

Public involvement across the UK's research ecosystem at systems-level – results from the INTEGRATE study, a freedom of information-based survey

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Public involvement across the UK's research ecosystem at systems-level – results from the INTEGRATE study, a freedom of information-based survey

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Abstract (149/150)

Funding bodies in many countries mandate patient and public involvement (PPI) in research study development and delivery. However, the extent of systems-level public involvement in strategic decision-making is unclear. We report a UK-based mixed-methods study using Freedom of Information requests to examine PPI within executive-level boards that set health research strategy across universities, funders and NHS organisations.

Of the 402 institutions that responded, 19.4% had PPI representation at executive level and 23.4% had a PPI advisory structure. Findings suggest that: 1) Health research strategy-setting boards are highly variable 2) executive-level PPI is more common in NHS organisations than universities and funders 3) in universities especially, most PPI is at study-level rather than systems level 4) some institutions found ways to involve the public at systems level.

In the UK, systems-level PPI is least developed where the most significant strategic and funding decisions regarding research are made.

Word count without methods: 3666 (max 4000).

Introduction (564)

Strategic governmental agency decisions about which research programmes to fund are not neutral. Research grants rarely match disease burden, as seen in National Institutes of Health's disproportionate funding of conditions that predominantly affect men relative to their societal impact.^{1,2} In the UK, maternal and perinatal health is underfunded and receives less than 1% of health research funding, which contributes to a gender health gap.³ To ensure research is relevant and inclusive, major international research funders in the USA, Canada, Australia and increasingly in Europe now require or recommend that researchers involve patients and the public in the design and delivery of research studies.⁴⁻⁷ However, patient and public involvement (PPI) is usually required at the level of individual programme grants and studies rather than at systems-level where institution-wide research strategy is set.⁸

The UK offers a well-established PPI model. In 1996, the National Institute for Health and Care Research (NIHR) established INVOLVE, a national advisory group and coordinating

centre for public involvement in health research.⁹ INVOLVE created clear definitions of patient and public *involvement* and *engagement* (PPIE). They drew distinctions between public *involvement* as shaping research, public *engagement* as sharing/disseminating knowledge, and *participation* as being a research study participant.¹⁰ They also defined national standards for delivering non-tokenistic public involvement.¹¹ This work informed funding bodies' expectations that meaningful public involvement shapes research design and delivery.¹² Since INVOLVE's dissolution in 2020, the NIHR has adopted a decentralised approach, embedding PPI into local, regional and theme-specific structures, which could reduce specialised support for PPI.¹³

In parallel, terminology has evolved from 'public involvement' to 'working with people and communities'.¹⁴ This reflects broader structural changes in public health policy within the UK, emphasising that health inequities can only be tackled by challenging the hegemony of the medical model, listening to and empowering communities, and democratising health through community-led local health care centres.¹⁵⁻¹⁷ By 2027/28 these community-led neighbourhood health plans are intended to drive funding priorities.¹⁶

In contrast, within the UK's research ecosystem most public funding remains centrally held and allocated and is mostly administered by universities.¹⁸ A smaller proportion is channelled directly through the National Health Service (NHS).¹⁹ While the public are involved with co-developing and delivering research studies, there is no requirement for universities to involve communities in central strategic decision-making.²⁰ This is at variance with the aforementioned direction of community empowerment across the healthcare sector. Universities continue to spend core government-allocated funding according to their own strategic priorities which may or may not align with local communities.^{21, 22} So, the lack of explicit public involvement on executive boards may mean lack of consultation at highly salient points.⁸ Recently the NIHR has encouraged and prioritised a move towards a more system-wide PPI approach across University hospital systems.²³

Research addressing the extent to which members of the public *are* currently involved at *systems* level is scant. A 2025 survey of 88 university staff members in the UK found that only 17% reported public involvement on higher levels (executive level or board of governors) within their university.²⁴ To our knowledge, there is no published research mapping the extent and nature of public involvement at a systems level across the UK's health research and funding ecosystem.

We report a UK-based mixed-methods study using Freedom of Information (FOI) requests to systematically examine whether and how the public is involved within boards that set health research strategy across universities, NHS organisations (NHS trusts and integrated care boards, and funding bodies.

Results (2013)

Response rates to the FOI requests (Table 1) were very high across all institution types (total 425/462, 91.3% and ranging from 85-98%). Of these, 402/462 (87.0%) contained information pertinent to our questions as some institutions did not hold the requested information (Fig 1A, Table 2).

The qualitative and quantitative data were derived from the same dataset (the FOI requests), and we used a weaving narrative approach to present the findings.²⁵ Analysis of the mixed-methods data generated five key concepts.

Health research strategy-setting board structures are highly variable and complex

We first asked institutions whether they have an executive board where health research strategy is set. The percentage of institutions answering “Yes” to that question ranged by institution type from 50.4% (58/115) in universities to 69.7% (147/211) in NHS trusts (or equivalent: regional Health Boards in Scotland and Health and Social Care (HSC) Trusts in Northern Ireland) (Table 2).

A review of university websites revealed that 96.5% of institutions had an executive board where health research strategy was discussed (Supplementary Fig 1). However, these boards exhibited diverse characteristics. Some specifically focused on health research strategy (40.0%, 46 of 115) while others considered it part of a broader university-wide research strategy (56.5%, 65 of 115). The qualitative data further highlighted the complexity and heterogeneity of health research governance structures. In universities, some respondents indicated that no overarching health research strategy existed. Responsibility was instead distributed to individual senior academics or multiple lower-level boards for individual schools, research institutes or centres. Other health research-producing universities embedded health research strategy within broader institutional research strategies, which may have contributed to respondents indicating that no dedicated health research board existed.

