



An Roinn Sláinte  
Department of Health

# Public Consultation on the draft Patient Voice Partner Policy: Department of Health, Ireland.

Fields marked with \* are mandatory.

## **A Public Consultation on a draft Patient Voice Partner Policy for the Irish Public Health System: Department of Health, Ireland.**

### **Background Information**

It is widely recognised in the health sector that patients have a central role to play in the development of health policy and the reform of health services. Throughout the health service, patient representatives make a significant contribution on an ongoing basis to the work of the Department of Health, the HSE and health agencies. Patient representation on committees and groups throughout the health service has been increasing in recent years as a means of enhancing the responsiveness and transparency of healthcare systems. Actively involving the public from the outset represents a cultural shift to one of mutual benefit for the public, patients and healthcare providers. Patients themselves are experts of their own experience and a person-centred approach in the context of healthcare delivery values patient representatives as active participants of the health service.

This policy emphasises the value of patient representatives, known in this policy as 'Patient Voice Partners' (PVP), in all aspects of health service development, reform and implementation. It outlines the different categories of PVPs with a

focus on frequency, regularity and level of contribution. A core aspect of this policy will focus on the selection of those PVPs who are involved in substantive, active and decision-making roles at a strategic level in the health service. It is intended that this specific cohort will be selected and remunerated, where appropriate, for certain defined committees, working groups, and similar formations across the health service.

The purpose of this Patient Voice Partner Policy is to:

1. Ensure that patient participation is embedded in health policy and service development
2. Ensure that Patient Voice Partners are recognised and valued for their contribution and,
3. Support the Sláintecare Implementation Strategy 2018 commitment to involving patients and service users in the design and delivery of the full range of actions identified in the Implementation Strategy
4. Support Department of Health Strategic Priority 3 “Make access to healthcare fairer and faster by promoting National Patient Safety Office (NPSO) initiatives for patient engagement”.

### **Purpose of this survey**

The Department of Health seeks the views and opinions of patients, service users, patient representatives, healthcare staff, interested members of the public and relevant organisations on some of the key elements of the draft policy. The views and opinions collected will be considered and will be used to inform the final draft of the policy prior to publication. It is recommended that participants read the draft policy prior to completing the survey. At a minimum, participants should read the executive summary. There is a link to both of these documents on the right hand side of this page under the 'Background Documents' section. These links will appear there throughout each page of the survey to assist participants.

## **Privacy Notice / Data Protection**

This survey is aimed at healthcare professionals and members of the public who are interested in patient involvement. The survey is being conducted by the Department of Health in Ireland.

All responses to the questionnaire are anonymous. A report will be prepared based on the responses to this questionnaire, however, individual responses will not be reported.

Participants should be aware that all submissions will be retained until such time as they are appraised by the National Archives to determine whether they warrant permanent retention as archives in accordance with the Department's obligations under the terms of the National Archives Act 1986.

Any personal information submitted to the Department will be treated strictly in accordance with the General Data Protection Regulation 2016/67 and the Data Protection Act 2018.

Please note people can request to see the submissions we receive under the Freedom of Information (FOI) Act 2014 so we may have to release submissions in response to an FOI request. This is more likely to happen for submissions from organisations. This means that the requestor might get your answers to the questionnaire, however, any personal information included in submissions would be redacted prior to release. If you have any queries, please e-mail [pvp\\_policy@health.gov.ie](mailto:pvp_policy@health.gov.ie)

### **Survey Outline**

There are 19 questions in this survey and they are divided up into 8 sections as follows:

Section 1: Your Details

Section 2: Guiding Principles

Section 3: Model for Engagement with Patient Voice Partners

Section 4: Guidance for Health and Social Care Organisations on the Recruitment and Selection of PVPs

Section 5: Supports for PVPs

Section 6: Diversity and Remuneration

Section 7: Implementation, Monitoring and Review

Section 8: Additional Information

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## Section 1: Your Details

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\* **Question 1:** Are you completing this survey on behalf of an organisation or in a personal capacity?

