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AGEING AMONG PEOPLE WITH HIV OR CHRONIC HBV/HCV IN THE ACT:

A BRIEF REPORT

APRIL 2019

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1 EXECUTIVE SUMMARY

AIMS

This is a health policy research project commissioned by the ACT Health Directorate. It aims to extend understandings of the complex and changing needs of the ageing populations living with chronic hepatitis B (HBV), hepatitis C (HCV), and human immunodeficiency virus (HIV) in the ACT.

KEY RESEARCH QUESTIONS

1. How is ageing impacting people living with HIV, HBV and HCV in the ACT?
2. To what extent is ageing impacting these people, and what evidence is available?

Specifically, this project examines evidence of:

- An increasing number of people aged 50 years and above living with HBV, HCV, and HIV in the ACT
- This older cohort's higher chronic illness burden, multiple co-morbidities, and prolonged and multi-drug treatment histories, as compared to those under 50 living with HBV, HCV and HIV in the ACT
- This population's increasing need to access multiple and diverse service providers (e.g. medical specialists, general and allied health practitioners, community peer-based professionals and aged care workers) across health and other social services
- Relevant policy, guidelines, and supportive mechanisms to cultivate continued service adaptation to this population's shifting needs
- The preparedness of key professional workforces in the ACT to respond to this population's increasingly complex and emerging needs.

OUTCOMES

This project identifies strengths and gaps in current health service provision for people living with HBV, HCV and HIV in the ACT.

This project also makes recommendations for improving the appropriateness, accessibility, and equity of health-service planning and future delivery to match this population's complex and changing needs.

MAIN APPROACHES/PROCESSES

From August 2017 to July 2018, this report's authors:

> Established an Expert Advisory Group, comprising of main stakeholders in the policy and services sectors

> Conducted a rapid-evidence assessment of relevant literature, current ACT policies and guidelines, as well as local service networks

> Conducted a series of site visits and in-depth stakeholder interviews and case studies to map organisational capacities, service referral pathways, and approaches to engage key consumers

> Synthesised evidence and made key recommendations through a co-production process

> Hosted a co-production workshop attended by key policy makers and advisors; aged care service providers; HIV clinicians and clinical network representatives; community-based service providers in HIV, hepatitis, and drug use; and consumer representatives.

KEY RECOMMENDATIONS

1

KEY RECOMMENDATION 1

Address the service gap for those aged 50-65 years living with HBV, HCV and HIV in the ACT, particularly those with chronic and complex needs, by:

> Identifying opportunities for policy and action-plan development, establishing new services, and linking affected people to existing services

> Focusing on providing home-based aged care services for priority populations and in various priority settings, in order to build resilience and preserve routine daily-life activities and basic functions.

The rationale and justification for this recommendation are underpinned by the Resilient Ageing framework, developed as a direct result of this report's findings, and an ageing-related policy review, which includes:

> The Commonwealth aged care funding framework, mainly implemented through My Aged Care

- Eligibility for My Aged Care is 65 years or above or 50 years and above for Aboriginal and Torres Strait Islander people, in service of the Closing the Gap initiative

> The chronic and complex needs of people living with HBV, HCV, and HIV
  - e.g. premature ageing, liver danger zone, long-standing and emerging social isolation, poverty, and inequity in service access
> Resilient Ageing: support chronic disease self-management and home-based independent living with adequate community support.

2

KEY RECOMMENDATION 2

Optimise existing nurse-led health service navigation models to better tailor services for older people living with HBV, HCV and HIV.

The rationale and justification for this recommendation are listed below, with further information included in Case Studies 1 and 3.

> These priority populations need to access a range of health care services (general practitioners, specialists, nurses, and allied health care professionals) and social services
> Clinical referral pathways and successful models already exist in the ACT and other jurisdictions
> Nurses serving people living with HBV, HCV and HIV often act as case managers within existing various clinical service referral pathways.

3

KEY RECOMMENDATION 3

Optimise peer-led service navigation models led by key community organisations to better tailor services to older people living with HBV, HCV and HIV.

The rationale and justification for this recommendation are listed below, with further information included in Case Studies 2 and 3.

> People living with HBV, HCV, and HIV experience stigma and discrimination and a lack of social support in general
> Community referral pathways and successful models already exist in the ACT and other jurisdictions
> Trained peers from these priority populations make critical and complementary contributions to the emerging aged care community workforce, increasing inclusivity and equity in service provision and delivery.

2 KEY FINDINGS

AIMS

This is a health policy research project commissioned by the ACT Health Directorate. It aims to extend understandings of the complex and changing needs of the ageing populations living with chronic hepatitis B (HBV), hepatitis C (HCV), and human immunodeficiency virus (HIV) in the ACT.

PART 1: LITERATURE REVIEW

People living with or affected by blood borne viruses—HBV, HCV, and HIV—represent a distinct cohort associated with specialised health needs within Australia's rapidly ageing population. The increasing life expectancy of this population warrants specific attention to the effects of co-morbidities and co-pharmacies that may contribute to or compound premature ageing, highlighting limitations to the effectiveness of mono-disease treatment. At the same time, behavioural, social, and structural factors may impede equity in health outcomes. The complex relationship between bio-physical, behavioural and lifestyle, and social and structural factors reinforces the need for a multifaceted approach incorporating care, treatment, and support of people over 50 living with or affected by chronic viral disease.

