PCC
PATIENT & CLIENT COUNCIL

PPI Secretary
Public Health Agency
Linenhall Street Unit
12-22 Linenhall Street
Belfast, BT2 8BS
Northern Ireland

19 December 2025

Dear Sir/Madam

RE: Consultation on the Public Health Agency's Partnership and Engagement Strategy

PCC welcome the opportunity to respond to this consultation on the PHA Partnership and Engagement Strategy which seeks to create a joined-up team of staff from both the Patient Client Experience and the Regional Personal and Public Involvement Programme programmes, integrating their work.

We acknowledge that the PHA is renewing its commitment to working in partnership with others, in the context of the duties laid out in the HSC Framework, through two key areas: listening to people’s experiences and involving them in shaping services. It is vital that these are reflected adequately and effectively in the implementation and delivery of this Strategy.

Vision and Aim of the Partnership and Engagement Strategy

There is much within the vision and priorities of the Strategy to be welcomed and it would be important to understand more about the resourcing and implementation plans for delivering on a number of the priorities.
In responding to this consultation, PCC are considering it within the context of a growing recognition of the need to more effectively engage the public, to ensure their voice is adequately heard and appropriately listened to in the following areas: Service change, Design and Commissioning and Delivery; Quality and safety; and Clinical and Social Care Governance.

At PCC we believe this is underpinned by the need to change the nature of the relationship between the public and services, from one of recipients to active partnership. As PCC has previously outlined, many of the terms such as public engagement, public and patient involvement, patient experience and co-production are well-known and widely used but arguably are not universally understood or applied across the health and social care system. This results in confusion for the public and others and constrains the potential benefits for all.

In establishing a more strategic approach to public participation, PCC believe there is a need to examine the roles of Personal and Public Involvement, Engagement and Patient experience, advocacy and complaints and how these aspects of involving the public in the HSC fit together. In this regard the intent outlined by PHA in this strategy is a step in the right direction.

Moving to People as Partners

The principle of harnessing the energy and agency of citizens as assets in resetting and reshaping public services, and health and care for the future, has been gaining traction for some time. As highlighted in PCC's People to Partners Report and throughout the roundtable discussion we hosted, a number of recent 'think pieces'[1]

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[1] Russell, C., (2025) Exploring the potential of community-centred public services [online]. New Local. Levin, M., Curtis, P., Castell, S., and Kapetanovic, H. (2024) Citizens' White Paper [online].

from the King’s Fund, New Local, Involve and Demos (amongst others), set out the benefit to citizens, civil society and public services from adopting a new relationship with the public.

This has included:

- Improved public agency and civic engagement
- Policies and services that are effective in meeting public need
- Increased trust in public institutions and representative democracy

The report, and its recommendations, was strongly endorsed by leaders at the roundtable, recognising the approach as a key opportunity to reset the relationship between the public and HSC services by embedding citizens as active partners in decision making, design and delivery. This work reflects the case that the PCC has been making for a more strategic approach to public participation across HSC, and for building a new relationship with the public, through which healthcare and wider public services ‘does with’ (and not ‘to’) to collectively tackle the challenges we face. The PHA’s Partnership and Engagement Strategy presents an opportunity to embrace and support the ambition set out in People to Partners.

The Current landscape within HSC

Whilst the Partnership and Engagement Strategy is welcome, structural and operational issues remain in how PPI and engagement are delivered in Northern Ireland, and PCC consider that not addressing these will continue to impact upon the approach outlined. The Strategy does not address these broader issues and how they will impact. We acknowledge the reference in the Strategy to the review of a ‘Strategic approach to public engagement’ being led by DoH and consider that the out-working of this review needs to be taken into careful consideration in finalising and implementing this Strategy.

Demos. Curtis, P. (2025) Upgrading Democracy: A new deal to repair the broken relationship between citizen and state [online]. Demos.

In our response to Health and Social Care NI (HSCNI) Involvement and Consultation Scheme[2], PCC outlined a number of issues with the current HSC landscape for PPI and Engagement, which we consider remain relevant to this consultation.

