

NIHR Policy Research Unit for Health Systems and Interface
with Social Care: ESHCRU II

Strategy for Patient and Public Involvement and Engagement
(PPIE)

Co-produced by the ESHCRU II Management Team and six PPI members of
ESHCRU II's advisory groups.

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What is ESHCRU II?

[ESHCRU II](#) stands for the policy research unit (PRU) in the Economics of Health Systems and the Interface with Social Care.

The overarching aim of ESHCRU II is to inform policy in the health and social care (H&SC) sectors. Our five year programme of work covers three broad research themes (known as Workstreams):

1. **Demand for health care:** understanding changes in the demand for H&SC from different population groups and the implications for how health and care services are provided and funded.
2. **Supply side efficiency:** measuring what is delivered for the money spent on H&SC to maximise quality of care and improvements in health and wellbeing.
3. **Organisation, incentive and regulation:** designing the organisation of health and care systems to make the best use of resources to deliver joined-up care for the population.

The researchers who work on ESHCRU II are health and social care economists from the University of York and the London School of Economics and Political Science (LSE). ESHCRU II is funded by the National Institute for Health Research (NIHR).

What We Mean by Public and Patient Involvement and Engagement (PPIE)

- **Involvement:** where members of the public are actively involved in research projects and research organisations.
- **Engagement:** where *and to whom* information and knowledge about research is provided and disseminated.
- **Public:** includes patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

These definitions come from the NIHR report [Going the Extra Mile](#).

Our Strategy for Patient and Public Involvement and Engagement (PPIE)

Our strategy for ESHCRU II draws on our PPIE experience from the [previous policy research unit](#). In response to feedback from that experience, we increased the number of public contributors on our main advisory group from two to four, and set up workstream advisory groups to support PPIE on individual projects.

The aim of our PPIE strategy is to support and embed meaningful and effective PPIE across ESHCRU II to ensure our research addresses issues that matter to patients, service users and carers, and that findings are accessible to a lay audience. So it is important to involve people with lived experience of health and/or social care services.

We developed the strategy in alignment with the goals in the NIHR report [Going the Extra Mile](#) and the [UK Standards for Public Involvement](#).

The **four objectives** of our PPIE strategy support this aim. They are:

1. To help identify and frame our research questions.
2. To direct the focus of investigations to key issues of importance to patients, service users and the public.
3. To identify implications of results for patients, service users, carers and the public.
4. To advise on and help with the dissemination of the findings of our research.

Our PPIE objectives also support the wider objectives of ESHCRU II (see **Appendix**).

How We Involve and Engage with the Public and Patients

We have three routes for securing meaningful, proportionate PPIE contributions to our policy research unit (PRU).

1. **PRU Advisory Group** (*meets once a year*). We will involve up to four public contributors on this Group. Members act as 'critical friends' to the whole research programme and may advise on any aspect of the policy research unit. The role of public contributors on the PRU Advisory Group is aligned with all four PPIE objectives.
2. **Workstream Advisory Groups** (*meet twice a year*). We will involve up to three public contributors on each of these Groups. The Groups will provide detailed input into individual research projects, such as [highlighting issues that matter to patients](#). The role of public contributors on the Workstream (WS) Advisory Group is aligned with all four PPIE objectives. We have set up one Group (WS1 and WS3); the Group for WS2 will be set up in 2020.
3. **PPIE Panel** (*ad hoc requests; no face-to-face meetings*). There are 18 Panel members, including seven members of the advisory groups. Panel members

are offered ad hoc involvement opportunities, and individuals may respond to these requests if they wish. Opportunities may include: commenting on our website, advising on issues of importance to patients and carers in responsive requests, suggesting and reviewing topics for future research, or reviewing lay summaries. The role of public contributors on the PPIE Panel aligns with PPIE objectives 1, 3 and 4. PPIE objective 2 implies direct involvement with ongoing research and falls in the remit of the advisory group members.

