Reaching Out: Part 1

A review of demographic data and relevant literature of people living with hepatitis C who are not current injecting drug users and are not engaged in hepatitis C clinical care.

December 2016

Prepared by Dr Jacqui Richmond on behalf of Hepatitis Australia

© Copyright Hepatitis Australia 2017. This publication is copyright and remains the intellectual property of Hepatitis Australia. No part of it may be reproduced by any means without the prior written permission of Hepatitis Australia.
Table of Contents

ACKNOWLEDGEMENTS............................................................................................................. 3
FOREWORD ................................................................................................................................. 4
1. INTRODUCTION....................................................................................................................... 4
2. BACKGROUND......................................................................................................................... 5
3. HEPATITIS C TRANSMISSION............................................................................................... 6
4. ESTIMATES AND PROJECTIONS OF THE POPULATION WITH HEPATITIS C IN AUSTRALIA .......................................................................................................................... 7
5. PEOPLE WHO PREVIOUSLY INJECTED DRUGS.................................................................. 7
6. ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH HEPATITIS C............. 9
7. PEOPLE LIVING IN AUSTRALIA WHO WERE BORN OVERSEAS.............................. 10
   7.1 Hepatitis C in high prevalence and high disease burden countries ......................... 12
       7.1.1 Egypt.......................................................................................................................... 12
       7.1.2 Pakistan.................................................................................................................... 13
       7.1.3 China ....................................................................................................................... 14
       7.1.4 India ......................................................................................................................... 14
   7.2 Hepatitis C in high prevalence and high disease burden continents and regions of the world ................................................................................................................................. 15
       7.2.1 Africa ........................................................................................................................ 15
       7.2.2 Asia ........................................................................................................................... 16
       7.2.3 Eastern Europe ........................................................................................................ 16
       7.2.4 Latin America ........................................................................................................ 17
   7.3 Summary of people living in Australia who were born overseas .............................. 17
8. PEOPLE WHO HAVE RECEIVED UNSAFE TATTOOOING AND/OR BODY PIERCING 18
9. GAY AND BISEXUAL MEN WHO HAVE HUMAN IMMUNODEFICIENCY VIRUS (HIV) 19
10. PEOPLE WITH BLEEDING DISORDERS......................................................................... 20
11. PEOPLE WITH MEDICALLY ACQUIRED HEPATITIS C.................................................... 21
12. CHILDREN BORN TO WOMEN WITH HEPATITIS C..................................................... 22
13. OTHER PEOPLE WITH HEPATITIS C WHO MAY NOT BE ENGAGED IN CLINICAL CARE ................................................................................................................................. 23
12. ENGAGEMENT IN HEPATITIS C CLINICAL CARE............................................................. 24
13. SUMMARY............................................................................................................................... 25
REFERENCES............................................................................................................................... 26
ACKNOWLEDGEMENTS

Hepatitis Australia would like to thank and acknowledge the following members of the Project Advisory Group for their assistance with the development of the report.

Dr Stephen Bloom
Alison Coelho
Professor Greg Dore
Dr Behzad Hajari-zadeh
Jane Little
Suzanne O’Callaghan
Fred Robertson
Garry Sattell
Dr Joanne Travaglia
Jack Wallace
Deborah Wanneke-Arnold
Pam Wood
Associate Professor Amany Zekry
FOREWORD

This Hepatitis Australia project is funded by the Australian Government Department of Health. The brief is to ‘develop and deliver general education and awareness on hepatitis C, available testing and treatment options to individuals with hepatitis C who have either not injected drugs or have done so in the past but no longer identify as a person who injects drugs’. This particular segment of the hepatitis C population was selected as the Department of Health funds other projects with a specific focus on people who inject drugs.

By focusing on the needs of people who do not identify as people who inject drugs, Hepatitis Australia is not suggesting that they are any more or less deserving of access to hepatitis C treatment than any other group. Indeed, Hepatitis Australia advocated strongly for universal access to the new hepatitis C cures so that every individual living with hepatitis C could have the opportunity of curative treatment.

1. INTRODUCTION

Since March 2016 when hepatitis C direct-acting antiviral (DAA) treatment became universally available in Australia for all people, regardless of stage of liver disease or drug or alcohol use, the public health focus steered toward eliminating hepatitis C from Australia. This is a goal that is replicated at the global level with the World Health Organization’s (WHO) elimination targets and adoption of a global health sector strategy for viral hepatitis elimination\(^1\) — a truly remarkable possibility. People living with hepatitis C are not a homogenous group; there are varying levels of engagement with clinical care and support services and significant diversity in hepatitis C awareness.

As part one of a three-stage project, the Reaching Out report describes the characteristics of people living with hepatitis C in Australia who do not identify as people who inject drugs and are not connected to hepatitis C clinical care. This includes people who:

- have injected drugs in the past, but no longer do so and are not engaged with drug treatment services
- were born or have lived in countries of high hepatitis C prevalence or high disease burden
- have received unsafe tattooing and/or body piercing
- are gay and bisexual men who have human immunodeficiency virus (HIV)
- acquired hepatitis C from unsafe medical procedures — including transfusion of blood and blood products before 1990.

The information presented in this report is a synthesis of the existing literature and expert opinion collated during a series of stakeholder consultations.
The purpose of characterising the subsets of the target population living with hepatitis C is to gain an insight into how best to communicate with these groups and identify strategies that aim to engage them in clinical care. Part two of the project involves developing a communication and engagement strategy including key messages and strategies for the defined sub-groups to engage them in hepatitis C clinical care.

Part three involves the development of a consolidated report that incorporates the findings and outcomes of parts one and two. The final consolidated report will provide an evidence-based national engagement strategy for the target audience and be publically available through the Hepatitis Australia website and disseminated to key stakeholders.

2. BACKGROUND

The hepatitis C virus was first identified in 1989 as a significant cause of post-blood transfusion hepatitis and liver disease; it was referred to as non-A, non-B hepatitis. It remains a significant global public health problem affecting people of all ages, genders, races and regions of the world.\(^2\) Hepatitis C is a blood borne virus (BBV) that causes a chronic infection in 75% of people exposed to the virus. Infection can lead to liver damage resulting in liver fibrosis (scarring), cirrhosis of the liver, hepatocellular carcinoma (HCC), and liver failure. Recent modelling conducted by the Polaris Observatory\(^3\) suggests that the global prevalence of hepatitis C viremia was 0.96% or 71 million people in 2015; whereas older estimates indicate approximately 184 million people had been exposed to hepatitis C (antibody positive), with an estimated three to four million new infections per year.\(^4\) Thirty countries account for 80% of the total global hepatitis C infections, while seven countries (China, Pakistan, India, Egypt, Russia, United States of America and Nigeria) account for 50% of the global infections.\(^5\) This inconsistency in global hepatitis C prevalence has been highlighted as having the potential to affect advocacy, allocation of resources and planning of health services.\(^6\)

In contrast to other communicable diseases, the burden of disease associated with viral hepatitis (specifically hepatitis B and hepatitis C) increased between 1990 and 2013.\(^7\) In terms of mortality, approximately 350,000 deaths are attributed to hepatitis C-related causes per year around the world.\(^8\) The disease burden associated with hepatitis C, including cirrhosis, liver failure and hepatocellular carcinoma (HCC), is expected to increase as the affected population ages. A modelling exercise using the global hepatitis C treatment paradigm from 2013 predicated that while the total number of hepatitis C infections was projected to decline or stabilise, the number of people with advanced liver disease would increase.\(^9\)

In Australia, an estimated 227,306 (range: 167,623 and 249,707) people were living with chronic hepatitis C at the end of 2015, of whom an estimated 29,070 (range: 21,437 – 31,935) people had severe fibrosis, 17,149 (range: 12,647 – 18,840) had hepatitis C-related cirrhosis, and an estimated 818 (range: 603 – 899) deaths were attributable to hepatitis C.
in 2015. Hepatitis C remains the leading indication for liver transplantation in Australia. Approximately 82% or 186,763 people have been diagnosed with chronic hepatitis C infection while the remaining 40,543 people are unaware of their hepatitis C status. Despite having one of the highest diagnosis rates in the world, the uptake of interferon-based therapy in Australia has been low; 22% or 50,172 people with hepatitis C had ever accessed antiviral treatment up to the end of 2015 and 32,139 people achieved a cure. The hepatitis C notification rate has remained stable over the last four years, except in the Aboriginal and Torres Strait Islander population where the rate of hepatitis C diagnosis increased in 2014 and was four times higher than in the non-Indigenous population.