The HSC Framework Document (2011)[3] outline the role of different organisations in relation to Public and Personal Involvement (PPI). Since this time, a number of Departmental Circulars have built on the position outlined in the legislation and HSC Framework in developing the roles and responsibilities of different organisations. Whilst the fundamentals of the requirements are fairly consistent, the PCC considers that a general review of existing PPI policies, procedures and practices, and how they interact with existing patient experience programmes, is necessary as part of developing a more strategic approach to public participation.

As well as bringing greater clarity, this would enable policy to reflect how the expectations of the public on participation, and the needs of the HSC system to engage the public as assets, have evolved over the past decade; to ensure consistency of language and expectations; and to ensure that guidance and circulars fully align with statutory responsibilities. Ultimately this is about cohesively improving the overall environment in which all HSC bodies operate, and in how the public receive, engage with, and experience services.

The role of the PCC

Whilst we welcome the reference within the document to ‘important and developing relations with the work of the Patient Client Council’ and note the statement ‘that the work of the PCC compliments the PHA focus on experience and involvement within HSC organisations’, in the absence of a more structural review, the PCC does not consider that the Strategy reflects the role of the PCC as laid out in its legislation and within the HSC Framework document.

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[2] PCC (2024) pcc-response-consultation-schemes-251124.pdf

[3] DHSSPS (2011) DHSSPS Framework Document – September 2011, Department of Health

The PCC is a statutory body established in 2009 to provide a powerful independent voice for patients, clients, and carers, and communities on health and social care issues within Northern Ireland through:

- Representing the interests of the public;
- Promoting the involvement of the public;
- Assisting people making, or intending to make, a complaint;
- Promoting the provision by HSC bodies of advice and information to the public about the design, commissioning and delivery of services; and
- Undertaking research into the best methods and practices for consulting and engaging the public.

HSC bodies have a duty to co-operate with the PCC in carrying out their functions, as set out in Article 19 of the Health and Social Care (Reform) Act (Northern Ireland) 2009 (the Act). The main legislation on Public and Personal Involvement (PPI) is provided in Articles 19[4] and 20[5] of the Act. Article 19 places two main types of obligations on health bodies.[6]

The first type, outlined in Article 19(1)(a)-(c) relates to the content of patient/service user engagement and can be summarised as:

- the promulgation of information to the public:
- obtaining information about patients' needs;
- Encouraging and assisting patients and service users to avail of care in an appropriate (effective and efficient) manner; and
- To maintain and improve their own health and social well-being.

The second relates to the baseline steps a body should take to undertake this engagement, namely the preparation of a consultation scheme, which must be submitted to the Department. The Department can seek revisions to any scheme and may, after consulting with the PCC, approve a consultation scheme. Article 20 outlines how a consultation scheme should be developed and implemented. This

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[4] https://www.legislation.gov.uk/nia/2009/1/section/19
[5] https://www.legislation.gov.uk/nia/2009/1/section/20
[6] Health bodies for the purposes of PPI are defined in Article 17(8) of the 2009 Act: https://www.legislation.gov.uk/nia/2009/1/section/17

includes making it clear how the HSC body will ensure that the following are directly, or through representatives, involved and consulted:

- Patient and Client Council
- persons to whom the care is provided; and
- carers

with regards to:

- planning and provision of care
- the development and consideration of proposals for changes in the way that care is provided, and
- decisions to be made by that body affecting the provision of that care.

Given the requirements set out in Articles 19 and 20, the PCC, does not consider that the Strategy adequately reflects the statutory role of the Patient Client Council.