*at most 1 choice(s)*

- Organisation
- Personal Capacity

\* **Question 2:** If completing on behalf of an organisation, what type of organisation?

*at most 1 choice(s)*

- Health and Social Care Provider
- Health and Social Care Regulator
- Health and Social Care Professional Regulator
- Patient Advocacy Provider
- Educational Institution
- Patient Representative Organisation
- Other

Question 2A: If other, please describe

*150 character(s) maximum*

Patient-led multi-stakeholder platform representing patients, science and industry in Ireland

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## Section 2: Guiding Principles

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**Chapter 2 outlines the guiding principles for the policy which were informed by extensive consultation with stakeholders.**

These include:

1. Maximising Patient/Service User Involvement
2. Promoting Equality of PVPs through Shared Decision Making
3. Supporting Effective Participation
4. Transparent Recruitment and Selection for Strategic Committees
5. Good Governance and Accountability

\* **Question 1:** Do you agree with the Guiding Principles as set out in Chapter 2 of the policy?

at most 1 choice(s)

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't know

**Question 2:** From your own perspective, please rank these principles in order of importance, with 1 being the most important and 5 being the least important. **(1 Answer per Column)**

	1	2	3	4	5
* Maximising Patient/Service User Involvement	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Promoting Equality of PVPs through Shared Decision Making	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Supporting Effective Participation	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
* Transparent Recruitment and Selection for Strategic Committees	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
* Good Governance and Accountability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

## Section 3: Model for Engagement with Patient Voice Partners

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Chapter 3 describes the model for engaging with Patient Voice Partners including a detailed description of the different roles that PVPs undertake and how each of these contributes to the work of the health service from one-off participation activities to regular involvement roles. The chapter explains the support and governance arrangements for the different roles as well as any associated remuneration.

Table 1 outlines the Categories that PVPs will be stratified into for the purposes of this policy.

Table 1.

Role requirements	Category 1	Category 2	Category 3
Nature of activity	People choose to attend, respond or comment on open access engagement opportunities e.g. responding to online surveys/ Patient representative is invited to attend workshops/events/focus groups on a one-off basis	Patient representative is a member of regular working group meetings (policy and service design, commissioning reviews, task and finish programmes, etc.)	Patient representatives within committees where patient representatives are considered to be undertaking a substantive and active (participatory, not solely advisory) role with accountability and strategic decision-making capacity, or those making strategic recommendations around health service delivery or reform
Level of Input	Inform the work of the Department of Health or the HSE	Input to the Department of Health or the HSE committees and working groups	Input and shared decision making in Department of Health or HSE committees and priority programmes, or involved in making strategic recommendations around health service delivery or reform
Expenses Category	No financial contribution from the Department of Health or the HSE	Reasonable out of pocket expenses* covered by the Department of Health or the HSE	Reasonable out of pocket expenses covered by the Department of Health or the HSE and Involvement payment (As set out in Chapter 6 of the draft policy).
Time	None specified by the Department of Health or the HSE/	Regular meetings, duration of tenure of any committee should be no more than 4 years after which alternative	Regular meetings. Tenure should be no more than 4 consecutive years and not more than 8 years in a 20-year period. This category

commitment	Duration of the one-off activity/event – usually expected to be one day or less	membership should be sought to support a diversity of views and membership	may also include programmes that require intensive input for a short-term programme.
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\* In line with standard public service travel and subsistence rates.

\* **Question 3:** The PVP Categories are easy to understand and applicable to PVP work across the Health Service.

*at most 1 choice(s)*

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't know

\* **PVPs contribute to the work of a broad range of health and social care services, e.g., maternity, cardiac, cancer, disabilities etc.**

**Question 4:** Do you think experience of the specific service or health condition that a committee relates to is a necessary requirement for PVPs to work with that committee? (e.g., the PVP has personal experience of maternity services in relation to a committee considering the design or reform of maternity services).

