



HEALTH CONSUMERS QUEENSLAND

SUBMISSION TO

National Safety and Quality Health Service Standards Version 2: Consultation draft

Australian Commission on Safety and Quality in Health Care

30th October 2015

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About Health Consumers Queensland

Health Consumers Queensland's mission is to support the voices of Queensland health consumers to achieve better health outcomes. We aim to strengthen the consumer perspective in health policy development and system reform and design. Health Consumers Queensland believes consumers should be central to all decisions that impact on their health care options and advocates for consumer involvement in health policy, planning and service delivery at local, state and national levels.

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

Health Consumers Queensland fully supports the delivery of consumer-centred, integrated healthcare that fully promotes the consumer's active participation in their healthcare and broader health services and systems.

Health Consumers Queensland's Response

Health Consumers Queensland welcomes the opportunity to provide feedback on the *National Safety and Quality Health Service Standards Version 2: Consultation draft*. Our submission contains feedback from members of our Statewide Consumer Network.

We commend the Australian Commission on Safety and Quality in Health Care for undertaking the review of the Standards and the extensive consultative process used.

These Standards, particularly the Partnering with Consumers Standard, underpins our daily work at Health Consumers Queensland and is integral in enabling more consumers and carers to take an active role in health policy decision-making and creating sustainable and systemic changes to the health care system. We observed a marked increase in consumer engagement activity by health services when the Standards were introduced and we look forward to the new iteration of the Standards strengthening the effectiveness of this engagement.

Health Consumers Queensland recommend: Numbering the standards instead of using the suggested letter acronyms.

Transparency

Health consumers are interested in a transparent health system where the leaders and care providers are accountable for their actions, decisions and the use of resources. For health consumers a key objective of these standards is to understand how their health providers have met and achieved them. It is important that in the process of revising these standards a robust discussion, involving consumers and consumer organisations, about how these standards can and should be implemented, monitored and evaluated occurs. Health Consumers Queensland hears concerns from consumers and consumer organisations that a hospital has gone through

accreditation, and passed, and they would like the opportunity to see on what grounds they have achieved 'partnering with consumers'.

Consumer-centred

Health Consumers Queensland believe that all people should receive healthcare that is tailored to their individual needs, preferences and circumstances; that is that consumer-centred care is the norm in healthcare.

We urge the Commission to ensure these standards are focused on ensuring people receiving healthcare get the best, dignified and tailored care possible. Therefore it is important that these standards demonstrate and model consumer-centred care to all the readers. We have made recommendations throughout our submission to ways in which this can be done, but we also suggest a separate process is used involving consumers to ensure it is as consumer-centred as possible.

Introduction Page 4

In the first paragraph of the introduction we suggest you also include consumer organisations and consumer representatives in the list of groups who have been involved in the transformation. In the eighth paragraph we support the greater emphasis on partnering with consumers.

Changes to the NSQHS Standards (p7)

In the final paragraph in this section it states that each action now identifies who is primarily responsible for implementing the action. We support this concept however we note that this is not done consistently through the standards. For example, in Partnering with Consumers, many of the Items do not identify 'who' is responsible for Actions, but 'what' for example 'systems are designed' or 'health service organisations understand' or 'health literacy is embedded.' Identifying *who* is responsible for each of the actions is imperative to its implementation.

New actions (p7)

We are pleased new actions relevant to the care of Aboriginal and Torres Strait Islander people, and people with a mental illness or cognitive impairment are added. We recommend this is expanded to also include people with a disability (e.g. hearing impairment, blindness etc) as these people face specific challenges that also need to be addressed.

Aboriginal and Torres Strait Islander health (p7)

We support specific actions that focus specifically on Indigenous people. We wonder why these actions do not apply to ALL health service providers – not just those who regularly provide care for Aboriginal and Torres Strait Islander people. All Australian health providers should be prepared and skilled to provide culturally appropriate care for Aboriginal and Torres Strait Islander people in line with the aims of Closing the Gap. We question whether it is enough for these other organisations to 'manage the risks of harm to Indigenous people from care' through the actions for improvement that relate to their whole consumer population when the Commission has seen the need to write actions specifically for Aboriginal and Torres Strait Islander people. These two ideas contradict each other. Given the immediate need to improve the health outcomes for Aboriginal and Torres Strait Islander people, no health provider should be exempt from these actions; and those who see

few Aboriginal and Torres Strait Islander patients should consider the barriers to access and any other issues that are impacting on these low rates of care.

