



public interest
ADVOCACY CENTRE LTD

**Response to Australian Commission on Safety
and Quality in Health Care's Consultation on
Consumer Engagement Strategies**

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Introduction

The Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) is an independent, non-profit law and policy organisation that seeks to promote a just and democratic society by making strategic interventions on public interest issues.

PIAC identifies public interest issues and, where possible and appropriate, works co-operatively with other organisations to advocate for individuals and groups affected.

In making strategic interventions on public interest issues PIAC seeks to:

- expose unjust or unsafe practices, deficient laws or policies;
- promote accountable, transparent and responsive government;
- encourage, influence and inform public debate;
- promote the development of law—both statutory and common—that reflects the public interest; and
- develop community organisations to pursue the interests of the communities they represent.

Established in July 1982 as an initiative of the Law Foundation of New South Wales, with support from the NSW Legal Aid Commission, PIAC was the first, and remains the only, broadly based public interest legal centre in Australia. Financial support for PIAC comes primarily from the NSW Public Purpose Fund and the Commonwealth and State Community Legal Centre Funding Program. PIAC also receives funding from the NSW Government Department of Energy and Water for its work on utilities, and from Allens Arthur Robinson for its Indigenous Justice Program. PIAC also generates income from project and case grants, seminars, consultancy fees, donations and recovery of costs in legal actions.

PIAC's work on health consumer issues

PIAC has undertaken a considerable amount of work on patient or health care rights over its 25 years, in particular around the development of an Australian Health Consumers' Charter. More recently PIAC welcomed the endorsement of the Australian Charter of Healthcare Rights by the Australian Health Ministers in July 2008. PIAC participated in the consultation process that led to the Commission's draft charter, including providing a written submission in response to the Consultation Paper on the draft charter.

One of PIAC's key programs is health and its strategic aims in this area for the period 2005-2008 are:

- To work towards making the health care system more accessible and transparent for health consumers.
- To assist in ensuring the delivery of appropriate quality of health care services for people in various institutional settings.
- To assist in ensuring appropriate care and treatment of people with mental illness that respects the dignity and rights of the individual.
- To assist in improving the interaction of the legal and health systems to ensure human and health rights are upheld.

Development of a Consumer Engagement Strategy

PIAC welcomes the opportunity to respond to the *Background Paper: Development of a Consumer Engagement Strategy for the Commission* (the Background Paper) released by the Australian Commission on Safety and Quality in Health Care (the Commission).

The Background Paper asks the general questions:

- What are your views about the Commission's approach to the development of the strategy? Is there anything in the statements that should be changed, added or deleted?
- Which specific groups or individuals should be involved in the Commission's work and why?
- What aspects of the Commission's work are most important for Consumer involvement?
- Which specific groups or individuals should be involved in the Commission's work and why?
- In what ways should consumers be involved in the Commission's work?
- What are the preferred models of involvement and/or a least preferred model?
- How could the Commission best support effective consumer involvement in its work?
- Are there any barriers to effective consumer engagement by the Commission that would need to be overcome?
- How could communication support the strategy and consumer involvement in the Commission's work?

The anticipated outputs of the strategy are set out at page 3 of the paper:

- The Commission's goals for consumer engagement
- The most effective ways in which patients, consumers, carers, health advocates and the general public can be involved in the various activities that the Commission undertakes
- How the strategy can be implemented and the resources that would be needed to implement it effectively.

PIAC submits that the Commission's goals for consumer engagement should address the issues that concern consumers at all stages of consumer interaction with the health system, not just the participation of consumers in the deliberations of the Commission. PIAC does not underestimate the importance of consumer engagement at the policy and strategy development level and addresses these issues in this submission. However, in Part 1 of this submission PIAC puts forward suggestions for broader policies and strategies to promote consumer engagement, in particular the engagement of consumers from disadvantaged groups. A specific focus is placed on possible strategies to engage health consumers who have been diagnosed with a mental illness.

In Part 2 of this submission, PIAC responds to the questions in the discussion paper, as set out above, about the direct engagement and participation of consumers in the Commission's policy-making and strategy-setting functions.

1. Part 1: Consumer engagement generally

1.1 Opportunities for consumer engagement?

Health consumers can engage in their health care at several levels:

- Accessing the health service
- At the point of health care
- After consumers receive their advice or care

PIAC maintains that the Commission should be encouraging the active participation and engagement of health consumers at all these levels. Each of these aspects of participation and engagement is considered below.

Consumers can also play a role in:

- service planning and evaluation;
- involvement in patient organisations, consumer organisations, NGOs or lobby groups;
- involvement in the political process when health issues are discussed either actively or relatively passively as voters in the electoral process.

