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### **ARCSHS' comment on the draft policy paper, Review of the Health Act 1958**

The Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University is pleased to have an opportunity to make comment on the *draft policy paper – for consultation: Review of the Health Act 1958*.

We congratulate the Department of Human Services Victoria on this timely endeavour to review the current Health Act 1958, and to update, clarify and broaden the scope of the new act which will guide our approaches and responses to individual and public health relevant for the twenty first century, and in a globally interconnected world.

ARCSHS hopes that this submission, together with the commentary to DHS from a diversity of other agencies, interest groups and individuals, will contribute to a comprehensive and insightful review of this draft for the proposed new Public Health Act.

Our suggestions do not cover the entire draft document. Rather we make comment (below) specifically from our experiences as researchers into the social implications and personal experiences of HIV, hepatitises, STIs and related issues and circumstances, and from our expertise as educators, trainers and developers of resources, and in translating research into practice and policy.

Our expertise is in the areas of:

- Public health research into individual, collective and policy aspects of infectious diseases, in particular HIV, hepatitises and sexually transmissible infections;
- the protection of personal identifying information gathered in the course of research conducted under appropriate ethics approval;
- access and equity issues;
- both the main-streaming and the making of a special and separate case for the infections HIV and hepatitis C;
- BBV testing considerations;
- pre- and post-test counselling requirements, including training, and
- BBV and sexual health risk management and awareness education.

There is much to **applaud in the draft Act, beginning with the name Public Health Act. Recommendation 1.**

We also **endorse Recommendations 2 – 12.**

In particular we **endorse Recommendation 13**, detailing the overarching principles which would context and guide decision-making in the details of all the following recommendations. Some of these principles, i.e. of evidence-based decision-making, the primacy of prevention, collaborative partnerships, and accountability are principles essential to and inherent in our research and education work at ARCSHS, and we believe are necessary foundations for all public health endeavours. One principle that **we recommend be added to the six currently detailed is the *Principle of best practice***, as defined by research and application, as the bench mark or standard for any decision or action in the area of health and well-being and public health.

#### **4.1 A Risk management approach**

##### **Recommendation 71 and Recommendation 72:**

We support this consideration on the practice of risk management, and **endorse Recommendation 71**

With regard to **Recommendation 72, we are concerned** that the term 'risk' is used as if it were absolute. There is no recognition of the contextual factors that make a significant contribution to risk *per se*, and to the assessments made of such risk. These include: environmental factors such as the availability and accessibility of information and preventive technologies (e.g. condoms); cultural factors such as differing community levels of knowledge and understanding around transmission and prevention; the sophistication of individual or group understandings of relative or cumulative risk; and the procedural, policy and practice environment in which a risk practice or event may occur. There is also a clear failure to recognise that risk exists along a continuum, and that theoretical risk is not equivalent to probabilistic or actuarial risk (as for example, the differing risk of HIV transmission in the circumstances of a blood spill as opposed to a needle stick injury).

We **suggest that Recommendation 72 is re worded**, with the following as an example of how it might read:

“That the Department of Human Services consider developing administrative guidelines where appropriate, to ensure that issues of risk are addressed effectively and in a contextually relevant and consistent manner ....”

The following detailed comments on selected parts of sections **5.4 Compulsory testing orders, 5.5 Public health orders, 5.6 Notifiable conditions and 5.7 Human immunodeficiency virus** are based on ARCSHS' collective professional experiences and associations in these areas of BBVs and social and sexual health.

Much of the social research at ARCSHS focuses on the experiences of being affected by or of living with HIV and hepatitis C. One of the education and training programs regularly conducted by us is the Counsellors' Accreditation Program (CAP) which trains health service providers as DHS accredited "persons of a prescribed class", competent to provide effective pre- and post-HIV antibody test counselling, according to the requirements of the current Health (General Amendment) Act 1988, no. 48, (p.19).

## 5.4 Compulsory testing orders

### Recommendation 164

We suggest that the following requirements are noted, to ensure that compulsory testing occurs only when:

- The incident is one that carries a realistic risk of infection transmission should the source be infected, e.g. an occupationally sustained needle stick injury; rather than blood spill contact with intact skin;
- The source person has been offered counselling and voluntary consent has been sought by a competent, experienced BBV testing counsellor, and that consent has been refused.