The population of people living with or affected by chronic blood borne viruses (BBV) highlights the need for training and resources in the healthcare sector, including access to effective diagnosis and treatment regimes. At the same time, training and resourcing need to be supplemented with policy innovation and foresight.

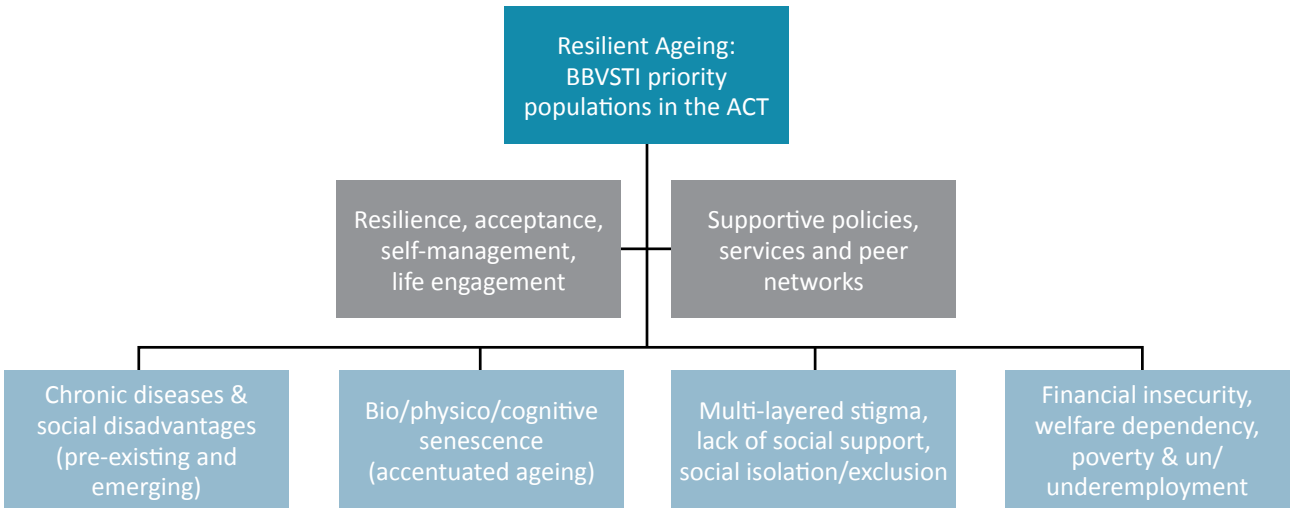
A more integrated, collectivised response to care and support is one that promotes resilience in ageing and preservation of quality of life, rather than strategies based on curing or treating disease only. Resilient ageing (Tkatch et al., 2016) is characterised by a range of objective and subjective determinants in adapting to negative life events and significant change (Emlet, Tozay, and Raveis, 2011).

Resilient ageing is the outcome of the intersection of wellbeing in physical, psychological, and social dimensions. It emphasises characteristics such as adaptation, independence, and positive engagement.

KEY FINDING 1

Resilient Ageing is the proposed framework, as opposed to healthy or successful ageing. This is in line with the principles of the *ACT Active Ageing Framework 2015-2018*, but also addresses special issues facing older people living with HBV, HCV and HIV in the ACT.

FIGURE 1: PROPOSED FRAMEWORK OF RESILIENT AGEING



MAIN RATIONALE:

> Being more inclusive, because resilience is attainable despite disadvantages and illnesses (Harris PB., pp. 43-61)

> Being more comprehensive:

a. The interdependence of individual resilience and social norms resilience

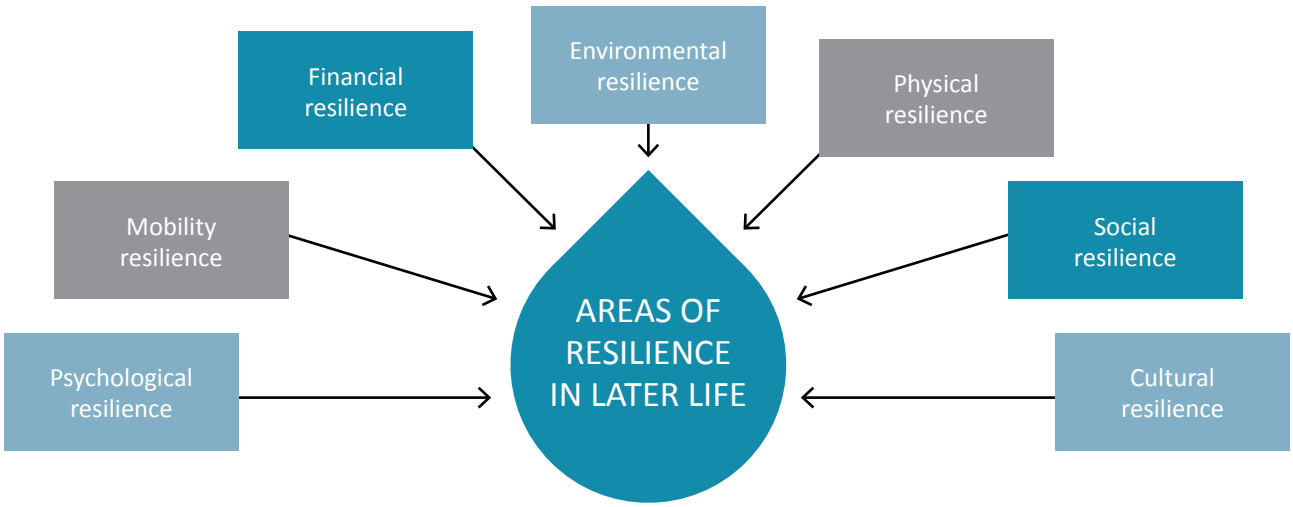
b. Meanings of resilience derived from older people (bottom-up engagement and empowerment)

