NIHR | Policy Research Unit
Palliative and end of life care

Patient & Public Involvement Strategy

January 2024 – December 2026

This strategy outlines our guiding principles, approach and goals for patient and public involvement in the Policy Research Unit in palliative and end of life care. It details our desired outcomes, how we will deliver these and how we will assess our impact and improve.

This strategy was developed in collaboration with our PPI Co-applicant and PPI Strategic Advisory Group.

University of Hull
King's College London

University of Cambridge
University of Leeds
Lancaster University

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About the Policy Research Unit

The Policy Research Unit in palliative and end of life care aims to support policymakers in improving care and reducing inequalities for children, young people and adults affected by life-limiting illnesses and their families/carers, including into bereavement.

The Policy Research Unit will provide policymakers at the Department of Health and Social Care—and related public bodies, including NHS England—with timely, relevant, and rapidly accessible evidence to help them make policy decisions that improve care and reduce inequalities for patients and families/carers.

The Policy Research Unit has assembled a world-leading, expert team that includes researchers and public partners from five Universities.

Our three-year programme (January 2024 – December 2026) of work covers three broad research areas:

1) **Workforce:** ensuring the 'workforce' (those who deliver care) can meet current and future needs.
2) **Inequality in access:** reducing inequalities in palliative and end-of-life care, such as ethnicity, socio-economic disadvantage and geography.
3) **Quality of care:** improving quality of care, particularly in the community and 'out-of-hours'.

As part of the unit, we will have a *rapid response facility* that delivers timely, high-quality evidence to policymakers, giving them the information they need to improve palliative and end-of-life care.
This document outlines the Unit's Patient and Public Involvement strategy.

What is Patient & Public Involvement?

The National Institute for Health and Care Research defines patient and public involvement (PPI) as research carried out 'with' or 'by' members of the public and not 'to', 'about' or 'for' them. (1) It should be a partnership between patients, carers, and members of the public with researchers to shape and deliver policy research effectively. (2)

PPI acts as a critical friend to the research process, ensuring that studies remain focused and aligned with public interests. (3) Engaging with the public is crucial for enhancing research quality, relevance, transparency, and trustworthiness. (4) It also fosters a research environment that supports more equitable, inclusive, and diverse policy outcomes. Given the potential of our research to directly influence policy, it is essential to integrate PPI throughout our work to ensure that our findings accurately reflect the public's priorities and needs.

Throughout this document, we will refer to our PPI members as public partners..

How the Policy Research Unit's PPI strategy was developed

This strategy was developed in collaboration with our PPI co-applicant, Rashmi Kumar, and the PPI Strategic Advisory Group. Rashmi worked with us to establish the unit's PPI structure and recruit public partners for the Strategic Advisory Group. While recruiting for the Strategic Advisory Group, we asked all 20 people who expressed interest in joining the group 'how we should enable meaningful and impactful public involvement' in the Unit. These conversations allowed us to capture what was important to our public partners and served as the foundation for the strategy's initial objectives. A summary of the themes that arose from these conversations can be seen in Appendix A.

Before engaging with the public, we explored the PPI infrastructure and values at all five Policy Research Unit university partners. (Appendix B) These existing PPI networks influenced our PPI strategy.

The strategy aims to foster meaningful and impactful PPI that enhances the quality and relevance of our work. We are dedicated to inclusivity, ensuring the full range of lived experiences, especially those less often heard, such as minoritised ethnic groups, older people, children, and those with socio-economic disadvantages, actively inform and shape our research.