Treatment of hepatitis C has undergone a rapid revolution since the days of combination pegylated interferon (self-administered via subcutaneous injection) and ribavirin, for 24 or 48 weeks depending on hepatitis C genotype. Interferon-based therapy resulted in a 50-80% viral clearance rate and was associated with significant side-effects, including flu-like symptoms, psychiatric disturbances and reduction in red and white blood cells. The new era of hepatitis C treatment is focused on direct-acting antivirals (DAA) which are all oral dosing (tablets), short duration (8-12 weeks) regimens with few side-effects and >95% cure rates. The DAAs have the potential to significantly reduce the individual and population burden of hepatitis C at a global and local level given their high cure rates and low side-effect profile. While access to the DAAs is restricted in many countries, all adults in Australia who hold a Medicare card have subsided access to the DAAs through the Pharmaceutical Benefits Scheme (PBS) for approved genotypes.

3. HEPATITIS C TRANSMISSION

Globally, there is significant variability in the routes of hepatitis C transmission. In Australia and most other developed countries around the world, the most common route for hepatitis C transmission is the sharing of used injecting equipment; the prevalence of hepatitis C antibody positivity among people who inject drugs attending needle and syringe programs in Australia has remained stable for 5 years, at 57%. Other key populations affected by hepatitis C include people born in high prevalence countries, gay and bisexual men living with HIV, and recipients of organs, tissues, blood or blood products before February 1990 in Australia, or before the implementation of mandatory screening of blood donors in other countries. While the WHO recommends all blood donations are screened for BBVs prior to use, several low resource countries are unable to screen all donated blood and rely on paid donations to maintain a supply, therefore, new infections continue to occur. Epidemiological studies exploring global patterns of hepatitis C transmission have identified breaches of infection control during medical procedures, unsterile injections for medications and immunisations, unsterile injections applied outside the medical settings, and tattooing and scarification as potential risk factors for infection. Failure to use sterile medical equipment and the increase in injecting drug use around the world, mean that hepatitis C transmission continues to occur in both low and high income countries.
4. ESTIMATES AND PROJECTIONS OF THE POPULATION WITH HEPATITIS C IN AUSTRALIA

In order to characterise people with hepatitis C who have never injected drugs, other hepatitis C transmission routes must be explored. In 2006, an estimated 82% of people with hepatitis C had been infected through injecting drug use; 11% were born overseas; the remaining 7% were infected through receipt of contaminated blood or blood products prior to February 1990, or unsterile skin penetration practices including tattooing and skin piercings, or mother-to-child transmission. While hepatitis C is not classified as a sexually transmissible infection, it is acknowledged that the risk of transmission is increased among gay and bisexual men with HIV. In addition, breaches in infection control among health professionals sustaining occupation exposures and among patients resulting in hospital acquired infections account for an undefined but small proportion of infections. Anecdotally, it is worth noting that a small proportion of people with hepatitis C report not knowing how they were infected.

If the proportion of hepatitis C transmission routes remained stable between 2006 and 2015, of the 227,306 people with hepatitis C, approximately 187,072 (82.3%) were infected through sharing injecting equipment, of whom 124,590 (67%) now no longer inject drugs. It is estimated that 93,000 people currently inject drugs in Australia and assuming a hepatitis C virological prevalence of approximately 45%, there are approximately 42,000 people who currently inject drugs living with hepatitis C. This equates to approximately 22% of people with hepatitis C. It should be acknowledged that the population of people who currently inject drugs dynamic, with many people transitioning in and out of drug use each year.

A further 25,000 (11%) people with hepatitis C were born in high prevalence or high disease burden countries/regions of the world; 15,910 (7%) were infected with hepatitis C through transfusion of unscreened blood and blood products, unsterile medical procedures, or mother-to-child transmission. Please note that the Kirby Institute in Infection and Immunity in Society is currently developing an updated Hepatitis C Estimates and Projections Report and once released it will provide more definitive data on the routes of transmission for people living with hepatitis C in Australia.

5. PEOPLE WHO PREVIOUSLY INJECTED DRUGS

It is estimated that of the people who acquired hepatitis C infection due to unsafe injecting drug use, approximately one-third to one-quarter currently inject drugs, and the remaining two-thirds to three quarters no longer do so. The National Drug and Alcohol Research Centre defines ‘current injecting drug use’ as occurring in the last six months. According to the National Drug Strategy Household Survey, just under 2% of the Australian population, or 313,500 people, reported having injected drugs at some time in their lives. Recent mathematical modelling estimated there were between 68,000 and 118,000 Australians (mid-range 93,000) who actively injected drugs in 2014 i.e.
46,000—80,500 males and 22,000—38,000 females.\textsuperscript{35} If a 45\% hepatitis C virus prevalence rate is applied to the mid-range estimate of 93,000 people who currently inject drugs, there are \sim 42,000 people who currently inject drugs living with hepatitis C or 22\% of Australians with hepatitis C.\textsuperscript{36}

Within the population of people who inject drugs which include female injectors, people with a history of incarceration, and Aboriginal and Torres Strait Islander people, have a particularly elevated risk of hepatitis C infection.\textsuperscript{37} Patterns of needle sharing differ between women and men, with women being more likely than men to engage in receptive needle sharing which increases their risk of hepatitis C infection. Men are twice as likely as women to have injected drugs in their lifetime, and recently (2.3\% compared with 1.2\% for lifetime use and 0.6\% compared with 0.3\% for recent use).\textsuperscript{38} In 2015, there were 48,522 people accessing opioid substitution therapy; two in three were male and the median age was 40.\textsuperscript{39} Over 80\% of existing and 90\% of new hepatitis C infections are attributed to injecting drug use. Sharing of used injecting equipment is by far the most significant risk factors for hepatitis C transmission in Australia.

There are fewer incident cases of hepatitis C infection occurring compared to fifteen years ago;\textsuperscript{40} however, the proportion of people with hepatitis C-related liver disease is increasing due to the ‘ageing cohort’ effect related to the higher incidence of hepatitis C acquired through injecting drug use in the 1980s and 1990s.\textsuperscript{41} National hepatitis C notification data shows that the number of older Australians (aged >50 years) diagnosed with hepatitis C rose from 13\% (2,059) in 2007, to 18\% (2,393) of diagnoses in 2011. It is likely that the increasing trend in older people being diagnosed with hepatitis C reflects an increase in late diagnoses rather than new infections.\textsuperscript{42}

The birth cohort hepatitis C screening program adopted in the United States, which involves offering a one-time hepatitis C antibody test to adults born between 1945 and 1965, is an example of an attempt to avoid the stigma associated with needing to disclose a history of injecting drug use which may create a barrier to accessing healthcare.\textsuperscript{43} Multiple settings and strategies have been trialled to determine the most cost effective method of screening ‘baby boomers’ for hepatitis C infection in the United States, including proactively screening patients in this birth cohort presenting to hospital emergency departments;\textsuperscript{44} dual screening for hepatitis C and colorectal cancer screening during admission for a screening colonoscopy;\textsuperscript{45, 46} innovative use of a hospital’s electronic medical record to identify people in the target birth cohort;\textsuperscript{47} and the Healthy Trucker Association of America (HTAA) which implemented a Truckers Against Hepatitis-C campaign that involved offering rapid hepatitis C testing to truck drivers attending an industry health expo.\textsuperscript{48}

A recent Canadian study using retrospective phylogenetic analysis suggested that the high prevalence of hepatitis C occurring in people born between 1945 and 1965 could be attributable to medical practices which included injections and blood transfusions administered with reusable glass syringes and metal needles that were subject to contamination despite boiling between patients.\textsuperscript{49} The spread of hepatitis C - genotype
Review of demographic data and relevant literature.