c. The influence of social structures and power inequities

d. The many "hidden resilience recourses" of marginalised communities that often go unseen or are not recognised in traditional models of resilience

e. A critical awareness of how resilience models can be used against older adults to blame people for their current situations.

FIGURE 2: SOME IMPORTANT AREAS OF RESILIENCE IN LATER LIFE



(Wild K. et al. 2013, pp. 137-58).

PART 2: POLICY REVIEW

The health policy documents of both the Australian Commonwealth and the states and territories do not address the sexual health needs of older Australians (Kirkman, Kenny, and Fox, 2013). This may be related to an overall cultural devaluation of older populations. Additionally, it means that older Australians who are sexually active are at risk of being overlooked in sexual health screenings.

At the same time, a focus on risk can unduly emphasise behavioural and lifestyle practices of people living with or affected by chronic viral disease (particularly in relation to gay or other men who have sex with men [MSM] and people who inject drugs [PWID]). This can negatively impact disclosure and the perception of stigma related to sexual health and viral status.

Furthermore, a review of overall existing guidelines for the primary care of lesbian, gay, bisexual, transgender, intersex, and queer [LGBTIQ] people found gaps that are specifically relevant for gay/other MSM who are living with or affected by chronic blood borne viruses, mainly the contentious and stigmatised nature of homosexuality coupled with infection status (McNair and Hegarty, 2010).

Overall, there are limited policies addressing the specific issues relating to ageing among people with HIV, HCV, and HBV, both at the jurisdictional level (including in the ACT) and the Commonwealth level. However, coverage of issues relating to ageing in LGBTIQ people is more developed, particularly at the Commonwealth level.

Further development of current policies and strategic plans that are specifically designed for ageing HBV, HCV and HIV populations is urgently required. In order to ensure that services are accessible, appropriate, and affordable, the following aspects should be incorporated into existing policies to address the specific needs of these groups, including:

- Fear of stigma and discrimination
- Lack of control over disclosure of personal identity or specific lifestyle
- Social isolation
- Access to aged care services at an earlier age
- Training and education on the needs of people living with HBV, HCV, and HIV for the aged care workforce, service providers, and community (LGBTIQ Ministerial Advisory Council, 2014).

KEY FINDING 2

As a starting point, explore opportunities to consider ageing in holistic and cohesive ways (e.g. the proposed Resilient Ageing framework) during implementation of the latest national blood borne viruses and sexually transmissible infections (BBVSTI) strategies at the jurisdictional level.

KEY FINDING 3

Advocate for the inclusion of people living with HBV, HCV, and HIV in Commonwealth-level policies and programs, such as My Aged Care and the National Disability Insurance Scheme (NDIS).

PART 3: OLDER PEOPLE LIVING WITH HBV, HCV, AND HIV IN THE ACT

3.1 DISEASE-FOCUSED (BIOMEDICAL AND PUBLIC HEALTH) UNDERSTANDINGS OF HBV, HCV AND HIV: PREMATURE AGEING & LIVER DANGER ZONE

HIV "ages" people (accentuated ageing). For individuals living with HIV, the chances of developing long-term, life threatening health conditions are significantly higher. These conditions include:

- Higher risk of cardiovascular disease
- Higher risk of diabetes
- Bone and joint disorders
- Hypertension
- Kidney disease
- Dementia and other neuro-cognitive impairment.

(ASHM, 2014)

KEY FINDING 4

The complex impact of multi-morbidity and poly-pharmacy on daily-life functions is typically characterised by the development of multiple chronic diseases and an uptake of a range of treatments. This is best addressed through strategies that focus on preserving function rather than curing disease, as evidenced by Geriatric Medicine and gerontology.

Chronic HBV or HCV infections commonly do not present with symptoms during the early stages. The average duration from initial HBV or HCV infection to the development of mild, moderate, or severe liver impairment (including liver failure and liver cancer) is greater than 20 years.

The liver danger zone (AIVL, 2010) relates to those who are aged 40 years and above and use opium-based, non-synthetic, and synthetic substances, including morphine, heroin, pethidine, oxycodone, fentanyl, methadone, and buprenorphine, as well as a variety of other less commonly prescribed pharmaceuticals and illicit substances. The average age at initiation of injecting drug use for recreational use is 18.8 years (The National Drug Strategy, 2007).