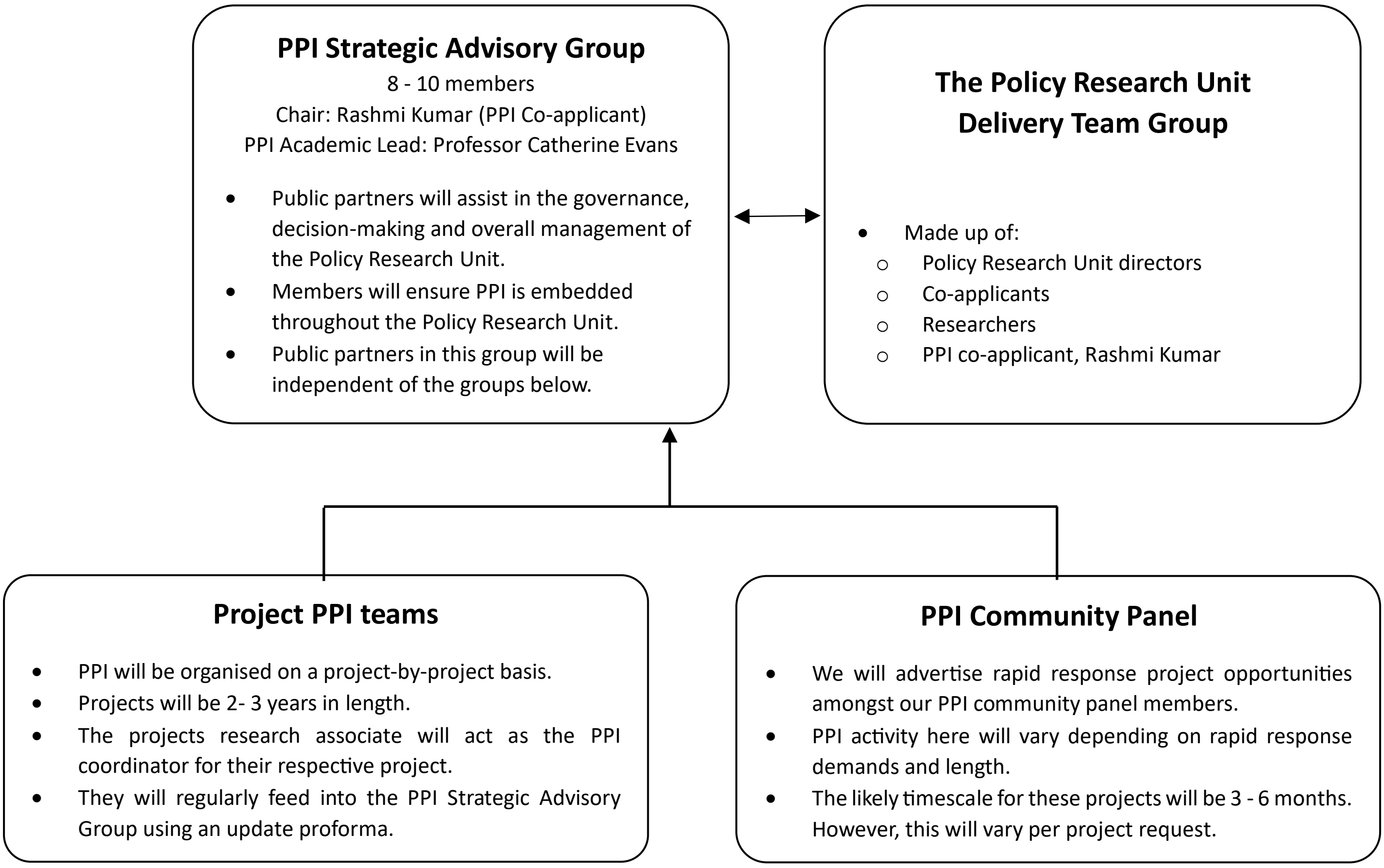
Informed by the NIHR UK Standards of Public Involvement, we have developed six goals to address our aim. (5) These six standards (governance, working together, communication, inclusive, learning and support, and impact) are embedded in the text below. Details about how these goals will be achieved, their measures of success, and timeframes can be seen in Appendix C.

Our Approach to Patient & Public Involvement

1. **Governance:** How we involve and engage with our public partners

Goal 1: We will ensure that Patient and Public Involvement is embedded throughout the Policy Research Unit, including the management and decision-making.

Patient and Public Involvement will be embedded in the Policy Research Unit in several ways. Public partners will support the Unit's overall governance, individual research, and rapid response projects. Figure 1 illustrates the PPI structure of the Unit. Figure 2 (seen in Appendix D) demonstrates how PPI is embedded within the Unit's organisational structure.



PPI Strategic Advisory Group

8 - 10 members

Chair: Rashmi Kumar (PPI Co-applicant)

PPI Academic Lead: Professor Catherine Evans

- Public partners will assist in the governance, decision-making and overall management of the Policy Research Unit.
- Members will ensure PPI is embedded throughout the Policy Research Unit.
- Public partners in this group will be independent of the groups below.

The Policy Research Unit Delivery Team Group

- Made up of:
  - Policy Research Unit directors
  - Co-applicants
  - Researchers
  - PPI co-applicant, Rashmi Kumar

Project PPI teams

- PPI will be organised on a project-by-project basis.
- Projects will be 2- 3 years in length.
- The projects research associate will act as the PPI coordinator for their respective project.
- They will regularly feed into the PPI Strategic Advisory Group using an update proforma.

