

Being Open / Duty of Candour Branch

Department of Health

Room D2.1

Castle Buildings, Stormont Estate,

Belfast

BT4 3SQ

28 March 2025

BY EMAIL ONLY

Dear Sir/Madam

Ref: Being Open Framework consultation

A welcome consultation

- 1. The PCC welcomes this consultation and the opportunity to respond. We acknowledge the work the Department of Health is undertaking in a number of areas to address the findings and recommendations of multiple public inquiries in Northern Ireland. This response has been considered and approved by the Council (Board) of the Patient and Client Council. We have identified the consultation questions to which each sub heading relates via a footnote, where appropriate.
- 2. PCC agrees with the Minister for Health, in his foreword to the consultation document, that all too frequently we have seen, from multiple public inquiries, that we, as a system, have failed to live up to the core values of being open

Patient and Client Council, 5th Floor, 14-16 Great Victoria Street, Belfast, BT2 7BA

- and honest and that families who have lost loved ones, or individuals where the standard of care has not been what we would have wanted, have too often found it incredibly difficult to get answers out of our system.
- 3. The PCC considers that the draft Being Open Framework is a helpful start to developing a more open, just and learning culture across the HSC. PCC welcomes in general terms the descriptors of an open culture, a just culture and a learning culture. We consider, however, that the framework needs to better reflect the agency and voice of the public. In particular it is essential that the voices of those with lived experience is heard. The reality PCC experiences through our work, is that for too many service users and families there is a disconnect between what organisations and policies say should happen, and their experience of what actually happens when things go wrong.
- 4. It is important to get the balance right between voices who can comment on the theory of how the system should work, or relay indirect views based on the experience of service users versus hearing directly from those with the lived experience of how the system worked and how it actually responded to them when things went wrong. It is the PCC's experience that it is the voices of those with lived experience which are most likely to be underrepresented, including within the process of developing policy. Whilst both need to be heard, the voices of people with lived experience (by nature more marginal and smaller in number), should be particularly valued and sought out. This is a key focus for the PCC which believes that the value of listening to direct lived experience cannot be underestimated in shaping better outcomes for all.
- 5. The PCC agrees with the following statements in the Patient Safety Overview section of the consultation document, when it states that 'part of this cultural change will include supporting an environment that welcomes, encourages and seeks the patient, family and staff experience to deliver continuous improvement to the delivery of care'.
- 6. Similarly we agree with the statement that 'the effectiveness of any Patient Safety System depends on robust mechanisms for organisations to receive

qualitative and quantitative information from various sources' and that 'all procedures and processes with a relevance to patient safety must interface with and influence each other appropriately in order to deliver effective Patient Safety Systems in HSC organisations and it is important to consider this wider context when providing your input to this consultation'.

7. Reflecting on these points, we consider there to be a number of significant gaps in the draft being open framework, which will impact on its ability to deliver upon the Department's stated objectives.

General Reflections

- 8. A summary of the main points of our consultation response are as follows:
 - The statutory role, functions and practices of the PCC have not been acknowledged or referenced in the draft Being Open Framework, which PCC consider to be a significant omission, especially given the proposal relating to monitoring openness in organisations and the proposed introduction of a Patient Safety Commissioner.
 - The voice and role of the public and those with lived experience is not adequately reflected in the Draft Being Open Framework, giving rise to the concern that it is too inward looking. There is a need to develop a strategic approach to public participation across the HSC.
 - The Being Open Framework should clearly recognise and include the need for independent advocacy services to support members of the public and the HSC system to fulfil its broad being open obligations.
 - There is a need for more holistic, regional and strategic triangulation of data and intelligence across the HSC, to fulfil the objectives of the Being Open Framework.

- The voice and experience of the public including those with lived experience needs to be appropriately embedded in the governance and assurance mechanisms developed to ensure the Being Open Framework is implemented and monitored in an appropriately accountable way.
- Training of HSC staff and HSC Trust Board members needs to include training on how to engage with and listen to the public and to ensure existing policies and procedures concerning complaints, SAIs and reviews are appropriately delivered.
- For those with lived experience where things have gone wrong, they have
 often been harmed, and in cases, traumatised by their experience.
 Training therefore needs to specifically address how to engage with these
 individuals and families in a supportive manner.
- The statutory Duty of Candour should extend both to individuals as well as to organisations.

