

IPPOSI

Our response to the Department of Health consultation on the draft Patient Voices Partner (PVP) policy

PUBLIC and **PATIENT** involvement requires **PEOPLE** with a **PASSION** and a **PURPOSE** with a **PLACE** to meet and a **PAYMENT** for their involvement. It requires a willingness to pursue **POLICY CHANGE** with **PERSEVERANCE** and **PERSISTENCE** while mindful of the need for **PRACTICAL APPLICATION** and in **PARTNERSHIP** with the health system.

IPPOSI's response to this consultation is informed by a number of interactions with our patient members, as well as discussion with members of the HSE National Patients' Forum (IPPOSI is the co-chair).

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What did patients think of the policy?

Most of our members were happy to see some steps being taken at the national level to acknowledge the important role of public and patient involvement (PPI) in building a better health sector and to present some guidelines for approaches to PPI. However, they were disheartened to see that the policy did not sit within a broader national framework (who should be doing PPI, when, and for what) and that the policy did not appear to have been meaningfully co-designed with patients. Many of our members therefore had mixed reactions to the policy, with frustration, confusion, and disappointment frequently being expressed.

LANGUAGE

The language used in the policy, even within the title, immediately put patients on alert. What is a PVP or a 'patient voice partner'? Why are we talking about 'patient engagement' and moving away from the community-standard term in Ireland of 'public and patient involvement' or 'PPI'? Why are we downgrading the role of the patient to 'engagement', when 'involvement' and 'partnership' which sit further along the participation spectrum are commonly accepted as the preferred destination? In short, why is patient involvement (as patients see it) being redefined...without them?

The language is further complicated by the draft policy being unable to draw upon language agreed (with patients) as part of a national policy framework around PPI (co-designed with patients). There have been no recent national conversations at Departmental level around how PPI can be mainstreamed across the health sector, in particular across the HSE, and around what policies are needed to progress this as a measurable sector strategic goal.

The language used does not reflect a rights-based approach to participation, and there does not appear to be an acknowledgement of the rights of individuals to participate in decisions about their own care or in the design of the health sector more broadly. This is perhaps again due to the lack of a national policy framework around PPI which sets out the vision for involvement across the Irish health sector.

Other terms used throughout the policy are inaccessible and reflect 'public sector-speak', such as 'parent organisation'.

“The PPI landscape is constantly changing and we need to ensure that this policy is not the be-all and end-all of PPI. My fear is that this document will be seen as the bible rather than a guide.”

IPPOSI patient organisation representative and carer

PROCESS

What was clear from the conversations we had with patients is that there is no lack of willingness among the patient community to get involved with this topic – they believe it is important and they believe it should be shaped by them.

However, the process for arriving at this draft policy is largely unclear to patients.

Firstly, they are curious about the content – why was this policy the starting point, what does it build upon, how does it work if we do not have a shared vision for advancing PPI across the health sector, how will those who should be doing PPI (and who are often not doing PPI) be mandated to change their approach?

Secondly, they would like to know about the authors – what patient representatives were involved in the policy development working group, who was consulted during the policy drafting process (and how), was it meaningful, was it representative, how was their feedback incorporated?

One member questioned what evidence had been gathered to inform the approach taken in the policy. They referred to the work already completed in this space by a working group comprising of representatives from the five nations.

Another member underlined that the process used to prepare policy around PPI must embrace the principles of PPI. It must be a patient-led process, and it must be a diverse community of patients who are invited to participate in the policy development process. There are existing inequities in who has the power to influence, these should be addressed (rather than exacerbated) by the process.

"This document is the beginning, but I would love to see it embellished with more real life patient experience of what it is that we do as partners, and the implications of this work for us!"

IPPOSI patient organisation member and individual patient

CATEGORISATION

The proposed categorisation of patient partners created confusion, and members struggled to work out what roles were considered a category 2 partner or a category 3 partner.

In principle, many members proposed that all partners, giving their time (beyond a certain minimal level) should be recognised, respected and remunerated. In practice, it was agreed that the categorisation should be carefully re-worked with patients, especially with those who already have extensive experience of involvement roles across the health sector and who can assess what time and effort they entail.

There was a strong feeling among members that all co-design, co-education, and co-evaluation activities should be remunerated, and therefore categorised accordingly.

PATIENT ORGANISATIONS

Several members highlighted the policy's failure to adequately consider the role of representatives from patient organisations. Firstly, the assumption that patient organisation staff and individual patient advocates are two distinct groups was challenged. Many patient organisation staff are patients themselves.

Secondly, the patient organisation staff member and the individual patient advocate can both contribute as patient partners – focusing (unduly or disproportionately) on individual patient advocates could be perceived as an attempt to isolate or divide the patient community. Patient organisation staff represent a broad community of patients who all have lived experience and trust in their patient organisation staff members to accurately represent their collective interests.

For example...

Would supporting the HSE to co-design a new national clinical programme, or a new model of care, or a new roadmap around engagement, or a new RHA PPI strategy be considered category 2 or 3?

