCH in Denmark Hill, London, SE5 9RS.**

The session will provide an update on studies from different departments. If you are interested in attending and/or would like more information please contact catherine.harvey15@nhs.net.

Spotlight on our studies: MND



June 21st marked Global Motor Neurone Disease (MND) Awareness Day. MND affects the nerves (known as motor neurones), found in the brain and spinal cord. It causes weakness that gets worse over time. There is no cure for MND, but there are treatments that help improve day-to-day life.

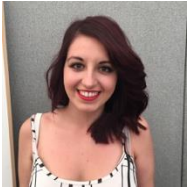
At King's CRF, we host several studies looking into treatment options for MND patients, particularly where the MND runs in families.

Pratik Solanki, a Clinical Research Practitioner, supports these studies:

“Research in this field is so important, as early detection and prevention of MND may help individuals stay more physically independent.”

To find support and/or to read more about MND please click [here](#).

Layla – Communications Officer



Layla joined in March 2024 as our new Communications Officer to help promote the research that is happening at the CRF and encourage more people to get involved. This includes sharing positive news about the CRF online and with the media, creating resources such as booklets and leaflets, and managing events.

Layla is passionate about making sure information is clear and easy to understand so it is accessible to all, with a particular interest in how communications can help encourage more people from underserved communities to take part in research.

For Layla, the most rewarding part of her role is speaking to patients about how research has positively impacted their lives and sharing their stories.

Anna – PPI member

Anna is a retired Further Education/Higher Education Programme Leader in Early Childhood Development. She did her Master's in Education as a mature student in her forties, and still felt she had something to offer at retirement age.



Anna got into PPI work almost by mistake; she had a hip replacement and ticked a little unobtrusive box asking for feedback on her experience. The rest, as they say, is history! Anna has extended her range of lived experiences because of life's little crises. She is committed to keeping intellectually active as there is a strong history of dementia in her family - *"if you don't use it, you lose it."*

Collaborative working with Guy's and St. Thomas' (GSTT) CRF



This year, we have been working closely with Guy's and St. Thomas' (GSTT) CRF to co-develop and co-deliver virtual events for our PPI members, as outlined in our [strategy action plan](#). Collaborative working is an important way for CRFs to share resources and skills, and for PPI members to meet as a wider group.

Since January 2024 we have successfully held the following:

Joint knowledge exchange style meeting

In late January, King's and GSTT CRF PPI Leads and PPI groups came together for a virtual meeting to learn about the different roles in clinical research.

July awareness days

International Self-Care Month 24/06-24/07

This month aims to celebrate self-care practices such as regular exercise, eating a healthier diet, and looking after your mental health. Read more [here](#).

National Schizophrenia Awareness Day 25/07

This day explores what it is like to live with a mental health condition that is often misunderstood and stigmatised. Read more [here](#).

World Hepatitis Day 28/07

This day is a call for action to end hepatitis, an inflammation of the liver, which is an entirely preventable disease. Low coverage of testing and treatment is the most important gap to be addressed. 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](#)

This includes a blog written by one of our members about their recent publication on a new rheumatology treatment [here](#)



Thanks so much to all our authors.

We heard from the Quality Assurance Manager and Deputy Manager at GSTT CRF and the Lead Nurse at King's CRF.

Topics covered by staff include:

- *Quality Assurance essentials such as study approval, risk assessment, and patient safety*
- *The day-to-day life of a Lead Nurse and working across varied multi-disciplinary teams*

The PPI Leads from both CRFs also provided an update on the progress of our PPI and EDI strategies.

Dragons' Den style workshop

In April, we held our first-ever dragons' den style workshop online with both King's and GSTT CRF PPI Leads and PPI groups. Six King's CRF PPI members attended, providing their feedback on four posters due to be submitted to the UK CRF Network Conference in July.

From King's CRF, Dani Nebres, our Lead Nurse, presented his poster about a staff survey and subsequent training sessions on EDI topics where staff feel they need to increase their knowledge and confidence. Cat Harvey spoke about her poster on the topic of a school open day held in February. This was attended by 34 students who listened to careers talks and had a tour of the facility. Amy Sutarz, our Lab Technician, also presented her poster on peripheral blood mononuclear cells (PBMCs) isolation. PBMCs are a critical component in the immune system to fight infection.

Feedback from PPI members was extremely helpful and practical. For example, asking presenters to include both QR codes and full website addresses on their posters for those who do not have smartphones. PPI members were sent final versions of the posters to see their feedback in action.

We will learn from the experience of all attendees at this workshop and aim to make future events even more successful!

