



**Health Issues Centre**  
Consumer voices for better healthcare

## **Health Issues Centre response**

### **A review of hospital safety and quality assurance in Victoria**

#### **Discussion paper:**

### **Strengthening safety in Victorian hospitals**

*April 2016*



**Health Issues Centre**  
Consumer voices for better healthcare

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## EXECUTIVE SUMMARY

*‘What is the value of engaging patients and families in improving safe care? Both research and practice show that engagement leads to safer patient care by improving the outcomes of care, improving the experience of care for individual patients, improving the work experience for caregivers, and—by helping the organisation change its processes—improving the outcomes for all patients.’<sup>1</sup>*

Health Issues Centre welcomes the review of Victorian hospital safety and quality assurance commissioned by the Department of Health and Human Services at the request of the Minister for Health. The discussion paper – Strengthening safety in Victorian hospitals’ – raises four broad themes covering a range of issues.

Health Issues Centre is committed to working towards a health system with better outcomes and experiences for all. We seek out and articulate consumer perspectives to ensure consumers are well-represented in shaping policy, practice and the experience of care. It is through this health consumer-focused lens that we are responding to this discussion paper. Our response is based on consultations with consumers, aimed at eliciting their views on the key themes of the discussion paper. The response is also informed by our knowledge and experience of working for over three decades to represent the views of consumers in health.

In its introduction, the discussion paper noted that *‘All ideas should be assessed against the criterion of whether they add value from a patient’s perspective, which is the guiding principle of this review.’* The most important point we wish to make in our response, emerging strongly from this consultation and a recurring theme worldwide in the health consumer movement, is that there remains a pressing need to embed this patient perspective on safety and quality throughout hospitals and hospital governance systems. To do this, several things must occur.

Patients and families need to be engaged in their own health plans and in becoming effective advocates for their own safety and quality of care. We believe there is a clear need for the department to advocate for a strongly patient centred approach to health for this goal to be achieved. This requires participation at an individual level to be embedded through regulated standards; however, it requires more than this. It is also essential to address the cultural and logistical barriers that continually thwart progressive change. There are a number of practical steps that could encourage a more participatory health system at the individual level on both the patient and the clinician side. This submission will address these.

First, patients continue to want a stronger, more protected role for families and carers, to be certain those people are able to be present and advocate powerfully for their loved ones. Consumers proposed that there be formal recognition of the right of designated family or carers to access information, be present and participate in health care decisions with them or on their behalf. We recommend the establishment of articulated ‘Family and Carer Rights’ to more cogently define and protect this role.

Second, embedding the patient perspective as standard practice will necessitate consumer engagement on a systemic level. For this to be accomplished, consumers must be properly recruited, trained and supported to operate at all levels of the health system. In order for consumer engagement to *actually* impact on safety and quality in Victorian hospitals, rather than just serve as a

symbolic gesture, the concerns and solutions of consumer representatives must be heard through agreed reporting channels all the way to the board and CEO.

Embedding the patient perspective also means hearing the voice of the patient and family when they flag risks, worries or complaints. To address this, consumers are calling for the establishment of a peer support or advocate role, such as a Patient Safety Partner (working title only) which would provide an externally funded peer presence on the ward to be an early warning system, facilitate real-time feedback and overcome blockages currently preventing patients and families from communicating their concerns. The rationale for this is that an invested, trained third party is in a good position to monitor potential communication breakdowns or adverse patient outcomes as a service to both patients and clinical staff. It is not intended as an adversarial watch-dog role. For the role of Patient Safety Partner to be developed, and be effective, there must be a wholehearted commitment by government to legitimise and by hospitals and health professionals to work with and respect the role. There remain glaring cultural obstacles to this which we will address.

There are two other major suggestions which we believe are core to an improved safety and quality system across Victorian hospitals. The first involves the responsibilities, skills and composition of hospital boards. There are worrying discrepancies not only between the skills in clinical governance of various boards, but also in their understanding of their responsibility in assuring the quality and safety of care in their hospital. Also, there is currently an almost total absence of an authentic patient perspective at the hospital governance level. Consumers believe that it is essential that at least one appropriately skilled and trained consumer member is appointed to the board of every Victorian health service. In order to assure that at least one board member has a genuine consumer focus, we will recommend guidelines for the skills and knowledge requirements for the currently designated board member who is meant to 'represent the views of users of health services'.

The final theme we will address is that of transparency of information within the health service. On this theme, the discussion paper raised the following question:

'Do the current statement of priorities indicators provide sufficient insight into hospital safety and quality for public reporting of the indicators to help consumers make meaningful choices about place of treatment?'

The answer to this question, according to our consultations, is emphatically 'No'. We will argue that if this is the standard by which these indicators are measured then the system is clearly currently failing consumers in this regard. Even highly motivated, resourceful and educated consumers find it all but impossible to determine if Hospital A is a safer place to have their appendix removed than Hospital B. And if they are concerned about important patient experience indicators such as patient centredness, shared decision-making or access to personal health information they would struggle even more. We will recommend a commitment by the Department to the goal of collecting and publishing appropriate and adequate safety and quality information that would enable the average consumer to make informed choices regarding places of treatment.

