Muckamore Abbey Hospital Inquiry

Closing Statement

The Patient and Client Council (PCC)

Date: 17th February 2025

1. The PCC was established as an Arm's Length Body (ALB) of the Department of Health (hereafter 'the Department') on 1st April 2009. The creation of the PCC was part of a major reform of health and social care in Northern Ireland, provided for by the Health and Social Care (Reform) Act (Northern Ireland) 2009 (hereafter 'the 2009 Act'). The functions of the PCC are described in the 2009 Act and have remained unaltered since 2009.

2. The PCC has provided two statements to the Inquiry of 27 January 2023 and 04 March 2024. Whilst the PCC's statutory functions have remained unchanged since 2009, the PCC's internal structures and the PCC's operating model have evolved and changed over time. As a result of various lessons learned exercises and operational reviews, the PCC can be considered to be a significantly different organisation post-2019 when compared to the pre-2019 PCC. Notable developments in the post-2019 PCC practice model include:
   - Increased engagement with patients and the public through a range of mechanisms including themed Engagement Platforms;
   - Using data and evidence to drive and improve our policy functions;
   - Improved methodology with respect to how PCC supports members of the public across a continuum of advocacy interventions.

3. The PCC's remit covers all of Northern Ireland, across the breadth of health and social care. Evidence from PCC is anchored in what we have '***learned***' from discharging our statutory roles of representing the interests of the public; promoting involvement of the public; providing assistance to individuals making or intending to make a complaint relating to health and social care; research into the best methods of engaging the public; and promoting the

provision by HSC bodies of advice and information to the public about the design, commissioning and delivery of health and social care.

4. The PCC is a small Arm's-Length Body with an annual budget of £2.1m. £1.8m is recurrent funds, £0.3m is non-recurrent funds relating to Inquiry related work. PCC employs 34 members of staff, excluding Council members. With a budget of £1.8m that is equivalent to ***less than £1 for each member of the public*** in Northern Ireland.

What the Public Should Expect

5. The Health and Social Care Service is a complex system at the best of times and in the current climate of fiscal constraint and resource pressures patients and clients face significant and sometimes enormous challenges when attempting to navigate it. Through PCC's engagement with patients and families, particularly during engagement on the Terms of Reference for this Inquiry, (PCC report on the engagement with current and former patient families and carers[1] paragraph 12.2 / 12.3) they stated that they "*believe that responsibility for the failure to act over the years points to systemic failures to hear the voice of the patients, families and carers... and called for improvements to staff recruitment and training, governance, safeguarding, and accountability mechanisms throughout Northern Ireland's adult social care services".*

6. In Muckamore Abbey Hospital, patients and families described situations in which they felt that they were ignored when they attempted to alert hospital staff, regulatory agencies, and other authorities about their concerns regarding patient care and treatment in Muckamore Abbey Hospital. This pointed to how families and patients experienced trying to be heard and alerting safeguarding matters. Initial complaints may have been safeguarding matters and required a clear process and rapid response to address, which is different from the complaints process.

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[1] PCC report on the engagement with current and former patient families and carers

7. The effective implementation of arrangements to address complaints and to provide advocacy support to patients and families are essential components of how clinical and social care governance operates to safeguard patients and their families. In Muckamore, adherence to complaints procedures and adverse incident reporting requirements appears to have been inconsistent. It does not appear that families and patients were routinely being made aware of the availability of the complaints process, and of advocacy services, or of the availability of support externally from organisations such as the PCC. It is also possible that there was a lack of expert analysis and understanding within the Trust, of what the data being generated from complaints and adverse incident reporting was showing was happening to patients in Muckamore wards. Alternatively, and perhaps in addition, given that the Trust did have data on complaints, adverse incidents and referrals to the police, it is possible that the interpretation of the data was subject to a form of confirmation bias. Trust management may have determined that issues were arising because of staff shortages and the merging of wards which somehow were beyond resolution because of resource constraints. Therefore, issues were managed and dealt with on that basis. The link between staff shortages and the issues which arose in Muckamore was specifically raised with PCC when engaging with families, particularly during the Terms of Reference, (PCC report on the engagement with current and former patient families and carers).

8. It could be proposed that if Trust management had followed a risk-based approach, regardless of potential resource constraints, the issues should have been escalated to the Trust Board and if necessary to the Department of Health.

9. No system is perfect, things do and will go wrong. Listening to and hearing patient and family's experiences should be the first line of defence when safeguarding vulnerable people from abuse at institutions whose purpose it is to keep them safe. To truly ***listen to understand***, organisations must critically demonstrate how patients have contributed to institutional change, improving the quality and safety of services for others.

