Embedding public and patient involvement in research at an institutional level:
2025 Longitudinal Report

PPI IGNITE NETWORK

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Contents

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Executive Summary

This longitudinal report, following up on the **2022 PPI Ignite Network Landscape Report**, assesses the progress of Public and Patient Involvement (PPI) embeddedness across participating Higher Education Institutions (HEIs) in Ireland between 2022 and 2025.

Key Findings

The data indicates that PPI embeddedness is maturing across all categories, confirming a strong, positive association between dedicated PPI funding and systematic institutional change. However, this maturity remains uneven, and progress is often siloed rather than integrated into core institutional functions.

Key findings across the **SIX DOMAINS** reveal both progress and persistent gaps:

GOVERNANCE and ETHICS:
Structures are improving (dedicated committees, formal reporting, some PPI members on Research Ethics Committees), but the involvement of Persons with Lived Experience (PWLE) in high-level decision-making remains informal and inconsistent.

FINANCE and HR:
Financial systems are improving with clearer reimbursement and budgeting templates. However, institutional human resources (HR) frameworks (for recruitment, appraisal, and career progression) are largely underdeveloped.

ACCOMMODATIONS and COMMUNICATION:
While there is strong recognition of relationship-building and emerging good practice in physical accessibility and universal design, these efforts often operate on a case-by-case basis, lacking formal, institutional policy.

Core Recommendations

To transition PPI from project-level activity to permanent institutional practice, the report makes five key recommendations focused on formalising PWLE influence and standardising best practice:

1. **Enhance Governance Structures**
   Establish formal, sustained roles for PWLE on major governance bodies, such as research committees and ethics boards, with associated core funding and mentorship.

2. **Institutional Policy Development**
   Co-design and endorse official PPI-related policies (in HR, Finance, and Ethics) with PWLE to ensure system-wide adoption.

3. **Co-create PWLE Progression Pathways**
   Invest in leadership development programs for PWLE, offering structured pathways, training, and practical leadership opportunities.

4. **Formalise Cross-Institutional Peer Support**
   Standardise best practice across the Network by establishing thematic learning groups and sharing templates for key processes like reimbursement workflows and governance models.

5. **Encourage Strategic Review Cycles**
   Move towards a strategic learning culture by embedding reflection and formal feedback mechanisms into existing review and reporting cycles to continuously inform system improvement.

This report underscores the growing maturity of PPI within institutions while clearly identifying the systems-level changes still needed to embed it as a core component of research culture. Its true value lies in its potential to catalyse action by supporting institutions to move from isolated good practice to coordinated, strategic implementation. By using these findings to develop shared frameworks, strengthen contributor leadership, and formalise inclusive policies, the PPI Ignite Network can not only enhance institutional practices but also advance a research culture grounded in equity, relevance, and accountability.

This work strengthens the foundation for more effective knowledge mobilisation and creates the conditions for impactful, people-centred research across disciplines. Acting on these insights will ensure that PPI is not just sustained but meaningfully shapes the future of research and innovation in Ireland.

Introduction

When the five-year PPI Ignite Network was established in 2021, five Work Packages were initiated, each targeting a different element of activity to further embed public and patient involvement (PPI) into health and social care research across Ireland. Work Package 3 (WP3) concentrates on exploring and improving the extent to which PPI in research (PPI) has been embedded into higher education institutions (HEIs) across the Network. This is explored through review of policies and procedures within HEIs, as this can give an indication of how ingrained / deep-seated PPI is in the institutional organisation. By gaining a better understanding of this HEI-specific activity we can group our efforts, share and expand best practices to support HEIs further.