The role of the PCC¹

9. It is the PCC's expectation that PCC and the role of the organisation, given our statutory functions, would have been cited and fully acknowledged within the draft Being Open Framework, in a similar way to that in which the role of RQIA has been. Whilst acknowledging that reference is made to 'PCC reports' in paragraph 2.23 of the draft Being Open Framework, this is the only mention of PCC throughout. The PCC is disappointed and surprised that its statutory functions, practice and role within the HSC system is not effectively reflected in the draft Being Open framework, particularly given the consideration in the document to how organisations are to monitor openness and the proposals for an Independent Patient Safety Commissioner, the stated role of which aligns to many of the functions that the PCC currently holds. We consider that the independent role of the PCC within the HSC system, its role in providing independent assurance to the Minister of Health, and the Department of

¹ This section is relevant to the proposals in their entirety and specifically Questions 1,2, 4.

Health's stated purposes for the PCC upon establishing it, is of pivotal importance to the Being Open Framework and the delivery of an effective Patient Safety System.

- 10. The PCC is a statutory corporate body established under the Health and Social Care (Reform) Act (2009). The HSC Framework Document (2011), produced by the Department, describes the roles and functions of the various health and social care bodies and the systems that govern their relationships with each other and the Department. The document stipulates that 'the overarching objective of the PCC is to provide a powerful and independent voice for patients, clients, carers and communities on health and social care issues through the exercise of its legislative functions'², which are:
 - 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.
- 11. The HSC Framework document further outlines that the PCC has an important independent assurance role for the Minister of Health, based on our statutory functions. The only other organisation that has such a role is the RQIA, whose functions and role are outlined in the draft Being Open Framework at paragraph 5.2. The PCC is directly funded by the Department of Health to safeguard its independence from HSC organisations.
- 12. Paragraphs 6.40 to 6.42 of the HSC Framework Document (2011) further outlines the independent challenge function the Department conferred on the PCC and the RQIA, which is as follows:

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² DHSSPS Framework Document - September 2011 | Department of Health

Independent Challenge

- 13.6.40. In considering how the HSC system is held to account, special mention should be made of the Regulation and Quality Improvement Authority and the Patient and Client Council, both of which have a particular role to play. They each provide an independent perspective on the performance of the HSC system, one which validates and challenges the system's own performance management arrangements.
 - 6.41. The RQIA focuses on the quality and safety of services, using statutory and other standards agreed by the Department to benchmark not only the services but also the governance frameworks within which they are provided. PCC focuses on the interests of patients, clients and carers in HSC services. This goes beyond a straightforward information or advocacy role; it includes working with HSC bodies to promote the active involvement of patients, clients, carers and communities in the design, delivery and evaluation of services. The RQIA and the PCC also have the power to look into specific aspects of health and social care and report their findings publicly to the Department.
 - 6.42. Both of these organisations provide important independent assurance to the wider public about the quality, efficacy and accessibility of health and social care services and the extent to which they are focused on user needs.
- 14. PCC's Council (Board) is constituted differently to other Boards across the HSC to reflect the public and attest independence, with specified representation from the public, elected Councillors, trade unions and the voluntary and community sector. Reflecting on these obligations, the PCC's Board developed a Statement of Strategic Intent 2022-2025³, setting out the vision and strategic direction of the organisation. Our vision is for a Health and Social Care Service, actively shaped by the needs and experience of patients, clients, carers and communities, and that in achieving this, the public voice

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³ PCC (2022) Statement of Strategic Intent

would be influential regionally and locally in planning and commissioning, and that the system responds openly and honestly when things go wrong.

15. In the long term the PCC hope to see two big differences:

<u>Strategic Objective One:</u> Through our engagement and impact work, the public voice is influential regionally and locally in the design, planning, commissioning and delivery of health and social care.

<u>Strategic Objective Two:</u> Through our work in advocacy, engagement and impact, the health and social care system responds regularly to people with openness, honesty and compassion to address difficulties or failures in standards of care.