KEY FINDING 5

There is a need to understand whether "age" is a proxy for "severity of liver disease", or whether there are specific age-related issues associated with HBV/HCV-related mild, moderate, or severe liver dysfunction (La Trobe, 2014).

3.2 SOCIAL UNDERSTANDINGS OF SERVICE NEEDS FROM A RANGE OF PRIORITY POPULATIONS: THE PROFOUND IMPACT OF STIGMA AND DISCRIMINATION

Significant cultural, social, and structural differences exist that complicate universal healthcare in Australia. People living with or affected by chronic HBV, HCV, and HIV represent diversity in the ageing population, with groups most affected including gay, bisexual or other men who have sex with men (MSM), people who inject drugs (PWID), sex workers, people from culturally and linguistically diverse (CALD) backgrounds, and Aboriginal and Torres Strait Islander people.

In Australia, the ageing population of people living with HIV [PLHIV] is concentrated among long-term survivors, mainly gay or other MSM, who are a well-educated and informed population with high access to a range of HIV- and non-HIV-related health services in urban centres (Jansson and Wilson, 2012).

People living with viral hepatitis B are more likely to be represented by ethnic minorities (approximately 50% of people with chronic HBV infection were estimated to be immigrants from either Southeast Asia, Northeast Asia or sub-Saharan Africa (MacLachlan et al., 2013).

Current and prior PWID account for 75-80 percent of the Australian population estimated to have been infected with HCV, and Indigenous people have high incidences of HBV (MacLachlan et al., 2013). These diverse groups have differing cultural attributes and face divergent social and structural barriers to equity in health care. While there are some overlapping needs owing to age and disease status, their unique health and social service needs should be recognised.

KEY FINDING 6

Multi-layered stigma, which is further compounded by pre-existing or emerging social and economic disadvantages, a lack of adequate social support, and a disproportionate burden of mental health conditions, creates substantial structural barriers for these people, especially when they access various health and community service systems and transit between them.

3.3 CLOSE-UP ACT LENS: PRIORITY POPULATIONS CURRENTLY LIVING WITH HBV, HCV AND HIV IN THE ACT

	HBV	HCV	HIV
Priority populations	Migrants/CALD, Indigenous populations	PWID (past, current), custodial settings	Gay and bisexual men Heterosexuals from high HIV-prevalence countries (e.g., sub-Saharan Africa, SE Asia)
Estimated disease burden in the ACT	Total: ≈4,800 ≥65 years old: ≈720 ≥50 years old: ≈1,440	Total: ≈4,000 ≥65 years old: ≈600 ≥50 years old: ≈1,200	350-500 ≥65 years old: ≈75 ≥50 years old: ≈150
Health and service investment	An emerging area of concern, but levels of prioritisation and funding allocation are the lowest among the three conditions.	A long-term interest with recourses substantially increasing since the introduction of Direct-Acting antivirals (DAA).	A priority for the last 30 years, more likely to be treated as a chronic condition afterward, but PLHIV still have unique needs.
Health and service management	Chronic disease self-management GP-led, nurse coordinated, multi-disciplinary, clinical workforce Community support and peer navigation Largely home-based aged care		

(The Kirby Institute, UNSW Sydney, 2017; The Doherty Institute, 2016)

3.4 ACT SECTOR STRENGTHS: A BRIEF SUMMARY

Following a strengths-based approach, this report highlights several enabling policy and practice factors in the ACT, which are in line with the future implementation of the above listed key recommendations. These are:

> An established record of vision in policies related to BBVSTI and ageing:

- The ACT is the first jurisdiction in Australia to include the sexual health needs of ageing people with blood borne viruses (ACT Health [2007], *HIV/AIDS, Hepatitis C, Sexually Transmissible Infections: A Strategic Framework for the ACT 2007-2012.* Canberra) (Kirkman, Kenny, and Fox, 2013)
- *ACT Active Ageing Framework 2015-2018* (for the general population), which could be further adapted to encompass the proposed Resilient Ageing framework

> An established record of recognising peer-based BBVSTI health promotion: the ACT allows legal possession of drug injecting equipment. Peer and extended distribution has been decriminalised. Anyone, including peers, who has completed NSP training, can distribute sterile drug injecting equipment

> Existing integrated health and social services for people with complex needs, for example, the Companion House model (people-centred integration and complex adaptive systems [CAS]) (Philipps et al., 2017, pp. 26-38)

> A rainbow-friendly city: Canberra is Australia's most inclusive city for LGBTIQ people.

3 CASE STUDIES

CASE 1

PROVIDED BY THE CANBERRA-BASED COMMUNITY OPTIONS

COMMUNITY OPTIONS CASE MANAGEMENT SERVICE MODELS

Community Options is a not-for-profit service provider specialising in case-management services to people with complex needs, including those people who are diagnosed with health conditions that are often highly stigmatised. These conditions include HBV, HCV and HIV. Community Options targets client groups that are socially and financially disadvantaged, and people who are often socially isolated due to their highly stigmatised health conditions. Very often, these client groups face significant difficulties with daily-living activities and organising their lives due to the impairment caused by their illness.