This report is a follow-up to the first HEI-self assessment undertaken by sites in 2022 which led to publication of the **PPI Ignite Network Landscape Report**. By revisiting these questions, we can assess the level of change / maturity across the Network, whilst identifying potential areas for focus for future HEIs joining the Network.
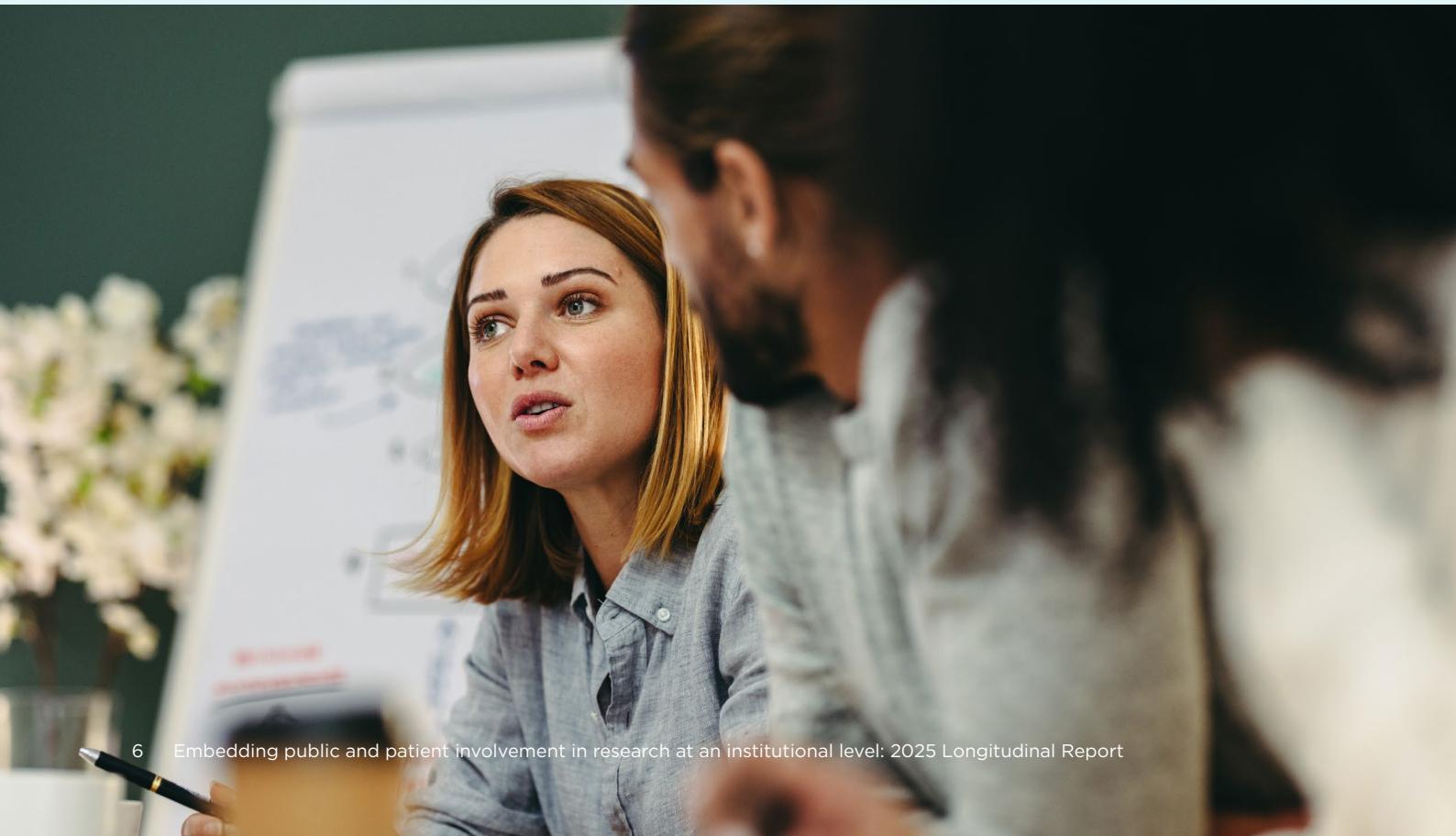
Brief methodology

Data Capture

The same instrument and instructions were used as per the landscape report[1]. To assess the implementation of the recommendations from the landscape report, a table was added that listed the recommendations and asked, "Did you take steps to implement this recommendation?" with options of Yes, Partially or No. There was a column provided for "More details (if applicable)". The instrument was distributed to the same nine HEI sites who were invited to complete the first self-assessment in 2022. Eight HEIs returned data.

Analysis

For the self-assessment score data, we translated the text ordinal ranking (planning; embryonic; developing; developed, mostly implemented; and implemented & embedded) into a 1-5 quantitative scale. As the data is ordinal, paired, and our goal is to identify whether there was an increase since 2022, we performed Wilcoxon Signed Rank Tests for paired data one-tailed at an alpha (significance level) of 0.05 to assess if there has been a statistically significant change in the self-assessment scores between 2022 and 2025.