10. The goal, and the challenge, is to build into the Health and Social Care system, from the highest level of governance and decision-making through to direct practice, a commitment to quality and safety driven first and foremost by ***'learning'*** from the ***'lived experience'*** of patients. For service providers, engaging with patients; capturing information on their lived experience; listening to their voices, should be central to and embedded in services, assurance arrangements and governance systems. This should include organisations' systems, processes and guidance which underpin service planning and delivery, governance, learning, and responding to adverse incidents and complaints.

11. Candour, courage and curiosity need to be expectations which are knitted into the fabric of all policy, processes, procedures and professional practice, creating a culture of openness and challenge. Clearly articulating learning, and consequent changes, guarantees that the voice of the public and particularly our most vulnerable people, does not get lost in the system.

Contextual Analysis of the HSC System

12. Present day reality is that health and social care services provided to individual members of the public routinely involves two or more HSC Trusts and on occasions cross border and private sector facilities and services. Service users thus experience the management of their care through a complicated matrix, which they feel they are left to navigate. Service delivery across the Trusts / cross border or private sector does not wrap around the individual, placing them at the centre.

13. The construction of our health and social care services governance and management is such that when things go wrong, Public Inquiries and investigations have routinely identified failures in communication as a key factor. Most significantly this involves failures to share information between different organisations, across and within organisations and failures to analyse information across and within organisations in order to be able to

identify the ***'bigger picture'.*** Red flags, significant learning opportunities and near misses may not be captured or explored in the most appropriate fora within and across organisations.

14. As an example, in Muckamore Abbey there were three separate external advocacy providers commissioned by five different Trusts each of which was primarily focussed on their own patients in Muckamore. There does not appear to have been a common approach amongst the five Trusts to commissioning these services, specifying what data each service provider was to collect on the issues being raised by service users and families, or to pool information from these advocacy service providers in order to see what the broader issues were in Muckamore.

15. The reality of how these services were delivered is described by Ms Marley (Bryson House) when she gave evidence to the Inquiry on 28th May 2024 (Day 84). In her evidence Ms Marley described how there were no formal or regular meetings or oversight meetings involving the advocacy service providers and how the advocacy providers met only patients who were referred to them rather than patients self-referring.

16. The reality of how access to these services was experienced by some patients and families was recorded by PCC when engaging with families, particularly during engagement on the Terms of Reference (PCC report on the engagement with current and former patient families and carers). Some families told the PCC that they did not report incidents of abuse or neglect out of fear, intimidation, or because they did not know who to go to with their concerns. These families wanted the Inquiry to determine whether advocacy and/or peer support was deliberately withheld from patients and families, and the role that this may have played in preventing abuse and neglect from being uncovered or addressed.

17. Several families of former patients reported that they were not made aware that formal advocacy or peer support services were available to hospital patients or their families. One respondent alleged that the South Eastern Health and Social Care Trust did not have a tender in place for advocacy

services at Muckamore Abbey Hospital until 2020. Respondents also alleged that the hospital restricted advocates’ access to client meetings and their presence on hospital wards, which prevented advocates from fulfilling the responsibilities of their posts (PCC Engagement on Terms of Reference, (PCC report on the engagement with current and former patient families and carers Paragraph 56). Taken together the evidence suggests that the methods available to communicate concerns were inadequate, confusing or non-existent.

18. Whilst communication within the Health and Social Care Services system is challenging and complicated, with the growth in the private sector health and social care provision, there is an additional concern with an emerging gap between both in information collection, exchange and communication.

19. The HSC Trusts have considerable autonomy when developing their individual policies, processes, systems and practices. Each HSC Trust can and does commission their own advocacy services. Whilst they are to be commended for this investment; the unintended consequence is fragmented provision in which a post code lottery exists. Thus, the quality and availability of what advocacy support is available to patients and families depends greatly on the value the Trust in which they live places on advocacy services.

20. The Statutory Duty of Quality introduced by the Department in 2003 was intended to ensure that clinical and social care governance around safety and quality was considered by HSC organisations at least on a par with financial governance. To meet this statutory duty requires that insights and intelligence gleaned from complaints and incidents, and systems which are in place to engage with service users and to capture information on service user experience of services, must form part of a service provider’s systems to identify quality and safety issues. Thereby managing and mitigating risks to service user safety and ensuring the provision of quality services.