1a before 1965 suggests that hospital acquired and/or iatrogenic factors may have contributed to the spread of hepatitis C. It appears unlikely that this pattern of hepatitis C transmission has been replicated in Australia, however, the possibility of alternative routes of hepatitis C transmission in addition to sharing of used injecting equipment may assist in relieving some of the stigma associated with hepatitis C, and could be used to encourage people to be tested.

Synthesis of the evidence suggests that people with hepatitis C who no longer identify as a person who injects drugs are likely aged over 50 years, and there are a higher proportion of males than females. Anecdotal information collected during this project suggests that while this group of people may not be engaged with alcohol and other drug rehabilitation services such as opioid substitution therapy (OST) services, they may remain connected to programs such as Alcoholic and Narcotics Anonymous groups.50

6. ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH HEPATITIS C

Evidence suggests that the proportional prevalence of hepatitis C infection is almost five times higher in the Aboriginal and Torres Strait Islander population than in the non-Indigenous population, with the rate of hepatitis C diagnosis increasing in 2015 compared to 2010.51 The proportion of respondents to the Australian Needle and Syringe Program Survey from an Aboriginal and Torres Strait Islander background has increased from 10% in 2006 to 15% in 2015, and the prevalence of hepatitis C antibody among Aboriginal and Torres Strait Islander participants increased from 57% in 2011 to 70% in 2015.52 This data suggests that sharing of injecting equipment is a significant risk factor for hepatitis C transmission among Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander people with hepatitis C who no longer identify as a person who injects drugs are difficult to characterise because there is very limited data. Identifying this group will require a concerted screening effort. The Well Person’s Health Check (WPHC) was a population screening program implemented in many Aboriginal and Torres Strait Islander communities in Australia during the 1990s and early 2000s. The aim of the WPHC was to detect and treat sexually transmitted infections, and detect and intervene early in cases of diabetes, renal and cardiovascular disease in the general Aboriginal and Torres Strait Islander population.53 The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) included screening for hepatitis C in the WPHC back in 2000.54
There are several possible barriers for Aboriginal and Torres Strait Islander people living with hepatitis C in accessing hepatitis C-related care and treatment including:

- co-morbidities such as physical disability and/or reduced mobility due to a range of other health factors
- mental health issues including depression and ensuing fatigue
- distrust of the health care system
- difficulties with travelling to visit health providers and clinical services
- low socio-economic circumstances
- access to culturally appropriate and safe hepatitis C care services.

Developing strategies that aim to engage Aboriginal and Torres Strait Islander people living with hepatitis C in clinical care need to be cognisant of the potential barriers and the context and priority attached to hepatitis C.

7. PEOPLE LIVING IN AUSTRALIA WHO WERE BORN OVERSEAS*

The following section of the report focuses on people living in Australia who were born in countries with high hepatitis C prevalence or regions of the world with a high hepatitis C disease burden. In particular, people who are culturally and linguistically diverse (CALD) in Australia. It is well recognised that people from CALD backgrounds experience numerous barriers to accessing clinical care, including communication difficulties due to limited proficiency in English, low health literacy, and distrust of Western medicine. A recent study conducted in New South Wales (NSW) found no association between late diagnosis of hepatitis C among people with hepatitis C-related decompensated cirrhosis and HCC and country of birth, suggesting high screening and diagnosis rates in hepatitis C risk migrant populations. Unfortunately, country of birth data is inconsistently recorded on the notification of hepatitis C infection. Therefore, this report highlights the overseas-born populations most at risk of hepatitis C infection in order to inform the development of targeted and culturally appropriate strategies to support engagement in clinical services after diagnosis.

At 30 June 2015, 28.2% (n=6.7 million) of Australia’s estimated resident population was born overseas; the top ten countries of birth include:

- United Kingdom, Channel Islands and Isle of Man: 1,207,000 people (5.1% of Australian population)

* Please note all hepatitis C prevalence rates quoted in this section of the report refer to the hepatitis C viraemic rate unless specified as hepatitis C antibody rates. The viraemic rate was chosen because this project is focused on diagnosing and treating people living with hepatitis C, therefore people with detected hepatitis C virus. The hepatitis C antibody rate includes people who cleared the virus via treatment or by spontaneous clearance, which is not the focus of the report.
- New Zealand: 611,400 people (2.6%)
- China: 481,800 people (2%)
- India: 432,700 people (1.8%)
- Philippines: 236,400 people (1.0%)
- Vietnam: 230,200 people (1.0%)
- Italy: 198,200 people (0.8%)
- South Africa: 178,700 people (0.8%)
- Malaysia: 156,500 people (0.7%)
- Germany: 125,900 people (0.5%)

Of the top ten countries, China and India have the most significant burden of hepatitis C infection. The number of Australian residents born in India has almost tripled over the last 10 years and residents born in China have more than doubled in this time. Sievert et al. (2011) estimated there were 49.3 to 64 million people with hepatitis C (antibody positive) in Asia, Australia and Egypt. Specifically, the burden of disease is most significant in China where an estimated 13 million people have hepatitis C, India where 9.5 million people are affected and 6.5 million people in Egypt, which has the highest prevalence per population of hepatitis C globally.

People born in the United Kingdom are most represented among people born overseas living in Australia; the overall hepatitis C prevalence rate in the United Kingdom is low (0.2-0.8%), with comparable transmission routes, predominantly transmission through sharing injecting equipment. New Zealand has a similar hepatitis C prevalence rate to Australia of 1.9%. Therefore, it is possible there are approximately 7,200 United Kingdom-born migrants and 11,600 New Zealand-born migrants living with hepatitis C in Australia. Neither of these overseas-born cohorts are the focus of this project because it is assumed that people born in the United Kingdom and New Zealand have a shared language and cultural background with Australia-born people with hepatitis C. Therefore, it is anticipated that engagement strategies targeting Australia-born with hepatitis C could also appeal to people born in the United Kingdom and New Zealand.

It is important to acknowledge there are small numbers of people living in Australia with hepatitis C who were born in countries or regions where hepatitis C might be a public health concern, however, they form a small proportion of the overall target community for this report. It is anticipated these small cohorts of people with hepatitis C will be captured through activities that target the broader migrant population.

It is also worth highlighting that the prevalence rates in immigrants’ country of birth may not be reflected in the cohort that migrates to Australia. Previous research has identified the “healthy immigrant effect”, where immigrants are in relatively better health on arrival to their new country compared to people born in the destination country. Over time it has been shown that the immigrant’s health declines to the level of the native-born
population. The concept of the ‘healthy immigrant effect’ has been specifically studied in Canada, and seen in the incidence of chronic health conditions for both men and women. It is thought that the ‘healthy immigrant effect’ is attributable to self-selection, where potential immigrants are generally physically and mentally healthier and financially prosperous and able to consider migration. In addition, the proactive health screening required by health authorities in receiving countries prior to the immigrant’s arrival may also lead to healthier immigrants.\(^6\) Caution about translating the hepatitis C prevalence rates between immigrants’ country of birth and the resettled cohort must be exercised.