*at most 1 choice(s)*

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't know

**Question 5:** Are there areas of the health sector that do not require PVPs to have specific knowledge of services or a specific health condition?

*550 character(s) maximum*

Yes. Not all opportunities will require knowledge of specific service/condition. Opportunities which relate to policy or strategy development or organisational change (culture, governance, impact) do not always require prior specific knowledge, but they do often require an understanding of how the health system works, of how patients currently interact with that system, and of the challenges patients encounter. The profile for each PVP role requires unique consideration. A diversity of voices is important (individuals/patient organisations).

\* **Chapter 3 of the draft policy also outlines the following benefits of engaging with PVPs:**

- Enhance the responsiveness and transparency of health systems.
- Ensures a person-centred focus in health system planning, design and decision-making.
- Actively involving the public from the outset represents a cultural shift to one of mutual benefit for the public, patients, and healthcare providers.

**Question 6:** Do you agree that these are benefits of engaging with PVPs?

*at most 1 choice(s)*

- Strongly Agree
- Agree

- Disagree
- Strongly Disagree
- Don't know

**Question 7:** Are there any other benefits of engaging with PVPs?

*550 character(s) maximum*

The benefits listed are not exhaustive (e.g. we need to detail the benefits to the patient as a result of their involvement). We need measurable benefits for HSCOs and patients, to allow PVP Committee to monitor (e.g. benefit: patients are systemically involved in the co-design of new programmes, measure: the number of new programmes co-designed with patients each year). Evidence to support the impact of patient involvement must be collected and publicly shared.

The language used in this section (& throughout) could be more 'lay' accessible.

## Section 4: Guidance for Health and Social Care Organisations on the Recruitment and Selection of PVPs.

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**Chapter 4 of the draft policy relates to guidance for health and social care organisations on the recruitment and selection of PVPs.**

Section 4.3.3 sets out the information to be covered in the PVP job specification and candidate information pack, including:

- Terms of reference for the group/committee
- Role of a patient representative
- Expectations for their participation
- Meeting times, frequency and duration
- Time commitment beyond meeting times
- What are the expected outcomes of their involvement
- Details of the training and support to be provided
- Expectations for communication among team members between meetings
- Reimbursement of expenses

**Question 8:** Is there anything else that should be communicated to PVPs in the job specification?

*550 character(s) maximum*

It should indicate that the PVP is a full and equal member. He/she/they can comment on all aspects of all items discussed, they are not restricted to sharing their lived experience, they are at the table to contribute fully to discussions.

The job spec should include a single point of contact within the HSCO who will answer queries and assist individuals who are less confident with the application process.

Ideally, the job spec should be co-created with existing patient advisors for readability, suitability and accessibility.

Table 2

Table 2 sets out the competencies that Category 3 PVPs may require when working on committees and working groups with a strategic focus.

	Competency	Description of Competency
1	Analysis and Decision Making	<ul style="list-style-type: none"> <li>• Ability to contribute to the Committee’s analysis of complex information and data, identification of key issues and development of evidence-based solutions to complex problems.</li> <li>• Ability to contribute to the Committee’s evaluation of potentially conflicting information and opinions and ultimately producing timely, objective and informed decisions in a transparent manner.</li> </ul>
2	Interpersonal and Communication Skills	<ul style="list-style-type: none"> <li>• Excellent interpersonal skills and communication.</li> </ul>
3	Commitment to Serve the Public	<ul style="list-style-type: none"> <li>• An understanding of and commitment to the principles of public service and an ability to demonstrate confidentiality, impartiality and objectivity.</li> </ul>
4	Teamworking	<ul style="list-style-type: none"> <li>• Ability to work collaboratively with a wide range of stakeholders including other patients and healthcare staff and management.</li> </ul>
5	Leadership	<ul style="list-style-type: none"> <li>• Ability to use their personal experience constructively. Desire to participate and contribute to meaningful change.</li> </ul>

**\* Question 9:** Do you agree with the competencies for Category 3 PVPs as set out in Table 2?

*at most 1 choice(s)*

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't know

**Question 9:** Are there any additional competencies that PVPs may require?

*550 character(s) maximum*

The 'analysis and decision making' and the 'commitment to serve the public' competencies may require further thought. Patients cannot - by definition of their role - provide 'objective' input into decision-making, they cannot also 'demonstrate impartiality and objectivity'.