## INTRODUCTION AND METHODOLOGY

Health Issues Centre aims to represent the voice of consumers in health issues across Victoria. It is from this consumer perspective that we are responding to this consultation and discussion paper requested by the Minister for Health and commissioned by the Department of Health and Human Services (the department). In order to effectively understand and reflect this viewpoint in our submission, we sought to enable Victorian consumers to express their views firsthand through either a face-to-face or on-line consultation.

Notwithstanding the restricted time-frame and short-notice, twenty-two consumers attended our face-to-face consultation and a further seventeen completed an on-line version of the consultation regarding safety and quality in Victorian hospitals. The views expressed by these consumers have informed our submission. Prior to a discussion of their views there are some important observations to be made about the consultation process.

Firstly, given that the invitation to participate was made immediately prior to the Easter break with a closing deadline shortly after, we consider that obtaining forty-two considered responses is indicative of a high level of consumer interest in engaging on safety and quality issues.

Secondly, consumers demonstrated that they had valid insights, based on personal experience, regarding the weak links in the chain of hospital safety and quality assurance. And they had many practical proposals as to how to address these.

Thirdly, consumers expressed an overarching frustration that their potential for contribution was undervalued, arguing for an investment in training and capacity development to enable consumers to make an effective contribution. They continue to face cultural barriers, endemic in health, restricting access to the levers of practice change. Participants didn't claim to have any silver bullet solutions, but were adamant that they could make significant contributions if they were supported and enabled to do so.

It should also be noted that the Terms of Reference and the discussion paper were both framed in work-based terminology and process, which is unfamiliar to people who don't work in hospitals. In addition, the themes and questions were constructed in a way that does not easily translate to the myriad of patient safety and quality issues that consumers regularly identify and for which they can offer important reflections. We rewrote both the questions for the online and the face-to-face consultations to more closely speak to the consumer perspective. We note this here because it is a common occurrence and one which belies stated objectives to solicit and value consumer inputs. We believe this represents yet another significant barrier for consumer involvement and input into health systems improvement.

### Theme 1: Fostering continuous improvement and clinical excellence

#### Improving patient participation at the individual level

*'Patients are, in fact, overly patient; they put up with unnecessary discomforts and grant their doctors the benefit of every doubt, until deficiencies in care are too manifest to be overlooked. Generally speaking, one can assume that the quality of care is, actually, worse than surveys of patient satisfaction would seem to show. Patients need to be taught to be less patient, more critical, more assertive.'* – Dr Avedis Donabedian<sup>2</sup>

Victorian consumers are telling us this same message: patients need to be empowered to speak up and that the health system needs to be encouraged to listen. Consumers feel that the role of patients and families in safety and quality assurance is at, best, underutilised and, at worst, disrespected.

*'You've got a voice. Use it. Okay, I am a public patient. I better keep my head down, mouth shut in case I don't get the help I need. People need to be educated that the consumer has a voice and will be heard. People don't know. They can't have a voice if they don't know they can speak.'* – Victorian consumer

Patients are the heart of the health and hospital system, its reason for existence. When the safety and quality of that system fails, it is patients (and their families) who suffer. For decades now, health care experts – like Avedis Donabedian quoted above, the founder of the study of quality in health care – have focused on the need for greater patient participation in assuring the quality of health care. Also, importantly, many of the world's leading experts in patient safety – Charles Vincent, Saul Weingart, Lucian Leape – have argued for greater patient participation in helping to prevent avoidable harm.<sup>3 4 5</sup>

The links between participation of patients in their own care and the safety of that care are growing. A study of 2025 patients at a US hospital compared levels of individual involvement in care and decision-making (understood the reason for admission, heard the pros and cons of treatment options, family member advocated for patient wishes) with experience of adverse events. They found that those who participated in their own care the most, were only half as likely to suffer an adverse event.<sup>6</sup>

And yet, patient and family participation in individual care continues to be far too limited and sporadic. Consumer participants reported dissatisfaction with how they were heard, respected, and kept informed. They did not feel able to participate in their own health care. Consumers emphasised the need for real-time information and 'report backs' as distinct from post-discharge reviews and complaints lodgement. At Health Issues Centre, this frustration with participation – particularly with not being heard – is one of the most consistent themes we hear from consumers.

*'Lack of sharing information between consumer and medical staff. As a consumer you might ask a question and it just stops, rather than [having] the information brought back to you. It just goes somewhere.'* – Victorian consumer

We believe there are significant barriers to patient participation in individual care; these are evident as both health professional cultural and logistical issues as well as patient-related obstacles. We will address these, and their possible solutions, in turn.

