GENETIC ALLIANCE UK

INVOLVEMENT BY DESIGN

How to address structural and cultural barriers to PPIE in academic research

LifeArc Translational Centres for Rare Disease Hub

Rare Disease Research UK.

Key terms used in this report

Patient and Public Involvement and Engagement (PPIE): A practice where researchers actively partner with people with lived experience of a condition (patients), service users, carers and members of the public to help shape research (working 'with' or 'by' rather than 'to', 'about' or 'for' them).

PPIE contributor: People with lived experience of a health condition, carers and members of the public that are involved in the research process.

Rare condition: A rare condition is any condition that affects less than 1 in 2,000 people. There are over 7,000 rare conditions with more being discovered all the time through scientific progress.

Rare condition research: Any research that is designed to better understand or make improvements to the diagnosis, treatment and care for people living with rare conditions.

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Foreword

Including people with lived experience as partners in research, distinct from studying them as participants, can positively impact research and those involved in many ways. It can lead to better targeting of investment to the most pressing unmet needs, and to improved study design and delivery. It enhances researchers' understanding of the reality of living with medical conditions, and also helps individuals outside academic research understand the scientific process and gain valuable personal development.

This type of involvement, as part of 'patient and public involvement and engagement', or PPIE, has become part of the health research landscape in the UK, not least in rare condition research. Funders are increasingly recognising the value of PPIE, and it is welcomed by many researchers and patient and public contributors alike.

Rare condition research in the UK is undergoing an impressive acceleration, with new investment, exciting technical progress, and the start of systems changes that should smooth the path for new treatments to reach individuals.

Rare Disease Research UK defines PPIE as a practice that encompasses both involving people with relevant lived experience as partners and advisors in research, and engaging wider audiences with scientific progress.

1 in 17 people

will be affected by a rare condition at some point in their lives

The challenge is to better support PPIE in rare condition research so that its benefits are more widely and consistently felt across the maturing research landscape. While there are many willing researchers and PPIE contributors – including those represented by our own community of member organisations – and a multitude of online resources and guidelines, delivery of effective PPIE is uneven. Even now, we see tokenistic approaches or last-minute 'involvement' from teams who should be setting a higher standard.

Our set of eight recommendations aims to trigger change in the structures and culture of academic research in the UK. The recommendations and associated suggested actions explored in the report are grounded in the experiences of rare condition researchers, but they are relevant across the breadth of other biomedical and healthcare research areas. In order for PPIE to be delivered more effectively in any area of research, it is clear that the institutional changes and PPIE infrastructure improvements we are calling for are necessary.

The reality of the financial stress on research organisations cannot be ignored – expecting them to do more with less will not lead to meaningful change. We hope the 'quick wins' among the suggested actions are recognised as such, for example, organising hands-on experience of PPIE for early career researchers. The bigger challenges need to be championed by those with influence in academia, in funding organisations and in scientific communications. We therefore offer this report as a springboard for decision-makers to bring about positive change for PPIE.

Dr Amy Hunter, Director of Research, Genetic Alliance UK

3.5+ million people in the UK

are living with a rare condition

Executive summary

Recommendation	Overview of how each could be implemented
1 **Take a shared approach to delivering PPIE so that responsibility sits with both organisations and individual researchers**	Fully fund PPIE infrastructure; create dedicated PPIE staff roles with protected time; coordinate PPIE across programmes or departments; promote collaboration within institutions to ensure continuity for PPIE contributors without over-burdening individuals, for example, coordinate opportunities to be involved in other projects and establish standing groups of contributors.
2 **Commit adequate project funding dedicated to delivering PPIE**	Provide clear expectations/signposting to researchers for costing PPIE activities. Ensure that funders explicitly recognise PPIE as essential to high-quality research and are equipped to assess PPIE activities and budgets.
3 **Professionalise and expand PPIE training for researchers**	Integrate PPIE training into professional development; include practical guidance on delivering PPIE; promote completion of training to embed practice early; ensure senior academics feel confident setting an example; and ensure PPIE staff are equipped to develop training programmes and support researchers.
4 **Develop organisational strategies to maximise diversity and inclusion in PPIE**	Support researchers to capture the wide range of experiences that different contributors offer, especially for rare conditions. Build relationships with intermediary organisations (e.g. charities) as trusted bridges to reach diverse and underrepresented communities and streamline communication.
5 **Simplify institutional reimbursement processes for PPIE**	Develop fast-track payment systems for PPIE contributors.
6 **Build a culture of peer sharing and learning-by-doing**	Complement researcher training with 'hands-on' exposure to PPIE activities ; share resources internally and externally; create institutional PPIE directories to avoid duplication.
7 **Integrate PPIE into career progression and appraisal frameworks**	Ensure that high quality PPIE is embedded into academic progression frameworks; champion high-profile academic recognition of PPIE via awards schemes and research quality assessment ; develop a career path for PPIE staff that includes high-level academic-associated appointments.
8 **Enhance visibility of PPIE in research outputs**	Publish PPIE papers and special issues on PPIE in peer-reviewed journals; encourage PPIE reporting in conference submissions. Establish clear guidelines including addressing confusion around the need for ethical approval.

