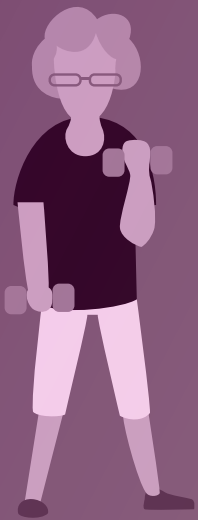




# A HIDDEN POPULATION:

**Supporting healthy ageing for people who inject  
drugs and/or receive pharmacotherapies**





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August 2019



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# INTRODUCTION

The Australian Injecting and Illicit Drug Users League (AIVL) is the Australian national peak organisation representing the state and territory peer-based drug user organisations and issues of national relevance for people with lived experience of drug use. AIVL's purpose is to advance the health of people who use/have used illicit drugs and for more than 20 years, AIVL has undertaken projects that seek to increase understanding and improve policy responses on issues that affect the lives of people who use drugs.

In 2018-19, AIVL has undertaken the *Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies* project, which aims to build capacity amongst aged care services to meet the unique needs of this ageing cohort. This project has been funded by the Australian Government Department of Health through the Dementia and Aged Care Services Fund.

By way of background, the population of people who inject drugs in Australia is an ageing cohort. Latest trend data has found that the average age of people accessing injecting equipment through needle and syringe programs has risen from 38 years in 2012 to 42 years by 2016 and at last data collection, approximately 34% of people accessing these services were between 40-49 years and 17% aged 50 years or more<sup>1 2</sup>.

The availability of the overdose reversal drug, Naloxone, and effective treatments for hepatitis C and HIV, mean that people who inject drugs are now living longer. People who inject drugs experience the same ageing-related issues experienced by the non-illicit drug using population, as well as additional complications related to drug use and blood borne viruses. The presence of older people who inject drugs in aged care services, and the ability to manage and respond to health issues such as hepatitis C, present new challenges for Australia's aged care system and aged care workers.

This project aims to build capacity within aged care providers to respond to the unique needs of older people who inject drugs, older people on pharmacotherapies and older people living with hepatitis C or hepatitis C-related complications. It undertook national consultations (workshops and interviews) across three sites (Canberra, ACT; Bunbury and Busselton, WA; and Newcastle, NSW) with aged care providers across the spectrum of aged care service delivery to gauge understanding of issues that affect older people who inject drugs and understand how healthy ageing can be supported amongst this cohort.

Older people who inject drugs were also consulted to identify key ageing issues and specific barriers that may prevent them accessing aged care or general health services.

The output of the project is this comprehensive needs analysis report that identifies the practitioner and system needs for supporting healthy ageing amongst older people who inject drugs, and makes recommendations for systemic change.

AIVL also invited stakeholders in the palliative care and related sectors to attend the consultations to provide advice on key issues and considerations for related sectors, given the intersecting cohorts. AIVL sought the assistance of participants to ensure that the project was able to capture and articulate the needs of the various stakeholders in a way that is meaningful for informing policy, program and operational level responses to the needs of this growing population group.

# SECTION 1

## COMMUNITY PERSPECTIVES: Emerging issues among ageing illicit/injecting drug users

As outlined in the Introduction, national consultations (workshops and interviews) were undertaken across three sites (Canberra, ACT; Bunbury and Busselton, WA; and Newcastle, NSW) with older people who inject drugs to identify key ageing issues and specific barriers that may prevent them accessing aged care or general health services.

These consultations were undertaken by a highly experienced peer worker, hence the consultations were undertaken by and for the affected community. The candid nature of engagement outlined, and information provided, in this section of the project report reflects the level of respect, trust and confidence that participants had in the peer worker undertaking the consultations. The following section of the project report has also been written by the peer worker who undertook the consultations.

Having the consultation framework developed, implemented and reported on by peers provides a unique and comprehensive look into the personal fears and sense of alienation the future holds for ageing drug users, while also providing important data on potential numbers and intentions regarding drug related habits into old age. As such, Section 1 is truly reflective of the 'consumer voice' in terms of describing the needs, wants and fears of the affected community.

### Introduction to the Generation

*"In the case of the older drug injector they become the marginal among the marginal of society."<sup>3</sup>*

This project builds on an earlier project AIVL initiated in 2010, which developed a discussion paper on the lives of opioid injectors as they aged - "Double Jeopardy Older Injecting Opioid Users in Australia 2010". Older drug users were a very new phenomenon and AIVL found no Australian papers<sup>4</sup> on the subject to that date, which strengthened our understanding this was truly a new cohort that needed attention.

We also understood a decade later, as we undertook this project, that the broader drug using population needed to be considered. Getting accurate estimations on the population of people who use illicit drugs is extremely difficult - "...such biases usually result in underestimation of the population size of problematic drug users"<sup>5</sup>.

This particular cohort are the children of the post-World War generation, born into a period of relative peace and prosperity. "Baby boomers" became known throughout their lives as a group that didn't automatically accept the status quo, pushing for social change and social justice.

*"Social gerontologists note the baby boomers have tested many of the deeply rooted social values and beliefs".<sup>6</sup>*

The sheer size of this population was noteworthy as it was twice the size of the previous generation (4.5 million compared to 2.5 million) - the "Silent Generation" - who were born into a period of hardship and endeavour, growing up through two World Wars, The Great Depression, and a flu pandemic that almost halved the population of Europe. This previous generation was known for its frugality and stoicism.

*"The likelihood is that older people in the past did not use drugs because they did not use them when they were young."<sup>7</sup>*

The use of drugs for non-medicinal purposes had been rare in previous generations, with small numbers of white middle class men and women being involved. In 1957 the Commonwealth Annual Report noted that only 33 people had been charged with illegal possession of drugs and 9 with trafficking. The maintenance of so-called therapeutic addicts was not challenged until the 1950s.



The first half of the 20th century, spurred on by the necessities of war, saw the rapid industrialisation of countries and the growth of a global trading market to move goods and military hardware. These naval highways carried merchandise of all descriptions and facilitated the distribution of unfamiliar goods to newly emerging markets. There had also been a considerable movement of populations escaping from war, poverty and persecution.

*“The influx of migrants to Australia following World War 2.... meant the baby boomers had the largest overseas born population of any previous generation.”<sup>8</sup>*

The post-World War era developed the social, economic, and intellectual circumstances for a range of drugs to be available and the people prepared to experiment with these new drugs and new methods of use. New working conditions and healthy pay packets resulted in a generation of people who had leisure time and money to spare on non-essentials. It was a period characterised by high rates of marriage and fertility, high levels of immigration, rising rates of female participation in both tertiary education and the workforce, and the genesis of the two-income household as the norm<sup>9</sup>. As baby boomers went through adolescence, the newly available drugs were experimented with. Such differences might, for example reflect the coincidence of being at a particular age at a particular time in history when drug use is at a high or low point<sup>10</sup>.

Unfortunately, there were no social understandings or cultural signposts to help people understand these drugs, their effects and how to best use them. As drugs were often associated with migrant populations and the assimilation of these groups took some time, it added to their mystique. Drug use with unfamiliar cultural traditions and social mores provided some discomfort to the existing populations. New drugs had been a feature of all migration as cultures took their rituals and practices with them to their new homes. The acceptability of the drugs enmeshed with cultural significance and regulated by social mores was tolerated.

This acceptability was significantly altered however, when those customs were adopted by other citizens, resulting in unusual behavior and socially questionable results. There was no space in which rational discussion could be had about these drugs once the push for the criminalisation and social rejection of their use was instigated.

Because of this early criminalisation and social distaste, drug users removed themselves from the mainstream gaze, which has resulted in the emergence of a group that is known as “hard to reach”. This illicit community practice has meant that mainstream society know little about this community - its size, its lifestyle, and its needs - which is why the imminent arrival of this cohort into aged care services is causing some concern and requires attention.

That population, born between 1946 to 1964, are in 2019 aged between 53 to 76 years. They are increasingly being exposed to the people and facilities that make up the aged care sector services system. The staff in these services hold many of the same negative views about illicit drug use and users as the general population and that is an issue of huge concern for this cohort. It is of ongoing concern that research and surveys, time and time again, cite discrimination by mainstream health and welfare services as one of the main reasons this group avoids medical appointments or services, often presenting very late for treatment.