For the text data, a structured qualitative content analysis was conducted on institutional submissions across six thematic areas (governance, HR, finance, ethics, accommodations, and communication) using tabulated responses from the eight HEIs. Data were reviewed for patterns, consistency, and evidence of maturity across institutions. Thematic coding was applied to identify strengths, gaps, and strategic alignment. Best practices and recommendations were drawn from cross-institutional benchmarking.

Findings

PPI embeddedness in HEIs is maturing

Overall, HEIs are maturing across all categories since 2024 (figure 1). The results category has had the least growth on average but is still significantly maturing.

Figure 1: Comparison between 2022 (spotted) and 2025 (stripped) mean self-assessment score of eight universities in each category. Error bars: Standard error of the mean.
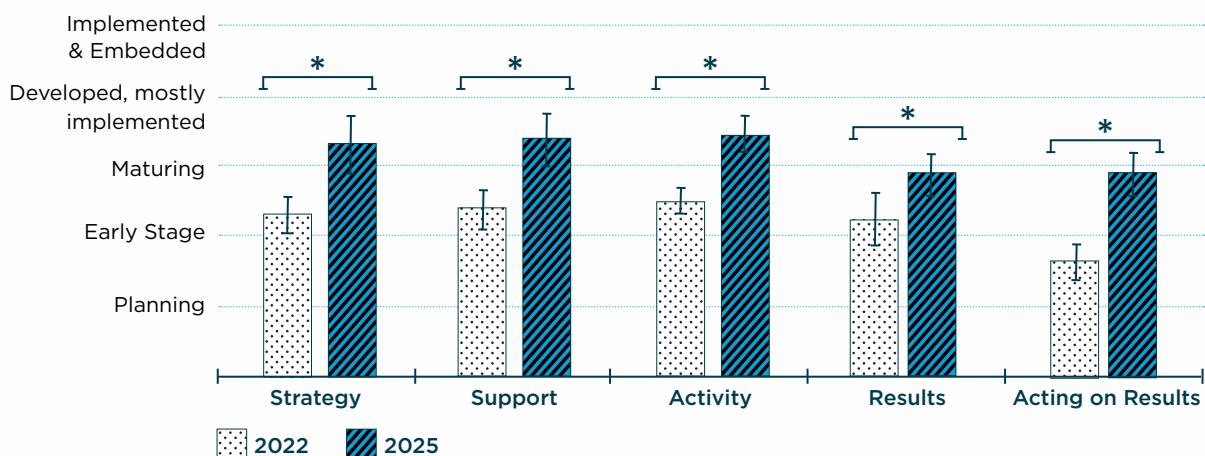
*Significance p<0.05.
X Axis: Self-assessment categories. Y- axis: Ranked development categories.

The data includes the seven HEIs that receive PPI Ignite Network funding and one Irish HEI that does not receive PPI specific funding. The HEI without dedicated funding remained static compared to 2022, whereas the HEIs of the PPI Ignite Network all reported growth. All PPI Ignite Network HEIs reported increase in PPI in strategy. The two newer HEIs (who received PPI funding in 2021, but not 2017) reported growth across all categories, reflective of the lag time between funding awarded and institutional change.

In summary, the data indicates a positive association between dedicated PPI funding and a maturing institutional PPI system. Continued iterative assessment should assist in confirming this association.

Findings across the six special interest domains

The assumption: **If PPI were fully embedded into an institution, we would expect to see mentions of PPI in policies and procedures related to the six key domains: Governance, Human Resources, Finance, Ethics, Estates/Environmental accommodations, and accessible communications.**

1. Governance

Across the PPI Ignite Network, governance structures increasingly reflect a commitment to embedding PPI at an institutional level. Several HEIs demonstrate strong models, with dedicated PPI committees, formal reporting to senior leadership, and integration into strategic planning processes. Advisory groups and involving estates, finance, and education units have enabled better alignment between PPI activity and institutional goals. However, governance maturity is uneven. In some institutions PPI governance remains decentralised or project-based. Governance can also lack institutional oversight or sustained contributor involvement in decision-making. Where committees exist, contributor roles are often informal or under-supported.