Standard GS: Governance for safety and quality

This helps everyone, including consumers and people new to the Standards, understand what this particular standard is about.

We support the inclusion of the new criterion (Leadership and governance) that includes explicit statements about the role of leaders and others in safety and quality. In particular we support Action GS1.1 b and c. We suggest that c is also included in the actions on '*Partnering with consumers*' because it does not explicitly state the need for leadership in the actions, other than in the initial opening paragraph of the standard.

Action GS2.3

Suggest that it explicitly states that the safety and quality is in the care of consumers, to make the consumers visible.

Action GS4.1 c

Recommend it is explicitly stated that this is for staff, and not to improve compliance of consumers.

Action GS5.1

- b) Recommend feedback is sought from the workforce *and consumers* about the quality improvement systems and their performance.
- c) We support including consumers in this point.

Item GS6 Variation in practice

We recommend that not only do health systems have systems in place to identify variations in practice within the health service, but compare their health service to other similar ones in case things that are 'normal' at their health service is at variance with the rest of the state.

Recommend that this variation is communicated to both consumers and the workforce and involve consumers in the system to address any identified variation.

Item GS8 Understanding diversity

Recommend that this is strengthened so it's not just the health service organisation seeking to understand the diversity of consumers who use its services and the local population but actively create a system that responds to the individual needs of those health consumers by providing consumer-centred care that is also culturally appropriate and addresses their specific needs and preferences.

Recommend wording become "The health service organisation understands the diversity of the consumers who use its services and plan for and with the diversity of the local population."

GS10 Feedback systems

Recommend this is considered with GS5 Quality improvement systems as the two are quite similar and there is some duplication.

GS10.1 recommend that feedback is sought from *consumers and community stakeholders*. Often the individual consumer and their carer/family may not be in a position to provide feedback but a support organisation, consumer organisation or community organisation is aware of the issues.

We recommend an additional point is added that consumers and consumer organisations including state and territory peak consumer organisations are involved in staff training and professional development.

GS10.2

Recommend this action is expanded beyond complaints system to include all feedback (positive as well). We suggest that an extra point is added for the organisation to identify what is working well and strengthen what is working well and share that information with other parts of the organisation to replicate. Consumers should also receive information about how their feedback has led to changes/improvements in services (closing the feedback loop).

GS12 Safety and quality systems

Pleased to see that consumers are visible in the opening paragraph.

GS12.2 We recommend that all staff in the health service organisation have access to training to improve their cultural awareness and competency.

GS13 Performance management

In subpoint a) we recommend that consumers are involved in the review of staff performance. How can performance be reviewed without understanding the outcomes and impact on the consumers? As an example in practice, the Australian College of Midwives' Midwifery Practice Review process involves consumer reviewers in its system.

GS14 Credentialing and scope of clinical practice

Recommend that consumers are involved in the credentialing process; identifying new areas of unmet needs as well as the decision-making about the process itself.

GS16 Evidence based care

Consider consumer's role in this; how do consumers know they are being recommended treatment that is evidence-based? What happens when there is an absence or inconclusive evidence?

GS17 Safe environment for the delivery of care

GS 17.1

- a) Recommend that the organisation designs the environment to maximise *dignified*, safe and high-quality care (our change is italicised).

We question why it is necessary to write “where relevant”. Is this to do with the constraints of the existing facilities? If so, make this clearer in the wording so that organisations do not decide it’s not relevant for them to provide dignified, safe and high-quality care.

GS17.2

Support this new action.

GS17.3 Recommend re-wording the term ‘consumer-based visitation’. Suggest “...that enables for consumers to decide when they would like visitors.” Ensure the word ‘allow’ is not used.

GS17.4 This action can be strengthened. What is a ‘welcoming environment’? Suggest the standards talks about designing an environment that is culturally safe e.g. birthing units on the ground floor, and the services are culturally appropriate.

Standard PC: Partnering with consumers

This standard gives leverage to health consumer organisations and individual health consumers and carers who want to be a part of shaping and influencing a specific part of the health system. Without it, many consumer organisations and individual consumer representatives may struggle to be heard about the type of health services they need and require. This is particularly so for sectors where the consumers and community are ready for major reforms but the institutions may be reluctant to embrace change and would prefer to keep the status quo.