Governance and Assurance, Reporting and Monitoring

The HSC Reform Act and the HSC Framework 2011, clearly set out an independent assurance role for the PCC and the RQIA in relation to PPI and consultation schemes. The HSC Framework[7] states the following:

> *The PCC also has an important challenge role for those HSC bodies prescribed in the Reform Act in respect of PPI, and will accordingly be expected to comment upon and scrutinise the actions and decisions of these bodies as they relate to PPI. In addition, it will provide independent assurance to the Department on the effectiveness of PPI Policy.* [Paragraph 5.10]

A separate section of the HSC Framework, relating to independent assurance states of the PCC and the RQIA that:

> *Both of these organisations provide important independent assurance to the wider public about the quality, efficacy and accessibility of health and social*

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[7] DHSSPS (2011) DHSSPS Framework Document – September 2011, Department of Health

> *care services and the extent to which they are focused on user needs.*
> [Paragraph 6.42]

A key part of the structures put in place to facilitate this independent assurance role, is the fact that under the Act, the PCC and RQIA are not subject to PPI requirements or the need to produce a consultation scheme. This maintains the independence in the assurance role and removes the (actual or perceived) conflict of interest which exists whereby the HSC bodies subject to PPI requirements, and the consultation schemes they produce, are responsible for developing the schemes.

The Strategy itself reflects some of this incongruity, when it speaks to actions the PHA will take to embed experience and involvement approaches within its organisation to fulfil its duties, whilst also seeking to lead on regional best practice, and the monitoring, reporting governance and mechanisms of experience and involvement in the HSC.

PCC retains the view that HSC organisations subject to PPI should articulate how independent assurance has been provided for, by way of engagement with the PCC in carrying out its statutory functions, and how HSC Organisation's Boards have considered that independent assurance as part of their reporting, monitoring and governance processes. PCC considers that this can best be addressed by the work being carried out by DoH on the strategic approach to public engagement.

Partnership and Engagement Strategy - Priorities

PCC welcomes reference to a regional training framework and within our assurance role would be keen to understand the scope, resourcing and development of this approach.

New practice, guidance, and policies require training and ongoing development to implement and maintain a change process. The development of a Regional Training Framework for partnership and engagement working has the potential to advance knowledge skills and collation of shared-learning to inform future practice.

PCC welcomes the reference to collaborating with related areas, such as safety and quality, to cross reference issues and analyse trends to support service improvements. This echoes some of PCC's strategic priorities, as articulated in our Statement of Strategic Intent 2022-25, on the need to better triangulate data and intelligence across the HSC system to learn early in the interests of patient safety and service delivery. PCC is interested to learn more about aspects of the priority, how PCC and PHA can collaborate to support this objective and how it can be integrated into data developments occurring across the HSC.

PCC is keen to understand more about how the Strategy will seek to practically address health inequalities and access issues related to marginalised groups. There is a public need to understand how health care will be delivered in the future. How the public experience information and media coverage are key findings from the PCC 'What the People think' report, referred to below. Careful consideration should therefore be given to how any education, awareness, and communication campaign is delivered, how it can be accessed, and how it extends to reach the most rural or marginalised sections within our community.

In addressing Priority 3 and 4 PCC would refer to our recent initiatives that demonstrate key learning opportunities in relation to connecting and engaging with the public, embracing the learning from lived experience and ensuring accessible ways are implemented to enable the public to take part and the inclusion of the marginalised voice. PCC has outlined information in relation to these initiatives in **Appendix 1** and trust that these will be of assistance to PHA. We are happy to engage on any aspects of this consultation response and the work of PCC set out in the Appendix.

Yours faithfully

Ruth Sutherland
M. Monaghan

Ruth Sutherland, CBE
Chair

Meadhbha Monaghan
Chief Executive

Appendix 1

1. People to Partner Initiative

Our People to Partner[8] report explores the development of a unique approach to building a new relationship with the public, harnessing energy and agency of citizens as assets to reset and reshape the agenda. The essence of ‘Do With’ (and not just for) is encapsulated in a number of approaches. In exploring what ‘Doing with’ entails, Adam Lent argues that the core practices these approaches have in common include:

- Deep understanding – an effort to build a deeper understanding of the people with whom the public sector engages;
- Versatile response – developing approaches that are truly versatile, meeting the preferences and particularities of individuals or groups;
- Collaborative delivery – developing and delivering approaches in close collaboration with the individuals and groups organisations serve, rather than assuming the public sector knows best.