## The Population

The population of Australia - like much of the developed world - is ageing.

In 2017, 15% of Australians (3.8 million) were aged 65 and over; this proportion is projected to grow steadily over the coming decades<sup>11</sup>.

Estimating the numbers of illicit drug users for the purposes of this project is very difficult. While there are some programs for opioid users - cocaine, methamphetamine and novel drug users have minimal if any contact with mainstream services as they have few dedicated harm reduction programs to entice them into contact, fewer treatment programs and no established, evidence-based pharmacotherapies.

In 2001, about 12% of Australians in their 40s had used an illicit drug in the previous 12 months. This had increased to 14% by 2013, and to 16% in 2016. People in their 40s were the only age group to show a significant increase in use between 2013 and 2016. People in their 50s generally have some of the lowest rates of illicit drug use but have also shown increases in recent use since 2001, from 6.7% to 12% in 2016.<sup>12</sup>

It is also noteworthy that a disproportionate number of people in the drug using community identify as “Forgotten Australians” - Australian and migrant children whose experience of institutional living has been so traumatising and disabling the Australian Government apologised on behalf of the nation and set up a redress scheme to help ameliorate their distress and ongoing hardships.

*“The approximately 500,000 children suffered institutional abuse and neglect while in the care of the State during their childhood. Forgotten Australians are now adults... all these children had life in (asylum) hospital, or in foster care and other forms of out-of-home care in the 20th century in Australia.”<sup>13</sup>*

## The Age Group

The Australian Government’s definition of ageing generally encompasses people over 65, however, AIVL’s consideration of the impacts of ageing starts at 40 years. AIVL’s 2011 discussion paper and what limited other research there is tells us the impact of a lifetime’s illicit drug use is devastating to the health of this cohort. It is worth noting that we have no accumulated information on the effect of lifelong use of these drugs as they were not used in this manner by previous generations.

The outcomes of prohibition appear to exacerbate many of the harms that lead to this early ageing process - the use of impure drugs sold at exorbitant cost, the hardships of a criminalised existence, endless discrimination and the very high chance of having concomitant blood borne viruses (BBV) and/or soft tissue infections.

In Australia, the baby boomers - some 4.5 million - were born between 1946 and 1964. They can, in the main, expect to live some 20 years longer than previous generations if no complicating health factor or accident intervenes.<sup>14</sup> This contrasts vividly with the projection for illicit drug users, which has them commencing the ageing process 20 years earlier than others.

## The Community Study

We used an exploratory-sequential mixed method in which quantitative design (survey) is built on the outcome of the qualitative design (focus groups). We designed the study to utilise two methods of exploratory information/data collection as we wanted to collect the most comprehensive information on the subject to date to facilitate

information flow and hopefully fast track the introduction of services and responses to this growing concern.

In our previous ageing study, we looked at the emerging population of ageing opioid users. However, in this study we felt it was time to get a more diverse range of participants, so users of methamphetamine, cocaine, crack, opioids and illicit pharmaceuticals were included in the focus groups.

The questions were designed to facilitate the development of a more intimate and complex picture of where ageing stood in relation to individual drug users’ lives and their communities’ understanding of this developing issue. This study was developed, implemented and reported on by peers. It provides a unique and comprehensive look into the personal fears and sense of alienation the future holds for ageing drug users, while also providing important data on potential numbers and intentions regarding drug related habits into old age.

We interviewed 40 illicit/injecting drug users with an age range of 40 to 72 years. We had slightly more males than females and we interviewed in metropolitan, rural and regional areas. We didn’t collect any data on drug of choice or frequency of use, however the fact that they had used injecting illicit drugs was required for participation. The responses have been collated in different ways, some questions stand alone and the responses are written underneath, others are a combination of questions that were similar but asked differently to gain a more nuanced response.

## Community Responses

### Did you think you would reach old age?

95% of respondents said they had never thought they would live to become an aged person.

Our first question addressed the ubiquitous belief in the community that illicit drug users do not live to old age. As the first generation to have been exposed to the various emerging elements that facilitated this unprecedented relationship with recreational drugs, there were no older role models for people to look to. Professor Ann Roche, Director of the National Centre for Education and Training on Addiction at Flinders University, says:

*“We used to talk about people either maturing out or dying from drug use but there is a sub population who*

*through improved health care and better drug regimes have survived longer into old age than would have been expected".<sup>15</sup>*

Our peers uniformly said they had not believed they would age and provided some interesting and thoughtful explanations as to why that might have been the case. Many responses spoke to untimely death through overdose or violence:

*"No, I expected to O.D. or pass away from violence."*

Peers talked about the death of older users when they commenced using. There were very few role models to demonstrate life as an older drug user.

*"Most of us were teenagers with dealers not much older."*

*"It was a way of marking the difference between us and the Oldies."*

The lack of experienced drug users was particularly noted by several women who had looked to older women for information on pregnancy and parenting. One participant stated:

*"I remember when I was having my first baby. It was hard to find another woman who had already experienced what I was going through, it was scary and the doctors knew nothing."*

Also mentioned was the belief by youth in the invincibility of youth - a common feature of adolescence and evidenced in the mainstream culture of adolescent drink driving.

*"I was young and impervious."*

Several peers also mentioned the impact of the Cold War on the belief a shorter than average life expectancy was inevitable.

*"I remember having drills at school about getting under our desks when the bomb dropped."*

*"My parents didn't help - having experienced so much tragedy in the World Wars the possibility of another war was very real for them."*

So the use of drugs and the belief that it lead to premature death was added to a reality which already questioned the possibility of reaching old age.

*"Having the bomb hanging over our heads made using more attractive, you didn't know if the next day would be you last so why not indulge?"*

### **What is it like ageing as an illicit drug user?**

Frightening and unpredictable was the consensus in relation to their futures as they aged. They were afraid of situations they had experienced previously, such as instances of discrimination. They were also frightened of issues that were completely unfamiliar, such as the health impact of a lifetimes' drug use. The tendency of doctors to put any health problem with no obvious explanation down to being a result of drug use and consequently not bothering to monitor or follow up appropriately was also noted.

One person wrote:

*"Horrible, stigma and discrimination."*

Another:

*"Scary. Not only do we deal with ageing in a conventional sense but as the first generation to go through this - to age - we have no idea really what to expect or more importantly how to stop the crap that we are going to go through."*

A point made by several peers went to the current state of drug policy and its impact on their lives:

*"Depressing, I used to (naively) believe that the accumulation of evidence about the failures of prohibition would eventually lead to its demise."*

### **Financial Difficulties**

Financial considerations weighed heavily on virtually every participant, even those people who had worked all their lives, as they have accumulated no superannuation, no property, nor savings in the main.

*"Drugs cost so much I didn't really save."*

*"The financial insecurity - I've never saved anything or got any super - I'm f@#ked."*

*"I wasn't getting old so why would I save my money?"*

The additional and unexpected health worries and impacts illicit drug use is starting to have on their lives was a constant source of concern, particularly as it often meant multiple consultations with numerous doctors, all of whom commented on their drug use.

Historically, this population has been disinclined to access mainstream health services as the stigma and discrimination is so unrelenting and intense that they prefer to risk the escalation of symptoms, so that when they eventually do present for medical attention there is no question of need and no accusations of drug seeking.

### **Hepatitis C**

Most participants (92%) currently had, or had been treated for, chronic hepatitis C. They are now seeing the impact of ignoring the disease on both themselves and/or their friends.

*"I mean they look fine, then the next time you hear they died of liver cancer."*

At the end of 2014, there were an estimated 230,000 people in Australia living with chronic hepatitis C. The latest information from Kirby Institute's monitoring data indicates:

*"The highest proportion of individuals treated were 51-60 years (33%), followed by 31-50 years (26%)."<sup>16</sup>*

While treatment certainly has captured some members of our community, evidence indicates the greatest number - and those at the most risk - are still not accessing treatment for hepatitis C.

Interestingly, when discussing treatment, a few people mentioned being ambivalent about treatment if it meant they would live longer in aged care settings.