Accessing the health service

Consumers have to make initial decisions about accessing a health service. Sometimes they have a choice as to what service they access (private/public; local/regional). Sometimes consumers from disadvantaged groups encounter barriers to accessing health services

For example many consumers experience racism, language problems, inability to pay and physical inaccessibility. People in institutional environments such as prisoners have limited choice in relation to their health care, and often cannot access particular health services available to members of the general public.

People in rural and remote communities often have restricted access to health services by virtue of limited or lack of choice or sometimes an absence of the services found in cities and regional centres. Many Aboriginal and Torres Strait Islander people live in remote areas of Australia where they encounter barriers generated by geographical remoteness and barriers generated by historical and current racism.

At the point of health care

Competent adults make their own decisions about health care on the advice and assistance of health professionals (informed consent). Those who do not have capacity, for example, people with severe dementia, an intellectual disability, brain damage, or those who are deemed not to have capacity (young children) have to rely on other people to make the final decision about their health care. They often still have capacity to participate in decisions about their health care.

Consumers, more often than not, not only participate in decisions about health care, but also play an active role in any treatment required.

After consumers receive their advice or care

Consumers are able to provide feedback to health professionals or health providers about the treatment or advice they received. This can be positive (praise, thanks), neutral (i.e. questions about their treatment and care), or negative (complaints) or combinations of all three.

The Commission's Goals for Consumer Engagement

It is now generally accepted that consumers have rights that they can exercise in all aspects of their interaction with the health care system. This is reflected in the Commission's Charter of Healthcare Rights. These rights should also be reflected in the Commission's goals for consumer engagement.

All the opportunities identified above should be seen by the Commission as central to its role in relation to consumer engagement. PIAC urges the Commission to consider how it can encourage consumer engagement in the health care system through:

1. Developing policies and strategies to provide consumers with information (clinical as well as information about the cost of services) about health services before consumers access them so that informed consent is meaningful and not just 'ticking the box' where in reality the consumer has little or no choice.
2. Identifying barriers to access and developing policies to redress lack of access to health care by members of disadvantaged groups, people in institutional settings, and those living in rural and remote locations.
3. Developing mechanisms that enhance the participation of health consumers in the decision-making process, including developing the promotion of health care rights to both consumers and participants in the health system including health professionals and administrators. (For example, the Charter of Healthcare Rights)
4. Developing programs that assist consumers to make informed decisions including both consumer education and education of health professionals about appropriate communication strategies.
5. Developing a national standard for the management of complaints in health care settings.
6. Developing strategies to engage consumers who would or could not respond to the usual methods of communication and engagement such as surveys or calls for public submissions.
7. Positively promoting 'open disclosure' by health providers and health professionals, both in terms of reaction to adverse events that effect patient safety and also in response to questions or complaints from health consumers about the care and treatment they have received.

1.2 Engagement with people who are diagnosed with a mental illness

PIAC believes that the Commission, in partnership with other bodies such as the Mental Health Council of Australia, should develop policies and strategies to enhance the capacity of people diagnosed with a mental illness to engage in decisions about their health care.

People diagnosed with a mental illness have particular needs and often encounter particular barriers in relation to participation and engagement in their health care. They have limited access to treatment for both their mental and physical conditions if they cannot afford private treatment and care. If their condition becomes acute, even if they have a capacity to pay for their care, private treatment in Australia is limited for people in an acute phase of a mental illness.

They can lose their decision-making rights if they are 'scheduled' under state and territory mental health legislation or placed on a Community Treatment Order (CTO). They also then find themselves facing barriers to accessing general health care during their—albeit often short—periods of institutional care.

They are often, even if they are not in an institutional setting, stereotyped as unable to make decisions about all aspects of their health care because of their diagnosis as a mentally ill person. Often because of the very reasons that lead to a diagnosis of mental illness, health consumers with a mental illness often cannot or do not complain about the treatment they receive. This heightens their already vulnerable position within the health system. Complainants can be summarily dismissed as delusional and their complaints characterised as further evidence of mental illness.

Diagnosis of mental illness is, of necessity, an imprecise science. However, how a person is treated (or not treated) often depends on the nuances of a particular diagnosis. Yet the capacity of a consumer to participate and/or engage in the diagnostic process is often limited because of the discounting of the consumer's narrative because of the stereotyping described above.

Public psychiatric treatment, either in institutional care or in the community, is drug rather than therapy focussed. Until recently there has been very limited access to psychological services, except for those with the capacity to pay for private services.

People who find themselves, either as convicted prisoners or 'forensic patients' (either found unfit to plead to a criminal charge or not guilty on the ground of mental illness) in a correctional setting together with a mental illness, lack an ability to engage or participate in their treatment decisions for all the reasons set out above. This is further restricted by the limited access to health care and security restraints found in a prison. In reality, these consumers have no choice in terms of which health care they can access and (unless through complaints mechanisms) only passively engage in decisions about their health care. The balance of power in a correctional setting adds an additional disincentive to use available complaints mechanisms.