16. To fulfil our statutory obligations the PCC has developed a delivery model focused on 4 key areas. These are PCC Connect, PCC Support, PCC Engage and PCC Impact. The model places an emphasis on relationship building; meeting people at their point of need and tailoring our support to each individual. The PCC understands its role within the system of governance and assurance as providing the wider public, HSC Trusts and other service providers and the Department itself with information, insights and evidence gathered as part of discharging our statutory functions. This includes our role in providing advocacy support, and advice on the best methods to engage with the public, and is primarily based on engagement with service users, patients, carers and families. As can be seen from our Strategic Objectives we consider that this work can and does have a clear impact on ensuring the HSC system responds to the public with openness, honesty and compassion to address difficulties or failures in standards of care, which are very similar objectives to the draft Being Open Framework.

Patient Safety Commissioner⁴

17. Developing the Framework and any recommendations to assist with its implementation would benefit from an appropriate assessment of the

⁴ This section is relevant to Question 12

legislative and organisational context of Northern Ireland. A first step would be an assessment and recognition of the existing assets, their role, and powers within this, and whether they could be augmented to address any gaps. PCC considers that appropriately reflecting and then investing in the existing assets of the HSC system is the most effective and efficient way to drive assurance and patient safety across the system.

- 18. There are several organisations including the Public Services Ombudsman and CoPNI whose remit is much wider than Health and Social Care and which have much stronger statutory powers to assist them in delivering their functions. It would be of benefit if their roles were reflected in the Framework.
- 19. Our understanding is that the particular combination of functions and statutory role that the PCC has in Northern Ireland is unique in the UK. PCC believes that whilst our overall approach within the HSC is the best way forward, our effectiveness would be increased if the PCC's potential was reflected in our resourcing and if PCC had stronger statutory powers which would increase our leverage within the HSC sector. Whilst the PCC would welcome changes to its primary legislation to bolster its role within the HSC, we consider that enhancing the PCC's role in relation to Patient Safety in the short-term can be achieved without recourse to legislative change. Appropriately reflecting our assurance role, amending the HSC Framework and broadening understanding of public participation and the public's voice in relation to patient safety in the ongoing strategic review into public engagement, offers opportunities in this regard.
- 20. Given the stated understanding of the need to ensure all procedures and processes with a relevance to patient safety must interface and influence each other appropriately, the PCC considers the lack of detailed reference to the role of the PCC to be a considerable omission and missed opportunity from the draft Being Open Framework. Particularly given the proposals for an Independent Patient Safety Commissioner, the stated role of which aligns to many of the functions that the PCC currently holds.

21. More information on the role, remit and delivery model of the PCC can be found at **Appendix 1**.

Advocacy Services Vital to Being Open⁵

22. Advocacy plays an important role in supporting people to express their views and in providing a source of support which gives them confidence to speak out. Advocacy is vital in cultivating trust and effectively supporting people to ensure their views are considered and heard. It should also provide an environment in which they can confidently raise any concerns they may have with their advocate in the knowledge that there are no conflicts of interest.

23. Advocacy:

- Safeguards people who can be treated unfairly as a result of institutional and systemic barriers as well as prejudice and individual, social and environmental circumstances that make them vulnerable.
- Empowers people who need a stronger voice by enabling them to express their own needs and make their own decisions.
- Enables people to gain access to information, explore and understand their options, and to make their views and wishes known.
- Speak up on behalf of people who are unable to do so for themselves."⁶
- 24. The importance of advocacy services was recognised by the Inquiry into Hyponatraemia-Related Deaths (IHRD) report⁷, with its recommendations outlining the need for service users, and families, to *have access to independent advocacy support*. Recommendation 37 (iv) being: '*Trusts*

⁵ This section is relevant to Questions 4, 5, 6,11, and 13.

⁶ NHS Scotland. (2013) Independent Advocacy Guide for Commissioners. <u>Independent Advocacy Guide for Commissioners</u>

⁷ Inquiry into Hyponatraemia related Deaths (2018) The Inquiry into Hyponatraemia-related Deaths Report Full-Report.pdf

should seek to maximise the involvement of families in SAI investigations and in particular: a fully funded Patient Advocacy Service should be established, independent of individual Trusts, to assist families in the process. It should be allowed funded access to independent expert advice in complex cases'.