*"I don't want treatment. I don't want to live longer. It's too f@#ked as a drug user."*

### **What are the good bits about ageing?**

*"Just living life."*

*"I found that I mellowed and I am happier - things don't worry me so much."*

*"Knowing more about the drug wars and not blaming myself for being f@#ked when it's really them that are f@#ked for letting prohibition take over."*

*"People don't immediately slot you as a drug user because you're old."*

*"Grandkids - my grandkids are my life."*

*"Knowledge and learning from life."*

*"Less idiot friends and better relationships."*

*"Don't care what people think."*

*"Familiarity with the 'system' - identity within a social group."*

*"Watching my daughter grow up and make a good go of life - does not use any drugs."*

*"It takes less to get me stoned."*

It's interesting that only a few people mentioned their own children and their relationship. However, grandchildren seem to be a source of much joy and are often a path to restoring ties and reestablishing family units.

### **What are the worst parts of ageing?**

Veins no longer being patent was a common problem, with some people saying they smoke ice (methamphetamine) and other drugs, saving their veins for heroin.

*"Watching as all your friends die and having very few friends left."*

*"Kids knowing now and not accepting you because of your drug use."*

Some spoke of the physical effects:

*"I look and feel much older than I am."*

Tied in with the myth drug users don't age, telling people you still use drugs as an older person is uncomfortable and the judgement is immediate. The judgmental attitude of people who assume older people (especially woman) don't use illicit drugs is particularly challenging.

### **What are your fears and worries?**

The knowledge that opiate related pain killers will in the main not be available to them, even in circumstances of severe pain, was a source of worry for nearly everyone, particularly as many of them already had conditions that were painful.

*"Even when they know you are in pain they won't help. It's like they are still punishing you for daring to try drugs."*

*"People's reaction when you tell them you are still using drugs is appalling so I'm frightened to tell anyone."*

In line with the prevailing belief there are no older drug users, when people find out that a person in their 60s or 70s is using, they are shocked, as it's clear that stopping is not probable.

*"That I won't be able to communicate and they stop giving me my methadone."*

### **What's it like ageing as an illicit drug user on a substitution program?**

Loss of mobility and the challenges in accessing reasonable takeaway doses was a universal point of distress. People spoke of recuperating from major surgery and still - as methadone clients - dragging themselves into the clinic or pharmacy to avoid risking being sanctioned for not accessing allocated doses.

*"I had a knee replacement and because I couldn't follow the instructions, I did further damage."*

*"I've been successfully on this program for over 3 decades and I am subjected to the same treatment and expectations as a newbie twenty-year-old."*

*"Having to get to the chemist when I have mobility problems."*

*"I couldn't get take aways when I was having knee surgery. It was ludicrous and cruel."*

### **Is staying at home an option for you as you age?**

*"I'd prefer it, but I'd have to deal with NDIS and they need training about drug users."*

*"I don't see how we can stay at home if nurses and others have to visit us, as nurses aren't allowed to visit patients who are known to be drug users. They are afraid of what could happen, so that would have to change."*

### **Do you think you'll still be using when you get older and need aged care services?**

96% of participants indicated they believed they would still be using illicit drugs and saw no reason to stop at this stage.

Two other respondents were hoping to become drug free as they were horrified that they were still using, believing as others had, that older people didn't use. They were very ashamed and disgusted with themselves.

### **What facilities would you like to see in place so you could age peacefully?**

*"Guaranteed safe housing."*

*"Pain relief, guaranteed non-judgmental support, methadone, access to own movies and music."*

*"Trained, non-judgmental staff."*

*"Facilities where people with the same past are able to live in a peaceful, quiet and accepting community."*

*"Legal protection against society. Peer support and representation that keeps our issues on the agenda of government."*

### **Do you think you could manage in an aged care facility?**

*"I'd commit suicide before I'd let that happen"* - was not an uncommon response from participants.

They simply could not see themselves beholden to mainstream carers when their past experiences had left them not accessing health services unless it was an emergency because of the unacceptable treatment they had received.

They were also frightened of the lack of confidentiality, accountability and the very good chance that their families would be told of their drug using behaviour.

A recent report into the ageing survivors of religious and government institutions for children spoke of agreements to suicide together before ever being taken into another institution. There is a considerable crossover between that particular community and the community of ageing people who use drugs.

*"No matter how pleasant or friendly the proposed 'home' may appear, the memory of their helplessness in the face of ill treatment is likely to provoke resistance and terror."<sup>17</sup>*

The overrepresentation of people who use drugs in custodial settings is also worthy of consideration in this context, along with intersecting cohorts of people who may have experienced institutional settings in the mental health, Aboriginal and Torres Strait Islander and refugee contexts. People with complex needs and issues of past trauma require specialised responses to address their particular barriers to accessing the residential aged care sector in particular.

The provision of age-appropriate care and infrastructure in custodial settings - and transition to community for these people – also requires separate consideration, given the well-documented ageing of the prison population across Australia<sup>18</sup>.

### **Do you have friends in the same situation?**

Many people commented that virtually all their friends from the drug using community of their era had died as a result of drug related issues, such as blood borne viruses, and they felt very lonely. They commented on the difference between their generation of drug users and the newer one and were nostalgic for the past as they felt it was a kinder, gentler community. Their place in the illicit drug using community was also being challenged as they aged and could no longer do the things required of a full-time illicit drug user.

### **A dual existence - ageing in two very different communities**

Illicit drug users have lived a dual life in two very different communities. As they age, their place in both spaces is threatened and compromised because of how ageing people are perceived. They have been estranged from mainstream society due to criminalisation and social abhorrence and increasingly they find themselves no longer able to keep their place in the netherworld of illicit drug use. Historically, they had an important and integral role in the illicit drug using community - they had experience and contacts - often dealing to people, they were also the repositories of cultural knowledge.

The ability to live the quite fast-paced and edgy existence of a daily user diminishes as you age. Safety is compromised. You can no longer move as fast or protect yourself:

*“Not being able to fend for myself.”*

Younger users, much like in the general community, have no sense of drug users ageing and some people commented that younger users had said they did not really like seeing older users. They didn't like the reminder that people continue to use drugs into old age.

The cohort that were experiencing adolescence in the 70s were also becoming increasingly unfamiliar with the current drug culture in which the use of multiple drugs is commonplace. Standing in shopping malls for hours sometimes, waiting for someone with a mobile phone, had replaced ducking into a house or car.

*“There wasn't many of us and drug use was a way of rebelling and dissociating ourselves from our parents and society - it wasn't to become career criminals. It was kinder and had a social justice aspect to it.”*

*“All my contemporaries were at Uni or learning the arts. We were a small group and kept ourselves as quiet as possible.”*

### **Conclusions from the community**

This emerging group of ageing Australians - those using illicit drugs for most of their adult lives - are needing to access aged care services earlier than their contemporaries due to the devastating impact illicit/injecting drug use - and related social determinants of health - have on the body.

The living standards of an individual have an enormous impact on morbidity and mortality. This fact, and outcomes of illicit drug use, combine to seriously reduce the quality and length of lives for many people who use illicit drugs. The impact of illicit drug use, hepatitis C and other related comorbidities are not well understood within the aged care sector and this does not bode well for future relationships between participants and those working in the sector.

The issue of illicit drug use, combined with issues of past trauma and other complex needs within this ageing cohort, present particular barriers for those needing to access services. Lack of adequate preparation may result in a cohort of ageing Australians who will not stay in aged care services and will join the swelling ranks of the homeless as again they are being problematised due to their particular form of drug use.

# SECTION 2

## SECTOR VIEWS: Key themes emerging from the consultations with aged care and related sector service providers

### Visibility of People Who Use Drugs in the Aged Care Sector

#### Clients on pharmacotherapies for opioid dependence?

For those consultation participants (participants) working in the palliative care space, contact with people on pharmacotherapies for opioid dependence (e.g. methadone, buprenorphine) was not uncommon. However, for participants working in the aged care sector responses were variable.

It was noted that the ability to quantify this varied across different aged care settings. In particular, providers of home care services noted that they would not necessarily know if service users received pharmacotherapies. Likewise, people in retirement village/villa-style, independent living accommodation would not need to disclose medications within that context. Service providers would only need to be provided with such information for people in in-patient, residential settings.