The intended audience for each action is indicated by the following:

- Research organisations *(e.g. NHS trusts, universities)*
- Senior academics
- PPIE staff
- Funders
- Journal editors and publishers
- Conference organisers

Introduction

Patient and Public Involvement and Engagement (PPIE) is central to producing research that is relevant, ethical and impactful. Involving people with lived experience of a medical condition ensures that research is grounded in real-world needs, which ultimately is more likely to lead to better health outcomes.[1-6] Despite this recognition, many academic environments remain structurally and culturally misaligned with the principles of PPIE, and systems are not designed to embed its practice or support individual researchers and staff delivering it.[7-9]

Structural and cultural barriers can lead to effective involvement becoming dependent on individual researchers rather than being embedded in organisational practice. Inconsistent support for PPIE within research organisations limits what it can achieve. For example, researchers are rarely rewarded for effective PPIE through career progression, and many early career staff lack the training and institutional support needed to feel confident delivering it.[8] Since many universities and NHS trusts rely on short-term research funding, this can result in a burden of 'hidden labour' on existing PPIE staff.[7] It also means that when research organisations do not coordinate responsibility for PPIE, opportunities for involvement and for delivering meaningful PPIE can be lost. Staff turnover and reliance on temporary posts can also weaken continuity and relationships with PPIE contributors when projects end.

People with lived experience, carers and members of the public contributing to PPIE also face structural and cultural barriers to being involved. These may affect their capability to support researchers, like practical barriers relating to the accessibility of research processes or having their needs met for involvement, as well as awareness of PPIE opportunities.[8] The National Institute for Health and Care Research (NIHR) reports PPIE most often takes place in the early stages of the research cycle and is neglected in the later stages.[10] For example, in 2023, only 30% of studies reported PPIE during dissemination activities, and 11% when mobilising study findings for implementation.[11] A lack of trust that their input will be valued beyond a 'tick box' exercise can leave PPIE contributors feeling uncertain about their role and reduce both motivation and confidence in the potential for research to deliver meaningful change.[12, 13]

The research environment for rare conditions highlights these barriers clearly. For people with rare conditions, high-quality involvement is especially important. However, fragmented approaches to PPIE across research organisations limit the potential for consistent, meaningful involvement in rare condition research, which has also been historically underfunded.[14] People with lived experience are often consulted across multiple studies,[15] and more complex needs or misalignment between research questions and family priorities can lead to fatigue and gaps in diversity.[16] Short-term, project-based approaches may also disadvantage contributors through conflicts of interest, particularly for ultra-rare or 'n of 1' conditions. This is ethically critical in a context where fewer than 5% of the 7,000 rare conditions have an effective treatment.

> 'Inclusion of under-represented rare [condition] communities in research remains limited, threatening representativeness and equity. Overcoming these barriers holds the potential to develop new treatments for the groups that are most in need and under-resourced, offering hope and optimism for the future.'
> *Mitchell et al. (2025)*[16]

Recommendations

This report sets out eight systems-level recommendations to address the structural and cultural barriers to PPIE in academic research. These recommendations were co-developed through a workshop held in June 2025 by Genetic Alliance UK, Rare Disease Research UK and the LifeArc Translational Centres for Rare Disease. The process for their development is outlined in the Appendix.

Each recommendation is supported by suggested actions on how to implement them, and organised into three themes explored in the workshop:

1. Practical facilitators for delivering PPIE
2. Team culture and support
3. Academic structure and incentives

> 'Funders, policy-makers and research organisations increasingly expect health researchers in the UK to involve patients and members of the public in research. [However], there has been little research into how health researchers feel about involving people, how they go about it, how they manage formal policy rhetoric, and what happens in practice.'
> *Boylan et. al. (2019)*[8]

This report is not a 'guide to good PPIE practice', but rather examines the systems, incentives and structures that either enable or block its success across all types of biomedical research, while being grounded in the experiences of researchers in rare conditions.

1 Recommendation
Take a shared approach to responsibility for delivering PPIE

Create dedicated, permanent and centralised roles for PPIE, and ensure existing posts also have protected time to support, coordinate and deliver PPIE across programmes or departments. Researchers often experience responsibility for PPIE falling to them as individuals.[7] Centralised PPIE coordination roles can support researchers across programmes and continuity for contributors. These posts should have protected time and authority to embed PPIE at an organisational level, not as an 'add-on' to existing academic or administrative roles. This is especially important in rare condition research, where populations and projects are limited.

Establish standing groups of PPIE contributors that are supported by PPIE staff to provide pre-award advice for researchers and promote continuity. With appropriate support from trained coordinators, standing panels can share their experiences across multiple studies, and offer a more efficient and sustainable way to help researchers ensure that PPIE design is feasible and properly resourced. However, their use must be balanced so that efficiency does not undermine inclusion; long-standing relationships may aid continuity but can narrow diversity and should not justify reducing resources for involving under-represented groups.