“We do not currently have a standalone board considering health research strategy matters, however, these are considered at our University Executive level by the Deputy Pro Vice Chancellor and Pro Vice Chancellor for Research.” (University 96)

Some integrated care boards (or equivalent: local health boards in Wales and integration joint boards in Scotland) collaborate with external community or voluntary sector partners to develop their research strategy, while others don’t have a dedicated research strategy because they don’t conduct research themselves.

“Our Research and Innovation Board met for the first time in March 2025. However, we do not carry out research ourselves but oversee our partners’ work.” (Integrated Care Board 17)

Within NHS trusts there were varied approaches to developing and governing research strategy, with responsibilities distributed across committees and reporting structures. This complexity made it challenging to determine which boards were responsible for health research strategy.

“R&D [Research and Development] reports to the Trust Board on a regular basis and a Chief Academic Officer (CAO) sits on the Board... The R&D Committee oversees Trust strategy and provides assurances on risk and reports to the Quality Committee which receives quarterly reports on the Catalyst for Change ambition. The Trust is also part of [name] whose Board meets regularly to consider research strategy across its partners.” (NHS Trust 136)

Some research funders do not have a specific health research strategy because they allocate block funding to universities, who decide how to use it.

“As a funder of predominantly formula-based block grants to universities, [funder] does not have a specific health research funding strategy. Higher Education Providers receive their allocation as a block grant and then determine how to allocate this funding according to their own institutional strategy.” (Funder 6)

For our primary and secondary outcomes, we considered that institutions that answered “No” to the first question did not have any PPI representatives or structures associated with their executive board.

Strategic-level public involvement in health research was more established within the NHS than within universities or funders.

Overall, 19.4% (78/402) of institutions that responded to the FOI request had a designated PPI representative at executive level and 23.4% (94/402) had an advisory PPI structure (Table 2, Fig 1B, Fig 1C).

There was wide variation in whether and how PPI was integrated into executive-level health research governance across institution types. In universities and funders, PPI representation at strategic levels was low. Only one funder 10.0% (1/10) had an executive board or committee with an explicitly defined PPI member and a separate or overarching PPI board. Among universities, only 8.7% (10 of 115) had a member of an executive research board or committee with an explicitly defined PPI remit and 16.5% had a separate or overarching PPI board which informed the board. When asked about whether PPI took place at strategic level, many universities instead described PPI activities at individual study-level. Responses rarely appeared to demonstrate an awareness of the role that PPI could play in shaping overarching health research strategy. Some universities indicated that the academic nature of the research strategy boards meant that public input was not suitable at this level of decision-making.

"[The university] does not have PPI representatives embedded within its executive governance structures. As an academic institution, the setting of overall institutional research strategy is led internally... PPI activity is applied at the research project or programme level in line with the study's aims, context, and ethical requirements." (University 37)

There were also differences in what was considered PPI. Many universities indicated having a staff member responsible for supporting PPI activities at the study level when asked about public involvement in strategic decision-making. Universities often discussed public input into broader strategies e.g. education delivery or public involvement strategies, but not health research-specific ones. Concerning health research, PPI was mostly focused at study-level.

"The University's Research Board in June 2024 established a PPI Task and Finish Group with a remit to develop guidance for both internal staff and members of the public engaged in PPI activities that spans research knowledge exchange and teaching". (University 47)

Universities awarding medical degrees were more likely to implement PPI at executive board level. Of the 15 universities with PPI representation or input on their executive board, 10 were in General Medical Council (GMC) awarding universities (Fig 2). There was no notable difference in PPI representation when comparing universities by whether they had achieved a gender charter (Athena Swan) gold or silver accreditation, a partnership with a NIHR Biomedical Research Centre (collaboration between universities and NHS trusts), a 2026 QS ranking (top 100 universities) or Russell Group membership (an association of 24 self-selected research universities).

Both NHS trusts and integrated care boards appeared to recognise the need for public involvement in research strategy more commonly than universities. 26.1% NHS trusts and 18.2% of integrated care boards reported having a health research-related executive board or committee with an explicitly defined PPI member. 25.6% (54/211) of NHS trusts and 30.3% (20/66) of integrated care boards reported having a separate or overarching PPI board to inform their governance structure (Table 1, Fig 1B, Fig 1C).

"The purpose of the group is to raise the profile of the partnership and to actively involve the public in the development and delivery of the research strategy" (Integrated Care Board 56)

NHS trusts and integrated care boards also referred to wider PPI activity aimed at improving clinical care and healthcare delivery in general. Integrated care boards often collaborated with Voluntary Sector and Community Organisations (VSCOs) through research engagement networks, which connect health systems with the public.

"Research for [Integrated Care Board name] has representation from the Research Engagement Network (REN). The REN is a collaborative VCSE [Voluntary, Community, and

Social Enterprise] network to better support diverse communities to get involved in research across [Region name].” (ICB 60)

Institutions reported a range of reasons for not having PPI at executive levels (see Table 3). Many institutions particularly NHS trusts and some funders indicated they are in the process of developing systems to incorporate PPI at this level, reflecting growing recognition of its value in health strategy agenda setting.

Mechanisms to involve the public at the executive board level varied considerably

Where public involvement did exist, there was substantial variation in the mechanism of public involvement across institutions. While a small number of institutions included PPI members directly on executive-level boards, PPI involvement was more commonly achieved through separate committees or advisory boards that reported to executive structures. In some cases, organisation-wide PPI groups were consulted intermittently on research strategy or reported to boards at regular intervals. In other institutions a staff member with a PPI role represented patient and public perspectives at board level. The range of mechanisms by which PPI members were included at the executive level is outlined in Table 4.

