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Re: Inquiry into Hepatitis C in Australia

The Australian Research Centre in Sex, Health and Society (ARCSHS) is a centre for social research into sexuality, health, and the social dimensions of human relationships. It works in partnership with communities, non-governmental organisations, government and professionals in relevant fields to produce research that promotes positive change in policy, practice and people's lives.

ARCSHS's Viral Hepatitis Social Research Program was established in 2008. The Program conducts high-quality social research into the experiences and needs of communities affected by viral hepatitis. We conduct research to inform and promote effective public policy responses to viral hepatitis, and our researchers bring to our work a range of experiences and disciplinary backgrounds including sociology, international development, public health, anthropology, nursing and medicine.

Our research challenges the traditional separation between the biomedical and the social dimensions of viral hepatitis. The social research approach taken within the program treats viral hepatitis as an issue where the biomedical, social, economic and political converge. We understand that viral hepatitis affects individuals and communities and shapes social relations and social practices. Our work critically engages with scientific progress, clinical practice, advocacy and policy to create knowledge that guides policy and practice.

We would like to provide our perspective to the Standing Committee on Health in response to the release of the Australian Government 4th National Hepatitis C Strategy 2014-2017 and highlight key issues affecting people with hepatitis C drawing on our own hepatitis C related research findings. We use the Priority Areas for Action of the 4th National Hepatitis C Strategy 2014 – 2017 as our framework.

Prevention

- Hepatitis C is primarily transmitted in Australia through the sharing of drug injecting equipment with 10,114 new cases of hepatitis C notified in 2012.(1)
- Hepatitis C transmission has been successfully reduced through the commitment of state, territory and federal governments in supporting the widespread distribution of sterile injecting equipment.(2, 3) In spite of this commitment, hepatitis C transmission which is essentially preventable, still occurs.
- Several barriers to the effective distribution of sterile injecting equipment remain. ARCSHS was funded by the Australian Health Ministers Advisory Committee in 2008 to investigate the regulations affecting the prevention of hepatitis C transmission in Australian correctional

settings, and through needle and syringe programs. In terms of the regulatory barriers affecting needle and syringe programs, the research found:

- While needle and syringe programs are one of several interventions supported to reduce the transmission of HIV, they are the primary intervention supported by governments to reduce the transmission of hepatitis C. In spite of this, little legislative change has occurred to improve the effectiveness of needle and syringe programs specifically in relation to hepatitis C.
- There are legislative barriers in most jurisdictions that if removed could strengthen the operation of the program including the repeal of self administration of drugs, permission for providing information about safe injecting, and being able to legally distribute injecting equipment other than needles and syringes.
- Unless a person has been authorised by the relevant state or territory government, distributing sterile injecting equipment is seen as aiding and abetting the use of illicit drugs. Most distribution of sterile injecting equipment in Australia is unregulated, with this equipment distributed through peer and friendship networks. This places people, who are performing an essential public health intervention, at risk of arrest.
- The requirement for state and territory governments to authorise people to distribute sterile injecting equipment has resulted in a range of administrative processes that are cumbersome, time consuming and which could be simplified.
- There is a lack of overt political backing for needle and syringe programs with often alarmist media reporting affecting the public support of the program. Several drug summits (in NSW, NT, SA and WA) have noted the impact of media attitudes on the operation of the needle and syringe program, but that has not been systemically addressed by any government.

- Hepatitis C is an essential correctional health issue. In relation to the prevention of hepatitis C transmission within Australian correctional settings, our research (*Regulating Hepatitis C: Rights and Duties*), preventing hepatitis C transmission in Australian Adult Correctional Settings found
  - In 2010, 22% of all inmates were infected with hepatitis C, and given the lack of regulated needle and syringe distribution the number of new infections occurring in correctional settings is significantly greater than found in the community. Correctional settings have been described as an 'incubator' of hepatitis C infection. This is of particularly significance for Indigenous communities, who are vastly over-represented in correctional settings and therefore at greater risk of hepatitis C exposure.
  - While the regulated distribution of needles and syringes is the primary form of evidence-based hepatitis C prevention intervention available in the community, there are currently no programmes supported in correctional settings in Australia and as a consequence unregulated and hazardous needle and syringe distribution is widespread.
  - Little consistency in the hepatitis C prevention programs that have been implemented within correctional settings across jurisdictions.
  - Legislation providing for the operation of correctional settings is fundamentally concerned with the enforcement of security. Within a correctional framework, providing health services such as hepatitis C prevention and treatment services is understood to be an exceptional, rather than essential, duty of care.
  - The Standard Guidelines for Corrections, a national statement developed by Correctional Administrators describes correctional services standards. This document states that inmates 'have access to evidence based-health services… comparable to that of the general community.' The Office of the Inspector of Custodial Services in Western Australia

contends a needs-based health services for inmates is more appropriate than a community equivalent.