Promote collaboration between PPIE staff within organisations and with external partners, to ensure contributors have access to opportunities without becoming over-burdened. PPIE Contributors are frequently approached by different teams from universities, NHS trusts and charities. Stronger networks of PPIE staff, including cross-institutional partnerships, would enable the sharing of contributor panels, where appropriate. For rare conditions, collaboration and efficiency are critical to avoid placing additional demands on families that are already balancing care responsibilities and complex health challenges.

Maintain long-term relationships with project-specific PPIE contributors for post-project communication and impact reporting. PPIE often ends once a grant closes, leaving contributors without updates on the outcomes of their work, but contributors may be invited to remain connected after projects conclude. Maintaining contact beyond the life of a project supports dissemination of findings and their impact, and builds trust that their involvement is not transactional but valued as part of an ongoing relationship between institutions and communities. With consent, contributors can be linked by PPIE staff to access future opportunities.

Research organisations *(e.g. NHS trusts, universities)* · Senior academics · PPIE staff · Funders · Journal editors and publishers · Conference organisers

Fully fund PPIE infrastructure, including permanent PPIE roles, associated activities and standing groups of contributors. Sustainable PPIE relies on consistent investment in the core systems that enable meaningful involvement, such as central coordination. A longer-term approach would help organisations retain skilled PPIE staff, maintain trusted contributor networks and plan PPIE activities to be more strategic, to align with the evidence that well-funded PPIE improves clinical trial recruitment, retention and outcomes.[2]

Standing panels of PPIE advisors

The University of Manchester's Primary Care Research in Manchester Engagement Resource (PRIMER) is a permanent group with a diverse range of backgrounds that can offer researchers insight into a range of topics, including for paediatrics and rare conditions. Great Ormond Street Hospital (GOSH) has a number of standing panels, such as the Parent and Carer Advisory Group, that supports multiple projects, and receives training on how to review PPIE plans submitted by researchers. The University of Swansea's Patient Experience and Evaluation Research (PEER) group, which meets on a monthly basis to discuss early ideas for research, has also been drawn upon by Rare Disease Research UK's node on Lipidomics and Metabolomics for Rare Disease Diagnosis.

2 Recommendation
Commit adequate project funding dedicated to delivering PPIE

Provide clear expectations to researchers for costing project-specific PPIE activities at the research design stage. When involvement is adequately costed, this helps avoid administrative delays and supports equitable access for contributors. Researchers need clear and consistent guidance on how to budget appropriately for PPIE, what to include and how payments may potentially affect entitlement to benefits to ensure PPIE contributors can make informed decisions. Signposting researchers to existing national guidance by research organisations (e.g. NIHR guidance) would help promote fairness and consistency between institutions.

Ensure that funders explicitly recognise PPIE as essential to high-quality research and are equipped with clear guidance for assessing proposed PPIE activities and budgets. Funders and grant review panels play a key role in setting expectations for meaningful PPIE. Grant reviewers should receive training to confidently assess PPIE plans and budgets to ensure it is valued alongside scientific design and feasibility. Some funders have begun to formalise this approach by requiring applicants to outline PPIE plans that will contribute to research quality. Ensuring this practice is universal would help standardise expectations and signal that well-designed PPIE is integral to excellence.

Anticipating potential pitfalls for PPIE during grant applications

NIHR grant reviewer guidance for PPIE emphasises a clear, realistic and inclusive approach to assessing how people with lived experience of health conditions and the public will be involved in research, including whether applicants have a named PPI lead, sufficient resources, a meaningful role for contributors, and plans for support, reward and evaluation. This is especially important for rare conditions, and several recent studies illustrate how these principles can be put into practice.

For example, the Genetic Rare Disease: Observational Cohort study (GenROC) worked with Unique, a rare chromosome and gene disorder charity, to define contributor roles early to enable realistic budgeting for coordination, remuneration and ongoing liaison with families. PPIE contributor experiences from the Coordinated Care of Rare Diseases study (CONCORD) have likewise found that upfront investment supported inclusion by allocating time and resources for contributors to shape research questions, refine materials and interpret findings. Some larger rare condition charities which fund research may also be resourced to offer guidance on how to anticipate the needs for PPIE activities early, such as DEBRA UK, which organises 'application clinics'.

'Having PPIE from the beginning, before [research] starts, is really important. But actually, making that happen is really challenging. One big obstacle is having funding to do PPIE properly. There's a separate issue about knowing what does it mean to do it properly.'
Workshop participant

Research organisations *(e.g. NHS trusts, universities)* · Senior academics · PPIE staff · Funders · Journal editors and publishers · Conference organisers

3 Recommendation
Professionalise and expand PPIE training for researchers

Integrate PPIE training into standard professional development schemes that are tailored to different levels of PPIE experience. Embedding PPIE within formal training programmes, such as via accreditation, would help ensure that PPIE becomes a recognised part of professional competence rather than an optional or informal activity. Training should be integrated into organisational frameworks for research and adapted for different career stages, normalising the expectation that researchers will work collaboratively with contributors.

