

HOW TO EMBED PPIE INTO RESEARCH OR CLINICAL SERVICE PROJECTS

Patient and public involvement and engagement (PPIE) is now widely recognised as part of good research and clinical service development. At its simplest, it means that work is shaped with patients, families and the public, rather than done to, about or for them. Public contributors are not simply participants in a study or recipients of a service; they are partners whose lived experience can change what is asked, how work is delivered, and how findings or service changes are communicated.

Despite this broad support, embedding PPIE effectively remains difficult. In a recent survey of the Evelina London Children's Hospital paediatric neurosciences department, attitudes towards PPIE were strongly positive, but practice was more variable. Respondents valued PPIE and described benefits around engagement, communication and collaboration. However, only 12% rated the department's overall integration of PPIE as good, and none rated it as excellent. Many also felt that PPIE was difficult to evaluate, with its perceived value lying more in engagement and support than in clearly measurable outcomes.

This pattern is not unique to this department.^{1,2} It points to two linked problems: a gap between belief and delivery (implementation), and a gap between valuing PPIE and being able to show what it changed (perception-impact). Neither gap is closed by enthusiasm alone. Both are closed by structure. PPIE needs to be planned, resourced, documented and evaluated in the same way as any other part of a research or service project.

A useful starting point is to stop treating PPIE as a single activity. Instead, teams should ask themselves two key questions:

(1) What is the involvement for? Contributors may help set priorities before a project begins, shape study design or clinical pathways, support governance during delivery, interpret results, improve dissemination, or provide feedback on existing services. Most projects will need PPIE for more than one of these.

(2) How much power will contributors have? In some projects, contributors may be consulted on specific questions while the team retains decision-making authority. In others, they may collaborate in key decisions or co-produce the work from beginning to end.

Higher levels of public involvement do not automatically make a project better. A focused or limited consultation may be appropriate, useful and honest. A project should only be described as co-produced if contributors genuinely share authority over the decisions made. The level of PPIE claimed in a project should match the contributors' experience.

In designing the type of PPIE to be used it can be helpful to use a simple grid that evaluates the level of contributor power involved at each stage. Examples of PPIE may include: an early-stage priority-setting exercise that sits at a high level of collaboration or co-production, a patient-information leaflet that involves consultation or active involvement around design and language, a service-improvement project that uses patient feedback repeatedly over time. These are all important uses of PPIE, but they are different with varied goals and objectives. Naming the difference clearly helps avoid tokenism and makes expectations explicit.

TYPE — what is the involvement for?

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	Pre-project	During delivery			Post-project / ongoing	
	A	B	C	D	E	F
	Priority Setting	Design & Methods	Governance & Oversight	Interpretation	Dissemination	Quality & Feedback
Contributor power ↑						
5 Co-produce						
4 Collaborate						
3 Involve						
2 Consult						
1 Inform						

Figure 1. A simple PPIE planning grid. Projects can be mapped by the purpose of involvement and the level of contributor power.

Recruitment is also an important part of the method; who is in the room shapes the evidence. Teams often begin with existing contacts, but meaningful PPIE usually requires wider reach: clinical networks, nurses and allied health professionals, charities, advocacy groups, schools, community spaces and targeted outreach to under-served or most-affected groups. The aim is not perfect representativeness, which is rarely possible, but rather, it is to be deliberate and transparent: Who was approached? Who contributed? And whose perspectives may still be missing? This should be recorded and evidenced.

Another very common challenge when PPIE is used is not that feedback is ignored, but that its route through the project is poorly documented. A contributor makes a suggestion; the team considers it; something in the project may or may not change; and the trail then goes cold. This makes PPIE difficult to evidence, compare or improve. It also risks undermining contributors' trust. When people are not told how their input shaped the work, or why it did not, their involvement can quickly feel extractive rather than collaborative. Without a feedback loop, even well-meaning PPIE risks being viewed as tokenistic.

Strong PPIE should be traceable. Each contribution should be followed from input, to decision, to change, to consequence, and back to the contributor as feedback. A simple change log is often enough: what was said, what decision it informed, whether anything changed, why it changed or did not change, and whether the contributor was told the outcome. This turns PPIE from anecdote into evidence. It also shows contributors that their time was taken seriously.

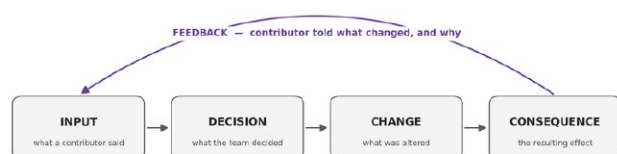


Figure 2. Traceable PPIE. Contributions should be followed from input to decision, change, consequence and feedback.

Evaluation does not need to be complex, but it should not be absent. A proportionate framework can consider five domains: the process, the outputs, the contributors' experience, the evidence of contribution, and a reflection on what should change next time. This is particularly important because many PPIE impacts are qualitative: improving wording, changing priorities, identifying assumptions, strengthening trust, or making outputs more usable.

The challenge with the adoption of PPIE is no longer simply persuading people or institutions that it matters; most already believe that it does. The current challenge is to build the infrastructure to do it consistently and meaningfully: choosing the right kind of involvement, recruiting deliberately, being honest about power, recording what changed, and reporting what was learned. Meaningful PPIE does not have to be large, expensive or elaborate to be effective. It does, however, have to be intentional, honest about power, and traceable from contribution to consequence.

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References

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