To make it clear what we expect from the Groups / Panel and what they can expect of us, we have drafted Terms of Reference for the [PRU Advisory Group](#), the [Workstream Advisory Groups](#) and the [PPIE Panel](#).

How We Know How Well We Are Doing (Monitoring / Reviewing)

To assess how well we are doing, we need to collect information systematically and have processes in place to review that information and take action to improve.

We use Google forms to record feedback from members after each advisory group meeting. We also email PPIE members individually to ask what went well, how they made a difference and what could have gone better.

The ESHCRU II management team reviews and discusses the feedback and considers how systems and processes might be improved, with changes made as appropriate.

| Milestone | What we will do | Who will do it | When we will do it |
|--|--|--|--|
| Monitoring the functioning of the PRU advisory group | Invite informal feedback from all members (including public contributors) via email and/or Google form. Informal review of feedback by ESHCRU II management team, with changes made as appropriate. | ESHCRU II management team | Annually after each Advisory Group meeting |
| | Feedback on changes made to the research in response to PPIE contributions summarised at the next advisory group meeting (and minuted). | Chair and/or project leads (project coordinator) | Annually at each Advisory Group meeting. |
| | Formal review: summary and analysis of feedback received | ESHCRU II management | Summer 2021 |

| Milestone | What we will do | Who will do it | When we will do it |
|--|--|---|---|
| | to date. Calls with public contributors for honest discussion of what has and has not worked well. | team | |
| Monitoring the functioning of the Workstream advisory groups | Invite informal feedback from all members (including public contributors) via email and/or Google form. Informal review of feedback by management teams. | ESHCRU II management teams. | Biannually after each meeting |
| | Feedback summarised at the next advisory group meeting. | Chair and/or project leads | Annually at each Advisory Group meeting. |
| | Formal review after 2 nd meeting. These are new groups and meeting frequency and/or format may change following review. | ESHCRU II management team | Biannually after each meeting |
| Monitoring contributions from PPIE members | Formal review of PPIE contributions, which are extracted by the project coordinator and reviewed as a standing agenda item by the ESHCRU II management team. | ESHCRU II management team | 6-weekly meetings of the ESHCRU II management team. |
| PPIE strategy | Review of the document, achievement against milestones. Identify areas for improvement and associated actions. Revise strategy accordingly. | ESHCRU II management team PPI advisory group members | Annually |

How We Know What Impact We Are Having

Simply involving people is not enough. We need to have a system to ensure contributions are reflected in our research (i.e. have an impact). Minutes of the advisory group meetings capture contributions by Group members, including public

members. Minutes are shared with all members of the relevant Group for their approval, corrections or additions.

Minutes are also shared with Project leads. They report to the management team on specific differences public contributors have made to the research and its interpretation. These are considered at the 6-weekly meetings of the management team meetings, where PPIE is a standing item on the agenda.

In our annual progress reports to our funder, we consider the impact PPIE has made to the work of ESHCRU II and provide examples. These reports are based on minutes and on feedback from project leads and public contributors. We also plan, with individuals' consent, to post further examples on our website. This will make contributions more transparent for researchers and the public and help support best practice.

These processes enable us to see how well we are doing in putting our **Principles into Practice** (see **Appendix**).

How We Deliver PPIE

1. Governance

Our Advisory Groups are part of the governance structure of the Unit. Public contributors are involved as equal members of the Advisory Groups.

2. Resources

Over the 5-year programme of work, 1.1% of our budget is allocated to fund PPIE involvement. This covers reimbursement for travel for meeting attendance, subsistence, refreshments, payments, carer costs (e.g. to enable meeting attendance) and overnight accommodation. We have a training budget to fund course attendance for PPIE members. We also offer regular feedback to public contributors, and a jargon buster for help with technical terms. We are exploring options for developing a 'basics' course on health economics.

The PPIE lead for ESHCRU II is Louise Campbell. Louise is the project co-ordinator for ESHCRU II and the first point of contact for our public contributors. This involves:

- Liaising with public contributors regarding meeting attendance and travel (advisory groups) and ad hoc requests (PPIE panel).
- Ensuring meeting rooms are accessible and any materials are in a format of their choosing.
- Providing and receiving feedback to and from public members after meetings, including training needs.