Promote completion of training to embed practice early, and ensure senior research staff feel confident setting an example. Ensuring that all researchers (including undergraduates, post-graduates and early career researchers) have access to training at the right level supports consistent standards and helps to build confidence across teams. Senior researchers who undertake training set an important precedent for the rest of the organisation, signalling that involvement is valued at every level. Universities and research centres could make completion of basic PPIE training a condition of supervision or project sign-off, fostering accountability and a shared understanding of good practice across departments.

Ensure training includes the value of PPIE and practical guidance on delivering PPIE that is ethical, accessible and inclusive. The effectiveness of PPIE depends on a clear understanding of its ethical foundations to ensure meaningful involvement. Additional consideration is required when working with children, people with disabilities or other underserved communities, especially in a rare condition context.[3, 16] Training should therefore combine practical guidance on offering flexibility in how PPIE is delivered with reflection on inclusivity.

Train the trainer: Equip PPIE staff to lead on development of training programmes and support researchers to implement their learning. Building internal capacity for delivery of training is essential to sustain quality. Research organisations should invest in PPIE coordinators who can design, deliver and update courses tailored to their research context. These staff can also provide ongoing mentorship and practical support for researchers to feel empowered to translate this learning into their day-to-day practice. Establishing peer-to-peer networks of PPIE trainers across institutions would encourage knowledge exchange, reduce duplication and provide peer support for people in these specialised roles.

'I understand why I should be doing this. You've signed me up. I want to do it. But actually, how am I going to do it? And who's going to support me [to] actually get started?'
Workshop participant

Embedding the capacity for PPIE and inclusive research practice in training

Across the UK, organisations have started to formalise PPIE training within institutional development frameworks to help researchers build skills and ensure that training is consistently applied in practice. For example, University College London Hospital's (UCLH's) Biomedical Research Centre runs a dedicated PPIE workshop series through its Doctoral Skills Development Programme. A patient and public working group has also been set up for early-career researchers to engage with contributors at the UCL Institute of Health Informatics. The University of Manchester has developed 'masterclasses in PPIE' as part of its training and development catalogue. These workshops have been co-designed and are facilitated in partnership with its PPIE standing group (PRIMER).

4 RECOMMENDATION
Develop an organisational strategy to maximise diversity and inclusion

Support researchers to capture the wide range of experiences that different contributors offer. Institutions should help researchers take a pragmatic approach to recruiting PPIE contributors by considering what axis of diversity is most relevant to their work. For example, specific demographic factors might be relevant (e.g. geography, age, ethnicity), or different experiences of the condition being studied (e.g. families who have accessed certain services, age of diagnosis). Researchers should also reflect on which perspective(s) someone is speaking from in a given context, and be encouraged to use more flexible formats to allow PPIE contributors to take part (e.g. online).

Acknowledge that this can be particularly challenging for rare conditions and develop pragmatic approaches to address it. Collaboration on PPIE across departments and institutions could be one way to address the challenge of being inclusive while working with smaller, more geographically spread populations. In addition, contributors may individually hold multiple roles, such as having lived experience, while also being carers, charity advocates or even researchers.[17] This can be efficient for recruiting different perspectives within small groups, but care should be taken to avoid excluding voices that are not influenced by 'professional' experience.

Build relationships with intermediary organisations and recognise their role as trusted bridges to reach diverse and underrepresented communities. Condition-specific charities, advocacy groups and community networks can connect researchers and underrepresented communities. Developing relationships and partnering with these organisations on community outreach, such as informal 'drop-in' sessions or online open days, can also help demystify research. This helps broaden the potential pool of PPIE contributors who might otherwise be excluded, and ensures involvement remains respectful, inclusive and sustainable.

Coordinate external communications to avoid multiple points of contact, especially for small organisations with limited capacity. Universities, NHS trusts and funders should streamline their approaches to working with small organisations (e.g. community and charity groups) via a single point of contact, such as a PPIE coordinator, to prevent duplication of requests and reduce the administrative burden of being involved in research to ensure partnerships are manageable.

> 'I think it's difficult to maximise diversity and inclusion…I think some sort of strategic approach to PPIE is particularly helpful so the same people aren't being asked to contribute to the same things all the time.'
> *Workshop participant*

Trusted bridges for under-represented communities

The All Party Parliamentary Group on Sickle Cell and Thalassaemia inquiry and subsequent report 'No one's listening' clearly shows how a lack of diversity in research risks perpetuating inequities in health policies and service provision. The Open University's GRACE Project notes that this challenge is amplified in rare condition research. For example, South Asian people account for 8% of the UK population but only 2% of participants in large-scale genetic databases like the UK Biobank. More flexibility with how PPIE is delivered may also be needed to involve some groups,[3] particularly those that have been underserved or marginalised in research.[18] Consulting diverse PPIE advisors can improve the reach and accessibility of research. For example, NHS England co-produced research with the charities Jnetics and Chai to inform the development and evaluation of the NHS Jewish BRCA Testing Programme for breast cancer.[19] Unique, an organisation representing families affected by ultra-rare conditions, which in many cases are poorly studied, also promotes opportunities for members of its community to contribute to research via its website, social media channels and its bi-annual members magazine.