The Community Options case management service is based on a collaborative service-delivery approach. This includes active assistance provided to clients, with navigation of various systems and government processes. It also offers the planning and delivery of a suite of services in accordance with the assessed needs and wishes of the client. As a case-management organisation, Community Options often works with some of the most vulnerable, disadvantaged, and marginalised members of the community. It assists with access to support services and resources that help to improve quality of life and reduce the impact of impairment and stigma associated with poor health conditions. Community Options works closely with affected people, enabling them to achieve a greater degree of independence and enjoy the best possible quality of life in their own homes and communities.

A combination of intensive case management and the brokerage/purchase of a package of support, including the purchase of essential goods and services, allows Community Options to achieve the desired service and quality-of-life outcomes for the clients and families it supports. Through case management, Community Options builds relationships with its clients and their families and actively assists to address a range of issues and challenges that clients face in their day-to-day lives.

Community Options works closely with clients and their families to ensure smooth and coherent service provision, which is achieved through assessing, planning, facilitating, monitoring, and coordinating clients' support needs. Community Options case managers also work closely with other organisations in the service system, including acute care and rehabilitation facilities, to ensure integrated referral pathways and the best possible service outcomes for clients and their families. Community Options case managers also represent a single point of contact for clients, their families, and other service providers. Case-management services also include care-plan development and monitoring, and provision of information and referrals to other services as required.

Community Options' case-management services seek to address people's holistic needs and include:

> ***Information, individual advocacy*** and active assistance, with ***referrals*** to other services available in the community

> Assistance with ***navigation*** of other human service systems, including the National Disability Insurance Scheme (NDIS); My Aged Care; Centrelink; ACT Government Social Housing, including Public Housing, Community Housing, and Affordable Housing; the educational system; and the ACT Health system

> ***Trouble-shooting*** assistance to address issues and barriers in order to improve quality-of-life outcomes for clients and family members.

Community Options' case-management approach delivers the following outcomes to meet people's needs:

> Clients are linked to internal and external services that address their holistic needs and improve their wellbeing

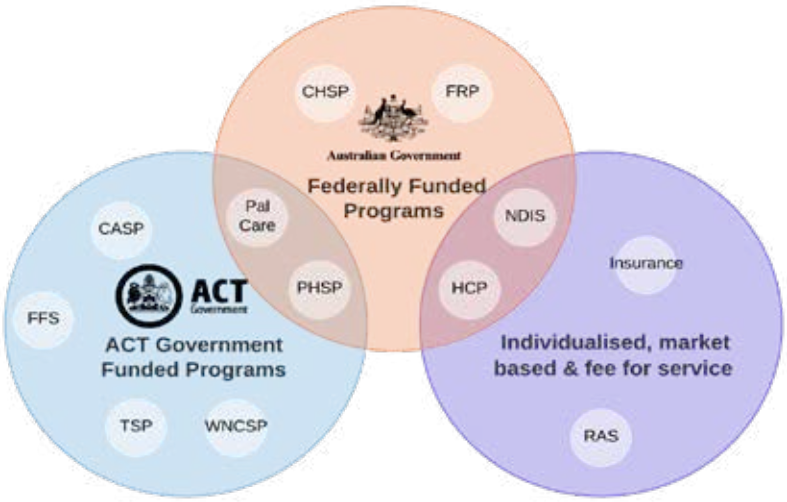
> Clients are supported into pathways of increased social inclusion and participation.

SUMMARY:

This case study demonstrates that mainstream community services that link Commonwealth and ACT Health-funded programs exist for older people living in the ACT. Future expansion of these services to cover older people living with chronic HBV, HCV, and HIV in the ACT should be prioritised. Community Options has completed LGBTIQ inclusiveness training, delivered by the AIDS Action Council.

Community Options
Serving the Canberra region

ABOUT COMMUNITY OPTIONS PROGRAMS AND SERVICES



PHSP - Four post hospital support programs:

- ACT Health-funded Palliative Care Program (**PCP**);
- Commonwealth and ACT Government-funded Continuity of Care Program (**COCP**);
- ACT Health-funded Transitional Support Program (**TSP**); and
- ACT Health-funded Women and Newborn Community Support Program (**WNCSP**).

CHSP - Commonwealth Home Support Program
HCP - Approved provider of home care under the Aged Care ACT 1997 - Home Care Packages Program
FFS - ACT Health-funded Flexible Family Support (FFS) Program - a respite program
FRP - Commonwealth Government-funded Flexible Respite Program (FRP) - funded under CHSP
CASP - ACT Health-funded Community Assistance and Support (CASP) Program
RAS - My Aged Car Regional Assessment Service (RAS) service provider in the ACT
NDIS - registered NDIS Provider: plan management and support coordination services

CASE 2
PROVIDED BY THE CANBERRA-BASED AIDS ACTION COUNCIL

AGEING POSITIVELY WITH HIV: A COMMUNITY PEER-BASED SERVICE MODEL

THE PROCESS

As the need for effective, non-judgmental health care and support increases, the AIDS Action Council (the Council) is a crucial point of contact for people living with HIV, their partners and families, and the Canberra community.

