

THE UK SEPSIS TRUST PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT (PPIE) IN SEPSIS RESEARCH:

GUIDANCE FOR RESEARCH ORGANISATIONS

August 2026, to be reviewed August 2028

This quick guide has been developed for Research Organisations to support meaningful, inclusive and safe involvement of patients, families, and communities in sepsis research.

WHY PPIE MATTERS IN SEPSIS RESEARCH

Sepsis is a life-threatening condition that arises when the body's response to an infection injures its own tissues and organs, with the immune system going into overdrive. 48,000 people die from sepsis each year in the UK alone, and survivors may experience continuing physical, psychological or cognitive aftereffects.

Sepsis can affect people of all ages and their families. PPIE should therefore be an integral part of sepsis research, not an activity added after the scientific design has been completed.

Research Organisations should enable people with lived experience of sepsis, including survivors, their families, carers and representatives of communities affected by sepsis, to influence:

- Product design.
- Research priorities and questions.
- Study design, outcomes and measures.
- Recruitment and retention approaches.
- Participant information and consent materials.
- Acceptability.
- Interpretation of findings.
- Dissemination of results.
- Implementation of results.
- Governance.

The Health Research Authority (HRA) defines PPIE as research undertaken “with” or “by” patients, service users or the public, rather than research undertaken only to, for or about them.

The HRA UK Policy Framework for Health and Social Care Research expects patients, service users and the public to be involved in research design, management, conduct and dissemination unless there is a justified reason not to.

RESEARCH ORGANISATION RESPONSIBILITIES

The HRA identifies four core principles of PPIE:

- 1. Involve the right people.**
- 2. Involve enough people.**
- 3. Involve people enough**
- 4. Describe how their involvement helped.**

Research Organisations should establish systems that make PPIE possible throughout the research cycle, including:

1. Involving people from the earliest possible stage.
2. Making sure patient and public involvement is considered when assessing study feasibility, acceptability and risk.
3. Confirming PPIE is included appropriately within research proposals and protocols.
4. Demonstrating that PPIE is valued as part of research quality and governance.
5. Ensuring PPIE provision is proportionate to the research.
6. Providing appropriate resources and budget.

RESEARCH ORGANISATION RESPONSIBILITIES

7. Agreeing the purpose, role, influence and expectations of Patient and Public Contributors.
8. Ensuring Patient and Public Contributors have meaningful opportunities to influence decisions.
9. Maintaining involvement throughout the study where appropriate.
10. Ensuring relevant PPIE information is available for regulatory and ethical review.
11. Monitoring PPIE quality and impact.
12. Documenting what was discussed, what changed and why.
13. Reporting PPIE activity and impact transparently.

THE SIX UK STANDARDS FOR PUBLIC INVOLVEMENT

Research Organisations should use the Six UK Standards for Public Involvement as a framework for planning, delivering and evaluating PPIE:

1. **Inclusive opportunities:** Reach people with different experiences of sepsis, including underserved and under-represented communities. Remove practical, financial, communication and accessibility barriers.
2. **Working together:** Build respectful partnerships. Recognise lived experience as expertise and agree roles, expectations and decision-making arrangements.
3. **Support and Learning:** Provide induction, accessible information, training and emotional support for contributors and researchers.
4. **Communications:** Use clear, accessible, non-technical language and provide timely two-way feedback.
5. **Governance:** Give Patient and Public Contributors meaningful opportunities to influence study management, oversight, priorities and decisions.
6. **Impact:** Record and share how PPIE changed, strengthened or challenged the research, including where suggestions were not adopted and why.

RECRUITMENT OF PATIENT AND PUBLIC CONTRIBUTORS

There is no single perspective of an experience of sepsis. Research Organisations should consider involving a range of relevant lived experiences, for example:

- People who have survived sepsis.
- People with experience of different pathways of care.
- Families and carers.
- People with experience of post sepsis syndrome and recovery.
- People from communities experiencing health inequalities.
- People with different ages, backgrounds, disabilities, communication needs and socioeconomic circumstances.
- Relevant community, voluntary-sector or patient organisations.