“The Public and Patient Involvement Assurance Group (PPIAG) are an independent group which meets monthly... recent highlights and updates are shared through bi-monthly reports to the ICBs [integrated care boards] System Quality Group and Quality and Safety Committee” (ICB 39).

Several institutions provided supporting documentation, including terms of reference and policy documents, outlining the scope of PPI activities, forms of involvement, and detailed scope of work. However, these institutional texts relate often to aspirations or guidelines and do not report on actual influence or decision making.

FOI responses indicated that PPI members’ preferences can lead to variations in how involvement is structured and implemented. For instance, in one university, representing a wider PPI group through a staff member who conveyed their views to the executive board was considered the most effective way to incorporate PPI perspectives into strategic decision-making.

“Not having a single PPIE representative on the committee is not an oversight, it is informed by decisions within the partnership, with members about where their involvement is most impactful and how their views and insights can be best represented... Sitting on formal panels has been identified by members as just as meaningful when led by the academic leads and PIER officers (who themselves have lived experience expertise) freeing up members to be involved in the ways they choose” (University 10).

Public involvement at universities is concentrated at lower, research-specific levels rather than institution-wide strategic levels.

Our data shows that 18.3% (21/115) of universities had lower-level boards (such as committees within research institutes, departments, NIHR biomedical research centres with clearly defined research themes, and applied health research collaborations), with a member holding an explicitly defined PPI role (Table 2). The qualitative data confirm this pattern of involvement:

“There is no representation on Faculty Board or the Faculty Research Committee. However, there is a community partner representative on the BRC Executive Committee. Community partners are involved in strategic developments throughout the BRC” (University 26).

Lower-level boards within universities often included PPI members on theme-specific boards or advisory panels. Some institutions cited the broad remit of executive boards and committees as a reason for the absence of PPI representation at that level (see Table 3).

In contrast, rates of lower-level PPI representation in other institution types were either similar to, or lower than, executive-level representation. Only 16.7% (11/66) of integrated care boards and none of the funding organisations had lower-level PPI involvement (Table 2).

NIHR guidelines shape PPI representative training and remuneration, but consistency within and across institutions is lacking.

In over half of universities with a PPI representative or an advisory structure at the executive level, PPI representatives were paid (52.4%, 11/21), while integrated care boards were less likely to do so (13.6%, 3/22). (Table 2, Supplementary Fig 3). In most cases, PPI representatives’ remuneration was reported to follow NIHR guidelines.²⁶

“Yes, they are remunerated at NIHR rate of £25/h plus travel expenses or other reasonable expenses to facilitate their attendance in line with NIHR guidelines, such as childcare costs, disability transport etc” (University 68)

Some NHS trusts and universities distinguished between attending committee meetings, where only travel expenses are covered, and PPI activities, such as supporting the writing of grant applications, where remuneration is provided.

“The [lived experience research partnership] meets monthly on a voluntary basis - any work done outside of this i.e. contribution to documents, research development / strategy meetings is remunerated” (NHS Trust, 128)

Training is mostly optional and offered on request. Mandatory training was only reported in 47.6% (10/21) of universities, 47.9% (35/73) of NHS trusts, and 18.2% (4/22) of the

integrated care boards. Some institutions rely on NIHR training programmes and Research Engagement Networks.

Discussion (1089)

Despite a clear public health policy direction to tackle health inequalities together with affected communities, our extensive study across the UK research ecosystem revealed limited patient and public involvement on the executive boards that set health research strategy. This was the case in universities, NHS trusts, integrated care boards, and funding bodies. Organisations like NHS trusts and integrated care boards which deliver healthcare had the most public involvement in setting their health research strategy. In keeping with this, universities that awarded medical degrees constituted two thirds of those with public involvement input on their executive board. This suggests that the value of public involvement may filter thorough from affiliated healthcare delivery organisations, such as university hospitals where public involvement in clinical care delivery is better established.

Many universities suggested that public involvement was only required and appropriate at study level and this highlights the lack of systems-level accountability to the public.²⁷ While executive-level PPI representation was rare, some lower-level boards included PPI members on theme-specific boards or advisory panels. This suggests public involvement is more easily integrated where research has a clearer clinical, community, or disease-specific focus, which may indicate that PPI is understood largely as relating to ‘patients’ with specific conditions or people from specific groups, as opposed to a broader civic mechanism of institutional accountability. Some institutions indeed cited what they saw as the *broad academic* remit of executive boards and committees as a reason for the absence of public representation at strategic levels. This implies a narrow appreciation of the critical importance of communities in shaping not only health delivery but research priorities themselves.