PPI Community Panel

- We will advertise rapid response project opportunities amongst our PPI community panel members.
- PPI activity here will vary depending on rapid response demands and length.
- The likely timescale for these projects will be 3 - 6 months. However, this will vary per project request.

Figure 1: Policy Research Unit’s Patient & Public Involvement Structure and Lines of Reporting

PPI Strategic Advisory Group: The Strategic Advisory Group provide the core PPI support for the Policy Research Unit. This group assists in the Unit's decision-making and overall PPI management, ensuring that meaningful PPI is embedded throughout the unit. The Strategic Advisory Group has 8-10 public partners and is chaired by Rashmi Kumar, the Policy Research Unit’s PPI co-applicant.

Our Strategic Advisory Group comprises public partners from diverse geographic locations, backgrounds and experiences recruited from our university partners’ PPI networks. Our public partners are current and/or bereaved carers for children, young people, and older adults. Upon recommendation from the Strategic Advisory Group, we have appointed an Equality, Diversity and Inclusion (EDI) champion for the group. The EDI lead will monitor and recognise EDI gaps so that PPI activities in the Unit can improve. A framework for more equitable, diverse, and inclusive Patient and Public Involvement in palliative care research will guide our approach. (6)

The group meets a minimum of four times annually, using online tools to maximise involvement and responsiveness. The Strategic Advisory Group Chair relays information between the group and the Policy Research Unit's delivery team group on the unit's PPI activities.

Project PPI teams: PPI groups are set up for each research project. The PPI structure and activity will vary depending on the project's demands and requirements. The PPI coordinators of their respective projects will regularly update the Strategic Advisory Group on their PPI activities through an update proforma. The PPI coordinator for the Policy Research Unit will facilitate this process.

PPI Community Panel: The PPI community panel will provide any necessary public involvement support activities in the Policy Research Unit. This group will be the first point of contact for PPI opportunities and recruitment for the Unit. This group will have public members routinely recruited using our university partners' PPI and local community networks. PPI members in this panel may contribute to rapid response projects. The PPI activities in rapid response projects will vary depending on the demands and requirements of the project, and the timescale (usually 3 - 6 months). The group will receive newsletter updates on the work of the Unit and opportunities for involvement and engagement.

Working agreements for each group will be developed to identify clear roles and responsibilities.

2. **Working together:** How we deliver Patient & Public Involvement

Goal 2: We will work in partnership with our public partners to build on the existing patient and public involvement resources and infrastructure at all partner universities.

Professor Catherine Evans is the PPI academic lead for the Policy Research Unit. Working closely with the PPI-co-applicant and PPI Coordinator, they will oversee the monitoring and evaluation of meaningful involvement of public members in the Unit, focusing on improvements for inclusive approaches, diversity of membership, and impact on the research, including core research and rapid response projects, and the Strategic Advisory Group. Responsibilities include:

- Provide/coordinate necessary support and relevant training to PPI members and the unit's necessary governance processes.
- Support with the necessary learning and development for PPI members (including 'peer and support buddies').
- Provide and manage any necessary community outreach, engagement and dissemination activities with the public partners.

The PPI co-applicant for the PRU-PEOLC and Chair of the PPI Strategic Advisory Group is **Rashmi Kumar**. He will provide a lived expert perspective and ensure that the public's priorities are at the heart of the unit's work. He will support with the following:

- Chair the PPI Strategic Advisory Group and ensure equal participation in meetings.
- Interface on information between the Strategic Advisory Group, respective research project PPI groups and the Delivery Team Group.
- Provide support to public partners and encourage involvement opportunities.
- Provide guidance on all PPI activities in the PRU-PEOLC.

3. **Communication:** The PPI coordinator

Goal 3: We will ensure all communication within the Policy Research Unit is transparent, timely, and respectful.

The PPI coordinator for the Policy Research Unit is **Georgina Macdonald**. She will be the first point of contact for public partners. She will support with the following:

- Liaise with public partners to coordinate meetings and ad hoc requests.
- Ensure PPI meetings are accessible and information available in the required format.
- Assist with the coordination of PPI member's training needs.
- Assist with managing PPI payment and expense requirements, including any necessary PPI support identified.
- Monitor and evaluate PPI activity in the unit and the impact of involvement of research activity and outputs.
- Support the chair of the PPI Strategic Advisory Group.