The three distinct groups that the Council assists are people living longer with HIV, the recently diagnosed, and women with HIV. The Council's client base predominantly features gay and bisexual men; however, it has recently seen an increase in sub-Saharan African women presenting with complex needs.

The Council's first group—people living longer with HIV—requires a broad range of psycho-social care that is both ongoing and multifaceted. Many of these clients have lived with HIV for decades. The challenges facing their management today are:

1. The stigma of HIV in day-to-day living
2. Crises arising from support needs
3. Clients' needs vs. wants and understanding the difference
4. Constant, complete, and up-to-date information-sharing between case workers
5. Apathy relating to long-term Council engagement (the mistaken feeling that there's nothing more to receive)

THE PATHWAY

The end goals of clients change as their life circumstances evolve. The Council stays connected to these changes through regular assessment and reassessment of client needs. The Council monitors and reviews care plans and directs clients to relevant services as required. Client feedback is also always welcomed.

Although perceptions of HIV have improved significantly over the last 30 years, discrimination, marginalisation, and stigma still exist. Some of these negative encounters can be avoided, while unfortunately, some have to be lived with. To manage this, the Council continues to link older clients with peer-support volunteers who have had similar experiences. These peer navigators support clients through areas of life via conversation, care, and support, and by using practical approaches.

This peer support goes a long way to staving off unexpected crises. So too does the Council's monitoring and review process. The more the Council regularly conducts "Where are you at?" types of discussions, the better it is able to anticipate arising issues. This can include deciphering the differences between needs and wants, such as medicine management. The Council does not prescribe treatment; however, it does support treatment adherence and links clients to support entities or groups who can capably deliver the appropriate services.

12 people within the Council, nine of which are full-time staff, help deliver a service that assists approximately 130 clients. Approximately 50 of this group are living longer with HIV. The Council shares "need to know" information among these internal personnel, always maintaining strict client confidentiality. This enables clients to move smoothly between workers, ensuring the best possible outcomes.

Being a community hub, the Council constantly invites contacts to provide information sessions in order to stay up to date with the latest HIV research, approaches, evidence, and technologies. This has resulted in our internally crafted education module *HIV 101* – a tome of information that evolves with the HIV landscape.

The Council is available around the clock to speak with clients, either face-to-face or by phone, as the need arises. This commitment to clients is at the core of the Council's service. Above all else, the Council is here for the community.

THE OUTCOME

The Council is not about hand-holding. It succeeds by empowering clients to ask, "How does HIV fit into *my* life?" Every day, the Council caringly brings individuals together through a community of remarkable support services.

The Council's clients may at first require case management services related to housing, travel, new job opportunities, and migration. After their initial needs have been met, the overwhelming majority of clients—92 percent—continue to be involved with the Council, from wanting to be included on the Council's mailing list to becoming more actively involved in social and educational opportunities. This particular statistic speaks volumes about the Council's positive impact on the communities it serves. It confirms the Council's status as a trusted source of information, and one that's achieving its goals.

SUMMARY:

This case study clearly demonstrates that there are existing peer-led support networks connecting various health and community-based services (particularly in the area of psychological counselling) for issues related to living with HIV and LGBTIQ inclusiveness. Future priority should be given to improving support services for older people living with chronic hepatitis and HIV in the ACT, through connections between the BBV sector and mainstream ageing services.

REFERRAL PATHWAYS TO THE COUNCIL

Most people self-refer to the Council and are aware of our services through community contact. The counselling service also accepts referrals from partners, family members and friends, in addition to referrals from a range of community and partnership organisations, including:

- Canberra Sexual Health Centre
- HIV service referrals such as positive organisations and networks
- A Gender Agenda
- Relationships Australia
- Qlife
- General Practitioners, Psychologists and other Counsellors.

The Senior Counsellor responds to referrals within one business day of contact with the service.

REFERRAL PATHWAYS FROM THE COUNCIL

Constructive referral relationships are made to a range of services provided by the Council itself, and to support services provided by other organisations. The Council provides in-house peer support services, workshops, information sessions and community connections. The Council will always get the client's informed consent prior to referral to community and partner organisations.

REFERRALS INCLUDE:

- The Council's community and peer-based workshops, information sessions and peer support social functions
- The Council's client services including peer support and case management
- Community connections through volunteer opportunities with the Council
- Testing clinics that are friendly to people who identify as LGBTIQ, sex workers and people who inject drugs
- Canberra Sexual Health Centre
- Relationships Australia
- General practitioners and other medical services.

(AIDS Action Council of the ACT, 2017)

CASE 3

BASED ON INTERVIEWS, OBSERVATIONS, AND CO-PRODUCTION PRESENTATIONS OF THE CAPITAL HEALTH NETWORK HIV PROGRAM AT INTERCHANGE GENERAL PRACTICE

NURSE NAVIGATION FOR PATIENTS WITH MULTIPLE AND COMPLEX NEEDS

Interchange General Practice (IGP) navigates patients through a complex system of care by providing direction, support and assistance. IGP helps patients access the required services, in the right sequence, and in a timely manner. It minimises barriers, increases health literacy, and optimises the use of available services.