We have verbal reports from health care workers in a major inner city hospital of needle-stick incidents where the source has refused consent for testing to a specialist doctor, however later consented following discussion with a staff member (a nurse in these examples) trained in pre- and post-test counselling skills.

### Recommendation 165

- A compulsorily acquired blood sample should be tested only for HIV, hepatitis B, C and D, for which there are appropriate antiviral agents which might prevent establishment of infection in the person sustaining the injury.

In section 5.6.4 **Form of Notification** (of notifiable conditions) **we strongly recommend that hepatitis C is included together with HIV** whenever HIV is noted as different or requiring special consideration. We appreciate that hepatitis C is absent from the current Health Act because it was not identified until 1990, after the current legislation was written. Like HIV, Hepatitis C is too often associated with overt stigma and active discrimination and sometimes rejection, making it different from most other notifiable diseases. Hence our suggestion of 'coupling' of these two viruses for purposes of legislative consideration.

Specifically **we recommend that hepatitis C be added to the Group D diseases of HIV and AIDS**. Consequently, the requirements relating to HIV and AIDS notification, such as coding, should be the same for hepatitis C.

The proposed legislation (p. 99) suggests that coding of Group C and D infectious disease notifications should not be necessary, given the protection of the Victorian privacy laws, i.e. the *Information Privacy Act 2000* and the *Health Records Act 2001*. This presupposes that community understandings of such legislative protections are both thorough and up to date. However, it must be thoughtfully acknowledged that the de-coding of notifiable disease information may encourage *public perceptions* of an increased risk of breaches in confidentiality, which may lead to a decrease in testing, delays in testing and diagnosis, and decreased willingness to disclose HIV or hepatitis status in health care settings. This would have significant consequences including increases in late diagnoses, poor health outcomes for those infected and increase in transmission of these viruses.

Given these consideration, **we recommend that coding requirements for Group C and Group D infectious diseases (re-named as “conditions”) are maintained**.

#### **Section 5.7 Human immunodeficiency virus**

Given the explanation above, we strongly **recommend that the words “and hepatitis C”** be added to all references to HIV in this section.

In addition we recommend that:

**A legislative requirement for both pre- and post-test counselling for HIV and hepatitis C is retained and formalised.**

In our education and training programs with health service providers (who work with a comprehensive cross-section of Victoria's diverse population) we continually hear evidence that there is still substantial ignorance, misunderstanding and apprehension about these viruses, both within the general population and among health professionals. Pre-test counselling provides an essential opportunity to inform, educate, clarify and prepare a

person for the social and emotional implications of both being tested and getting a test result; the post- test counselling session is essential to clarify understanding about the implications of a test result (either negative or positive), to educate for prevention or reduction of risk and/or transmission of infection, and to discuss crucial personal and clinical management issues. There is a wealth of clinical and social research, both domestically and internationally that clearly indicates that quality pre- and post test discussion for BBVs results in improved health outcomes for those who test positive and reduced transmission of the viruses through increased protective practices of both those who test positive and negative. These counselling requirements *must be included* in the new legislation.

In addition the legislative requirement to become a “prescribed person” for the purpose of pre and post test counselling makes a significant contribution to public health by motivating a large number of non-medical health professionals to do specialised training in this area. This training not only ensures the workforce is better informed about these infections, but also challenges many preconceptions about the type and nature of people likely to be at risk or infected. We believe it would be counter-productive to give up a requirement which is having such a positive impact on the workforce awareness, skills and practice.

#### **5.7.1 Pre and post-test counselling provisions, and Recommendation 185**

Associated with our position, described above, on pre- and post-test counselling for HIV and hepatitis C, is our response to this discussion sentence in 5.7.1, p. 100:

“On further consideration, it appears that a legislative requirement for pre-test counselling is no longer required, and may present obstacles to introduction of screening programs, such as antenatal HIV screening.”