To improve, institutions could formalise PPI governance structures with clear mandates, contributor representation, and reporting lines to senior management. Embedding persons with lived experience (PWLE) on central committees and co-developing governance terms of reference could improve legitimacy and influence. Greater sharing of processes and templates from advanced institutions could support more consistent progress across the network in relation to governance.

2. Human Resources

PPI integration into human resources (HR) systems across the PPI Ignite Network is still emerging in many HEIs. Some HEIs have begun to embed PPI in staff recognition through awards, training opportunities, and inclusion in promotion or workload models. PWLE involvement in staff development activities and early-career researcher training is also being reported, albeit in a minority of HEIs. However, formal HR frameworks that embed PPI across recruitment, performance appraisal, and career progression are still underdeveloped in most institutions. A few reference job descriptions or structured onboarding processes that included PPI were reported, but these tended not to be standardised even with the reporting HEI. Support for PWLE development, such as mentorship or progression pathways, is similarly inconsistent.

To strengthen HR integration, institutions could co-develop guidelines for recognising PPI in academic and professional roles. This could include PPI in staff development plans, and the adaption of research job descriptions to reflect PPI responsibilities. A shared HR toolkit across the network could support adoption, drawing on strong examples from the HEIs more advanced in this area.

3. Finance

Financial systems to support PPI are improving across the PPI Ignite Network, with several institutions developing clear reimbursement procedures, dedicated budget codes, and pre-award planning supports. Good practice was demonstrated in aligning funding with strategy, tracking seed funding impact, and integrating PPI-informed revisions to finance policies.

However, PPI finance systems remain inconsistent across the network. In some institutions reimbursement is still ad hoc or delayed, and financial processes are not fully adapted to meet PWLE needs. Another challenge is that budgeting for PPI is often limited to project level rather than being systematically included in institutional financial planning or grant support structures.

To improve, institutions could embed standardised PPI budgeting templates and reimbursement guidance into grant development and financial policies. Finance offices should collaborate with PPI leads and contributors to streamline processes, ensure equity, and reduce administrative barriers. HEIs should also focus on consistent implementation and consider promoting a rights-based approach to recognising contributor time, effort, and expertise.

4. Ethics

Ethical considerations around PPI are increasingly being addressed across the PPI Ignite Network. Some HEIs are now actively integrating PPI into research ethics systems. There are PPI contributors reported on some HEI research ethics committees, although this is still not the norm. Across HEIs there was increased reporting of activities demonstrating the recognition of the ethical dimensions of inclusion, power-sharing, and responsibility in PPI.

Many institutions still treat ethics and PPI as a project-level consideration rather than an institutional priority. Formal mechanisms for PPI input into Research Ethics Committees (RECs) are rare, and few institutions have reported updated ethics forms, policies, or reviewer training to reflect evolving PPI practices. PWLE experiences are not always systematically considered in ethics reviews or post-project reflection.

To address this, institutions should explore including PWLE roles within RECs and aligning PPI with broader research integrity and safeguarding policies. Training for both researchers and ethics reviewers could include scenarios that reflect real-world lived experience perspectives.

5. Environmental accommodations

Environmental and accessibility-related considerations are emerging areas of good practice within the PPI Ignite Network. Multiple HEIs demonstrate maturity in this area by incorporating universal design principles, adjusting venue choices based on contributor feedback, and collaborating with estates and access offices to improve physical access, parking, and signage for PWLEs.

Environmental accommodations remain inconsistently embedded at the institutional level as many address access and accommodations on a case-by-case basis, rather than through formal policy or strategic commitment. There is limited evidence of institution-wide protocols to address situational barriers such as sensory access, or digital exclusion. There was a gap in the reporting of systematic audits or budget allocations for physical and informational accessibility.

To strengthen practice, institutions could co-develop an institutional PPI accommodations policy in association with other units focused on inclusive design and practice. Accessibility audits covering physical, digital, and procedural practice for all PPI activities should be considered. Some HEIs offer scalable examples that could form the starting point for a shared Network environmental accessibility toolkit to support consistency, equity, and inclusive participation across the network.

