



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

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

Section 1: Your Details

* **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

We are a national network for Public Patient Involvement (PPI) in research in Ireland, 7 Universities, 10 national partners, >50 local partners.

Section 2: Guiding Principles

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 type="radio"/>	<input type="radio"/>	<input checked="" 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 checked="" type="radio"/>	<input type="radio"/>	<input 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 type="radio"/>	<input checked="" type="radio"/>
* Good Governance and Accountability	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Section 3: Model for Engagement with Patient Voice Partners

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. There are times/topics where direct experience is not essential, dependent on the working group focus. There are topics where an objective, independent, public voice, drawing on overall life and work experience is important. Experience of organisational change & strategy development in other sectors may be key experiences.

Staff in patient organisations & charities, who may not have direct lived experience, have an in-depth and broad knowledge of specific population and can also bring a valuable perspective to the table.

* **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

Other benefits include potential that:

- Services are more tailored to the needs of people they are designed to serve
- KPIs used to determine the success of health system reflect what matters to service users
- Trust in the health system is enhanced
- Better coordination across the various services occurs, as input from public/patients/ carers means each service will reflect the many different services relevant to a person's needs: service users are ideally positioned to understand intersectionality based on their lived experience

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

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

Section 1.2 Scope is very clear: "PVPs are not employees"

We propose replacing the language of employment with the language of partnership & provide training to DoH staff:

- why language matters
- what meaningful involvement means
- issues related to power dynamics

Chap 4 does not demonstrate an understanding of these issues, which will undermine stakeholder credibility.

In addition to a focus on partnership, to achieve diversity, we recommend with a combination of targeted & open EOI calls using different media (video, audio)

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">• 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.• 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.
2	Interpersonal and Communication Skills	<ul style="list-style-type: none">• Excellent interpersonal skills and communication.
3	Commitment to Serve the Public	<ul style="list-style-type: none">• An understanding of and commitment to the principles of public service and an ability to demonstrate confidentiality, impartiality and objectivity.
4	Teamworking	<ul style="list-style-type: none">• Ability to work collaboratively with a wide range of stakeholders including other patients and healthcare staff and management.
5	Leadership	<ul style="list-style-type: none">• Ability to use their personal experience constructively. Desire to participate and contribute to meaningful change.

* **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

We agree that competencies 3, 4, & 5 are important. We disagree that no. 2 is essential, the lived experience of communication challenges and of alternative interpersonal skills may be essential for some topics.

Other points:

- Consider the need to adapt the work culture to facilitate PVPs in analysis & decision making.
- Add active listening as a competency.
- The personal attributes listed are very important, place much more emphasis on these.
- (App 3) Rate lived experience 100 marks
- An employment-type reference not appropriate

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

There is a perception (valid or not) of a lack of transparency in development of the policy, impacting credibility in HSCOs roll-out.

This public consultation is a welcome step. To revise the policy, DoH can build on this to generate a ground swell of support from key stakeholders by working closely with stakeholders currently active in PPI in Universities, patient organisations & charities, community sector.

We strongly recommend that a person with lived experience of contributing to governance bodies sits on the assessment panel

Section 5: Supports for PVPs

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

We welcome supports proposed, adding:

- Make information materials available in different formats (video, easy read)
- Take personalised approach to supports
- Provide individualised technical support if needed
- Use existing guides eg on ppinetwork.ie

There should be greater emphasise the role of the Lead Person. Meaningful inclusion of the patient voice depends on the human relationship with the Lead Person, who must have strong people skills, & be properly trained & resourced.

Provide training to all working group members also

Section 6: Diversity and Remuneration

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

We note with disappointment there is no question specifically around remuneration. We welcome the question re increasing the diversity of those involved.

It is absolutely essential that the DoH addresses the status of people on all social welfare benefits, by direct interaction with DSW. Key to diversity is to ensure that involvement is not limited to those who can financially afford to be involved.

Section 7.11 & Supports, Chap 6 are strong, but there is insufficient evidence of these sections informing the rest of the policy.

Section 7: Implementation, Monitoring and Review

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

This draft policy is a good start but will benefit from increased transparent stakeholder input.

The DoH now has opportunity to generate a ground-swell of support from key stakeholders, by working with them to finalise the policy. With Comms support from stakeholoders, a Comms Plan can use many channels & media, reach a significantly broader audience, have greater impact & generate a diverse pool of people to contribute to important working groups.

Key stakeholders perhaps: PPI Ignite Network, active PPI contributors, HRCI, IPPOSI

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

550 character(s) maximum

The policy is a good start but we think it requires significant redrafting.

We propose DoH builds key relationships now. Learn from the extensive national expertise in this area in the research community, charities & patient organisations, in other HSCOs including Tusla Child and Family & HSE R&D, and among the general public, including patients who are active already in shaping services.

Continue to use these relationships to communicate about the policy, to advertise opportunities as they arise, to reflect & revise the policy.

*** 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

Very helpful resources are available, developed in Ireland for use in Ireland by the research community and by public & patients & patient organisations. Check out www.ppinetwork.ie for resources & signposts to resources.

We recommend that the DoH releases a revised policy as "Draft for consultation and use" for a 6 month trial period, creating awareness, building support, seeking feedback and learning from the trial to revise the policy.

Section 8: Additional Information

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

1500 character(s) maximum

We welcome this draft policy as an important step forward recognising the importance of involving & valuing public & patient perspective to shape health services. We urge DoH to learn from extensive national expertise.

Key feedback:

- 1) Use PPI (public & patient involvement) terminology currently used, PVP is confusing
- 2) Define the legislative & policy context underpinning policy
- 3) Redefine the proposed categories of contribution
- 4) Ensure ongoing training of DoH staff working with PPI contributors
- 5) Resolve barriers to involvement of recipients of all social welfare benefits

6) Replace the language of employment with the language of partnership

7) Engage with diverse & marginalised groups to find diverse voices; create an enabling environment to support diverse voices

8) Broaden thinking on supports required to enable contributions; focus on educating DoH staff & all working group members

9) Be consistent re the reach of this policy, refer consistently to social care, include involvement in DoH research

Re Pt 3 above:

PVP Category 2 purpose is not clear, appears very tokenistic, Cat 2 examples (App 3) are Cat 1. We recommend a Cat 2 (no Cat 3) who are:

- Equal & involved in decisions
- Adequately supported
- Paid time & expenses
- Identified by combination of targeted and open EOI calls

Re Pt 5 above:

DoH must work with DSW to ensure that a person on any social welfare benefits can be involved, essential required voices.

Background Documents

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

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

Contact

[Contact Form](#)