It is unlikely the ‘healthy immigrant effect’ will apply to refugees who enter Australia either formally or informally due to the circumstances that led them to flee. Between 2012 and 2013, the top five countries for refugee and special humanitarian visa entries to Australia were Iraq, Afghanistan, Burma (Myanmar), Bhutan and the Democratic Republic of Congo.\(^6\) The hepatitis C prevalence rate has been estimated as: Myanmar (0.9\%) Iraq 3.2\% (hepatitis C antibody prevalence), Afghanistan 0.6\%, Bhutan 1.3\%\(^6\) and Congo 4.3\%.\(^6\) Hepatitis C prevalence data is limited for many of the countries that refugees are fleeing due to conflict, natural disasters and extreme poverty which affect the systematic collection and storage of data. In addition, refugees often come to Australia from countries with limited health care services and may be unaware they have hepatitis C.\(^6\)

The data presented on the characteristics of people born overseas living in Australia is based on the result of the 2011 Australian Census. At the time of writing this report, data from the latest census in 2016 was not available.

### 7.1 Hepatitis C in high prevalence and high disease burden countries

Countries known to have a hepatitis C high prevalence include Egypt and Pakistan. China and India are classified as low to intermediate hepatitis C prevalence countries, however, due to the large population in both countries, the total number of people with hepatitis C is high. Therefore, China and India have a high hepatitis C disease burden. Characteristics of the people from both high prevalence and high disease burden countries are presented.

#### 7.1.1 Egypt

Egypt has one of the highest hepatitis C prevalence rates in the world, with an estimated 10\% of the population infected.\(^6\) There is significant intra-country variability consistent with exposure through the reuse of needles and repeated intravenous injections to resolve schistosomiasis (infection with a parasitic worm) which occurred in the 1950s to 1980s. Geographic areas near the Nile River (the parasitic worm hatches in freshwater) demonstrate higher infection rates than other parts of the country, and the prevalence is higher in older Egyptians compared to younger people; 55-59 year olds had an estimated prevalence rate of 39.4\%.\(^7\) Egypt’s mass campaigns to treat schistosomiasis represent the largest example of iatrogenic (caused by medical examination or treatment) transmission of a BBV.\(^7\)
While Egypt is not represented in the top 10 countries of birth among migrants in Australia, the significant exposure of the Egyptian born population to hepatitis C infection means they are a group worth exploring. At the time of the 2011 census, it was estimated there were 36,533 Egypt-born people living in Australia; 50% were living in NSW and 34% were living in Victoria (34%). Due to recent political unrest in Egypt, it is possible there has been a recent wave of migration of Egypt-born people seeking refugee status; this will most likely be captured in the 2016 census. Seventy-six per cent of Egypt-born people arrived in Australia before 2001, meaning that many could have been exposed as children to the schistosomiasis treatment campaigns. Generally the Egypt-born population is older, with a median age of 56 years. The main languages spoken at home by Egypt-born people in Australia were Arabic (56%) and English (20%). Eighty-eight percent of people who spoke a language other than English at home indicated their English was very good or good. Egypt-born people were strongly affiliated with religion, with 36% affiliated with Oriental Orthodox, 22% Catholic and 15% Eastern Orthodox. Sixty-four per cent of the Egypt-born population held a higher non-school qualification, and 50% were employed, which is lower than the Australian-born population participation rate of 65%, perhaps reflecting the older demographic of the Egypt-born population (more likely to have retired). Considering the 10% prevalence of hepatitis C in Egypt and that Egypt-born people are in the older age group (45 to >85 years who comprise 69.5% of the population living in Australia, \( n=25,390 \)), are more likely to have been exposed to the schistosomiasis treatment campaigns, so it is possible that 2,539 Egypt-born people living in Australia have hepatitis C (25,390 people aged 45 to >85 years x 10% hepatitis C prevalence).

7.1.2 Pakistan

The prevalence of hepatitis C in Pakistan is unknown due to a lack of general surveillance or reporting systems, however, recent estimates suggest an adult viraemic prevalence of 5.8%. It is projected that hepatitis C transmission continues to occur frequently because there are no systems to monitor the safety of the blood supply, and Pakistan has one of the highest rates of injections by health professionals in the world. The overuse of injections for administration of antibiotics, vitamins and intravenous fluids for hydration in hot weather and inadequate implementation of infection-control practices, such as single use needles, increases the risk of exposure to a potential route of hepatitis C transmission. In addition, public shaving of men’s beards in Pakistan and reuse of the blades is common and has been identified as another potential transmission route.

According to the Census in 2011, there were 30,221 Pakistan-born people in Australia; an increase of 77.8% from the 2006 Census. The median age of the Pakistan-born people in 2011 was 31 years, which is significantly younger than other overseas born and Australia-born people, and there were more males (58.8%) than females. Seventy-two per cent of Pakistan-born people spoke Urdu at home, and of those who spoke a language other than English at home, 89.5% spoke English very well or well. The majority of Pakistan-born people (88%) followed Islam. Sixty-eight per cent held a higher non-school qualification and 46.3% were employed in either a skilled managerial, professional, or trade
It is possible that based on a hepatitis C prevalence of 5.8%, there are 1,750 Pakistan-born people living in Australia with hepatitis C.

7.1.3 China
The projected hepatitis C viraemic prevalence in China is 0.8%, however, hepatitis C epidemiology in China remains largely unknown because of a lack of systematic population-based estimates. There appears to be significant variability in estimated prevalence between rural and urban settings across China. While injecting drug use is increasing in China, transmission of hepatitis C has predominantly occurred through unregulated medical practices, including reuse of intravenous injections with glass syringes and unscreened transfusion of blood and blood products. There is a significant stigma related to hepatitis B and C infection in China. Testing for viral hepatitis can occur within schools and workplaces and while legislation no longer restricts access of people with viral hepatitis to education or employment, infection can have a significant social impact.

As of the end of June 2015, there were an estimated 481,800 China-born people in Australia. Based on data collected in the 2011 Australian census, the majority of China-born people live in Australia’s main cities, and more than half of this population live in Sydney. The median age was 35 years and there were more China-born females (56%) than males (44%). The main language spoken at home by China-born people is Mandarin, and 67% indicated they spoke English very well or well. Sixty-three per cent of China-born people did not state any religious affiliation, which was higher than the Australian-born population (22%). In terms of education and employment, 58% of China-born people aged over 15 years had a tertiary degree and 51% were employed in either skilled managerial, professional or trade occupations. The unemployment rate was higher at 11%, compared to the Australian-born unemployment rate of 5.6%. The China-born population in Australia can be characterised as young, living in capital cities (predominantly Sydney), with proficient English and high levels of education and professional employment. The estimated number of China-born people living in Australia with hepatitis C could be 3,850 people (0.8% x 481,800).

7.1.4 India
Hepatitis C is an emerging infection in India; the consequences of hepatitis C-related morbidity and mortality are predicted to be significant in the future. There is no national surveillance reporting system so prevalence data is incomplete and appears to vary across the country. The estimated prevalence in India is 0.7%. A National Blood Policy was not established until 2002 and both private and government operated blood banks are poorly regulated, therefore, the risk of contracting hepatitis C through blood or blood product transfusion remains high, possibly accounting for between 38-75% of hepatitis C infections. The predominant transmission route for hepatitis C is hospital acquired infections. Parenteral transmission involving reuse of glass syringes which was practiced by 18% of physicians, haemodialysis and a history of surgery are all listed as common risk factors.
The migration of India-born people to Australia commenced in the 1800s, but flourished between 2007 and 2011 when 45% of the current population arrived, with the majority moving to Victoria and NSW. At the end of June 2015, there were 432,700 India-born people in Australia. In the 2011 census, the India-born population was young with a median age of 31 years, and there were more males (56%) than females (44%). Twenty-one per cent spoke English at home and 93% indicated they spoke English very well or well. Hindi (20%) and Punjabi (19%) were the next main languages spoken at home. The majority of India-born people in Australia were affiliated with a religion, predominantly Hinduism (47%) and Sikhism (19%). Overall, the India-born population is well educated, with 80% having a higher non-school qualification compared to 56% of the Australian-born population. Seventy-seven per cent were employed, with 48% working in either a skilled managerial, professional or trade occupation.