- 25. The availability of independent advocacy assists in creating a culture of openness and transparency and plays a fundamental role in governance, assurance and addressing inequality.
- 26. PCC believe that appropriately supporting independent advocacy services provides a level of assurance that HSC Trusts and organisations are committed to being learning organisations, committed to meeting their Statutory Duty of Quality, are appropriately invested in the Duty of Candour and, most importantly, to protecting patients.
- 27. In relation to Openness with a focus on learning and when things go wrong, the PCC recognises the requirement for psychological safety, where staff, patients and service users feel able and supported to talk about difficult experiences without fear of disproportionate or unfairly punitive responses. PCC would reiterate the important role advocacy services and support can play in providing psychological safety and support to both the public and healthcare professionals with a view to resolving issues early and learning from them. PCC's advocacy model has a focus on early resolution, resulting in 57% of cases in 23-24 being resolved prior to formal complaint, an increase from 45% in 22-23.
- 28. PCC notes the following paragraph in the draft framework:

A liaison person should be appointed from the organisation whose responsibility it is to keep the patient, service user or nominated family members or representatives apprised of the progress of whatever formal processes are involved. (IHRD recommendation 37iii and iv).

- 29. PCC consider that this would contribute to fulfilling the requirements of recommendation 37 (iii), which is: 'Families should be given the opportunity to become involved in setting the terms of reference for an investigation⁸. However, PCC do not feel that this would address recommendation 37 (iv), which relates specifically to Advocacy Support: A fully funded Patient Advocacy Service should be established, independent of individual Trusts, to assist families in the process. It should be allowed funded access to independent expert advice in complex cases.'
- 30. Key to this recommendation is independence which is at the core of the effectiveness and efficacy of advocacy, and which underpins openness. The PCC expects, and we believe the public expect, that organisations providing advocacy services should be independent of service providers i.e. structurally, financially and psychologically independent⁹. Ensuring the integrity of independence, advocacy service providers' accountability arrangements should be independent of Trusts to ensure freedom to act without potential adverse consequence on the contractual arrangement.
- 31. The PCC believes the following aspects should underpin the provision of advocacy services within the Health and Social Care system:
 - Advocacy services should be commissioned as regional services;
 - Advocacy services should be commissioned independently of HSC Trusts:
 - Advocacy services should be commissioned on the basis of agreed standards which include addressing the role of these advocacy services in dealing with complaints and concerns raised by clients, responding to safeguarding issues, and systems of regulation of services and the workforce;
 - The service specification with providers commissioned to provide advocacy services should specify how these service providers relate to

⁹ <u>Independent Advocacy Principles, Standards & Code of Best Practice - Scottish Independent Advocacy</u> Alliance

⁸ https://www.ihrdni.org/Vol3-09-Recommendations.pdf

- the Patient and Client Council in the discharge of its statutory roles (where the PCC is not the provider or commissioner of the service);
- The same specification should specify a minimum data set to be collected by the service provider both for the purposes of monitoring the provider's performance and for the purpose of identifying issues of service quality and safety with services provided by HSC Trusts; and
- Access to these advocacy services should be client-led and not solely dependent on a referral by HSC Trust.
- 32. The PCC's interest is in having systems and structures which promote and maximise openness, patient outcomes, purpose, quality and safety of services and governance and assurance. The PCC is not seeking to position itself to be involved in every complaint / SAI or Review. PCC recognises the expertise and contribution of a wide range of voluntary sector organisations which provide specialist knowledge-based advocacy services and the PCC itself avails of those services. The PCC is not seeking to displace or replace those providers. It is critically about how to "connect the system to more of itself "(Myron's Maxims) and to deliver better outcomes for the public.
- 33. PCC considers it a missed opportunity that the draft Being Open Framework makes no reference to independent advocacy support for the public and its significant role in delivering an open and just culture across the HSC.

Triangulation of data and intelligence¹⁰

34. PCC welcomes the clear recognition and importance within the draft framework placed on data collection and reporting metrics. How we triangulate the data 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

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¹⁰ This section is relevant to Questions 10 and 11.