CONTEXT

Located in a high-HIV caseload practice, IGP caters to patients:

- ~50% over 50 years
- ~20% over 60 years
- At least half of whom have more than one co-morbidity (most commonly diabetes, respiratory, cardiovascular, musculoskeletal, renal, or mental health conditions)
- ~40% have an HIV GP Management Plan/HIV GP Team Care Arrangement
- ~ 50% of those PLHIV >50 years received diagnosis before the highly active anti-retroviral (HAART) era (i.e. prior to 1996)
- Who are increasingly exhibiting signs of frailty, more co-morbidities, mental health problems, and isolation.

MAIN SERVICE AREAS FOR NURSE NAVIGATION

- Deciding which services could be useful
- Facilitating contact with services
- Interceding with services
- Consolidating information
- Avoiding service duplication
- Finding out what's working and what's not
- Improving patient understanding of HIV management and services
- Following up after clinical events.

EXAMPLE

The current rollout of Direct-Acting Antivirals (DAA) for HCV clearance (trained and sponsored by the Merck Sharp & Dohme (MSD) Australia Nurse Champions Program, *Spread the Cure*), IGP leads the nurse-led model in the ACT, which:

- Utilises nurses in a range of settings to improve the uptake of HCV screening, treatment, and test of cure
- Breaks down the process into a number of manageable steps that are easy for nurses and doctors to follow, further streamlining the patient journey
- Aims to re-engage patients with care
- Utilises Nurse Champions to educate others (usually nurses) to use the MSD resources to help eliminate HCV.

Specifically, the nurse navigator's role is to:

- Identify patients with HCV (extract data from medical software)
- Engage patients and educate them about HCV
- Motivate them to learn about the cure
- Coordinate GP/specialist bookings, blood tests, and scans
- Provide continuous support
- Ensure follow-up through to Sustained Virological Response (SVR)
- Discuss reinfection and the need for follow-up testing.

SUMMARY:

This case study demonstrates that there are existing general practices where nurse-led referral pathways to a range of clinical and community-based services in the ACT have been well established for people living with chronic HBV, HCV and HIV. To respond to the emerging needs of older people in the ACT living with these conditions, the ACT should prioritise increasing sustainable, equitable, and efficient support and training, and should work to optimise existing services.

FURTHER INFORMATION ABOUT NAVIGATION IN HEALTHCARE SYSTEMS

Navigation is necessary due to:

- An increase in the number of people with chronic health problems
- Complex individual healthcare needs
- The complexity of the healthcare system
- The disempowerment of some health consumers
- A lack of IT competence and limited access to computers
- The need to prioritise among an overwhelming number of tasks
- The need to move from fragmented to holistic care.

The main functions of the navigators are to provide:

- Access to patients requiring navigation assistance, external referral (to an individual or an organisation), and location in an agency that already has similar clients
- Cultural understanding and personal ease
- Understanding of patients' clinical issues
- Knowledge of, access to, and familiarity with relevant clinical and community agencies in the sector.

EXISTING MODELS

In general, nurses have access to and understanding of clinical information. They also have many opportunities to directly engage with patients.

> Dedicated Nurse Navigators:
  - *Qld Nurse Navigator Services* (for complex chronic conditions)
  - *Jane McGrath Breast Care Nurses*
  - *Emergency Journey Coordinator* (NSW)
> Incidental Nurse Navigation: most other nursing settings (may be limited by resourcing)

NURSE NAVIGATION IN A GENERAL PRACTICE SETTING

The effectiveness of nurse navigation depends on the resources and priorities of the practice.

Context: a general practice is:

> A strategic location for a navigator—the patient's GP is often their primary access point to health care

> A repository for information from other service providers

> A source of referrals to other services

> Experienced in coordinating care

> A place where GPs are in regular contact with patients who have chronic conditions

> An environment where patients usually understand the benefits of sharing information (and giving consent for this to happen).

Mechanisms: in a general practice, there is frequent and direct patient contact and opportunities for navigation, including:

> Clinical interactions (blood tests, wound care etc.)

> Health assessments

> Booking appointments and follow-ups

> Discussing results and management

> Input into GP Management Plans

> Coordinating specialist appointments and results etc.

4 APPENDIX

APPENDIX 1: KEY REFERENCES & REFERRED POLICY DOCUMENTS

PUBLICLY ACCESSIBLE POLICY DOCUMENTS:

- *ACT BBVSTI Statement of Priorities*
- *Alexander Maconochie Centre Strategic Framework for the Management of BBVs*
- *ACT Aboriginal & Torres Strait Islander Health Strategy*
- *ACT Drug Strategy*

The *Hepatitis B, Hepatitis C, HIV, Sexually Transmissible Infections: ACT Statement of Priorities 2016-2020* (*The ACT Statement of Priorities*) was developed in response to the five national strategies on blood borne viruses and sexually transmissible infections (BBVSTIs) as a framework to guide localised responses.

The ACT Government's priorities for target populations, as stated in the Canberra Plan: Towards Our Second Century, are:

- Assessing the quality of health care provision through the following domains:
  - Early intervention and prevention
  - Timely access to acute and primary health care
  - Enabling service cultures that enhance patients' overall wellbeing, safety, dignity, and agency
- Identifying enabling community cultures that improve resident safety and social inclusiveness. With the understanding that the target populations are vulnerable to stigma and discrimination, further exploration of strengths and weaknesses within existing services will be conducted.
- Intervention programs that support chronic disease self-management, independent living, and engagement with communal support, with the aim of eventually reducing internalised stigma and facilitating full participation in community life.