6. Communication and relationship building

There is strong recognition of the importance of relationship-based approaches to PPI across the PPI Ignite Network. More than half of PPI Ignite Network HEIs demonstrated well-developed practices for sustained engagement, including regular contributor check-ins, feedback loops, co-designed events, and relationship-based advisory groups. Further, most institutions embed PPI into training sessions, clinics, and co-delivered workshops, which help build trust and ongoing collaboration with PWLE.

There is a lack of formal policies to support relationship building and communication practices can still be focused on project delivery rather than ongoing partnership. Feedback mechanisms do not appear to be consistently structured and/or used to inform future planning. Accessible communication formats beyond plain language, such as translation or sensory-inclusive materials, are not yet widespread or routinely used.

To strengthen this domain, guiding principles including expectations for ongoing dialogue, co-learning, and mutual accountability could be developed. Co-created feedback frameworks and contributor support plans should be adopted in a more standardised and consistent manner.

Recommendations

Implementation of previous recommendations

The reported implementation of the recommendations from [1] is consistent with the qualitative information reported. Figure 2 below illustrates the progress in implementing those recommendations across all sites. Recommendation three is in the process of being addressed at a Network level, which should improve the implementation of this recommendation. Recommendation four is highly dependent on how HEIs and funding bodies categorise this information. The implementation of this recommendation relies on other actors such as research finance officers, who may not prioritise addressing this issue. Across the recommendations generally, those that can be led by PPI Ignite Network Offices have better implementation compared to those that are highly dependent on support from other units. The exception to this is recommendation eight.

Half of the HEIs were unable to action recommendation eight, even partially. This reflects the previously highlighted issue that PPI offices are often at capacity with development and activities and thus evaluation of these activities may not happen. However, although not adopted Network-wide, this recommendation has led to notable advances in several institutions. For example, one HEI reported including PPI contributors in reporting to governance structures and strategy presentations, directly linking contributor input to institutional learning and planning. This example and others show that some institutions are actively involving contributors in institutional-level review cycles to some degree, not just individual projects, and using that input to shape policies, funding, and communication.

Figure 2: Bar chart showing HEI responses to meetings recommendations (R1-R8) from the first HEI self-assessment [1] as met, partially met, or not met.
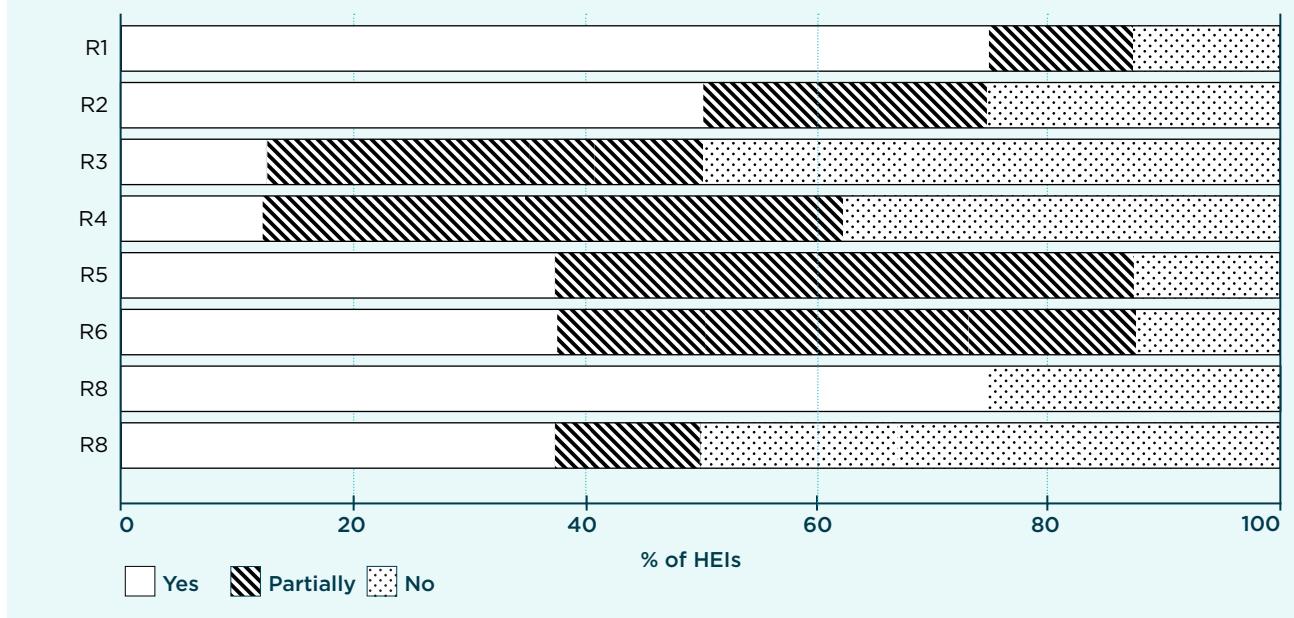
R1 Ensure that evidence is showcased and briefed upwards. Include University Management as critical stakeholders and develop suitable communication briefs iteratively as appropriate to each institution.

