

Care Alliance Ireland Submission to the Public Consultation on the draft Patient Voice Partner Policy

Department of Health

April 2023

Additional Submission

Introduction

In March 2023, Care Alliance Ireland submitted to the Patient Voice Partner Policy consultation, via the provided survey link.

We were initially very pleased to see consideration being given by the Department of Health to the topic of remuneration and formalisation of the patient voice and participation in policy development.

However, as an organisation we have significant concerns regarding elements of the proposed policy which we were unable to comment on in the existing consultation process. This was due to the closed and inaccessible nature of the survey as a methodology for consultation (which we discuss later in this document), along with the leading questions asked in the consultation survey itself.

This additional submission is being sent to the consultation email address, being made available on our website (www.carealliance.ie) and will be shared widely amongst our membership and colleagues across the sector.

For some background, Care Alliance Ireland have been involved in the area of patient involvement for many years; most prominently as a partner with the University of Limerick in the PPI Ignite project, funded by the Health Research Board, continuously since 2018. Our commitment to inclusive research and involving the voices of family carers and our member organisations in policy is demonstrated in the various projects we have been involved in which have centred the experience and views of family carers. This includes a guidebook, developed as part of the UL PPI Ignite Project, for small community organisations new to PPI research¹. We are also active members of the HSE National Patient Forum, advocating for the meaningful inclusion and involvement of patients, carers, and

¹ https://www.carealliance.ie/userfiles/files/PPI_Guide_NPF.pdf

members of the public in policy matters that affect them on a daily basis as key users of health and social care services across Ireland.

In this document, we have picked out three core issues we feel need to be highlighted in much greater detail than the submission process allowed. Given the critical importance of involving patient and organisations voices in this policy, we are confident that the Department will take note of our concerns, and those of other organisations who are making similar additional submissions.

Consultation Process

Care Alliance Ireland feels strongly that the consultation process for this draft policy was not only insufficient, but also inappropriate given the topic. It is not clear who was involved in the drafting of the policy, nor is it clear what organisations or individuals were consulted initially for their expertise on the matter. The draft document makes no reference to consulted bodies involved in developing the policy, which leads us to the conclusion that either no groups were involved or consulted, or that any feedback given at that initial stage was not included or considered for this draft policy. If this conclusion is incorrect, we welcome any clarifications.

Article 4.3 of the United Nations Convention of the Rights of People with Disabilities clearly states that countries which sign up to the UNCRPD are obliged to actively engage and consult with people with lived experience of disabilities when developing legislation and policy. As such, representative organisations working in the area of disability should have been actively consulted at the drafting stage of this policy. We have been unable to identify any such disability organisation who was consulted.

The draft policy references a number of patient involvement policies in other jurisdictions yet in our view, fundamentally misunderstands or contradicts many of their key tenets by not fully involving and engaging with patients and representative bodies in the drafting of this initial policy. We encourage the Department to take the feedback on this draft (as we know from our discussions with colleagues across the sector that we are not alone in our disappointment in this initial consultation and draft policy), and work closely with relevant organisations and patient involvement partners, to co-author a second, more appropriate policy.



In addition, we are taking this opportunity to raise the issue of the methodology used in this particular consultation on the draft policy. In this instance there is only one route of consultation for organisations and individuals, namely through an online survey. This survey is made up of leading questions and minimal opportunities to discuss the nuances of the issue, and as a result it appears that the Department is not fully committed to engagement and involvement with patients and patient representative organisations like ours. This is why this second more in-depth submission was necessary.

Understanding the role of patient and carer voices

Without going into unnecessary detail, the clear and central contribution that involving patients in policy and research brings is that they are able to share their first-hand experience of the reality on the ground in accessing and utilising health and social care services. Many times, we have heard from family carers and others that even though a policy is in place, with great intentions, it is not being followed at implementation level. Without hearing these voices, and listening to the actual lived experience of those accessing our health and social care services, it is not possible for professionals, and policy makers to be able to fully understand the impact of their decisions/practices.