4. **Inclusive:** Equality, Diversity and Inclusion champion & payment for our public partners

Goal 4: We will endeavour to engage with diverse groups of various ethnicities, genders, lived experiences (current or bereaved family carers, living with life-limiting conditions), and geographic locations in England.

Equality, Diversity and Inclusion Champion

Upon recommendation for our PPI Strategic Advisory Group, we have an Equality, Diversity, and Inclusion (EDI) champion in the Patient and Public Involvement Strategic Advisory Group; this lead is crucial in ensuring engagement with diverse communities across England. The EDI lead actively champions the inclusion of voices from various ethnicities, genders, lived experiences, and geographic locations, helping to shape inclusive and equitable practices in the Unit. This role is vital for identifying and addressing potential barriers to participation. By integrating these diverse perspectives, the EDI champion supports creating more accessible, culturally responsive, and geographically relevant initiatives, ultimately enhancing the reach and impact of the PPI group's work.

Remuneration policy

Our payment policy outlines how public partners will be remunerated for their contributions (Appendix E). These are based on the NIHR rate for the public's involvement in meetings and activities. Payment is in accordance with NIHR Centre for Engagement and Dissemination guidance. (7) There will also be a supplementary payment for any necessary informal care costs and attendance at online meetings to cover home working costs and Wi-Fi. We will provide verbal or written thanks for all contributions from our public partners.

5. **Learning & Support:** Training for our public partners

Goal 5: We will work to ensure inclusive PPI, with the availability of flexible support and learning opportunities tailored to the needs and priorities of our public partners.

Our Policy Research Unit public partners will be signposted to any necessary training based on their needs and skill levels. It is imperative that we equip our public partners with the ability to confidentially and meaningfully be involved in our Policy Research Unit. We will develop training or presentations for our public partners about the UK policy landscape to inform them about how policy decisions are made. Training for Strategic Advisory Group members will also be developed to provide skills to strengthen the unit's strategic thinking.

6. **Impact:** Monitoring and reporting the impact of Patient & Public Involvement

Goal 6: We will continuously monitor and evaluate all patient and public involvement activities within the Policy Research Unit to improve our public collaboration services.

In the Policy Research Unit, we will continuously monitor our patient and public involvement and make improvements to enhance public engagement. We will do this by actively seeking feedback from researchers and public partners to foster shared learning and identify areas for improvement.

We will track the impact of patient and public involvement through our engagement log, which we developed using the Marie Curie Research Centre’s Public Involvement in Research Impact Toolkit and the ‘you said, we did’ impact log. (8) The Unit’s team is committed to regularly updating this log. The PPI coordinator will oversee its usage and remind all to engage with it.

The information gathered in the engagement log will be systematically analysed to identify trends, successes, and areas for improvement. The results will inform our strategies and actions to enhance public engagement. The Unit’s directors, PPI research leads, and PPI co-applicant will review the engagement log and will use the insights to implement necessary changes to our involvement practices. This process ensures that feedback directly translates into actionable improvements, fostering a culture of continuous enhancement and meaningful public engagement.

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Appendix

A. “How would you ensure meaningful and impactful PPI throughout the unit?”

In the Strategic Advisory Group recruitment calls, we asked all public partners, “How would you ensure meaningful and impactful PPI throughout the unit?”. We received a theme of responses that guided our strategy development. These are found in the table below.

Concept	Explanation
Training	• Training for policy research • Training in policy, governance, and language • Once a year training sessions with everyone
Communication	• Transparent & open communication • Planning meetings ahead of time to recognise and respect people's time. • Regular check-ins and updates about the unit. They don’t want to be left in the dark. • Feeding back information and results from public involvement. For example, because of your comment this change happened. • Managing expectations of public collaborators by establishing terms of reference or ground rules. • Establishing what everyone's communication styles are • Researchers should be transparent about the barriers they may face in managing the expectations of the public involved. • Two-way process • Manage expectations of what can and cannot be achieved • Regular newsletters with updates on the PRU • Communicate how much they will be paid.
Respect	• Fair and timely compensation • Planning meetings ahead of time to recognise and respect people's time. • Voice as a live expert is valued and heard by all on the team. • All professionals respect and understand input from the public. • Working in partnership with respect and understanding for everyone's unique experiences of PEOLC • report back to the public what impact they have had. • Early involvement • Feedback what impact public collaborators had or what the final product is
Monitoring	• Ensure PPI is embedded at every level of the Unit and routinely evaluate its performance and ways to improve. • A tangible way to measure and capture the impact of PPI. • Tangible goals • Auditing from both sides - are the researchers happy with the PPI and vice versa • Gives example of researcher documenting all contributions made by the public members.
Relationships	• Establish rapport with the public collaborators. • Network building