The health professional culture continues to be slow to acknowledge the critical role of patients in protecting their safety and improving the quality of their health and health care. The unwillingness or inability of health services to listen to and take seriously the concerns of patients and families has been a theme consistently bemoaned in the wake of repeated health services failures both in Australia and internationally. In the aftermath of Mid Staffordshire, Don Berwick's report clearly highlighted this as one of the factors leading to the failures there:

*'In some instances, including Mid Staffordshire, clear warning signals abounded and were not heeded, especially the voices of patients and carers.'*<sup>7</sup>

In response to this, Berwick highlighted the need for cultural change in the relationships between health services and patients:

*'The system must...reassert the primacy of working with patients and carers to achieve health care goals.'*<sup>8</sup>

We believe a wholehearted commitment to patient centred care is required on the part of health services and health professionals. Patient centred care is increasingly seen as integral to high quality, safe and appropriate health care. Organisations such as the Institute of Medicine, the Institute for Healthcare Improvement and the Australian Commission on Quality and Safety in Healthcare have all noted the growing importance of a participatory, patient centred approach to health. The core principles of patient centred care as defined by the Institute for Patient and Family Centred care are: respect and dignity, shared information, participation and collaboration.<sup>9</sup> In patient centred care, participation refers to the ability of the patient or family to be involved in care and decision making at the level they choose.

Though the movement towards a more patient centred health care system is underway worldwide and in Australia, this work is far from complete. At best, the shift is patchy and there is at least strong anecdotal evidence to suggest that marginalised groups are least likely to be able to fully participate in their health care.

*'I work to support a lot of people on the streets as I grew up on the streets, so that's all my families, my communities and the majority of my friends. I have seen first-hand, over and over and over again the levels that the hospitals are failing the most disadvantaged peoples in our communities, and the levels of discrimination (especially against homeless peoples, Aboriginal and TSI peoples, black peoples, mentally ill peoples and drug-injecting communities).'*'—Victorian consumer

A serious commitment to embracing patient centred care at a system-wide level across Victorian hospitals will require recognition that institutional culture is the most pervasive barrier to change. This must be prioritised above its current status as a footnote to participation. Culture change invariably requires leadership commitment, but this commitment to a patient centred culture varies greatly between health services. Even CEOs with best intentions frequently lack the skills and tools to drive institutional culture change. Most culture change programs relate to building values alignment and teamwork within the workforce. The challenge of changing cultural norms regarding interaction with patients is a far more complex matter and represents largely uncharted waters.

Until now, we have relied on evidence-based persuasion and the blunt instrument of regulatory compliance to emphasise the importance of patient centred culture change. However, ingrained behaviour can be impervious to evidence (witness climate change denial) and culture change cannot be delivered through compliance regimes. The table below is an adaptation of one previously presented by Helen Bevan of the NHS outlining the difference between a framework for change based on compliance and one based on commitment.

Compliance	Commitment
Defines a minimum, universal performance standard	Identifies collective benefit in an aspirational outcome
Uses authority, systems and standard procedures to impose outcome	Based on shared goals, values and collective endeavour
Penalties/sanctions and peer pressure (shame, scorn) drive momentum through fear of failure	A common purpose creates energy and enthusiasm for success

Adapted from: Helen Bevan

It is clear that the determinants of a change model based on commitment (aspirational outcomes, shared goals, common purpose) require a culture based on values alignment rather than one which is driven by regulation. As such, we believe that accreditation standards will be ineffective for delivering the cultural context in which patient participation is welcomed and supported.

So, what changes might encourage Victorian hospitals to overcome cultural resistance and move towards a more participatory approach? In a study investigating US health organisations renowned for implementing best practice patient centred care, Luxford, et al. found that the key enabling factors include:

- strong, committed senior leadership
- clear communication of strategic vision
- active engagement of patients and families throughout the institution
- sustained focus on staff satisfaction
- active measurement and feedback reporting of patient experiences
- adequate resourcing of care delivery redesign
- staff capacity-building
- accountability and incentives
- a culture strongly supportive of change and learning.<sup>10</sup>

Our experience suggests some health professionals view patient participation as intrusive, an erosion of their authority and a devaluation of their expertise. We believe that such concerns reflect the human condition and need to be supportively addressed. Health services cannot be left to their own devices to address this challenge; departmental support and resources will be needed. Training in how to affect culture change is an important starting place.

Clearly, it is not just health professionals who need to revise their personal behaviours and attitudes. Our experience with consumers – both in this consultation and previous ones – suggests that issues such as holding a traditional view of the clinician-patient relationship, limited knowledge of their healthcare rights and responsibilities, and a lack of confidence in speaking up are definite barriers to participation. We are certainly not the first ones to note this, as evidence builds about the barriers to patient participation.<sup>11</sup> This, we believe, is prime territory for government involvement in promoting a public health campaign aimed at educating all consumers about their role in making care safer for

themselves and their loved ones. The National Patient Safety Foundation's Lucian Leape Institute has recommended seven key actions that patients can do to be safe, for example.<sup>12</sup>

There are many precedents for social behaviour change programs directed at consumers. The most successful of these historically have been the dramatic progress in the field of smoking cessation and drink driving. Importantly, behaviour change programs have also been successful in promoting self-empowerment (domestic violence prevention, work-safe practices and addiction rehabilitation). The lesson from these programs is that successful culture change requires a multipronged program of intervention including public awareness, regulation and price signals, rather than a single strategy. The sobering reality in health is that approximately one in ten patients will suffer an adverse event in hospital—some of whom will die as a result—and this requires teaching people how to protect themselves from this dire outcome.

