

Patient and Public Involvement Strategy – 2022-2025

Vision:

Placing patients and the public at the centre: To include patient and public involvement (PPI) in all areas of clinical trial design, set-up, governance and dissemination at the Southampton Clinical Trials Unit (SCTU). To ensure that all PPI is meaningful, impactful, appropriate, and inclusive.

SCTU is a UKCRC registered CTU with expertise in the design, conduct and analysis of multicentre interventional clinical trials. We work in partnership with investigators to deliver high quality trials that will directly influence routine clinical practice ([SCTU website](#))

Timescale:

This document sets out our three-year PPI strategy to April 2025, outlining our goals for the short term (one year) and medium to long term (two to three years), as well as identifying successful outcomes and achievements. This strategy will be reviewed regularly to ensure we are meeting our goals, updating them and rescrutinising where needed.

Key Priorities

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: Offering public involvement opportunities that are accessible and that reach people and groups according to research needs. (section 1, pages 2-3)
	Working Together: Working together in a way that values all contributions, that builds and sustains mutually respectful and productive relationships. (sec 2, pages 4-5)
	Support and Learning: Offering and promoting support and learning opportunities that build confidence and skills for public involvement in research. (sec, 3 pages 6-7)
	Governance: Involving the public in research management, regulation, leadership and decision making. (section 4, pages 8-9)
	Communications: Using plain language for well-timed and relevant communications, as part of involvement plans and activities. (section 5, pages 10-11)
	Impact: Seeking improvement by identifying and sharing the difference that public involvement makes to research. (section 6, pages 12-13)



1. Inclusive Opportunities

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

Key aims:

- Ensuring available PPI opportunities are open to a wide range and demographic of participants.
- Ensuring public contributors are reimbursed for their time and expenses in line with the NIHR INVOLVE payment guidelines.
- Ensuring those affected by and interested in research are involved early in the development of a research project.
- We aim to make all PPI materials accessible, easy to understand, and relatable to all.

Successful outcomes to date:

- **Building public involvement networks:** As a co-founder of the [Wessex Public Involvement Network](#) (PIN) we work on ways to involve the local community in public involvement opportunities. This has included attending events at community hubs, such as the local mosque, an information and engagement stand at the Southampton Mela Festival and inviting local service providers to talk to the PIN operations board.
- **Building a PPI group to develop SCTU trials as research partners:** A recent example includes an online forum where public contributors gave feedback for the proposed ALCHEMI trial. From this meeting the team also identified a PPI co-applicant for the funding application. Investigators working with and within SCTU also regularly access the Wessex PIN coffee mornings, where public contributors are available to provide feedback. A new pilot project has also begun to include PPI members on trial IDMCs.
- **Utilising digital approaches to working:** Holding virtual and hybrid meetings allows public contributors who may not be able to attend in-person to take part in involvement activities.
- **Reaching out to hard-to-reach communities:** In October 2021, SCTU's PPIE Manager took part in an hour-long programme on a local Asian radio station Awaaz FM to talk about the work of the SCTU and how people can get involved with research.

Future goals:

ACTIVITY	METHOD	TIMESCALE	ACTIONED BY
SHORT TERM:			
Identifying underserved groups in our public involvement	Create an EDI monitoring form for our public contributors to assess which groups are underserved	Q4 2022	PPIE Manager Public contributors Trial Managers
Improve access to underserved communities	Work with Wessex PIN to find new ways to connect and communicate with local communities.	Ongoing	PPIE Manager
	Collect ethnicity data as a default in all SCTU trials to analyse success in including under-served communities	Ongoing	Lead SCTU statistician
Improve local knowledge on accessibility	Wessex PIN training on accessibility and allyship	Q4 2022	PPIE Manager
Improve accessibility of SCTU documents and website	Review SCTU comms and PPI documents for accessibility, including possible translation.	Review by Q4 2022	PPIE Manager Public contributors
		Ongoing	
MEDIUM TO LONG TERM:			
Increase links with underserved communities	Work with Wessex PIN and other partners to increase opportunities for underserved communities	Q2 2023 Ongoing	PPIE Manager Public contributors
Improve accessibility of all SCTU documents	Ongoing review of all patient-facing materials and public SCTU documents for accessibility issues.	Q2 2023 Ongoing	PPIE Manager Public contributors Trial Managers SMT
Appoint an 'EDI champion'	Engaging a member of the public to act as an EDI Champion for the SCTU and review inclusivity in PPI.	Q2 2023	PPIE Manager Senior management team
Include EDI and PPI in future Chief Investigator training	Via the CRUK CI training and support Working Group ensure appropriate training in EDI and PPI.	2023	Director of SCTU



2. Working Together

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

Key aims:

- Ensuring the role of a public contributor is clearly defined for each study /meeting and setting out roles and responsibilities.
- Ensuring that public contributors feel respected and listened to in meetings.
- Listening to and where appropriate actioning feedback from public contributors and where appropriate actioning their suggestions and concerns.
- Recognising the rewarding the valuable work of public contributors.