Working with young people via the GenerationR model

GenerationR Alliance Young People's Advisory Groups (YPAG) have become a well-established approach to institutional PPIE. The model convenes a group of young people aged 8-19 years to advise on paediatric studies to ensure projects address issues important to both children and families. There are many YPAGs across the UK: some meet frequently and come together with other YPAGs for a national meeting once a year to feed into the design and delivery of health research in children and young people. By operating as a standing panel across different research programmes, YPAGs also create a space for mentorship between contributors, ultimately demonstrating how institutional networks can strengthen both research quality and help build community.

'The GenerationR setup is absolutely fantastic - our two PPIE officers [at Alder Hey] have done such a wonderful job creating the group. I really believe they are [an] exemplar for how PPIE groups should be run.'
Workshop participant

Research organisations *(e.g. NHS trusts, universities)* · Senior academics · PPIE staff · Funders · Journal editors and publishers · Conference organisers

5 RECOMMENDATION
Simplify institutional reimbursement processes for PPIE

Develop fast-track payment systems so that PPIE contributors are compensated promptly and to an agreed timeline. Researchers frequently report that PPIE contributors experience lengthy delays, inconsistent practices across institutions and uncertainty about when or how they will be reimbursed. In some cases, payments are routed through multiple administrative systems, such as between a university and an NHS trust, leading to further complexity. Delays particularly affect contributors from lower-income backgrounds, who may rely on payments to cover travel or care costs, and may discourage future involvement. Establishing systems that fast-track this process would show that institutions value and prioritise involvement of people with lived experience. However, improvements must go hand in hand with creating centralised, permanent PPIE roles and infrastructure that is supported by both funders and organisations. A sector-wide approach that is guided by shared standards, such as a national PPIE charter, would help embed consistency and sustainability across organisations.

'One of my biggest issues at the moment, as a rare disease and PPIE researcher, is the payments issue – it is a constant battle. Researchers need real support in this area. A change is needed at the funder level – otherwise the current 'more for less' push on researchers is going to mean that there will not be meaningful change.'
Survey respondent

Timely, flexible payment practices

The NIHR-funded HealthTech Research Centre in Brain and Spinal Injury in Cambridge carried out a recent survey of 76 public contributors and found that over 60% preferred payment by cheque or bank transfer.[20] Respondents also highlighted delays and inconsistent practices as barriers to continued participation. In response, the Centre introduced an online payment system managed by a dedicated coordinator, ensuring reimbursements were processed within a week. Contributors could choose between payment options such as bank transfer, vouchers or non-cash alternatives, supported by clear written guidance to explain processes and safeguard benefits eligibility. For rare condition research, where participants often face additional costs and logistical challenges,[16] adopting similar rapid and flexible reimbursement systems would help remove financial barriers and support sustained involvement.

6 RECOMMENDATION
Build a culture of peer sharing and learning-by-doing

Complement formal PPIE training with 'hands-on' exposure to PPIE activities during teaching and supervision. Embedding practical experience into formal training ensures researchers not only understand the principles of PPIE but also develop the confidence to apply them. This should be offered to undergraduates, post-graduates and early career researchers whether their focus is basic, translational or clinical research. Supervisors who model inclusivity in research reinforce the importance of PPIE, and institutions can strengthen this approach by pairing less experienced researchers with established PPIE leads, creating mentorship opportunities that build a culture of shared learning and confidence.

Create institutional directories of PPIE activity to prevent duplication and strengthen collaboration. Establishing central directories or registries for up-to-date records of current PPIE groups, contributor panels and institutional leads would help researchers identify existing local resources and promote opportunities for PPIE. Many contributors and patient organisations report being approached repeatedly by separate teams unaware of one another's activities. A shared directory would enable better coordination, more efficient use of contributors' time and a stronger sense of institutional community.

Facilitate sharing of resources that demonstrate effective PPIE internally and externally, ensuring a diversity of experiences and contexts is included. Sharing examples of how 'good' PPIE can be achieved (e.g. case studies, papers, toolkits, blogs) helps normalise and recognise the value of PPIE and encourages reflective practice. It also ensures visibility for contributors' voices. Institutions should curate and promote diverse examples of PPIE, including work from different types of condition, population groups and methodological settings. This could take the form of internal seminars, shared online repositories or cross-institutional collaborations showcasing case studies and toolkits.

Mapping PPIE activity across institutions to support research teams

While several advisory panels and discussion groups may already exist within different teams or departments, a lack of awareness can mean this work is duplicated across PPIE initiatives. To address this, an internal directory of PPIE activity that lists active groups, key contacts and areas of focus would allow researchers to identify existing networks and seek advice from other teams with relevant expertise. Dedicated PPIE coordinators could have a key role in ensuring information remains up to date and facilitating introductions to support new researchers quickly connect with contributors and similar initiatives. For example, the GOSH Biomedical Research Centre documents contributor involvement in its impact reports, including lay-summary reviews, advisory group work and mentoring roles. Cardiff University's College of Biomedical Life Sciences recently launched an online PPIE Training Programme and Resource Hub. Championed by a senior academic, the interactive platform offers researchers training modules and theme or context-specific guidance, templates and toolkits, and a searchable repository of over 50 case studies of effective PPIE from across the school.