We recommend the Department demonstrate a strong commitment to the promotion of a culture change towards a patient centred health care system through:

1. development of skills, resources and appropriate tools to assist CEOs in implementing effective culture change programs;
2. provision of training in patient centred care, and endorsement of its importance, for executive teams and boards;
3. commitment to empowering patients to participate through a social behaviour change program.

### **Clearly acknowledging the role of families and carers in safety and quality**

*'So, it's not only about patients being heard, but also critical that the role of family and carers should be respected and have a role in the care.'* – Victorian consumer

In the context of improved patient and family participation in individual care, we specifically acknowledge the critical role of families and carers in ensuring the safety and quality of their loved ones. In both the recent and previous consultations, it was strongly emphasised by consumers that families and carers continue to feel disempowered, lack adequate information and often do not feel heard or respected when they raise safety or quality concerns.

*'I can't begin to explain the worry I felt about where I could go for help with W's health in the future. I had lost all trust in the hospital system. Why didn't anyone at the hospital have enough respect for me to take my concerns about W's health seriously? Why did so many health professionals ask me if W was my first child after I put forward my concerns?'* –Victorian consumer

This experience is, unfortunately, far from uncommon for families and carers. In recent years, there have been accounts published of medical personnel finding themselves in the role of family or carer in hospital, shocked at even their inability to be heard. Jonathan Welch's sad account of his mother's death due to medical error and his total incapacity to prevent it is one such story highlighting the need to protect and support the voice of those who best know the patient.<sup>13</sup>

We believe there is a need for a clear demonstration of the government's endorsement of the role of families and carers in safety and quality. This should apply across visiting rights, the right to be present at every stage of a patient's journey, ability to access full information and the right to make

informed decisions when the patient is unable to do so. We call for a government commitment to ensuring that patients are uniformly able to designate who they consider 'family' and also to guarantee the right of designated family to make informed decisions regarding the patient's care where necessary. Taking our lead from the recognised authority of a Substitute Decision Maker who is designated and empowered to make decisions in the event of patient incapacity, we call for the establishment of articulated 'Family and Carer Rights' to more cogently define and protect this role. Particular care must be shown to respecting the rights of patients and families from marginalised groups.

The application of varied visitation policies across Victorian hospitals, for example, continues to mean that families and carers are often indiscriminately separated from loved ones when they most want and need to be with them. Visitation policies are best developed in conjunction with a group of engaged consumers at the health service, such as the Community Advisory Committee, to avoid seeing only a staff perspective on this issue which matters enormously to patients and families.

There is tremendous scope for further embedding the essential role of families and carers in the safety system. Many hospitals (including at least one Victorian health service) have developed other ways of partnering with families in a clear and structured way (for example, through parent-activated MET calls).<sup>14</sup>

In support of the essential role of families and carers, we recommend:

4. the development of an official code of 'Family and Carer Rights' to help protect and enable the role of families and carers, as designated by the patient, as full and active participants throughout the health care journey of their loved one;
5. development of clear guidelines from the department to health services regarding visitation policies for all families and carers;<sup>15</sup>
6. support and training for health services in working with families and carers (through CACs and other forums) to develop and initiate programs for legitimising the role of family and carers as members of the safety team.

## **Embedding partnering with consumers at a system level**

In Don Berwick's aforementioned response to the Francis Enquiry in the NHS, there were recommendations for fundamental reform of the health service to improve patient safety across the system. The third recommendation states:

*'Patients and their carers should be present, powerful and involved at all levels of healthcare organisations from wards to the boards of Trusts.'*<sup>16</sup>

Although there has been a significant trend towards embedding consumers in the governance, planning, delivery and evaluation of Victorian health services in the past decade, the total scope and impact of those consumers is still far from systematic or influential. And there are some levels of governance, such as the board, where the consumer voice is virtually non-existent. This will be addressed below. The need for much more systematic, respectful and meaningful engagement of consumers across Victorian health services as a means for improving the safety and quality of patient care was a strong theme from our consumer consultations.

There is a need for a dramatic scale-up of consumer engagement both in influence and number. Consumers we spoke to believe that lack of training and issue-specific knowledge is working as a handbrake on the ability of consumers to contribute to change and improvement in health services. Those who have developed relevant skills and training have, by and large, done this through their own initiative, volunteering not only their time but often fully self-funded attending conferences and courses. Consumers who are serving in a governance or advisory capacity need to be supported to do their work in the same way as other members of those committees; this is currently happening on only a very limited and ad hoc basis across Victoria. The current practice by which consumers are invited to participate without compensation or adequate and relevant training is the literal epitome of a 'hospital handpass'.