Participants noted that it would be useful if numbers of people in the relevant age cohort currently receiving pharmacotherapies in the community could be quantified to inform service planning. For instance, how many pharmacotherapy clients are over 45 years old in the service catchment area? A need for access to further information and data was identified, with one participant noting that:

*"This is a hidden population for the aged care sector."*

Participants across all locations felt that the management of prescription opioids is a significant, emerging issue. Within this context it was noted that benzodiazepine management is also challenging in residential aged care settings. Participants spoke of reservations in relation to the implementation of the new Aged Care Quality Standards<sup>19</sup> as of 1 July 2019, with new reporting requirements in relation

to psychotropic drugs of particular concern. There was widespread concern that any more onerous reporting/accountability requirements could have the unintended consequence of further limiting access to the full range of treatment options and medications/ pharmacotherapies.

Across all consultations, service providers were very clear that the aged care sector needs additional resourcing to be able to respond to the challenges associated with providing services for people with complex health and social needs. Workforce constraints loomed large in these discussions and are explored at length in a later section of this paper.

In terms of other drug using sub-populations, consultations in both metropolitan and regional sites identified that methamphetamine users (e.g. truck drivers), were considered to be very challenging to manage in aged care, particularly given the current absence of any established, evidence-based pharmacotherapy options.

#### Hepatitis C, other Blood Borne Virus (BBV) and Sexually Transmissible Infection (STI) prevention, testing, treatment and care services in aged care settings

Participants generally felt that universal precautions were applicable and adequate in relation to the prevention of hepatitis C in aged care settings. That being said, few seemed to have considered the possibility of ongoing injecting drug use by residents in aged care facilities.

In terms of testing and treatment for hepatitis C, participants across jurisdictions noted that often people lose access to their own General Practitioners (GPs) on entry to residential aged care. This was thought to significantly impede continuity of care for people entering aged care facilities. For GP care to be comprehensive, patient histories are required. Consequently, facilities don't necessarily know if

people need testing and/or treatment for hepatitis C. Participants across jurisdictions also agreed that often in-house primary care in aged care facilities is quite superficial due to a shortage of clinicians. Participants spoke often about the absence of access to clinicians and how this was a significant challenge to the achievement of better integrated care in aged care facilities.

Some participants also noted that treating hepatitis C will prevent hospital admissions amongst this cohort. A number of people spoke about the lack of awareness of hepatitis C treatment among average GPs nationwide. It was noted that many people in the community – as well as GPs - are not aware of the new hepatitis C treatments. Many felt that this challenge to hepatitis C treatment uptake was exacerbated by the dominance of GP Superclinics in many areas – there was widespread concern that people don't get personalised, long-term care from GP Superclinics when they are still living in community settings prior to entering aged care.

Some participants were concerned that the new Aged Care Quality Standards may make consent more problematic to manage in terms of testing and treatment for BBVs and STIs in residential aged care settings, creating a further potential barrier to hepatitis C testing and treatment. While the complexity of these intersecting challenges was noted in discussions, the consensus was that hepatitis C treatment needs to at least be available and offered in aged care settings.

## Access

### Eligibility for services

Participants working in both residential and home care settings spoke about the significant barriers to accessing the aged care system, which are particularly exacerbated for marginalised and disadvantaged groups. It was universally agreed that people need assistance to access the aged care system and related supports – knowing where to start and how to navigate bureaucracy are skills that many older people don't have.

Many participants talked about restrictive eligibility criteria and long waiting times to access services.

For instance, people under 65 years of age are ineligible for the Home Care Packages Program<sup>20</sup> and many other aged care services. This is problematic, because previous literature reviews undertaken by

AIVL<sup>21</sup> on older people who use drugs have found that the ageing-related issues that the non-illicit drug using population experience typically occur within people who use drugs at an earlier age. On top of this are complications related to hepatitis C – even where the virus has been treated and cured. As such, an 'older' person who uses drugs can be considered to be as young as 40 years, as this is when physical capabilities start to decline and visible signs of ageing become apparent.

Even for those who do meet the current eligibility criteria, long waiting times apply. At the time of writing this report, the Australian Government's My Aged Care website stated that wait times for Level 2, 3 and 4 Home Care Packages were "12+ months"<sup>22</sup>. Participants stated that it was not uncommon for people to require residential aged care by the time the waiting period for Home Care was over – people's physical condition can deteriorate significantly in 12 months, especially in the absence of home care that has been assessed as necessary. Participants stressed that this was the situation for 'standard', non-complex cases.

Participants across jurisdictions also expressed concern that the implementation of recommendations arising from the current Royal Commission into Aged Care Quality and Safety<sup>23</sup> may make services more expensive, hence reducing access for a whole range of marginalised and disadvantaged groups. That said, it was repeatedly noted throughout the consultations that the aged care sector needs resourcing to be able to respond to complex needs. This issue is explored further in the 'Workforce Issues' section of this paper.

In terms of the visibility of people who use drugs in the aged care sector, a number of participants noted that methamphetamine users were another emerging sub-population that could be very challenging to manage in aged care. Participants spoke of the resourcing implications of accepting clients with complex needs such as mental health and alcohol and other drug issues that required specialised interventions, including in terms of access to appropriately qualified staff. Within this context it was noted that infrastructure in traditional residential services needs adaptation to accommodate people with complex needs. Participants spoke about the growing need to manage agitation among residents, whatever the cause. There were also discussions about the need for different aged care settings to respond to the needs of this growing cohort, for instance group homes.



## Availability of services

Participants across jurisdictions spoke about how a lack of access and waiting times for non-acute services were leading to people ending up in acute residential care settings (such as hospitals and palliative care) because of a lack of appropriate and safe health and aged care services. The sentiment often expressed was that people had progressed from ageing to dying while waiting for access to services that could prevent or delay that progression. Participants spoke about how many of the people they were working with in residential contexts would have preferred home-based assistance but had been let down by a lack of availability of services.

Many participants also acknowledged that the social and cultural barriers to access are as challenging as the physical absence of services in terms of affecting actual and perceived availability. Peoples' lifetime experiences of stigma and discrimination from mainstream health and related social support services affect their willingness to engage with a new part of the health and social system, and their perception of how they will be treated in any new context.

## Equity

### Health services and medications

Throughout the consultations there was a lot of discussion about the perceived widespread inability of the aged care sector to respond adequately to people with complex health and social needs. Participants felt that this was reflected in large numbers of people in aged care being prescribed anti-depressants – there was a prevailing belief that anti-depressants were a band-aid solution for a broader problem in relation to people not having their health and social needs adequately met in aged care contexts.

Pain management was an area of particular concern for participants across jurisdictions. A number of aged care facilities reported the provision of complementary therapies as part of long-term pain management, but it was noted that such interventions are often inadequate for people with dependence issues. It was further noted that the majority of the aged care sector is not well-equipped to manage dependence issues in terms of both workforce and infrastructure. A number of participants noted that this project and the related consultations have at least prompted conversations within the sector in relation to unmet need.

There was also widespread agreement that the aged care sector is generally not adequately equipped to manage pain and it was noted that unmanaged pain also leads to depression in residents. There were a lot of discussions in relation to the need for clinical in-reach to aged care facilities, with pain management a key area of concern.

In terms of pain management, a number of participants highlighted the important point that pain affects people on opioid maintenance treatment (OMT) too and that people with dependence issues often have difficulty getting their pain management needs met in both aged care and other healthcare settings. There was a strong view among participants that people on OMT need access to effective and specialised pain management in aged and palliative care settings. It was further noted that pain management for people with dependence issues requires a multi-disciplinary approach.

The need for greater access to clinical in-reach services came up repeatedly throughout the consultations, including in the context of pain management and access to OMT. In this context in particular participants felt that there was a definite need for more nurse practitioners who can prescribe to do in-reach and also be on-site at facilities. The need for in-reach from community pharmacy was also discussed in terms of the dispensing and management of OMT.