PIAC in its submission to the Senate Select Committee on Mental Health in 2005 said:

PIAC believes that the provision of assistance to people with mental illness is, unfortunately, driven by the turbo of crisis management. Accordingly, services are often provided in a responsive and ad hoc manner with agencies doing the best they can in extreme circumstances. PIAC believes that generally services are limited to people with mental illness in crisis because there are limited resources to provide services more widely. That crisis often arises from the potential for self harm or harm to third parties.¹

In this context, participation in decision-making by the consumer is generally negated because of limits on their capacity due to their mental illness. If, however, they are not in the middle of a life-threatening crisis, then participation is generally seen as a luxury the system cannot afford.

Often consumers who have a mental illness seek a second opinion regarding their diagnosis, medication or general care. For these consumers in the public system (either on a CTO, 'scheduled', or unable to access private psychiatric care for financial reasons) access to a second psychiatric opinion is purely a theoretical proposition only. Finding a psychiatrist who bulk bills or is willing to travel to a public psychiatric hospital to see a patient is a very rare occurrence. Even if they would attend, there are usually institutional barriers to private practitioners consulting patients in the public hospital system. Yet people who are 'scheduled' have strict restrictions on their movements outside the hospital setting.

¹ Public Interest Advocacy Centre, *Submission to the Senate Select Committee on Mental Health* (2005) 6.

PIAC in collaboration with Legal Aid NSW funds the Mental Health Legal Services Project (MHLSP). The project being undertaken by PIAC has the broad aim of exploring the unmet legal needs of people who are mentally ill and through piloting innovative strategies, enabling those needs to be better met. The intention is to go beyond the usual criminal and civil matters and to encompass other relevant issues such as health care and service delivery. One of the pilot projects under active consideration is to, with the co-operation of NSW Health, place a consumer-focussed and independent advocate in a public psychiatric unit. Part of the role of such an advocate would be assisting the consumer to negotiate with the Hospital's health practitioners about treatment and care.

PIAC supports the provision of independent advocates who are able to work proactively as well as reactively with consumers in public mental health settings. PIAC urges the Commission to consider the consumer and health care benefits of such advocates in the context of its current work on consumer engagement.

2. Part 2: Consumer Engagement in the Commission's work

2.1 Which specific groups or individuals should be involved in the Commission's work and why?

PIAC maintains that there should be no limit to who is engaged in the strategy in that all Australians at one time or other are health consumers. However, the Commission should adopt policy that positively promotes the engagement of consumers from disadvantaged groups.

Because of the barriers present in both accessing health care and in participating in health care decisions encountered by members of disadvantaged groups, any strategy of consumer engagement should attempt to positively discriminate by the deliberate inclusion of consumers that are also members of these groups.

In particular, representatives of Aboriginal and Torres Strait Islander people, people with a physical and /or mental disability and people of a non-English speaking background should be represented. People who are diagnosed with a mental illness should also receive special representation (see below). There should also be recognition of geographic remoteness as a factor in both access and medical decision-making in choosing people to consult and participate in Commission decision-making.

Engagement should also include interaction with authorities, community legal centres, NGOs and consumer organisations concerned with the rights and welfare of prisoners, particularly those who are diagnosed with a mental illness. Consumer representation may also be possible by the involvement of former prisoners. It may be also be possible to obtain the participation of serving prisoners through negotiation with prison authorities. The Consumer Consultative Committee of Justice Health in NSW is currently in the process of expanding its representation of both former and current prisoners on the Committee.

Involvement of representatives of the above groups is essential. Australia cannot maintain that it has a health system operating on 'world's best practice', if particular consumers have substantial barriers to accessing health care or if they are unable to make informed decisions about their health care to the level experienced by other consumers.

2.2 What aspects of the Commission's work are most important for Consumer involvement?

PIAC believes that all areas of the Commission's work lend themselves to consumer involvement and participation.

The Commission's role is to:

- lead and co-ordinate improvements in safety and quality in health care in Australia by identifying issues and policy directions, and recommending priorities for action;
- disseminate knowledge and advocate for safety and quality;
- report publicly on the state of safety and quality including performance against national standards;
- recommend national data sets for safety and quality, working within current multilateral governmental arrangements for data development, standards, collection and reporting;
- provide strategic advice to Health Ministers on best practice thinking to drive quality improvement, including implementation of strategies; and
- recommend nationally agreed standards for safety and quality improvement.²

Consumers can and should play a role in all these areas.

Consumers are well placed to identify areas for improvement in patient safety and the quality of health care. Consumers can also play a role in the dissemination of knowledge through consumer organisations and through individual advocacy. It is in the interest of consumers to advocate for safety and quality of health care. Consumers can also play a role in contributing to the development of agreed standards for safety and quality improvement, and provide feedback on the performance indicators that best assist consumers to make decisions about their health care.