The current scope of consumer engagement across Victoria is extremely small relative to the potential opportunities for consumer input in safety and quality improvement. Currently recruitment of consumers occurs in a very haphazard, uncoordinated way, varying enormously between services, depending largely on resources. One of the major limitations of consumer involvement today is that it does not adequately reflect the diversity in the community. A broader, more coordinated recruitment drive could focus attention on recruiting consumers from different ethnic and cultural groups, age, ability, sexual orientation, and socio-economic groups.

Consumers continue to raise concerns about the need for better reporting lines from consumers going upwards so that input, ideas and expertise move from tokenistic to reality. This will have an impact on the ability to retain consumers; those who do not feel heard, do not stay. Another message we heard from our consumers is that a lack of understanding or buy-in on the part of health service staff is an ongoing obstacle to meaningful engagement.

*'Consumer reps need to be screened and interviewed for committees/board positions to ensure that their contribution is meaningful (that they have the experience to contribute). In turn, committees and boards need to know why the consumer is there and should seek their input.'* – Victorian consumer

Within the context of consumer engagement, we believe that the introduction of the National Health Service Standards, specifically Standard 2: Partnering with Consumers, has been a very important step forward towards the establishment of a true culture of partnership in health. However, we have concerns about the effectiveness of the current hospital accreditation approach to measuring and assessing partnership and success in embedding consumer engagement.

We would also argue that much of the heavy lifting needs to be done at a collective, rather than at an individual health service, level. For instance, consumer representatives bemoaned their sense of isolation and their need for peer support and information exchange.

Similarly, while consumers need to be inducted into their local circumstances, capacity building and training (particularly in domains such as quality and safety and clinical governance) would best be delivered as an outsourced service, not by every health service.

To improve the safety and quality of patients through consumer engagement, we recommend the following:

7. investment in the provision of appropriate training for consumer representatives (in quality and safety, governance, board skills, etc.);
8. broad recruitment campaign to engage consumers in health service improvement;

9. commitment to broadening the diversity base of consumer representatives to more accurately reflect the diversity within the community;
10. development of an effective platform for networking amongst consumers;
11. development of clear guidelines for health services on linking consumer committees into reporting lines with executives and the board, so input is heard and acted upon;
12. training for health professionals and hospital staff in the motivation, evidence and value of consumer participation to improve buy-in and development of a more collegial and cooperative environment between staff and consumers.

Beyond these initiatives, and as argued previously, compliance is an ineffective and blunt instrument in addressing culture change. At the minimum, however, standards should reinforce the need for culture change, designate the essential role of the CEO (with their leadership team) to drive that change, and require that a program be developed and put in place toward this end (similar to requirements for organisations to develop OH&S plans). We acknowledge, however, that there are no off-the-shelf solutions available to meet this end and recommend the department address this vacuum as a matter of priority.

### **Strengthening the ability of patients and families to complain and for complaints to lead to improved quality and safety**

*'There's a need for real-time reporting of concerns to the hospital, so they're aware right away rather than waiting six months for reports to be produced. There's an optimum time for issues to be addressed and that's being missed....'—Victorian consumer*

Although the question of complaints was not directly raised within the context of this review, the consumers we consulted continue to hold significant concerns regarding the ability of patients and families to complain freely and for those complaints to translate into safety and quality improvements. We believe there are two separate, though equally important, issues here.

Although the public generally rates doctors and nurses very highly in terms of being respected and trusted professions, when it comes to making a complaint against those same health professionals, many patients and families are fearful and, thus, reticent about expressing dissatisfaction with care. Reasons cited for this include fear that future care will be compromised, concern about being seen as 'ungrateful' or labelled as 'difficult'. Most health services now make a concerted effort to inform patients about how to complain, providing brochures and signs encouraging complaints, and make a commitment to follow through with complaints. Yet fear and hesitation still persist, resulting in not only unresolved issues for patients and families but significant missed opportunities for improvement. Our consumer consultation also revealed a particular concern with the continuing inability of health services to capture or respond to real-time feedback about potential safety concerns, poor quality of care or other complaints.

*'Consumers who speak to nurses about concerns are often not taken seriously...consumers might not be able to articulate well and are thus dismissed...consumers need reassurance to communicate...it's often not clear who to complain to...would be better if they could speak to a peer which would reduce the hurdle of blame.'* – Victorian consumers (aggregated)

We see an opportunity here for an innovative approach to capturing real-time feedback, stories, and potential safety and quality risks through the external employment of a peer 'listener'. Flinders Medical Centre in South Australia developed the role of 'Consumer Representative' within the

paediatric unit six years ago. The aim of the position is to provide patients and families with an objective outside person who can not only hear things staff may not be able to hear, but see things that are difficult for staff to notice. This kind of ‘canary in the mine’ is an essential role in health, but one we believe is currently missing in our safety systems in Victoria.