- better use and triangulation of data and insights across health and social care services to learn early and drive improvement.
- 35. Reflecting on the proposed measures outlined in Table 3 of the draft framework and the supporting narratives, the PCC considers that the measures being considered would benefit from being broader and more outward-looking. For example, there is a lack of reference to important sources of information and intelligence external to HSC staff and organisations, over and above Service User/PPI Feedback. 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.
- 36. Careful consideration is required on how to collate and analyse all HSC data on early alerts, adverse incidents, complaints and advocacy cases systemwide, 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. PCC would also welcome consistency in this 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.
- 37. 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.
- 38. Such an approach could be 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. There may also be a role for undertaking/advising on reviews into serious adverse incidents and

offering independent advice to Trust Boards, the Department and other agencies on individual incidences and reviews. The PCC considers that an open HSC system needs to give more consideration on how it uses and coordinates and considers the data and intelligence that it holds to learn from good practice, learn early from emerging issues and when things go wrong. The draft Being Open Framework should be further developed in this regard.

Strategic Approach to Public Engagement¹¹

- 39. The Framework mentions using Personal and Public Involvement (PPI) as its means of involvement. Many of the terms such as public engagement, PPI, patient experience, co-production and consultation 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.
- 40. At PCC we firmly believe there is a need to establish a more strategic approach to public participation, through which we can critically examine the roles of Personal and Public Involvement, Engagement, Patient Experience, public consultation, Advocacy and Complaints and how these aspects of involving the public in the HSC fit together to ensure the voice of the public is adequately heard and appropriately listened to in the following areas:
 - Service Change, Design Commissioning and Delivery;
 - Quality and Safety; and
 - Clinical and Social Care Governance.
- 41. A clear objective of taking a more strategic approach is to improve outcomes for the public and their experience of HSC services and to build trust between the public and services.

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¹¹ This section has relevance to the consultation as whole and Questions 1, 2 and 3.

- 42. To ensure that a culture of public participation is knitted into the HSC system and the Being Open Framework, PCC would recommend the promotion of the public as partners in their care and of embracing the public as assets.

 Ultimately this involves recognising the individual agency of citizens and particularly those in receipt of care, by changing the nature of the relationship between the public and health and social care, from one of passive recipient to more active partnership. To embrace the public as assets, we need a meaningful system wide approach to better embrace and engage patients as active partners in their own care, which will have a significant impact on how open the HSC system is. Much more can and needs to be done.
- 43. PCC considers that the three levels are helpful and provide a good structure to conceptualise a Being Open Framework. Greater consideration, however, should be given in the draft to how the service user and public's voice, agency and participation in each of the three levels is valued and articulated.
- 44. For example, the routine openness level should be considered to be founded on a relationship between healthcare professionals, members of staff and the public to share information with each other and build trust. Patients and members of the public should not be considered passive recipients of care and routine openness, but should be considered partners in their care and routine openness. There are examples of patients withholding information from healthcare professionals where there is limited trust, such as being concerned that surgical procedures may be delayed or cancelled if they share the information they hold¹². As outlined above, to embrace the public as assets, we need a meaningful system wide approach to better embrace and engage patients as active partners in their own care, which will have a significant impact on how open the HSC system is. PCC considers that focusing on this aspect of cultural change is crucial.

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¹² Learn - Patient Safety Learning - the hub

Oversight and assurance to promote openness – the role of the public and PCC

45. The PCC welcomes the proposal that oversight and monitoring of the draft Framework will be undertaken by the Patient Safety and Quality Committee of the HSC Trust Board. The voice of service users and the best interests of service users need to be at the heart of governance, structures, systems, policies and processes underpinning health and social care. Oversight and assurance is about Trust Boards weighing up the evidence, including from independent sources, and determining for themselves that standards and the requirements under the Being Open framework are being met. The PCC considers it important that the voice of service users is included as part of the independent assurance, governance and oversight of the Being Open Framework. To assess whether or not they are assured HSC Boards and the Department need to be aware of and actively assess the full range of evidence that is available to them from a variety of sources. This makes the volume, quality and sources of data and intelligence considered by Patient Safety and Quality Committees and Trust Boards to be vitally important, as outlined above.

