HCQ HEALTH CONSUMERS QUEENSLAND

Health Consumers Queensland submission

Discussion Paper:

Expanding healthcare quality and patient safety reporting

Queensland Health

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About us

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity and we believe in improving health outcomes for people in Queensland.

Consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system.

Consumer engagement is when health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels.

OUR MISSION

Health Consumers Queensland empowers Queensland consumers to lead and drive better health outcomes.

OUR GUIDING PRINCIPLES:

Health Consumers Queensland is committed to:

- Influencing individual and system change in health services through ensuring the consumer perspective is central in the planning, design, delivery, monitoring and evaluation at all levels.
- Partnerships and collaboration with organisations, service providers and stakeholders.
- Quality, safe, affordable, timely and accessible services that deliver the right care, at the right time and the right place.

DIVERSITY

All people have a right to affordable and accessible health services that meet all of their physical, social, emotional and cultural preferences.

Health Consumers Queensland focus on increasing the voices of vulnerable population groups and assist them to understand how they can have a voice in developing health services. With access and equity in mind, we partner with people and organisations with a focus on the following:

- Culturally and linguistically diverse (CALD)
- Physical and intellectual disability
- Lived mental health experience
- Socially and geographically isolated
- Socioeconomically disadvantaged

Background

One of our guiding principles is that as an organisation, we are committed to Queenslanders receiving quality, **safe**, affordable, timely and accessible services, that deliver the right care, at the right time and the right place.

Every year we consult with our Statewide Network of consumers and carers, asking which are the issues that are important to them in order to help guide the future direction and focus of Health Consumers Queensland's strategic focus and advice. **Public reporting of safety and quality data** was in the top five areas of importance for consumers (out of a possible list of twenty) in our 2017 annual surveys. The other areas of importance were consumer and carer engagement, mental wellbeing, accessibility of services and end of life planning and euthanasia.

On 4 August 2017 the Hon. Cameron Dick, Minister for Health and Minister for Ambulance Services announced that the State Government was seeking public feedback to the discussion paper about reporting: *Expanding Healthcare Quality and Patient Safety Reporting Discussion Paper 2017,* with the aim of seeking the views and expectations of the community about public reporting of healthcare quality and patient safety information.

Our organisation has welcomed this opportunity to gather community feedback about what helps Queenslanders know if the services we receive are safe, who we seek this information from and what else would help us decide which services are safe.

In September we hosted two Community Conversations on public reporting of patient safety and quality data, one face to face and one teleconference for rural/remote consumers (see attached agenda/questions). Our response to the consultation survey draws on the rich feedback and experiences of consumers who took part in these events, as well as our significant organisation knowledge in this area.

Health Consumers Queensland's response to Discussion Paper questions

1 Do you currently access healthcare quality and patient safety indicators/information?
2 If yes, what information do you access and for what purpose?

As Queensland's peak consumer organisation, it is of interest to us that consumers and carers can easily access timely information on the safety and quality of Queensland health services.

At recent focus groups, we asked members of our Network the following questions:

1. What information is important to you when making decisions about the safety and quality of health services you access?

2. What information don't you currently have, which would make a difference?

They shared the profound challenge of making choices within our health system:

- **difficulty in knowing what health services are available to them - from which individual clinicians and which facilities (both public and private)**
- **lack of awareness of what data is available for individual clinicians and facilities, and where to find that information now**

"What are the service capabilities and limitations? People don't even know what is available at each hospital, to be able to decide what options they are trying to choose between, let alone which are the best quality. ie is there an emergency department within a hospital? eg Private Emergency Department?" Consumer.

Choice of clinician and health service is further limited in rural and remote communities, often removing autonomy around choice.

We are aware that safety and quality information is currently published by a range of health services and bodies, as listed in the Discussion Paper (p. 2-4). Consumers and carers did not identify that they routinely seek information from those locations when making decision (including the My Hospitals website, reports from QH or the Office of the Health Ombudsman, etc).

Instead, some reported mainly relying on their GP for referral to trustworthy health professionals and facilities.

"Our GP is the only person in the system that we can trust, he has earnt that trust" Parent.

Others report being unable to find a GP who can help them navigate the health system.

"It's hard with a good GP, let alone without them. There is a lack of access to the public services I want, they are just not avail in my HHS". Consumer.

