Patient and Client Council (PCC)

The Role of the PCC

The Patient and Client Council (PCC) is a statutory corporate body established in 2009 to provide a powerful, independent voice for patients, clients, carers and communities on health and social care issues within Northern Ireland[1] 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.[2]

We provide 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, ensuring 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.

The PCC welcomes this consultation and inquiry into Access to Palliative Care Services. Whilst our advocacy and casework numbers are small in relation to Palliative Care, our clients and those we engage with have raised some issues and concerns. We have considered the general nature of the information that we hold, whilst useful to the Committee, does not lend itself to answering the Committee’s survey questions.

Advocacy work

In the last five years there have been 28 concerns raised through our Advocacy work. Whilst these numbers are small they reflect a variety of experiences with Palliative Care Services to draw evidence from. Issues raised included with the speed of care packages and hospital equipment being provided when Palliative Care is taking place at home. Other issues involved delays in discharge from hospital, which have caused distress to patients and families who have planned for their loved one to be cared for and pass at

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[1] DHSSPS Framework Document – September 2011, Department of Health

[2] Health and Social Care (Reform) Act (Northern Ireland) 2009

home. In other cases, families deemed the coordination of support services to be lacking, leaving families to navigate and seek support services themselves.

Some families were concerned about how ‘Do Not Resuscitate’ discussions took place. They felt the discussions were vague and ‘not to the point’, with patients not understanding exactly what was being discussed. Some families told us that they only discovered a ‘Do Not Resuscitate’ order after the patient had passed away, leaving them distressed that they had not been made aware of it.

Concerns were raised by some families about the internal communication structures between staff as well as with patients’ family members. The concerns include incorrect medicines administered, the lack of detail when informing relatives about the treatment plan in the time before a death, the ‘insensitive’ manner in which the news of a loved one’s passing was delivered to relatives, and the timeliness of the completion of relevant documentation following a death.

One case highlighted the conflicting guidance they received regarding isolation when a family member is receiving palliative care. This was concerning for the family who were unsure if their relative would survive the isolation period.

Advanced Care Planning

In 2021 the PCC facilitated engagement with the public on Advance Care Planning and the development of new policy for NI. The PCC held a number of sessions to gain the views of the public. We also ran a dedicated phone line to assist the public in completing the consultation. In October 2022, following this extensive engagement, the regional Advance Care Planning policy was launched.

Bereavement Charter work

The PCC, as part of the NI Bereavement Network, worked on the development of a Bereavement Charter for NI. We established an Engagement Platform with members of the public, representatives of the community and voluntary sector, and others with an interest in bereavement. In 2022 we published a report summarising our engagement. Through our discussions on grief and bereavement some of our members talked about anticipatory grief in the lead up to a loved one’s death. Members spoke of the fear, worry, anxiety and guilt they felt before a death. Some spoke of the lack of support they had available to them and their families before a death. Members said:

- “It’s not just grief, but fear coming up to that loss, or guilt too that someone will die and there’s nothing you can do in the run up to the loss.”

- “the anticipatory loss is one full of worry, anxiety and fear … I wasn’t expecting the amount of fear, the paralysis, lack of sleep and panic attacks which went on for 6 months after the death.”

The PCC continues to support the work on the NI Bereavement Network in the design of a Bereavement Charters for Adults and for Children and Young People in NI.

Continuous involvement

The PCC welcomes the approach the Health Committee is taking to its review and is happy to engage with the Committee on ensuring the ongoing involvement of patients, their families and stakeholder organisations in the next stages of the review. PCC recognise, and have been driving conversations regionally and with the Department on, the need for greater strategic cohesion in public engagement in HSC. The PCC considers that involving the public in the development of policies at an early stage, makes for better policies and also affords fuller understanding of concerns and positions at an early stage. It affords the opportunity for concerns and issues to be appropriately addressed as policies and proposals are developed. Through harnessing the shared experiences of a diverse range of people, there is the potential to develop better and safer policies and services, which deliver better outcomes, built on a foundation of participation, which itself builds support and trust.

The PCC is happy to discuss with the Committee for Health any aspect of this consultation response.