Training¹³

46. PCC considers that training for HSC staff needs to be more focused than what is outlined in the draft Framework document. For example, in dealing with complaints HSC Trusts are expected to have trained their staff so that they are aware of the HSC complaints system and how to deal with complaints. In PCC's experience, it is not always evident that HSC Trust staff have been trained on the appropriate complaints process and this potentially reduces the ability of the system to be open, increases risk to service user's safety and collapses proper procedural requirements. Without this there will be a failure to mitigate risk through appropriate patient care monitoring.

¹³ This section is relevant to Questions, 10, 11, 13 and 14.

- 47. With the pending introduction of the Northern Ireland Public Sector Ombudsman's Model Complaints Handling Policy across the HSC, there is an opportunity to ensure that supporting regional policies, procedures and training are appropriately updated and implemented. PCC considers that the need to understand the role of advocacy in safeguarding, and the requirement for clear information about how to make a complaint, should be included in such training as a key aspect of being open. There should also be a mechanism, independent of the safeguarding process, where a member of the public can raise concerns about how their safeguarding issue is being handled.
- 48. HSC Trust Staff and the staff of organisations commissioned to provide services by HSC Trusts should be trained and have familiarity with HSC complaints processes, SAI processes and safeguarding as a cornerstone to patient safety learning and developing a Being Open culture. This training should be specified as a key part of the Being Open Framework, allowing the RQIA and the PCC to provide assurance in relation to its application.
- 49. In response to the Hyponatraemia Inquiry, the Department of Health developed extremely detailed guidance for Board members of Arm's Length Bodies (ALBs). To our knowledge as yet, new training centred on this new guidance has not been developed although this has to be understood in the context of the COVID pandemic when understandably the Department's resources were heavily focussed on the pandemic response.
- 50. The PCC would welcome the development of such a training course for Board members and advocate for the direct engagement of patients and service users providing an input. This would ensure that Board members would be alive to their experience and the need to have that voice amplified when monitoring patient safety. PCC would welcome the opportunity to participate in the development and delivery of this training.

51. The training to Trust Board members should also address good practice in monitoring complaints, SAIs and incidents and listening to service users and families.

The Duty of Candour¹⁴

- 52. In 2021 PCC facilitated Duty of Candour engagement sessions on behalf of the DoH. On the whole the feedback during engagement sessions was positive. The introduction of a Statutory Duty of Candour was seen as a positive step in the right direction.
- 53. There was a unanimous agreement amongst those that the PCC engaged with that a Statutory Duty of Candour needs to be introduced as soon as possible. However, there was some scepticism around the implementation and if it would actually make changes to practices within Health and Social Care in Northern Ireland. Participants said a cultural change was required to ensure that all staff across Health and Social Care are open and honest, though they were concerned that it would take many years before the changes became apparent.
- 54. PCC considers the Duty of Candour should extend beyond the value of 'openness' endorsed by the HSC system presently, to reflect the need to converse in "an open and honest way in relation to the provision of health and social care services with patients and service users". The PCC's position, is that the statutory Duty of Candour should extend both to individuals as well as to organisations. Organisations cannot deliver on a Duty of Candour unless the individual staff within them consistently report incidents and are open and honest in recording what has happened particularly when things go wrong.
- 55. The PCC welcome an ongoing conversation with the Department on any aspect of this consultation response.

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¹⁴ This section is relevant to Questions 7, 8 and 9.

Yours faithfully

Ruth Suthwood

Ruth Sutherland, CBE

Chair

M. Monaglan

Meadhbha Monaghan

Chief Executive

Appendix 1

The Role of the PCC

The Patient and Client Council (PCC) is a statutory corporate body established in 2009 under the Reform Act¹⁵ to provide a powerful, independent voice for patients, clients, 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.

In addition, PCC has an important independent assurance role for the Minister of Health, as set out in the HSC Framework document¹⁶, one of only two organisations that have this role, the other being the RQIA.

The PCC's effectiveness in fulfilling its' functions is partly dependent on building constructive and productive relationships and arrangements with service providers, the third sector and other statutory bodies who have powers to investigate and take enforcement action where there are problems with the quality and availability of health and social care services. The approach of establishing partnerships and building relationships with others can mean that the PCC is able to exercise a positive influence on the sector – albeit via **soft skills** such as mediation and collaboration rather than though hard statutory obligation. However, this approach requires a significant commitment of time and resources for a small organisation like PCC and can take longer to reach a point when results are being achieved.