R2 Liaise with offices within your HEI responsible for research analytics to identify additional ways to evidence PPI to build support and evidence to advocate for the inclusion of PPI in strategy documents.

R3 There is a positive movement that varies greatly by institution. There is an excellent opportunity for inter-institutional knowledge exchange about the progress made to date in HR practices. A network-level mechanism to share good practices and processes should be developed.

R4 There is a gap in evidencing financial income/PPI-related grant income. Processes for better capturing of data would assist in making an institutional case for PPI.

R5 Finance needs to be considered in the broader context. More significant interaction with research offices and research finance offices within HEIs may give you a better understanding of PPI's context in resourcing and/or grant incoming. It may also give you scope to inform and update these offices about PPI and its needs.

R6 Continued collaboration with EDI offices and Access offices (and similar) in liaising with Estate services within institutions seems to be a sensible approach to the continued development of more accessible and inclusive campuses. Those HEIs whose PPI officers have yet to engage with these other aligned offices may find it beneficial to do so to further this objective.

R7 Improved capturing and sharing of knowledge pre-existing within the HEIs would greatly benefit the community.

R8 Greater focus on mechanisms for routine inclusion of a PWLE perspective in reflection, reviewing and evaluating institutional aspects of PPI. This will benefit institutional practices and assist in the sustainability of PPI communication & relationship management practices.

Recommendations arising

Analysis of the self-assessments and implementation of the previous recommendations have led to the development of the following actionable recommendations. These recommendations are based on the stated goals and vision of the PPI Ignite Network and designed to be actionable with the current resources available.

1. Enhance PPI in governance structures

Many strong practices remain isolated within pockets of excellence (departments, projects, or individuals), without full institutional reach. Recommendation one is to establish formal roles for PWLE in governance structures. This promotes direct access to institutional decision-making and ensures lived experience informs policies.

How this may look in practice
- Relevant PWLE membership in major governance structures such as research committees, or research ethics boards.
- Institutional PPI advisory council with defined reporting line to executive leadership in order to create a permanent space for collective lived experience to inform institutional planning and policy.

Enabling actions
- Provide training and mentorship for contributors serving in governance roles.
- Advocate for core funding (not linked to projects) to provide training, honoraria, and mentorship to PWLEs serving in governance roles.

2. Institutional policy development with integrated lived experience

Policy mechanisms are generally underdeveloped across HEIs. Few institutions have formal HR policies, finance models, or governance mandates for PPI. Recommendation two is to advocate for institutional buy-in of PPI practices with the goal of transitioning to policy endorsement. PWLE should be involved in the co-design and review of PPI related policies.

How this may look in practice
Run policy co-creation workshops with PWLE and staff. Involving PWLEs in co-creating and reviewing policies moves involvement from provision of reactive feedback to a place of co-authorship of institutional culture.

Enabling actions
- Identify the key actors for policy development in the target area (Ethics, Finance, HR) and the dates for review or development of policies.
- Identify areas of shared interest or mutual benefit with said actors to initiate dialogue.
- Keep up to date with national or international policies that could aid your goals by signing up to, for example, European Commission R&D newsletters or influential societies (IUA, CESAER, EARMA) newsletters. This can help strengthen your advocacy and find internal and external allies.

3. Co-create contributor progression pathways

All institutions demonstrate consistent investment in researcher training and contributor engagement. However, there is a gap in investment in PWLE leadership. Recommendation three is to focus on leadership development programmes for PWLEs.