*‘Much though we try – we cannot see problems from the patient’s perspective....in addition, the patient in hospital is vulnerable and often does not feel empowered to speak their mind when they can see how things could be better. Having someone to represent the patient, who is neither selected nor employed by the health service, ensures that the client has a voice.’<sup>17</sup> –Dr Brian Coppin, Clinical Director*

The Consumer Representative at Flinders has significant personal experience with the health system, is paid from an external source and is not so much a complaints liaison officer as a patient safety advocate. It has been important at Flinders that the staff see this role not as one meant to police them, but meant to help improve the overall safety, quality and patient experience in their unit. This is something that everyone is seeking. A similar program across Victorian hospitals, hiring a Patient Safety Partner, could be exceptional value for money, providing an opportunity to hear the patient voice directly (A poster with highlights of the project is attached as Appendix 1 to this submission.).

*‘.....it is really helpful to have a non-threatening presence at the coalface that they can share their thoughts and opinions with. It gives us a lot of valuable information and often, things that are raised are things we hadn’t noticed or thought of. Things that we can, more often than not, easily put plans in place to resolve.’<sup>18</sup> –Sharon Crowley, Clinical Services Coordinator*

There will be a need to train and develop capacity for consumers to work in the Patient Safety Partner roles. We recommend that the government commission training materials and courses specifically to develop capabilities of consumers in their roles as real-time interfaces between patients and their care teams, and preparing consumers for governance responsibilities at board level (including clinical governance). We recognise that we could be seen to have a vested interest in recommending this, given Health Issues Centre’s role. However, whether or not we would be in consideration for this work, we believe it is warranted.

In order to strengthen the ability of patients and families to express real-time concerns and have them acted upon, we recommend:

13. the establishment of a department-endorsed and funded peer support role, such as a Patient Safety Partner, within health services with associated training and capacity development for consumers filling that role.

## Theme 2: Improving hospital governance

### Clarifying, and supporting, the role of boards in clinical governance

Patients and families need to have complete confidence in not only the safety but the adequate governance of Victorian health systems. Our experience points to the fact that most patients know very little about governance mechanisms in the health system and may have limited faith in those systems to advocate for what matters to patients. Patients often have little knowledge of the purpose or accountabilities of hospital boards beyond fiscal governance. Our recent consultation found that even some consumer representatives with significant experience of the health system had little understanding of the role or responsibilities of hospital boards for ensuring safe and high quality

care. Events like the recent tragedy in Bacchus Marsh, which found serious failures of the board in understanding and carrying out its clinical governance responsibilities, further erode public confidence in hospital governance.

In order to restore public confidence in hospital governance systems, such as boards, it would be useful to demonstrate to patients that these systems focus on the things that matter to patients. We know that patients place a high value on the safety and quality of their care, for example. However, there is little solid evidence about how much hospital boards involve themselves in safety and quality discussions as opposed to, for example, fiscal oversight of the hospital; that which there is suggests safety and quality may not be top priorities.<sup>19</sup> A recent Australian study of Victorian public health service boards found that there were large variations in time spent on quality-related issues as well as knowledge, experience and training in clinical governance and quality.<sup>20</sup> This is despite the fact that there is emerging evidence of a relationship between the level of knowledge and involvement of hospital boards in quality issues and the hospital's performance on some care and mortality outcome measures.<sup>21</sup>

The Victorian Clinical Governance Policy Framework defines clinical governance as: *'the system by which the governing body, managers, clinicians and staff share responsibility and accountability for the quality of care, continuously improving, minimizing risks, and fostering an environment of excellence in care for consumers/ patients/residents.'*<sup>22</sup> Given that the board is responsible for the overall governance of its health service and that clinical care is the main service provided, it would be seen by the community as nonsensical for boards not to have some understanding of how clinical governance works in order to assess whether or not their health services is truly providing *'an environment of excellence in care.'*

We believe Victorian hospital boards need training and education to clearly understand and be able to carry out their responsibilities when it comes to the safety and quality of the care their hospital provides. And, as one board member involved in our recent consultation points out, the knowledge of safety systems and understanding of clinical governance should not rest with a very limited few.

*'In my experience on a hospital board, there were insufficient people with clinical experience to answer complicated questions including risks issues. We often relied on the CEO for answers, which is not always good enough.'* –Victorian hospital board member

One of the Health Issues Centre staff involved in writing this submission has over seven years of experience as a consumer member of a major metropolitan hospital's clinical quality and safety committee. Her experience from this committee, and several other high-level appointments, is that there is a strong tendency for non-clinical members to feel intimidated about asking questions or speaking up on issues of a clinical nature. This view is backed up by other engaged consumers. This is a risky situation, given the importance of clinical governance and the limitations of only bringing one perspective to the careful consideration of safety and quality issues. We would argue that basic clinical governance training can provide a framework for board members to understand the key issues, including pertinent safety and quality KPIs, to be able to ask important and timely questions. If the full board, including consumer members, received such training we believe the overall 'safety net' would be strengthened.

