

NIHR St George's Clinical Research Facility

Patient and Public Involvement Strategy – 2022-2027

Vision:

St George's Clinical Research Facility (CRF) is an NIHR accredited CRF with expertise in delivering early phase research studies and translational research studies.

Our main vision is to ensure that the participants recruited to CRF studies reflect the community St George's sits in. We would also like to make participation in clinical research studies open to everyone. We aspire to make our studies as inclusive as possible and to become leading experts in embedding diversity at all stages.

Patients and public should be at the centre of how the facility operates from study setup, outreach to recruiting patients. This includes ensuring that any Patient, Public Involvement (PPIE) activities are inclusive of views and participation from patients and the public in the process of identifying research priorities, as members of PPIE steering group and so forth. This is in line with incorporating feedback from key groups when developing any material for research and carrying out research to ensure co-designed interventions and information.

Timescale:

This document sets out our, five year PPI strategy to August 2027 outlining our goals for the short term (one two years) and medium (two to three years) to long term (three to five years), as well as identifying successful outcomes and achievements. This strategy will be reviewed regularly among key stakeholders to ensure that we are meeting our goals, updating them and re-scrutinising where needed as advised.

St George's CRF is at the early stages of PPI involvement so this document will evolve and change with new insights and processes with time, learning from others and internal and external stakeholders.

Key Priorities

1. Build on our established local partnerships and outreach models to **engage a variety of patient groups and enable our community members to shape our research plans**. We will do this through the Patient and Public Involvement and Engagement Steering Group and study/disease specific partnerships.
2. **Break down key barriers to involvement and participation, improving equity of access to trials and opportunities to influence our research**. We will work with trusted messengers in communities and pilot a CRF outreach model. Building on treatment outreach programmes in viral hepatitis, we will use an existing mobile clinic in a specially converted van to run research roadshows and pilot recruitment to translational studies in community locations.

3. **Actively raise the profile of the CRF**, providing engagement and education opportunities and clear information to the public about our research plans. We will co-produce a PPIE
4. **Communication Plan** to include increasing our social media presence, patient friendly website pages, increased tours and open days and CRF community roadshows.

We have used the UK Standards for Public Involvement in Research to establish the key priorities for our PPI strategy. (<https://sites.google.com/nihr.ac.uk/pi-standards/home>)

Inclusive Opportunities:	Support and Learning:	Communications:
Offering public involvement opportunities that are accessible and that reach people and groups according to research needs.	Offering and promoting support and learning opportunities that build confidence and skills for public involvement in research.	Using plain language for well-timed and relevant communications, as part of involvement plans and activities.
Working Together:	Governance:	Impact:
Working together in a way that values all contributions, that builds and sustains mutually respectful and productive relationships.	Involving the public in research management, regulation, leadership and decision making.	Seeking improvement by identifying and sharing the difference that public involvement makes to research.

1. Inclusive Opportunities

Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

- Build PPIE Steering Group that will provide advice on PPI issues for NIHR St George's CRF.
- Ensuring available PPI opportunities are open to everyone.
- Aim for PPIE Steering Group to represent the local population Southwest London.
- PPI materials should be accessible, easy to understand, and relatable to all.
- Build, improve and automate the Edge and iClip reporting systems that that record PPIE patient recruitment information.

2. Working Together

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

- Ensuring that public contributors feel respected and listened to in meetings.
- Listening to and where possible actioning feedback from patient and public contributors.

3. Support and Learning

Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

- Providing ongoing support and guidance to our public contributors
- Providing and signposting to training and resources to public contributors, CRF staff and researchers.
- Developing new training when necessary. This could be how to record relevant patient details in Edge and our own course for staff and public involvement.
- Working with our partners to ensure resources are aligned and coherent.

4. Governance

Involve the public in research management, regulation, leadership and decision-making.

- Including patient representative in quarterly management meetings
- Inviting public contributors to comment on key reports and strategies
- Ensuring oversight of PPI activities
- Ensure oversight and privacy of public contributors' personal information.

The governance structure for St George's CRF is outlined below.