Successful outcomes to date:

- Central point of contact – ensuring public contributors have a named contact and email address for the SCTU staff member they are working with. This could be the trial manager for specific trial PPI, or the SCTU PPIE Manager for oversight groups and general PPI enquiries/feedback.
- Faculty of Medicine – SCTU was one of the departments who helped trial the University of Southampton Faculty of Medicine’s PPI Reward and Recognition pilot scheme in 2021/2. This recognises the contribution of public contributors with a certificate and an invite to the Faculty’s annual conference. A SCTU public contributor was nominated and is among those recognised. This will be an ongoing scheme.

Future goals:

ACTIVITY	METHOD	TIMESCALE	ACTIONED BY
SHORT TERM:			
Improve ways for PPI contributors to feedback to the CTU	Create a feedback form to be available for public contributors to send feedback to SCTU	Q4 2022	PPIE Manager Public contributors Trial Managers Senior management team
Ensure a positive involvement environment	Create guidance/best practice charter for researchers and trial teams who are including PPI in their trial meetings	Q4 2022	PPIE Manager Public contributors Trial Managers
Recognising public contributions to research	Organise an annual reward and recognition event for our public contributors	Q4 2022	PPIE Manager Trial Managers
MEDIUM TO LONG TERM:			
Recognising public contributions to research	Continue to nominate SCTU public contributors to the FoM Reward and Recognition scheme	Ongoing	PPIE Manager Trial managers
Ensure clear processes for working together	Continually review and develop our PPI induction handbook and PPI materials with input from public contributors, to ensure that researchers, trial teams and contributors are working together.	Ongoing	PPIE Manager Public contributors Trial Managers Senior management team



3. Support and Learning

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

Key aims:

- Providing ongoing support and guidance to our public contributors
- Providing and signposting to training and resources to public contributors, SCTU staff and researchers.
- Developing new training when necessary
- Working with our partners to ensure resources are joined-up and coherent.

Successful outcomes to date:

- PPI Handbook – We provide a SCTU Patient and Public Involvement Handbook to new public contributors to set out how we work with the public, the support provided and where they can find help and resources.
- PPI hub on the SCTU website – In 2021, we created a dedicated Patient and Public Involvement section of our website with links and access to resources and training for public contributors, SCTU staff and researchers.
- Central point of contact – ensuring public contributors have a named contact and email address for the SCTU staff member they are working with so they can request support and training. This could be the trial manager for specific trial PPI, or the SCTU PPIE Manager for oversight groups and general enquiries.

Future goals:

ACTIVITY	METHOD	TIMESCALE	ACTIONED BY
SHORT TERM:			
Continue to review resources and training	Review the resources and training we offer to new PPI members, including ongoing review of our PPI handbook and resources hub on the website.	Q4 2022	PPIE Manager Trial Managers Senior management team
Grow our in-house training resources	Develop a dedicated training plan for public contributors sitting on our trials' IDMC panels (see pilot project outlined in the Governance section).	Q4 2022	PPIE Manager Trial Managers Statisticians
CRUK PPI training	Work with Cancer Research UK and public contributors to design and create a new PPI training resource specifically for CRUK CTUs.	Q4 2022	PPIE Manager CRUK CTU PPI Task and Finish Group
MEDIUM TO LONG TERM:			
Grow our wider training resources	Work with the Wessex PIN and wider PPI groups in the Wessex region UK to design and create a new PPI training course.	Q1 2023	PPIE Manager CRUK Wessex PIN Public contributors



4. Governance

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

Key aims:

- Including public involvement in all areas of SCTU governance, trial development and oversight
- Inviting public contributors to comment on key SCTU reports and strategies
- Ensuring oversight of PPI activities and privacy of public contributors' personal information.
- Ensuring public involvement is costed into SCTU governance and trial budgets

Successful outcomes to date:

- Including public contributors in SCTU governance – public contributors sit on our Trial Review Group, Trial Steering Committee, individual Trial Management Groups.
- Inviting feedback on key reports – inviting public contributors to review SCTU reports such as major funding submissions and strategy documents that have PPI aspects.
- PPI coordinator role – The SCTU PPIE Manager is the point of contact for public contributors and has oversight of PPI resources, contributor feedback, contact lists and privacy of contributors' personal information.

