

Submission

No 43

## INQUIRY INTO THE OPERATION OF THE HEALTH CARE COMPLAINTS ACT 1993

**Organisation:** Positive Life NSW  
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28<sup>th</sup> October 2009

Mr Mel Keenan  
Committee manager  
Committee on the Health Care Complaints Commission  
Parliament House  
Macquarie Street  
SYDNEY NSW 2000

Dear Mr Keenan

## **Operation of the Health Care Complaints Act 1993 – Discussion Paper**

Please find enclosed the submission of Positive Life NSW in response to the Discussion Paper on the Operation of the Health Care Complaints Act 1993.

Positive Life NSW advocates for the health care needs of people with HIV in NSW and is particularly interested in the operation and conduct of the health care complaints system.

In response to the Discussion Paper, Positive Life would like to highlight issues of importance to people with HIV that, in our opinion, have not been adequately addressed in the discussion paper.

The issues include:

- A more simple, efficient and effective complaints system that is easier to understand and use by consumers with HIV in NSW
- The HCCC improving communication and working more cooperatively with the Anti-Discrimination Board and Australian Human Rights Commission to achieve better outcomes for complain involving discrimination by health care providers
- The HCCC use its considerable knowledge and experience of complaints to generate systemic improvements in health care policy and practice in NSW
- The HCCC be in a position to receive and consider complaints in relation to the use and abuse of the electronic health and medical records and make recommendations for improvements to the security and operation of the system.

Positive Life would like to take this opportunity to thank the Committee for granting an extension of time to progress this submission and respond to the Discussion Paper.

We would be happy to provide further information to the Committee if requested.

Yours faithfully



Rob Lake  
Chief Executive Officer

# **Inquiry into the operation of the Health Care Complaints Act 1993**

## **Submission of Positive Life NSW**

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### **Introduction**

Positive Life NSW is a non-profit health consumer organisation that advocates for the health care needs of the approximately 9,500 people with HIV in New South Wales. We have extensive knowledge and experience of the contextual issues impacting on the health and welfare of this population.

We would like to take this opportunity to thank the Committee for the opportunity to respond to the Discussion Paper on the Health Care Complaints Commission. In preparing this submission, Positive Life has consulted with ACON<sup>1</sup>, the HIV/AIDS Legal Centre, and People with Disability Australia to assess their support for this submission. ACON strongly supports this submission.

We note in the Executive Summary that in preparing the Discussion Paper, the Committee has relied on the expertise and experience of a range of stakeholders, including health care consumers, to flag issues which lead to a more effective and efficient Health Care Complaints system in NSW.

We would like to take this opportunity to respond to each of the chapters in the discussion paper and highlight areas of importance to people with HIV that we believe have not been adequately addressed in the discussion paper.

### **Chapter one - Background**

#### **Principles of a complaints handling system for the 21<sup>st</sup> century**

Positive Life applauds the Committee's consideration and comparison of operating principles for complaints handling systems in other jurisdictions and supports the principles of accountability, transparency, fairness, effectiveness, efficiency and flexibility. Additionally, we submit that ease of use of the health care complaints system in New South Wales is an important principle that would further support efficiency and effectiveness of the complaints system.

### **Chapter Two - A complex health care complaints system**

Positive Life commends the Committee's attempts to simplify the health care complaints system in NSW and agrees that the current system is complex and multi-faceted and not well understood. People living with HIV and other chronic health conditions, rely on quality health care services to monitor and maintain optimal health and wellbeing. Patients have the right to be treated with respect, dignity, fairness and consideration. They should also have the right to be informed about services, treatment, options and cost in a clear and transparent way.

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<sup>1</sup> ACON is a community-based gay, lesbian, bisexual and transgender (GLBT) health and HIV/AIDS organisation. They promote the health and wellbeing of the GLBT community and people with HIV. They also provide information and support for people at risk of or affected by HIV, including sex workers, people who use drugs and the family and/or carers of people with HIV.

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Positive Life supports a provision that the Health Care Complaints Commission should consider the Australian Charter of Health Care Rights when assessing or dealing with a complaint.