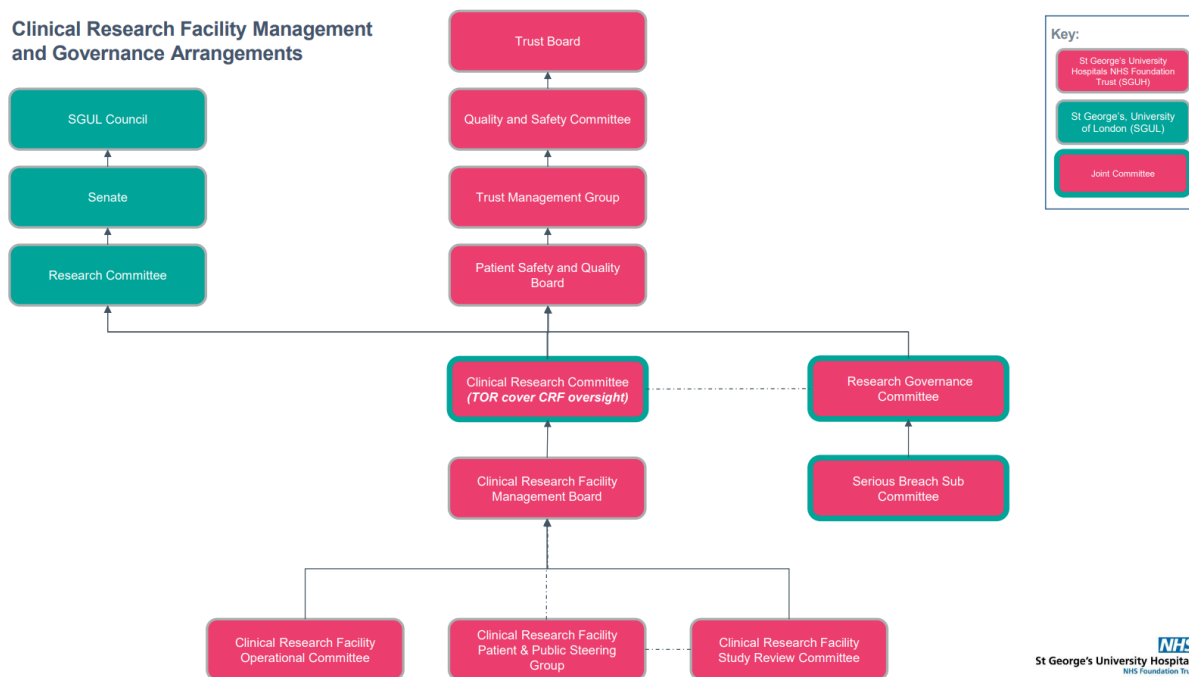


Figure 1. Clinical Research Facility Governance Structure

5. Communications

Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

- Ensuring timely, targeted and clear communications are planned for all public involvement activities
- Creating and maintaining accessible resources for public contributors
- Providing ways for public contributors to give honest feedback (anonymously if preferred)
- Ensure public-facing materials produced by St George's CRF use plain, easy to understand language, while still being informative.

6. Impact

Seek improvement by identifying and sharing the difference that public involvement makes to research.

- Communicating PPI success stories to promote and encourage public involvement social media, CRF website and other sources
- Assessing and gathering feedback on public involvement activities through testimonials, surveys and focus groups
- Identify and report on studies that recruit from underserved communities to reflect the importance of diversity and inclusion

Our Starting Point

St George's Clinical Research Facility as a newly accredited NIHR CRF is at the early stages of a formal PPI approach for our studies.

The department has hired a new PPI Manager who should be starting in at the beginning of Q1 2023/24 financial year. This person will be the main person responsible for the majority of PPI issues in the department. We are waiting for this person to start until we incorporate the majority of our new PPI processes and systems.

Groups

There are currently a small number of PPI groups linked to certain specialties in the hospital. There is a Paediatric group called FRIEND and a maternal group, these groups meet once quarter and consist of previous studies participants.

The Vaccine Institute, which forms a part of the NIHR CRF have setup a BAME group consisting of members of the public. The involvement of the members of this group will be to provide feedback on patient facing material with a view to recruiting a more diverse group of people to research studies.

Clinical Research Facility

Within the CRF, we are proposing the development of PPIE steering groups which will consist of patients, community leads and the general public and relevant project partners. The views from these groups will inform the focus of the life-span of this strategy project but also future research projects. Active involvement of PPIE will ensure relevance, acceptability, clarity and sensitivity of research within the CRF but also at a Trust level and will encourage co-production of research priorities, materials and any interventions.

Events

The Vaccine Institute has a large number of outreach programs aiming to improve public engagement, promote vaccine research and sign members of the public up to the vaccine volunteer registry. Public events they have been involved in include:

- Yearly Balham and Tooting Community Association Community Fun Day
- Regular pop up events in the hospital
- Science Museum lates once a year - to promote Centre for Neonatal and Paediatric Infection though games and talks about vaccine research.

- Regular school visits in the surrounding areas to educate students about vaccines and clinical research.

Planned Clinical Research Facility events ____

- Community Health Screening events across the local borough
- International Clinical Trials Day within the Trust
- Participation in relevant Trust patient engagement events
- NIHR CRF patient outreach events

Reporting

St George's Hospitals NHS Foundation Trust and the Clinical Research Facility current use the Edge database as the main clinical research governance database. Study and patient details are recorded in Edge.