In summary, the India-born population living in Australia is young and has high levels of English proficiency, education and employment. India-born people are more likely to be living in urban cities, particularly in Victoria, and have a religious affiliation. The uncertain prevalence data means it is difficult to estimate the prevalence of hepatitis C in the India-born people living with hepatitis C in Australia but it could be approximately 3,030 (0.7% x 432,700).

7.2 Hepatitis C in high prevalence and high disease burden continents and regions of the world

Reliable hepatitis C prevalence data is not available from all countries around the world, therefore, the following section provides a regional overview of hepatitis C prevalence in the absence of country-specific data.

7.2.1 Africa

The African continent is made up of 54 countries resulting in Africa-born people displaying diverse cultural, linguistic, racial, religious, educational, and employment backgrounds. Large-scale migration from Africa to Australia is a recent phenomenon with the majority of migrants coming from southern and eastern Africa. Data on emerging communities will be reported as a part of the 2016 Australian census. An indication of the changing demographic was reflected in 2013 when the Australian Special Broadcasting Service (SBS) began broadcasting in six new languages spoken by the growing migrant and refugee communities from Africa. Among these are Dinka of South Sudan, Swahili of Tanzania and the African Great Lakes region, and Tigrinya of Eritrea and Ethiopia. South Africa-born people are represented in the top ten countries for migration in Australia, with 178,700 people living in Australia. The majority of South Africa-born migrants are of British descent (only a very small proportion are of Afrikaans descent), financially prosperous due to their professional background and migrated in the 1990s. As such, they have a very different characteristics profile to the more recent Sub-Saharan refugees. Migration from countries that have been devastated by decades of natural disasters, political unrest, war, drought and famine from regions including South Sudan, Ethiopia and Somalia, are expected to increase. There has been a 50% increase
in the number of Ethiopia-born people in Australia between the 2006 and 2011 census to number 8,452,88 and 32% increase in Somalia-born people in the same timeframe to number 5,687.89 In the 2011 census there were 3,487 South Sudan-born people in Australia and is it expected this will have increased and be reflected in the 2016 census.90

The hepatitis C prevalence data across Africa is incomplete; however, epidemiological studies available suggest considerable variation in prevalence rates within some areas reaching levels of up to 10%.91 This equates to more than 28 million Africans with chronic hepatitis C. The prevalence of hepatitis C in South Africa is estimated to be 1.7% (hepatitis C antibody prevalence), while in Ethiopia, the estimated hepatitis C antibody prevalence is 1.3%,92 Somalia — 1% and Sudan — 2.8%.93 A recent review reported hepatitis C prevalence among the Sub-Saharan African population to be 2.98%.94

The emerging nature of the migration patterns of people born in Africa to Australia and the diversity of the 54 African countries means it is difficult to estimate the burden of hepatitis C in these communities in Australia.

7.2.2 Asia

Included in the top ten countries of birth for people born overseas living in Australia are the Philippines, Vietnam and Malaysia. Vietnam (2–2.9%) and the Philippines (0.9% hepatitis C antibody rate) are classified as intermediate prevalence countries, and Malaysia (1.1%) is classified as low prevalence.95,96

An estimated 230,200 Vietnam-born people were living in Australia to end of June 2015; a significant increase since the 2006 census.97 Estimating the prevalence of hepatitis C in Vietnam is challenging because of the lack of a general surveillance system. The most significant risk factor for hepatitis C transmission in Vietnam is receipt of a blood or blood product transfusion, because a large proportion of the blood donors are paid and hepatitis C screening is not mandatory. In addition, being hospitalised or undergoing unsterile tattooing have led to moderate rates of infection.98 In Australia, hepatitis C infection among Vietnamese people is often associated with injecting drug use, however, among the older generation, hospital acquired exposure is more likely.

Gower et al.99 estimate the hepatitis C antibody prevalence in the Philippines is 0.9% (0.2 – 2.0%). However, there is limited information available about the transmission patterns of hepatitis C in the Philippines, so the prevalence remains uncertain.

7.2.3 Eastern Europe

According to the United Nations Statistics Division, Eastern Europe comprises the following countries (estimated hepatitis C prevalence in brackets): Belarus (0.9%), Bulgaria (1.1% hepatitis C antibody), the Czech Republic (0.5%), Hungary (0.7%), Moldova (4.5% hepatitis C antibody), Poland (2%), Romania (4.5%), Slovakia (1%), the Ukraine (4%) and the most western part of the Russian Federation (4.1%).100 While migration from Eastern Europe is not high, there was significant post war migration between the 1940s and 1960s. It is most likely at this time that hepatitis C transmission occurred primarily through iatrogenic and hospital acquired routes, including transfusion of blood and blood
products. The burden of hepatitis C in this population is mostly likely reducing as migrants from Eastern Europe age and die.

7.2.4 Latin America
Latin American comprises 20 countries and extends from Mexico to Chile, and includes the Caribbean islands. The prevalence of hepatitis C in Latin American countries is generally low; Peru (1.2% hepatitis C antibody rate), Venezuela (1.5% hepatitis C antibody rate) and Brazil (1.3%), however, the disease burden in Brazil is high with an estimated 3.2 million people with hepatitis C. Migration of people from Latin American to Australia has occurred in two waves; in the 1970s people came mainly from Chile, Uruguay and Argentina. The second wave occurred in the 1980s and included people from El Salvador and other Central American countries who were escaping civil war. Sydney is home to the largest proportion of Latin America-born Australians. In the 2011 Census, Brazil became the largest source of immigrants from Latin America in Australia, with a total of 147,509 Brazil-born people in Australia; an increase of 93.6 per cent from the 2006 Census. The prevalence and incidence of hepatitis C in Brazil is decreasing, however, it is possible there are 1,910 Brazil-born people living with hepatitis C in Australia.

7.3 Summary of people living in Australia who were born overseas
In order to summarise the data presented on people born overseas with hepatitis C and inform the development of tailored strategies to engage people in care, the migration data, estimated hepatitis C prevalence and estimated number of people with hepatitis C is presented in the following table. For consistency, the lower end of hepatitis C viraemic prevalence was used to calculate the estimated number of people with hepatitis C in Australia.

There are many limitations to this approach which need to be considered when interpreting the data. The project is not intended to be a mathematical modelling activity, and the author has no epidemiological or modelling expertise. The estimated number of people with hepatitis C is a crude estimate, based on 2011 census data multiplied by the estimated hepatitis C viraemic prevalence. It is unknown whether the source country hepatitis C prevalence can be applied to migrating populations; the healthy immigrant effect casts doubt over the accuracy of this assumption.

Estimates regarding the number of people with hepatitis C born in regions or continents with a high disease burden or high hepatitis C prevalence, have not been included in this table. This is due to gaps in the data relating to either migration patterns or hepatitis C prevalence of specific countries and the limited utility of presenting region or continent level data considering the significant cultural and language diversity. It is also acknowledged there are people with hepatitis C who were born in low prevalence regions or continents of the world, living in Australia. They have not been included because they form a small proportion of the overall target community for this report.
Table 1: The estimated burden of hepatitis C infection in people born overseas living in Australia.