PUBLICLY ACCESSIBLE REPORTS

1. Australian Surveillance Report 2017, the Kirby Institute, UNSW Sydney.

2. First National Hep C & Fourth National Hep B Mapping Project Reports 2016, WHO Collaborating Centre for Viral Hepatitis Epidemiology, The Doherty Institute, ASHM.

3. Aged Care Workers and HIV and Ageing 2014, ASHM.

4. Double Jeopardy Report 2010, Australian Injecting and Illict Drug Users' League (AIVL).

5. Hep C and Ageing Report 2014, Australian Research Centre in Sex, Health and Society, La Trobe University.

KEY JOURNAL ARTICLES

1. Emlet, C.A., Tozay, S., & Raveis, V.H. 2011. "I'm not going to die from the AIDS: Resilience in aging with HIV disease", *The Gerontologist,* 51 (1) pp. 101-111.

2. Harris PB. 2008. "Another wrinkle in the debate about successful aging: the undervalued concept of resilience and the lived experience of dementia", *International Journal of Ageing and Human Development*, 67, pp. 43-61.

3. Jansson, J., & Wilson, D.P. 2012. "Projected demographic profile of people living with HIV in Australia: planning for an older generation", *PLoS One* 7, (8):e38334.

4. Kirkman, L., Kenny A. & Fox, C. 2013. "Evidence of absence: Midlife and older adult sexual health policy in Australia", *Sexuality Research and Social Policy* 10, pp. 135-48.

5. MacLachlan, J.H., Allard, N., Towell, T., & Cowie, B.C. 2013. "The burden of chronic hepatitis B virus infection in Australia, 2011", *Australian and New Zealand Journal of Public Health,* 37 (5), pp. 416-422.

6. McNair, R.P., & Hegarty, K. 2010. "Guidelines for the primary care of lesbian, gay, and bisexual people: a systematic review", *The Annals of Family Medicine* 8 (6), pp. 533-41.

7. Philipps, C., Hall, S., Elmitt, N., Bookallil, M., & Douglas, K. 2017. "People-centred integration in a refugee primary care service: a complex adaptive systems perspective", *Journal of Integrated Care,* 25, pp. 26-38

8. Tkatch, R., Musich, S., MacLeod, S., Alsgaard, K., Hawkins, K., & Yeh, C.S. 2016. "Population Health Management for Older Adults: Review of Interventions for Promoting Successful Aging Across the Health Continuum", *Gerontology and Geriatric Medicine* 2:2333721416667877.

9. Wild K., Wiles, J.L., & Allen R.E.S. 2013. "Resilience: thoughts on the value of the concept for critical gerontology", *Ageing & Society*, 33, pp. 137-58.

APPENDIX 2: ACT HEALTHCARE WORKFORCE MAPPING: KEY STAKEHOLDERS INVITED TO CONTRIBUTE TO THE DEVELOPMENT OF THIS REPORT

BBVSTI/PRIORITY POPULATION-BASED HEALTH SERVICES: 'SPECIALIST MODEL'

- Canberra Hospital (the Liver Clinic)
- Canberra Sexual Health Centre (CSHC, located at the Canberra Hospital)
- Sexual Health and Family Planning ACT (SHFPACT)
- Interchange GP (IGP)
- Companion House
- Alexander Maconochie Centre (AMC)
- Winnunga Nimmityjah Aboriginal Health Service
- Pharmacies (hospital & community-based)

MAINSTREAM HEALTH SERVICES

- GP (e.g., National Health Co-op)
- Capital Health Network (CHN) ACT
- Nurse Practitioners, allied healthcare workforce
- Specialists

ACT-BASED COMMUNITY ORGANISATIONS AND SERVICES (EXAMPLES)

- BBVSTI:
  - AIDS Action Council
  - Hepatitis ACT
- Priority populations:
  - Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)
  - A Gender Agenda (AGA)
  - Alcohol Tobacco & Other Drug Association (ATODA) ACT
- Mainstream
  - Community Options
  - Suburb-based community services
  - Council on the Ageing (COTA) ACT
  - Dementia ACT
  - Carers ACT

APPENDIX 3: GLOSSARY OF TERMS

- BBVSTI: Blood borne viruses and sexually transmissible infections
- CALD: Culturally and linguistically diverse
- HBV: Hepatitis B
- HCV: Hepatitis C
- HIV: Human immunodeficiency virus
- LGBTIQ: Lesbian, gay, bisexual, transgender, intersex and queer
- MSM: Men who have sex with men
- PLHIV: People living with HIV
- PWID: People who inject drugs

AGEING AMONG PEOPLE WITH HIV OR CHRONIC HBV/HCV IN THE ACT:

A BRIEF REPORT

UNSW SYDNEY
CSRH Centre for Social Research in Health
ACT Government | ACT Health
AIDS ACTION COUNCIL
Interchange General Practice
Community Options