More than one quarter (27.2%) of respondents to the HIV Futures 5 national research survey have experienced less-favourable treatment at a medical service as a result of having HIV. When asked what form this treatment took, the most common responses were increased infection control (35.6%), avoidance (34.5%), confidentiality problems (31.6%), treated last (29%), refusal of treatment (29%), rushed through (27.7%), harassment (9.3%), and abuse (8.4%)<sup>2</sup>. This data also indicates that people experience more than one category of unsatisfactory behaviour and treatment.

Positive Life notes that there are a number of agencies that have general mandates to monitor and improve health care quality, policy and practice in NSW. When a person with HIV experiences unacceptable treatment or discrimination from a health care provider, they require a simple and efficient complaint process. The current system is complex and not well understood by most people with HIV.

### **Chapter Three – The assessment and investigative powers of the Health Care Complaints Commission**

#### **Timelines**

Positive Life notes that a considerable number of submissions to the Committee expressed dissatisfaction with the timeliness of the Commission's processes. Positive Life NSW and the HIV/AIDS Legal Centre assert that the Commission's investigation and conciliation processes are unnecessarily prolonged. Many complainants will not have the energy or stamina to continue with a process that often exceeds the one-year period. In the experience of the HIV/AIDS Legal Centre, the current process makes any complaint process an unattractive option for all but the most stoic and committed of complainants, or the most severe complaints.

Additionally, individuals who use the Commission in the first instance to resolve a complaint limit their ability to pursue other legal options with the Anti-Discrimination Board or the Australian Human Rights Commission if the investigation and conciliation process is drawn out (complaints made under the Anti-Discrimination Act (NSW), the Sex Discrimination Act (Commonwealth) and

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<sup>2</sup> Jeffrey Grierson, Rachel Thorpe and Marian Pitts, HIV Futures Five - Life as we know it, The Living with HIV Program at The Australian Research Centre in Sex, Health and Society, La Trobe University, October 2006, p68-69

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the Race Discrimination Act (Commonwealth), are subject to a limitation period of one year).

### **Outcomes**

As the Commission can not award compensation or damages, the only likely outcome is an apology. While this may be satisfactory for some complainants, it is a laborious process, particularly if no apology is forthcoming. The Commission appears to be only interested in severe cases of malpractice and breaches of registration or professional practice. In the opinion of the HIV/AIDS Legal Centre, people who have been treated in an undignified or disrespectful manner, and who believe their confidentiality has been breached, seem to attract less interest from the Commission.

### **Chapter Four – Information-sharing between the Commission and Area Health Services and Registration Authorities**

The emerging area of electronic health records holds significant concern for Positive Life NSW both in the establishment phase and into the future operation and monitoring of the system. The Health Care Complaints Commission should be in a position to receive and consider complaints in relation to the use and abuse of electronic records and make recommendations for improvements to the security and operation of the system.

Positive Life believes that a 'more generous' reading of the Commission's responsibilities under the Act might allow for the Commission to increase its engagement with the wider NSW health care system to improve health care quality and policy and practices generally. In doing so, the Commission would draw on its direct and detailed knowledge of complaints to undertake a process of reporting thematically that would generate dialogue and systemic improvements to health care policy and practice.

### **Conclusion**

Positive Life suggests that there is an opportunity to improve the usefulness, efficiency and effectiveness of the Health Care Complaints Commission for people with HIV who are unsatisfied with the quality and provision of health care services in NSW. Working more cooperatively with the Anti-Discrimination Board and the Australian Human Rights Commission and improving communication would achieve better outcomes for complainants with HIV.

We also suggest that the Commission could use its considerable knowledge and experience of complaints to improve health care policy and practice at a systemic level by generating and reporting thematic analysis annually and instigating dialogue between agencies that identifies potential improvements in health care policy and practice in NSW.

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### **Submission of Positive Life NSW**

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Positive life would like to thank the Committee for this opportunity to provide comment on the operation of the Health Care Complaints Act 1993 and the Health Care Complaints Commission, and would be happy to provide further evidence to the Committee if required.