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HCCA Submission on The ACT Immunisation Strategy 2012- 2016

3 April, 2012

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Background

The **Health Care Consumers' Association (HCCA) of the ACT** was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers

The HCCA is dedicated to the promotion of consumer-centred health care, which we believe can be successfully achieved through the application of five key principles:

1. **Respect**
2. **Choice and empowerment**
3. **Consumer involvement in health policy**
4. **Access and support**
5. **Information**

It is with reference to these principles that the HCCA has developed its submission to the Immunisation Strategy.

The HCCA is pleased to have the opportunity to comment on the draft proposal for the ACT Immunisation Strategy 2012-2016. The HCCA agrees with the importance of maintaining the ACT's high standard of immunisation coverage and strongly supports the vision stated in the Strategy. However, the HCCA would like to highlight a number of issues that need to be addressed in addition to those raised in the draft proposal.

In developing our response, the HCCA has consulted with a number of additional representative bodies, including the Alcohol Tobacco and Other Drug Association ACT (ATODA), the Canberra Multicultural Community Forum (CMCF) and the Youth

Coalition of the ACT. In addition, a general email was sent to the members of the HCCA, from whom we received a number of written responses and also completed interviews with HCCA members. The issues raised by consumers have been incorporated into this submission.

The feedback provided in this submission is primarily aimed at ensuring that the new Immunisation Strategy will fulfil all of the necessary requirements outlined in the Australian Charter of Health Care Rights¹. Furthermore, the HCCA is dedicated to working with the ACT Government to make certain that these rights are extended to all members of the ACT community.

A) Summary of Issues

The aims of this submission will be to:

- Raise the possibility of developing a strategy to deal effectively with epidemics and any issues arising as a result.
- Recommend the development of a clear framework for how to detect and manage adverse reactions that is easily accessible for consumers.
- Emphasise the importance of open channels of communication between immunisation providers and consumers. This includes creating a non-judgmental environment that facilitates questioning and allows consumers to participate in our own health care.
- Highlight the need for effective communication between immunisation providers and CALD health care consumers, particularly for members of migrant communities who may have missed out on vaccinations in the past.
- Recommend the provision of expertly trained immunisation providers for members of the community who are immunosuppressed, have a history of severe allergic reactions, or are living with autoimmune diseases.
- Recommend that support be redirected from Youth drop-in centres to other youth services and facilities with regard to vaccine provision.

B) Layout

The HCCA is concerned that the Layout of the current Immunisation Strategy needs to be made more comprehensive. For instance, it would be worth considering the inclusion of an introductory paragraph for each focus area placing the objectives in context.

¹ Australian Charter of Healthcare Rights. (July 2008). *Australian Commission on Quality and Safety in Health Care*.

C) Scope

The HCCA recommends that the Scope of the Immunisation Strategy be extended to include the development of a comprehensive strategy in the event of any vaccine preventable epidemic. In the past, there have been inadequate measures put in place in order to handle epidemics when they arise, such as the outbreak of seasonal influenza in WA in 2010, which resulted in poor handling of adverse events following vaccination². This has highlighted the importance of communication between health care providers and consumers during these events as well as publicly accessible reporting of adverse effects associated with the vaccines being used. There also needs to be a predetermined course of action for dealing with adverse side effects that is clearly presented to consumers. It may be worth considering a possible role for the Walk-In Centre in instances of an epidemic.

D) Focus Area 1: Childhood Immunisation

The HCCA supports the involvement of pre-school and primary schools as a means of achieving higher rates of immunisation coverage for ACT children. However, The HCCA urges that steps also be taken in order to open up better communication channels with parents of children who are not enrolled in the school system, whether they are being home schooled or are temporarily unable to attend school. The HCCA notes that communication with parents of home-schooled children is included in Focus Area 2. This could also be included in Focus Area 1, as it is particularly important to ensure that younger children have timely access to vaccines.

It is also worth considering the development of a follow-up procedure for situations where a child has been absent or unwell on the day scheduled for school based vaccinations. This often leads to confusion for parents, who may be unsure about who is responsible for rescheduling the vaccination.

It is also essential that parents of children being immunised through their schools are provided with adequate information regarding vaccines being administered. This information needs to go beyond simply stating what vaccinations are required. It must also convey the nature of the vaccine, its role and any possible adverse effects associated with it. The HCCA also strongly urges that parents also be given adequate information regarding the risks involved should they choose not to give consent for their child to be vaccinated.

The communication channels between parents, schools and immunisation providers need to be developed in such a way that any questions or concerns can be addressed. This is in accordance with the Health care consumers' right to participation in their own health care as well as access to all relevant information. This reciprocal communication will also assist in the development of mutual trust between immunisation providers and consumer.

² Prof. Bryant Stokes. (August 2010) "Ministerial Review into the Public Health Response into the Adverse Events to the Seasonal Influenza Vaccine", Government of Western Australia, Department of Health. 32

Finally, parents need to be assured that their children will be adequately monitored following vaccination, especially when parents often cannot be present at the time. In the case of any delayed adverse effects, parents will also need to be given clear instructions as to how to report the event and more importantly, where to seek assistance.

