

**Att: Professor Chris Baggoley**

Chief Executive

Australian Commission on Safety & Quality in Healthcare

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5<sup>th</sup> March 2008

Dear Professor Baggoley,

**RE: NATIONAL PATIENT CHARTER OF RIGHTS**

The Australian Injecting & Illicit Drug Users League (AIVL) welcomes the opportunity to provide the Australian Commission on Safety & Quality in Healthcare with comments on the draft *National Patient Charter of Rights* and to address the question posed in the consultation paper.

Before outlining our specific views on the draft *National Patient Charter of Rights* and the questions provided however, we would like to briefly explain why AIVL has a unique and important voice to add to this consultation process.

**Who does AIVL represent?**

The Australian Injecting & Illicit Drug Users League (AIVL) represents issues of national significance for people who use or have used illicit drugs including people currently in drug treatment and is the national peak organisation for state and territory drug user organisations. AIVL and its members are 'peer-based' organisations which mean they are run *by* and *for* people who use/have used illicit drugs. Although AIVL and its members provide a range of programs, activities and services in relation to health, legal and social issues for people who use/have used illicit drugs, unlike other non-government organizations, AIVL and its members have direct experiences of many of the issues we seek to represent and in this sense, act as the 'voice' of people who use and have used illicit drugs in Australia.

In this context, AIVL represents the needs and issues for some of the most marginalised and socially excluded people in the community such as:

- people who inject drugs;
- people with drug dependencies;
- people on opioid substitution programs;
- people accessing other forms of drug treatment; and
- people with drug-related comorbidities including mental health issues, hepatitis C, HIV/AIDS, etc.

The levels of harm potential associated with illicit drug use (particularly long term injecting drug use) means many of the people AIVL represents often come into contact with the health system and sometimes under difficult circumstances. The needs and issues of people who use/have used illicit drugs are often complex and associated with extreme levels of stigma and discrimination. Research evidence has shown that a significant amount of the discrimination and poor treatment experienced by people who use/have used illicit drugs occurs at the hands of healthcare providers.<sup>1</sup>

### **General Comments on the Draft Charter**

In general terms AIVL welcomes the National Patient Charter of Rights and believes it is an important document particularly for those sectors within the health system that have been neglected in relation to policy frameworks to support patient or consumer rights such as the drug treatment sector. This document will provide a critical resource for consumer organisations that are engaged in advocacy and lobbying in relation to patient/consumer rights in this area.

### **Response to Consultation Questions**

#### ***1. National Patient Charter on Rights and National Patient Charter Principles***

Whether the language used in the Charter and the Principles is appropriate?

*The language is mostly appropriate but it needs explanatory notes for particular health settings i.e. drug treatment services, pharmacotherapy services, primary health settings, general practice, public hospitals, etc. These should be written by consumers – also see answer below.*

Preferred option (including structure, style and presentation) for articulating patient rights and entitlements for patients and providers?

*AIVL believes that consumer input and consultation has to be included in the structure, style and presentation of articulating patients' right and entitlements. This is particularly important in health care settings where consumers/patients are disempowered, isolated, used to a culture of discrimination and poor treatment and therefore feel they have no voice or right to have a voice. This information being written by consumers for consumers will ensure that the language is appropriate and understandable, and the important points are explained within a context and from a view point that only consumers can provide.*

#### ***2. Rights Included in the Charter***

The rights included in the Charter are sufficient to cover the range of patient and human rights?

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<sup>1</sup> ADBNSW, *C-Change: Report of the Inquiry into Hepatitis C Related Discrimination*, Anti-Discrimination Board of NSW, Sydney, 2001.