21. Consistent with the requirements imposed by the statutory duty of quality, the guidance and standards issued by the Department places the responsibility for establishing and operating a complaints procedure on the organisations

providing the service. In the case of HSC Trusts, the Chief Executive is accountable for the handling and consideration of complaints. It is the responsibility of the organisation providing the service to ensure that all of their staff are familiar with the HSC complaints process. When engaging with patients and families (Engagement on Terms of Reference, PCC report on the engagement with current and former patient families and carers para 50) they repeatedly described situations in which they felt that they were ignored when they attempted to alert hospital staff, regulatory agencies, and other authorities about their concerns regarding patient care and treatment in Muckamore Abbey Hospital. Patients and families felt that it was important for the Inquiry to investigate how complaints, concerns, incidents, regulatory reviews and inspection outcomes/recommendations were monitored and acted upon. Within the Inquiry investigation, these concerns were highlighted by patients and families and explored in more detail.

22. Changes which require primary legislation can take a long period of time to realise. There are changes which would be best underpinned by new legislation and/or amendment to existing primary legislation. However, overwhelmingly changes could be delivered in the interim period by amendments to Department policy, guidance and Direction. We have detailed a number of areas for potential change in our previous statements to the Inquiry.

Advocacy Support and Services

23. Advocacy is the first line of defence when safeguarding vulnerable people. Although advocacy support was provided to patient and families at Muckamore through a range of models such as independent advocacy, peer advocacy, self-advocacy and family advocates, there was an apparent absence of commitment, investment and promotion of advocacy services to those most in need of them. That absence of commitment means that this important first line of defence did not readily disincentivise perpetrators of abuse.

24. Advocacy availability assists in creating a culture of openness and transparency and plays a fundamental role in governance, assurance and addressing inequality. PCC believe that appropriately supporting advocacy services provides a level of assurance that Trusts 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.

25. HSC Trusts, as the first point of contact for the public when things go wrong, and a complaint or SAI has been enacted, need to consistently inform and direct the public to the independent support available from PCC, and commissioned advocacy services. Based on evidence provided to the Inquiry, the referral to an advocacy service at Muckamore was dependent upon which Health and Social Care Trust the patient resided in before admission. Had the PCC or other independent advocacy service been signposted at Muckamore, then potentially complaints may have been investigated effectively and patterns may have emerged that may have informed the Trust's approach to monitoring staff. This contributed to concerns not being properly identified and consequently concerns were not adequately responded to.

26. 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 independent**. 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. The decision on which advocacy organisation is identified to provide support to a service user with a complaint; SAI and Lookback reviews should also be made independently of Trusts. At the present time Trusts can commission their own advocacy services and can promote these ahead of the services provided by the PCC. They are expected, as part of the complaints system, to make service users making a complaint aware of the role of the PCC but are not required to promote the role of the PCC ahead of the services they have themselves commissioned.

27. PCC does not believe that the public can be assured that the current advocacy commissioning arrangements within the Trusts can deliver this independence i.e. structural, financial and psychological. Currently very few advocacy services are commissioned regionally and independently of HSC Trusts. There were no independently commissioned advocacy services within the dedicated advocacy services provided in Muckamore Abbey Hospital prior to the introduction of a PCC service on site in 2020.

28. As stated in my Corporate Witness Statement to the Inquiry 4th March 2024, *"In Muckamore Abbey Hospital it appears that three separate organisations were employed by the five HSC Trusts to provide advocacy services. From the perspective of effective governance, the PCC do not have clarity on what arrangements were in place to ensure that the management team in Muckamore Hospital had access to data from the different advocacy providers aggregated to give them an overall picture of any issues".*

29. 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 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.

30. The need for this is borne out by evidence given to the Inquiry by Ms Marley, recently retired Director of Bryson Care, in relation to Organisational Module 1, Patient Advocacy and Representation. In paragraph 73 of the transcript, Day 84, Counsel to the Inquiry highlighted paragraph 25 of Ms Marley’s Corporate Witness Statement where she had stated that *“The **challenge function of advocates was impacted by the commissioning approach** to procurement in that the Belfast Trust funds and sets priorities for the service which **dilutes the true independence of the service***” and that it “*..needs total independence from the Trust to challenge more robustly where the Trust disagrees with a process or outcome.“* She also stated that “*if you’re receiving funding and you’re in a contractual relationship with the Trust, it **does make it difficult to feel totally independent of them**, and we would prefer to have some kind of arm’s length arrangement where the funder or commissioner is not the Trust”,* explaining that on occasions the Trust had reminded Bryson House that this was ***“a contract with the Trust”*** when Bryson House staff were raising an issue with the Trust.

31. The PCC’s interest is in having systems and structures which promote and maximise 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.