Therefore, we particularly take issue with the inclusion of 'impartiality and objectivity' within the relevant key competencies for patient partners involved in Category 3 activities. We agree wholeheartedly with the comments made by IPPOSI in their Response to the Department of Health Consultation on the Draft Patient Voices Partner (PVP) Policy (<https://t.co/mgRFEaOiw>) that "*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*". By requiring impartiality and objectivity in patients, there appears to be a lack of desire to hear alternate viewpoints from a first-hand account. Patients who have both positive and negative experiences should be able to feel confident in disclosing those without fear of being labelled 'difficult' or having a lack of impartiality. That is not to say a level of understanding and willingness to see other sides is not necessary for patients involved in this work. However if the inclusion of these 'key competencies' within this policy is to avoid uncomfortable discussions around the table, then that is wholly inappropriate.

To misunderstand this is to fundamentally misunderstand the core principals of involvement, and that such an important policy, which has at its core a remit to ensure proper acknowledgment and involvement of patient partners, does so is very concerning.

Issues with Remuneration

We are of course, very pleased to see the issue of adequate remuneration of patients involved in this work being considered by the Department. However, it is the proposed solutions to this concern that makes it most obvious that patients and patient representative organisations were either not consulted at all, or their concerns about this issue dismissed.

Many of the most regular and long-term users of our health and social care services are those who, for whatever reason, find themselves in receipt of social welfare payments. This includes, quite obviously, those in receipt of disability or illness payments, alongside those likely to be in receipt of Carers Allowance or Benefit. Many of these individuals are amongst the most at-risk of poverty in the State as their health difficulties, and those of the people they care for, require that they forego regular employment, and are therefore dependant on welfare payments.

This policy proposes that not only would any payments for involvement in Category 3 groups be liable for tax, the clear assumption here is that they will also be counted towards means for their eligibility to continue to receive their welfare payments. The advice, within this proposed policy, that each individual consult professionals to ascertain their tax liability, etc., before applying to take part in such groups, is further exclusionary. These two issues combine to make it likely that those most impacted by health and social care policy in this country will exclude themselves from taking part in these initiatives, on the possibility that their payments and eligibility for supports may be lost.

This is likely to ensure that only those who can afford to lose their welfare payments and supports, or those who are arguably less economically and socially disadvantaged will make up the bulk of patients involving themselves. This will impact the diversity of these panels, negatively affecting the true impact that patients can have on policy and decision making. Hearing the effects of policy and service implementation decisions from only those who are more economically advantaged will not lead to the kind of positive impact from patient involvement that is necessary.

Once again we support our colleagues in IPOSSI (<https://t.co/mgRFEaOiw>) who suggest that the Department of Health work with the Department of Social Protection to find a solution to this issue. Ensuring that income from participation in such patient involvement work is disregarded is vital to ensure participation from as diverse a representation of the users of our national health and social care services.

Conclusion

As discussed, Care Alliance Ireland is very disappointed by the process to date of consultation and drafting of this proposed policy. We hope that this is not an indication of a lack of respect for the vibrant patient and public involvement (PPI) community that has been growing in Ireland for the past number of years, funded in significant part by the Departments own Health Research Board.

We trust that this submission, and those of other organisations and individuals within this space, will be taken in the spirit of a genuine desire for significant cooperation between ourselves and the Department.

We look forward to making further comments on a redrafted policy in due course.

About Us

Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life for family carers. We work with organisations to provide better information and supports to family carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We deliver a number of carer specific projects; namely an Online Family Carer Support Project and a Back to Work Project.

There are in the region of 500,000 family carers in the Republic of Ireland. Family carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions. We work with our 90+ member organisations and other agencies to support them in their work with family carers.

Our legitimacy derives in part from our membership base which includes a wide range of organisations currently providing services to Ireland's family carers. Our

T +353 1 874 7776

E info@carealliance.ie
W www.carealliance.ie



@CareAllianceIrl

A Coleraine House
Coleraine Street
Dublin 7, Ireland
DO7 E8X7

Registered Company No
461315
Charity Registration No
20048303
CHY No 14644



membership is comprised of both large and small, regional and national organisations.

Submitted by

Zoe Hughes

Senior Policy & Research Officer

zoe@carealliance.ie

0868834942