Selection should be driven by the research proposal and study population, rather than relying on the same small group of contributors for every study.

The National Institute for Health and Care Research (NIHR) resources emphasise the importance of diversity of experience and reaching groups who are underrepresented in research.

PPIE THROUGHOUT THE RESEARCH PROCESS

Identification and prioritisation

- Identify the communities, lived experiences and priorities relevant to the research.
- Involve Patient and Public Contributors when developing the research question and proposal.
- Provide a clear description of how research findings will be disaggregated by protected characteristics
- Agree and document clear PPIE objectives at the outset of the project.
- Provide a plain English summary of the research plan for Patient and Public Contributors and wider communities.
- Co-develop the PPIE plan, including roles, budget, accessibility and support.
- Test whether the proposed research is understandable, relevant, acceptable and feasible.
- Review contributor-facing materials.
- Help ensure the research addresses issues that matter to patients, carers and communities.

Research design

- Develop a Patient Advisory Group (PAG) activity plan with agreed timelines and milestones.
- Prepare contributor documentation including role descriptions, person specifications, recruitment criteria and confidentiality requirements.
- Establish agreed terms of reference.
- Define how Patient and Public Contributors will influence decisions.
- Provide appropriate training and support.
- Ensure accessibility, expenses and payment arrangements are in place.
- Include PPIE within project governance and reporting arrangements.
- Help refine the research question and study design.
- Advise whether proposed methods are ethical, practical and acceptable.
- Provide input on Equality, Diversity and Inclusion (EDI) considerations.
- Ensure the study reflects patient and public perspectives.

Grant application

- Develop a Working with People and Communities Summary describing planned involvement activities and expected influence.
- Contribute to defining meaningful outcome measures.
- Review and strengthen funding applications.
- Help demonstrate patient and public involvement within the proposal.
- For grant applications, the HRA expects Research Organisations to explain who was involved, how and when they were involved, whether involvement will continue, and how their input improved the ethical acceptability, relevance or acceptability of the study.

Recruitment and data collection

- Maintain regular two-way communication with contributors.
- Ensure Patient and Public Contributors serve on project steering groups or research advisory groups.
- Help write and review study protocols, participant information sheets and consent forms.
- Identify barriers to recruitment, retention and participation.
- Advise on participant burden, study communications, accessibility and inclusivity.
- Review emerging issues and provide ongoing feedback where appropriate.
- Monitor whether involvement remains representative and meaningful.
- Provide opportunities for contributors to raise concerns or challenge decisions safely.

Analysis and interpretation

- Contribute to interpreting findings from a patient and public perspective.
- Help identify key themes, messages and implications within the data.
- Challenge assumptions and provide alternative interpretations.
- Co-produce plain-language summaries and other dissemination materials.
- Jointly present findings at conferences, meetings and community events.
- Help communicate findings in accessible formats.
- Share findings with relevant communities and wider audiences.
- Provide feedback on what changed because of contributor involvement.

Implementation

- Help develop patient information for new services, treatments or interventions.
- Advise on how findings can be applied in practice.
- Support the adoption of research outcomes in healthcare and community settings.
- Contribute to evaluating whether research has led to meaningful change.

Evaluation

- Reflect on the experience and process of involvement.
- Assess the impact of patient and public involvement (PPIE).
- Consider whether the research has made a difference and why.
- Identify lessons learned and recommendations for future research.

CONSIDERATIONS FOR PATIENT AND PUBLIC CONTRIBUTORS WHO HAVE EXPERIENCED SEPSIS

Post Sepsis Syndrome

People affected by sepsis may have experienced a range of physical, psychological and cognitive symptoms. Offer flexible approaches, including shorter sessions, remote involvement, breaks and the option to pause or withdraw.