Others shared the difficulty they find in hospitals or PHNs giving them clinicians names (citing the issue of "professional gain").

3 What is the primary reason public reporting of healthcare quality and patient safety indicators / information should occur?

Reducing unnecessary harms to consumers by driving a continuous increase in quality and safety of our health services.

4 Are there any other reasons why public reporting of healthcare quality and patient safety indicators / information should occur? What are they?
5 How would you use published healthcare quality and patient safety indicators / information if available?

Publishing a wider range of quality and safety information, in formats that are more accessible to community would enable greater consumer choice of services which are right for us – services that are safe and feel safe.

"Transparency and accountability are extra important when there is limited or no choice" Consumer.

6 Should public reporting of healthcare quality and patient safety indicators / information apply to:

c) Both public and private facilities.

Overwhelmingly consumers reported wanting data on all health facilities.

"Consumers want transparency, they want reporting from public and private facilities" Consumer.

7 How important is it that there be national consistency in healthcare quality and patient safety indicators / information?

National consistency of the public reporting and transparency quality and safety information is a key priority of all the state and territory peak consumer organisations such as ourselves, as well as our national peak body Consumers Health Forum.

It is vital not to inform individual decision making of consumers who receive care across state/territory borders and to reduce variation in care across the country.

8 Should reporting arrangements be:

c) Set out through a legislative or regulatory mandate.

Our organisation believes it is likely that only legislation, regulation or a requirement against accreditation can guarantee timely, consistent reporting of quality and safety information.

9 Who is the primary audience for healthcare quality and patient safety indicators / information? Why?

The audience is threefold and all are equally important. All groups need to have timely and easy access to accurate data in order to maximise choice, access and safety:

- **consumers and carers – to assist us in making the right decisions for us;**
- **clinicians – to drive individual improvements in safety and quality and provide the highest quality referral pathways to their patients; and**
- **health system (health service Exec/Board members, Government policy makers) – to drive systemic improvements in safety and quality.**

10 What healthcare quality and patient safety indicators/information should be publicly reported?

"We need clarity on what is published now, what is already collected now that could be published, and then what new things could be developed, collected and published". Consumer.

Consumers reported not knowing what data is available and reported publicly now (see questions 1).

They are also uncertain about what data is collected and not publicly reported.

"What we could do tomorrow is identify existing data that is already in quarterly reports from hospitals and collected by data units. It's all just there and with some work would be very simple to publish that information which is not currently available eg. caesarean rates at different hospitals" Consumer.

Consumers are very interested in more sophisticated measures of patient experience being co-designed with consumers, using mechanisms that are consumer friendly. One such existing mechanism could be the Australian Hospital Patient Experience Question Set. The Australian Commission on Safety and Quality in Health Care has committed to making it available to state and territory governments and health services to enable local collection and use of information about patient experiences to improve services (p.93, Vital Signs 2017: The State of Safety and Quality in Australian Healthcare, ACSQHC).

"Measuring and analyzing communication is different to gathering communication data. We need questions such as "Did you receive the care you expected?" and answer "How happy are people overall?". Not in the way patient experience surveys are now. Satisfy and satisfaction aren't enough. People don't know how to answer that. A lot of this needs to be developed in a group with equal consumers and clinicians" Consumer.

"You need strategically minded consumer representatives and Queensland Health staff to sit down and create them" Consumer.

"I want to know from other consumers – did you receive the care you were expecting? Then questions underneath - right site surgery, was it good care, were you listened to, did you receive timely access to care and medication? Did you feel there was transparency and trust when you received your care – did you know what was going on, do you know the care plan, what procedure is next and when? There needs to be opportunity for more than a tick box, needs to be text fields" Consumer.

"The feedback mechanisms that are used to collect qualitative data must be capable of a true reflection of patient experience and be an easy platform on which consumers can provide the feedback. One example - Lady Cilento Hospital patient experience wall. People post on the wall and the hospital will repost it on Facebook with a response. It's actually predominantly positive. If you want to understand people's experiences you have to get on their platforms, not create new ones" Parent.

Consumers and carers want to know the number of complaints but also resolutions, from the consumer perspective. They suggested published case studies.

They suggested similarly for public reporting on how health services have responded to safety mistakes such as sentinel events.