PCC and the Northern Ireland Confederation for Health and Social Care (NICON) launched a new report, ‘People to Partners – Developing a Unique Approach for Northern Ireland’, at the NICON 2025 Conference.

2. PCC Support in the Community

To deliver on Priority 3 the Strategy and subsequent programs of work will need to reach out to communities who are hard to reach to identify and address barriers and challenges, build upon already existing and trusted networks, establish regular outreach, and address current health inequalities.

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[8] Northern Ireland Confederation for Health, and PCC (2025) *People to Partners – Developing a Unique Approach for Northern Ireland,* Accessed here: people-to-partners-final-for-print-081025.pdf

This will require a new way of thinking, and delivery, including operating in areas affected by rural isolation and deprivation and with vulnerable and hard to reach communities.

In November 2024 we established ‘PCC Support in the Community’, and through this initiative PCC have been able to reach out to members of the public who may not usually access our services and to help combat health inequalities through the provision of advocacy support. Our service provides:

- Trained Staff at physical locations, to listen to individual’s concerns/ issues about health or social care
- Free support, advocacy and advice, to help individuals find a resolution or raise concerns appropriately
- Access to resources tailored to their needs
- Support through a complaints process, which will always be focused on ensuring the individual’s voice is heard and listened to.[9]

The initiative aims to support those most affected by health inequalities; migrants, LGBTQ+, people experiencing homelessness, those in contact with the justice system, and people with disabilities or neurodivergence. We have also targeted demographics that are less aware of the PCC and our services such as men; 18-34-year olds; Working Class, Retired, students, those not in work, the Belfast and Southern Regions. This initiative covers the whole of Northern Ireland, both rural and urban communities.[10]

This approach links PCC with established and locally trusted organisations, and other services to enable engagement within local communities. By building trust and relationships within these settings, the PCC have created regular and accessible touchpoints for advocacy and engagement via community-based outreach support services in locations such as local advice centres, migrant support hubs, community and wellbeing centres, men’s sheds, primary care MDTs, and organisations within the voluntary and community sector, places where people live, gather, and seek

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[9] This paragraph answers questions 3-5, 15

[10] This paragraph answers questions 7,9,10, 14, 16

help. This includes collaborations with Healthy Living Centre's, Prisoner Support, Empowerment Programmes, Libraries NI and Migrant Support and many more.

3. Remuneration and Reciprocity

The 2018 Department of Health Co-Production Guide[11] has a section on *'Reciprocal Recognition'.* It notes that at the heart of co-production is a commitment to value, reward and recognise the contribution of all partners, particularly people with lived experience.

Core literature on co-production recognises the principle of reciprocity, which is defined as ensuring that people receive something back for putting something in, and builds on the premise of recognising and valuing people's contribution. Examples of Reciprocity include mutual respect, equality of opportunity, joint learning, recognition, flexible rewards, and ***remunerating people for their role and contribution***. This can also include benefits in kind, such as 'out of pocket' expenses, and meeting training and development costs.

In 2019 the Patient and Client Council (PCC) through Transformation Funding, was commissioned by the Public Health Agency (PHA) to analyse the potential for paid service user and carer involvement[12]. Analysis concluded that the current model for involving service users and carers does not universally recognise or acknowledge the contribution made by them.

This was supported by service user feedback from a workshop hosted by PCC and PHA in 2022 (see section *'PCC and PHA Research'* for further information) which found that Service Users and Carers were unanimous in feeling that their contribution should be recognised in a way that is meaningful to them. There should be a ***reciprocal recognition*** and remuneration should form a part of how we acknowledge service user and carer involvement. ***Creating equality*** was also

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[11] Department of Health NI (2018), *"Co-production Guide Connecting and Realising Value Through People"* 126493 H&SCB - Co-Production Guide.indd (hscni.net)

[12] PCC (2019) *'Exploring Paid Service User/Carer Involvement in Health and Social Care Settings'*

important to Service users and carers. They felt that payment for specific involvement, among other support mechanisms afforded to employees such as personal development opportunities, would have positive impact on creating an environment of mutual respect and true equal partnership.