Limited funding for strategic-level infrastructural PPI may further constrain meaningful activities at this level.⁸ Indeed, some institutions funded only travel time rather than time to attend and contribute to meetings, in contrast with payment typically expected for study-level PPI.²⁸ This lack of funding for reimbursement could relate to organisational funding constraints, internal guidelines about remuneration or lack of appreciation of the value of public contributors. Failure to remunerate public contributors raises clear equity concerns as this can create barriers to participation for underserved populations who cannot afford to volunteer their time, resulting in disproportionate involvement of those with sufficient means.^{27, 29} This lack of diversity among study-level public contributors is well-documented. Most NIHR public contributors are White women over the age of 50.³⁰ Other barriers to participation may include lower education levels, health literacy, and language barriers.³¹

The provision of training for strategic-level public contributors in our study was limited and mostly ad-hoc. While NIHR training and remuneration guidance are useful, they were not universally implemented. This echoes the literature concerning individual studies where guidance on and provision of appropriate training opportunities for public contributors are inconsistent.³¹⁻³³

This study has several important limitations. While using an FOI-approach meant that we had a very high response rate (91%), the quality and detail of responses varied considerably. As FOI officers are responsible for directing the request to the most appropriate staff member in the organisation, it was not possible to determine who provided the information, their level of knowledge of the topic, or how our requests were interpreted. The wording of the request, particularly the term "executive-level board," may also have led to underreporting of boards involved in health research strategy that were not described using this terminology. In addition, responses ranged from detailed accounts to very limited information, and the FOI approach did not allow for real-time follow-up and probing, restricting the depth of the qualitative analysis of the free texts.

Despite these limitations, this is, to our knowledge, the first study to evaluate the whole public health research eco-system regarding systems-level patient and public involvement across the UK. We have shown a concerning lack of systems-level public involvement within health research. This adds to the lack of data on systems-level PPI within health research, with studies focussed largely on the study level.^{31, 32, 34} Our study adds to findings from a survey sent to 88 university staff, which showed that <20% had PPI at higher-levels at their university.²⁴ Our study was broader as it included all universities and other institutions from across the UK research ecosystem, and included questions about implementation, remuneration and training of public contributors.

Our research shows that there is no one-size-fits-all model for executive-level public involvement across institutions. However, we identified a growing appreciation of the importance of strategic public involvement within many organisations, but a lack of clarity on how to implement this at executive board level. Equally, we have identified several clear examples where organisations delivering health research have well-established public involvement structures within their executive and governance frameworks. This provides potential models for other similarly structured organisations to strengthen public involvement in strategic decision-making. Yet, PPI representation at the strategic level alone does not ensure meaningful involvement. Public involvement at study level itself is the subject of extensive debate regarding how to meaningfully involve contributors with lived experience.^{35, 36} Some argue that institutionalising PPI may make other grassroots forms of PPI invisible and prioritise formalised or tokenistic inclusion without real power sharing.⁹ Additionally, studies of patient and public representatives on health service boards and clinical commissioning groups have found that there was limited opportunity for representatives to actually influence 'top-down' decision-making,

a lack of clarity on roles and expectations of patient and public representatives and concerns about tokenistic inclusion.^{37, 38}

However, public perspectives are as central to defining health research priorities as they are to healthcare delivery. Failure to integrate public perspectives within strategic academic environments risks worsening research gaps and widening inequities through lack of transparency, accountability and lack of relevance.³⁹ The highly limited representation observed within universities suggests that strategic-level public involvement remains an underdeveloped component of the UK health research ecosystem. Furthermore, this lack of representation in universities doesn't align with the UK's current political landscape's spirit of democratising public health and devolving decision-making to the level of communities.^{15, 17} Public involvement that spans universities, NHS trusts, integrated health boards and funding bodies is necessary to strengthen public influence over research priorities. Future research should therefore move beyond the presence or absence of public representation to better understand how potential models of high-level public involvement could be developed and evaluated. Qualitative participatory and action-focused studies exploring barriers and facilitators to strategic-level involvement, alongside consensus-building among public contributors, researchers, and funders, could further help establish principles of good practice that could be extrapolated to research ecosystems both within and beyond the UK.

Methods

FOI-based research

This study used FOI-based survey methodology to request information that is not in the public domain based on a tailored request from multiple public institutions and to ensure a high response rate. The public has a legal right to access recorded information from public institutions based on the FOI Act 2000 (England, Wales, and Northern Ireland) and the FOI (Scotland) Act 2002 acts.⁴⁰ Public institutions have 20 working days to respond and may only withhold information if it falls under a specific exemption e.g. the information is already published, it is a repeated request, the request will cost more than the threshold (£450), or is sensitive information such as personal data.⁴¹

Patient and public involvement

The SHARE research Collaborative, steered by an independent PPI Board of experienced lived experience community advisors from under-served populations, conducted this study. The Board reviewed the study protocol, study design and methods. The initial findings were presented to this group, and their feedback shaped our interpretation, including which results to prioritise and the importance, and practical challenges of including diverse voices on PPI boards.

Study design and data sources

To evaluate public involvement on boards and panels we submitted FOI requests to public institutions concerned with health research production and funding in the UK:

- **Research-active universities concerned with health research** (n=123). Defined as universities that submitted to Research Excellence Framework (REF) 2021 within units of assessment 1-4 (Clinical Medicine, Public Health, Health Services and Primary Care, Allied Health Professions, Dentistry, Nursing and Pharmacy, Psychology, Psychiatry and Neuroscience).
- **NHS trusts** (n=245) (NHS organisations responsible for providing and managing health services across England, their equivalent structures are regional Health Boards in Scotland and Health and Social Care (HSC) Trust in Northern Ireland) identified through NHS and public health provider directories.
- **Integrated care boards** (n=81) (NHS organisations responsible for budgets and performance management of health services in England, their equivalent structures are local health boards in Wales and integration joint boards in Scotland), identified through NHS and public health provider directories.
- **Public institutions that fund research** (n=13) predominantly about health, identified through searching government websites and UKRI councils.

Public institutions were asked 7 open questions (Table 1). We piloted the FOI-based survey with three different institutions. Based on this the FOI-request wording was adapted, and two questions were added (Q4 and Q5, Table 1).