In terms of access to pain relief, there was universal agreement that the aged care sector needs to ensure the provision of adequate pain relief for everyone. A number of participants highlighted that dementia patients have pain too – they just struggle to articulate their needs and have them acknowledged/heard. Structural and systemic barriers to better pain management were raised across jurisdictions. For instance, there were concerns that real time monitoring systems, as they are currently being implemented in several jurisdictions, are creating a new disincentive for prescribers to work in aged and palliative care settings. There was also talk about Pharmaceutical Benefits Scheme (PBS) crackdowns on the already limited number of prescribers working in the aged and palliative care spaces. There was a strong view that these well-meaning but not necessarily well implemented initiatives could have the unintended consequence of creating further disincentives for prescribers to use effective medications to manage pain and/or prescribe OMT. Participants across all locations stated that it must be recognised that appropriate pain

management in palliative and aged care settings is NOT the same as over-prescribing. There was widespread concern that media reports, community and political perceptions in relation to the perceived 'over-medication' of people in aged care may result in worse pain management outcomes.

In terms of equity in the provision of health services and medications in aged care contexts, at the Canberra consultation it was noted that there are currently not enough private GPs providing OMT at all in the ACT, including in aged care settings. These comments were reflected in the regional consultations in both NSW and WA where access to alcohol and other drug services is also limited. Participants across several sectors highlighted the lack of incentives and training for GPs to provide OMT, noting a need for consideration of support and incentives at a policy level if demand for OMT is to be met in both community and aged care settings. The need for bulk billing incentives to enhance access and outcomes for marginalised and disadvantaged people was also raised.

In terms of other alcohol and other drug-specific services and medications in particular, it was noted by several participants that there is not currently an established, evidence-based pharmacotherapy for the management of methamphetamine dependence. Discussions around the management of people with problematic behaviours (with varied causes including mental health, alcohol and other drug, disability and/or dementia issues) led a number of participants to question whether medicinal cannabis might be a helpful additional medication in terms of managing agitation in aged care settings.

In numerous discussions across multiple consultation sites there was widespread agreement that the aged care sector would benefit from in-reach from specialist alcohol and other drug services, in terms of providing both formal and informal workforce development and contributing to the development and implementation of care plans tailored to individual need.

### **Workforce issues**

#### **LACK OF ACCESS TO CLINICAL STAFF**

The two headline concepts that were raised in every single consultation across jurisdictions were:

1. *the need for more prescribers in the aged care sector; and*
2. *the aged care sector not being adequately funded/ resourced to manage complex needs.*

These concepts are worth considering in the specific context of workforce issues, because the challenges are intrinsically linked.

The need in relation to lack of access to clinical staff was characterised in two ways. Firstly, the need for more in-house prescribers in aged care (e.g. GPs, nurse practitioners and pharmacists in-house) was highlighted. Participants stated that accessing clinicians in aged care settings is generally difficult, hampering responsiveness and medication access. Secondly, participants spoke about the need for clinical in-reach to aged care facilities, particularly where resourcing and funding constraints made the creation of additional in-house clinical positions impractical.

Participants noted that better links/service from GPs in primary care would lead to less hospitalisations of aged care residents. Many participants spoke passionately about the particular need for access to nurse practitioners who can prescribe to do in-reach and be on-site at larger facilities. The need for in-reach from community pharmacies was also seen as a way to facilitate continuity of care for people in residential facilities. It was noted that most GPs are generally too busy to engage in specialist areas of practice, such as OMT, pain management and ageing. The absence of GP capacity in these areas in the community is reflected in even more limited access in aged care contexts.

There was a widely held view among participants that lack of resourcing for and access to clinical staff was directly contributing to the inability of aged care facilities and services to respond to complex needs. As previously indicated, participants felt that this was reflected in high numbers of people in aged care being prescribed anti-depressants. The link between inadequate pain management and depression was also noted in this context. There was overwhelming agreement that the management of complex needs in aged care needs a multi-disciplinary approach. In terms of the profile of alcohol and other drug use within the broader context of management of complex needs, there was widespread agreement that the aged care sector would benefit from in-reach from specialist alcohol and other drug services, in terms of providing both formal and informal workforce development and contributing to the development and implementation of care plans tailored to individual need.

#### **LOW HEALTH LITERACY OF MAJORITY WORKFORCE**

Low levels of education and health literacy among the majority of the aged care workforce were also seen to contribute to the aged care sector's inability to manage complex needs. Participants across

jurisdictions noted that Certificate 3 and 4 workers have relatively low health literacy. Many participants felt that workforce skills development is pivotal to ensuring adequate responses to complex needs within different aged care settings.

Participants spoke at length about the need for workforce development in de-escalation skills (e.g. such as the training provided to staff at Sydney's Medically Supervised Injecting Centre) for Certificate 3 and 4 workers in particular. It was felt that de-escalation skills would be beneficial in helping Certificate 3 and 4 workers in responding to behavioural incidents, no matter what the cause (e.g. mental health, intoxication, cognitive impairment).

There were numerous discussions across jurisdictions about the need for access to alcohol and other drug (AOD) workers and/or the applicable elements of the AOD worker skill set in the aged care sector. Participants in the ACT suggested that it would be great if aged care sector workers were eligible to undertake the current AOD Skill Set Course under the ACT AOD Qualification Strategy<sup>24</sup>.

There was widespread agreement that de-escalation and/or AOD-specific workforce development and training would be broadly beneficial, and that such skills would be nationally applicable. Such workforce development initiatives would be facilitated and complemented by in-reach from specialist AOD services.

In summary, there was a widely held view among participants that low levels of education, training and health literacy among the majority of the aged care workforce meant that the aged care sector was unable to adequately respond to the presentation of complex health and social needs. Participants acknowledged that significant additional funding and resourcing would be required to enable the upskilling of the workforce, including consideration of the breakdown between clinical and non-clinical positions. Low levels of education, training and health literacy among the majority aged care workforce mean that staff often lack de-escalation, pain recognition and other critical skills within the aged care context.

A number of participants across jurisdictions also spoke about the impact low levels of workforce education and health literacy had on the likelihood of service users experiencing stigma and discrimination in relation to drug use and related issues. There was a view that the majority workforce's knowledge and perceptions would currently be shaped by personal and cultural views, rather than on evidence and best practice, in the absence of any formal education or training on alcohol and other drugs and related

issues. Participants were concerned about the potential for service users to experience stigma and discrimination within this context, and in particular about how such experiences may negatively impact people's willingness to disclose relevant information about their medical history that could contribute to more effective care planning.

The significant need for workforce development is probably best summed up by this comment from one of the consultation participants:

*"The aged care sector needs workforce education and training, NOT more regulation and policy frameworks."*

## Stigma and discrimination

### Perceptions of the aged care sector

While the issue of stigma and discrimination as a barrier to access is explored in the previous section of this report, it is interesting to note the reflections of aged care and related service providers in this context.

A number of participants noted that they had had contact with people who use drugs who had avoided engaging with the aged care sector due to experiences of stigma and discrimination in the broader health and social sectors. It was noted that stigma and discrimination and an absence of physical access can be equally problematic barriers to engagement with services. As highlighted earlier, avoiding accessing aged care services can lead to people ended up in acute settings (e.g. hospital, palliative care) as a result. There was a widespread view that the aged care sector needs additional resourcing to be able to respond to complex needs through the provision of skilled staff and supportive environments.

Interestingly, numerous participants raised the issue of family pressure as a barrier in the effective management of alcohol and other drug issues in aged care. Several participants highlighted that families often have a zero-tolerance approach to alcohol and other drug use that is neither evidence-based nor helpful. This can present challenges for staff, particularly when family members hold Power of Attorney.