<table>
<thead>
<tr>
<th>Country</th>
<th>Estimated number of people living in Australia</th>
<th>Estimated hepatitis C prevalence</th>
<th>Estimated number of people with hepatitis C living in Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>China</td>
<td>481,800</td>
<td>0.8%</td>
<td>3,850</td>
</tr>
<tr>
<td>India</td>
<td>432,700</td>
<td>0.7%</td>
<td>3,030</td>
</tr>
<tr>
<td>Brazil</td>
<td>147,509</td>
<td>1.3%</td>
<td>1,910</td>
</tr>
<tr>
<td>Egypt</td>
<td>36,533</td>
<td>10%</td>
<td>2,540*</td>
</tr>
<tr>
<td>Vietnam</td>
<td>230,200</td>
<td>2-2.9%</td>
<td>4,600</td>
</tr>
<tr>
<td>Pakistan</td>
<td>30,221</td>
<td>5.8%</td>
<td>1,750</td>
</tr>
</tbody>
</table>

* An assumption has been made that the hepatitis C prevalence applied to people aged over 45 years because the predominant risk factor for transmission was inadequate infection-control procedures during the implementation of schistosomiasis treatment campaigns in the 1960s to 1980s. Therefore, the estimated number of Egypt-born people with hepatitis C has been calculated on the number of people aged 45 to >85 years recorded in the 2011 Census.

While the data presented provides a crude insight into the number of people born overseas with hepatitis C living in Australia, the level of engagement of people born overseas with hepatitis C clinical services remains unclear.

8. PEOPLE WHO HAVE RECEIVED UNSAFE TATTOOING AND/OR BODY PIERCING

It is well recognised that unsterile tattooing and body piercing are an independent risk factor for hepatitis C infection. The risk associated with unsafe tattooing in custodial settings is heightened due to sharing of unsterile tattooing needles and ink. In the general Australian population there has been a significant increase in the proportion of Australians with tattoos; one in five (19%) Australians has one or more tattoos with a higher proportion of women with a tattoo (24%) compared to men. Over one third of people with a tattoo (36%) reported getting their first tattoo aged 26 years or older, and one in five (20%) got their first tattoo in their mid-30s or older. In the past, tattoos were associated with rebellion and non-conformity; in modern day Australia tattoos are now symbols of personal meaning and life-change. The widespread prevalence of tattoos increases the importance of appropriate infection-control procedures during their application. The tattooing industry in Australia is regulated at the jurisdictional level, and local public health regulations related to skin penetration. The highest risk of hepatitis C transmission is related to tattooing and body piercing that occurs in unregulated settings including custodial settings and ‘backyard’ tattooing which is driven by easy access to tattooing equipment on the internet. Tattooing and body piercing performed overseas in developing countries is a potential risk factor for hepatitis C transmission due to the lack of regulation and enforcement of infection-control procedures. An American study found that people with hepatitis C were four times more likely to report having a tattoo, even when other risk factors were accounted for. However, the percentage risk of
hepatitis C infection associated with unsterile tattoos is unknown, so too is the proportion of people infected via this transmission route.

9. GAY AND BISEXUAL MEN WHO HAVE HUMAN IMMUNODEFICIENCY VIRUS (HIV)

Over the last decade there have been increasing reports globally, of sexual transmission of hepatitis C virus among HIV-positive gay and bisexual men. High-risk sexual practices that result in bleeding and/or mucosal trauma appear to account for some of the transmission, however, concomitant illicit drug use including sharing of injecting drug equipment cannot be excluded as a potential route of transmission. It is estimated that nine per cent of gay and bisexual men with HIV and two per cent of HIV-negative gay and bisexual men have hepatitis C. Gay and bisexual men are at higher risk of hepatitis C exposure because the rate of injecting drug use is estimated to be 10 times higher than among the general Australian population. Further evidence suggests that people co-infected with HIV and hepatitis C may have a higher baseline hepatitis C viral load and higher concentrations of hepatitis C virus in semen than people mono-infected with hepatitis C.

It is difficult to determine if there are gay and bisexual men with hepatitis C +/- HIV who are not engaged in care. The HIV care cascade in Australia indicates that of the estimated 27,150 people with HIV, 88% (n=23,800) have been diagnosed and 73% (n=17,470) are receiving treatment. Hence, it could be assumed that gay and bisexual men co-infected with HIV and hepatitis C are predominantly engaged in clinical care. A Spanish study reported that people who acquired HIV through injecting drug use were at higher risk of late presentation, delayed initiation of antiretroviral treatment and death, compared to people who acquired HIV by sexual transmission. Numerous studies have found that hepatitis C infection attracts more stigma than HIV among gay and bisexual men because of the association with injecting drug use. The impact of the stigma and discrimination associated with hepatitis C and injecting drug use on restricting access to appropriate health care, information and support is widely acknowledged. Therefore, it is possible that gay and bisexual men who are co-infected with hepatitis C and HIV may not be accessing appropriate care, indeed people with hepatitis C/HIV co-infection report significant morbidity, poorer prognosis, and significantly reduced health-related quality of life compared to mono-infected people. In light of the new hepatitis C treatments available in Australia, it is worth noting that people co-infected with hepatitis C and HIV achieve the same high cure rates (<95%) and experience few side-effects including drug-drug interactions which were problematic with the previous treatment regimens.

A study of 474 gay and bisexual men, of whom 48 respondents were hepatitis C positive, recommended that a variety of strategies were needed to deliver gay and bisexual men-specific hepatitis C information and support services. Due to their experience in delivering information to marginalised communities, Australian hepatitis organisations
and illicit drug user organisations were seen to be well positioned to develop gay and bisexual men-specific, hepatitis C-related information and services. Integrating HIV and hepatitis C health care and education for gay and bisexual men via primary care was also supported by respondents of the study. In terms of the content and targeting of hepatitis C strategies, another study that compared hepatitis C knowledge and risk practices among HIV positive, HIV negative and HIV-untested gay and bisexual men, suggested that hepatitis C education and prevention strategies for gay and bisexual men would be most effective if they were tailored according to HIV status. Men who have sex with men with HIV had less negative attitudes towards hepatitis C, suggesting a shared sense of vulnerability. Hence, developing hepatitis C education and prevention interventions that focus on specific sexual practices as well as the biological, virological and immunological factors that facilitate hepatitis C transmission were perceived to be more likely to have an impact on educating gay and bisexual men at risk of hepatitis C infection.

While it is recognised that some gay and bisexual men with HIV are at higher risk of hepatitis C exposure, their high level of engagement in clinical services demonstrated by the HIV care cascade and anecdotal clinician experience suggests they are not a focus of this project.

10. PEOPLE WITH BLEEDING DISORDERS

The main bleeding disorders in Australia are haemophilia which affects more than 2,700 people, predominantly males, and Von Willebrand disease (VWD) which is the most common inherited bleeding disorder worldwide affecting approximately 200,000 Australians. Von Willebrand disorder affects both females and males from all ethnic backgrounds.

Many people with bleeding disorders were exposed to hepatitis C through transfusion of blood products, particularly plasma-derived clotting factor concentrates prior to the introduction of universal screening of the blood supply in 1990 and hepatitis C viral inactivation processes in the manufacturing of clotting factor concentrates in 1993. A prevalence study at the Alfred Hospital found that 52% (219 of 700 patients with an inherited bleeding disorder) were hepatitis C antibody-positive; in people with severe bleeding disorders the prevalence was approaching 100%. It cannot be assumed that people with a bleeding disorder are universally engaged in hepatitis C clinical care. Northcott et al. reported that 73 of 219 (33%) had received hepatitis C treatment; of the 130 patients with chronic hepatitis C, 29% (n=38) there was no evidence of follow-up with a liver specialist in the past 2 years. The authors concluded that hepatitis C testing among people with bleeding disorders is incomplete and treatment and clinical monitoring rates are low.

People with a bleeding disorder and hepatitis C who are not connected to care may include people with mild bleeding disorders such as mild haemophilia or VWD who do
not experience bleeding problems for long periods and therefore are not connected to a haemophilia treatment centre for care of their bleeding disorder. People exposed to hepatitis C through transfusion of a plasma-derived clotting factor prior to 1993 (when hepatitis C inactivation processes had been introduced into manufacturing of clotting factor products, in particular super-heat treatment), may have acquired hepatitis C and be unaware of their status.