After piloting, we sent FOI requests to all remaining institutions through the website whatdotheyknow.com (30/1/2025-31/3/2025). Public bodies not available on whatdotheyknow.com were contacted individually. Public institutions that did not respond after 20 days were sent a follow up email as a reminder. We also sent follow-up emails requesting clarification for the following reasons (agreed upon by both researchers who dual-coded the response): if the response was incomplete, unclear, contradictory or if it was clear that some questions had been misunderstood.

We developed a data extraction tool in Excel where we documented responses to each question across all institutions. We first piloted the extraction tool on a selection of FOI responses during meetings with all researchers involved in data collection and made iterative adjustments. FOI data was then extracted independently by two researchers and then reconciled, with a third researcher consulted when agreement could not be reached. We recorded the exact responses provided by the institutions. Based on the information provided in free text fields, we also recorded our interpretations of the answers (results presented in Supplementary Fig 1 and 2). For universities, we further triangulated the data in the FOI responses with internet searches for Q1-3 through

checking university websites, due to the high numbers of institutions that reported that they did not have health research strategy boards. Follow-up emails were sent to universities to ask for clarification if information from their website contradicted their FOI response (21/11/25-5/12/25), and updated information from follow-up responses was then added to the extraction tool. The finalised extraction tool was tabulated as: the institutions' responses, our interpretation of the response and internet searches.

Endpoints

The primary endpoint was the percentage of public health research producing, and funding institutions in the UK with executive boards or committees that have a member with an explicitly defined PPI role. Secondary endpoints included the percentage of institutions with a separate PPI board that feeds into their governance structure and the percentage of institutions with lower-level boards that have a member with an explicitly defined PPI role. We considered the following as lower-level: specific institutes or departments within universities, biomedical research centres, clinical research facilities, research centres and clinical divisions.

To better understand factors that may affect PPI involvement within university boards, we compared the following characteristics between universities with and without a PPI representative on the executive board or a separate advisory PPI board: having an Athena Swan accreditation (gold or silver versus bronze or non); being a General Medical Council (GMC) awarding body; having a NIHR Biomedical Research Centre (collaboration between universities and NHS trusts); being in the QS rank 2026 top 100; being a Russell group university (an association of 24 self-selected research universities). The source for each characteristic is indicated in supplementary material.

Analysis:

The text data produced in the FOI requests varied, with some institutions providing detailed descriptions of their PPI processes alongside answers to our questions, whereas others answered very briefly. We took a convergent mixed-methods approach to analyse the FOI request through both quantitative and qualitative methods.²⁵

Statistical analysis

Descriptive statistics were used to report on the primary and secondary outcomes. Analyses were stratified per institution type. For each outcome, the response denominator is provided to indicate potential missing data. Analyses were performed in R version 4.4.2.

The statistical analysis plan was pre-published on an open-access platform (<https://doi.org/10.17605/OSF.IO/K9QGN>)

Qualitative analysis

Qualitative data from the FOI responses were analysed using NVivo v.14.0 and charted into thematic matrixes in Excel using Framework analysis with a deductive and inductive coding approach,^{42, 43} which remained flexible to the addition of new codes throughout. Deductive codes were developed from the UK Standards for Public Involvement and other key areas of interest.¹¹ The initial analytical framework was developed from six FOI requests then adapted and applied to all FOI requests. Weekly peer debriefing took place in the research team to maintain consistency and a detailed audit trail of decision-making, and coding framework evolution was maintained. Interpretation of the data were discussed and developed in team meetings.

Contributors

CO conceptualised the study. CO and MD acquired funding for the study. CO, MD, AE and MS wrote the study protocol, which was reviewed by AN, MH, BK. Quantitative data extraction was conducted by CP, NH, AE, LU and MD. CP conducted data management, statistical analyses and validation. CP, MD, NH and CO contributed to data visualisation. Qualitative data analysis was led by MD with input from NH, AE, OLL, CP, SP and CO. All authors contributed to results interpretation. CP, MD and CO drafted the manuscript. All authors reviewed and refined the manuscript.

Data sharing statement

Data will be shared upon reasonable request.

Competing interests

The authors have no competing interest relating to this manuscript. General competing interests of authors include:

SP has received research grants from ViiV Healthcare and Gilead Sciences. BK has received speaker honoraria and consultancy fees from Gilead Sciences, GSK, and ViiV Healthcare. CMO has received honoraria for advisory boards, lectureships, and travel sponsorships from Janssen, Gilead Sciences, ViiV Healthcare, MSD and Bavarian Nordic and has received research grants from Janssen, Gilead Sciences, ViiV Healthcare, MSD, Bavarian Nordic. RD has received speaker fees from ViiV Healthcare and Gilead Sciences. CP has received research grants from ViiV Healthcare. MH has received consultancy fees from NIHR Health Protection Research Units. AT has received research support from the UK MS Society, NIHR, ADR UK, Roche, Merck, Genzyme Sanofi, Barts Charity, the Michael J. Fox Foundation for Parkinson's Research and the Horne Family Charitable Trust and has received speaker honoraria from Novartis, Merck, Roche and Neuraxpharm. All other authors have no conflicts of interest.

Ethical approval

As the study will use a FOI based survey and does not involve collected personal data, ethics approval was not required.

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Figure 1.

Bar plots showing, by institution type, the FOI response rate (A: percentage of institutions who answered the FOI request), the primary outcome (B: percentage of institutions with executive boards or committees that have a member with an explicitly defined PPI role, and C: the percentage of institutions with a separate PPI board that feeds into their governance structure. The data is based on their answer to the FOI request. Dark shading corresponds to institutions who provided response with data available, light shading corresponds to institutions who answered to our FOI request, but the response did not contain responses to our questions. Navy blue corresponds to universities, teal blue to NHS trusts, orange corresponds to integrated care boards (ICB), and green to funders.