Consumers are also able to assist in the development of quality improvement in health care. The use of individual case studies based on the direct experiences of health consumers can act as a vital tool in driving quality improvement.

2.3 In what ways should consumers be involved in the Commission's work? What are the preferred models of involvement and/or a least preferred model?

The models are set out on page 12 of the Background Paper under the heading of 'Possible Components of a Consumer Engagement Strategy'.

All these models are valid and potentially effective strategies to involve consumers in the Commission's work.

However caution should be applied to the term 'consumer experts'. Consumers add value to decision making through their experiences, insights and often emotional response to their interaction with the health system. Because consumerism itself has been the object of academic study, there may be a temptation to appoint someone who is an expert on consumerism rather than someone who has had experience of the ups and downs of the health system. This temptation could be greater given the truism that everybody, at some time, is or has been a health consumer.

PIAC submits that someone who has had first hand experience in difficulties in accessing health services and/or difficulties in negotiating their own autonomy in making decisions about their health

² Australian Commission on Safety And Quality in Health Care (2008) <<http://www.safetyandquality.org/>> at 22 August 2008.

are preferable representatives than someone who is an 'expert' on the health consumer movement. He or she may have carried out a great deal of research on health consumerism but may not be seen as a true consumer representative by other health consumers and health consumer organisations and NGOs. If the Commission believes that this sort of expert can value add to its decision making processes, then this participation should be as an expert adviser rather than as a consumer representative. The Commission should consider the capacity of individual health consumers to not only draw on their own experience, but to seek out and draw on the experiences of others.

PIAC again emphasises the importance, within the practical restraints of available resources, of engaging representatives of all disadvantaged groups in any consultative process about health care.

2.4 How can the Commission best support effective consumer engagement?

Consumer representatives in decision-making need adequate resourcing to be effective. Access to information is the key in this regard. Unless consumer representatives have the same access to information as other decision makers, they are likely to be less effective. Independent access to research staff, and information resources (of course limited by the capacity of the organisation to provide such research assistance), leads to better-informed consumer representatives, which in turn leads to better decision making.

Geographic isolation can be a barrier to effective consumer engagement (see below) so reimbursement of travel costs to attend meetings is essential. Electronic or telephone access to meetings and consultations remain a second-best option to face-to-face communication. If the consumer representative is always the contributor via a telephone hook up, while all the other participants are physically present at a meeting, it is easy for the person not physically present to feel and be marginalised and disengaged.

2.5 Are there any barriers to effect consumer engagement by the Commission that would need to be overcome?

For members of disadvantaged groups, the barriers to effective participation in decision making of an organisation like the Commission may be the same barriers encountered in society. If English is a second or third language, communication problems will arise.

Overuse of jargon and 'management speak' is also a potential barrier to communication. Continual use of abstract terms and concepts can be a frustration to somebody who believes their best contribution is to communicate their own concrete experiences and emotional responses to that experience.

Geographical isolation can be a barrier to accessing adequate health services. It can also be a barrier to effective consumer engagement unless the Commission recognises and takes steps to balance this situation. Isolation can lead to a deficit in information available, despite increased information accessibility through the Internet.

Whether through geographic isolation or disadvantage, not all consumers have equal access to research material and data, whether it can be sourced electronically or in the more traditional forms (books, reports, journals, official reports). Steps need to be taken to minimise the impact of such inequalities.

2.6 How could communication support the strategy and consumer involvement in the Commission's work?

PIAC has emphasised the importance of effective communication in the health system elsewhere in this submission. An effective communication strategy would consist of taking steps to overcome the barriers to effective consumer engagement set out above.

A communication strategy that would support and enhance the Commission's work would:

1. Publicise and disseminate information about the Commission to the general public, using plain English as well as community languages, targeting in particular those members of disadvantaged groups who encounter barriers in accessing health services and in negotiating decisions about their health care.
2. With regard to information, adequately resource community representatives, including providing access to the Commission's own research resources.
3. Avoid managerial or technical jargon in communication with consumer representatives. If such language has to be used, provide practical examples of its use in settings familiar to the consumer as illustrations of the abstract arguments.
4. Within the limits of resources, fund consumer representatives to travel to meetings and hold meetings and consultations where possible in regional locations.
5. Adopt proactive strategies to attempt to communicate with those who are less likely to respond to consumer surveys, public consultations, etc. Otherwise the danger is that those with the greatest needs are the least likely to be heard.

PIAC encourages the Commission to use whatever resources are available to enable the participation of consumers in its deliberations. Consumer participation and engagement in the Commission's deliberations and decision making will enhance all the Commission's key roles. Further the involvement of people from disadvantaged groups in the Australian community will enable the Commission to develop policies and strategies that benefit all Australians.