- Attending NIHR PPIE meetings on behalf of ESHCRU II.
- Processing payment and expenses forms.

The ESHCRU II director, Anne Mason, has overall responsibility for the PPIE strategy and ensuring that members of the public are involved in a meaningful way in individual research projects and in our PRU advisory group. She will work with the project co-ordinator and the ESHCRU management team in the following ways:

- Drafting and reviewing Terms of Reference for Advisory Groups and the PPIE Panel. These help ensure the Groups work constructively and in an open, respectful atmosphere, and that expectations of Panel membership are clear.
Action: Review annually (management group)
- Drafting and reviewing a PPIE payment policy.
Action: Review annually (management group)
- Ensuring Advisory Group Chairs receive written guidance on best practice for involving lay members in meetings.
Action: sent two weeks before each meeting (LC)
- Developing and updating a 'jargon buster' of technical terms.
Action: Review after each Advisory Group meeting.
- Exploring options for developing a 'basics' training course in health economics.
Action: Draft paper on options by July 2020 (AM)
- Monitoring the functioning and structure of the Advisory Groups, with a formal review in summer 2021.
Action: see milestones.
- Recruiting new public contributors as needed.
Action: review at 6 weekly ESHCRU II management meetings (standing item). Group members' term of office is 3 years, so new recruitment planned for 2021.

How We Develop Our Strategic Plan

- Initial draft by ESHCRU II management team.
- Comments, criticisms and contributions invited from PPIE advisory group members, and revised to reflect feedback.
- Draft shared with wider ESHCRU II team for comments.

If you have any questions or comments about our strategy, please contact the ESHCRU II coordinator Louise Campbell: che-eshcru@york.ac.uk

Appendix

Strategic objectives – Link between PPIE Strategy and ESHCRU II

The overarching aim of ESHCRU II is to inform policy in the health and social care (H&SC) sectors. We do this by applying robust methods and theory from the discipline of economics. ESHCRU II's strategic plan has eight objectives:

1. Deliver an agreed programme to address the Department of Health and Social Care's (DHSC) short, medium and long-term policy research needs.
2. Disseminate our findings in ways that promote impact.
3. Build on our long-term trusted relationship with the DHSC, to ensure our research supports policy priorities, reflecting a mutual understanding of the policy and research processes.
4. Develop our responsive facility to accommodate the continually evolving nature of the H&SC policy environment.
5. Keep abreast of the evolving policy environment and of the present and longer term challenges facing the H&SC system by ensuring we are 'plugged in' to relevant networks.
6. Ensure our research programme considers diversity wherever possible and informs policies to tackle H&SC inequalities.
7. Aim for excellence in our data governance credentials.
8. Promote the development of early career researchers to increase the availability of H&SC economists with expertise in policy analysis.

The four objectives of our PPIE Strategy are aligned with ESHCRU II's objectives.

The table below shows the relationship between the two sets of objectives and gives examples of the type of roles public contributions may take.

The PPIE objectives relate to most of ESHCRU II's objectives, with the exception of objectives 3 (the relationship between the research team and DHSC), 7 (data governance) and 8 (building research capacity).

| PPIE objectives | ESHCRU II Objective | Example PPIE roles |
|---|---------------------|--|
| 1. To help identify and frame our research questions. | 1, 4, 5, 6 | <ul style="list-style-type: none"> - Propose topics for future research - Contribute to shaping the overall direction of the programme - Review study proposals |