We recommend the following:

14. the department commission training and education for all health service boards (including consumer members) on their role in quality and safety as well as providing a basic knowledge of clinical governance.

### **Commitment to appointing appropriate consumers to health service boards**

Consumers believe that every Victorian health service board ought to have at least one appropriately skilled and trained consumer member appointed to it to better represent the priorities and concerns of users of those services. In order to assure that at least one board member has a genuine consumer focus, we recommend the following guidelines for the skills and knowledge requirements for the currently designated board member who is meant to ‘represent the views of users of health services’

In addition to having the necessary board-level skill and knowledge requirements, any person aiming to fill a consumer or community role on the board must have evidence of all of the following:

- Personal experience as a patient or family/carer of a patient of the health service.
- Ongoing involvement, preferably via both formal and informal structures, with health consumers in order to gain and maintain a broad community perspective.
- Skills and experience (or appropriate training) in community advocacy on health as well as knowledge of what issues are broadly most important to patients and families.

Consumers expect and deserve proper representation on health service boards. We recommend:

15. at least one consumer member be appointed to every Victorian health service board;
16. the department assure that the appropriate consumer skills and knowledge assessment be applied for consumer or community members (as outlined above).

### **Theme 3: Strengthening oversight of safety and clinical governance**

We will not be commenting on theme 3.

### **Theme 4: Advancing transparency**

#### **Collecting and publishing appropriate and adequate safety and quality information to allow patients to make informed choices**

In response to the question of transparency, we received less specific feedback from consumers on this issue than we had anticipated. Consumers expressed a strong message that the health system was not currently ‘transparent’ but this tended to relate to issues such as complaints, discrimination, and lack of access to one’s own personal health information.

The discussion paper broadly described the issue of transparency as *‘Advancing transparency within the health sector, so that communities can verify that their local hospital is rapidly identifying and rectifying important defects in care when they arise.’*

While we applaud the review panel for defining transparency in this way, unfortunately, based on the data that is publically reported (and accessible), it is currently a fantasy to think communities or consumers would be able to assess whether their local hospital was addressing defects in care when they arise. This is not information that hospitals readily publish. If it were to be published, it would be

very unlikely to be in an easily accessible form or location. The reality is that consumers have very limited information about the actual safety and quality of the care that their local hospital provides.

The discussion paper also raised the following question:

‘Do the current statement of priorities indicators provide sufficient insight into hospital safety and quality for public reporting of the indicators to help consumers make meaningful choices about place of treatment?’

The answer to this question, according to our consultations, is emphatically ‘No’. The average consumer would have no way of accessing adequate relevant information to be able to make an informed decision about place of treatment. Based on publically reported data, the average consumer would not be able to answer the most relevant safety questions, such as ‘Which hospital has the lowest complication rate for the surgery I’m having?’ They would also be unable to answer other questions that they might consider vitally important. For example, ‘Where am I most likely to be able to be involved in decisions about my care?’ ‘Where can I be assured of care that is tailored to my needs?’ ‘Where can I find a clinician who will respect my cultural beliefs and values regarding health care?’

We would suggest that the issue of transparency for consumers is often about more than just making informed choices. It may well be about restoring confidence and trust in your local health service, believing that the quality of care and the safety of that care can be trusted. Consumers spoke to us about the challenge, particularly in smaller towns, of not having choices about where to go. This is an issue even in metropolitan areas for patients with complex or rare conditions that are only managed at one hospital. We believe that transparency should be about the continuous striving for excellence in safety and quality – it’s the very essence of what the review is addressing here – ‘assurance’.

Because we are currently so far from this ideal, our recommendations are general in nature. To begin the long road toward transparency that is enabling for consumers we recommend:

17. that consumer consultations be held to understand what information and in what form would be the most useful for consumers hoping to make decisions about their health care;
18. a commitment by the department to the goal of collecting and publishing appropriate and adequate safety and quality information that would enable the average consumer to make informed choices regarding places of treatment;
19. a commitment by the department to the goal of collecting and publishing appropriate and adequate safety and quality information that would enable the average consumer to be assured *‘that their local hospital is rapidly identifying and rectifying important defects in care when they arise.’*

## SUMMARY

It is obvious that consumers, as the stakeholders with the most to lose, have a vested interest in ensuring excellence in the safety and quality of health service delivery. We, therefore, welcome the explicit recognition within the Terms of Reference of this inquiry that consumers have a significant role to play in quality and safety monitoring and improvements. That having been said, the current mechanisms to enable this role remain woefully inadequate.

The collective experience of the dozens of consumers who participated in our consultations was, in general, one of ongoing frustration with issues like disrespect, inadequate information and limited participation. In terms of their consumer engagement, many have achieved some level of 'success', largely due to their dogged determination and emotional resilience. Most have taken up their roles in response to adverse personal experience and with a commitment to improving the health journeys of their fellow citizens. It is unconscionable for the system to acknowledge the intrinsic value of consumer participation, but to rely on heroic individual effort to tap into this resource.