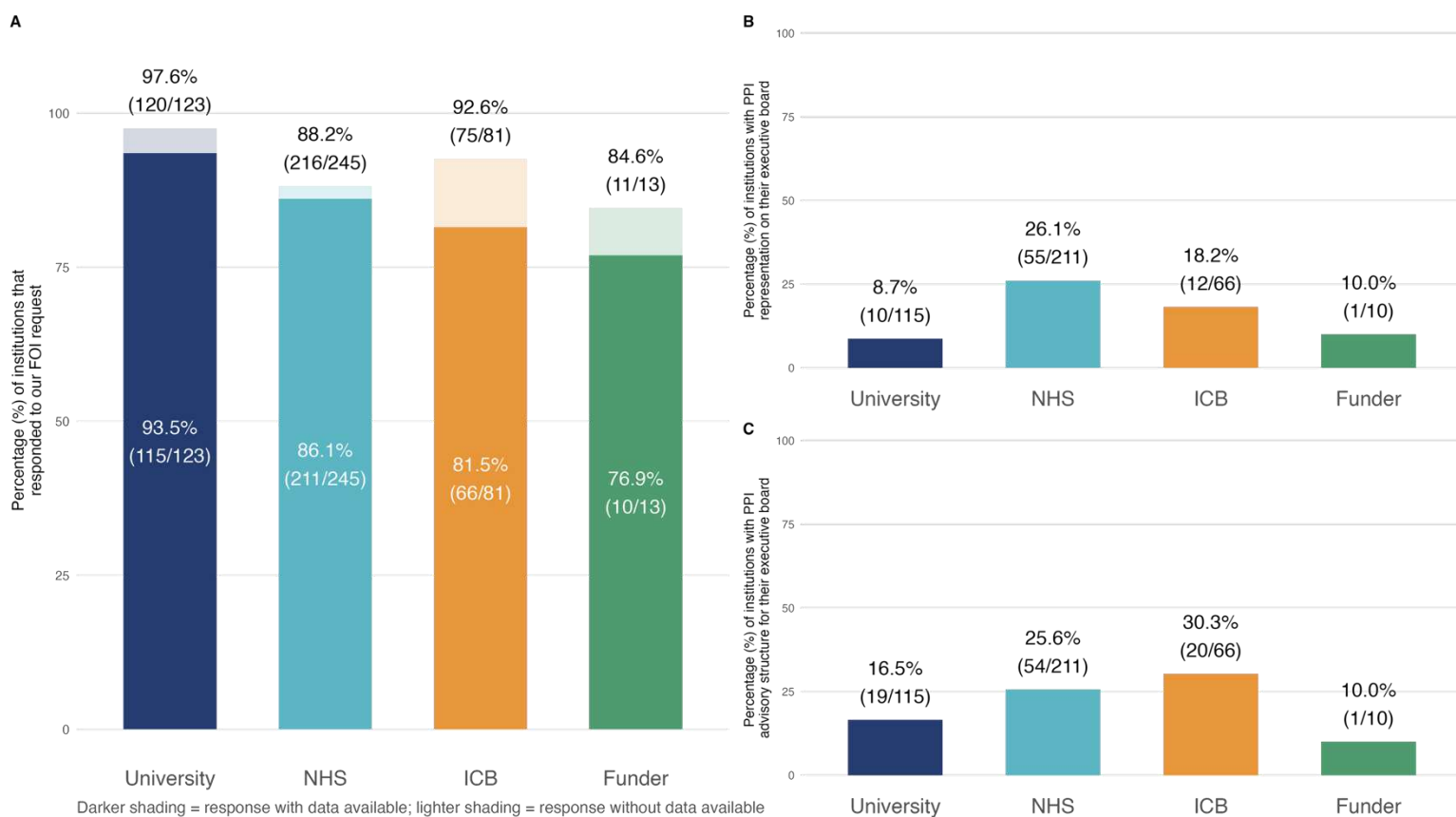


Figure 2.

Bar plot comparing the percentage of universities with specific characteristics (whether the university has Gold or Silver Athena Swan Award at university level; has a GMC awarding body; has a BRC; is in the QS top 100 2026; is part of the Russell Group) among universities with a PPI representative on their executive board or a PPI structure feeding into their governance (dark blue) versus all universities (light blue).