If it is considered category 3, is the HSE likely to incorporate patient partners into its work given the administrative and financial burden created by this policy, and given the absence of any requirement (from a national PPI policy) to do so?

If it is not considered category 3, category 2 becomes a 'catch-all' for co-design work, which is in essence the 'bread and butter' of PPI (and arguably the space where PPI has real added value), so why is it not being remunerated?

EQUALITY

The policy may result in potential patient partners having inequitable access to PPI roles. Many members expressed concerns that individuals with chronic illnesses or disabilities would encounter additional (if not, insurmountable) barriers to their participation as partners in category 3 roles.

Currently, the policy places the burden on the individual to understand whether there are any implications for their tax or social welfare circumstances. As a result of engagement and coordination between the Department of Health and the Department of Social Protection on this issue, this policy should be revised to provide a clarification of the situation for individuals. Patients should be able to participate fully with the peace of mind of knowing that their income (upon which they rely upon to live and manage their conditions) is not jeopardised. Even the small reference to welfare payments in the draft policy has caused several of our experienced patient partners who are in receipt of social welfare payments to exit the PPI space for fear of being (wrongly) accused of being in receipt of additional 'income'.

“I want to be able to do advocacy work, without the feeling that someone is going to come along and say if you are fit enough to do ABC, you are fit enough to work.”

Individual patient advocate

Additionally, the ‘job application’ approach taken to category 3 partner roles, will make it challenging for people with literacy or communication issues, for those with health conditions which affect their cognitive attention, to apply. To express interest for one of these roles, many individuals are likely to need assistance, and without this one-to-one mentoring, they may opt to automatically de-select themselves. New entrants to the PPI space may also be potentially intimidated by the approach.

From a patient perspective, the policy may result in shrinking, rather than multiplying, the number of voices coming forward for category 3 roles.

On a related note, the policy may also cause health sector ‘parent organisations (or directorates and teams within these organisations) who are considering dipping their toe in the PPI pool to reconsider doing so, in view of the administrative and financial burden created by establishing a category 3 role.

From a provider perspective, the policy may stifle, rather than nurture, the number of PPI roles being created.

“It can never be those who can just afford to do it – your lived experience is worth its weight in gold in terms of the contribution towards policy formation, and helping those at departmental and government level, helping people to understand what needs to be done and how it can be done.”

Individual patient advocate

COMPETENCY

The competencies that patient partners are asked to demonstrate do not fully consider the reality of the situation.

- Patients cannot - by definition of their experience and their role - provide 'objective' input into decision-making, they cannot also 'demonstrate impartiality and objectivity' in line with the principles of public service.
- Patients should not (on their own) be asked to do an 'analysis of complex information', rather patients should be supported to ask questions about complex information and the health and social care organisations involving patients should be minded to facilitate a sharing of all relevant information so that patient partners have access to the same information as everyone else around the decision-making table.

The lived experience of patient partners must be weighted equal to the other competencies listed. The marking scheme template in appendix 3 must be amended to reflect this equal weighting, by raising lived experience from 50marks available to 100marks.

Emphasis should also be placed on ensuring that other partners involved in activities falling under the policy (from the health and social care side) can demonstrate competencies in the area of patient partnership, including but not restricted to - an understanding of the different types of patient partners, an understanding of how to assess the needs of individual partners, an understanding of the equal role of patient partners, and understanding of the supported needed to ensure meaningful, sustained and equal participation by patient partners etc.

What would patients like to see next?

Sector-wide consultation

Patient members were unanimous in calling for a sector-wide conversation about PPI to take place in 2023 between policy makers, patients, and health/social care organisations. They want to be able to meet together to air their concerns and suggestions and to plan for a way forward with policy makers. They suggested that this should be an annual dialogue in an effort to give life to the commitment to involve patients and service users in matters relating to the planning, provision and evaluation of health services.

Cross-departmental coordination

In preparation for any future PPI policy around remuneration, members called for the Department of Health (DoH) to establish a line of communication with the Department of Social Protection (DSP) around the treatment of 'payments' made to patient partners. It was suggested that the DoH should work with the DSP to have 'payments' to patient partners for involvement activities treated as 'disregarded income' for individual patients who may be in receipt of invalidity, disability or carer pensions. There needs to be formal recognition made of the 'involved patient' status.

Transparency

Members called for the details of the engagement completed to draft the policy to be made public and included in the text of the draft. Members also called for the steps in progressing towards a final policy document to be clearly defined, and for opportunities to be created for cross-sector conversation. Members underlined the importance of involving patients in the implementation and evaluation, as well as in the design, of the policy.

“The remuneration issue is fundamental, but it cannot just be seen in isolation, there are other aspects to involvement that need to be considered. And what we have learnt from engaging internationally around this issue is that when the model for involvement is not in place you cannot meaningfully and equally implement such a policy”

Derick Michell, IPPOSI CEO

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