32. The PCC as a statutory body escalates individual / group cases / issues and matters of concern as appropriate to and within HSC Trusts; to the RQIA; to

the PSNI; to the Ombudsman; to NICCY and CoPNI. The PCC would note the absence of a co-ordinated model across the network of advocacy services provided by the voluntary and community sector to ensure similar escalation. This needs urgently to be addressed; vital information is potentially not being communicated to assist in mitigating service quality and safety risks, and implementing service improvements.

33. Implementing a culture of connectedness, working across a continuum, advocacy services require a mechanism to support the development of advocacy policy, practice, training and standards e.g. an ***independent regional body*** acting as a ***'hub'***. To leave matters as they are, risks the persistence of the confused patchwork of advocacy and miscommunication which contributed to the failures at Muckamore Abbey Hospital.

34. In the absence of a 'hub', the PCC is currently creating a new model of a ***'network of networks'***. Given the breadth of the PCC remit across health and social care, it is critical that within our individual and group advocacy work we take account of any networks, complementing the role of other professionals or advocates working within a case, particularly where they might have a specialist or expert role in an area. This initiative has been driven by the need to connect to the range of voluntary sector advocacy services.

35. In the interim HSC Trusts should link the PCC with HSC Trust commissioned advocacy services to support a co-ordinated approach to the provision of support / advocacy to the public.

Complaints

36. The complaints system is focussed on processing complaints according to HSC procedures, seeking a resolution to complaints raised by individuals and their families. Earlier in this statement in paragraph 5 and 6, I noted that patients and families described how they were ignored when attempting to alert hospital staff to concerns about patient care. The adherence to complaints procedure appeared inconsistent in Muckamore Abbey Hospital.

37. The Trusts are required by the Department's Complaints Direction, to share information about PCC with those making a complaint. The HSC Trusts can do so, for example, by providing a list of organisations from whom complainants can get support which includes PCC on that list as just one option / one provider of advocacy services. The PCC do not necessarily come top of this list, even though the public have a right in legislation to PCC advocacy when making a complaint about health and social care. It is important that there is openness and transparency within the HSC as to how the HSC responds to complaints.

38. The PCC acknowledge current work ongoing by NIPSO to introduce a Model Complaints Handling Procedure (MCHP) across the public sector, to include HSC. It is our understanding that the Department of Health's Complaints Direction, Standards and Guidance, or an equivalent accountability framework will continue to underpin the MCHP. Our commentary here applies equally to the underpinning accountability framework of any future model.

39. Inadequate training is an area that does not always get the attention it deserves but in PCC's view, it was a contributing factor to the events that took place at MAH. Broadly, 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. It is not always evident that HSC Trust staff have been trained on the appropriate complaints process and this potentially increases risk to service user's safety and a collapse of the proper procedural requirements. Without this there will be a failure to mitigate risk through appropriate patient care monitoring.

40. Therefore, 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. At paragraph 51 of my Corporate Witness Statement, 4 March 2024 I set out what the PCC considers should be within such training, including the need to understand the role of advocacy in

safeguarding, and the requirement for clear information about how to make a complaint. 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.

Safeguarding

41. PCC have experienced, in their work with vulnerable patients and clients, that initial complaints may actually have been safeguarding matters that require a clear process and rapid response to address, which is different from the complaints process. The events at MAH suggest that the safeguarding controls and polices in place were inadequate.

42. Ms McConvey noted in para 38 of her statement to the Inquiry, 27th Jan 2023 that "The engagement work regarding the Terms of Reference of the Public Inquiry led to additional advocacy casework and work related to safeguarding. The PCC's advocate assisted patients and carers to raise historic and/or ongoing adult safeguarding concerns in the hospital and the community, and provided ongoing advocacy support to patients and carers throughout the adult safeguarding investigation process. In the period November 2020 to July 2021 the PCC advocate escalated 25 cases to the relevant Trusts for safeguarding investigations and attended 33 meetings in relation to safeguarding investigations/SAIs".