We call for the government to adequately legitimize, define, train, resource and support consumers in the key roles we have proposed based on the wisdom of experienced consumers. If their input is truly valued, consumer participation must be reconceived as an intrinsic cost of health service delivery. We believe this is a cost that will provide a significant return on a modest investment.

For any enquiries about this submission, please contact Susan Biggar on (03) 9664 9343 or [s.biggar@healthissuescentre.org.au](mailto:s.biggar@healthissuescentre.org.au)

## Health Issues Centre's Recommendations

### Theme 1: Fostering continuous improvement and clinical excellence

#### **Improving patient participation at the individual level**

We recommend the Department demonstrate a strong commitment to the promotion of a culture change towards a patient centred health care system through:

1. development of skills, resources and appropriate tools to assist CEOs in implementing effective culture change programs;
2. provision of training in patient centred care, and endorsement of its importance, for executive teams and boards;
3. commitment to empowering patients to participate through a social behaviour change program.

#### **Clearly acknowledging the role of families and carers in safety and quality**

In support of the essential role of families and carers, we recommend:

4. the development of an official code of 'Family and Carer Rights' to help protect and enable the role of families and carers, as designated by the patient, as full and active participants throughout the health care journey of their loved one;
5. development of clear guidelines from the department to health services regarding visitation policies for all families and carers;<sup>23</sup>
6. support and training for health services in working with families and carers (through CACs and other forums) to develop and initiate programs for legitimising the role of family and carers as members of the safety team.

## **Embedding partnering with consumers at a system level**

To improve the safety and quality of patients through consumer engagement, we recommend the following:

7. investment in the provision of appropriate training for consumer representatives (in quality and safety, governance, board skills, etc.);
8. broad recruitment campaign to engage consumers in health service improvement;
9. commitment to broadening the diversity base of consumer representatives to more accurately reflect the diversity within the community;
10. development of an effective platform for networking amongst consumers;
11. development of clear guidelines for health services on linking consumer committees into reporting lines with executives and the board, so input is heard and acted upon;
12. training for health professionals and hospital staff in the motivation, evidence and value of consumer participation to improve buy-in and development of a more collegial and cooperative environment between staff and consumers.

## **Strengthening the ability of patients and families to complain and for complaints to lead to improved quality and safety**

In order to strengthen the ability of patients and families to express real-time concerns and have them acted upon, we recommend:

13. establishment of a department-endorsed and funded peer support role, such as a Patient Safety Partner, within health services with associated training and capacity development for consumers filling that role.

## **Theme 2: Improving hospital governance**

### **Clarifying, and supporting, the role of boards in clinical governance**

We recommend the following:

14. the department commission training and education for all health service boards (including consumer members) on their role in quality and safety as well as providing a basic knowledge of clinical governance.

## Commitment to appointing appropriate consumers to health service boards

Consumers expect and deserve proper representation on health service boards. We recommend:

15. at least one consumer member be appointed to every Victorian health service board;
16. the department assure that the appropriate consumer skills and knowledge assessment be applied for consumer or community members, including:
  - personal experience as a patient or family/carer of a patient of the health service;
  - ongoing involvement, preferably via both formal and informal structures, with health consumers in order to gain and maintain a broad community perspective;
  - skills and experience (or appropriate training) in community advocacy on health as well as knowledge of what issues are broadly most important to patients and families.

### Theme 3: Strengthening oversight of safety and clinical governance

No recommendations

### Theme 4: Advancing transparency

## Collecting and publishing appropriate and adequate safety and quality information to allow patients to make informed choices

To begin the long road toward transparency that is enabling for consumers we recommend:

17. that consumer consultations be held to understand what information and in what form would be the most useful for consumers hoping to make decisions about their health care;
18. a commitment by the department to the goal of collecting and publishing appropriate and adequate safety and quality information that would enable the average consumer to make informed choices regarding places of treatment;
19. a commitment by the department to the goal of collecting and publishing appropriate and adequate safety and quality information that would enable the average consumer to be assured *'that their local hospital is rapidly identifying and rectifying important defects in care when they arise.'*

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<sup>1</sup>Safety is Personal: Partnering with patients and families for the safest care. The National Patient Safety Foundation's Lucian Leape Institute, Boston, MA, 2014, p. 4.

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- <sup>8</sup> Berwick, D et al *A promise to learn – a commitment to act; Improving the Safety of Patients in England* National Advisory Group on the Safety of Patients in England, August 2013, p 4.
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- <sup>17</sup> Hearing the consumer voice – Loud and clear. Poster, Flinders Medical Centre and SA Health.
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- <sup>22</sup> Victorian Clinical Governance Policy Framework: A guidebook, 2009, glossary.
- <sup>23</sup> The Institute for Patient- and Family-Centered Care has developed an excellent resource for this which could be easily adapted for the Australian context. Changing hospital “visiting” policies and practices: supporting family presence and participation. Institute for Patient and Family Centered Care, Bethesda, MD. <http://www.ipfcc.org/visiting.pdf>