*Although principles such as “Access” and “Respect” should cover the issue of discrimination and negative attitudes towards particular sections of the community i.e. people who use/have used illicit drugs, AIVL is concerned that they may not be enough to address the entrenched attitudes and values of some health service providers. Discrimination is a significant barrier to access and people who use/have used illicit drugs are so accustomed to being treated without respect, without dignity and with little consideration in so many areas of their lives that they come to expect, and accept as normal, poor treatment in many health care settings. For example, when as a patient or consumer people expect to be treated poorly and a health care provider does little more than provide a basic level service, they often view that service as a ‘good service’ that ‘treats them well’ even if that service would not meet the standards and rights articulated in this Charter. This is because perceptions of poor treatment and high quality treatment are based on consumer/patient expectation. Their expectations have been met (even if they are low expectations) and the service is not challenged to provide a better or more ethical service.*

*The first section of the National Patient Charter principles (that expands on these headings) could make explicit that discrimination and negative attitudes are included in these sections. As mentioned in the introduction to this submission, there have been numerous studies and research on the level of discrimination experienced by certain groups within the health care sector in particular people who use/have used illicit drugs including people with hepatitis C, HIV/AIDS, etc. In this context, AIVL believes there needs to be a strong commitment to the elimination of discrimination and stigma in health care settings which needs to be strongly supported in practice by a national implementation plan to address these issues including benchmarks and outcome indicators tied to funding agreements.*

*The issue of pain relief for patients who are labelled as drug dependant is a significant human rights problem. Many patients who enter hospitals are denied adequate pain relief as they are accused of ‘drug seeking behaviour’. Any patient who is in pain and needs pain relief should be entitled to this assistance regardless of their history of illicit drug use or whether or not they are currently on a pharmacotherapy program. Adequate pain relief for a patient who is suffering is a basic human right and AIVL believes this needs to be made explicit in the Charter.*

*Consumers should be fully involved in the development and monitoring of the above strategies and as part of this approach it will be necessary to develop consumer-driven resources and training to educate and empower consumers to undertake this role effectively.*

The extent to which the rights represent concerns when receiving health care?

*From AIVL’s perspective, if the issues of discrimination, pain relief and attitudes are adequately addressed as outlined above then the principles as articulated will cover the main concerns.*

### **3. Points included in the Principles**

Whether the explanations included assist in understanding the rights and responsibilities of patient and providers?

*AIVL believe the points made above about including consumer driven and written explanations would greatly increase the understanding among patients/consumers of the rights and responsibilities as articulated. Different consumer groups representing the diverse range of health consumers could assist by adding explanation specifically targeting key consumer groups. Each group has some very specific and different issues that need to be addressed within the health system and consumer representatives with assistance from consumers would be best placed to developed these explanations.*

Additional points that could be included in the principles to adequately explain the meaning and application of rights?

*Please see answers above concerning consumer development and writing of additional points.*

#### **4. Rights and Responsibilities**

Are there other rights, roles and responsibilities that impact on patients and provider that should be included?

*As previously mentioned the issue of discrimination has a massive impact on ability of certain patients/consumers to access basic primary health services and obtain the best possible care. Addressing ingrained negative attitudes towards certain groups in the community is imperative if client rights are to be truly recognized and make a difference to quality of care.*

#### **5. Existing Charters**

The potential value added by having a National Patient Charter of Rights.

*AIVL believes a National Charter, that is followed up with a comprehensive implementation plan, will ensure standards of care are consistent across the country and will also ensure that the standards within health services in certain states/territories will not diminish with changes in governments, Executive Directors, Boards of Management, etc. It will assist with providing guidance for local health care settings in ensuring that they are meeting the national standards expected of all health services.*

#### **6. Possible Uses of the Charter**

*AIVL believes it is critical that a comprehensive implementation plan is developed to ensure the principles and rights contained in the National Charter are delivered in practice. If this occurs, AIVL believes the Charter will be useful in the education of parliamentarians, advisers and government officers and could be used to develop a core training program on patient/consumer rights in health care to be undertaken with health care professionals and students of medicine, pharmacy, etc.*

## ***7. How the Charter Applies in Different Sectors & Settings***

*Please see comments above in particular comments about the specific needs of highly marginalised health consumers and the need for an implementation plan to ensure the application of the Charter principles in practice.*

### **Conclusion:**

As a national consumer based organisation representing some of the most marginalised people who access health services, AIVL would be very happy to meet with the Commission to discuss the issues we have briefly outlined in this submission in more detail. If you would like to meet with us, please do not hesitate to contact me at AIVL.

Once again, AIVL would like to thank the Commission for the opportunity to provide comments on the draft Charter and we look forward to using the final document in our rights based advocacy in the future.

Yours Sincerely,  
**Annie Madden**  
**Executive Officer**