E) Focus Area 2: Adolescent and Adult Immunisation

The HCCA strongly supports the need for working with youth services in order to provide opportunistic vaccination for adolescents who may be socially at risk of vaccine preventable diseases or otherwise unlikely to be able to access vaccination.

However, it has been brought to our attention that many of the youth drop-in centres will be either closing down or soon have a significantly reduced drop-in capacity as a result of changes to the funding program in the Community Services Directorate³. As such, the HCCA recommends that the Strategy re-direct support and education to a number of other youth support services that will be receiving adequate funding to undertake vaccination programs. These could include mental health, youth health and alternative education services. (This also applies to Focus Area 3, Objective 3).

Furthermore, the HCCA recommends that efforts to increase immunisation coverage in adolescents also include the provision of vaccination services through juvenile detention programs, rehabilitation programs and programs for adolescents seeking treatment for the use of alcohol and other drugs.

F) Populations at Risk

The HCCA welcomes the extensive efforts of the ACT Health Directorate to provide accessible immunisation services to Aboriginal and Torres Strait Islanders in culturally appropriate environments. The HCCA recommends that in addition to the measures outlined in Objective 1, the new Strategy needs to aim to improve communication with indigenous members of the community regarding information about vaccines, their importance and how they can be accessed.

The HCCA also acknowledges the importance of providing 'timely access to vaccines' to all people medically at risk of severe complications from vaccine preventable diseases. However, this objective would also benefit from the inclusion of measures to ensure that individuals about to undergo any type of immunosuppressive treatment are advised on which vaccinations they may require prior to treatment. Research has found that the best time for administering vaccines to these individuals is shortly after diagnosis⁴, making this the optimal time for such information to be provided. There is also a need for expertly trained immunisation

³ "Child, Youth and Family Services Program Service Delivery Framework : 2011-2015", ACT Department of Health and Community Services, Office for Children, Youth and Family Support.

<http://www.dhcs.act.gov.au/__data/assets/pdf_file/0019/283015/Service_Delivery_Framework.pdf> accessed 27 March 2012.

⁴ Gil Y. Melmed MD et. al., "Immunosuppression Impairs Response to Pneumococcal Polysaccharide Vaccination in Patients With Inflammatory Bowel Disease", *The American Journal Of Gastroenterology*, 105 (2010) 153.

providers available to individuals who are already immunosuppressed who are able to determine which vaccinations can still be safely administered. For instance, it may be worth considering whether the Cancer Care Coordinators could play a role in this instance.

The HCCA also believes that there is a need to facilitate cross-specialty consultations following the development of new vaccines so that individuals living with autoimmune diseases such as Multiple Sclerosis can be advised as to any side-effects they are likely to experience. For these individuals, adverse side effects are often unique to their condition and unrelated to the disease they are being immunised against. This makes it essential that immunisation providers be aware of the possible side effects of vaccines for specific conditions so that they are better able to identify them if they occur.

The HCCA notes that injecting drug users have been dropped from the category of 'Populations at Risk'. However, we have been informed that ATODA will be following up on this issue in a separate submission.

G) Communication and Education

While the HCCA agrees with the importance of educating immunisation providers about vaccines and populations at risk, we are concerned that the Strategy has not addressed the need for this information to be passed on to consumers as well. The HCCA strongly advocates the provision of all relevant information related to health care to consumers in accordance with consumer-centred care and the Australian Charter for Health care Rights.

The provision of information to consumers is also fundamental in the process of obtaining valid informed consent, which is a legal requirement for any vaccination to be administered. Furthermore, health care consumers need to have access to clear and comprehensive information about immunisation services so that they are able to participate in our own health care. This has been proven to increase the efficacy of health care services and achieve better health outcomes.⁵

The HCCA would also like to stress the importance of providing information about immunisation in such a way that consumers are able (and encouraged) to ask any questions they may have. Furthermore, this type of communication needs to occur in an environment that is free from any stigma or prejudice, so that consumers are able to feel comfortable discussing any issues that may be considered sensitive.

We also note that Objective 2 includes updating the Health Directorate web page, presumably with regard to immunisation information. The HCCA feels that this web page is currently difficult to navigate, preventing many consumers from accessing the information they require. The updated web page needs to be made more comprehensive and straightforward. In addition to this, the HCCA recommends that Objective 2 also include the provision of immunisation information on additional web pages, especially those likely to be accessed by specifically targeted groups.

⁵ Judith H. Hibbard, "Engaging Health Care Consumers to Improve the Quality of Care", *Medical Care*, 41:1 (2003) 68.

However, it is also important to note that individuals considered 'socially at risk' in the new Strategy may not have internet access, and so need to be able to access this information through other means.

It is also essential that the Strategy address the need for effective communication with migrant groups in general, and not just refugees. Australian research has indicated that members of the Australian migrant community are particularly vulnerable to vaccine preventable diseases and are likely to have had limited access to vaccines in the past⁶. It also appears that in many cases, migrants do not have sufficient information regarding the severity of vaccine preventable diseases and their methods of transmission⁷. As a result, they become vulnerable to these diseases and are less likely to be tested for them or seek vaccination. Furthermore, the transition between health care systems can also often result in a loss of immunisation records, leading to difficulty in determining what vaccinations may be required.

