

Research Matters: Sharing Knowledge, Building Trust

Perrin Lecture Theatre, Blizard Institute, Whitechapel, E1 2AT.

Thu 23rd May 2024 5.30–7.00pm

PROGRAMME



PART 1 – 5.30PM

Welcome and introduction

The Make It Public Campaign: Making research open and accessible to all

Summary

Clive and Frances will cover the role of the HRA, and its responsibilities in promoting research transparency. They will then speak about the make it public campaign and the cross-sector group of people and organisations that supports it, followed by some thoughts from Frances about her direct experience with the campaign and why transparency in research is so important.

Speakers

Clive Collett, Head of Policy and Engagement, Health Research Authority

Clive Collett has been with the Health Research Authority (HRA) since 2011, and with the national research ethics service before this. He is currently Head of Policy and Engagement at the HRA, with a focus on research transparency, clinical trials regulations policy, and more broadly steering the organisation's policy and engagement activities and agenda. He is also a member of Ministry of Defence Research Ethics Committee (MODREC).

Frances Mossie, Public Research Champion, Maidstone and Tunbridge Wells NHS Trust, and member of the make it public campaign group.

Frances has been a public research champion with Maidstone and Tunbridge Wells NHS trust (MTW) for 8 years. Frances has also worked with the NIHR patient and public involvement team on urgent public health review studies. In April 2020, Frances was awarded the patient research champion individual impact award by the Kent, Surrey, Sussex Clinical Research Network, together with an award to the MTW Research and Development team. She has started her own study and is now working with a team looking at the experiences and the perceived impact of the NIHR research ambassador initiative locally.

Inclusion in Action: Working with the voluntary and community sector to reach under served and marginalised communities

Summary

Members of the voluntary, community and social sector will share their experiences of being involved in a strategic initiative to establish a 'research engagement network' across north-east



London, in partnership with NHS and academic organisations. Funded by NHS England, the partnership has focused on reaching on underserved communities and the team will share key insights gathered from over 500 local residents about their views towards healthcare research.

Speakers

Marilyn Mensah - Community Engagement Manager, Compost London

Joined Compost London in 2023, an experienced stakeholder engagement specialist, having worked in both the voluntary and private sectors. Marilyn delivers training, provides capacity building support, facilitates networks and project manages events. She has spearheaded the Compost marketing and online presence and taken a strategic lead in mobilising groups and unlocking key discussions within the voluntary sector.

Viv Munn – Community Engagement Manager, Compost London

Joined compost London in 2023, with an in-depth knowledge of the area, and a background of working across the public sector, she was brought in to work with groups based in or providing services in Newham, providing capacity building, facilitating networks and running events. Building effective relationships and responding to and highlighting issues faced by the diverse and marginalised communities in the borough is key to the role.

Compost London

Compost London was formed in 2019, by a team of community development professionals who had been working in East London's Voluntary Community Sector for many years. They came together around a shared concern about the diminishing infrastructure support for the Voluntary, Community and Faith (VCF) Sector, across London. At Compost, they have one simple goal: 'to help organisations grow, develop, and thrive'. They provide targeted support for groups within Newham and across London through one-on-one advice sessions, facilitating networks, helping to obtain funding, and running events and training.

Ronke Olulana – Director Harmony Community Projects

Ronke is a general nurse practitioner, counsellor, and community leader with over 30 years' experience. She has a heart for reaching people at grassroot level in a way they can understand and identify with. As a community champion, with skills sets that cut across various health and social deprivation, Ronke provides a rounded approach to overcoming barriers to reaching the marginalised community and many unique projects have been initiated by her and the team to help improve overall well-being of people locally.