'I think one of the challenges I have sometimes is setting up the PPIE group itself. And that takes time, especially if you look at if the grant is in an area that you haven't been working on.'
Workshop participant

7 RECOMMENDATION
Integrate PPIE into career progression and appraisal frameworks

Ensure that teaching of and delivery of high quality PPIE are embedded into academic progression frameworks. Embedding PPIE within academic progression frameworks ensures it is recognised as a key component of research excellence rather than a voluntary or peripheral activity. Research organisations need to communicate what high-quality PPIE looks like and provide criteria that align with research, teaching and impact metrics. This would enable PPIE to be meaningfully assessed within promotion and appraisal processes and help standardise expectations across departments. Clear definitions would also help researchers evidence their contribution and give parity to PPIE alongside other recognised indicators of academic achievement.

'There is a real need to integrate training for researchers and to have PPIE core competencies recognised within institutional research strategies and promotion structures.'
Survey respondent

Develop a career path for PPIE staff, which includes establishing high-level academic-associated appointments. PPIE staff play a crucial role in coordinating contributor panels, supporting researchers and ensuring that involvement is impactful, ethical and inclusive, yet these roles are often fixed-term and lack clear progression routes. Establishing career structures that include senior academic-associated appointments would help retain skilled staff, strengthen institutional memory and enable continuity across programmes. These posts could be linked to academic departments but focus on delivery, training and evaluation of PPIE to bridge research administration and academic leadership.

Champion high-profile academic recognition of PPIE via awards schemes and research quality assessment processes. To raise the status of PPIE and its unique contribution to the quality of research, institutions and funders should celebrate excellence through awards, annual showcases and inclusion in research quality assessment frameworks. Recognition schemes can help demonstrate that PPIE adds measurable value to research outcomes, while distinguishing it from broader public engagement activities.

Research organisations *(e.g. NHS trusts, universities)* · Senior academics · PPIE staff · Funders · Journal editors and publishers · Conference organisers

Embedding PPIE in academic progression pathways

High-profile recognition of PPIE helps normalise involvement as part of 'good' research, encouraging academics to weave PPIE into both research and teaching practice. Some clinical educators also now include aspects of PPIE in exam questions and student projects. NHS Research Scotland showcased two categories of PPIE awards ('Newcomers' and 'Impact') in an event with the Chief Scientist Office of the Scottish Government. The University of Birmingham integrated PPIE into its academic career framework via a dedicated Enterprise, Engagement and Impact pathway to allow staff to demonstrate PPIE as a recognised area of excellence within promotion. One stakeholder shared that the application process for training fellowships with Kidney Research UK places a substantial emphasis on how people living with kidney conditions will be involved; applicants were also invited to present proposals to the charity's patient group for feedback before final submission.[21]

'I think this [process] was great, it gave everybody applying the opportunity to incorporate feedback into their proposal if they otherwise didn't have avenues to do this. In terms of PPIE, I couldn't rave more about the representation!'
Workshop participant

8 RECOMMENDATION
Enhance visibility of PPIE in research outputs

Invite submission of reflective PPIE manuscripts and publish special issues on PPIE in peer-reviewed journals. Many PPIE activities generate learning that is rarely shared because there is no widespread culture of including it in scientific articles, and standard article formats do not encourage PPIE reporting. Flexibility in structure and length of articles would enable richer descriptions of process and impact, particularly in rare condition research. Encouraging journals to publish reflective PPIE manuscripts should raise the visibility of involvement and demonstrates that it is a legitimate and valued area of academic work. Dedicated collections or special issues provide an accessible repository of good practice that can guide other teams.

Create clear guidelines for publishing PPIE activities and research findings in academic journals, and address confusion around the need for ethical approval. Researchers often report uncertainty about when PPIE work requires ethical approval or how to describe involvement activities in publications. Developing clear and consistent guidance would help remove this barrier and ensure that reporting is both transparent and proportionate. Journals and institutions could collaborate on standardised guidance to provide clarity and help normalise the publication of involvement work alongside traditional research outputs.

Encourage PPIE reporting in conference submissions. Recognising PPIE within conference presentations and abstracts supports parity between PPIE and other aspects of research delivery. Conference organisers can promote inclusion by inviting submissions that explicitly describe how contributors shaped study design, delivery or dissemination. Including contributors as co-presenters also demonstrates shared ownership of findings and provides a platform for diverse voices within academic forums. This approach would help to embed PPIE within mainstream research communication and reinforce its value across disciplines.