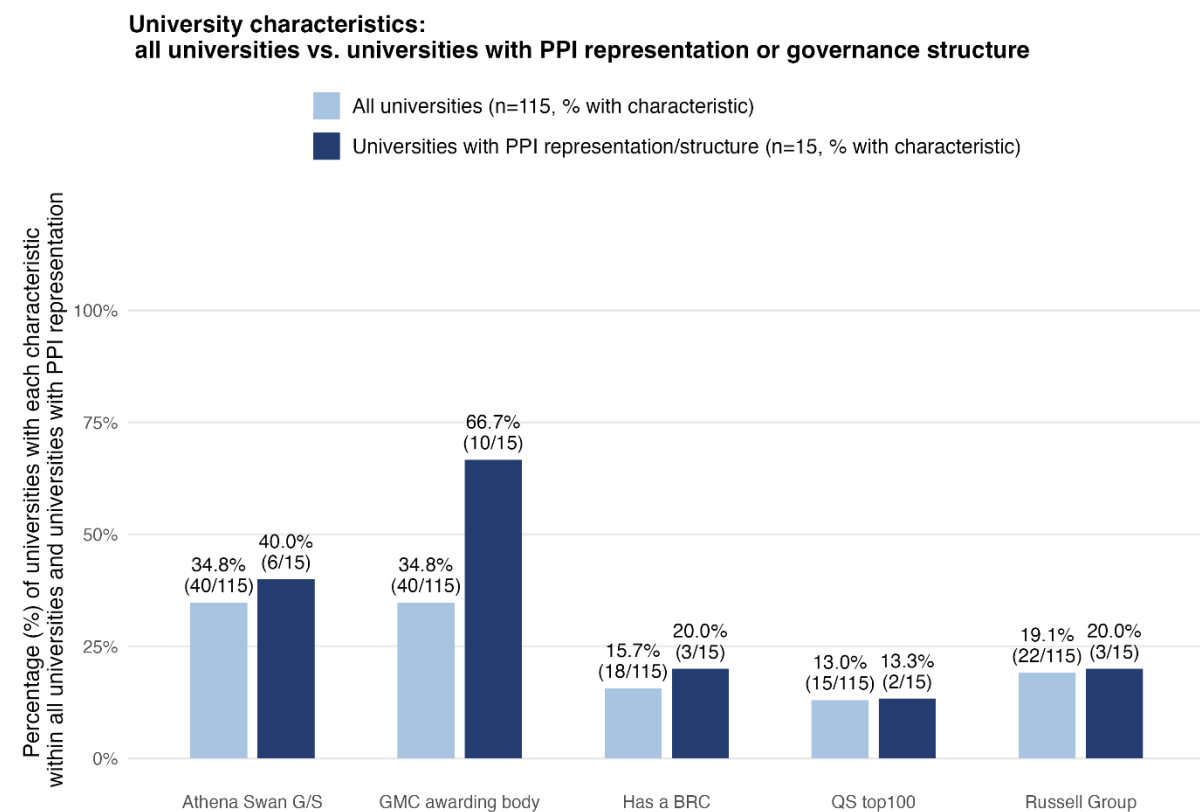


Table 1. Questions in the FOI request

	Questions asked
Q1	<i>[Universities without medical schools]</i> Does your University have an executive board where health research strategy is set (i.e the type of research submitted to REF UoA 1-4)? <i>[Universities with medical schools]</i> Does your Faculty of Medicine/Faculty of Medicine and Dentistry have an executive board where health research strategy is set? <i>[Integrated Care Board]</i> Do you have an executive board where health research strategy is set? e.g. the medical sciences board or other relevant high-level board? <i>[NHS trusts]</i> Do you have an executive board where health research strategy is set? e.g a Research and Innovation Board or other relevant high-level board. <i>[Research Funders]</i> Does your organisation have an executive board where health research funding strategy is set?
Q2	If yes, is there a PPIE (patient public involvement engagement) representative on this board with the specific remit to provide insights into research agenda setting from the perspective of a patient with lived experience of health issues or as a member of the public/community? [I am not referring to the presence of a lay chair].

Q3	Is there a PPIE advisory structure (e.g. board, committee, panel) which provides PPIE insights to inform the work of the executive board? (not within individual study groups- I refer to high level feedback into your research strategy meetings).
Q4	<i>[Universities]</i> Is there a PPIE representative on any lower-level boards (e.g BRC)? <i>[Integrated Care Boards]</i> Is there a PPIE representative on medical specialty specific boards e.g women's health? <i>[Research Funders]</i> Concerning health research, is there a PPIE representative on any lower-level board/committee (e.g individual funding calls).
Q5	If yes to question 2, 3 or 4, please provide the most recent minutes/agenda with a list of members with designated roles/remits (not names).
Q6	Are PPIE representatives remunerated?
Q7	Do you require PPIE representatives to do any training? If yes, please specify e.g NIHR training or in house-training.

Table 2. Summary of findings.

	University	Public Health System Body	Integrated Care Board	Funder
Number of identified institutions	123	245	81	13
Response to the FOI request	97.6% (120/123)	88.2% (216/245)	92.6% (75/81)	84.6% (11/13)
Response to the FOI request containing pertinent information	93.5% (115/123)	86.1% (211/245)	81.5% (66/81)	76.9% (10/13)
Designed PPI representative at executive level	8.7% (10/115)	26.1% (55/211)	18.2% (12/66)	10.0% (1/10)
Advisory PPI structure for the executive level	16.5% (19/115)	25.6% (54/211)	30.3% (20/66)	10.0% (1/10)
PPI on lower-level boards	18.3% (21/115)	Not collected	16.7% (11/66)	0.0% (0/10)
PPI remuneration (among institutions with PPI representation or advisory PPI structure at executive level)	50.0% (11/22)	42.1% (32/76)	12.0% (3/25)	100.0% (1/1)
Training (among institutions with PPI representation or advisory PPI structure at executive level)	45.5% (10/22)	48.7% (37/76)	20.0% (5/25)	0.0% (0/1)