43. Families and patients require a clear, simple understanding of the safeguarding process, particularly at times of great distress. This should include a method to escalate concerns about the safeguarding process, independent of it. In para 146, Ms McConvey's Statement to the Inquiry 27th Jan 2023 suggests that responding to safeguarding in a different way going forward would assist families to navigate the complexity of safeguarding investigations. In particular, PCC would emphasise the need for:

    i. Joint training with Trust staff and advocacy providers with regard to safeguarding procedures for children and vulnerable adults, ensuring that patients and families are fully informed and guided through the process;

ii. A clear escalation process for safeguarding concerns being investigated in each Trust, mapped out on one page, which patients, families and advocates can trigger or enact when they feel or experience challenges, blockage or delays in addressing their concerns;

iii. In line with a clear escalation process, each Trust should appoint an ***independent senior designated officer*** (who is not operationally responsible for the programme of care being investigated), as the person to whom matters are escalated by Trust staff, advocates and family members;

iv. A clear feedback process for families and patients to understand how the safeguarding matter is being investigated, how it has been addressed and what remedial measures or learning has been identified to prevent a repeat of similar incidents in the future; and

v. Consideration to be given to how lessons learned from safeguarding incidents are communicated in a similar way to that of learning identified in Serious Adverse Incidents (SAI's) i.e. regional/cross-sectoral/cross-organisational.

Serious Adverse Incidents

44. PCC have experience where complaints should have been identified as SAIs or patient safety events. The Serious Adverse Incident (SAI) review process is different from complaints, which focus upon seeking a resolution, in that it is a system mechanism designed to ***identify learning*** when something has gone wrong. This is particularly relevant in light of a recent RQIA inspection report on Muckamore (July 2023- May 2024)[2] which identified issues re. staff training and awareness and compliance with regional reporting of incidents i.e. the issues around incident reporting and escalation are not just historical, they persist in recent times.

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[2] 020426_MuckamoreAbbeyHospital_Care_19072023.pdf

45. While the same event can result in a complaint and an adverse incident report, they are separate systems and it is important that there is clarity amongst all stakeholders about their separate purposes and to manage the interface between the two. For example, when Trusts apologise to families it is important to families that Trusts can articulate what exactly they are apologising for. This might therefore require a review of an adverse incident to be completed before the response to a complaint can be concluded.

46. Service users and families see the starting point for any SAI Review as the need to ***establish the facts of what happened***. The extent to which facts are established in a way which is comprehensive, unambiguous and accessible to service users can vary significantly. The foundation of the SAI review process is not intended to assign blame to individuals. Service users and families struggle with the idea that ***professional failings by individuals are not addressed*** within the SAI Review process. The tension between identifying system learning and addressing the role of individuals in a SAI, which may require individual staff to receive training, or in some instances referral to a professional body, ***needs to be explicitly resolved.***

47. The Department is undertaking a review of the current SAI process. They are at the policy development stage and have committed to carrying out a public consultation in due course.

48. PCC's experience of the current SAI Review process means that there is often a need to provide advocacy support to families engaged in SAIs for up to five years. The IHRD report and its recommendations recognised the need for service users, and families, to ***have access to independent advocacy support***. The PCC would call for the implementation of recommendation 37 (iv) '*Trusts 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*[3] *cases' (IHRD Report 2018).*

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[3] A definition of 'complex' will be agreed with Serious Adverse Incident Workstream

49. PCC would highlight that although the current SAI guidance issued by the HSCB (now SPPG) refers to the PCC, ***the PCC role in SAI Guidance is not specified in the same way it is in the Complaints Direction*** issued by the Department of Health. Thus, service users and families who engage with the SAI process do not routinely report a level of awareness of the PCC or having been given contact information about the PCC.

50. To ensure high level oversight the PCC would ask for Annual Reporting on the requirement, as set out in the HSC Board Member's Handbook, that Board Members should seek assurance that the organisation has fully engaged with service users/family and carers in SAI reviews.

51. There would be considerable value in the Department issuing a Direction to underpin the SAI system, and requiring, as part of the Direction, that Trusts report on how they have met the requirements of the SAI guidance and the Direction itself.

Triangulating data and insights for early intervention

52. Building on Trust-based complaints / incident / review data, essential to mitigating quality and safety risk, there is clearly the potential of creating a coalition and networking of service data and learning experiences.

53. The **Early Alert** System provides a channel which enables Chief Executives and their senior staff (Director level or higher) in HSC organisations to notify the Department in a prompt and timely way of events or incidents which have occurred in the services provided or commissioned by their organisations, and which may require immediate attention by Minister, Chief Professional Officers or policy leads, and/or require urgent action by the Department.

54. Careful consideration is required on how to collate and analyse all HSC data on 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. Any approach or unit established to carry out this work

should also enable the triangulation of this information with patient experience data, such as that collated through engagement work and the current regional Patient Experience programmes including Care Opinion and 10k Voices.

55. Such an approach could be an independent locus 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.

56. PCC have previously proposed to the Department in taking forward the implementation of ***IHRD recommendation 91*** i.e. *"The Department, HBSC, PHA, RQIA and HSC Trusts should **synchronise** electronic patient safety incident and risk management software systems, codes and classifications to enable effective oversight and analysis of regional information"* that implementation should include **PCC and third sector providers of advocacy services within the HSC system as part of contractual agreements**.