“

It was a really valuable opportunity to present the poster to the PPI members. They gave great feedback to ensure the poster is accessible and we discussed many things I may not have considered before. Thank you to everyone involved!

”

Amy, Lab Technician, and workshop presenter

Equality, Diversity, and Inclusion (EDI) staff training

We have put together an EDI working group made up of four PPI members, three CRF staff members, and two Trust EDI staff members.

Since November, the group has made significant contributions to materials used for training sessions for staff on pertinent EDI topics. This has included sessions on feeling comfortable raising concerns and cultural intelligence. Contributions are recorded using a 'you said, we did' document which supports conversation, transparency, and accountability between staff and PPI members.



“It's a refreshing change to be listened to, especially on such an important subject matter (EDI) which affects lives. We had the chance to ask questions, challenge content, change/adapt the narrative, and become as thorough as needed. I really enjoy the group because we all have our own equity lens that we bring to the work thus making it as inclusive as we can for staff, service users, and Carers. I look forward to doing more.”

AI, PPI member and EDI working group member

The most recent training about cultural intelligence, held in March and May, enabled staff members to take a psychometric test that revealed their cultural values (for example, whether they preferred direct or indirect communication), and their areas of strength and weaknesses when interacting with people from different cultures. PPI members made excellent contributions to the training materials for this session. For instance, asking the facilitator to speak about hand gestures in the section on communication. Members noted that hand gestures differ across cultures and may be misunderstood by others.

Full reports are written after each training session, and the 'you said, we did' documents are included in these. All reports are hosted on a dedicated section of our website, and training slides are available upon request. Please visit: <https://www.maudsleybrc.nihr.ac.uk/nihr-kings-clinical-research-facility/edi-reports-and-resources/>

Our next staff training will focus on transgender awareness, and the EDI working group will be meeting to discuss this in due course. To read more about the diverse lives of transgender people in the UK and across the world please visit: <https://www.stonewall.org.uk/our-work/campaigns/trans-hub>

Training needs survey results and plans

Towards the end of last year, we asked you all to complete a survey about how we can best support you and improve your experience as PPI members. Thank you so much to everyone for your responses!

Your responses were reviewed by a small working group of three PPI members and together we developed an action plan for the coming year:



Your survey responses

- 85% would like training on **co-production**
- 77% want to learn more about being an **author or co-author**
- 92% know that we offer payment for most PPI activities, however, just 69% know what our **reimbursement rate** is and only 31% know they can **request vouchers or certificates instead**
- 77% do not know who the **staff PPI champions** are at the CRF
- Free text responses show that members would like to know more about **building a PPI CV and EDI**

Our training plan

- Host **co-production training in summer 2024**
- Host **authorship training in winter 2024**, which will cover the definition of authors and contributors from the [International Committee of Medical Journal Editors \(ICMJE\)](#)
- Review **information on the website about payments, reimbursements, and staff PPI champions**. If needed, co-develop a written document on this to be distributed via email
- Develop and deliver **preparing for a new PPI role training in winter 2024**, including putting together a PPI CV
- Adapt and deliver cultural intelligence **EDI training for PPI members in early 2025**

Do you have an idea for more training sessions in the future? Let us know via catherine.harvey15@nhs.net

Work Experience and Nursing Students

We continue to host a range of students at King's CRF, and so far, this year we have:

- 1) Hosted 1 student seeking work experience to help gain their first job after university (January 2024)
- 2) Held a school open day for 34 Year 10 and 12 students to explore different research careers (February 2024)
- 3) Hosted 8 work experience students from local schools (April – July 2024)
- 4) Hosted 3 nursing students on their university placements (January – July 2024)

We speak to all students about the role of PPI in research, particularly emphasizing the importance of the [UK Standards for public involvement](#).

We are keen to keep improving our students' experience, so we gather feedback from them. For school-aged work experience students, we use an evaluation form that asks whether their time with King's CRF met their expectations, and which activities they enjoyed most and least. Students enjoyed observing the processing of blood samples and meeting researchers from across different departments such as cardiology and rheumatology.



The nursing students give feedback presentations to all CRF staff about their placements. This allows us to learn how best to support the next generation of medical professionals, and hopefully inspire them to careers in research.

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CRF



Visit our website:

<https://www.maudsleybrc.nihr.ac.uk/crf-home/>

Have a virtual tour of our facilities:

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

If you would like to receive this newsletter in a different format, please let us know.

Please also get in touch if you have any feedback or queries for us. We'd be more than happy to hear from you.