Testing

- An on-line survey of Australian people with hepatitis C, conducted by ARCSHS in 2014, *Findings of the Charting Health Impacts (CHI) Study* found:
    - In spite of the National Hepatitis C Testing policy stating that "confidential, voluntary testing … and pre-test and post-test discussion is fundamental to Australia's response to hepatitis C", 57% of the 170 survey participants were initially diagnosed by a general practitioner and did not receive any or only limited information about hepatitis C when first diagnosed.
    - Pre-test and post-test discussions were reported by only 14% and 58% of participants, respectively while 17% reported no discussion with their medical practitioner at the time of diagnosis.
    - While most people with hepatitis C are diagnosed through general practice, the proportion of people provided with information was greater when they were diagnosed by the Australian Red Cross Blood Service or at a sexual health service.

Management, Care and Support

- Hepatitis C treatments, until the recent introduction of direct acting antivirals, were challenging in terms of side effects. This in addition to service barriers to treatment has meant that few people with hepatitis C have ever used treatment. ARCSHS have conducted several research projects looking at better understanding and improving access to hepatitis C clinical services and treatment. (4, 5)
- Of the 86 participants in the CHI Study (2011), who had been treated for hepatitis C:
    - 65% completed treatment, among whom 55% had cleared the virus. For people who didn't complete the treatment course, the most frequently reported reason was treatment failure (61%) and unmanageable treatment side effects (43%). Of participants with current or past experiences of hepatitis C treatment, 64% experienced side effects with fatigue (89%) and sleep disturbance (84%) being the most common.
    - The most frequently reported barrier to treatment for people in this study who had not been treated was of fear of side effects (59%).
    - Most participants (89%) used medical treatments to alleviate treatment side effects while 65% used complementary or alternative therapies to do so. Non-prescription pain killers (73%) was the most commonly used medical treatments. Supplements (29%) and low impact exercises (27%) were the most commonly used complementary treatments.
- One key strategy to increase access to hepatitis C treatment is for treatment to be provided in community settings. Hepatitis C, while a complex infection with some patients, is generally relatively straightforward to clinically manage in community settings. ARCSHS was invited to evaluate the Queensland Health Hepatitis C Shared Care Program in 2009. This program recognised that treatment access by people with hepatitis C could be improved by involving a range of clinical service providers, including clinical nurse consultants and general practitioners in delivering this treatment. The research found:
    - That providing additional resources by Queensland Health to participating liver clinics increased their capacity to treat.
    - The trial included resources for psychological support thereby seeking to ameliorate side effects associated with treatment. This support meant that people, who had previously been judged by clinicians as too difficult to treat, were able to access treatment.

- The shared care initiative increased access to treatment for people living at significant distance from specialist liver clinics, and to patients described as 'harder to treat'.
- Clinical nurse consultants provide fundamental emotional and practical support for people accessing treatment.