Concept	**Explanation**
Existing services	• Building on existing PPI services amongst the university's partners
Inclusivity	• Ensure representation from diverse groups based not only on ethnicity. • Address barriers to involvement prospectively • Need to be inclusive • Being flexible with involvement methods (by email, call, video, letter, using chat function, etc)

B. Existing Patient & Public Involvement services in the Policy Research Unit in PEOLC

Existing Patient & Public Involvement Infrastructure at the Policy Research Unit Universities

King's College London	Cicely Saunders Institute (CSI): • **CSI Public Involvement Forum:** This online forum has been designed to support discussions between our research teams, patients, carers, and public members to improve the quality, relevance, and impact of our work. • **CSI Patient and Public Involvement Members Handbook:** This handbook provides new PPI members with information about PPI, how to get involved, and available support. • **PPI Buddy Scheme:** This scheme allows new public collaborators to become more familiar with the research process by having another community member as their buddy, with whom they can ask questions and gain support. • **Dragons Den:** These sessions allow researchers to present new or ongoing research to patients, carers, family and the public for immediate feedback. • **PPI Research Training Video Series:** This six-part video series explains PPI and how public members can be involved in each stage of the research process. • **CSI PPI Strategy 2024-26:** This strategy outlines the ambition, principles, and goals for public involvement at the Cicely Saunders Institute over the next three years. It details what the institute wants to achieve, how it will deliver these, and how it will evaluate its impact. • **Working with parents with experience of bereavement and/or seriously ill children:** Short video animation which details recommendations on working with parents of seriously ill children or who have experienced bereavement. • **Working with parents of children with serious illness and bereaved parents:** A two-page summary of recommendations on how to collaborate with parents of seriously ill children or who have experienced bereavement. NIHR Applied Research Collaboration South London: • **A collection of resources to support public involvement in research for researchers, non-researchers and public contributors.**
University of Hull	• **INVOLVE Hull:** This online forum was created to ensure that patients, carers and people who use health and care services have the opportunity to shape the research at the University of Hull. • **The making of Involve Hull: our riverside story**: This story details what it's like to be a member of the INVOLVE network at the University of Hull

	• **Strategy for Public Involvement 2024 - 26:** This document outlines the Public Involvement Strategy for the Institute for Clinical and Applied Health Research (ICAHR) at the University of Hull. •
University of Leeds	• **PPI Recipe Book:** This book details how to approach a PPI meeting around palliative care as a public contributor and a researcher. • **PPI EDI Paper:** A framework for more equitable, diverse, and inclusive Patient and Public Involvement for palliative care research.
Lancaster University	• Existing networks and relationships with community stakeholders from minoritised ethnic communities. • Applied Research Collaborative North West Coast promotes a model of Patient, Public and Community Involvement, Engagement and Participation.
University of Cambridge	• **Community Nursing Research Forum:** This forum supports community nurses with research opportunities, peer support, and mentorship.

C. Our Patient & Public Involvement Goals

Our aim is to foster meaningful and impactful PPI that enhances the quality and relevance of our work. We are dedicated to inclusivity, ensuring the full range of lived experiences, especially those less often heard, such as minoritised ethnic groups, older people, children, and those with socio-economic disadvantage, actively inform and shape our policy research.

Informed by the NIHR UK Standards of Public Involvement, we have developed six goals for how to address our aim. (5)

Our PPI goals will be reviewed and updated annually with guidance from our Strategic Advisory Group.