Ensuring examples of impactful PPIE are celebrated

In Newcastle, members of the YPAG North East have previously presented their project on young people's perspectives of consent for biobanking at a Royal College of Paediatrics and Child Health conference, and two young researchers co-authored an article published in BMC Medical Ethics.[22] The 2025 NIHR GOSH Biomedical Research Centre Showcase Recent Achievements & Future Directions invited members of the public to hear research highlights from a range of early-career researchers followed by a session dedicated to PPIE, which included hearing from a young person's testimonial participating in research. In Manchester, the PRIMER @ 10 Celebration Book features testimonials from researchers and its PPIE standing panel and the achievements of the group.

Making a visible commitment to PPIE in the literature

Reporting standards for writing up PPIE are available (e.g. the GRIPP2 checklist),[23] but publishers can go further than this. The open-access journal BMC Research Involvement and Engagement, which is accredited under The Patients Included Charter, invites contributors to be co-editors and reviewers of submissions. However, this does not have to be limited to journals set up specifically for co-production. Making space to increase the visibility of PPIE in other publications helps normalise co-authorship and supports transparency, which is especially important when it is used to develop novel technologies for healthcare, such as genomics services.[24] Publishers can also launch special issues dedicated to PPIE, such SpringerOpen's cross-journal PPIE collection on patient-reported outcome research. The BMJ also ran a patient-led special issue marking ten years of its patient and public partnership strategy in 2024.

Summary of learnings

There is a wealth of guidance and examples of best practice for how to do 'good' PPIE – in this report we have outlined some of the structural and cultural barriers to its delivery. These barriers can lead to an environment that can make it very challenging for researchers to embed PPIE as a meaningful part of their research. By bringing together researchers at different stages of their career to explore these issues in more depth, we have developed a set of recommendations to address these challenges and help drive systems-level change in academia.

The eight recommendations we have set out focus on what needs to change. These recommendations are intended for both institutions and individuals across the research ecosystem, including research organisations, senior academics, publishers and those responsible for training and supporting early career researchers, and aim to address the core structures, resources and incentives needed to embed meaningful PPIE across the research system. While they are grounded in the experiences of rare condition researchers, they are relevant across the breadth of biomedical and healthcare research.

1. Take a shared approach to responsibility for delivering PPIE
2. Commit adequate project funding dedicated to delivering PPIE
3. Professionalise and expand PPIE training for researchers
4. Develop an organisational strategy to maximise diversity and inclusion
5. Simplify institutional reimbursement processes for PPIE
6. Build a culture of peer sharing and learning-by-doing
7. Integrate PPIE into career progression and appraisal frameworks
8. Enhance visibility of PPIE in research outputs

Crucially, these recommendations are not a call for organisations or senior staff to do more to stretch existing resources, nor do they place the burden solely on researchers. While the bigger challenges we have outlined need to be championed by those with influence in academia, in funding organisations and in scientific communications, the report also offers a number of practical 'quick wins' as realistic starting points for embedding change now.

If embraced, these recommendations have the potential to strengthen the quality, relevance and impact of research. Addressing practical constraints on researchers and building trusted partnerships with people with lived experience helps foster a research culture in which PPIE is visible, valued and rewarded. For rare condition research, where there is a high level of unmet need, meaningful PPIE offers a powerful route to ensuring that research focuses on what matters most and delivers real-world benefit for people living with rare conditions.

This report is offered as a springboard for decision-makers to bring about positive change for the practice of PPIE.

While full implementation of these recommendations will require sustained commitment and appropriate resourcing, we offer this report as a starting point to help embed meaningful and impactful PPIE in ways that are realistic, fair and sustainable.

Appendix

How the recommendations were developed

These recommendations are grounded in the experiences of researchers in rare conditions, but remain transferable to other research areas. The recommendations were co-developed through a workshop, post-workshop analysis informed by existing literature, and a broader stakeholder survey.

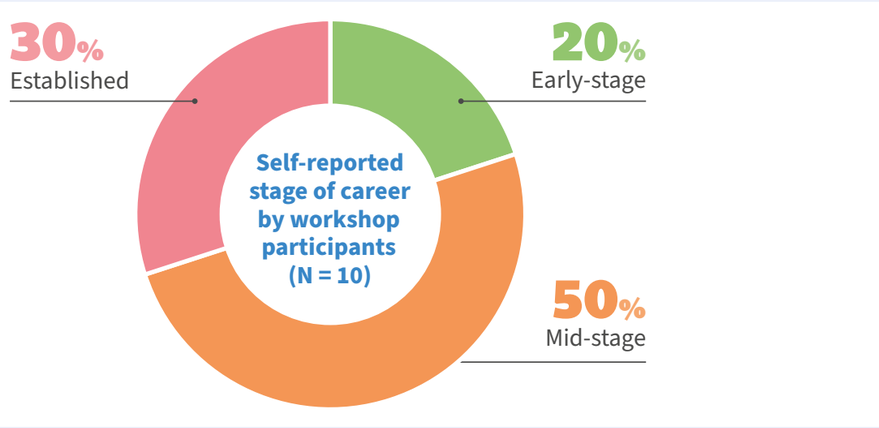
Workshop with academics

Ten stakeholders (listed below) attended an online workshop in June 2025 hosted by Genetic Alliance UK, Rare Disease Research UK and the LifeArc Translational Centres for Rare Disease, and facilitated by an independent consultant, Sheela Upadhyaya. Participants represented both the LifeArc Centres and Rare Disease Research UK, with a balance across career stages, gender (six identifying as female) and ethnicity and geography. Themes were drawn from Boylan *et al*. (2019).[8] Discussions were recorded through a participatory process capturing barriers and facilitators to PPIE in academia in a live document, which was reviewed at the end of the session to confirm accuracy, and a final copy shared with attendees:

