

**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
PPI members of ESHCRU II's advisory groups.

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1 What is ESHCRU II?

[ESHCRU II](#) stands for the policy research unit 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).

2 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 changes to these definitions are in shown in red.

3 Our PPIE Strategy – aims and objectives

Our strategy for ESHCRU II draws on our PPIE experience from our [previous policy research unit](#). In response to feedback, we increased the number of public contributors on our main advisory group from two to four to provide a broader range of views, 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.

We developed the strategy in line with the goals in the NIHR report [Going the Extra Mile](#) and the [UK Standards for Public Involvement](#). Information on how these principles inform our strategy are in the **Appendix**.

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, including issues relating to equity.
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**).

4 How We Involve and Engage with the Public and Patients

We have a [structured way of running our policy research unit](#) that includes advisory groups. Public contributors are involved as equal members of these advisory groups.

We have three routes for securing meaningful, proportionate PPIE contributions to our research.

1. **Programme Advisory Group** (*meets once a year*). We 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. [Current members](#) are listed on our website. The role of public contributors on the Programme 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](#). Membership includes academics, independent consultants, and representatives from DHSC and its arm’s length bodies. The role of public contributors on the Workstream (WS) Advisory Group is aligned with all four

PPIE objectives.

3. **PPIE Panel** (*ad hoc requests; no face-to-face meetings*). There are 18 Panel members, including current 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 regarding DHSC requests for specific pieces of new research, suggesting and reviewing topics for future research, or reviewing lay summaries to make the research more accessible. 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 is suited to 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 [Programme Advisory Group](#), the [Workstream Advisory Groups](#) and the [PPIE Panel](#). Details of how we deliver PPIE, in terms of roles and responsibilities, can be found in the **Appendix**.

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

To assess how well we are doing, we need to collect information in an orderly way and put processes in place to review that information and take action to improve.

We invite feedback from all members after each advisory group meeting. We also contact PPIE members individually to ask what went well, how they made a difference and what could have gone better. They can respond using a method of their choosing (e.g. phone call, Google form, email). We use paperless methods whenever possible to minimise the impact on the environment, but offer alternatives to those who wish to respond in a different way.

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 Programme advisory group	Invite informal feedback from all members (including public contributors) via email, phone call 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
	Responses by researchers 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 to date. Public contributors invited to provide feedback on what has and has not worked well	ESHCRU II management team	Summer 2021
Monitoring the functioning of the Workstream advisory groups	Invite informal feedback from all members (including public contributors) Informal review of feedback by management teams.	ESHCRU II management teams.	Twice a year, after each meeting
	Responses by researchers to PPIE contributions summarised at the next advisory group meeting (and minuted).	Chair and/or project leads	Twice a year 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	Completed
Monitoring our response to contributions from PPIE members	Regular review of how our research takes account of PPIE contributions. Considered 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

6 How We Know What Impact We Are Having

Simply involving people is not enough. We need to have a system to ensure that their contributions are reflected in our research. When we talk about the **'impact' of PPIE** we mean that **people's contributions help shape how we do our research**. This includes all four aspects of the research process outlined in our objectives.

For example, one of our objectives is to *direct the focus of investigations*. A PPIE member may highlight the impact of availability of community care on study findings. This suggestion would be taken back to the wider research team, who then carefully considers its desirability and feasibility, for instance by exploring possible datasets. The suggestion may or may not lead to a material change in the research, but it has influenced its focus and so would be counted as successful 'impact'. It is important to note that 'impact' in PPIE does not refer to effects on health and care services or on health and wellbeing, but on what and how research is undertaken

Minutes of the advisory group meetings capture contributions by Group members, including public members, and include actions for the research teams. Minutes are shared with all members of the relevant Group for their approval, corrections or additions. If meetings are held remotely, members can comment in the 'Chat' function. The Chat is saved and shared with research teams who then consider the implications for their research.

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 the researchers and public contributors. We also plan, with individuals' consent, to post further examples (case studies) 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 Error! Reference source not found. (see **Appendix**).

7 How We Deliver PPIE – payments and training

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. Our [PPIE payment policy](#) sets out further information and we review this policy regularly to ensure it complies with the latest guidance.

We provide feedback on impact to public contributors at advisory group meetings, and a '[jargon buster](#)' for help with technical terms and a list of [online materials on health economics](#). We are developing a 'basics' session on health economics and policy evaluation.

8 How We Develop Our Strategic Plan

- Initial draft by ESHCRU II management team.
- Feedback and contributions invited from PPIE advisory group members, and draft revised accordingly.
- Draft shared with wider ESHCRU II team for comments.
- Annual review: Strategy reviewed by management team, with PPIE advisory group members invited to identify areas for improvement.
- Revised strategy uploaded to the ESHCRU II website.

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

9 Appendix

This section explains how our PPIE objectives are informed by high-level national principles for PPIE. We then explain how our four objectives in our PPIE strategy relate to the strategic objectives of the policy research unit. We conclude by explaining some of the ‘nuts and bolts’ involved in delivering PPIE in ESHCRU II.

9.1 Principles into Practice

The NIHR [Going the Extra Mile](#) report 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, such as [People in Research](#), [global networks](#) or mailing lists run by local [Clinical Research Networks](#).

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. Individuals are recruited on the basis of how they meet the criteria in the person specification. Whilst personal experience of using health and care services is a requirement of the role, we do not discriminate on the basis of age, gender, race, sexual orientation or religion. Nonetheless, we recognise the value of drawing on advice from a diverse panel of PPIE members. When recruiting new members, we therefore think carefully about any obstacles people from different groups might face when applying, and make it clear if applications from particular groups are especially welcome.

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

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

ESHCRU II is focused on economics and so is largely concerned with the quantitative analysis of data at the level of health and care 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 have developed, and maintain, 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. This also includes an example of how a lay member from our previous policy research unit made a difference to our research, and we continue to 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](#).

9.2 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, which has been agreed with DHSC, 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 [on policy decisions or on health and care services].
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.
<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.

9.3 How We Deliver PPIE – roles and responsibilities

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 to ensure the Groups work constructively and in an open, respectful atmosphere, and that expectations of Panel membership are clear.
- Drafting and reviewing a PPIE payment policy.
- Ensuring Advisory Group Chairs receive written guidance on best practice for involving lay members in meetings.
- Developing and updating a 'jargon buster' of technical terms.
- Exploring options for developing a 'basics' training course in health economics.
- Monitoring the functioning and structure of the Advisory Groups, with a formal review midway (summer 2021).
- Recruiting new public contributors as needed.