1. **Governance:** How we involve and engage with the public partners

Goal 1: *We will ensure that Patient and Public Involvement is embedded throughout the Policy Research Unit, including the management and decision-making.*

How will this be achieved?	Measure of success	Timing
1. The PPI co-applicant is engaged and informed about activity in the PRU-PEOLC.	The PPI co-applicant represents public members at the PRU Delivery Team Group meetings. The co-applicant will report PPI updates to the delivery team and feedback information to the PPI Strategic Advisory Group.	Ongoing
2. The PPI co-applicant assists with PPI decisions, such as recruitment, meeting planning and strategy development.	Bi-weekly meetings with the PPI coordinator and co-applicant are established.	Ongoing
3. Patient and Public Involvement is a standing agenda item for the Management Group and Delivery Team Group.	Each PRU Project will report on PPI using an agreed template with the PPI Strategic Advisory Group. Patient and Public Involvement will be included as a standing agenda item at the	Ongoing

How will this be achieved?	Measure of success	Timing
	Management Group and Delivery Team Group meetings, respectively.	
4. The Strategic Advisory Group oversees how PPI is embedded in the PRU-PEOLC and monitors PPI activity and impact. This group will monitor on meaningful and impactful public collaboration.	The PPI Strategic Advisory Group members are recruited, and the group is established.	Year One
5. The Terms of Reference for the PPI Strategic Advisory Group are developed in collaboration with our public partners.	Terms of Reference developed and agreed with the Strategic Advisory Group.	Year One
6. The PPI Strategic Advisory Group will co-develop the PPI strategy of the Policy Research Unit.	Develop PPI Strategy with the PPI co-applicant and the Strategic Advisory Group.	Year One
7. The PPI Strategic Advisory Group will monitor the goals of the PPI strategy, support delivery and evaluation to drive improvements in meaningful and impactful involvement	Monitoring and evaluating goals in the PPI Strategic Advisory group. Establish annual review and evaluation of the impact of PPI for inclusive and diverse involvement and impact in the PRU-PEOLC.	Year Two

2. **Working together:** How we deliver Patient and Public Involvement

Goal 2: *We will work in partnership with our public partners to build on the existing patient and public involvement resources and infrastructure at all partner universities that make up the unit.*

How will this be achieved?	Measure of success	Timing
1. We will recruit public partners using networks established at the partner universities in the unit.	Advertise PPI opportunities with the partner universities and engagement networks and platforms.	Year One
	Recruitment of public partners from partner universities from across geographic regions.	Year One
2. We will create a PPI community with our partners and ensure regularly engagement on PRU-PEOLC activity including hosting annual PPI events.	Establish a quarterly co-developed newsletters on all PRU-PEOLC activities.	Year Two
3. We will develop a buddy scheme to pair those less experienced public partners with more experienced public partners.	Establish the buddy scheme programme and roll it out amongst our public partners.	Year Two

3. **Communication:** PPI Coordinator for the Policy Research Unit

Goal 3: We will ensure all communication within the Policy Research Unit is transparent, timely, and respectful.

How will this be achieved?	Measure (s) of success	Timing
1. We will establish quarterly updates to Strategic Advisory Group on the PPI activity in the research and rapid response projects.	Co-develop a project update report template. The PPI coordinator of each research project will report quarterly to update the Strategic Advisory Group on the project's PPI activity.	Year One
2. We will establish a quarterly newsletter to update our public partners on activity in the Unit.	Co-develop newsletter with our public partners.	Year Two
3. We will provide feedback to public collaborators about the impact of their involvement in the project.	Establish an impact log with our public partners.	Year Two

4. **Inclusive:** Payment and remuneration for Patient and Public Involvement

Goal 4: *We will endeavour to engage with diverse groups of various ethnicities, genders, lived experiences (current or bereaved family carers, living with life-limiting conditions), and geographic locations in England.*

How will this be achieved?	Measure (s) of success	Timing
1. We will establish an Equality, Diversity and Inclusion (EDI) lead within the Strategic Advisory Group.	Appointment of an EDI lead within the Strategic Advisory Group.	Year One
2. We will have children and young people representation within the Strategic Advisory Group.	Recruitment of children and young people PPI representatives to the Strategic Advisory Group.	Year One
3. We will offer timely compensation for involvement activities.	Establish a PPI payment and expenses policy for the PRU-PEOLC. This payment policy can be seen in appendix E.	Year One
4. We will advertise involvement opportunities for diverse audiences, including connecting with community gatekeepers.	Engage with our partners' PPI networks to advertise PPI opportunities.	Year One
5. We will engage with our partner's community network to improve on diversity involvement	We will establish regular update and engagement opportunity with stakeholders' and community network partners.	Year Two

5. Learning & Support: Training for our public partners

Goal 5: *We will work to ensure inclusive PPI, with the availability of flexible support and learning opportunities tailored to the needs and priorities of our public partners.*