Page 19 explains the ‘Partnering with consumers’ standard is for ‘leaders of a health service organisation to develop, implement and maintain systems to partner with consumers.’ However this is the only time the ‘leaders of a health service organisation’ is explicitly stated as all the actions for each item only states ‘the health service organisation’, not the leaders. We recommend it is made explicit.

Intention of this standard

We agree with the intention of this standard that it is about creating organisations where consumers are partners in:

- planning, design, delivery, measurement and evaluation of systems and services
- their own care, to the extent that they choose.

Action PC2

We believe this is an excellent item and actions and will welcome working with the Commission and Queensland-based health service organisations to enable effective monitoring of the systems for partnering with consumers, supporting actions to improve the systems and their performance, and reporting on effectiveness and outcomes.

Action PC3.2

We suggest that this item is expanded, or a new action is created, to explicitly state the need for the leaders in the health organisation to demonstrate appropriate resourcing and funding is allocated to enable effective consumer partnerships.

Funding and resourcing is a key barrier to the effectiveness of establishing consumer partnerships. Funding is needed to train health service staff on how to partner with consumers effectively, to develop resources that may improve consumer partnerships, and importantly, to support consumer representatives not only in their work but on-going orientation, training and education.

Too often, we see that consumer representatives cannot sustain on-going involvement with health services because they are incurring costs (out-of-pocket expenses, time, paying a carer) and are not reimbursed for these. Consumers often feel their contributions are not valued because there is no financial value attached to their expertise.

Action PC3.3

We recommend that a link to the glossary is made so that it is clear what 'diversity' captures.

Action PC3.4

We understand extensive consultation is occurring with Aboriginal and Torres Strait Islander health services, community organisations and individuals to ensure the standards are culturally appropriate and effective. We have concerns that the word 'where' means that some health organisations could choose to opt out of working on this action.

Action PC3.5

This action seems less direct and less strong compared to the current 2.6.2. The word 'involved' implies direct involvement in the delivery of training whereas 'to incorporate their views and experiences' is not as direct nor strong. It could mean that by sharing some feedback in a patient experience survey in the training the service has 'incorporated their views and experiences' but much more can and should be done. The action should imply direct involvement of health consumers in the design and delivery and evaluation of training and education for the workforce (especially training involving Aboriginal and Torres Strait Islander people and culturally and linguistically diverse people and groups).

Action PC4.2

Recommend that this action involves 'a diversity of consumers in its development and review' to be consistent with PC4.1.

Action PC4.3

Part c could also include information about other services and organisations (not just health-related) who can help improve integration of healthcare.

Importantly, to be consistent about providing consumer-centred care, the information the clinician provides should answer the questions and specific concerns of the health consumer and enable the consumer to be the key decision-maker in their own care. This is currently absent from the actions.

Action PC5.1

We question whether it is necessary for individual health service organisations to develop their own charter of rights and not simply endorse and support implementation of the Australian Charter of Healthcare Rights. From a consumers' perspective, it doesn't make any sense to have localised and potentially weakened

charters of healthcare rights, as the rights captured in the national document are universal and should apply in all healthcare settings. A health consumer visiting Cunnamulla in Queensland should have the same rights and responsibilities to healthcare as that same health consumer has when they receive healthcare in their normal place of residence in Cairns, for example.

Action PC5.2

We recommend that this action should state (our additions are italicised):

The health service organisation ensures that its informed consent *and refusal of treatment systems comply* with legislation and best practice *and involve consumers in their design and monitoring*.

Action PC5.3

Recommend that this action states it is for both informed consent and 'refusal of treatment' as different issues and perspectives need to be considered for each.

Action PC6.1

Recommend it is changed to 'Clinicians enable consumers to lead their own healthcare by planning, discussing, setting goals and making decisions in collaboration with their health professional(s).'

Action PC6.4

We support the inclusion of carers in this action. We think the standards would be strengthened if throughout the document it is clearly identified when it is pertinent solely to the consumer and when it could be useful to word it 'consumer and/or carer' to be inclusive. The role of the carer is crucial to many people in accessing and receiving their healthcare.

Standard CC: Comprehensive Care

Health Consumers Queensland recommends you reconsider the name of this standard – we think the intention is very much around providing care that is focused on the consumer and carer and meeting all of their needs and preferences (not simply considering their clinical needs). We suggest that 'consumer-centred care' might be more appropriate.

Intention of this standard

We recommend that this paragraph is inclusive not only of the consumer's health issues on their life and wellbeing but also their bio, psycho-social and spiritual beliefs.