A number of participants also spoke about media, community and political perceptions in relation to the 'over-medication' of people in aged care facilities, and the potential for this to impact negatively on pain management and palliative care outcomes. In the words of one participant:

*"People in pain and in palliative care in particular need adequate access to medication."*

# RECOMMENDATIONS

In responding to the community perspectives and sector views outlined in this report, AIVL makes the following recommendations for systemic change to support the identified practitioner and system needs for supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies:

- The aged care sector needs access to existing available datasets on ageing cohorts, including the number of people aged over 45 on pharmacotherapies in the community, in order to inform effective health and aged care service planning.
- Hepatitis C prevention, testing and treatment services should be available and offered in aged care settings.
- Eligibility requirements for aged care services require greater flexibility to accommodate the premature ageing of this cohort.
- Addressing the lack of access to clinical staff through the utilisation of innovative models of care, including -
  - more in-house prescribers in aged care settings; and
  - clinical in-reach to aged care facilities, particularly where resourcing and funding constraints are an issue.
- Funding for in-reach capacity for specialist alcohol and other drug and palliative care services, including peer-based drug user organisations, to –
  - provide formal and informal workforce development;
  - contribute to the development and implementation of care plans tailored to individual need;
  - facilitate linkages with community pharmacy services (dosing, prescriptions, deliveries, disposals);
  - provide health promotion, advocacy and support services to individuals; and
  - contribute to strategic service planning.
- The needs of Aboriginal and Torres Strait Islander peoples and communities require separate, dedicated consultations and consideration, given the intersecting layers of stigma and discrimination impacting this cohort and the particular intergenerational impacts arising from the Stolen Generations.



# ATTACHMENTS

## Attachment A

### Consultation Workshop 3 – “Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies”

(expecting to run for approximately 1 hour and facilitated by AIVL staff) - ‘we need to speak about how we manage drug use and old age’

#### Introduction

AIVL has been successful in securing project funding from the Commonwealth’s Dementia and Aged Care Services Fund for the first time in 2018-19. This new project builds on initial work undertaken by Jude Byrne for AIVL a number of years ago. The project proposal to the Aged Care Services Fund was supported by both the Office of Health Protection (that funds AIVL’s current BBV/STI work) and the Alcohol, Tobacco and other Drugs Branch – hence the dual focus on hepatitis C and AOD pharmacotherapy access.

**The project aims to build capacity within aged care providers to respond to the unique needs of older people who inject drugs, older people on pharmacotherapies and older people living with hepatitis C or hepatitis C-related complications. We want to ensure that AIVL can advocate effectively in relation to the needs of our ageing cohort and provide a rationale for our member organisations who may wish to expand their service offering in this area.**

We anticipate that there will be three parts to this process:

1. *Providing this information ahead of the workshop so that participants can consult with their friends and colleagues beforehand;*
2. *Going through the consultation questions below in a group at the Annual Meeting to enable identification and discussion of emerging trends and issues; and*
3. *Follow-up with member organisations post-Annual Meeting.*

As part of the 2018-19 AIVL workplan, consultations will also be undertaken with aged care providers across the spectrum of aged care service delivery to gauge understanding of issues that affect older people who inject drugs and understand how healthy ageing can be supported amongst this cohort. The activity will produce a comprehensive needs analysis report that identifies the practitioner and system needs for supporting healthy ageing amongst older people who inject drugs, and will make recommendations for systemic change.



## Questions

1. What proportion of your organisation's service users do you estimate are at the point of needing to engage with the aged care sector, either in community settings or in residential aged care settings? This might be indicated by things like more frequent and ongoing contact with acute clinical services, increased number of hospital admissions etc.
2. What are people in this situation saying about their needs and fears about getting older? Are any of them talking about the aged care sector?
3. Has your organisation had any experience in terms of helping people to negotiate the aged care sector? If so, please describe.
4. Will the unique needs of older people in this cohort impact on services currently being delivered in the Aged Care Sector? How?
5. What particular BBV/STI prevention, testing and treatment measures do you think need to be a focus for aged care providers delivering services to this cohort?
6. What AOD prevention, harm reduction and treatment services need to be a focus for aged care providers delivering services to this cohort?
7. What sort of innovative approaches might need to be considered to supplement existing services to meet the needs of this cohort?
8. Would your organisation like to provide additional services designed to support people in this cohort who are needing to engage with the aged care sector? If so, please provide a brief description of what sort of support your organisation could provide.



## Attachment B

### Consultation Workshop 3 (Monday 26 November 2018) Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies

#### Consultation questions and answers provided by participants

- 1. What proportion of your organisation's service users do you estimate are at the point of needing to engage with the aged care sector, either in community settings or in residential aged care settings? This might be indicated by things like more frequent and ongoing contact with acute clinical services, increased number of hospital admissions etc.*

  - Pain management crossover
  - People on high pharmacotherapy doses – masking pain/health issues
  - WA
    - Pain management – people being inappropriately reduced to get off program
  - NSW
    - Mainstream providers think any drug use is problematic
  - US/Canada experience – reduced willingness to prescribe S8s
  - ACT
    - Discussion re S8 pain medication for people who are opioid dependent
    - Now – people with opioid dependence can get S8 pain relief too – looks at issues of tolerance
  - Benzodiazepine users
    - Getting harder to get scripts – part of codeine crackdown maybe?
    - Doctor shopping
  - Stigma and judgement
    - Does the way people treat drug users' change as they age?

*2. What are people in this situation saying about their needs and fears about getting older? Are any of them talking about the aged care sector?*

  - Fear of homelessness
  - Fear of having to continue engagement with the black market
  - Social isolation and loneliness
- 1. What proportion of your organisation's service users do you estimate are at the point of needing to engage with the aged care sector, either in community settings or in residential aged care settings? This might be indicated by things like more frequent and ongoing contact with acute clinical services, increased number of hospital admissions etc.*

  - Harm Reduction Victoria
    - Staff training with home care provision provider re intro to working with our community
  - How do we know people are ageing?
    - Hormone levels?
    - Osteoporosis and fractures?
    - Vitamin D levels?
  - NSW
    - Crossover with HIV positive community too
    - Yes – people are starting to talk about this
  - Harm Reduction Victoria
    - Recent study re ED presentations and cost (CREDU?)
  - SA
    - Our people trying to avoid both primary care and aged care because services can't meet their needs
  - Need health promotion for this cohort re
    - Hydration
    - Medications etc.
  - HIV sector delivering training to aged care providers
  - Pharmacotherapy access – dosing is an issue

- A lot of people with no money to go into retirement villages
- Isolated from their peer group of 'old people' – left behind in the community with no access to services or support
- People being transferred from hospital to 'nasty' public aged care facilities due to lack of community/family support to stay at home

3. *Has your organisation had any experience in terms of helping people to negotiate the aged care sector? If so, please describe.*

**AND**

4. *Will the unique needs of older people in this cohort impact on services currently being delivered in the Aged Care Sector? How?*

- Harm Reduction Victoria
  - Staff training with home care provision provider re intro to working with our community
- NTAHC
  - Yes – in the HIV and LGBTI space – could build on approach
- NSW
  - Aboriginal-specific residential aged care services not inclusive of people who use drugs
- Smoking – costs – financial and health costs
- Drug driving
- Pharmacotherapy access
- Medication management in context of dementia

5. *What particular BBV/STI prevention, testing and treatment measures do you think need to be a focus for aged care providers delivering services to this cohort?*

**AND**

6. *What AOD prevention, harm reduction and treatment services need to be a focus for aged care providers delivering services to this cohort?*

- Blood Borne Virus (BBV) prevention, testing and treatment
- Lack of clinical staff, low levels of training – stigma and discrimination
- Health promotion – need to promote general infection control procedures
- Hepatitis C treatment
  - Need for ongoing monitoring of liver health
- Testing
  - Vein access issues (for people with a history of injecting drug use)
- Confidentiality
  - Need to consider in context of stigma and discrimination for residents
- Euthanasia was raised as an option
  - People are afraid of living into old age – many threats, financial and social
  - Fear lack of control
- Need to raise awareness of issues around ageing, to dispel myths to reduce fears among
  - Service users
  - Service providers
- Pharmacotherapies – need equitable availability to facilitate community transitions
- Policies re drug use in aged care settings (e.g. cannabis smoker in a group home)
  - Criminalisation needs consideration in this context
  - Loss of independence – access issues
- Again (message also received in other workshops), need to explore pharmacotherapy options for methamphetamine users
- Need to ensure evidence-based treatments only (e.g. noting the potential face value appeal of options such as naltrexone implants)



7. *What sort of innovative approaches might need to be considered to supplement existing services to meet the needs of this cohort?*

**AND**

8. *Would your organisation like to provide additional services designed to support people in this cohort who are needing to engage with the aged care sector? If so, please provide a brief description of what sort of support your organisation could provide.*