These findings demonstrate the need to transcend the difficulties posed by language barriers and cultural differences when providing education about immunisation. The HCCA recommends that ACT Government continue to work with migrant support groups in order to communicate effectively with Culturally and Linguistically Diverse (CALD) individuals as well as those who may not be familiar with the Australian health care system. Consumer feedback has also indicated that there is a need for better communication with community leaders of different cultural and religious groups to ensure that information is being effectively distributed amongst these groups. Education campaigns would need to be designed with careful consideration for maintaining respect for consumer perspectives and beliefs.

Finally, the HCCA is concerned that the Progress Indicators for both objectives in this focus area are too limited. It may be worth expanding these indicators to include measures of increased information accessibility for the public.

H) Supply and Safety of Vaccine

The HCCA strongly supports the emphasis that has been placed on ensuring the safety of procedures for delivering and administering vaccines. Safety is one of the key aspects of consumer-centred care and needs to be an integral aspect of every health care policy. In particular, the inclusion of strategies to provide education for the community regarding 'the importance of cold chain management' and to encourage consumers to report all adverse effects events to the Centre for Disease Control and Prevention (CDC) is a very important step towards consumer-centred care.

The HCCA also welcomes the inclusion of measures that will be taken to ensure adequate supply of vaccines (Objective 1). However, it is also important to provide a

⁶ Susan A. Skull et. al. "Incomplete immunity and missed vaccination opportunities in East African immigrants settling in Australia", *Journal of Immigrant and Minority Health* 10 (2008) 265

⁷ Lan V. Hu et. al., "Hepatitis B Knowledge, Testing, and Vaccination Among Chinese and Vietnamese Adults in Australia", *Asia-Pacific Journal of Public Health*, 24:2 (2010) 381

strategy for effectively distributing vaccine supplies in the event of an epidemic. In these situations it will be essential to provide vaccines efficiently and in such a way that the most vulnerable members of the Canberra community will be able to access them with ease. It is also worth considering how the ACT Government will communicate with individuals to ensure that they are aware of the steps being taken and how they can seek treatment. This consideration also needs to be extended to the provision of information to CALD individuals.

Another issue related to this is the early detection of cases of vaccine-preventable diseases. This allows for more timely provision of information and health warnings to consumers, enabling them to seek vaccination. In instances such as the recent outbreaks of Pertussis, this process has not been efficient enough to prevent the disease from spreading to a number of school-aged children before a health warning was released. Steps taken to improve this process may help to prevent the emergence of epidemics in the first place, reducing the burden on vaccine providers.

Consumers have also expressed concern that there is insufficient information provided regarding what steps can be taken in the event of an adverse reaction to a vaccine. This is particularly important in the event of a delayed adverse reaction, when consumers may not be under the observation of trained immunisation providers. Consumers need to be clearly informed as to where to go to receive treatment, and not just how to report the event. This could also be reflected in the Progress Indicators for Objective 2 by including an assessment of the effective management of patients presenting with adverse reactions.

It is also excellent that the new Strategy has included the provision of “education for immunisation providers to detect and treat early adverse events”. The HCCA urges that this be extended to ensure that highly trained immunisation providers will be available to vaccinate individuals with either a general history of severe allergic reactions or adverse reactions to vaccinations. Currently, these individuals are often advised not to seek vaccination as the risks are too high. Immunisation providers also need to be able to ascertain exactly what a vaccine contains, in order to confidently assess whether the vaccine will be appropriate for individuals based on their previous reactions. Alternatively, more information could be provided regarding the role of the special immunisation clinic and the referral pathways available to individuals at elevated risk of adverse reactions.

I) Links with Other Plans

The HCCA is concerned that this section does not provide any information regarding how links with other plans and policies will be developed and operated.

There are also a number of other plans and policies the HCCA would like to see associated with the Strategy. First and foremost of these is the Australian Charter of Health Care Rights, which the HCCA believes is integral to the provision of all health care services. We also recommend that the Strategy be linked with the ACT Quality and Safety Framework for Health Care, as part of the Strategy’s commitment to the safe supply of vaccines (Objective 5). Lastly, it is worth considering the development of a link with the ACT Chronic Disease Strategy 2008-2011.

J) Key Stakeholders

The HCCA is pleased that a wide variety of stakeholders have been consulted in the drafting of the new Strategy but we note that relatively few consumer groups have been listed as stakeholders. We would like the Health Directorate to work with consumer groups in finalising the Strategy, as they represent the individuals who are the focus of this strategy and will be most affected by it. As a part of this endeavour, it is important that representatives of migrant groups are also consulted. CALD individuals represent a significant proportion of the ACT community, and are entitled to be able to shape the policies relating to the services being provided to them.

The HCCA would also like to see the Office for Children, Youth and Family Support added to the list of key stakeholders, as they represent the members of the ACT community that are often most vulnerable.

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K) References

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