Table 3. Reasons why institutions did not have PPI at executive levels

Institution	Reason	Quote
Integrated Care Board, university	View having staff member with PPI remit as sufficient	<i>"There isn't a PPIE representative. The ICB Director of Communications and Engagement is a member of the Strategic Planning and Integration Committee with the role to make the link between insights from people and communities and the work of the committee."</i> (ICB 47)
		<i>"There is no PPIE representative with direct lived experience on CLT - however there is member of the College leadership team who is responsible for the collation of PPIE activity from across the College"</i> (University 90)
Integrated Care Board, university	PPI at study or delivery group level	<i>"No, PPPs (Public and Patient Partner) tend to be recruited more to working groups/delivery groups rather than board level"</i> (ICB 27)
		<i>"No, PPIE is focused in project-specific activities."</i> (University 104)
University	Institution is too small	<i>"While some of this activity is supported on an informal basis, the size of the institution does not warrant the types of activities listed in your request"</i> (University 36)
University	Academic focus of committee not appropriate for PPI	<i>"Every faculty at the [University] has a Faculty Research & Innovation Committee (FRIC). The functions and membership for which are standardised and are set centrally, with a strong academic focus. We therefore do not have a specific PPIE representative at FRIC"</i> (University 100).
Integrated care boards	PPI committees being amalgamated into other governance structures or dissolved completely	<i>"The ICB has until February had a Public Partnership Committee, a formal sub-committee of the ICB Board, whose membership included lay representatives. This committee will be amalgamated within the ICB's new</i>

		<i>Strategic Commissioning and Integration Committee from April 2025.” (ICB 27)</i>
Integrated care boards, NHS trusts	Institution does not conduct research themselves	<i>“Please be advised that [NHS Trust] does not currently run its own research studies. We participate in other peoples’ research studies which will have already been through PPIE panels when they were in the design stage.” (NHS Trust 184)</i>
		<i>“Currently, [ICB] acts as a collaborative partner in research studies where PPIE is mostly led by the leading research organisation”. (ICB 9)</i>
NHS trust	Challenges with engaging with specific groups/population	<i>“There is not, however, a formal structure composed of patients with lived experience of research, specifically. As you may be aware, it is not straight-forward for the paediatric patients to be available during office hours (e.g. because of overlap with school hours) on a regular basis.” (NHS Trust 194)</i>
University, NHS trusts, funders	Currently developing PPI at strategic levels	<i>“No - but as part of the new Trust Research Plan 2025-2030, there is representative on this board with a requirement for PPIE” (NHS Trust 15)</i>
		<i>"There is not currently a patient representative on this Board, we are in the process of re-developing our Patient and Public Involvement (PPI) programme with a proposal to include a patient on the Board" (NHS Trust 152)</i>
		<i>"The [funder] committed to establishing a Public Advisory Group in the [funder] public partnerships strategy 2024 to 20274, which was published in July 2024. The Public Advisory Group will be established “to guide ways of working and ensure effective public partnerships throughout the [funder] research community”. " (Funder 2)</i>

		<i>"This is an aspiration we are currently working towards. We have developed a bottom up approach to the development of the PPI group and the next steps are to share insights with the University Research Ethics Advisory Board and plan the strategic future direction of the PPI group" (University 72).</i>
University, NHS trusts	Broad remit of the committee	<i>"No - one person cannot provide lived experience from the perspectives of all the services we provide...The Trust would expect individual researchers to ensure there is proper PPIE supporting specific research themes and studies." (NHS Trust 108)</i>
		<i>"The Faculty Research and Innovation Committee is responsible for collating and prioritising research themes within the Faculty, but these are broader than simply Health. [There is no PPIE] given the broad remit of the Faculty committee highlighted above." (University 52)</i>

Table 4. Types of PPI structures

PPI structure type	Description	Example	Type of involvement
PPI board member with PPI advisory group	The institution has a PPI advisory board that feeds into the executive board and a member of this group also sits on the board.	University has a user research group made up of 8 PPI members and two members of this group sit on the Faculty of Health research committee.	Integrated public involvement
		ICB has two members of the Public and Community Advisory Group that sit on the board and executive group and the public and community advisory group	

		has 6 members. All lower-level networks/groups on specific health topics have PPI representation.	
PPI board member	The institution has a PPI representative which sits on the board/committee where research strategy is set.	NHS Trust has a PPI representative with lived experience on both the 'Research Governance Group' and the 'Research Advisory and Ethics Group'. The research strategy is agreed and monitored through the 'Research Governance Group', which is chaired by an executive director, and feeds into the Trust board.	Direct public representation
PPI board member and separate PPI advisory group	The institution has a PPI member that sits on the research committee and a separate advisory board that feeds directly into the executive board.	Research strategy is reviewed by the 'Research Governance Committee' which reports to the 'Clinical Governance Committee' and has a public involvement member who actively engages in the committee. The Board also has a 'Public Involvement Group' which has input from their public involvement member	Dual channel public involvement
PPI group with staff representative and ad-hoc PPI involvement	The institution has a PPI advisory board made up of PPI members and staff members and a staff member feeds into the board with ad-hoc involvement of PPI member on the board	University has a PPI advisory structure that meets regularly, university staff involved in this group are members of the Research and innovation committee and academic board, PPI experts from the advisory structure are regularly invited to committee meetings but are not regular members.	Consultative involvement
PPI group with staff representative	The institution has a PPI advisory board made up of PPI members and staff members	University has a citizen Academy Steering Group with at least 4 PPI members, feedback is given via the	Indirect public involvement

	and a staff member feeds into the board, PPI members do not sit or attend board meetings	citizen academy director to the faculty of medicine and health executive.	
Representation from community and voluntary organisations	The institution has a REN and representatives from the REN are on the board.	ICB has a REN (led by the voluntary sector) which are involving the public in shaping the research agenda. At board level, both Healthwatch and community/voluntary organisations are represented.	Community and voluntary sector direct representation
	The institution has a REN that feeds into the health strategy but a member from the REN does not sit on the board.	ICB has a Research Inclusion group chaired by Healthwatch set up under the REN. It also had a system-wide participation and involvement network. The group meet every 6 weeks and includes VCSO members from a range of sectors.	Community and voluntary sector advisory

Supplementary Files

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