| PPIE objectives | ESHCRU II Objective | Example PPIE roles |
|--|---------------------|---|
| | | <ul style="list-style-type: none"> - Refine existing research questions. - Provide ad hoc advice on responsive requests from DHSC. |
| <p>2. To direct the focus of investigations to key issues of importance to patients, service users and the public.</p> | <p>1, 2, 5, 7</p> | <ul style="list-style-type: none"> - Explain how policies might affect service users and carers. - Identify factors we may have overlooked that could materially impact our findings or their interpretation. - Identify issues affecting marginalised, vulnerable or under-researched groups. - Highlight issues that would be of interest to service users and carers. - Provide a patient perspective to support the case in our applications for datasets. |
| <p>3. To identify implications of results for patients, service users, carers and the public.</p> | <p>2, 6</p> | <ul style="list-style-type: none"> - Consider potential impacts on patients, service users and carers at an early stage in the research. - Advise on the interpretation of findings, especially for vulnerable groups. - Suggest alternative angles for the research enabling findings to be framed in a more accessible way. |
| <p>4. To advise on and help with the dissemination of findings of our research.</p> | <p>2, 6</p> | <ul style="list-style-type: none"> - Advise on dissemination and impact of research findings. - Help draft, or comment on, lay summaries for research reports. - Review our website for user friendliness. - Share relevant news and events via their own networks. |

Principles into Practice

The NIHR [Going the Extra Mile](#) report which sets out a 10-year strategy (2015-2025) for PPIE in research. Our objectives align with the six strategic goals from this report.

1. Opportunities to engage and become involved in research are visible and seized by the public.

To reach a wide range of people, we advertise opportunities through national and local channels. All applicants are invited to complete an anonymous questionnaire for equal opportunities monitoring. This voluntary process helps us check whether our recruitment practices are fair and appropriate, so we can improve the way we plan and target future recruitment.

To facilitate contributions beyond membership of the formal Groups, we invite a wider group of applicants to join our Panel.

2. The experience of patients, service users and carers is a fundamental and valued source of knowledge.

Our Unit is focused on economics and so is largely concerned with the statistical analysis of data at the level of systems. So it could be harder to engage with public contributors than if we were focused on research on people's experiences, attitudes or views. We need to think carefully about how to work with public contributors in a way that values their contributions (UK standard – [working together](#)) and ensures their perspectives inform the research.

To support meaningful involvement, researchers prepare their talks and questions ahead of meetings, identifying issues and questions where input would be most helpful. As our Advisory Groups also include individuals with technical expertise, meetings may include technical discussions. If so, the Chair will explain this to the Group then direct questions appropriately. We provide best practice guidance for Chairs to help ensure public voices are heard, valued and respected (UK Standard 4-[governance](#)). We are developing a 'jargon buster' to help build confidence and skills (UK Standard 3 – [support and learning](#)). The process of recognising and defining technical terms should help researchers to be more aware of the way they communicate.

3. Public involvement is a required part of high quality research conducted by researchers and their institutions.

Public involvement is essential, but must be proportionate so that individuals' time and efforts are effective. We therefore involve public contributors to inform research questions, advise on aspects of the methods, interpretation of findings, and dissemination.

4. Public involvement is locally driven and relevant whilst strategically consistent with the NIHR's goals.

Our overarching aim is to involve people in a way that supports the [NIHR](#) mission to conduct “leading-edge research focused on the needs of patients and the public”. Most research conducted by our policy research unit relates to national policies and services. We advertise opportunities for involvement nationally, so individuals from any part of England may apply but also advertise through regional channels, e.g. the Yorkshire & Humber Clinical Research Network. This helps ensure we reach individuals according to our research needs (UK standard – [inclusive opportunities](#)).

5. Evidence of what works is accessible so that others can put it into practice

Our website has a [page devoted to PPIE](#), where examples of successful involvement can be shared. On the [ESHCRU II front page](#), we include an example of how a lay member from our previous Unit made a difference to our research, and will add further examples of impact as the programme develops (UK Standard – [impact](#)). We have put processes in place to offer, gather and action feedback with the public contributors (UK Standard – [communications](#)).

6. The NIHR has maintained its global presence and influence for working in partnership with the public.

ESHCRU II supports this NIHR goal by aligning its PPIE strategy and plans in accordance with NIHR best practice and by promoting its activities and findings via its [website](#).