How this may look in practice
- Opportunities for mentorship by senior staff or experienced PWLEs.
- Inclusion of available places for PWLE in staff development activities and academic seminars.
- Developing structured pathways for PWLEs such as training, shadowing or progression frameworks to build capacity and confidence.

Enabling actions
- Build structured "next steps" into involvement opportunities so contributors can see where they might progress.
- Provide practical leadership opportunities by giving the option to lead in existing spaces, for example by inviting PWLEs to co-chair a meeting, lead on an agenda item.

4. Formalise Cross-Institutional Peer Support

There is a widening gap between HEIs that have instigated change and those in early development especially in areas like ethics, HR, finance systems, and communications. Recommendation four is to formalise peer support between HEI sites.

How this may look in practice
- Establish thematic learning groups for areas like REC integration, human resources or payment processes.
- Co-develop Network-wide shared HR templates for job descriptions that include PPI responsibilities.
- Share templates for reimbursement workflows and governance models.

Enabling actions
- Create a simple "who has what" (templates, guidance) table. This avoids duplication and helps people know where to go.
- A quarterly internal operational-focused newsletter can support cross-institutional peer support by celebrating and crediting teams that share resources. This encourages a culture of openness without requiring funding.

5. Encourage Strategic Review Cycles

Some HEIs evaluate activity but don't consistently apply results to system improvement or strategic reform. Recommendation 5 is to move towards a strategic learning culture.

How this may look in practice

- Embed reflection into existing meetings by dedicating time at the end of existing PPI or governance meetings to ask: "What worked well? What could we change next time?".
- A task-specific 'learning lead' who can be rotated among staff/PWLEs, to summarise what has been learned and suggests how it might inform future work.

Enabling actions

- Create a "You said, we did" simple running document that tracks feedback, associated actions, and outcome. This shows if and how learning is applied without creating new reports.
- Add a short section on "system learning and improvement" into annual reports already being submitted to funders or internal governance. Even if the funder doesn't require it, inclusion encourages reflection.

Strengths and Limitations

Using the same instrument for the repeat self-assessment allows us to compare past and current states across HEIs and observe for trends in PPI practices. Explicitly requesting information related to the six key domains ensured HEIs gave an extensive account of their respective PPI landscape. Requesting a narrative report also allowed us to capture other incidental findings and emerging details, due to different interpretation of the questions being asked, or different judgements of priority information to report on. The limitation of this is the subjective nature of responses. An absence of detail from HEI reports does not necessarily indicate a gap in practice. Another limitation was the resource-intensive nature of data capture. To fully engage with the self-assessment HEIs had to gather details from multiple departments / peers / colleagues including senior management level.

Conclusions

The dial is moving and HEIs have demonstrated, to varying degrees, that PPI is being embedded into institutional policies and practices. This is most evident when supported by financial commitment and personnel support, which indicates that the PPI Ignite Network is facilitating these advancements.

Further actions are needed to prevent widening the gap between institutions that have financial and systems support to embed PPI and those that do not.

More can also be done to develop ways for people with lived experience to influence HEI systems, through sustained roles, decision-making power, investment, and visibility.

About this report

This report is the second in a series aimed at capturing the extent to which PPI has been embedded into specific domains within research-active higher education institutions (HEIs) in Ireland. The first was the landscape report published in 2023 and available at https://doi. org/10.6084/m9.figshare.21995156.v2.

How to cite

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Glossary

EARMA - Euopean Association of Research Managers and Administrators.

CESAER - An international association of 50+ universities of science & technology from all across Europe and beyond. CESAER stands for 'Conference of European Schools for Advanced Engineering Education and Research' although normally only the short form CESAER is used.

EDI – Equality, Diversity and Inclusion

HEI – Higher Education Institution

HR – Human Resources

IUA - Irish Universities Association

PPI – Public and Patient Involvement. In this report, when we use the abbreviation PPI we are referring to PPI in health and social care research.

PWLE – Person(S) With Lived Experience. Related term: PPI contributor.

REC – Research Ethics Committee

R&D - Research and Development

WP3 – Work Package 3

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1. Dorris, Emma; Kerin, Lorna; Lieggi, Nora; Flood, Michelle; Cavalleri, Gianpiero; Kroll, Thilo (2023). Embedding public and patient involvement in research at an institutional level: A landscape report. Figshare. 10.6084/m9.figshare.21995156.v2

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