Action CC2

We recommend that in part c it is clearly identified who the report is intended for.

Action CC3

The meaning of this action is unclear to us. We recommend you make the consumer the focus of this action. We recommend "The health service organisation has systems to ensure the consumer receives care at the right time and place that is appropriate for their needs and preferences."

CC5.2

We hope that the consultations the Commission is doing with Aboriginal and Torres Strait Islander people and organisations comment on the safety and appropriateness of this action. Anecdotally we have heard that some Aboriginal and Torres Strait Islander people feel that the attitudes of their health carers change negatively when they identify their culture. If this standard remains, we suggest it is also extended to include culturally and linguistically diverse people.

CC5.3

Part c we recommend you remove 'socioeconomic status' as for many people it only refers to financial status and replace it with a more inclusive term "bio, psycho-social, spiritual status'.

CC5.4

In part b we suggest you also include disability and/or cognitive impairment and domestic and family violence.

CC7.1

Support the inclusion of the family and carers in this action.

Standard RH: Reducing harm

Page 31 Criteria 6 End-of-life care

As a consumer organisation we sometimes hear from consumers or carers that while care received could be deemed clinically safe, it felt unsafe or undignified to them because it didn't meet their needs and preferences (or those of their family or carer/s), they didn't feel respected or included in decision making processes.

RH3.1

Recommend that this action adds '...and involves consumers and carers.'

RH3.2

Recommend that this action adds '...and involves consumers and their carers in this.'

RH3.3

Recommend that this action adds 'and involves and educates consumers and their carers.'

Health Consumers Queensland has heard of incidences where consumers and their carers received appropriate equipment to prevent pressure injuries in the home but not the training/education needed to use them properly.

RH4.1

Recommend that this action adds '...and involves consumers in this.'

RH4.2

Recommend that this action adds 'and includes involvement and education (and/or active participation) of the consumer and their carer' and that it is not exclusive to equipment and devices but other support as well (could be community or peer support).

RH4.3

Suggest that this action is also adapted for 'pressure injuries' as well.

RH5.1

Recommend that this applies to both the consumer and their carer (not simply just the consumer) as some carers may not have had the opportunity to eat for a lengthy period of time leading up to the hospitalisation and some hospitals do not have food outlets available so the carer has no access to food and/or drink themselves.

RH5.2

We support his new action.

RH7.2

In Part a) also includes the ability for consumers to develop or agree to an advanced care plan if they don't already have one.

RH8.1

Recommend that this action adds '...and in consultation with the consumer.'

RH8.3

As a consumer organisation the meaning of this action is unclear to us. We suspect it probably makes sense to those working in a health service but suggest it needs to be more clear so that consumers understand its intention and meaning without needing to draw their own conclusions.

RH9.1

Recommend another part to this e) involve the consumer and/or their carers in decision-making about this.

Standard CS: Communicating for safety

On page 37, Criteria 3 'Communication of critical information' says '...with clinicians who can make decisions about the care of consumers.' It needs to be clear that consumers have the right to bodily autonomy and it is they who make decisions about their care after considering the advice from their health care providers; it is not the right of clinicians to make decisions about the care of consumers.

The actions in the item CS6, needs to ensure that it is clear to all readers that clinicians do need to communicate new critical information to each other as well as to the consumer and their family and carers so that the consumer (not the clinicians) make decisions about care.

Action CS6.2

The meaning of this action is unclear. It reads that the clinicians are making decisions about care, the consumer, and family and carers; but we suspect it is about clinicians identifying the family and carers who are identified by the consumer as their support people.

CS8.1

Part c) the consumer is not central to this sentence, it's the 'mechanism' that is central and this points to the flaw in our current health care system. If consumers are central and the key focus, then systems are designed around them, not the other way around. We would recommend that the Commission does not perpetuate this problem by using this language in the standard.

Standard MS: Medication safety

Recommend as previously stated that the acronym MS is not used as most people know it to stand for multiple sclerosis.

MS7.1 Recommend you add an addition part d) ensure the consumer and their carer understands the medications they are prescribed and when and how to take them and see if they have any questions or

concerns about their medication (including the chance to tell their healthcare provider of any other alternative herbal or other supplements they are also taking).

Standard RR: Recognising and responding to acute deterioration

RR7.1

Recommend considering adding in this action that clinicians also involve carers in these discussions as they too could shed light on the stated preferences of the consumer.