Harmony Community Projects (HCP) is a non-religious charitable organisation with a health arm known as Harmony Clinic. HCP provides health initiatives and services to a varying range of people with the aim of improving well-being by reducing health inequality and social deprivation, particularly amongst the marginalised communities. A team of doctors, four GPs, 25 nurses and roughly 15 allied health professionals offer their services voluntarily through the clinic. Initiatives include ongoing health checks to help reduce risk of cardiovascular diseases, holding awareness events to tackle childhood obesity, promoting need for various forms of screening for bowel cancer, breast cancer, prostate cancer, amongst others. In the last 12 months, HCP has provided services to 450 people at various events, 12 cases were referred to a GP, 106 people referred to exercise on prescription and 52 cases of detected high blood sugar were referred to the diabetic nurse.



Dianne Barham, Chief Executive, Local Voice and Healthwatch Waltham Forest

Dianne has over 25 years' experience in community engagement, working alongside a diverse range of community, voluntary and statutory organisations. She has led three local Healthwatch's, worked within NHS North East London (NEL) as a Senior Engagement Manager and leads the nationally recognised NEL Healthwatch community insights project.

***Local Voice** uses evidence-based community insights to bring the voice of local people into health and care service design and delivery focusing on quality improvement and tackling inequalities.*

***Healthwatch Waltham Forest** is an independent organisation set up to champion local residents' views of health and social care in Waltham Forest. Their goal is to make the services we all use better, and to work together to make that possible.*

Q&A

PART 2 – 6.15PM

Action on diversity in cancer trials at Barts Health

Summary

Barts Experimental Cancer Medicine Centre (ECMC) cares for one of the some of the most ethnically diverse and socio-economically deprived communities in the United Kingdom. Our approach places Patient and Public Involvement and Engagement (PPIE) and Equity, Diversity and Inclusion (EDI) at its core. Barriers to trial access are complex. We have taken a multi-faceted strategic approach to reduce inequalities to help broaden access to clinical trials for our communities. The pro-active cancer PPIE group has helped shape our policies to widen access to clinical trials. We are collaborating with NHS, charitable partners and the third sector to develop patient-facing materials and empower patients to be informed of their treatment options and to improve patient experience through a better understanding of clinical trials and cancer.

Speakers

Dr Adam Januszewski, Consultant in Medical Oncology

Dr Adam Januszewski is a consultant in thoracic oncology at St. Bartholomew's Hospital, with expertise in trials and translational research. He is chief and principle investigator on numerous international phase ii – iii clinical trials and has a particular interest in widening access to clinical trials.

Miss Maria Lapuente, Lead Oncology Research Nurse, Barts ECMC

Maria is working as a Lead Oncology Research Nurse at St. Bartholomew's Hospital. She has specialised in immunotherapy, Anti-Drug Conjugated (ADCs) therapies and novel treatments; particularly in phase i and ii combination trials. She co-leads the PPIE group at St. Bartholomew's Hospital ECMC. With a focus on promoting equity, diversity, and inclusion within clinical trials. She is part of the CRUK Senior Oncology Research Nurse Team.



Aligning public representatives in the data access committee

Summary

The Barts Health Precision Medicine Platform is a cutting-edge health data portal. It includes a data access service to the extensive electronic health records of a diverse community of over 2.5 million people held by Barts Health NHS Trust. The platform facilitates data-led innovation while prioritising patient confidentiality, fairness and equity. Barts Health are committed to being transparent and building trust of the local community by involving patients and the public in the governance processes regarding how their data is being stored, processed, managed, used and shared. This is facilitated through the Precision Medicine Programme Board and the Data Access Committee (DAC), ensuring compliance with legal and ethical requirements.

Speakers

Steven Newhouse, Deputy Chief Information Officer, Precision Medicine Informatics, Barts Health NHS Trust

Steven leads a small team, funded by Barts Charity, focusing on providing safe and secure large-scale access to health data within Barts Health NHS Trust, for clinical and research purposes. Health data (patient records, GP records, images, etc.) can provide insights into how individual patients with similar conditions respond to treatments, or the incident of particular conditions. Before starting at Barts, Steven was head of IT at a European Bioinformatics Research Institute leading teams providing storage and analysis for very large volumes of life-science data. Previously, he has led a European wide collaboration providing IT infrastructure for researchers, written software at Microsoft for researchers, and worked in research computing within UK universities.