Patients are there to share their 'lived experience', they should be subjective.

The goals/measures of progress set by the group/committee should be objective.

**Chapter 4 describes the relevant competencies that PVPs may require to work on committees. A balance needs to be struck between the requirement for PVPs to have the relevant competencies as well as lived experience to carry out the role. On the one hand, competencies such as leadership and analysis of problems are important to ensure PVPs have the skills to work on groups at a strategic level in the health sector. On the other hand, lived experience of interacting with the health services is important because PVPs will draw on this experience to contribute to the work of the group.**

**\* Question 10:** Which of the following do you think is most important for Category 3 PVPs working on committees and working groups with a strategic focus?

at most 1 choice(s)

- Lived experience of using or working with health and social care services
- Competencies outlined in Table 2.
- Don't know

**It is important to have a transparent recruitment process for Category 3 PVPs. Complaints, appeals and feedback mechanisms are recommended to increase the transparency of the process, and this is set out in Chapter 4 of the policy.**

**Question 11:** Are there any other steps that health and social care organisations could take to improve the transparency of this process?

550 character(s) maximum

Before selecting a PVP, a criteria outlining who will be ineligible to apply should be clearly communicated e. g. current health service employees.

After selecting, the full membership should be publicly communicated.

A declaration of interests should also be required as part of the application process to improve transparency. Declarations should be made public. A policy on managing conflict of interests should be developed.

Agendas and minutes of group/committee meetings should be public, by default.

## Section 5: Supports for PVPs

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**Chapter 6 of the policy outlines the supports and training relevant for PVPs working with health and social care organisations.**

**\* Question 12:** Do you agree with the induction, training and supports proposed to help PVPs integrate into the groups they work with?

at most 1 choice(s)

- Strongly Agree
- Agree

- Disagree
- Strongly Disagree
- Don't know

**Question 13:** Are there any other supports that would be helpful for PVPs?

*550 character(s) maximum*

A Patient Engagement Unit should be established within the DoH to work with charities who have extensive experience of PPI and materials to do PPI, to respond to the (self-identified) needs of PVPs.

A central approach will adopt best practice (informed by third sector) and avoid duplicating resources among HSCOs. Practically, PVPs cannot log into multiple "hubs".

The DoH should urgently engage with the DSP to identify a way for patients in receipt of disability, invalidity payments (and their carers) to continue their advocacy activities.

## Section 6: Diversity and Remuneration

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**Under this policy a payment will be offered to Category 3 PVPs to remunerate them for their time given up and increase the diversity of the pool of PVPs working with health and social care services.**

**Question 14:** Are there any other ways to increase the diversity of the pool of PVPs?

*550 character(s) maximum*

If diversity is a goal, charities representing patient communities and special interest groups must be extensively re-consulted.

A payment for category 3 PVPs is welcome, but the policy (as is) is extremely unlikely to increase the diversity of PVPs. The category 3 'job application' approach will challenge those with communication or literacy issues and those unfamiliar with the job market.

Time given by category 2 PVPs should be treated equal to category 3 PVPs.

Persons in receipt of welfare must be facilitated into category 3 roles.

## Section 7: Implementation, Monitoring and Review

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**Chapter 8 of the daft policy outlines the plan for implementation, monitoring and review of the policy.**

The implementation of the policy will be monitored by the PVP Approval Committee through the following mechanisms:

- Requesting annual reports from organisations on the number of approved Category 3 committees under their remit, the number of individual Category 3 PVPs under their remit, and on their implementation of the PVP policy.