RR8

Recommend that this action includes involving family/carer in these discussions.

Roles for safety and quality in health care (p63)

Consumers

Currently reads:

“They also *participate in* making decisions about their own health care;...” (our emphasis in italics).

Patient autonomy means that the final decision (except where there are issues of capacity) must lie with the consumer.

We recommend it states:

“They *make* decisions about their own health care...”

We recommend the final sentence should read:

“Health care can be improved when consumers feel safe to share with clinicians issues that may affect their compliance with treatment plans.”

Clinicians

We recommend some changes to this could strengthen the consumer-centredness of these standards.

We recommend that the following inclusion to the second sentence: “They are essential in delivering safe and high-quality health care *that meets the needs and preferences of the consumer.*” Immediately following this sentence we recommend the Commission then has the paragraph about consumers that begins, “When clinicians form partnerships with consumers...”

Then continue on with “The system can *also* be improved when clinicians actively participate in organisational processes...” We recommend an addition to the sentence preceding the bullet points:

“Clinicians can make health care systems safer and more effective *for health consumers* if they:

The final sentence in the final paragraph on clinicians sounds alarming. “A key role for this group is to notify clinicians when concerns exist about a consumer.” The kind of concerns that should be notified need to be defined to reduce alarm for consumers.

Page 64

The third sentence in the ‘highest level of governance’ can be more consumer-centred by stating “The role of the highest level of governance is ultimately to be responsible for the safety and quality of healthcare provided to *its healthcare consumers.*”

The final sentence regarding partnering with consumers uses the word 'approach' which seems weaker than the previous sentences that uses terms such as 'strategic direction' and 'monitors'. We suggest a word change such as 'commitment' or 'imperative'.

Glossary

Consumer-based visitation: As previously discussed we recommend you find a better phrase to describe this.

Consumer-centred care: We recommend an alternative definition to this. There are a variety of definitions but we prefer the definitions where consumers are placed at the centre of care (not simply mutually beneficial partnerships) and where the needs of the consumer come first.

The NHMRC in their 'National Guidance on Collaborative Maternity Care' (2010) defines "woman-centred care is focused on the woman's individual, unique needs, expectations and aspirations, rather than the needs of institutions or maternity service professionals. This type of care recognises the woman's right to self determination in terms of choice, control and continuity of care." This definition could be adapted to consumer-centred rather than woman-centred.

SA Health also has an alternative definition for 'patient-centred care' which is more aligned with our values of what consumer-centred care is:

<http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+resources/safety+and+quality/partnering+with+consumers+and++the+community/patient+and+consumer+centred+care> (accessed 29 October 2015).

Diversity: suggest that a person's gender and sexual identity is included in this definition.

Informed consent: We recommend the term 'medical officer' is replaced with 'health professional' as all health professionals including allied health professionals, should ensure informed consent.

Safety culture: We recommend in the first sentence that 'patient' is added before 'safety' so it is clear that consumers are at the centre of care and safety.

Shared decision making: This term needs to be very carefully used/defined as it can be seen by some consumers as a coercive process that infringes upon their bodily autonomy and decision making rights. It is clear in legislation that the health consumer is the decision-maker about what health care they accept and decline and this needs to be respected and reflected in all key policy documents, guidelines and standards. Clinicians have a key role in sharing information and recommendations with the health consumer about their health care but the decisions ultimately rests with the consumer.

A paper published in September 2014 by participants in the Evidence Communication Innovation Collaborative of the IOM Roundtable on Value and Science-Driven Healthcare states that "At the heart of SDM is the ethical imperative of respecting the informed preferences of individual patients, even when they differ from the preferences of the average patient, the average practitioner, or the particular practitioner making a treatment recommendation". (Shared Decision Making Strategies for Best Care: Patient Decision Aids Sep 2014).

<http://www.iom.edu/~media/Files/Perspectives-Files/2014/Discussion-Papers/SDMforBestCare.pdf>

Conclusion

In conclusion, Health Consumers Queensland again commends the overall intent and content of version 2 of the National Safety and Quality Health Service Standards.

Health Consumers Queensland looks forward to reading all submissions to consultation process and hearing about the learnings of the pilot sites testing the new standards. We will welcome the opportunity to be involved in on-going development and implementation activities.

For queries relating to Health Consumers Queensland submission, please contact Melissa Fox, General Manager on 07 3012 9090 or melissa.fox@hcq.org.au