

Submission to Committee on the Health Care Complaints Commission

2024 Annual Review of the Health Care Complaints Commission

Health Consumers NSW

Health Consumers NSW (HCNSW) is the peak organisation and advocacy body for health service users in NSW. We are an independent member organisation and a registered charity. We provide a voice for patients, their family members and carers, patient leaders, health consumer representatives in NSW, and health consumer organisations.

Our vision is high-quality health systems, policies, services, and research driven by strong consumer voices.

Health Consumers

In this submission, health consumers are defined as people who use, have used, or are potential users, of health services including families and carers.

Consumers may participate as individuals or collectively, through informal groups or via consumer organisations.

We are aware that the term 'health consumer' is contested. Some groups feel the term blurs the distinction between the needs and experiences of patients and carers, while others are critical of the association of the word 'consumer' with market-based approaches to delivering healthcare. The term was originally used by consumers of mental health services in the 1990s as part of a rights-based discourse. It is in this spirit that we use the term.

The Experience of Making a Complaint

HCNSW does not have a dedicated funding stream or staff member working on complaints or engagement with the health complaints system in NSW. We cannot, therefore, provide the committee with a consumer-focused analysis of the performance measures reported in the HCCC's annual report. We can offer an overview of the **experience** of making a complaint, as reported to us by our members.

Members report that starting the complaints process online can be confusing and unsettling, especially for people unfamiliar with online systems. One member told us that once their complaint was submitted the page refreshed too quickly for them to print or write down the reference number, and they were left unsure of if the complaint had been successfully submitted.

Stakeholder Engagement

The term 'engagement' has come to mean many things in health service management. For some, engagement is a one-way communication process, from the service to the stakeholders. Successful engagement is seen to be when stakeholders receive and understand the messages from the agency. For others, engagement means the two-way collaborative processes by which stakeholders are involved in the design and governance of services. Both are important and required for successful complaints management, HCNSW recommends the committee develop a definition of 'stakeholder engagement' and seek measures from the Commission that show both communication and collaboration outcomes.

Wide and Strong community awareness of the role and functions of the Commission

HCNSW does not believe there is wide and strong community awareness of the role and functions of the HCCC.

The complaints process in NSW is overly complex. Consumers often tell us they do not know where to start a complaint or give feedback. We are aware that the HCCC is working with other co-regulators to develop a 'no-wrong door' approach to complaints, where people are guided to the correct agency to make their complaint. HCNSW welcomes this much needed initiative, we would like to see experience measures in future annual reports that show the impact of this on complainants' experience.

We also believe that there is confusion in the community about the role of the HCCC and other co-regulators. Many people do not know the HCCC exists, and those that do are often confused about the function of the Commission. The patient safety and system improvement role of the HCCC is not well understood; with many people believing that the complaints process is a way for them to achieve restitution.

This misunderstanding, paradoxically, also means less complaints are lodged with the commission, and valuable data on safety patient is lost to the system. HCNSW has encouraged some members to make a complaint after hearing their story. People tell us they want to see system change, but did not consider making an official complaint because they were not seeking monetary restitution.

Independent support for Health Consumers Making Complaints

Health is one of the few human services that does not fund or resource independent individual advocacy services. People need support in navigating both the extremely complex health system and the equally complex complaints system in NSW.

In recent years, health services have supported new roles to assist people navigate the health system. There are growing numbers of care navigators,

coordinators and peer support workers who help people through the healthcare system. As well as funded consumer and community groups that provide support and advice to different consumer populations.

No such support or services exist for people caught in the complaints system.

Funding an independent consumer and community organisation to support people through the healthcare complaints process would be an effective way to:

- improve consumer awareness of the role and function of the Commission,
- reduce people's time in making a complaint and navigating the system, and
- Provide a better experience for complainants.

Such services exist in other jurisdictions, and the experience of aged care and disability services also provides a model for how such an advocacy and support service could operate.

We recommend that NSW investigate establishing an independent advocacy and support service, to assist community members through the health complaints process.

HCCC engagement with the Commission

HCNSW has worked with the HCCC in providing advice on how to involve more consumers in the design of HCCC systems and processes, in complaints management, and in governance. We meet regularly with their consumer engagement team. We have helped them source consumers for user testing of their website.

In recent months HCNSW has been working with the HCCC, the Australian Health Practitioner Regulation Agency (Ahpra), and the Health Professional Councils Authority (HPCA) on an engagement project. This project seeks to design better communication about the work of the Commission and the other co-regulators. HCNSW has held a focus group with our members to better understand the perceptions and experience of consumers and consumer organisations of the HCCC and other co-regulators.

This work is very welcome, and we are heartened by the commitment of the colleagues from HCCC, Ahpra, and HPCA to improve their engagement with consumers. This work is progressing more slowly than any of us would like. HCNSW has limited capacity to resource this work within our current agreement with NSW Health, and none of the co-regulators have a dedicated budget to engage HCNSW to support this project.

Sharing and Analysis of Complaints and Feedback Data

HCNSW is concerned that the patient safety and system improvement function of the HCCC, and other co-regulators, is restricted by incomplete and immature data sharing processes. Consumers can make complaints and offer feedback to multiple agencies at different levels in the health system: complaints can be made at individual facilities, Local Health District, or at a state level.

There is no effort to centralise and analyse feedback and complaints data on a state level. The under sharing and analysing of this data means emerging risks to patient safety are being missed, trends overlooked, and solutions and systems improvement not identified and shared.

Additional Performance Measures

HCNSW recommends that the following performance measure be developed:

- Experiential measures – measures that show both people’s satisfaction with the complaints process, as well as the overall outcome of the complaint.
- Engagement measures – the level to which health consumers and members of the community are involved in design and governance, and the experience of stakeholders involved in these collaborative processes.
- Impact on patient safety and system improvement. Qualitative and quantitative information on how the work of the HCCC has resulted in improved patient safety

Additional Recommendations

HCNSW further recommends that the Committee:

- Develop a definition of ‘stakeholder engagement’ and seek measures from the Commission that show both communication and collaborative outcomes.
- Recommend the establishment of an independent advocacy and support service, based in a consumer or community organisation, that assists community members through the health complaints process.
- Recommends that Health Consumers NSW, and other consumer organisations, be resourced to support the Commission, and other co-regulators, to partner with consumers in the design and governance of complaints processes
- Recommend that systems be developed to centralise and analyse feedback and complaints data on a state level.