- A key population experiencing a greater proportional prevalence of hepatitis C are Aboriginal and Torres Strait Islander people. ARCSHS investigated strategies to improve the access of Aboriginal and Torres Strait Islander people to hepatitis C treatment services in Victoria. The study, *Recognising and response to hepatitis C in Indigenous communities in Victoria: A research project exploring barriers to hepatitis C treatment* found that
  - One barrier to care and treatment services by Indigenous people was the limited knowledge about the virus within their communities. This was accentuated by stigma and shame associated with hepatitis C transmission and infection, which stopped people talking about hepatitis C and ultimately seeking support and health care.
  - Health care and community workers working with Indigenous communities need training about hepatitis C, including addressing stigma and how to reduce the impact of shame associated with hepatitis C.
  - Information about hepatitis C needs to be provided in a way that is culturally appropriate and accessible to Elders and to young people. Art based programs to improve community knowledge and reduce stigma such as the production of ''*Chopped Liver*" need to be supported and their reach broadened.
  - Group treatment, where small groups of peers or friends are treated at the same time needs to be explored as an alternative for Indigenous people. Our findings show that the dominant medical model based on treating individuals does not allow for alternative models which favour providing antiviral treatment for people within a group setting.
- Another group within the community experiencing significant challenges in accessing hepatitis C treatment services are people from culturally and linguistically diverse backgrounds who have hepatitis C. The ARCSHS study, *Improving and increasing access to hepatitis C treatment: A research project exploring barriers to treatment for people of Vietnamese and Cambodian backgrounds* recommended the following:
  - The development of community-based liver clinics, including increasing the role of GPs in managing hepatitis C patients and acknowledge and support the pivotal role of Clinical Nurse Consultants in treatment and care education and support
  - Services that specifically address the cultural needs of their patients, including interpreters as central to the running of the clinic, cross cultural training of staff, recruitment of staff of similar cultural background to client group and flexibility in the delivery of care to accommodate patients' difficulties in attending appointments
  - Develop culturally appropriate information about hepatitis C including its natural history, monitoring and treatment.
  - Counteract the negative image of treatment in the community
- As previously noted, current interferon-based hepatitis C treatments can have challenging side effects and this reduces access to clinical services. One ARCSHS study sought to investigate the decision making processes of people with hepatitis C who choose to be treated. *Making decisions about hepatitis C treatment* found:
  - Treatment decision making is not straightforward. Treatment involves a heavy time and, for some, a heavy financial commitment, involving weekly visits to specialist services for between six and twelve months.

- Hepatitis C is a mostly silent infection, with few symptoms. The fact that symptoms associated with hepatitis C are often not as significant for an individual as the potential side-effects of treatment makes the decision to begin treatment particularly difficult. Uncertainty associated with the success of treatment also limits willingness to begin treatment.
- People with hepatitis C noted the following issues helped people decide against treatment:
  - Personal and social reasons:
    - Impact treatment will have on family/ friends and/or on work
    - Can't commit myself to a long treatment program
    - Wanting to have children in the near future
    - Costs associated with treatment
    - Liver clinic too difficult to get to
  - Clinical reasons
    - Because of feeling well
    - Treatment success rate is not good enough
    - Side-effects of treatment
    - Liver status is good (minimal scarring)
    - Because I don't know enough about treatment

- As noted previously regarding correctional settings, where in many gaols a majority of inmates are infected with hepatitis C, regulations affect treatment access with inmates being excluded from direct access to Medicare. This fundamentally affects the capacity of correctional services to provide clinical health care as universal health care access is denied in these settings. It is one of the many areas where implementing a human rights framework in correctional regulation provides for health service delivery as an entitlement, and by doing so directly and demonstrably improves the health of inmates.

Other key issues

- Ageing
  - A discussion paper for the hepatitis C sector was developed by the ARCSHS Viral Hepatitis Social Research program in response to gaps in the previous national hepatitis C strategy. The paper, *Hepatitis C and Ageing, a community brief* highlighted that an estimated 226,700 people in Australia live with chronic hepatitis C and while the numbers of people estimated to have been infected with hepatitis C has reduced over the past 15 years, the number of people with hepatitis C-related liver disease is increasing.
  - Growing older and duration of infection are significant determinants in the progression to cirrhosis amongst people with hepatitis C and there is a lack of social research describing the experiences of people with hepatitis C as they grow older. Older people with hepatitis C are not identified as a priority population nor are their needs discussed in the National Hepatitis C Strategy 2010-2013. A comprehensive, strategic approach to hepatitis C and ageing is needed to ensure that the needs of older people with hepatitis C do not continue to go unrecognised.
- Research sustainability
  - The ARCSHS has received funding from the Australian Government since 1995 which provides for a program of social research to support the implementation of the suite of national blood borne virus strategies. There are a range of issues related to this funding including that the initial funding of the program was to conduct projects supporting the implementation of national HIV strategies. Over time the number of strategies in which

the organisation is to support has increased to include other sexually transmissible infections, hepatitis C and hepatitis B, without any concomitant increase in funding.

- The lack of certainty of funding affects the capacity of organisations such as ARCSHS to effectively and efficiently plan and conduct the necessary research.