¹⁵ Health and Social Care (Reform) Act (Northern Ireland) 2009

¹⁶ Department of Health (2011) DHSSPS Framework Document

The PCC is a small Arm's-Length Body with an annual budget in 2024-2025 of £2.1m. £1.8m of this is recurrent funds, £0.3m is non-recurrent funds relating to inquiry related work. PCC employs 31 members of staff, excluding Council members.

The PCC has a Council made up of a Chair and Council Members, recruited from across Northern Ireland under the Public Appointments Process. It currently has 13 members¹⁷.

With a budget of £1.8m – equivalent to less than £1 for each member of the public in Northern Ireland that PCC is tasked to serve – it is a challenge to fulfil the statutory functions outlined below, across engagement and support, across the breadth of health and social care services. As such the PCC has to prioritise within this resource where it focuses its efforts to best support the population of Northern Ireland; combining delivering a service to individuals with trying to make a strategic impact; informing Department policy, as well as Department and HSC decisions on HSC structures and decisions on how, when and where services are delivered.

Our vision is for a Health and Social Care Service, actively shaped by the needs and experience of patients, clients, carers and communities, and that in achieving this, the public voice would be influential regionally and locally in planning and commissioning, and that the system responds openly and honestly when things go wrong.

The PCC has developed a Statement of Strategic Intent 2022-2025¹⁸, setting out the strategic direction of the organisation over the next three years. In the long term we hope to see two big differences:

<u>Strategic Objective One:</u> Through our engagement and impact work, the public voice is influential regionally and locally in the design, planning, commissioning and delivery of health and social care.

<u>Strategic Objective Two:</u> Through our work in advocacy, engagement and impact, the health and social care system responds regularly to people with

¹⁷ https://pcc-ni.net/about-us/our-council/council-members/

¹⁸ PCC (2022) Statement of Strategic Intent

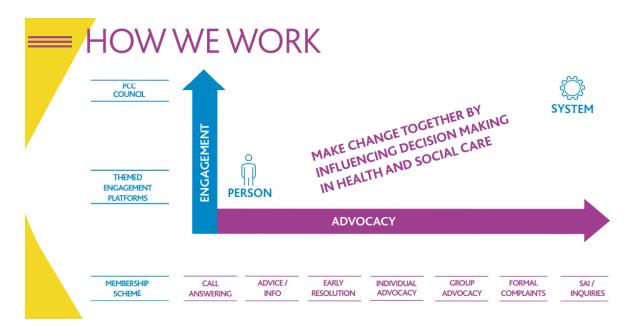
openness, honesty and compassion to address difficulties or failures in standards of care.

PCC provides advocacy services for the public, which range from helpline advice, early resolution of issues, individual advocacy, to supporting people through formal complaints and serious adverse incidents. If we identify a specific need that we cannot help with, we will connect individuals to a partner organisation within the voluntary and community sector or beyond, seeking to ensure people do not fall through gaps in the system.

We also bring members of the public, with common interest and lived experience, together with decision makers from the Department of Health (DoH) and Health and Social Care (HSC) organisations to improve existing HSC services and plan for the future.

PCC Delivery Model

A new practice model, introduced in response to the outcome of the 2019 review, updated and re-designed how the PCC provide support to the public across three core functions; advocacy, engagement and policy impact and influence, see diagram below.



PCC Connect

PCC Connect is about connecting the right person, at the right time, to the right information. Our *PCC Connect Freephone service*, often the first point of entry to the PCC, is the foundation of PCC Support; beginning with the provision of advice and information to the public.

PCC Connect also captures the initial stages of PCC Engage structures; particularly our *Membership Scheme* and our '*Make Change Together*' involvement methodology, which seeks to ensure the public can access involvement opportunities with us, across the HSC and beyond. This is supported by working in partnership with external stakeholders through a 'network of networks' approach and the development of 'positive passporting'.

PCC Support

PCC Support is our advocacy and support model.

Our advocacy and support model focus on **relationship building** and a **partnership approach**, putting the voice of the person at the centre of our work. This approach uses **advocacy and mediation skills** on an individual and group basis, to enable us to provide assistance (by way of representation or otherwise) to individuals making or intending to make a complaint relating to health and social care in the most effective way.