There are several possible barriers for people with bleeding disorders and hepatitis C accessing hepatitis C-related care and treatment including:130

- co-morbidities such as physical disability and/or reduced mobility due to haemophilia-related arthritis
- mental health issues including depression and ensuing fatigue
- distrust of the health care system
- difficulties with travel to health providers
- low socioeconomic background
- carer responsibilities.

11. PEOPLE WITH MEDICALLY ACQUIRED HEPATITIS C

Another group who warrants consideration are people who acquired hepatitis C through medical procedures including blood or blood product transfusions, primarily conducted prior to 1990, but also including people who were infected through medical accidents. These people do not have a bleeding disorder and are therefore considered separately.

The Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006 report indicated there could be 15,910 people who were infected with hepatitis C through transfusion of unscreened blood and blood products, unsterile medical procedures, or mother-to-child transmission.131 In 2004, the Australian Department of Health and Ageing reported to the Senate Inquiry into hepatitis C and the blood supply that it was not possible “to obtain comprehensive or definitive figures on the number of people infected with hepatitis C through blood transfusion. Many people with [hepatitis C] are asymptomatic and may therefore never have been diagnosed”.132 However, the Australian Red Cross Blood Service (ARCBS) estimated that between 3,500 and 8,000 Australians contracted hepatitis C through blood transfusion, including an estimated 1,350 people with haemophilia.133 The ARCBS conducted a formal Lookback program in the 1990s in an attempt to trace blood products which may have been contaminated with hepatitis C. At its best, the ARCBS reported that the Lookback program was an imperfect process hampered by significant delays between blood exposure and contact with the Lookback program, inaccurate or incomplete medical records which restricted the breadth of the lookback and the challenges confronted by multiple donors.
It is likely the number of people with medically acquired hepatitis C is smaller than the estimates in 2006, considering the exposure was more than 25 years ago and many may have died because they were unwell at the time. Nonetheless, it is worth considering that people infected with hepatitis C through medical procedures may confront many barriers to accessing clinical services, namely distrust of a system that infected them with hepatitis C.\textsuperscript{135} It cannot be assumed they are accessing clinical care.

12. CHILDREN BORN TO WOMEN WITH HEPATITIS C

The transmission of hepatitis C from mother to infant during pregnancy or at the time of delivery is recognised as the most common way that children are infected with hepatitis C. Approximately six per cent of children born to hepatitis C virus-positive women develop chronic infection. The risk is increased to 10\% for a woman co-infected with hepatitis C and HIV.\textsuperscript{136} Neither mode of delivery (vaginal delivery versus caesarean) nor breastfeeding represents a significant risk factor for hepatitis C transmission. The evidence suggests that hepatitis C transmission most likely occurs during the birthing process, so limited clinical interventions are advised to avoid blood-to-blood contact between the mother and the infant.

In Australia, pregnant women are universally offered hepatitis C testing during the initial antenatal period, thus the risk of hepatitis C transmission should be known prior to delivery.\textsuperscript{137} However, international evidence suggests that many at-risk children remain untested.\textsuperscript{138} An infant born to a woman with hepatitis C will inherit her hepatitis C antibodies and test antibody positive until the child is aged between 15–18 months, at which time the antibodies tend to disappear. Therefore, it is recommended that infants born to women with hepatitis C are tested for hepatitis C antibodies at two years of age or have a hepatitis C virus by polymerase chain reaction (PCR) test at eight weeks followed by a confirmatory test four to six weeks later.\textsuperscript{139} Adherence with the National Hepatitis C Testing policy for follow up testing of infants in Australia is unknown.

The number of people with hepatitis C born to a hepatitis C- positive mother in Australia is unknown. Based on several assumptions: one third of the population with hepatitis C are women (n=74,910); the average fertility rate in Australia is 1.846 births per woman;\textsuperscript{140} 138,283 infants were born to women with hepatitis C. Assuming a hepatitis C vertical transmission risk of six per cent, an estimated 8,297 infants could have been infected with hepatitis C. Obviously, this calculation is a rough estimate and does not take into account the reproductive age of the women or changes in fertility rate over time.

Uncertainty about the prevalence of follow up hepatitis C testing in infants born to women with hepatitis C means there may be infants/children/adults with hepatitis C who have not been diagnosed and are not engaged in clinical care.
13. OTHER PEOPLE WITH HEPATITIS C WHO MAY NOT BE ENGAGED IN CLINICAL CARE

The hepatitis C epidemiology and health service utilisation of Australian war veterans and people who use performance and image enhancing drugs (PIED) were considered during the research for this report. However, due to limited information and data, they cannot be included as a target for future engagement strategies, though a brief overview of the issues are provided.

In the United States of America, veterans comprise a significant proportion of the population with hepatitis C. However, in Australia, data on the prevalence of hepatitis C among veterans is not clear. General data regarding liver disease is available, however, alcohol consumption appears to be the most significant aetiology. It is unclear if Australian service men and women could have been exposed to hepatitis C through hospital acquired or iatrogenic routes, injecting drug use or tattooing and body piercing. More data is required to determine if Australian veterans are at risk of hepatitis C and require interventions to support testing and engagement in clinical services.

There has been a sudden increase in the use and availability of performance and image enhancing drugs (PIED) through the online market. An Australian study conducted at the needle and syringe programs (NSP) of the Kirketon Road Centre (KRC) in Sydney indicated that hepatitis C prevalence among people who injected PIED was zero; participants rarely reported administering PIED intravenously (6%), or being tested for hepatitis C in the last year (32%). These results reflect the findings of a study from 2002 that reported that rates of needle sharing among people who inject PIED was low, however, the risk of blood exposure was present due to the use of intramuscular injections and large gauge needles to administer the viscous steroids which may result in bleeding from the puncture site. Therefore, environmental blood contamination was considered a potential route of transmission. The number of people who inject PIED accessing Australian NSPs has increased recently, however, it has been reported that NSP workers lack knowledge about PIED and there is a need to engage in workforce training which will ultimately allow the workers to more effectively engage with PIED users in relation to effective harm reduction strategies.

People who inject PIED are more likely to be male and gay or bisexual and reported rates of receptive needle sharing are low. However, an over-reliance on personal networks and internet forums for accessing both the drugs and injecting equipment limits this groups’ access to objective harm reduction advice and primary care services. There may be a need to provide PIED-focused health information and promotion to encourage more frequent hepatitis C testing for this group of injectors.
12. ENGAGEMENT IN HEPATITIS C CLINICAL CARE

One of the most significant barriers to engagement in hepatitis C clinical care is lack of knowledge and understanding of the diagnosis. It is safe to assume that none of the 40,543 people with undiagnosed hepatitis C are engaged in hepatitis C clinical care, however, they may be engaged with other specialist and primary health care services.

In addition to people who have not been diagnosed, are people who have been misdiagnosed or experienced incomplete testing. A Victorian-based modelling activity estimated that approximately 58% of people (n=20,400) notified with hepatitis C between 2001 and 2012, did not receive either a negative test for viral nucleic acid or a viral genotyping test during the study period, meaning that their hepatitis C diagnosis was incomplete.**148** Viral confirmation using PCR and genotype testing after an initial hepatitis C antibody test, was consistently lower in males than females, particularly in younger age groups. Almost half of the Victorians with incomplete virological assessments were aged over 45 years in 2012. However, uptake of confirmatory virus testing (using PCR) improved with age (45 and 55 years), most likely indicating that people who were diagnosed when they were younger, were catching up on diagnostic services because long-term chronic infections were becoming clinically apparent with the development of liver disease.