Future goals:

ACTIVITY	METHOD	TIMESCALE	ACTIONED BY
SHORT TERM:			
Growing PPI in SCTU governance	Inviting a public contributor to sit on all SCTU oversight Groups and IDMC pilot project (plus more contributors for the future roll-out of the project if successful).	Q4 2022	PPIE Manager Trial Managers Statisticians Senior management team
Review our current PPI on oversight groups	Constantly monitor the involvement of public contributors on STCU oversight groups and review and update where necessary.	ongoing	PPIE Manager Senior management team
Ensure PPI in early trial design	Set-up and run a cancer-specific PPI group with the local CRUK nurses and ECMC to give feedback and input to trials in the early phases of development	Q4 2022	PPIE Manager CRUK Senior Research Nurse ECMC Senior management team
MEDIUM TO LONG TERM:			
Qualitative study into IDMC pilot	Possible qualitative study into the IDMC PPI pilot project to gain valuable feedback and inform future work in this area.	Q2 2023	PPIE Manager Trial Managers Statisticians Qualitative researcher



5. Communications

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

Key aims:

- Ensuring adequate communications are planned for all public involvement activities
- Communicating clearly and regularly with our public contributors
- 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 SCTU use plain, easy to understand language, while still being informative.

Successful outcomes to date:

- PPI webpage – creation of a dedicated Patient and Public Involvement section of our website with information, resources and contact details for public contributors and researchers.
- PPI mailing list and newsletters – we have created a secure mailing list of our SCTU public contributors and send out regular emails and newsletters containing updates, involvement opportunities and training resources, as well as ways to contact the SCTU.
- PPI blog – Inviting patients and public contributors to write or be featured in blog articles about their involvement experiences which are shared on the SCTU blog and PPI sections of our website.

Future goals:

ACTIVITY	METHOD	TIMESCALE	ACTIONED BY
SHORT TERM:			
Improve public facing materials	Create a guidance document for trial teams to use when writing patient and public facing materials to outline expected use of plain understandable language.	Q4 2022	PPIE Manager Public contributors Trial Managers
Improve PPI communications	Ensure that communications with public contributors on SCTU oversight groups and trial management groups is done on a regular basis and in an understandable manner.	ongoing	PPIE Manager Trial Managers
Facilitate annual update for public contributors	Organise an annual for public contributors to give SCTU updates and yearly overview, plus reward and recognition.	Q4 2022	PPIE Manager Trial Managers
MEDIUM TO LONG TERM:			
Create a PPI resource hub	Create a closed online hub (SharePoint page) for SCTU public contributors where they can access SCTU specific resources and get peer support.	Q1 2023	PPIE Manager Senior management team
Review PPI guidance and communications	Annual review of all PPI and public facing documents to ensure they are fit for purpose and adhere to communication guidelines	ongoing	PPIE Manager Public contributors Trial Managers Senior management team



6. Impact

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

Key aims:

- Disseminating funding outcomes to public contributors involved in submissions
- Keeping public contributors informed of the results and outcomes of trials
- Communicating PPI success stories to promote and encourage public involvement
- Assessing and gathering feedback on public involvement activities

Successful outcomes to date:

- Feedback on SCTU trials – ensuring timely feedback to public contributors about funding applications and trials they have been involved with.
- PPI blog and news stories – Sharing the experiences of public contributors and patients involved in SCTU trials to show the vital impact that public involvement has in research.

Future goals:

ACTIVITY	METHOD	TIMESCALE	ACTIONED BY
SHORT TERM:			
Review our PPI impact and processes	Create an annual Public Contributor Experience Survey to review our PPI work and impact.	Q4 2022	PPIE Manager Public contributors Trial Managers Senior management team
Dissemination of results	Ensure that public contributors and trial co-apps are involved in publications and the dissemination of trial results.	ongoing	Trial Managers Senior management team
Improve feedback on trial applications	Ensure that public contributors are given feedback on funding applications for trials they have helped to develop.	ongoing	PPIE Manager Trial Managers
MEDIUM TO LONG TERM:			
PPI Case studies	Create a suite of testimonials and case studies in various formats (written, video, audio) to show the impact of PPI on clinical research	Q1 2023	PPIE Manager Senior management team