Psychological safety

Discussions may involve experiences of bereavement, deterioration, intensive care, disability, or loss. Research Organisations should:

- Approach involvement sensitively and without pressure.
- Agree in advance how distress will be recognised and what support or signposting is available.
- Give notice to contributors about potentially distressing content.
- Allow people to decline involvement in PAG activities.
- Provide appropriate breaks and follow-up.
- Establish a named contact for concerns.
- Have an organisational approach to safeguarding and wellbeing.

CONFIDENTIALITY

Patient and Public Contributors should understand the boundaries of confidentiality, particularly when discussing individual experiences. Do not share identifiable participant information with Patient and Public Contributors unless there is an appropriate, documented basis for doing so.

HRA guidance states that involving patients, service users or the public in the design, management, conduct or dissemination of research should not be managed as research in its own right. However, if an individual is actually participating in the research, the appropriate research and ethics requirements apply.

PAYMENT AND ACCESSIBILITY

Research Organisations should budget for:

- Payment for contributors.
- Travel and other reasonable expenses.
- Childcare or caring costs where appropriate.
- Communication needs.
- Interpreters.
- Digital equipment where required.
- Training.

Payment and reimbursement arrangements should be explained before involvement begins, with consideration of individual circumstances.

MEASURING QUALITY AND IMPACT

Research Organisations should maintain a simple PPIE record covering:

- Who was involved?
- What relevant experience did they bring?
- In which stages of the research were they involved?
- Which activities, questions or decisions did they contribute to?
- What changed as a result?
- What was learned and how will this influence future research?

Examples of impact include changes to:

- The research question.
- Study design.
- Recruitment.
- Information materials.

MEASURING QUALITY AND IMPACT

- Inclusion of underserved populations.
- Study outcomes.
- Interpretation of results.
- Dissemination of results.
- Implementation plans.

NIHR recommend providing feedback to contributors on actions taken and PPIE impact within 8 weeks of relevant involvement activities where possible.

Where a Patient and Public Contributor suggestion is not adopted, Research Organisations should explain why in order to demonstrate accountability.

MINIMUM STANDARDS

Every sepsis research project should have:

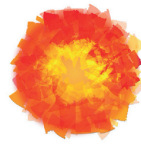
- ✓ Patient and Public involvement from an appropriately early stage.
- ✓ A clear research plan.
- ✓ A plain English summary of research plan.
- ✓ A project summary.
- ✓ PPIE objectives.
- ✓ A Working with People and Communities Summary.
- ✓ PPIE costings and budget information.
- ✓ A PAG activity plan, including timelines.
- ✓ Patient and Public Contributor documentation, including a plain English role profile, person specification, recruitment criteria, and confidentiality requirements.
- ✓ A clear description of how research findings will be disaggregated by protected characteristics.

MINIMUM STANDARDS

- ✓ A main point of contact for Patient and Public Contributors, who can offer support as appropriate.
- ✓ Two-way feedback to Patient and Public involvement from an appropriately early stage.
- ✓ Provide feedback on PPIE impact to Patient and Public Contributors within 8 weeks of relevant activities.
- ✓ Consideration of emotional wellbeing and safeguarding.
- ✓ Documented PPIE activity and impact
- ✓ Appropriate involvement in dissemination and sharing findings.

FURTHER READING

- [Health Research Authority: Best Practice](#)
- [Health Research Authority: Planning and Improving Research](#)
- [Health Research Authority: UK policy framework for health and social care research](#)
- [NIHR Guidance for applicants on working with people and communities](#)
- [NIHR Learning for Involvement: Payments](#)
- [NIHR Payment Guidance for Members of the Public Considering Involvement in Research](#)
- [NIHR Public involvement in research](#)
- [NIHR Resources and training for public involvement in research](#)
- [NIHR Strategic Commitments for Public Partnerships 2025-2030](#)
- [Six UK standards for public involvement](#)



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