- Opioid Substitution Treatment (OST) provision AND Hepatitis C treatment – both should be easy to manage in residential care contexts
- Naloxone (overdose prevention) training for both staff and peers
- Issue of over-medication for management of behaviour
  - How does this affect other drug use?
- Need to understand intersection of issues
- Confidentiality – need to protect peoples' confidentiality with families etc.
- Peer treatment support/case management workers to help people navigate interactions with the aged care sector
- Need training for aged and primary care staff (e.g. AIVL's 'A Normal Day' stigma and discrimination podcast training through ASHM)
- Need to explain/demystify role of our organisations (AIVL member orgs)
- Human rights framework
- Drug use as a health issue
- Need to document features of healthcare
  - Shift framing from 'special', 'extra' services
  - It's a set of principles re provision of healthcare which is inclusive of people who use drugs
  - Package of stuff to meet holistic needs of older people

- Need to consider supply issues in aged care context
- Need to educate aged care sector
  - Not all drug use is problematic
- Need to learn from HIV and mental health sector work in this space
- Health framing
  - Health NOT criminal justice
  - Complex needs in community and residential contexts
- Need to develop/build on peer navigation and peer treatment support models
- Need to address drug use as an exclusion provision for some mainstream services
- OWLS (Frankston) service
  - Service for over 60s drug users who are ageing
  - Holistic
  - Long term and evaluated
  - Frankston Integrated Health Centre (David McDonald has reference)
- Transport and access issues
  - Implications for changing drug use patterns
- Dental health is a key issue for this cohort too.

## Attachment C

# Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies project

### Project Advisory Group

Angela Corry  
Chief Executive Officer  
Peer Based Harm Reduction WA, Perth WA

Samantha Edmonds  
National Project Manager, Silver Rainbow  
National LGBTI Health Alliance, Newtown NSW

Kate Reed  
Nurse Practitioner Clinical Advisor  
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Medical Educator- Hepatitis C  
MSD - Medical Affairs, Macquarie Park NSW

Nikki Johnston  
Palliative Care Nurse Practitioner  
Calvary Public Hospital, Bruce ACT

Dr Peter Higgs  
Burnet Senior Fellow  
The Burnet Institute, Melbourne VIC



## Attachment D

### Consultation questions for aged care sector service providers: Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies

As outlined in the invitation to this consultation, this project is taking everyone involved – service users, services, clinicians, government, aged care sector workers - into uncharted territory as this is the first time these groups have needed to understand and respond to the health and social needs of illicit drug users as they age. People who inject drugs experience the same ageing-related issues experienced by the non-illicit drug using population, as well as additional complications related to drug use and blood borne viruses. The presence of older people who inject drugs in aged care services, and the ability to manage and respond to health issues such as hepatitis C, present new challenges for Australia's aged care system and aged care workers.

The Australian population is ageing - the number of people aged over 65 years has been steadily increasing over the past century. In general, the Australian Government considers people over the age of 65 to be "older" whereas in the context of hepatitis C in particular, community consultation participants have described ageing as affecting people older than 55. In 2010 an investigation by AIVL described people who inject/use drugs who are over 40 years as being impacted by factors associated with ageing<sup>25</sup>,

By 2050, it is estimated 23% of the population will be over 65 years of age. At a service delivery level, the 'baby boomer' generation are already currently experiencing the effects of ageing and increasingly needed to engage with different parts of the aged care sector. This is a cohort of people who grew up during a time when drugs were available, people had money to spend and time in which to use drugs. Many people in this cohort started to inject during the '80s and 90s and while they continue to inject today, the effects of continued injecting on their life course and health needs are poorly understood<sup>26</sup>

The 2016 National Drug Strategy Household Survey (which has some limitations with targeting those most likely to be using) overview says there are approximately 114,5000 people using an illicit drug at least weekly and 4.9% of those are aged 50-59 years.

Data suggests there is a cohort of ageing drug injectors. Current figures for opioid users show that of the 48,500 thousand people on substitution programs 22% percent were aged over 50. The number of older opiate users who have never accessed treatment services is unknown and the number of methamphetamine users of any age is less well understood - an all ages estimate by Professor Paul Dietze at the Burnet Institute estimates 34,377 to 57,947 people are in this group.

This means we are talking about potentially tens of thousands of people needing support from different types of aged care service providers. Often this cohort has multiple and complex needs as stigma and marginalisation has meant their access to the health care sector in general has been sporadic at best.

This survey is hoping to get a picture of where things are situated in the sector to see what your needs are in terms of delivering services to this cohort and how we can best facilitate an easy transition for all concerned.

### Consultation Questions:

1. *Do you currently have any clients who are on pharmacotherapies for opioid dependence (e.g. methadone, buprenorphine)?*
2. *Are you aware of the recent rescheduling of codeine?*
  - a. *How do you think this will impact on your service response to pain issues?*
  - b. *How else do you currently manage pain issues?*
3. *How familiar are you with the effects of illicit drugs and the needs of people who use them?*
  - a. *Would staff working in the aged care sector benefit from education/training on illicit drug use issues and implications for service delivery in different aged care contexts?*
  - b. *How would your response or support differ in residential aged care compared to home care?*
4. *Do you currently have any clients who have been treated for hepatitis C or are living with chronic hepatitis C?*
  - a. *Are there issues with access to prevention, testing and treatment for hepatitis C in particular in the aged care context?*
  - b. *How would your response or support differ in residential aged care compared to home care?*
5. *Do most workers in the aged care sector have an understanding of issues around blood borne virus (BBV) and sexually transmissible infection (STI) transmission and prevention measures?*
  - a. *Would people working in the aged care sector benefit from education/training on issues associated with BBV/STI prevention and transmission and implications for service delivery in different aged care contexts?*
  - b. *How would your response or support differ in residential aged care compared to home care?*
6. *Do you think your organisation/service has the necessary prevention and infection control tools, protocols and equipment to respond to the particular BBV/STI issues impacting on this new cohort of service users?*
7. *Can you think of any new measures that would need to be implemented to enable your facility/service to manage the needs of this new group of clients?*
8. *Do some policies, protocols and quality frameworks in the aged care space need to be developed and/or adapted to reflect the needs of this new client group?*
  - a. *Do you know about the Actions to Support LGBTI Elders – A Guide for Aged Care Providers that includes actions to support people living with HIV and other blood borne viruses?*
9. *Is there anything you would like to add in terms of the needs of either service users or service providers?*

## Attachment E

### **SUMMARY: Canberra consultation for aged care sector service providers - Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies**

Monday 13 May 2019, Orpheus Room, Hellenic Club, Matilda Street, Woden

#### **Introduction**

The Australian Injecting and Illicit Drug Users League (AIVL) is the Australian national peak organisation representing the state and territory peer-based drug user organisations and issues of national relevance for people with lived experience of drug use. AIVL's purpose is to advance the health of people who use/have used illicit drugs and for more than 20 years, AIVL has undertaken projects that seek to increase understanding and improve policy responses on issues that affect the lives of people who use drugs. AIVL is currently undertaking the *Supporting healthy ageing for people who inject drugs and/or receive pharmacotherapies* project, which aims to build capacity amongst aged care services to meet the unique needs of this ageing cohort. This project is funded by the Australian Government Department of Health through the Dementia and Aged Care Services Fund.

This project aims to build capacity within aged care providers to respond to the unique needs of older people who inject drugs, older people on pharmacotherapies and older people living with hepatitis C or hepatitis C-related complications. It is undertaking six national consultations across three sites (Canberra, ACT; Bunbury, WA; and Newcastle, NSW) with aged care providers across the spectrum of aged care service delivery to gauge understanding of issues that affect older people who inject drugs and understand how healthy ageing can be supported amongst this cohort.

The output of this project will be a comprehensive needs analysis report that identifies the practitioner and system needs for supporting healthy ageing amongst older people who inject drugs, and will make recommendations for systemic change. AIVL is also inviting stakeholders in the palliative care and related sectors to attend the consultations to provide advice on key issues and considerations for related sectors, given the intersecting cohorts. AIVL is seeking the assistance of participants to ensure that the project is able to capture and articulate

the needs of the various stakeholders in a way that is meaningful for informing policy, program and operational level responses to the needs of this growing population group.