**We are strongly opposed to the use of HIV and hepatitis testing as screening tools**, and recommend that the wording of the new Act reflect the

public health aim of *offering* diagnostic opportunities to large numbers of people, such as pregnant women, as relevant, without coercion, seeking to test only in an informed and voluntary context. The pivotal effectiveness of competent pre-test counselling is evident when it is recognised that pre-test counselling is the only process by which a meaningful risk assessment can be made, and informed consent be given by the patient or client, taking into account individual circumstances and risk history.

In the course of facilitating training programs we have had numerous reports about the impact of a test result on a person tested without awareness or consent, i.e. without pre-test counselling.

One young woman, tested without her knowledge or specific consent on admission to major surgery, has described her positive test result as “totally devastating” and an impediment to her optimal recovery.

**In summary, we oppose Recommendation 185.**

#### **Recommendation 186**

**We strongly oppose this Recommendation 186.**

The Health (General Amendment) Act 1988, no. 48, Division 6 - Special Provision relating to the Human Immuno-Deficiency Virus, sections 127 (1) and (2), mention "a person of a prescribed class", i.e. a person who has undergone specialist training, as different from a medical practitioner, who by implication is exempt from accreditation via specific training in HIV counselling (p.19).

For many years some of ARCSHS' staff have been involved in the conduct of the Counsellors' Accreditation Program (CAP), the DHS-supported program that provides the above accreditation. These facilitators have experience of at least 35 of these 6 day training programs attended by approximately 420 health service providers, mainly nurses, midwives, alcohol and other drug workers, prison nurses, youth workers and counsellors.

In the course of conducting these training programs we have been repeatedly confronted with the consequences of insufficient education, training, knowledge, experience and competence among health care professionals when dealing with blood borne viruses. Without exception, participants in every training program have raised serious concerns regarding the practices of health care professionals, including GPs, medical specialists and ancillary health care workers in relation to BBVs. Areas of concern identified by program participants include poor understanding of: the motivations and barriers to testing; the role of testing in patient management and health promotion; patient understanding of test results and the social meanings these results may have (for example, 'evidence' to continue risk practices in the absence of infection); the psycho-social consequences of a positive test result; patient concerns around disclosure, confidentiality, discrimination and access to services. What is evident from our experience, and from the vast international literature on clinical patient relationships, is that clinical training *per se* does not necessarily prepare health practitioners to deal sensitively, competently or thoroughly with the consequences of stigmatised infectious diseases. This has been widely recognised in relation to the ongoing management of people infected with these viruses, but to date there has been little attention paid to these shortcomings in relation to testing issues, including pre and post test counselling.

We recognise that in Victoria there are a number of medical practitioners extremely skilled in discussing blood borne virus issues and implications with patients. Many of these work in general practices with a high HIV case-load, in sexual health clinics or in specialist clinics in hospitals, such as liver clinics or infectious diseases clinics. These, and other medical practitioners involved in HIV and hepatitis C testing could be registered as "accredited" on the basis of competence developed through experience, as evidenced by their manager or place of employment .

We also make the point that the giving of a negative test result is the optimal opportunity for prevention education and risk reduction, a priority public health

aim. A negative result, in principle, should never be given over the phone, only in person.

In summary, we suggest that **Recommendation 186 be re-written** to provide for:

- **The inclusion of the pre-test session in the regulation for “prescribed diseases” counselling;**
- **The addition of hepatitis C to the “prescribed diseases” group;**
- **The provision of both a positive and a negative test result in the context of counselling.**
- **That accreditation as “a prescribed person” either be on the basis of successful completion of a specific training program (as is the case now) or on the basis of competence developed over N years of experience, as attested to by an appropriate person or agency.**

#### **Recommendation 188**

**We do not support this recommendation.** Rather the old provision should be retained, with the addition of hepatitis C, on the grounds that these viruses are still associated with substantial stigma and negative consequences to health and well-being.

#### **Recommendation 189: We support this recommendation.**

In conclusion, we at ARCSHS appreciate the opportunity to provide these carefully considered comments on the *draft policy paper – for consultation: Review of the Health Act 1958*, for your deliberation.



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