How will this be achieved?	Measure (s) of success	Timing
1. We will identify and offer training services to our public partners on the PEOLC policy landscape and policy research.	Identify the Department of Health & Social Care (and other relevant groups like NIHR) on how policy research functions and its importance.	Year One
2. We will identify and offer training opportunities to our public partners to improve their confidence.	Training opportunities will be identified from either existing services or are developed in-house and offered to public collaborators based on their needs and preferences.	Year Two
3. We will offer flexible methods of involvement and communication (email, phone, letter, video call, etc.)	We will run annual survey digitally or narratively (methods to be agreed with Strategic Advisory Group) about their PPI experiences.	Year Two
4. We will be flexible in our availability to collaborate with public partners, particularly when collaborating with public partners who have caring or work responsibilities.	We will run annual survey digitally or narratively (methods to be agreed with Strategic Advisory Group) about their PPI experiences.	Year Two

6. Impact: Monitoring and reporting the impact of Patient & Public Involvement

Goal 6: *We will continuously monitor and evaluate all patient and public involvement activities within the Policy Research Unit to improve our public collaboration services.*

How will this be achieved?	Measure (s) of success	Timing
1. We will monitor the PPI activity in the PRU-PEOLC.	Co-creation of an engagement log based on the ‘you said, we did’ tool.	Year One
	Regular collation and reporting of activities and impact shared with the Strategic Advisory Group and monitored by the PPI coordinator.	Ongoing
2. We will review of PPI activity annually to seek areas which have impact and areas for improvement.	Annual review of PPI activity in the PRU-PEOLC.	Ongoing

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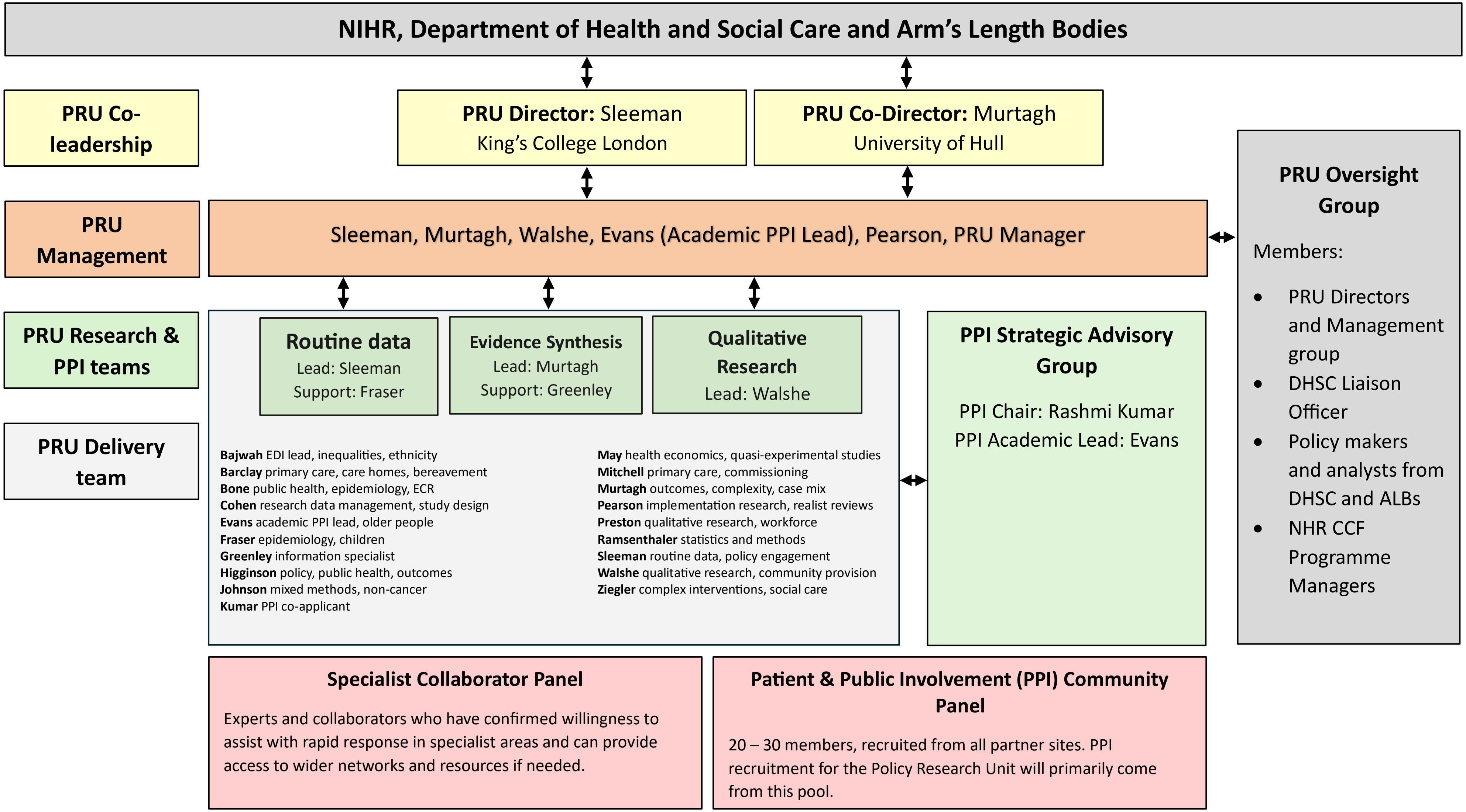
D. NIHR Policy Research Unit in Palliative and End of life Care Organisational Structure