- On an ongoing basis, annual reports should contain feedback from a sample of Category 3 PVPs and Committee Chairs on the implementation of the policy.
- It is intended that after the policy has been in place 12 months a detailed consultation with Category 3 PVPs and Committee Chairs (or working group chairs etc as appropriate) will be undertaken to assess the progress of the implementation of the policy.
- The Department will review the Patient Voice Partner Policy periodically, the first review to take place no longer than 3 years from date of commencement of this policy.

\* **Question 15:** Do you think the mechanisms outlined for monitoring the implementation of the policy will help to embed the policy within the public health and social care sector?

*at most 1 choice(s)*

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't know

**A communications programme will be rolled out to create awareness of the policy once it is published.**

**Question 16:** What information needs to be included in the Communication Programme to create awareness of this policy?

*550 character(s) maximum*

Taken in isolation the benefits will be very difficult to communicate to both the patient community and to the HSCOs. More collective cross-sectoral engagement is needed before the text is finalised.

The policy needs to be situated in a broader policy framework, ideally a vision or a strategy for PPI which details who must do involvement, for what issues, why, when and how.

Without this, PPI remains voluntary for orgs and this policy is 'light touch' encouragement at best, an 'administratively cumbersome' deterrant at worst.

**Question 17:** Are there any other ways to enhance the implementation of this policy?

*550 character(s) maximum*

We think the policy may be difficult to progress in its current format, and we encourage the NPSO to collectively engage patients in drafting a second iteration.

The categorisation needs to be much clearer, and consider two paid categories: 3A 'mid level operational roles with an Eol style process' & 3B 'high level advisor roles with a job application style process'.

A job application process for each HSE co-designed strategy/programme/project is onerous, it may result in less patients coming forward & less HSC professionals doing PPI.

\* **Question 18:** The appendices and templates are helpful and will assist with the implementation of the policy.

*at most 1 choice(s)*

- Strongly Agree
- Agree
- Disagree
- Strongly Disagree
- Don't know

**Question 19:** Are there any other resources or templates that would assist organisations with the implementation of the policy?

*550 character(s) maximum*

A broader policy framework around PPI should complement the final policy. This framework should require certain parts of the health system to do PPI, to make annual plans and allocated budgets to PPI, and to make progress against KPIs/measurable objectives. This framework should be co-designed with patients, and have patient representatives on working groups.

Other useful tools would include:

- a rolling database of opportunities which involve patients
- a checklist for recruiting patients
- a patient scorecard to share their experience

## Section 8: Additional Information

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Do you have any further comments on any aspect of the policy?

*1500 character(s) maximum*

We acknowledge the good intention behind the policy, but we are not confident that the policy (in its current format) will successfully deliver on this intention.

We think the whole patient community (organisations and individuals) need to urgently come together with the DoH and with the HSCOs to discuss and agree a workable, patient-led way forward. For many, the current draft has likely raised more questions than it has solved, and if implemented, it could potentially push both PPI partners and PPI practitioners out of the PPI space on the grounds that it is administrative, unclear, or even unfair.

In consulting our own members, a number of concerns were put forward - not least, the language used (attempt to redefine PPI as PVP), the process adopted (hand-picking people to consult rather than discussing in open forum), the categorisation proposed (treating PVP time unequally), the administration introduced (formalising what should be an informal space).

The policy requires a more person-centered approach. The time people give to share their lived experience should be valued, remunerated (without jeopardising disability/carers payments), and equally treated.

The policy may revisit the extensive work already ongoing in this space nationally (charity, universities, HSE, HIQA) and internationally (NIHR).

Lived experience should be equally weighted at 100% (appendix 3).

The terms 'PVP' or 'parent org' should not be used.

We look forward to more engagement.

## **Background Documents**

[20230117 Draft PVP Policy for consultation CLEAN.pdf](#)

[20231701 PVP Policy Executive Summary.pdf](#)

## **Contact**

[Contact Form](#)