57. Without the above there will be a failure to mitigate risk through appropriate patient care monitoring.

Duty of Candour

58. Predominately the PCC work directly with families in distress, requiring assistance to navigate a complicated system to understand what has gone wrong in the care and treatment of their loved one. When things go wrong in health and social care services and the response is not managed appropriately, it can result in a toxicity that tarnishes the system as a whole.

59. The public rightly hold the strong expectation that candour and openness should be exhibited routinely, day-to-day. People are naturally devastated and outraged if and when they find this not to be the case. PCC believe that 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"[4].

60. Northern Ireland is a small community. People are often connected through family, professional background or live in the community as neighbours close to their place of work. The impact, power and influence of personal relationships needs to be considered when holding others to account. When engaging with patients and families on the Terms of Reference for this Inquiry, families set out how they felt, and experienced, that the interconnectedness of personal relationships impacted on quality of care and safeguarding;

    "Respondents repeatedly alleged that a large number of the Muckamore Abbey Hospital staff were related to one another. Respondents alleged that staff "acted like a large family" in the sense that even those who were not related to one another were exceptionally close. In light of this information, respondents ask the inquiry to uncover the scope of nepotism within the hospital. Concern was raised about the extent to which relationships between hospital staff prevented individuals from being held accountable for poor performance or misconduct". (Terms of Reference, PCC report on the engagement with current and former patient families and carers Paragraph 57)

61. The PCC believe 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.

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[4] (https://www.health-ni.gov.uk/sites/default/files/consultations/health/doh-duty-of-candour-being-open-consultation-document.pdf Duty of Candour and Being Open Policy Proposals for Consultation March 2021 para 4.39 and Cited in PCC DoH Consultation on the Introduction of a Statutory Duty of Candour: PCC Council Response)

62. Evidencing support for advocacy services provides a level of assurance that HSC Trusts are committed to being learning organisations, committed to meeting their statutory duty of quality and are appropriately invested in the ***duty of candour and a culture of openness and transparency***.

HSC Trust Boards and Governance

63. The relationship between the Department and its ALBs is described in a 'Framework Document[5]' which was produced by the Department itself, to meet a requirement of the 2009 Act, and which has been subject to updates by the Department.

64. It is important to explain to the Inquiry what the PCC understands as its role and responsibility within the HSC system of Governance. Paragraph 6.42 of the Framework Document states the PCC role *"provided 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".*

65. The PCC understands its role within the system of governance and assurance as providing HSC Trusts and the Department 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.

66. The specific assurance which PCC can provide is in relation to how the PCC has discharged its statutory functions, within PCC's stated limitations (see para 87, 88 and 91). The HSC Trusts and by extension the Department **are not passive recipients of assurance** provided by the PCC, RQIA and others**.** It is for the Boards of HSC Trusts and for the Department to weigh all of the evidence they have from multiple sources and ***actively decide for***

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[5] DHSSPS Framework Document - September 2011 | Department of Health

***themselves** whether or not they are 'assured' or reassured in regard to the services provided or commissioned by HSC Trusts.*

67. The PCC does not understand its role to be that of providing a positive objective assessment i.e. assurance to either HSC Trusts or the Department that ***'all is well'*** in health and social care or at least that things are being appropriately delivered and managed, with risks appropriately managed. ***Nor is it PCC's role to provide reassurance*** to either the HSC Trusts or the Department.

68. In the case of HSC Trusts in particular, they should make these assessments in the context of a range of statutory responsibilities placed on them including the Statutory Duty of Quality. To make these assessments of whether or not they are 'assured'; HSC Trust 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 including PCC, RQIA, NISRA, DoH Statisticians, PHA etc. They also need to be aware of the gaps in information which exist, particularly in relation to data on social care.