- **AJ McKnight**, Professor of Molecular Epidemiology and Public Health, Queen's University Belfast
- **Andy Chetwynd**, Tenure Track Fellow, University of Liverpool
- **Faye Johnson**, Postdoctoral Research Associate, University of Manchester
- **Chloe Williams**, Nephrology Clinical Research Fellow, Alder Hey Children's Hospital
- **Neil Roberts**, Lecturer, University of Manchester
- **Olalekan Lee Aiyegbusi**, Associate Professor, University of Birmingham
- **Shwetha Ramachandrappa**, Consultant Clinical Geneticist, Guy's Hospital
- **Steven Julious**, Professor of Medical Statistics, University of Sheffield
- **Tara Clancy**, Senior Lecturer, University of Manchester
- **Victoria Homer**, Senior Biostatistician, University of Birmingham

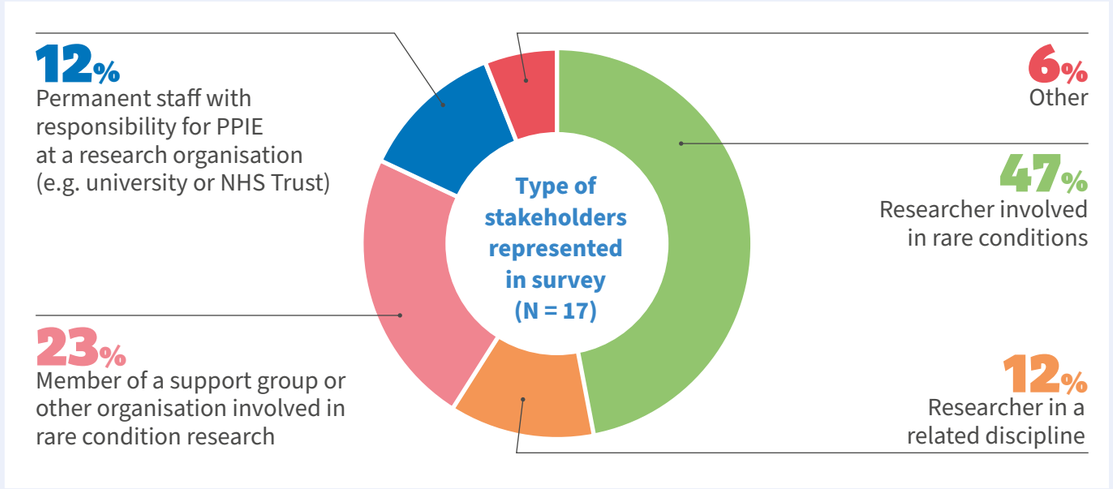
Post-workshop analysis

Findings from the workshop were collated and reviewed through a structured analysis involving transcription by two researchers to identify recurring themes, areas of consensus and points requiring clarification. Draft recommendations were refined and shared with the workshop attendees and a small group of stakeholders for targeted feedback. This process informed the development of a survey and ensured that emerging recommendations reflected participants' chosen language and priorities.



Broader stakeholder survey

The refined recommendations and accompanying survey were widely distributed to invite input from a wider group of stakeholders from research, policy and patient-facing organisations. Respondents were asked to indicate their level of support for the recommendations and comment on their clarity, relevance and potential impact, as well as identify any missing elements or audiences. In total, 17 responses were received, with 88% (15 of 17) agreeing with the recommendations as written with comments for adjustments needed.



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LifeArc

LifeArc is a self-funded medical research organisation aiming to transform the lives of people living with rare diseases and drug-resistant infections.
By conducting and funding pioneering research and working with partners, they accelerate the translation of scientific breakthroughs into much-needed new tests and treatments.

lifearc.org

GENETIC ALLIANCE UK

Genetic Alliance UK is an alliance of over 220 organisations, charities and support groups working together to improve the lives of everyone in the UK living with genetic, rare and undiagnosed conditions. Our members are at the centre of everything we do. We actively support progress in research and engage with decision makers and the public about the challenges faced by our community.

geneticalliance.org.uk

Rare Disease Research UK.

Rare Disease Research UK (RDRUK) was established to connect and enhance the UK's strengths in rare disease research. The platform aims to foster greater collaboration between academic, clinical and industry researchers, patients, research charities and other key organisations in rare disease research to accelerate the understanding, diagnosis and treatment of rare diseases.

rd-research.org.uk