PCC advocacy and support begins with the first point of entry to the PCC, which can often involve the provision of *advice and information to the public* over the phone or via email. PCC contact details are widely available across a number of different sources including the NI Direct website (the official government website for Northern Ireland citizens), within the HSCNI Complaints Procedure; within complaints literature shared by each of the HSC Trusts who signpost complainants to PCC for independent support; on the PCC website; on social media platforms; and in literature shared by PCC.

Our focus is on seeking *early resolution of issues* through facilitated conversations with parties involved in a particular case. This can include a wide range of other service providers, HSC bodies and individual professionals. Our advocacy and support can include signposting and 'positive passporting' as noted above.

Where immediate early resolution cannot be achieved PCC advocacy and support carries through to *individual and group advocacy casework*. The formal complaints process can be onerous and difficult for members of the public. Therefore, the PCC focus is on assisting members of the public to achieve a resolution to their complaint where possible without invoking the formal aspects of the complaints process.

In some cases, this support and advocacy will however progress to a formal complaint process. The PCC also provides independent advocacy support in relation to serious adverse incidents (SAIs) and Public Inquiries.

PCC Engage

The objective of the PCC is to provide a powerful, independent voice for patients, clients carers and communities on health and social care issues through the exercise of its functions. PCC's new practice model provides the best method of facilitating the conversations, having their voice heard and building relationships between service users, patients, carers and families and the system which serves them. To meet this objective, PCC designed and created a *theme-based engagement platform* model of practice. Themed engagement platforms provide members of the public with a forum for engagement on specific areas of work and connect them with the Department and with representatives across health and social care and voluntary and community sectors. This is critical in fulfilling our statutory functions of *promoting the involvement of the public* and *representing their interests*.

An Engagement Platform is a space to bring together a group of people, with a common theme or interest and **lived experience**, to work together and make change in health and social care. Engagement Platforms allow participants to communicate their experiences and thoughts, related to a policy programme, with the PCC, as well as being able to share their views directly with decision-makers in health and social care. Engagement Platforms are a significant opportunity for decision makers in health and social care to have meaningful input from experts by experience, in service areas under review, development and reform.

Running alongside our engagement and involvement structures is the continuum of **advocacy and support** that the PCC offer in meeting our core statutory function of providing assistance (by way of representation or otherwise) to individuals making or intending to make a complaint relating to health and social care.

Engagement Platforms can also provide the opportunity for participants to raise their individual issues and concerns with the PCC directly whilst engaging in ongoing theme-based work. This may be in the course of a participation event itself and as part of group discussions. Online technology allows the PCC team to place a participant into a separate virtual room, during these discussions, where they can, in private or on a one-to-one basis, seek advice and discuss concerns with PCC staff. It can also happen after a session or event has concluded when PCC staff are approached by an attendee to raise an issue or complaint they have. In both cases, PCC staff would offer the individual support and advocacy to assist to address the issue they have raised during engagement.

In line with our statutory function to *undertake research into the best methods and practices for consulting and engaging the public,* PCC continues to develop our engagement structures, working alongside the public and our partners, and building on the learning from previous years.

PCC Impact

PCC Impact focuses on measuring and demonstrating the impact of our work, and communicating this externally. Through PCC Impact we seek to bring change on an individual, collective and systems level. PCC has a critical role in securing a 'seat at the table' for the public. The goal is to connect the evidence gathered through PCC advocacy and engagement work under PCC Connect, Engage and Support to influence change. Under PCC Impact, the aim is to ensure a focus on the best methods and practices for consulting the public about, and involving them in, matters relating to health and social care.

The PCC policy advocacy role is the process of negotiating and mediating a dialogue through which influential networks, opinion leaders, and ultimately, decision makers take ownership of the ideas, evidence, and proposals, presented by PCC on behalf of the public and subsequently act upon them.

The PCC's approach today is that it will contribute to and seek to influence policy and service developments by the Department and HSC bodies. The PCC will do so by attending and contributing to groups and meetings established to take forward such work; by engaging with service users and members of the public to seek their views; and by submitting evidence. This evidence is based on what those engaging

with PCC tell us as well as the practice experience of our staff who provide advocacy and support to the public.