69. Currently data and evidence received by HSC Trust Boards is provided predominantly by the Executive Teams who are responsible for the operational delivery of the services about which assurance should be sought and provided. This was evidenced by Mr Dillon (Retired CEO Belfast Trust) who, when giving evidence, Day 113, 9th Oct 2024, para 130 in response to the question *"would [it] be open to any director to bring a matter to the Chair. How would that practically have been done; at a Trust Board meeting?" stated* that *"the normal route would be up through the executive; the director would say there is something I want to escalate to exec team. **Then we decided that this is where they have been escalated up to Trust Board"**.*

70. Mr Dillon went on to state in para 161 that *"It was the summary level information that the Board can interrogate, constructively challenge and satisfy itself that those things were being properly discharged and done through the organisation".*

71. The Inquiry Panel member, Dr Maxwell questioned further this matter stating in para 255, page 174 "*The Inquiry has heard a lot of evidence about red flags; the increase in incident reporting; the number of patients who were inappropriately in hospital, it wasn't the right environment for them; the staffing crisis, and you're saying it was being triangulated at Directorate level. You have also told us the Board weren't looking at the safeguarding reports…"* to which Mr Dillon responded *"Not the individual reports".*

72. The PCC view is that additional data, evidence, insights and direct experience of patients and clients from sources external to internal Trust systems/structures is required to balance this process of information management and communication. Governance, assurance, performance and accountability arrangements need to place much greater weight on the voices and experience of service users and their families.

73. Being curious, and Trust Boards' potential lack of curiosity, was explored during the evidence provided by Ms Jack (CEO Belfast Trust, recently retired) 16th Oct 2024, (para 211 - 213). Ensuring there is a diversity of opinion / experience of members and information presented will create the opportunity for, and build, a culture of curiosity. PCC believe that it is essential that HSC Trust Non-Executives should routinely receive information and data on service user and family's experiences of services directly, and in addition to/independently of that provided through HSC Trusts Executive Teams. Assurance is ***about HSC Trust Boards weighing the evidence, including from independent sources, and determining for themselves that standards are being met***.

74. Effective and successful governance in a Trust is determined by its internal policies, structures and processes including risk management, dealing with and learning from complaints and adverse incidents and engaging with the public and listening to the service user voices - the ***'lived'*** experience.

75. To fulfil their role effectively, HSC Trust Non-Executives must have the skills and expertise to undertake the role of independent reviewer, having oversight

to determine whether or not these internal policies, structures and processes; particularly relating to learning, complaints, adverse incidents and engaging with and listening to the public voice; are fit for purpose to deliver quality and safety in the services that the Trust provides.

76. Unlike HSC Trusts, the PCC Council (Board) is composed entirely of Non-Executives. In this respect the relationship between the Council and Chief Executive and Executive Team in terms of accountability for the performance of the PCC is straightforward. The Chief Executive and Executive Management Team are charged with delivering on the organisation's functions in line with the strategic direction set by the Council and are accountable for both what the PCC delivers and, crucially, how it delivers on its objectives and targets. The PCC Council (Board) in turn are accountable to the Minister and the Department.

77. In contrast, within HSC Trusts there is an '***integrated Board',*** in that membership includes both Executive and Non-Executive members operating as a single corporate Board. Those with operational responsibility and accountability in the Executive Team are also members of the HSC Trust Board. This Integrated Board structure may provide challenges when it comes to understanding how accountability and governance arrangements are to be applied, and how they are perceived to be accountable to the public.

78. The PCC believes that the resources invested in, and the policies and systems underpinning, governance, advocacy, complaints, adverse incidents and involvement need to be treated as key components of the delivery of safe, good quality front line services and not as systems which are separate from, or running alongside, front line service delivery. 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. Trust Boards need to systematically ***integrate the voice of lived experience*** in their membership, representing the most vulnerable

groups including looked after children, people with learning disabilities, people with mental health issues and older people, as examples.

79. The Duty of Quality and requirements to have effective systems of governance sit with each HSC Trust, its Board and management. The PCC would suggest the introduction of a requirement for HSC Trusts to report to their Board at the end of each year, and include in their Quality Report, information on how they have complied with each of the individual DoH complaints standards, and with any equivalent advocacy standards or adverse incident/SAI standards which may be issued by DoH.

80. To meet the statutory duty requires that insights and intelligence gleaned from complaints and incidents will form part of a service provider's systems to identify quality and safety issues, thereby managing and mitigating risks to service user safety and ensuring the provision of quality services.

81. Given the PCC's statutory functions, if resourced to do so, it could have a role in representing the interests of the public and providing independent assurance at Board level, as set out in previous statements. As a practical example, the PCC could have an influential and impactful role on behalf of the public at Board level through the following:

- The introduction of a requirement for the HSC Trusts to consult PCC on their internal complaints, SAI, PPI and Lookback policies and to include PCC assessments of same in papers to their Boards when seeking approval for those policies.
- Changes to Departmental requirements for the HSC Trust's Annual Quality Reports to require that a section of the report be provided independently by the PCC setting out how patients / service users experienced engaging with that Trust.

82. 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.

83. 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.