"Health services can build the trust of consumers in the health system through us knowing that when they've identified a problem, what have they done to fix it? ie. when there were SAC 1 events, what work has been done to ensure that doesn't happen again? Yes or no or numbers won't answer that, we need case studies" Consumer.

They want information on how a health service is responsive on a day-to-day basis to consumers' needs, without them needing to enact Ryan's Rule. Public reporting against the 2nd edition of the National Standards may go some way to this (the new Comprehensive Care Standard and new Communicating for Safety Standard).

"Why can't it just happen routinely eg. data on consistency of clinical handover with the patient, across wards. where appropriate? Consumers need to have a good routine way of feeding back information and clinical care they require in the moment that they need it" Consumer.

They also want greater, more timely financial transparency – out of pocket costs eg. maternity scans when receiving care through a public hospital.

For mental health consumers and carers (who represented a significant group in our consultations), there is an extra imperative for transparency and reporting in regard to forced treatment / involuntary treatment.

Consumers expressed interest in public reporting on staffing levels, especially with the move to nurse to patient ratios.

"Staffing levels, sick leave rates, nurse to patient ratios and reporting on these are crucial. The system is always looking at increased discharge planning and reduction in bed days, but not looking at the cost of low staffing" Consumer.

"Our GP has been unable to get our son timely intervention that would have prevented his deterioration. Hospital is understaffed, staff burnt out, working double shifts. Why are incidents happening. Need to look at why" Parent.

Consumers want to know when there are gaps in integrated care - when a hospital stay could have been avoided with earlier primary care interventions, or if there were flow or access issues that prevented a GP referring someone to hospital care earlier.

"GPs have a role to play if something could have been prevented and someone didn't end up needing to go to hospital" Consumer.

"If there had been an intervention 7 days earlier there wouldn't have been an episode. We need to enable our good GPs to assist patients to access mental health care" Carer.

Infection rates in hospital in the home services was identified as an area of reporting interest.

11 What healthcare quality and patient safety indicators/information shouldn't be publicly reported? Why?

Patient confidentiality must be maintained to ensure privacy of individuals in the community.

12 What mechanisms do you think should be adopted to ensure that key stakeholders are involved in the decision making surrounding indicators / information to be publicly reported?

The National Safety and Quality Health Services Standards require hospitals to involve consumers in the review of safety and quality performance, participate in quality improvement processes, participate in the review of patient feedback data and participate in activities to improve patient experience. It is reported that the majority of health services are meeting their requirements (p.95, Vital Signs 2017: The State of Safety and Quality in Australian Healthcare, ACSQHC).

However it should be noted that accreditation of health services against the National Standards is largely assessed by surveyors who are health service staff. Only a few surveyors are consumers. It would provide greater assurance to consumers if consumer engagement on safety and quality processes were routinely assessed by consumer surveyors.

In the absence of this, Queensland consumers would benefit from having access to a public report for each hospital that sets out each facility's:

- **quality assurance process;**
- **a report on the involvement of consumers and carers**
- **statement on how they use their patient safety info to improve their services**

This report could also be the location for publishing the number and severity of sentinel events and what health services have put in place to prevent them happening again (see question 10).

13 What level should healthcare quality and patient safety indicators / information be reported at:

a) Individual clinician;
c) Hospital;
d) Hospital and Health service; and
e) Whole of Queensland.

All of the above.

Consumers report wanting transparency at every level of the health system.

When it comes to individual clinician data, the response was varied.

Most consumers do want accurate information on individual clinicians, in order to feel safe and help them make an evidence-based, informed choice.

"Most surgeons if you ask them about their infection rate, they react with horror. It's very difficult to get their infection rates and error rates for procedures. I had major surgery, I wanted to go somewhere where I knew it had relatively low infection rates. For that health professional and for that procedure" Consumer.

"I googled the name of our clinician. There was some negativity in the media at that time about him around the death of a child. It was very distressing, as I needed to have trust in him. He ended up being amazing. But where was his individual data from a reputable source when I needed it?" Parent.

For the majority of consumers who do wish to be able to access safety data on the outcomes of an individual clinician, they recognise that there may be areas of healthcare when this is valid and useful to them, and times when it would not be possible or useful:

"In public it might not happen very often (because of multidisciplinary care) but in private when a lead clinician is the model of care, it's essential". Consumer.