#### **Consultation questions and answers provided by participants**

1. *Do you currently have any clients who are on pharmacotherapies for opioid dependence (e.g. methadone, buprenorphine)?*
  - Yes, in palliative care, some participants yes and some no in aged care.
  - Would be good to find ways to quantify this moving forward i.e. how many pharmacotherapy clients are over 60 years old in the ACT?
  - In terms of different aged care settings, aged care providers wouldn't know if people living in retirement villages/villas were on pharmacotherapies or not – independent living.
  - Prescription opioids and management is an issue, benzodiazepine management also challenging in residential aged care settings.
  - 1 July 2019 – new reporting requirements re psychotropics in particular.
  - Need numbers and data – this is a hidden population for the aged care sector.
  - Canberra Alliance for Harm Minimisation and Advocacy (CAHMA) – AIVL's ACT member organisation – spoke about people who use drugs avoiding aged care due to stigma and discrimination.
    - People ended up in acute hospital settings as a result.

- Participants also spoke about people ended up in palliative care because of a lack of appropriate and safe health and aged care services.
  - People preferring home-based assistance where possible – been let down.
  - Barriers to accessing aged care system – people need assistance to access.
  - Cost prohibitive – fears that compliance with recommendations arising from the current Royal Commission may make this worse.
  - Aged care sector not adequately funded to manage complex needs.
  - 64% of people in aged care are on anti-depressants.
  - Aged care sector needs resourcing to be able to respond to complex needs.
2. *Are you aware of the recent rescheduling of codeine?*
- a. *How do you think this will impact on your service response to pain issues?*
- b. *How else do you currently manage pain issues?*
- Aged care facilities try complementary therapies but this isn't adequate for people with dependence issues
    - Not well-equipped to manage dependence issues in aged care sector.
  - This project and the related consultations have at least prompted conversations within the sector.
  - Need more in-house prescribers in aged care (GPs and nurse practitioners, pharmacists in-house) – access is difficult.
    - Hampers responsiveness and medication access.
  - Stigma and discrimination and access – equally problematic barriers.
  - Need for clinical in-reach to aged care facilities.
  - Aged care sector not adequately equipped to manage pain – leads to depression in residents.
- Pain affects opioid maintenance treatment (OMT) clients too.
  - Needs multi-disciplinary approach.
  - Need access to pain management for people on OMT.
  - Need more nurse practitioners who can prescribe to do in-reach and be on-site.
  - Need in-reach from community pharmacy too.
3. *How familiar are you with the effects of illicit drugs and the needs of people who use them?*
- a. *Would staff working in the aged care sector benefit from education/training on illicit drug use issues and implications for service delivery in different aged care contexts?*
- b. *How would your response or support differ in residential aged care compared to home care?*
- Need to ensure adequate pain relief for everyone.
  - Pressure re perceived “over-medication” of people in aged care.
  - Need better links/service from GPs (primary care) – would lead to less hospitalisations.
  - Not enough private GPs doing OMT at all in the ACT, including in aged care settings.
  - Lack of incentives and training to do OMT – need more support (e.g. Interchange General Practice moving from Civic to Tuggeranong – disproportionate impact on OMT clients due to lack of other prescribers).
    - Bulk billing - no incentives – massive need.
  - Methamphetamine users (e.g. truck drivers), very challenging to manage in aged care, no established pharmacotherapy.
    - Infrastructure needs adaptation –
      - » Requires resources/funding
      - » Needed to manage agitation, whatever the cause
      - » Need for different settings e.g. group homes.

- Might medicinal cannabis help in terms of managing agitation in aged care settings?
  - Need workforce development in de-escalation skills (e.g. such as the training provided to staff at Sydney's Medically Supervised Injecting Centre) for Certificate 3 and 4 workers in particular.
  - Need access to alcohol and other drug (AOD) workers/skill set in aged care sector –
    - Would be great if aged care sector workers could undertake the AOD Skill Set Course under the ACT AOD Qualification Strategy (see: <http://www.atoda.org.au/projects/qs/>).
    - Skills would be nationally applicable.
  - In-reach from specialist AOD services would be beneficial.
4. *Do you currently have any clients who have been treated for hepatitis C or are living with chronic hepatitis C?*
- a. *Are there issues with access to prevention, testing and treatment for hepatitis C in particular in the aged care context?*
  - b. *How would your response or support differ in residential aged care compared to home care?*
- Universal precautions are applicable and adequate in relation to hepatitis C.
  - People lose their own GPs on entry – often in-house care is superficial.
  - Facilities don't necessarily know if people need treatment –
    - Need histories for GP care to be comprehensive.
  - Treating hepatitis C will prevent hospital admissions.
  - No continuity of care for people entering aged care facilities.
  - Lack of awareness re hepatitis C treatment among average GPs.
  - Many people and GPs are not aware of the new hepatitis C treatments.
  - GP Superclinics – people don't get personalised, long-term care.
  - Need better integrated care.
  - Consent is an issue under the new aged care standards too – potential barrier.
  - Treatment needs to at least be offered.
5. *Do most workers in the aged care sector have an understanding of issues around blood borne virus (BBV) and sexually transmissible infection (STI) transmission and prevention measures?*
- a. *Would people working in the aged care sector benefit from education/training on issues associated with BBV/STI prevention and transmission and implications for service delivery in different aged care contexts?*
  - b. *How would your response or support differ in residential aged care compared to home care?*
- See answers to previous questions – nothing further to add.
6. *Do you think your organisation/service has the necessary prevention and infection control tools, protocols and equipment to respond to the particular BBV/STI issues impacting on this new cohort of service users?*
- See answers to previous questions – nothing further to add.
7. *Can you think of any new measures that would need to be implemented to enable your facility/service to manage the needs of this new group of clients?*
- AND**
8. *Do some policies, protocols and quality frameworks in the aged care space need to be developed and/or adapted to reflect the needs of this new client group?*
- a. *Do you know about the Actions to Support LGBTI Elders – A Guide for Aged Care Providers that includes actions to support people living with HIV and other blood borne viruses?*
- Danger of having too many frameworks.
  - Certificate 3 and 4 workers have relatively low health literacy – workforce skills development is key.
  - Stigma and discrimination/harassment – barriers to disclosure in residential aged care context.

- Need more in-reach from AOD specialist services.
  - Hammond Care does particularly well with workforce development.
  - Meanwhile, what's the skill set of NDIS staff?
    - And home care provider staff?
  - And what about NSW? ACT gets cross border health refugees from NSW too.
9. *Is there anything you would like to add in terms of the needs of either service users or service providers?*
- Reinforcing the need for more prescribers in the aged care sector.
  - GPs are generally too busy to engage, including in this space.
  - Need more nurse practitioners too.
  - Need more OMT prescribers, particularly.
- Pain issues – real time monitoring is a disincentive for prescribers in aged and palliative care settings –
    - PBS crackdowns on already limited number of prescribers – further disincentives for prescribers to use effective medications to manage pain and/or prescribe OMT.
  - It must be recognized that pain management is NOT over-prescribing.
  - Dementia patients have pain too – they just struggle to articulate their needs and have them acknowledged/heard.
  - The aged care sector needs workforce education and training, NOT more regulation and policy frameworks.
  - Family pressure is an issue in the management of AOD issues in aged care –
    - Families often have a zero-tolerance approach to AOD use that is neither evidence-based nor helpful
    - People in pain and in palliative care in particular need adequate access to medication.



## Attachment F

### Organisations participating in aged care sector service provider consultations: by location

#### Bunbury and Busselton, WA

Capecare, Busselton  
Bethanie, Bunbury  
Regis, Bunbury  
Wattle Hill Care, Bunbury

#### Newcastle, NSW

Maroba  
Bupa Villages and Aged Care  
Anglican Care

#### Canberra, ACT

La Trobe University  
Canberra Health Service  
ACT Health Alcohol and Drug Service  
Capital Chemist  
AIDS Action Council of the ACT  
Karralika Programs  
Palliative Calvary Care  
Goodwin Aged Care  
Palliative Care Australia  
Calvary - Bruce  
ACT Health Alcohol and Drug Service  
St Andrews Village  
Health Care Consumers' Association  
Hepatitis ACT  
Calvary - Clare Holland House  
Directions  
Burrangiri Aged Care - Residential  
CAHMA



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