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

85. Most importantly, there is a wealth of evidence from research and other public inquiries on the vulnerability of people with learning disabilities. In the context of Muckamore Abbey Hospital there are now a large number of service users who historically would have lived in and been treated in the hospital. This population is now dispersed across a large number of facilities and services in the community. In many respects, the care they receive can be less visible and potentially less open to scrutiny than it was when they were in the hospital.

86. Governance arrangements need to be proportionate and sufficiently robust to protect the interests of this population where they are living now and to mitigate risk. These mitigations need to include **robust mechanisms for hearing directly the experience of service users**, and mechanisms for independent assurance. Internally, the voices of individuals and their family's need to be heard within the system of governance and risk management, knitted into practice and organisational culture. We have set out elsewhere in this statement and in previous statements, proposals, external to Trusts or service providers, which might add strength, and independence, to that voice.

Role, Reach and Powers of the PCC

87. Given the reality of PCC's budget, size and remit, the PCC has to prioritise within its current 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 Departmental and HSC decisions on HSC structures and on how, when and where services are delivered.

88. Current legislation and PCC resourcing do not, in reality, reflect the critical nature of the PCC's role to the system and its assurance mechanisms, as portrayed in official documentation**.** The current PCC legislation, and guidance around PPI, complaints, SAIs and Lookback exercises has created the position that ***HSC Trusts can determine for themselves how and when they engage with the PCC.*** The PCC has highlighted these issues and we will continue to engage with the Department around the changes we would like to see to legislation, guidance and resourcing.

89. The Health and Social Care Reform Act NI 2009 states that HSC Trusts ***must co-operate*** *with the PCC* with the following ***caveats:***

> *2) In particular, such a body must—*
>
> *(a) consult the Patient and Client Council with respect to such matters, and on such occasions****, as the body considers appropriate****, having regard to the functions of the Council;*
>
> *(b) furnish to the Council,* ***subject to such conditions as the body may specify, such information*** *as the Council considers necessary to enable it properly to exercise its functions*

90. To effectively support and advocate for service users, the PCC would welcome changes to the Health and Social Care Reform Act NI 2009 to remove the caveats in relation to the duty to co-operate so that HSC Trusts ***must co-operate with the PCC.***

91. The approach of establishing partnerships and building relationships with others can mean that the PCC is able to exercise a positive influence in/on the system – albeit via soft skills such as mediation and collaboration, rather than through 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 where results are being achieved. It must be stated therefore that the ***limitations of the PCC's statutory powers coupled with the PCC's size and budgetary constraints*** means that the PCC can and does lack the desired leverage when seeking to achieve the positive change expected by the public.

92. That being said, PCC have demonstrated the potential of a new model of practice, following a significant journey of change and development in the provision of advocacy services. This includes a focus on early resolution, which seeks to achieve timely, constructive outcomes for those affected, to issues or complaints. In 2018-2019, approximately 85% of those assisted by the PCC Client Support Service were supported through the Health and Social Care formal complaints process. Only 15% were supported through an informal or early resolution complaints process. In 2023-2024, with the implementation of our new practice models, **57% of cases were resolved through early resolution**. We recognise that the development in practice is a continual ongoing process as we gather, understand and integrate our learning from our practice, reviews, inquiries and research.

Concluding

93. We know that **effective advocacy clearly plays an important role in helping to safeguard, and empower, patients, their families and carers**. Listening and hearing people's experience is the first line of defence when safeguarding vulnerable people. Access to advocacy plays a fundamental role in governance and assurance. PCC believe that ultimately advocacy has the potential to **lower systemic costs** as potential problems would be addressed early and possibly more constructively. Trusts engaging proactively with advocacy providers and user experience could provide an opportunity to **be alerted to emerging trends** before they become costly scandals. This is of

overall benefit to the public, to service providers and to the most vulnerable in our society.

94. The successful promotion of patient and family engagement with advocacy services is to a large degree determined by the DOH and HSC system's commitment to, and investment in, advocacy. Understanding that advocacy provision may not be able to fully prevent a crisis, it can certainly help to deal with it at an earlier stage through improved patient engagement and contribution to system-wide trend spotting. Many of the proposals outlined in this statement and previous will require the reconfiguration of current resources within the HSC and/or additional investment, but they have **real potential to be impactful at scale**.

95. Many of the gaps and weaknesses in HSC systems have been identified by Public Inquiries which have already completed. The full implementation of the recommendations from the Neurology Inquiry (2022) and the Inquiry into Hyponatraemia Related Deaths (2019) on Complaints; the statutory Duty of Candour, SAI process; SAIs involving deaths; Trust Governance; and Culture and Litigation would go a considerable way to restoring public confidence.