They also identified that to maximise the collection of accurate data, individual clinician data needs to be collected within a culture of improvement and not punishment.

"Need to move from a punitive model of reporting. Being responsive, not reactive. Not using someone as a scapegoat, as care is usually provided by a team. This is a challenge when looking at individual clinician data" Consumer.

"We can't do this without reducing fear of litigation/impact or losing a career. This fear leads to poor quality of reporting ie. because of concerns about registration. We need to be developing a culture within health of individuals identifying and accepting when they make a mistake. And telling consumers they recognize the mistake, apologising and explaining what will prevent it happening to someone else. There has to be a cultural shift to reach 90,000 staff to say that when a clinical incident happens it's identified. And to prevent staff members using reporting mechanisms to report each other" Consumer.

Due to these issues of culture, some consumers can see how there could be greater public benefit in keeping clinician level data within a facility for in-house comparison and improvement (similar to the current situation with local or benchmarked data which is not publicly available).

Other consumers identified the benefit of sending individual clinician data to an independent quality body outside of the health services for analysis.

14 Should comparisons of healthcare quality and patient safety indicators / information be made between the following:

a) Individual clinician compared to another individual clinician:

Yes, comparison data would be very useful especially within the private system, to enable consumer choice and drive quality.

When expressing a desire for clinician-level data, consumers frequently use examples of wishing to compare individual infection rates and complications for different procedures.

b) Specialty in Hospital A compared the same Specialty in Hospital **Yes**
c) Hospital A versus Hospital B **Yes**
d) Hospital and Health Service A versus Hospital and Health Service B **Yes**
e) Queensland versus other States **Yes**

Consumers want comparison data for facilities which also includes the proportion of adverse events at all hospitals, hospital acquired infection rates and length of stay per diagnostic group compared to state average.

15 Thinking about the primary reason of public reporting, how often would reporting of healthcare quality and patient safety indicators / information be needed for effective use:
a) Monthly;
b) Quarterly;
c) Half-yearly;
d) Annually; or
e) Other (please describe).

This would vary, but the most important aim should be to reduce the time it takes to release data to consumers, from the point in time of collection.

16 What is the preferred medium for this information to be released:
a) Interactive website site;
b) Published report on the internet;
c) Published hard copy report;
d) Newspaper; or
e) Other (please describe).

All above.

We identified a lack of knowledge amongst consumers about where to currently find publicly reported data. This speaks to the need for a consumer-friendly portal for easy to access and understand information that matters to people and helps us make decisions.

"People who use health care most, are least able to access and interpret data and info" Consumer.

Many different formats and methods of communication should be used, including those listed above and more eg. posters and booklets in public areas in hospital, mobile apps, etc. The language, messaging and formats must be co-designed with consumers, in order to maximise their useability and uptake.

"Data needs to be translated/presented in a creative manner so that all consumers can understand it ie. good summary that accompanies graph/data at an appropriate literacy level. If someone is just

interested in PICU or maternity – make it clear and easy to find, search terms and understand. And have access to other people's experiences in a story format" Parent.

17 Who should publish healthcare quality and patient safety indicators / information:

a) Queensland Department of Health **YES**

b) Individual Hospital and Health Services / private hospitals **YES**

c) Other Government agency / department (please describe); **YES – Office of the Health Ombudsman**

d) External private company; or

e) Other (please describe): **We received feedback from consumers that there would be great value in having an external body publish an independent level of analysis of data gathered/produced by health services. They reported this would provide a sense of trust and independence to the data. This body could be either consumer-driven, or a body independent of Government with a focus on quality improvement (similar to the NSW Clinical Excellence Commission).**

18 Are you a patient / healthcare consumer?

Yes

Do you represent a consumer organisation? Yes – Health Consumers Queensland

19 Are you a clinician?

No

20 Are you a healthcare administrator?

No

21 What is your main interest in completing these consultation questions?

As Queensland's peak consumer organisation, consumers constantly tell us that Government and health services must develop a shared vision with the community for greater transparency and accessibility of the public reporting of safety and quality data. Only in this way will services become safer, and can we be empowered to choose the safest and best care for ourselves and our families.