For the majority of CRF studies patients are recruited, the team record date of birth and study consent date so the participant's age at consent can be calculated. Hospital numbers are also recorded so that we can report on participant demographics through the trusts EPR.

In late 2021 we reported on the ethnicity breakdown of the 50 highest priority studies run through the facility in recent years. In the 50 studies reported on, 43% of participants identified as BAME, versus 46% in our hospital population, with broadly matched deprivation rates. Our ability to engage a diverse group of participants is an explicit reason why our research partners and funders work with us.

Action Plan

Inclusive Opportunities

Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Activity	Method	Timescale	Actioned By
Setup a PPIE Steering Group	Invite members of the currently active disease specific PPIE groups to be members of the PPIE Steering Group whilst also including members outside of these groups to ensure equity of opportunities and bringing forth new ideas. Our aim is for the group to be an accurate cross-section of the local community across demographics where possible.	Q1 2023/24	PPIE Manager, Disease specific PPIE groups leads
Review of PPIE Strategy	Communication and Dissemination of current strategy to PPIE Steering Group for review and contribution from Group's perspective	Q1 2023/24	PPIE Manager, PPIE Steering Group PPIE Strategy Group, CRF Directors, CRF Management team
Select protected characteristics to report across early phase and translational research	PPIE Steering group to be consulted in identifying key protected characteristics data to capture and report on	Q2 2023/24	NIHRCRF Management Team, PPIE Steering Group, Performance, and Information Officer
Build systems to collect agreed data for recruited patients	Utilise existing data capture and performance systems in the Trust and Research governance infrastructure, such as Edge and Electronic patient records e.g. iClip to collect agreed data	Q3 2023/24 Ongoing	CRF Operations Manager, Trust Information team and Performance and Information Officer

Working Together

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Activity	Method	Timescale	Actioned By
Develop processes for PPI contributors to feedback on CRF operations	Create a co-designed feedback form with public contributors to send feedback to St George's CRF to ensure it is fit for the community it is aimed for.	Q4 2023/24 - ongoing	PPIE Manager, PPIE Steering Group, NIHR CRF Management team

Build collaborations with local community groups, Trust and University patient groups linked to PPIE	Attendance of CRF Reps and/or Researchers at Trust patient events and local community events to raise CRF and research profile and foster relationships with underserved community groups and speciality or disease specific groups in the Trust University, and Wandsworth.	Q2 2023/24-ongoing	PPIE Manager, PPIE Steering Group PPI Group Leads, Researchers
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Support and Learning

Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

Activity	Method	Timescale	Actioned By
Training for Researchers and PPIE group on PPIE for early phase and translational research	Produce calendar of training events for Clinicians and Researchers and research staff in Trust on PPIE in research including workshops, toolkits in addition to training PPIE Steering group with the right tools to make the group as effective as possible	Q3 2023-ongoing	PPIE Manager
Review PPIE training procedures	These documents should be reviewed on a yearly/ongoing basis	Q4 2024/25 - ongoing	NIHRCRF Management Team. PPIE Manager

Governance

Involve the public in research management, regulation, leadership and decision-making.

Activity	Method	Timescale	Actioned By
Inclusion of PPI representatives in the NIHRCRF Management Board Meeting and THE PPIE Steering Group as outlined in figure 1 on page 3	1-2 representatives appointed by PPIE steering group to attend quarterly NIHR CRF meetings.	Q4 2023/24	PPIE Manager, PPI group

Communications

Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

Activity	Method	Timescale	Actioned By
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Develop CRF Communications Plan	NIHR CRF Management team and PPIE Steering Group to establish a communication plan with CRF objectives and PPIE needs in mind.	Q4 2023/24	NIHR Management Team, PPIE Steering Group
Impact			
Seek improvement by identifying and sharing the difference that public involvement makes to research.			
Activity	Method	Timescale	Actioned By
Review our PPI impact and processes	Create an annual Public Contributor Experience Survey to review our PPI work and impact.	Q1 2024/25 - ongoing	PPIE Manager, NIHR CRF Management Team
Communicate PPIE activities and achievements	Include PPIE groups, events and statistics on CRF Website with PPIE page.	Q4 2023/24	PPIE Manager and TACRI Manager
Identify potential studies and maintain log that recruit from underserved communities	Circulate expressions of interest on studies in underserved communities to relevant researchers to consider participation. Create live reports for underserved community recruitment/studies using Power BI and Edge. Utilise CRF website to display reports	Q1 2024/25- ongoing	CRF Operations Manager, Research Governance Facilitators, Performance and Information Officer