- Partnership approach to Australia's hepatitis C response
  - Australia is unique in that government support at national and state and territories is provided to organisations representing the needs of people, and at risk of infection with hepatitis C. This ensures that the national response is informed by the experience of the people most affected by the infections through Hepatitis Australia and the Australian Injecting and Illicit Drug Users League. The organisations funded to so this provide research centres such as ARCSHS with a level of expertise and insight that cannot be provided by any other organisation. The community based hepatitis and injecting drug use organisations need continued support to provide their unique insights and resources.
- World Health Organisation, *Framework for the Prevention and Control of Viral Hepatitis*.
  - Over the past couple of years, there have been substantial changes in the global policy context in which Australia responds. This has come as a result of two World Health Assembly resolutions on viral hepatitis, and the development of their strategic document, *Framework for the Prevention and Control of Viral Hepatitis* in 2012.
  - This document reinforces that Australia led the world in the development of nationally coordinated strategies to reduce the national burden related to hepatitis C. Australia lies in the Asia Pacific region, which while having 48% of the world's population, experiences 75% of the global mortality related to viral hepatitis.
  - Australia, with its experience and location can play a substantive role in supporting global efforts to reduce the burden of hepatitis C. The ARCSHS is already participating in this response through conducting social research looking at the policy response to viral hepatitis in Taiwan, and identifying the needs of people with viral hepatitis in China.
- Treatments
  - As previously mentioned, only a small minority of people with hepatitis C have ever access hepatitis C treatment. This has occurred for many reasons, one being the impact and fear of side effects. A new generation of hepatitis C treatments has been developed and change the landscape for treatment. Hepatitis C could be eradicated with these new treatments given their efficacy and accessibility.
  - Interferon-free treatments needs to be made available to the broadest range of people with hepatitis C – and while there are clear economic challenges, particularly with the unjustifiable pricing for the first generation of these interferon-free drugs, competition from other drug companies will allow for the pricing to decline
  - The use of direct acting antivirals also provides for a new impetus to develop new clinical models that use community based services, rather than maintaining hepatitis C treatment access solely through specialist services. These models of treatment delivery need to focus on the needs of the individual rather than the specialist.

The way forward:

As a result of the research conducted by ARCSHS and the significant level of expertise and experience of the staff involved in the Viral Hepatitis Social Research Program, the following suggestions are made in relation to the implementation of the Australian Government 4th National Hepatitis C Strategy 2014-2017:

- State and territory governments identify the regulatory barriers associated with the operation of the needle and syringe program. It should be noted that this has occurred in many jurisdictions, and the recommendations of these reviews need to be acted upon.
- Hepatitis C transmission occurs within Australian correctional settings as a result of the unregulated distribution of injecting equipment. As a human right, and on public health grounds, regulated needle and syringe programs need to be implemented within correctional settings.
- Hepatitis C testing needs to be accompanied with an effective and systematic process of providing information about the infection to people diagnosed with the infection. The National Hepatitis C Testing policy needs to be implemented across general practice.
- For greater access, hepatitis C treatment needs to be made available within community settings including through general practice and community health centres. Providing additional resources increases their capacity; provides for culturally and linguistically appropriate services and psychological support of patients being treated.
- There are inadequate levels of knowledge and information, and a low priority of viral hepatitis within Indigenous health services in spite of the greater proportion of Indigenous people infected with the viruses. Systematic resourcing for Indigenous health services needs to be used to redress this gap, including through art based programs.
- Correctional settings provide a unique context in which hepatitis C treatment can be delivered to a population experience a greater prevalence of infection. Successful models of treatment delivery have been developed and are being implemented, particularly in New South Wales.
- The partnership approach needs to be effectively resourced and a commitment made to its continued participation
- The next iteration of the National Hepatitis C Strategy needs to:
    - Be written in the global context of the World Health Organisation activity occurring to reduce the global burden of the infection. Australia has a unique role to play in the Asia Pacific in support of this activity
    - Address the impact of the ageing population and its relationship with hepatitis C including service and treatment access

Thank you for the opportunity to provide this submission. A bibliography of the research used to inform this submission appears as Appendix A. Please contact Jack Wallace on j.wallace@latrobe.edu.au if you require any further information about this submission.

Yours sincerely

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