Reflecting on the need to appropriately recognise and acknowledge the contribution made by service users and carers in co-production work, there is a principled and ethical argument, based on acceptance of the principle of reciprocity, to introduce a regional remuneration policy.

Remuneration as a method to increase diversity and inclusion

Whilst there is limited quantitative data in relation to the diversity of service users and carers in coproduction and engagement activities, throughout, our analysis work and engagement with the public, it was considered that service user and carer involvement is largely unrepresentative in terms of the age, socio-economic background and ethnicity of those involved.

Work carried out by organisations seeking service user and carer involvement in scientific research echoes this position. For example, research published in the BMJ, when referring to patient involvement in research states that *“ensuring diversity—so that the interests of well educated, white, middle class people do not dominate—is challenging. Patients from underserved groups are still excluded from scientific research”*[13]. The National Institute for Health and Care Research (NIHR) state that paying people for their involvement in research helps to support more equal partnerships between researchers and members of the public. It helps to support the inclusion of people who might not otherwise be able to get involved, whether for financial or other reasons relating to access. Consequently, it widens the potential pool of people who might influence the course of research[14].

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[13] The British Medical Journal (2018) *‘Involving underserved patient populations in* research’ Involving underserved patient populations in research | The BMJ

[14] NIHR (2022) *‘Payment guidance for members of the public considering involvement in research’* Payment guidance for members of the public considering involvement in research | NIHR

When we consider documented and recognised health inequalities and access to service issues amongst marginalised groups, it is vital that co-production and engagement activities, which have the potential to help shape future services, are not blind and silent to the issues and concerns of marginalised groups and those already facing health inequalities.

There are numerous barriers to including individuals form marginalised groups in coproduction and engagement activities, including language barriers, capacity, physical ability and wellbeing, however, financial implications for people providing their time without compensation is a significant consideration as an additional and barrier to ensuring diversity and inclusion.

In March 2024, the PCC submitted to the Department of Health a thought-paper on the need for a regional remuneration policy in Northern Ireland. The paper explored a series of potential implementation options along with an options appraisal to advise the Department on the development of a Departmental policy position.

4. The Big Discussion Initiative

Decision makers can often hold assumptions on what they think the public feel and experience. These assumptions may not always be true. In the development of the current strategy it is important for programs of work to collage best practice guidance and the inclusion of this within the strategy will develop the principle of shared learning and decision-making. There is a need to engage with the public and understand people’s experiences. PCC refer to the Big Discussion Initiative as an example of shared learning and the importance of collating data, and developing mechanisms to identify trends and improve learning on an evidential basis.

Between March and April 2025, the Chief Nursing Officer (CNO) and Chief Medical Officer (CMO) convened the ‘Big Discussion’ workshops across Health and Social Care in NI to design a system approach to addressing ‘winter’ pressures. The need to engage with the public was a strong and recurrent theme emerging from these workshops. The CNO asked the PCC to consider how a ‘Big Discussion’ with the public on this issue might be approached.

PCC recommended that the work should be carried out in different phases, with an initial phase focused on generating a regional baseline understanding of the public's beliefs and feelings about health and social care, and their knowledge of winter pressures. PCC designed the first phase and attitudinal survey with the intention that it would have broader applicability to a range of initiatives that are ongoing across health.

PCC commissioned LucidTalk to conduct a Northern Ireland (NI) Attitudinal Poll (survey) to ensure we had a sample that was representative of NI population. With the results from the survey we wrote a key finding report from a key finding report[15].' The findings provide an important regional baseline to inform initiatives such as the '*Big Discussion – Whole System Flow'* led by the Chief Nursing and Chief Medical Officers, and the Minister for Health's '*HSC Reset Plan'*. Key findings include, 51% stating they felt disconnected for HSC services. Results were mixed in relation to how well informed the public feel they are in relation to their health and how to manage it with 53% agreeing or strongly agreeing and 47% stated they were neutral or did not feel informed.