A study conducted by Bloom et al. (2016) sought to assess the prevalence of liver disease in patients aged 18-80 years, with chronic hepatitis C or B who had not been assessed by a liver specialist (<18 months), attending high case load primary care practices in Melbourne, Australia. The study found that 15.9% of patients with hepatitis C had cirrhosis and 40.6% had significant fibrosis rates comparable to those attending hospital services.**149** The high rate of cirrhosis in patients not engaged with specialist liver health care is of significant concern. Older age, longer duration of infection, body mass index, waist circumference and high alcohol intake (>140gms per week) were associated with cirrhosis. Of concern, these at-risk patients were not being monitored and over two-thirds had not received specialist opinion about their health condition, suggesting they were not receiving the level of care and intervention required. Secondly, it highlights significant deficits in the knowledge and understanding of primary care physicians about liver disease and the sequelae of hepatitis C infection. While the hope that advancing liver disease will be a trigger for either referral to a specialist service or intensive engagement in the clinical system, it appears that neither is guaranteed.

The triggers for a primary care practitioner to either prioritise the patient’s hepatitis C for treatment and management or to refer a patient with hepatitis C to a specialist for assessment of liver disease in 2016 remains largely unknown. A survey conducted in 2005 with men and women living with hepatitis C reported that only 37% and 52% respectively had ever been referred to a medical specialist for hepatitis C-related care,**150** suggesting that women could be more likely to be referred than men. Obviously there are patient-related factors including personal motivation to be cured and/or a desire to understand better the health of their liver. The Deloitte Centre for Human Solutions 2015 survey
identified six distinct segments of consumer engagement with the health system. The segments vary from each other in the level of engagement with health professionals, health systems and understanding of the individual’s health status, attitudes towards partnering with health professionals to achieve health goals, use of social media and other health technologies to improve and/or monitor health and preferred communication patterns.151

The hepatitis C diagnosis and care cascade suggests that 186,763 people have been diagnosed with hepatitis C.152 However, not all these people are engaged in hepatitis C care. The latest treatment data suggests that 26,360 individuals initiated DAA treatment between March and July 2016.153 The extremely high number of people treated in the first year of DAA availability most likely reflects treatment of people who have been ‘warehoused’ by the tertiary clinics in anticipation of the availability of the DAAs, and therefore were already engaged in hepatitis C care. The early adopters of hepatitis C treatment most likely accessed DAAs through independent buyers’ clubs, clinical trials (before PBS listing) and as soon as the DAAs were available on the PBS. This group was knowledgeable and motivated to access treatment early.

13. SUMMARY

The number of Australians living with hepatitis C who do not identify as a person who injects drugs and are not engaged in clinical care remains unknown. It is proposed that the characteristics of this group are extremely diverse and include people aged in their fifties who used to inject drugs; Aboriginal and Torres Strait Islander people who used to inject drugs; people born in Egypt, Pakistan, China, India, Vietnam, Brazil, and Africa living in Australia; and a small proportion of gay and bisexual men with HIV, people with bleeding disorders, people who acquired hepatitis C through medical procedures and people who received unsafe tattooing and body piercing. The current public health response to hepatitis C in Australia is focused on treating as many people with hepatitis C as possible regardless of the route of infection. The next challenge will be identifying people with hepatitis C who are not engaged in clinical care and are at risk of developing undiagnosed liver disease and complications.154 The purpose of this report is to synthesise the evidence and inform the development of tailored communication and engagement strategies for people with hepatitis C not currently engaged in hepatitis C clinical care.
REFERENCES

1 World Health Organisation. Global Health Sector Strategy on Viral Hepatitis 2016-2021: Towards ending
4 Mohd Hanafiah K, Groeger J, Flaxman AD, Wiersma ST. Global epidemiology of hepatitis C virus
Apr;57(4):1333-42.
5 Blach S, et al. (November 2016). Polaris Observatory – Global prevalence of hepatitis C. Poster session
presented at the American Association for the Study of Liver Disease (AASLD), Boston, USA. Proceedings
of the AASLD Liver Meeting 2016, p.168A.
6 Basnayake SK, Easterbrook PJ. Wide variation in estimates of global prevalence and burden of chronic
7 Stanaway JD, Flaxman AD, Naghvai M, et al. The global burden of viral hepatitis from 1990 to 2013: findings
8 Mohd Hanafiah K, Groeger J, Flaxman AD, Wiersma ST. Global epidemiology of hepatitis C virus
Apr;57(4):1333-42.
9 Razavi H, Waked I, Sarrazin C, et al. The present and future disease burden of hepatitis C virus (HCV)
The Kirby Institute, University of New South Wales Australia, Sydney.
11 Gidding HF, Topp L, Middleton M, et al. The epidemiology of hepatitis C in Australia: notifications,
The Kirby Institute, University of New South Wales Australia, Sydney.
The Kirby Institute, University of New South Wales Australia, Sydney.
The Kirby Institute, University of New South Wales Australia, Sydney.
17 European Association for the Study of the Liver (EASL) (2015). EASL Clinical Practice Guidelines:
with daclatasvir plus sofosbuvir in patients with hepatitis C virus genotype 3 infection: ALLY-3 phase III
treatment with daclatasvir plus sofosbuvir in patients with hepatitis C virus genotype 3 infection: ALLY-3
The Kirby Institute, University of New South Wales Australia, Sydney.
National HCV Testing Policy Expert Reference Committee – a joint working party of the Blood Borne Virus
and Sexually Transmissible Infections Subcommittee (BBVSS) and the Ministerial Advisory Committee on
Blood Borne Viruses and Sexually Transmissible Infections (MACBBV). 2012. Available:
http://testingportal.ashm.org.au
at: http://www.who.int/mediacentre/factsheets/fs279/en/

29 Dore G. Personal communication, 27th October 2016.
31 Laney S. Estimating populations PWID. Paper presented at the 10th Australasian Viral Hepatitis Conference; 30 September 2016; Gold Coast, Australia.
32 Dore G. Personal communication, 27th October 2016.
35 Laney S. Estimating populations PWID. Paper presented at the 10th Australasian Viral Hepatitis Conference; 30 September 2016; Gold Coast, Australia.
36 Dore G. Personal communication, 27th October 2016.
44 Rein DB1, Smith BD, Wittenborn JS, Lesesne SB, Wagner LD, Robin DW, Patel N, Ward JW, Weinbaum CM.
51 Personal communication with McIntyre-Smith K, Hepatitis Australian Capital Territory (ACT) Board member on 19th October 2016.
52 The Kirby Institute, Hepatitis B and C in Australia Annual Surveillance Report Supplement 2016. The Kirby Institute, University of New South Wales Australia, Sydney.
53 The Kirby Institute, Hepatitis B and C in Australia Annual Surveillance Report Supplement 2016. The Kirby Institute, University of New South Wales Australia, Sydney.
Summary


Sattell G. Personal Communication on 28 September 2016.


106 Hellard ME, Hocking JS, Crofts N. The prevalence and the risk behaviours associated with the


130. Personal communication with O’Callaghan S, Policy Research and Education Manager, Haemophilia Foundation Australia, Wednesday 19th October 2016.


132 Senate Community Affairs References Committee. Hepatitis C and the blood supply in Australia. Canberra: Senate Community Affairs References Committee Secretariat, 2004; p.15.

133 Senate Community Affairs References Committee. Hepatitis C and the blood supply in Australia. Canberra: Senate Community Affairs References Committee Secretariat, 2004; p.15.

134 Senate Community Affairs References Committee. Hepatitis C and the blood supply in Australia. Canberra: Senate Community Affairs References Committee Secretariat, 2004; p.80.

135 O’Callaghan S. Personal Communication on 12th December 2016.


143 van Beek I, Chronister KJ. Performance and image enhancing drug injectors’ access to needle syringe programs: Responding to a public policy dilemma. Int J Drug Policy. 2015 Sep;26(9):868-74.

144 van Beek I, Chronister KJ. Performance and image enhancing drug injectors’ access to needle syringe programs: Responding to a public policy dilemma. Int J Drug Policy. 2015 Sep;26(9):868-74.


147 van Beek I, Chronister KJ. Performance and image enhancing drug injectors’ access to needle syringe programs: Responding to a public policy dilemma. Int J Drug Policy. 2015 Sep;26(9):868-74.