NIHR, Department of Health and Social Care and Arm's Length Bodies

PRU Co-leadership

PRU Director: Sleeman
King's College London

PRU Co-Director: Murtagh
University of Hull

PRU Management

Sleeman, Murtagh, Walshe, Evans (Academic PPI Lead), Pearson, PRU Manager

PRU Oversight Group

Members:

- PRU Directors and Management group
- DHSC Liaison Officer
- Policy makers and analysts from DHSC and ALBs
- NHR CCF Programme Managers

PRU Research & PPI teams

PRU Delivery team

Routine data
Lead: Sleeman
Support: Fraser

Evidence Synthesis
Lead: Murtagh
Support: Greenley

Qualitative Research
Lead: Walshe

Bajwah EDI lead, inequalities, ethnicity
Barclay primary care, care homes, bereavement
Bone public health, epidemiology, ECR
Cohen research data management, study design
Evans academic PPI lead, older people
Fraser epidemiology, children
Greenley information specialist
Higginson policy, public health, outcomes
Johnson mixed methods, non-cancer
Kumar PPI co-applicant

May health economics, quasi-experimental studies
Mitchell primary care, commissioning
Murtagh outcomes, complexity, case mix
Pearson implementation research, realist reviews
Preston qualitative research, workforce
Ramsenthaler statistics and methods
Sleeman routine data, policy engagement
Walshe qualitative research, community provision
Ziegler complex interventions, social care

PPI Strategic Advisory Group

PPI Chair: Rashmi Kumar
PPI Academic Lead: Evans

Specialist Collaborator Panel

Experts and collaborators who have confirmed willingness to assist with rapid response in specialist areas and can provide access to wider networks and resources if needed.

Patient & Public Involvement (PPI) Community Panel

20 – 30 members, recruited from all partner sites. PPI recruitment for the Policy Research Unit will primarily come from this pool.

Figure 2: Organisational Structure of the Policy Research Unit in Palliative and End-of-life Care

E. Our payment policy

Payment is in accordance with NIHR Centre for Engagement and Dissemination guidance. (8) We offer up to £25 per hour rate for all involvement activities (attending workshops, reviewing lay abstracts, etc). Public partners should be compensated for time taken to prepare for meetings. It should be made explicit how many hours public partners will be compensated for this prep work. This estimate should be realistic and fair.

We offer up to £5 supplementary payment for all online meetings and workshops. This supplementary payment enables our public partners to be involved virtually as the payment is for various working virtually (Wi-Fi) costs.

Formal caring arrangements and costs to be agreed in advance of involvement.

Payment can be in the form of BACs payment or vouchers.

We may not offer any financial advice to our public partners. However, we can signpost them to relevant resources and organisations that may be of their assistance, such as Citizens Advice Bureau or Benefits Advice Services.

F. Acronym list

Acronyms	Definitions
PPI	Patient and Public Involvement
PPIE	Patient and Public Involvement and Engagement
PRU-PEOLC	Policy Research Unit in Palliative and End of life Care
PRU	Policy Research Unit
SAG	Strategic Advisory Group
DHSC	Department of Health and Social Care
NHS	National Health Service
NIHR	National Institute for Health and Care Research
KCL	King’s College London
CSI	Cicely Saunders Institute
EDI	Equality, Diversity and Inclusion
BACS	Bankers' Automated Clearing System