Francene Clarke-Walden, PPIE (Public, Patient Involvement and Engagement) Communications & Engagement Manager, Precision Medicine Informatics

Francene role involves bridging cutting-edge scientific advancements with the broader community. She firmly believes that by fostering trust and collaboration, precision medicine can truly transform healthcare and benefit everyone.

With a background in marketing and communications, Francene brings a unique perspective to her position. She doesn't just aim to share information but strives to initiate meaningful conversations and foster a sense of common purpose within the community. Through strategic communication efforts, she works to clarify the complexities of precision medicine and highlight its significant impact on individuals and local communities.

Reshma Punjabi, Public Representative, Precision Medicine Data Access Committee

I was a carer for many, many years and I still have caring responsibilities. Some years ago, a friend of mine – who is a keen supporter of PPI – said: “You should take part in a bit of PPI. You have so much experience of caring, you could help a lot.”

I was very nervous to begin with, but the researchers, project managers and fellow PPI contributors were very helpful and friendly. I slowly began to settle in.

With time, I began to understand research ideas better. I also discovered I could bring my real-life caring experiences to the research as I got over my nervousness.

It came as a huge surprise that many of my ideas were welcomed by the research community, and in fact incorporated into studies. Some of my thoughts and inputs have even been quoted in journal publications.



Shared study development with patients and participants - how much involvement can you handle?

Summary

The PERSONAL HTN study was inspired by experience of patients with high blood pressure. Co-developed with those patients at every stage and then reborn for remote care after lockdown as PERSONAL-CovidBP.

Mirroring the way that the study happened, Paul and David will describe how personalising treatment and more autonomy changed participant's experience of being able to manage their blood pressure. This talk answers these key questions:

- How much did Covid affect this trial?
- How much of the forced innovation involved was worthwhile?
- How much can patients be involved?

Speakers

Dr David Collier, Clinical Director, William Harvey Research Institute Clinical Research Centre

David trained in medicine at Barts, won one of the first Wellcome trust prize studentships to do a PhD in Physiology during his medical degree, led the research team on the British Mount Everest Medical Expedition in 1994 (with Andrew Pollard) and has worked on clinical trials since 1997. He is Joint Clinical Director - William Harvey Clinical Research Centre, Clinical and Public and Patient Involvement/Engagement Lead - Barts Cardiovascular Clinical Trials Unit, Public and Patient Involvement & Engagement Strategy Lead - Barts Biomedical Research Centre and Deputy Director - Barts CTU (UKCRC registered Clinical Trials Unit). His clinical research centre, working for Professor Sir Mark Caulfield, has recruited large numbers of patients (such as 1157 patients for ASCOT) for 22 years and working with those patients they have influenced the development of many new therapies, and patient collaborations such as Chiaroscuro- marking the 70th anniversary of the Nuremberg Trials, the last interviews with [Ralph Koltai CBE \(Part 1\)](#) and [Part 2 with Simon Callow](#)

Paul Bowers Isaacson

Paul is a professional educator working in the areas of curriculum development and assessment nationally, for example developing the extended project qualification for sixth form students. He is also an experienced facilitator and offers facilitation and presentation training for various voluntary groups. Some years ago, Paul joined a clinical trial overseen at the William Harvey Clinical Research Centre. Paul's interest in clinical trials had started a few years earlier in the context of developing a level science and society with the Nuffield Curriculum Centre. He has since worked with David Collier at William Harvey to create [TrialsConnect](#), a voluntary organisation of patients inspired by the power of 'patient story'. Paul is patient co-director of the NUHR Biomedical Research Centre at Barts (alongside Professor Sir Mark Caulfield).

Q&A and closing remarks

CANAPE RECEPTION – 7.00PM