When asked what matters to them when accessing treatment and care, it was most important to people that their care and treatment is safe and high quality, timely, and delivered by the most appropriate and expert healthcare professional. In addition, people significantly prioritised safe, timely and expert care over how far they had to travel or whether the care was delivered in their own home or in the community. People ranked being actively involved, having choice and a sense of control in their care and treatment, over the distance to travel for care and whether that care is in their home or local community. Notably, 45% felt they are actively involved in their care with healthcare professionals and staff. 48% did not think any action they took would make a difference to pressures on the health service, compared to 40% that thought it would. Most people knew when to it was appropriate to use an ED, however older people (65+) were more likely to use EDs for different reasons compared to other age categories. 19% of 65+ did not believe that a life-threatening

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[15] PCC (2025) *'What the Public Think' Key findings from a PCC Attitudinal Report on People's Experiences of Health and Social Care and 'winter' pressures*, Accessed here: what-the-public-think-key-findings-from-a-pcc-attitudinal-report-on-people-s-experiences-of-health-and-social-care-and-winter-pressures.pdf

issue was an appropriate reason for attending ED, 45% of 65+ were more likely to say an appropriate reason for attending an ED was to get tests done such as x-rays or blood tests and over 65s were the most likely to consider not being able to access your GP (37%) as an appropriate reason to attend ED. Whilst 58% of people were confident that they knew how to access alternative care pathways, only 38% were confident the alternative care pathway would meet their needs.

5. Triangulation of data and Intelligence

Within PCC data and knowledge is recorded and analysed to identify emerging trends and issues and demonstrate impact. The importance of understanding existing data and intelligence provides vital knowledge and a base-line of experiences, key learning and insights which, can be utilised to promote good practice, identify what is working well and replicate it, as well as identifying opportunities to improve performance and health outcomes.

How data is triangulated and insights gained from people's care experience, advocacy, complaints and their experience of the impact of decisions, to learn early, inform service delivery and service change is vitally important to ensuring an open HSC and patient safety. The PCC believes there should be better use and triangulation of data and insights regionally and across health and social care services to learn early and drive improvement.

PCC reflects on their submission to the Being Open Framework. The PCC considered that the measures being considered would benefit from being broader and more outward-looking and trust that this has been reflected upon.

The information held by the PCC in relation to our advocacy and engagement work, as well as information from regional Patient Client Experience programmes, provide a clear source of insights and intelligence which should be drawn upon to give a level of external corroboration or challenge when triangulated with internal HSC Trust data sources.

Careful consideration is required on how to collate and analyse all HSC data on engagement, early alerts, adverse incidents, complaints and advocacy cases system wide, and on how to monitor that appropriate regional learning and action is taken, if necessary by developing a mechanism for the regional collection of data and assurance of quality of data and intelligence and Priority 4 requires further development in this regard.

PCC would welcome consistency in recording and collection as well as more information on how these data sources and the themes arising from analysis of them will be used. This should include clarity on the structures that are in place to analyse data, and to disseminate learning.

There is a potential of creating a coalition and networking of service data and learning experiences, that builds on Trust-based complaints, incident and review data, but which includes other sources including advocacy data and cross-sectoral insights which are essential to mitigating quality and safety risk.

PCC reiterate their view that such an approach could be reflected upon to continue an independent hub of expertise, providing independent expert analysis to Trust Boards and the Department on patterns, trends, clusters and emerging quality and safety concerns.

The PCC considers that an open HSC system needs further development, and needs to give more consideration on how it will develop mechanisms, how it uses, co-ordinates and considers the data and intelligence that it holds to learn from good practice, and to learn early from emerging issues and when things go wrong.